UNIVERSITY OF SOUTHAMPTON

FACULTY OF ENVIRONMENTAL AND LIFE SCIENCES

School of Health Sciences

Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia

by

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Thesis for the degree of Doctor of Philosophy

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ABSTRACT

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ORGAN DONATION BEHAVIOUR: UNDERSTANDING THE FACTORS STIMULATING THE DECISION TO REGISTER AS A POTENTIAL ORGAN DONOR IN MALAYSIA

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Organ donation in the Malaysian context has started to become an accepted medical treatment to save lives. Currently, Malaysia has approximately one donor for every one million population (Hooi and Mansor, 2014). However, the figure is meaningless as supply of the needed organs remains insufficient and organ transplantation procedures cannot take place. A reported key factor in low donation rates in Malaysia is that family rejection when they are not aware of the deceased's preferences regarding organ donation (Tumin *et al.*, 2013a). Thus, Malaysia has developed registers in order to provide a platform for potential donors to record their donation intention. The aim of this thesis was to understand individual lived experiences in deciding to register as an organ donor in Malaysia.

Using descriptive phenomenological approach, this study recruited 19 participants; 16 registered potential organ donor participants and 3 non-registered participants but they have had intention to donate organ. Single face to face semi-structured interviews were carried out with all 19 participants with resulting transcripts undergoing data analysis based on Giorgi's 5-steps framework.

Nine categories were generated underlying four psychological concepts underpinning participant decision making related to registration or non-registration as a potential organ donor in Malaysia. The four psychological concepts are; belief and attitude, feelings and emotions, cognitive readiness, and external influences.

The study offers insight into the experience of making the decision to register as an organ donor from the Malaysian perspective. The implications of this study have been considered in terms of public engagement campaigns, practice, and future research.

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   Author: Dilla Syadia Ab Latiff, Carol Rival, and Tracy Long-Sutehall
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Academic Thesis: Declaration Of Authorship

I, Dilla Syadia Ab Latiff declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

ORGAN DONATION BEHAVIOUR: UNDERSTANDING THE FACTORS STIMULATING THE DECISION TO REGISTER AS A POTENTIAL ORGAN DONOR IN MALAYSIA

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signed: Dilla Syadia Ab Latiff

Date: 20 November 2020

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Definitions and Abbreviations

BCT - Behaviour Change Technique

HTA - Human Tissues Act

JBI - Joanna Briggs Institute

MOH - Ministry of Health

NTRC - National Transplant Resource Centre

PCC - Participants, Concept, and Context

TPB – Theory of Planned Behaviour

WHO - World Health Organization

Chapter 1 Introduction to the Research

1.1 Introduction

Chapter 1 will outline the reason why this topic area was chosen and will provide an introduction to the topic area of organ donation. After presenting an overview of the challenges to organ donation from a global perspective the chapter will focus on the situation in Malaysia and more specifically on donor registration behaviours. The chapter concludes by providing a summary of the layout of the thesis.

1.2 Research Origin

This research is predicated on both professional involvement and personal experience. Prior to beginning PhD studies, I was a lecturer in medical law and ethics at one of the largest public universities in Malaysia. In one of the semesters, the undergraduates' project was to invite an external speaker to give a talk on any topic of interest. The invited speaker was Dr. Muhammed Anis bin Abdul Wahab, Cadaveric Organ and Tissue Donation Expert from the Malaysia National Transplant Registry. Dr Anis bin Abdul Wahab spoke about the organ donation situation in Malaysia with the aim of raising awareness. During the lecture the speaker posed the question "what if your child or someone you care for and love needed an organ to live, would you accept someone else's organ?" This question made me think and visualize myself in this devastating position. Taking into consideration that I might need a donor organ in the future, I signed the organ donor register in Malaysia.

In addition to my professional involvement, my personal experience of the very polarised views held by two important people in my life (my closest friend and my husband) have further stimulated my interest in how people make decisions to become an organ donor. Norizah (not her real name), my closest friend registered as a donor on the same day that I did. She returned home to share her action with her husband. Norizah's husband disagreed with her action, as he believed that their religion (Islam) does not allow organ donation. Despite this, Norizah did not withdraw herself from becoming a donor, but continued in the knowledge that her husband did not agree with her pledge. This left me wondering what might happen if she were to die, as generally the public in Malaysia are aware that next of kin can decline organ donation wishes on behalf of the deceased family member when approached by the healthcare practitioner.

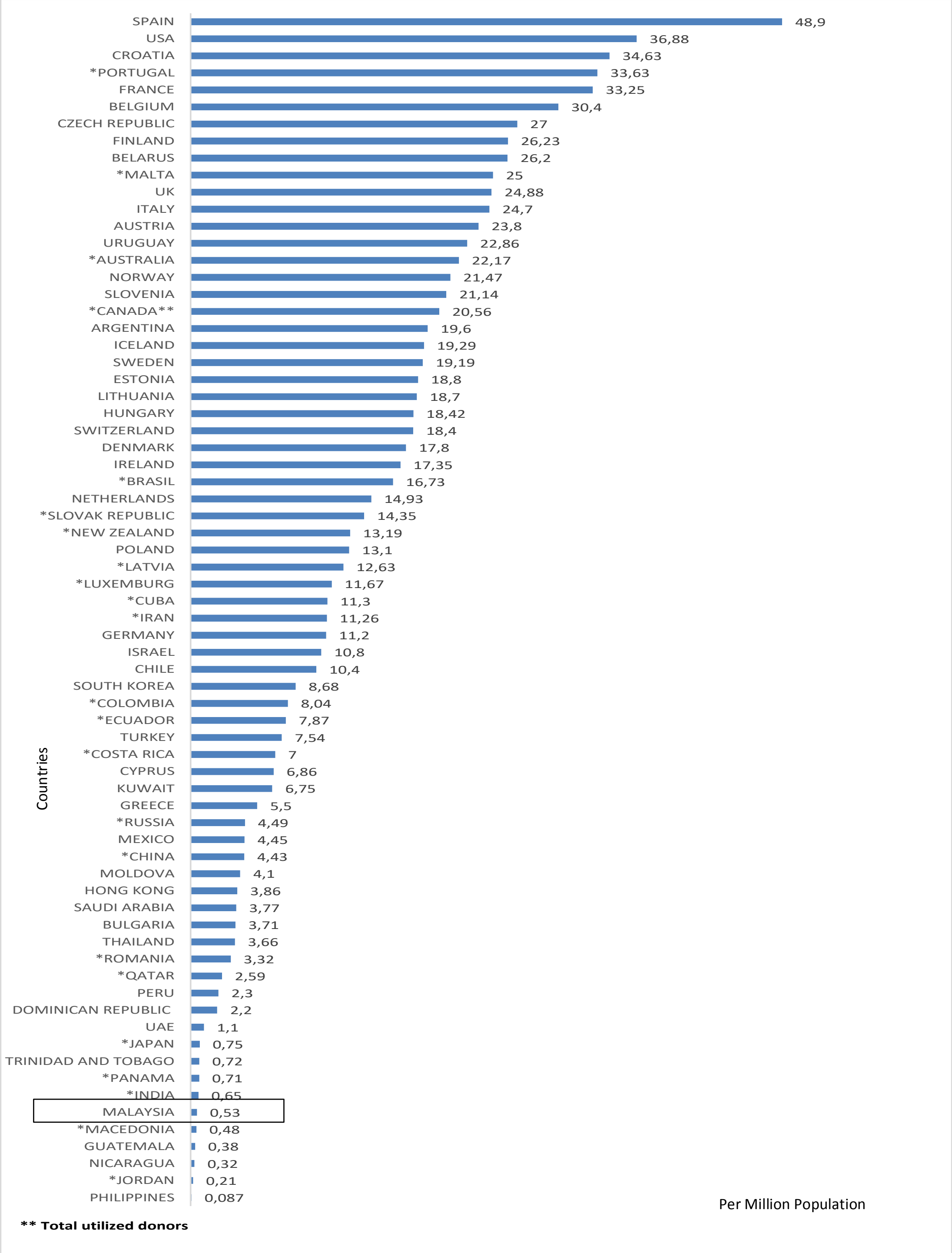
Personally, when I shared my decision to become an organ donor with my husband, he also disapproved of my decision. My husband, who I would describe as someone who is highly educated and modern minded, believes that when we die we should be buried with the body intact. This belief in the need to be buried with all body parts is reported as a key barrier to donation among Malaysian communities, particularly the Malay (Tumin et al. 2013).

In view of these diverse views in my personal life, I was stimulated to explore broadly the issue of organ donation in Malaysia and develop a comprehensive understanding of why the number of people registering to become a donor is relatively low, despite many Malaysians being aware of this shortage of organ donors. My desire to understand why the donation rates in Malaysia are low is the stimulus for undertaking the research completed in this thesis.

1.3 The gap between supply and demand in organ donation: a global challenge.

Worldwide, transplantation has become a viable and effective treatment for patients with end-stage organ failure (Siminoff *et al.*, 2001). Since 1954, when the first kidney transplant was successfully performed, the demand for organs has escalated rapidly (Ehrle, 2008; Testa and Siegler, 2014). However, despite 60 years of progress in organ transplantation the supply of donor organs is insufficient to parallel demand. Figure 1.1 illustrates current deceased donation rates per million in populations from around the world (International Registry in Organ Donation and Transplantation, 2020) for the year 2019, which is not meeting the current demand for organs (Abouna, 2008).

Figure 1.1 Worldwide Actual Deceased Organ Donors 2019 per million population, (International Registry in Organ Donation and Transplantation, 2020)



**** Total utilized donors**

Worldwide, low donation rates have been linked to a lack of public awareness and knowledge about organ donation and transplantation in general (Siminoff and Mercer, 2001), misleading interpretation of religious fatwas or decrees in relation to organ donation (Wakefield *et al.*, 2010), cultural concerns about how the dead body will be treated (Ashkenazi, *et al.*, 2015), and mistrust of the healthcare system (Anwar, *et al.,* 2014). A consistent finding from studies investigating barriers to increasing the number of organs available for transplantation is the rejection of the option to donate organs by the potential donors' next of kin (Coppen *et al.*, 2010). However, a further finding from this body of work (Siminoff and Mercer, 2001; Sque and long, 2003; Lawlor and Kerridge, 2009; Coppen *et al.*, 2010; Siminoff, Traino and Gordon, 2010; Anker and Feeley, 2011; Ghorbani *et al.*, 2011; Hyde and White, 2013; Ralph *et al.*, 2014) is that next of kin are less likely to reject the option of organ donation if they know the deceased's preferences or wishes at the time that they are asked to consider organ donation. Therefore, countries around the world have developed registers in order to provide a platform for members of the public to record their wishes or intention to become an organ donor after their death (World Health Organization, 2009).

1.4 Organ donation in Malaysia: cultural and religious perspective

Malaysia sits within the Southeast Asia global region and is physically divided between west and east. West Malaysia is now known as Peninsular Malaysia and is on the mainland of Asia, while East Malaysia known as the island of Borneo, comprises two states, Sarawak and Sabah. Peninsular Malaysia stretches from the border with Thailand to the island of Singapore, while East Malaysia is next to Brunei. As of 2019, Malaysia's population was estimated at 32.6 million (Department of Statistics Malaysia, 2020), with most large cities, industries and businesses concentrated on Peninsular Malaysia while East Malaysia is less populated.

It is also important to understand the dynamics of Malaysia, which comprises a mixed population, with varying practicing religions and customs. The three main ethnic groups are the native Malays, followed by large populations of Chinese, and Indians. The composition of these three main ethnic groups is as follows: Native Malay (69.3%), Chinese (22.8%), Indian (6.9%), and others (1%) (Department of Statistics Malaysia, 2020). Each ethnicity comprises groups, each group having its own culture, where there is a specific language, traditions, behaviours, perceptions and religious beliefs that are shared among the people. As for religious orientation, the Malays are defined in law as being Muslim, the Indians are normally Hindu or Christians, and the Chinese are typically Buddhist, Christian or Taoist. Thus, with such diverse cultural backgrounds, Malaysians' view of health, healthcare expectations and treatment choices are greatly influenced by their religious beliefs and practices.

Malaysia's healthcare system is divided into a public and private sector. The government funded public healthcare system caters to about 65% (Quek, 2009; Ministry of Health Malaysia, 2018) of the population and is the option for most of the population especially in rural areas, as it is a much cheaper option. The public hospital system has problems with congestion, long waiting hours, and heavy workloads due to the high number of patients, which lead to lack of personal attention from the healthcare staff (Quek, 2009; Jaafar *et al.*, 2013; Abdul Rashid, 2016; Ministry of Health Malaysia, 2018).

In contrast, the growing number of private hospitals are mostly located in urban areas and offer advantages such as faster services as a result of more doctors, who are attracted to higher salaries and better working conditions (Quek, 2009; Ministry of Health Malaysia, 2018). In spite of the remarkable growth of both public and private hospitals, and increasing availability of advanced medical technology, the number of patients with chronic diseases continues to escalate, as does the number of those waiting for organ transplant. As of 2019, chronic diseases that require long-term treatment, such as diabetes, heart disease and cancer are responsible for about 70% of deaths in Malaysia (WHO: Western Pacific Malaysia, 2020). At present 3.6 million (11%) of the total Malaysia population has diabetes and their age distribution is mainly in the 55-64 and >65 years age groups (The National Renal Registry, 2018). Diabetic patients are now the leading cause of the longer waiting list for organ transplants (Ministry of Health, 2018). However, there is a variation of acceptance towards organ transplantation and organ donation within Malaysia's multi-ethnic society.

Organ donation in the Malaysian context has started to become an accepted medical treatment to save lives. Malaysian law on organ procurement and transplantation practices the opt-in system, which is a consent-based system. It means that only those who have agreed explicitly by consenting to organ donation will be organ donors, whether as living or cadaveric organ donors, with cadaveric donations more encouraged and prioritized. The only legislation to regulate organ transplantation activity in Malaysia is the Human Tissues Act 1974 (HTA from here onwards). This five section act has never been revised or amended since its inception (Ismail, 2012). The HTA focuses only on cadaver donors who donate any body parts after death for therapeutic purposes, medical education or research (Human Tissues Act 1974 (Act 130)). There are two conditions enforced by the HTA before removal of organs from the deceased is allowed: first, the potential donor must explicitly express in writing or orally, the wish or intention to donate, and second, the deceased's surviving spouse or next-of-kin must not object to the deceased's intention.

To date, the HTA that is in place states that organ donation and transplantation cannot proceed if there is an objection made by spouse or next of kin even though the deceased has expressed and registered their intention to be on organ donation on the organ donor register. This is typical of other countries such as the UK and the Netherlands where family members can prevent organ donation and transplantation from taking place even though the deceased has recorded their intention to donate organs (Miller, *et al.*, 2019; National Health Services, 2020). In Malaysia the family institution has a powerful role regarding daily routines as well as decisions made for the future. The key issue in understanding the influence of family in this context is that family is the final decision maker and has the legal right to override the consent of the deceased for organ donation made whilst still living, and this is in line with the HTA 1974, which stipulates that the family's consent has to be obtained before procuring organ(s) from the body of the deceased, even when registration has taken place before death (Tumin *et al.*, 2015). According to social psychologist Gerard Hendrik Hofstede, Malaysia is a collectivistic society (Hofstede Insights, 2020) and individuals typically perceive themselves to be members of familial and religious groups, across all Malay, Chinese, and Indian cultures. In a collectivist society, organ donation rejection by the family usually starts to interfere even before the individual registers as an organ donor: family pressure can stop potential donors from expressing their intention by joining the register. If the potential organ donor holds strongly to collectivistic culture, the registration won't take place. But if registration takes place, the family may still object to donation and can prevent it taking place despite the individual's intention being recorded.

1.4.1 The development of organ donation in Malaysia

Following publication of the HTA 1974, the organ transplant programme in Malaysia commenced with a living related kidney transplant and a year later, the first deceased kidney transplant was undertaken. The transplant programme in Malaysia is administered by the National Transplant Resource Centre (NTRC) based in Kuala Lumpur Hospital, and since the establishment of NTRC in 1997 organ donation is actively performed throughout Malaysia. The NTRC is responsible for increasing the number of people registering as an organ and tissue donor on the donor register, providing information and knowledge regarding organ and tissue donation and transplantation by running national campaigns and educational programs (e.g. National Organ Donation Awareness Week), and ensuring the records of potential organ donors in the database is up-to-date (MyHealth, 2020).

Since the commencement of the organ donation program, the total number of transplant operations completed (as at 2017) is 2,079, of which 638 were deceased donors (National Transplant Resource Centre, 2017), reflecting the dominance of living donation in Malaysia. There is inconsistency with earlier argument where deceased donations are more encouraged and prioritized, but living donor remains an important source of organ due to shortage organ from deceased donors. Currently Malaysia has 3.4 p.m.p of living donor and 0.53 p.m.p of deceased donor for every one million population (IRODAT, 2020). This low donation rate from deceased donor has raised concerns about the national ability to increase the number of potential organ donors and reduce the organ transplant waiting list, which in 2018 was recorded as including 21, 826 individuals (National Transplant Resource Centre 2018 per communication).

However, a reported key factor in low donation rates in Malaysia is the fact that Malaysia is a multicultural and multi-religious society (for further discussion see Chapter Two) and the fact that the evidenced intention to become an organ donor is low. In a population of approximately 32.6 million, only 424, 143 people (1.3% of the population) have registered to be a potential organ donor (National Transplant Resource Centre 2019 personal communication). Exploration of the reasons why Malaysia has a low registration rate were the stimulus for the research presented in this thesis.

1.5 The development of donor registers

In response to the current system (opt-in) and the findings that next of kin consent to organ donation is higher when the deceased has indicated their desire to be an organ donor by registering, the number of countries that now hold organ donor registers has increased from 64 in 2010 (Gomez *et al.*, 2012) to 111 in 2016 (Manyalich, Gómez and Reis, 2018). In the United Kingdom (UK), registration on the National Health Service (NHS) Organ Donor Register (ODR) established in 1994 (Rosenblum *et al.*, 2012) has increased from 8.3 million people in 2000 to 25.3 million people by March 2019 (NHS Blood and Transplant, 2019).

Donor registers facilitate individual choice regarding organ donation to be recorded on a central database which is usually situated within the organisation responsible for overseeing donation activities within each country (Gomez *et al.*, 2012; Zuniga-Fajuri, 2015), for example, NHS Blood and Transplant (BT) in the UK and the National Transplant Resource Centre (NTRC) in Malaysia. This central resource can then be accessed by health care professionals who are intending to raise the issue of potential organ donation with next of kin and share the knowledge that the deceased has registered their wishes, and what those wishes were (Manzano and Pawson, 2014).

Whilst more countries now have donor registers there is limited empirical work explaining why people choose to join registers. There is evidence that individuals in the Netherlands who have knowledge about organ donation often hold positive attitudes towards organ donation and have a stronger intention to register (Reubsaet *et al.*, 2001). Evidence from Poland, however, reports that knowledge and awareness about organ donation does not necessarily correlate with registration as an organ donor (Perenc, Radochonski and Radochonski, 2012), suggesting that this provides insufficient reason for individuals to decide to donate. In general, even though the public may have an awareness of the need for organ donation, awareness alone is not a guarantee of registration.

1.6 Donor registration in Malaysia

A small but growing body of work in Malaysia (Loch *et al.*, 2010; Wong, 2010a; Tumin *et al.*, 2013c; Tumin *et al.*, 2013d; Riyanti *et al.*, 2014; Tumin *et al.*, 2014) has generated baseline information about the possible factors that may be impeding individuals from registering as potential donors. These include myths and misconceptions about organ donation as well as cultural and religious beliefs (Loch *et al.*, 2010; Wong, 2010a). Work carried out by Wong (2010a) who conducted 17 focus groups with participants from three ethnic populations (Malay [47], Chinese [36], and Indian [22]) in Malaysia, had an aim of identifying the factors limiting organ donation among diverse ethnic groups. Wong (2010a) reported that participants perceived their religion as prohibiting the act of organ donation and that they were also swayed by cultural superstitions that a dead body should be intact, and that the body can still 'feel' pain if organ donation is performed. However, Tumin *et al.* (2013d) reported that religion and cultural factors were not an impediment for Malaysians who were considering becoming a donor after death. The contradiction in findings between Tumin *et al.* (2013d) and Wong (2010a) may be a result of the differing participants' cultural backgrounds, as in Wong (2010a) the study participants were composed of Malay, Chinese, and Indian ethnic groups, whereas in the Tumin *et al.* (2013d) study the participants were only Malays, whose religion is Islam.

Furthermore, Tumin *et al.* (2013d) sought to identify the factors influencing the decision to become an organ donor after death among Muslim Malaysians. Of 900 Malaysian Muslims approached to complete a questionnaire, 508 (65%) were aware of the organ donor shortage but responded 'NO' when asked if they were willing to become an organ donor. The authors suggest that the main reasons for the unwillingness to register as a potential organ donor included a lack of information about organ donation and lack of confidence in the government's ability to properly administer organ donation procedures. However, the authors did not explore the precise information people needed prior to making the decision to register as a potential organ donor.

Tumin *et al.* (2014) carried out a further survey with the aim of understanding the reasons that impede Malaysians from becoming organ donors. In total, 1420 Malaysians were approached to complete a questionnaire with 1311 agreeing to participate (response rate of 91.5%). It was found that 581 (44.3%) said 'YES' to organ donation but out of that number only 25 (4.3%) were registered as a potential organ donor. The authors report that the reasons for not registering included not knowing the procedure for registering and a lack of motivation to register. Whilst this and other studies (Loch *et al.*, 2010; Wong, 2010a; Tumin *et al.*, 2013c; Tumin *et al.*, 2013d; Riyanti *et al.*, 2014; Tumin *et al.*, 2014) have investigated the reasons why people do not register, no work has been carried out looking into the reasons why people do register. So far there is a gap in our knowledge base about what stimulates people to register their intention to be an organ donor, thus it is deemed important to learn about what drives registration so that future organ donation campaigns can be informed.

A further consideration is the finding from Tumin *et al.* (2013a) that one of the reasons given by participants for not registering was that they were concerned that their family members might be upset by their decision to donate an organ. Currently this finding has received no further investigation and so the factors associated with individuals' inclination to communicate their view about organ donation to family members or whether the extended family is included in the decision-making is unknown. Research in Western cultures has indicated that if the wishes of the deceased are known pre-mortem by family members the chances of family overruling the deceased's decision about becoming an organ donor are reduced (Newton *et al.*, 2010; Siminoff, Traino and Gordon, 2010; Ralph *et al.*, 2014). Therefore if and how individuals who have signed the donor register choose to share this information with their extended family members is important missing knowledge. As organ donation in Malaysia cannot occur without the permission of a person's next-of-kin, it is important to understand the level of communication and discussion that should take place prior to registering as an organ donor.

In conclusion, currently, how the intention to donate an organ becomes a decision and an act of registration has received little attention in the organ donation literature from a non-western perspective, therefore the following research question and objectives were developed to guide the research presented in this thesis.

1.7 Research question

What individual factors influence organ donation registration in Malaysia?

1.7.1 Research objectives

1. To explore the reasons why individuals in Malaysia decide to register as potential organ donors.
2. To explore whether religious and cultural beliefs play a role in the decision to register as a potential organ donor in Malaysia.
3. To identify what information individuals in Malaysia seek prior to registering as a potential organ donor.
4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine the information discussed with the family.

1.8 Chapter outline

The research question and objectives have guided the thesis that follows and therefore, to conclude this introductory chapter, an overview of the thesis is summarised.

1.8.1 Chapter 2 – Scoping review

Chapter 2 presents the systematic scoping review that was undertaken to establish the current knowledge base relating to organ donor registration globally, and then specifically related to Malaysia. The review demonstrated that: i) there is a small amount of literature examining registration as a donor from non-westernised countries particularly from the Southeast Asian region including Malaysia, ii) there is no literature offering any information regarding the type of information referred to in making a decision to register for organ donation in Malaysia, iii) there is minimal literature that examined religious and cultural perspectives, and iv) there is wider coverage of the family influence particularly in western culture, however little attention has been given to the predictors of family discussion concerning organ donation, and the information shared with family is still unknown.

1.8.2 Chapter 3 – Methodology

Chapter 3 presents the methodology guiding the empirical research: Phenomenology. It examines the philosophical foundations of Husserlian descriptive phenomenology and justifies the choice of this methodology and associated methods.

1.8.3 Chapter 4 – Design and Methods

Chapter 4 presents the research process is discussed including criteria for participant selection, method of data gathering and analysis, and ethical considerations. The chapter concludes with a discussion of how rigour was assessed in the research undertaken.

1.8.4 Chapter 5 – Data analysis

Chapter 5 presents the analysis conducted following Giorgi (1985) five step framework. This chapter illustrates the meaning units and categories developed during analysis with the aim of describing and explaining the phenomena under investigation in the study. To illustrate the process involved in the application of Giorgi's five step framework, examples of quotes from the transcripts, meaning units, and memos are presented.

1.8.5 Chapter 6 – Findings, discussion, and conclusion

Chapter 6 presents the findings from the research undertaken. Findings are discussed in relation to the information gathered as a result of the methodology utilised. The results section simply states the findings, without bias or interpretation, embedded within the current knowledge base. The purpose of the discussion is to interpret and describe the significance of the findings in light of what was already known about the research problem being investigated, and to explain any new understanding of, or fresh insights into, the problem. This chapter concludes with a brief discussion of the study's limitations.

1.8.6 Chapter 7 – Recommendations and limitation of study

This chapter presents and discusses implications of the findings for practice and policy. This is followed by recommendations for future research work particularly in the area of organ donation registration.

Chapter 2 Scoping Review

2.1 Introduction

Chapter 2 commences with the justification for the choice of review methodology, a scoping review, and continues with the aim of this review. The review follows the process laid out by the Joanna Briggs Institute (JBI). The chapter concludes by providing the key findings of the review.

2.2 Rationale of the choice of review methodology

The existence of different approaches in conducting a literature review can be partly explained by the current emphasis on the continuous development of evidence-based practice across various sectors (Grant and Booth, 2009). Particularly in the healthcare industry, the practitioner needs accurate and up to date information about what works, and this requires evidence reviews. Each type of review has a different purpose and choosing which review format is appropriate depends on a number of factors including the needs of the writer and the aim of the review. Is the aim to identify theory, review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? Scoping review methodology is particularly useful for examining a broadly covered topic to comprehensively and systematically map the literature and identify key concepts, theories, evidence, or research gaps (Arksey and O'Malley, 2005; Anderson *et al.*, 2008; Davis *et al.* , 2009; Levac *et al.*, 2010; Daudt *et al.*, 2013). Additionally, key differences between scoping reviews and other types of review, particularly systematic reviews, is that it is usual not to assess the quality of the reviewed papers. The aim is rather to identify the range, type and focus of evidence available so that what is known and what is not known about a topic can be identified.

2.3 JBI scoping review methodology

An initial scoping review applying the original framework by Arksey and O'Malley (2005) framework was carried out in 2015. In view of recent developments to scoping review methodology which was further advanced and extended by Levac *et al.,* (2010) and was further refined by a working group from JBI in 2017 (Peters *et al.,* 2017). Thus, an updated review was undertaken in 2019, applying the Joanna Briggs Institute (JBI) scoping review methodology and PRISMA-ScR (PRISMA extension for scoping review) (Joanna Briggs Institute, 2020). Listed below is the JBI scoping review process including eight steps (Table 2.1):

Table 2.1 The JBI framework for scoping reviews

JBI Steps	**Description on how implemented**
Review authors - at least two reviewers. Author with 34 papers being reviewed by supervisors.	
Step 1: Developing the title, question, and objective	The PCC (Participants, Concept, and Context) structure in JBI framework directly guided the process of this scoping review, including the development of the review question and objectives.
Step 2: Background	The background to the issue of organ donation in Malaysia is presented in Chapter One and has clarified that organ donation registration rates and donation rates in Malaysia are low.
Step 3: Establishing inclusion criteria	The PCC structure (see Table 2.2 for detail description) in JBI framework directly guided the process of this scoping review, including inclusion and exclusion criteria. The basis on which sources were considered for inclusion in the scoping review; • Participants: of which could include age and other qualifying criteria. • Concept: the core concept or the principle focus • Context: specific clinical settings, cultural context/ countries; • Types of sources: the design/methods, empirical and non-empirical work. See Table 2.4, Section 2.3.3, for the inclusion and exclusion criteria.
Step 4: Search strategy	A three-step search strategy is recommended: • an initial limited search of seven online databases relevant to the topic, and an analysis of the text words contained in the title and abstract of retrieved papers, and of the index terms used to describe the articles, • a second search using all identified keywords and index terms across all included databases, • lastly, the reference lists of all identified reports and articles were searched for additional studies. The database selection and search strategy is outlined in section 2.3.4.
Step 5: Source of evidence selection	A narrative description of the search decision process accompanied by the search decision flowchart. The flow chart clearly detailed out the review decision process; indicate the results from the search, removal of duplicate citations, study selection, full retrieval, and additions from reference list searching and final summary presentation. See Figure 2.1 in section 2.3.5.
Step 6: Extraction and charting of the results	Results were extracted and charted into an Excel spreadsheet based on; author(s), year of publication, study location, aims of the study, methodology/study design, method of data collection, sample/participant, and key findings. See Table 2.6, Table 2.7, and Table 2.8 in section 2.3.6.
Step 7: Analysis of the evidence	Studies were collated in relation to the country in which the study was completed, the methodology applied and the populations sampled to provide a compressive overview of the spread and nature of the empirical evidence included. See section 0.
Step 8: Presentation of the results	Finally, content analysis of the retrieved studies was carried out with findings categorised under headings (Table 2.9), which are then used to present the key findings. See section 2.3.8.

2.3.1 Step 1: Developing the title, question, and objective

Step 1 is to develop a review question that is congruent with the research title. The review question was: what are the evidenced factors that stimulate a decision to register as a potential organ donor, with regard to the global literature. The objectives for the review follow on from the research objectives as the required outcome of the review was to identify what was known from this literature so that this knowledge could be considered in relationship to the findings from the study presented in this thesis, situating those findings in the wider literature and illustrating the contribution they make to the current knowledge base.

Review objectives:

1. To explore the reasons why individuals decide to register as a potential organ donor.
2. To explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.
3. To identify what information individuals refer to prior to registering as a potential organ donor.
4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine the type of information discussed with the family.

2.3.2 Step 2: Background

The background to the issue of organ donation in Malaysia is presented in Chapter One and has clarified that organ donation registration rates and donation rates in Malaysia are low. Donor registration is intended to ‘record’ donation wishes and stimulate discussions regarding donation.

As communication of wishes regarding donation is evidenced as facilitating organ donation (Newton *et al.*, 2010; Siminoff, Traino and Gordon, 2010; Ralph *et al.*, 2014), it is important to understand the level of communication and discussion that is taking place about registering to be an organ donor before or after the event of registration. Currently, who is registering to be an organ donor in Malaysia and what is driving registration decision making has received little attention.

2.3.3 Step 3: Inclusion and exclusion criteria

A search strategy commences with the identification of specific search terms. In order to develop specific search terms for each stage of the search, the Population Concept Context (Table 2.2) mnemonic was applied to each of the stated objectives. The key words and related synonyms were combined using Boolean operators AND/OR, and truncation '* (Table 2.3).

Table 2.2 PCC framework; Population, Concept, Context

PCC Elements	**Description**
P – Participant	Important characteristics of participants, which could include age and other qualifying criteria. This review considered all studies that focus on participants who are registered or have considered registering for organ donation, tissue donation, kidney donation, blood donation, deceased organ donation. Since the minimum age to register as a potential organ donor in most countries is 16 and above (Rosenblum *et al.*, 2012), studies were eligible if they included participants over the age of 16 years, which is in line with registration requirements in most countries.
C– Concept	The core concept examined by the scoping review should be clearly articulated to guide the scope and breadth of the inquiry. This scoping review considered studies that report on registration behaviour of the participant. The synonym keywords considered were register, sign up, or record.
C- Context	This may include religious and cultural factors such as geographic location and/or specific racial or gender-based interests. In some cases, context may also encompass details about the specific setting. This review considered studies that encompassed four areas, which is in line with the review objectives. The contexts were around factors, information, beliefs, and family communication surrounding the decision towards registration. The synonyms considered were: • Factor, determine, drive, influence, motivate, perception, stimulate, or thought • Information, data, evidence, fact • Religious belief, spiritual belief, faith, religion, spiritual, cultural belief, culture • Family communication, family discussion, family, next of kin, relative, sibling, parent, spouse, partner, wife, husband, communicate, discuss, or talk • Decision, decide, decision making, or choice

Based on the PCC Framework (Table 2.2), this serves as the basis of the inclusion criteria for which sources were considered for inclusion in the scoping review. Thus, the four stages of the literature search began by utilizing the PCC framework (Table 2.3).

Table 2.3 Core search terms for each objective and Boolean Operators

Stage	Objectives	Keywords	Boolean Operators
First	1. To explore the reasons why individuals decide to register as a potential organ donor.	P – organ donor C– register C- factors, decision	"organ donor" AND register* OR "sign* up" OR record* AND factor* OR determin* OR drive* OR influence* OR motivate* OR perception* OR stimulate* OR thought* AND decision* OR decid* OR "decision making" OR choice*
Second	2. To identify what information individuals refer to prior to registering as a potential organ donor.	P – organ donor C – register C – information, decision	"organ donor" AND register* OR "sign* up" OR record* AND information OR data OR evidence OR fact* AND decision* OR decid* OR "decision making" OR choice*
Third	3. To explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.	P – organ donor C – register C – religious belief, cultural belief, decision	"organ donor" AND register* OR "sign* up" OR record* AND "religious belief*" OR "spiritual belief*" OR faith OR religion OR religio* OR spiritual* OR "cultural belief*" OR culture* AND

			decision* OR decid* OR “decision making” OR choice*
Fourth	4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine type of information discussed with the family.	P – organ donor C – register C – family communication, decision	“organ donor” AND register* OR “sign* up” OR record* AND “family communication*” OR “family discussion*” OR famil* OR “next of kin” OR relative* OR sibling* OR parent* OR spouse* OR partner* OR wife OR wives OR husband OR communicat* OR discuss* OR talk* AND decision* OR decid* OR “decision making” OR choice*

In order to maximise the potential to identify relevant material for review, inclusion and exclusion criteria were established at the beginning of the search process (Table 2.4). Defining the inclusion and exclusion criteria prior to searching helps improve both the transparency and the rigour of the review by ensuring screening is conducted in a consistent and relatively unbiased manner. The start date for the search was set at 1978 as the focus of this review is to look at registering behaviour and the first register was established by Israel in 1978 (Rosenblum *et al.*, 2012). Whilst the minimum age to register as a potential organ donor in most countries is 16 and above (Rosenblum et al., 2012), France and the Netherlands have a minimum age requirement of 12 and 13 respectively. This review set the minimum registrants’ age at 16 years in line with registration requirements in most countries. Inclusion criteria also included the most common registration methods; e.g. via a donor card, electronic registration, and driving licence and passport renewal.

Studies that report on body donation were excluded from this review, as the intention to donate a whole body does not speak to donating organs for use in transplant operations. In Malaysia, whole body donation is only accepted for medical education and research (Saw, 2018; The Star, 2018). Presumed consent and prisoners were also excluded because presumed consent assumes that everyone is willing to be an organ donor after death unless they document objection during their lifetime (Abouna, 2008) via the registration system available, and the WHO have argued that a prisoner cannot become an organ donor as this is not considered as an act of free will because of their situation, even if the prisoners agreed to organ donation whilst they are imprisoned.

Table 2.4 Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Those who register for: Organ donation Tissue donation Kidney donation Blood donation Deceased organ donation Participant age – above 16 years old Time line to search – 1978 to current	Body donation Presumed consent Prisoner Participant age – below 16 years old
Routes to registration: Electronic register Donor card Driving licence Passport	-
Language – Malay, English	

2.3.4 Step 4: Search Strategy

As recommended by JBI, the approach utilised in searching for studies for a scoping review followed a three-step search strategy. First, an initial limited search of a selection of relevant databases, followed by an analysis of text words contained in the title and abstract, and of the index terms used to describe the article. Then, a second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies.

2.3.4.1 Database selection

The following databases related to health, social care, psychology and sociology accessed via the University of Southampton library were searched in 2015 and again in 2019: Cochrane, MEDLINE, CINAHL, EMBASE, PsycINFO, World of Science (W.O.S), and Scopus (Table 2.5).

Table 2.5 Databases

Database	**Selection criteria**
Cochrane Library	The availability of systematic reviews, technology assessments, economic evaluations and individual clinical trials.
MEDLINE	Medline is the largest and most widely used database in the health sciences. It covers journal articles and other reference types in medicine, dentistry and nursing, including biomedicine, medicine, nursing, dentistry, allied health, pre-clinical sciences and psychology.
CINAHL	Offers broad coverage of journals in nursing, midwifery and allied health.

EMBASE	Offers a range of journal articles in biomedicine
PsycINFO	Contains journal articles, books, dissertations and theses in core psychology disciplines, behavioural sciences and mental health.
World of Science	Provides access to a wide range of fields particularly covering science, health, social science, humanities.
Scopus	The largest abstract and citation database of peer-reviewed literature. It comprises the world's research in the fields of medicine, social sciences, and arts and humanities.

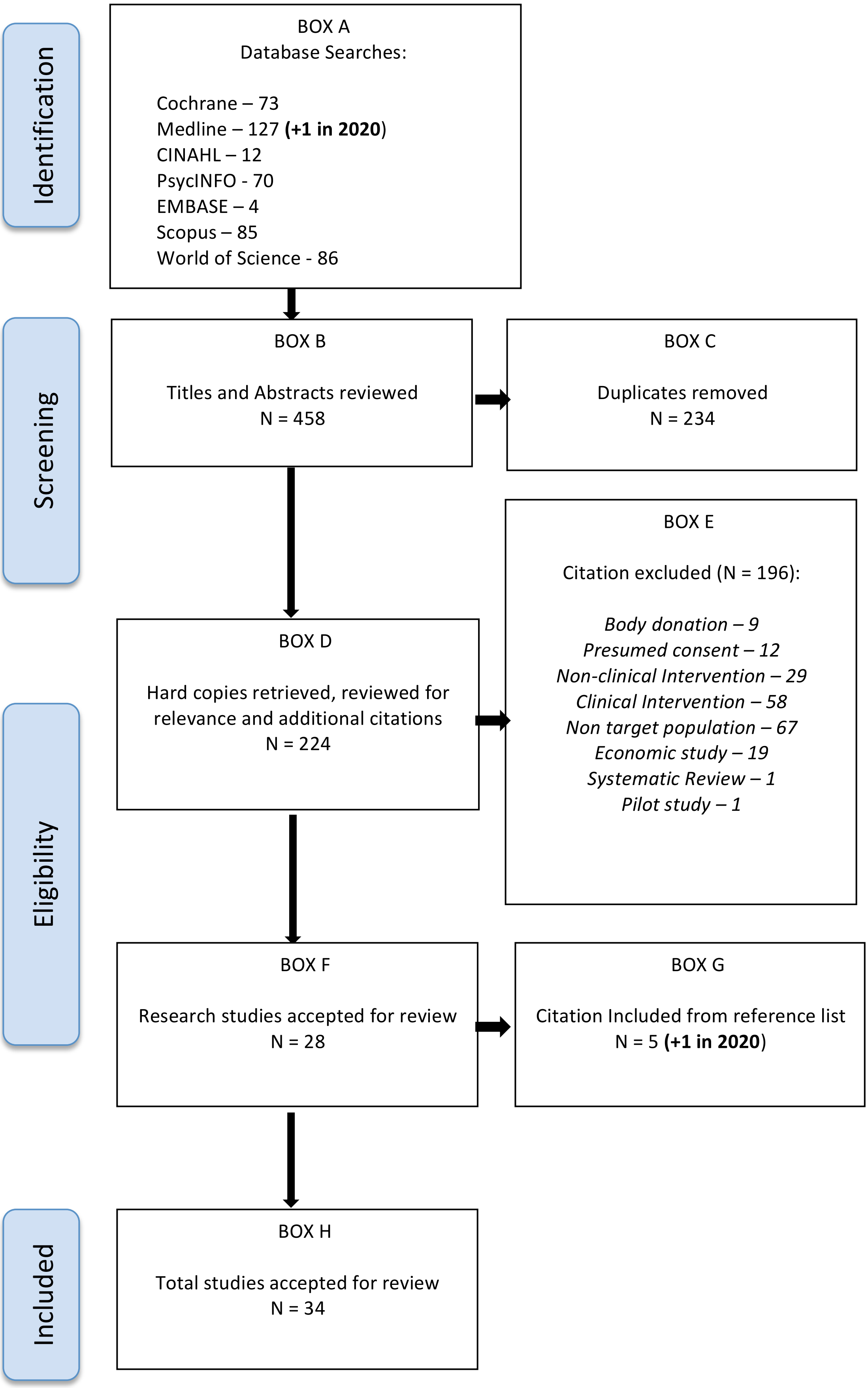
2.3.4.2 Search procedure

The search terms for each objective (Table 2.3) were entered in 'All Fields'. Applying 'All Fields' is important in a scoping review, as the whole point of scoping the field is to be as inclusive as possible in identifying primary studies for answering the central research question. The search strategy was done in four stages to reflect each objective and this is illustrated in Appendix A.

2.3.5 Step 5: Source of evidence selection

The four-stage search strategy resulted in a total of 458 hits (see box A and B of Figure 2.1), which included 1 new paper retrieved in the 2020 search. Using the inclusion and exclusion criteria (Table 2.4) all the 458 titles and abstracts were screened and 234 duplicates removed (see box C, D and E Figure 2.1). That left 224 papers for review, and from the review process a total of 196 citations were excluded. The reasons for exclusion are available in Box E of Figure 2.1. A total of 28 full papers were retrieved and read to check for relevance and further citations. The reference lists of these 28 full papers were reviewed for other relevant publications using the inclusion and exclusion criteria as in Table 2.4, which resulted in an additional 6 citations to be included (see box G of Figure 2.1). Thus, a total of 34 papers met the criteria for inclusion in the final review (See Table 2.6, Table 2.7, Table 2.8 for the list of final papers).

Figure 2.1 Flowchart of study selection procedure using PRISMA-ScR



2.3.6 Step 6: Extraction and charting of the results

The following data from the retrieved studies was entered into an Excel spreadsheet: author(s), year of publication, study location, aims of the study, methodology/study design, method of data collection, sample/participant, and key findings. Summary tables that list the final studies included in the review are presented in Table 2.6, Table 2.7, and Table 2.8.

Table 2.6 Review Objective 1: Overview of the studies relating to the factors that stimulate the decision to register as a potential donor.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Cohen and Hoffner (2013) Country: USA Title: Gifts of giving: the role of empathy and perceived benefits to others and self in young adults' decisions to become organ donors.	To determine the relative influence that self-benefit perception or other-benefit perceptions exert on people's organ donation decisions.	N = 131 university students Age: 18 to 29 Gender: 45 male, 86 female	Design: a survey research design. Data collection: Organ Donation Attitude Scale (ODAS) Data Analysis: Hierarchical regression analysis and T-test	Reason for registering: self-benefits were a stronger predictor than other-benefits. Examples of self-benefits are pride and satisfaction.
Downing & Jones (2018) Country: USA **Title:** A Qualitative Study of Turning Points or Aha! Moments in Older Adults' Discussions About Organ Donation	The aim of this study was to understand insights of older adults about organ donation. This study identified turning points as "Aha!" moments that occurred during a dialogue intervention where older adults discussed benefits, barriers, and process to organ donation.	N = 198 participants, in 21 focus groups. Age: 50 to 70 Gender: not reported	Design: Qualitative applying focus group. Data Collection: Group interview Data Analysis: Open coding and developed themes	The research identified moments in the dialogue where possible learning about organ donation may have occurred. From the dialogue, there are three themes which include benefits of organ donation (30%), barriers about organ donation (39%), and organ donation process (31%). After participation in the dialogue process, there was an increase in intent to register to be an organ donor, organ donation discussion with family and friends, and organ donor registration.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Dubay, Ivankova, Herby, Wynn, Kohler, Berry, Foushee, Carson, Redden, Holt , Siminoff, Fouad and Martin (2014) Country: USA Title: African American organ donor registration: a mixed methods design using the theory of planned behavior.	To identify the factors associated with becoming a registered organ donor among African American in Alabama. (Theory-driven -TPB)	N = 22 registered OD, 65 nonregistered OD Age: 19 - 88 Gender: 21male, 66 female	Design: a mixed method research design. Data Collection: Focus group and survey Data Analysis: Qualitative data - thematic analysis followed with content analysis. Quantitative data - Pearson (association, t-test and Wilconxon Rank-Sum test (comparison)	Factors for registering: having the autonomy to make ones' own decision, information Factors for not registering: fear, lack of information, perception that organs from African Americans were often unusable
Farside (2010) Country: UK Title: Perceived responsibility to act: an investigation with respect to registering willingness to become a posthumous organ donor	To investigate the relationship between perceived responsibility to register willingness to posthumously donate one's organs and actual registration behaviour. (Theory-driven -TPB)	N = 497; 269 university student, 228 non-students Age: 17 - 71 Gender: 208 male, 289 female	Design: a survey research design. Data Collection: Questionnaire was generated by the researcher in response to the literature to measure 'responsibility' and incorporate established questionnaire of TPB Data Analysis: Factor analysis and multiple regression.	Sense of obligation (responsibility) does promote the behaviour of organ donation
Feeley, Reynolds-Tylus, Anker and Evans(2014) Country: USA Title: Reasons for (not) signing the state registry: surveying Department of Motor Vehicles customers in New York state.	To understand motives associated with donor registration.	N = 1325 customers exiting 18 DMV offices in 9 counties in New York State. Age: 18-91 Gender: 667 male, 658 female	Design: a survey research design. Data collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Descriptive statistics	Reason for registering: altruistic benefit, personal experience Reason for not registering: No reason. Individual is unsure why she or he did not register as a donor.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Galanis, Sparos, Katostaras, Velonakis and Kalokerinou (2008) Country: Greece Title: Factors that influence Greeks' decision to register as potential bone marrow donors.	To examine the factors that influence the decision to be registered as potential bone marrow donors.	N = 565 (250 registered and 315 not registered potential bone marrow donors.) Age: not reported Gender: not reported	Design: a survey research design. Data collection: Questionnaire Data Analysis: Descriptive statistics, Logistic regression	Reason for registering: Had discussion with family and gained support, Peer pressure, Personal experience (relative or friend in need of BMT and the respondent is a regular blood donor)
Georgiadou etc (2012) Country: Greece Title: Attitudes and behaviour toward organ donation in Greece	To explore the determine factors associated with differences in willingness to donate organs among Greeks	N = 2263 adult Age: 18 - 83 Gender: 1189 male, 1066 female	Design: a survey research design. Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Chi-square, logistic regression	Influence on attitude: media, magazine, health personnel
Godin etc (2008) Country: Canada Title: Factors predictive of signed consent for posthumous OD	To identify factors predictive of signed consent for posthumous organ donation by using the TPB. (Theory-driven - TPB)	N = 602 Age: mean 41.6 Gender: 240 male, 362 female	Design: a survey research design. Data Collection: Questionnaire was generated using the guideline of TPB Data Analysis: Logistic regression	Factors in registering: intention, perceived behavioural control, moral norm, and past behaviour
Hyde and White (2011) Country: Australia Title: A comparison of registered and unregistered organ donors' perceptions about transplant recipients.	To examine the influence of perceptions about transplant recipient's previous behaviour on the decision to register as organ donor.	N = 465 (283 university students, 182 community members) Age: 17 -65 Gender: 121 male, 344 female	Design: a survey research design. Data collection: Questionaire Data Analysis: Chi-square, ANOVA, MANOVA,	Reason for registering and not registering: Potential donors' perceptions about transplant recipients' behaviour influences donation registration decision.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Hyde & White (2014) Country: Australia Title: Perceptions of OD and willingness to donate organs upon death: a test of the Prototype/Willingness Model	To examine decisions to donate organs while living and to communicate consent for donation to family by incorporating PWM and TPB. (Theory-driven - PWM)	N = Study 1: 210 & Study 2: 307 Age: Study1: 17-76 & Study2: 17-77 Gender: Study1: 58 male, 152 female & Study2: 107 male, 200 female	Design: Nominal Group Technique Data Collection: Questionnaire was generated using the guideline of PWM Data Analysis: Regression	PMW highlights the importance of people's perceptions about organ donors in their donation decisions. When comparing their own characteristics to that of a typical organ donor, people who believed they had more characteristics in common to the typical donor were more willing to donate.
Irving, Jan, Tong, Wong, Craig, Chadban, Rose, Cass, Allen and Howard (2014) Country: Australia Title: What factors influence people's decisions to register for organ donation? The results of a nominal group study.	To determine the relative importance of individual factors that influence willingness to register as organ donor.	N =114 Age: 18 - 25 (n = 34), 26 - 49 (n = 42), 50 and above (n = 38) Gender: 56 male, 58 female	Design: qualitative applying nominal groups. Data Collection: Nominal group technique and ranking Data Analysis: Descriptive statistics	Reason for registering: Saving lives, own decision to donate, family opinions, benefit to recipients, process of organ donation.
Joshi (2011) Country: UK Title: Whose Decision is it? Organ Donation Attitudes Among Young UK South Asians	To investigate the organ donor attitudes and donor card behaviour of young adult with particular focus of South Asian origin.	N = 382 Age: 17-31 Gender: 164 male, 218 female	Design: survey Data Collection: Questionnaire Data Analysis: Descriptive statistics, Factor analysis	Reason for registering: moral reasons (the right thing to do), personal reasons (someone you know needs it), and emotional reasons (image of those in need). Reason for not registering: not understanding about the topic, disapprove of donation.
Karim etc (2013) Country: UK Title: A survey of South Asian attitudes to organ donation in the United Kingdom	To explore South Asian attitudes to organ donation	N = 556 South Asians Age: 16 - 70 Gender: 225 male, 331 female	Design: survey Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Descriptive statistics, logistic regression	Factors that explain donation consent: Religious guidance, parental pressure, distrust of the health service, poor publicity

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Morgan (2006) Country: USA Title: Many facets of reluctance: African Americans and the decision (not) to donate organs	To explore the barriers and facilitating factor that African Americans experience in the process of making the decision to become potential organ donor.	N = 310 African American adult Age: Mean 45 Gender: 126 male, 184 female	Design: survey. Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Logistic regression	Factors that explain donation consent: knowledge, attitude, social norms, low medical mistrust, low need for body integrity, and lower in religiosity
Morgan, Harrison, Afifi, Long and Stephenson (2008) Country: USA Title: In their own words: the reasons why people will (not) sign an organ donor card.	To explore the reason why people will (not) sign an organ donor card.	N = 78 family-pair dyads. (33 partner-spousal dyads, 30 parent-child dyads, 15 other dyads (sibling, stepparent)) Age: 18 - 67 Gender: 45 male-female dyads, 26 female-female dyads, 5 male-male dyads, 2 not reporting dyads.	Design: Qualitative study applying naturalistic conversation between family members Data Collection: Dyadic interview Data Analysis: Open coding and developed themes or concepts. Using Ethnograph (a qualitative software) to assist the analysis	Reason for registering: Religion, desire to help others Reason for not registering: Mistrust, belief in black market, deservingness issue.
Morgan etc (2008) Country: USA Title: Facts versus Feelings: How rational is the decision to become an organ donor?	To construct a model of the forces that shape the decision to donate	N = 4426 respondents of large university Age: Unknown Gender: 1681 male, 2745 female	Design: survey. Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Structural equation modelling	Factors that explain donor card status: Noncognitive variables (bodily integrity, jinx factor, ick factor, medical mistrust). Cognitive variables such as knowledge and attitude are relatively weak predictors.
Murray, Miller, Dayoub, Wakefield and Homewood (2013) Country: USA Title: Communication and consent: discussion and organ donation decisions for self and family.	To examine factors that influence individual's willingness to donate organ.	N = 267 (200 community volunteered, 67 university students) Age: not reported Gender: 68 male, 199 female	Design: survey research design. Data Collection: Organ Donation Attitude Survey (ODAS) Data Analysis: Binary logistic regression, ordinal logistic regression	Reason for registering: Prior discussion and gaining support from family influences registration decision.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
O'Carroll etc (2011) Country: UK Title: The 'ick' factor, anticipated regret, and willingness to become an organ donor	1. to test the role that noncognitive emotional factors play in relation to organ donation 2. to manipulate the emotion of anticipated regret to test if this increases the intention of nondonors to register.	Experiment T 1: N = 141 adult; 56 (donor), 85 (nondonor) Age: 32 (donor), 28.7 (nondonor) Gender: 23m 33f (donor), 44m 41f (nondonor) Experiment 2: N = 138 adult; 47 (donor), 91 (nondonor) Age: unknown Gender: 20m 27f (donor), 39m 52f (nondonor) Experiment 3: N = 342 adult; 149 (donor), 193(nondonor) Age: unknown Gender: 61m 88f (donor), 95m 98f (nondonor)	Experiment 1: Design: survey. Data Collection: Questionnaire was generated in response to the literature and TPB Data Analysis: t-test Experiment 2: Design: a survey research design. Data Collection: TPB and anticipated regret Experiment 3: Design: a survey research design. Data Collection: Questionnaire was generated in response to the literature and TPB Data Analysis: t-test	Experiment 1: Noncognitive factors (ick, bodily integrity, jinx, medical mistrust, perceived benefit) distinguish organ donors from nondonors Experiment 2: Partially replicate findings of experiment 1 (ick factor and bodily integrity only). There were no differences in the cognitive factors (TPB) between donors and nondonors. Lastly, anticipated regret manipulation increases the intention to become donor. Experiment 3: Replicate the findings that emotional factors clearly differentiate donor and nondonor. Anticipated regret manipulation increase the intention to become donor.
Robinson etc (2012) Country: USA Title: Testing the utility of a modified Organ Donation Model (ODM) among African American adults	This study attempts to test an adaptation of the ODM that increases its cultural relevance to African Americans by incorporating trust in the organ allocation system and religious beliefs relevant to donation. (Theory-driven - modified ODM)	N = 585 Age: 19 - 96 Gender: 181 male, 404 female	Design: cross-sectional Data Collection: Questionnaire was generated in response to the literature and ODM Data Analysis: Descriptive statistics, Pearson, T-Test, Chi-Square, test the fit of model using AMOS	Trust and religious belief are associated with attitudes, which in turn associated with donation intentions. * From strongest to weakest association: religious belief, trust, and knowledge

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Salim etc (2010) Country: USA Title: Contributing factors for the willingness to donate organs in the Hispanic American population	To identify factors that contribute to intent to donate organs in Hispanic American individuals.	N = 524 Hispanic American Age: 18 - 65 Gender: 202 male, 322 female	Design: cross-sectional telephone survey. Data Collection: Questionnaire was generated in response to the literature Data Analysis: Logistic regression	Only 31% intent to become a donor. Factors that increase intention: family influence, and awareness of driver licence registry Opposite: low acculturation, religion, belief that organ donation will disfigure the body and impact on the funeral, perception that wealthy people are likely to receive organ transplants.
Schwettmann (2015) Country: Germany Title: Decision solution, data manipulation and trust: The (un-) willingness to donate organs in Germany in critical times	This study aims to investigate differences in trust and willingness to donate after implementation of the decision solution (2011) and after data-manipulation scandal (2012) that happened in Germany.	N = 3573 Age: 18 - 65 Gender: Unknown	Design: survey Data Collection: Two set of questionnaire were generated in response to the literature Data Analysis: Chi-square, regression	After implementation of the decision solution: trust increases with information, thus the number of people holding ODC is high. After the scandal: trust was destroyed. Thus, the number of people who hold ODC decreased.
Studts, Ruberg, Mcguffin and Roetzer (2010) Country: USA Title: Decisions to register for the National Marrow Donor Program: rational vs emotional appeals.	To compare the efficacy of a rational appeal (RA) with emotional appeal (EA) as methods of increasing the intention to register.	N = 102 Age: Not reported Gender: 47 male, 55 female	Design: an experimental research design (testing and intervention) Data Collection: Medical students were assigned to 2 groups. 1 group received RA questionnaire (statistical information about the need for stem cell donors) and the other received EA questionnaire (narrative story of a donor and a recipient). Data Analysis: t-Test, Multivariate logistic regression	Reason for registering: Those received EA has higher tendency to register with M=4.77 with statistically significant value of $P<0.001$.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Tartaglia, Dodd-McCue, Myer, and Mullins (2014) Country: USA **Title:** Organ Donation in the 50+ Age Demographic: Survey Results on Decision Rationale and Information Preferences	This study examined the 50+ age demographic to identify the rationale for donation decisions, preferred media methods of donation information delivery, and responsiveness to an age-tailored donation message.	N = 579 Age: 50 years old and above Gender: 231 male, 348 female	Design: a survey research design. Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Logistic regression	Overall result found respondents prone to self-select themselves as medically ineligible based on current medication and health status, even if they are medically suitable donors. Their motivation to search for more information on organ donation is limited except when motivated by personal accounts within their families and communities. They favor the printed or spoken word for donation information delivery. The results suggest an opportunity for those working with older adults to develop more personalized, localized donation education programs targeting this age demographic.
Webb, Phillips, Reddiford and Neuberger (2015) Country: UK Title: Factors Affecting the Decision to Grant Consent for Organ Donation: A Survey of Adults in England.	To explore the factors influencing personal decision to donate.	N = 1549 Age: 18 24 (199), 25-34 (362), 35-44 (334), 45-54 (261), 55-64 (173), and 65 and above (220) Gender: 678 male, 871 female & Focus group: 24 couples and 14 small family groups (the finding were used as a basis for the questionnaire)	Design: mixed method research design. Data Collection: Focus group and online survey Data Analysis: Multiple ordinal regression	Reason for registering: Altruistic, reciprocal benefit, avoidance of waste.

Table 2.7 Review Objective 2: Overview of the studies relating to the religious and cultural beliefs that stimulate the decision to register as a potential donor.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Bresnahan (2007) Country: (USA, Japan, Korea) Title: Reservations of the spirit: the development of a culturally sensitive spiritual beliefs scale about organ donation	To investigate the effects of spiritual factors on willingness to become an organ donor in three different cultural settings; Japan, Korea, and United States.	N = 146 (Korea), 134 (Japan), 146 (USA) - ALL University students Age: 17-26 (Korea), 18-29 (Japan), 18-29 (USA) Gender: 64m, 77f, 5x (Korea), 54m, 80f (Japan), 55m, 76f, 15x (USA) Religion: 54 Christian, 15 Buddhist, 77 no religion (Korea), 2 Christian, 30 Buddhist, 100 no religion (Japan), 111 Christian, 7 Jewish, 25 no religion (USA)	Design: a survey research design. Data Collection: Questionnaire was generated from finding of a focus group Data Analysis: exploratory and confirmatory FA, multiple regression	Overall, the results found in the 3 countries in this study are remarkably similar. Spiritual connection with potential recipients correlated with positive attitude and low fear of organ donation. Spiritual concerns correlated with more fearfulness about organ donation and less likelihood of indicating behavioural intention.
Salim (2012) Country: USA Title: A focused education program after religious service to improve organ donation in Hispanic Americans	The purpose of this study was to investigate the effect of an educational program targeting Hispanic Americans organ donation in places of worship.	N = 341 Hispanic American Age: 40 - 65 Gender: 120 male, 215 female, 6 X	Design: cross-sectional survey. Data Collection: 182 pre-surveys and 159 post-intervention surveys in 4 churches. Data Analysis: Logistic regression	The post-intervention survey found a significant increase in correct answers describing organ donation knowledge, perceptions regarding OD, and OD belief. BUT there was no significant difference between the two groups in the intent to donate. * Factors influencing intention: religious obstacle (fear delay to funeral, fear body mutilation, fear for afterlife) * Family support influences decision

At the point where the search was completed by April 2020, there was no data available looking into Review Objective 3; which was to identify the information individuals refer to prior to registering as a potential organ donor.

Table 2.8 Review Objective 4: Overview of the studies relating to the family communication that stimulate the decision to register as a potential donor.

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Afifi, Morgan, Stephenson, Morse, Harrison, Reichert and Long (2006) Country: USA Title: Examining the Decision to Talk with Family About Organ Donation: Applying the Theory of Motivated Information Management.	To examine the factors that influence individuals' willingness to talk directly to their family about OD and the impact of the discussions. (Theory-driven - TMIM)	N = Study 1: 391univ students & Study 2: 39 dyads (21 spouses dyads, 12 parent-child dyads, and 6 siblings dyads) Age: Study1: 18-35 & Study2: 18-64 Gender: Study1: 126 male, 215 female & Study2: 34 male, 44 female	Design: a survey research design. Data Collection: Study 1: the researcher in response to the literature and incorporating TMIM generated questionnaire. Study 2: dyadic interview Data Analysis: Structural equation modelling	Objective 1: factors influencing communication - outcome expectancy and communication efficacy Objective 2: the impact of the discussions: attitude improves post interaction, the amount of information seeking was positively associated with post interaction, the amount of information seeking was positively associated with post interaction intention to discuss OD with other family members.
Hyde & White (2009) Country: Australia Title: Disclosing donation decisions: the role of organ donor prototypes in an extended TPB	To examine the potential influence of donor prototype perceptions on people's decisions to register their consent on a donor register and discuss their organ donation wishes with family. (Theory-driven - TPB)	N = 359 (registering questionnaire), 282 (discussing questionnaire), 106 (both) Age: 17-65 Gender: 94m 265f (registering), 73m 209f (discussing)	Design: a survey research design. Data Collection: questionnaire was generated by the researcher in response to the literature and TPB Data Analysis: confirmatory factor analysis & SEM	Donor prototype evaluations predict discussing intentions only. This means the impact of people's perceptions of a typical donor on their decisions to discuss their organ donation preference, improve understanding of the factors influencing individual's communication processes. But, donor prototype evaluations do not predict intention/decision to register on the register.
Hyde & White (2009) Country: Australia Title: Communication prompts donation: exploring the beliefs underlying registration and discussion of the organ donation decision	To explore the beliefs underlying communication of the donation decision for people who had not previously registered their consent on a donor register or discussed their decision with significant others. (Theory-driven - TPB)	N = 123 Age: 17 - 76 Gender: 44 males, 79 females	Design: a survey research design. Data Collection: questionnaire was based on TPB measures. Data Analysis: SEM (predict intention/willingness)	Across both behaviours (registering and discussing), the significant belief predictors of intention are; behaviour belief (the advantages and disadvantages of both the behaviours) AND normative beliefs (perceptions of approval or social pressure from important referents).

Authors, Year, Country, Title	Aim(s) of study	Sample	Design, data collection, data analysis	Main Findings
Hyde & White (2010) Country: Australia Title: Are organ donation communication decisions reasoned or reactive? A test of the utility of an augmented TPB with the PWM	To explore whether people's organ donation consent decisions occur via a reasoned and/or social reaction pathway. (Theory-driven - TPB and PWM)	N = 339 (registering questionnaire), 315 (discussing questionnaire) Age: 17 - 77 Gender: 119m 220f (registering), 110m 205f (discussing)	Design: a survey research design. Data Collection: Questionnaire was based on TPB and PWM measures. Data Analysis: SEM (predict intention/willingness), logistic regression	A decision to register is a more reasoned decision (requires planning to obtain the necessary resources to register correctly). Decision to discuss involves both reasoned (thinking about the content of discussion) and reactive (reliance on the opportunity to have a conversation about donation with another person) elements.
Hyde & White (2013) Country: Australia Title: A test of three interventions to promote people's communication of their consent for organ donation	To explore the effectiveness of three interventions compared to a control condition to increase individual consent (registering and discussing donation wishes) for organ donation. (Theory-driven - TPB)	N = 177 Age: 18 - 80 Gender: 73 males, 104 females	Design: experimental (testing an intervention) Data Collection: 4 groups; 1. Motivational extended-TPB intervention, 2. Volitional intervention, 3. Combined intervention 4. Control condition Data Analysis: descriptive analysis, ANOVA, Chi-Square	H1: stronger intention to register in the motivational group compared to non-motivational group. However, no differences in the intention to discuss between the 2 groups. H2: increased registering behaviour in the volitional group compared to non-volitional group. However, no effect on discussing between the 2 groups. H3: greatest proportion of registering with participants in combined group. However, no effect for discussing behaviour.
Long et al.(2012) Country: USA Title: When families talk: Applying IPA to African American families discussing their awareness, commitment, and knowledge or organ donation	This study seeks to develop an understanding of how African American families make sense of their experience in discussing their willingness to donate organs.	N = 39 dyads (10 sibling & first cousin dyads, 6 parent-child dyads, and 4 spousal dyads) Age: Mean 34 Gender: 13 male-female pairs, 4 male-male pairs, 3 parent-child pairs	Design: Qualitative applying Interpretative Phenomenological Analysis Data Collection: dyadic interview Data Analysis: Open coding and developed themes.	Three central themes emerged: Knowledge, Awareness, and Commitment

Authors, Year, Country, Title	**Aim(s) of study**	**Sample**	**Design, data collection, data analysis**	**Main Findings**
Newton et al. (2010) Country: Australia Title: A profile of Australian adults who have discussed their posthumous OD wishes with family members	To investigate if there were psychosocial differences in the profiles of individuals who have communicate & registered, communicate but not registered, registered but not communicate.	N = 409 Age: 18 - 71 Gender: 99 males, 305 females	Design: survey research design. Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: Chi-square, t-test, ANOVA	Christians and those of higher income were more likely to have communicated their donation wishes. Participants were less likely to have communicated their donation wishes if they were unregistered and undecided, or fearful of death. Overall, whether participants had communicated, registered, or communicated and registered was associated with age, gender, religion, attitude, and recall of media content about OD.
Smith et al. (2004) Country: USA Title: Encouraging family discussion on the decision to donate organs: the role of the willingness to communicate scale	To investigate the role of Willingness to Communicate (WTC) scores in the process of encouraging family discussion about wishes regarding OD.	N = 207 university student Age: mean 19.57 Gender: 56 male, 151 female	Design: survey. Data Collection: Questionnaire was generated by the researcher in response to the literature Data Analysis: confirmatory factor analysis, ANOVA	Willingness to communicate was due to: prior thought and intent to sign and organ donor card, perceiving organ donation messages as credible, feeling relatively low anxiety after reading organ donation messages, worrying about lack of donors, and having an organ donor card witnessed.

2.3.7 Step 7: Analysis of the evidence

Unlike a systematic review, scoping reviews do not strive for synthesis of evidence from different studies but for a thematic construction that presents a narrative or description of the existing literature (Arksey and O'Malley, 2005). As stated by Arksey and O'Malley (2005) scoping reviews should help the reader quickly get a flavour of the main areas of interest and consequently identify where the significant gaps are.

Firstly, studies were collated in relation to the country in which the study was completed, the methodology applied, the populations sampled, and theories identified to provide a compressive overview of the spread and nature of the empirical evidence included. Finally, content analysis of the retrieved studies was carried out with findings categorised under headings (Table 2.9, section 2.3.8), which are then used to present the key findings.

2.3.7.1 Country of origin

All of the retained papers were written and published after 2004 as countries across the globe have sought to understand the factors that influence the continuing gap between demand and supplies of organs for use in transplant operations. From the 34 papers being reviewed, 17 studies were carried out in the USA, five in the UK, eight in Australia, two in Greece and one each in Canada and Germany. Therefore, all 34 studies retrieved were undertaken in western societies, illustrating the gap in the knowledge base regarding registration as a donor in non-westernised cultures. As the systematic search strategy implemented in this review found no studies from the Southeast Asian region there is an obvious need for research that explores registration motives and behaviours from a broader cultural perspective.

2.3.7.2 Methodology of choice

The dominant research design applied in the retrieved studies was quantitative with 25 surveys and two intervention studies. These studies aimed to provide an understanding of general attitudes and knowledge about donation. Four studies applied qualitative approaches with the aim of providing rich contextual detail that facilitated an understanding of life experiences and justification of human behaviour, thereby generating a different knowledge base.

Of the 25 surveys, three (Robinson *et al.*, 2012; Cohen and Hoffner, 2013; Murray *et al.*, 2013) employed a standardized tool for data collection, the Organ Donation Attitude Scale (ODAS) (Parisi and Katz, 1986). Eight used questionnaires that incorporated an established model or guidelines such as the Theory of Planned Behaviour (Godin *et al.*, 2008; Hyde and White, 2009b;

Hyde and White, 2009a; Farsides, 2010; O'Carroll *et al.*, 2011b; Hyde and White, 2013), Prototype/Willingness Model (Hyde and White, 2014), and Theory of Motivated Information Management (Afifi *et al.*, 2006). Fourteen studies (Smith *et al.*, 2004; Morgan and Lafayette, 2006; Galanis *et al.*, 2008; Morgan *et al.*, 2008b; Newton *et al.*, 2010; Salim *et al.*, 2010; Hyde and White, 2011; Joshi, 2011; O'Carroll *et al.*, 2011a; Georgiadou *et al.*, 2012; Karim, Jandu and Sharif, 2013; Feeley *et al.*, 2014; Tartaglia *et al.*, 2014; Schwettmann, 2015) employed questionnaires that were either self-constructed or developed in collaboration with clinical experts. The four studies that adopted qualitative approaches collected data via interviews (Morgan *et al.*, 2008a; Long *et al.*, 2012), the nominal group technique (Irving *et al.*, 2014) and focus group (Downing and Jones, 2018). Thus, there is limited literature examining registration as a donor from the qualitative research tradition, potentially limiting understanding of people’s beliefs as opposed to attitudes. Qualitative research is able to capture broader narratives embedded in specific contexts, thereby offering the potential to generate descriptions and explanations of why people hold particular views and engage in certain actions.

2.3.7.3 Participants included in the studies

The participants identified in the reviewed studies were from the following populations: university students (Smith *et al.*, 2004; Bresnahan *et al.*, 2007; Morgan *et al.*, 2008b; Cohen and Hoffner, 2013), customers exiting the Department of Motor Vehicles (DMV) offices in the state of New York (Feeley *et al.*, 2014), older adult age 50 years old and above (Tartaglia *et al.*, 2014; Downing and Jones, 2018) and the general public (Morgan and Lafayette, 2006; Galanis *et al.*, 2008; Godin *et al.*, 2008; Morgan *et al.*, 2008a; Hyde and White, 2009b; Hyde and White, 2009a; Hyde and White, 2010; Newton *et al.*, 2010; Salim *et al.*, 2010; Studts *et al.*, 2010; Joshi, 2011; O'Carroll *et al.*, 2011b; Georgiadou *et al.*, 2012; Long *et al.*, 2012; Robinson *et al.*, 2012; Salim *et al.*, 2012; Hyde and White, 2013; Karim, Jandu and Sharif, 2013; DuBay *et al.*, 2014; Hyde and White, 2014; Irving *et al.*, 2014; Schwettmann, 2015; Webb *et al.*, 2015). The participants in the remaining studies were a combination of university students and public (Afifi *et al.*, 2006; Farsides, 2010; Hyde and White, 2011; Murray *et al.*, 2013).

Seeking public participation in donation studies is justifiable because it is the public who are going to register and become a donor. Bresnahan *et al.* (2007) stated that most real-life organ donation campaigns try to reach people of all ages including college students, however he argues that there may be limitations in seeking a student-based sample due to the fact that samples from this population display different characteristics to the general public. For example, students may have different behaviours and values due to the educational level they have achieved and therefore their responses may not be representative of the general public who may not have attained the same educational level.

2.3.7.4 Theories identified

Four theories of behaviour and behaviour change were identified from 10 papers out of the 34 papers being reviewed. The theories are; Theory of Planned Behaviour (TPB) (Godin et al., 2008; Hyde and White, 2009; 2009; Farsides, 2010; Hyde and White, 2013; DuBay et al., 2014), Prototype Willingness Model (PWM) (Hyde and White, 2010,2014), Organ Donation Model (ODM) (Robinson et al., 2012), and Theory of Motivated Information Management (TMIM) (Afifi et al., 2006). These are listed in Table 2.6, Table 2.7, and Table 2.8 along with the lead author, year of the paper, and country of origin that utilized the theory. The dominant theories applied in the retrieved studies were TPB,). These studies aimed to provide an understanding of general attitudes and knowledge about donation. In line with past empirical research which found that TPB as a health behaviour theory has provide insights in the understanding, predicting, and changing of health related behaviour (Sniehotta et all. (2014), Meister et all. (2014), Neil et all. 2016). As an example in a study by Dubay et all. (2014) conducted in USA with an aim to identify the factors associated with becoming a registered organ donor among African American in Alabama, it provide insights into what influences African American in Alabama to engage or not to engage in organ donation registration behaviour.

2.3.8 Presentation of the results

Content analysis (Joanna Briggs Institute, 2020) of the retrieved studies resulted in the factors outlined in Table 2.9. Factors reported as influencing respondents' willingness to register or not register as a donor were identified and categorised into broad concepts: psychological motivation, social/societal factor, benefits, knowledge/information and trust (Table 2.9).

Table 2.9 Outcome of content analysis of retrieved studies: factors that influence the decision to register or not register as a donor

Factors in registering:	**Factors in not registering:**
Psychological motivation • Empathy-induced altruism ○ Desire to save lives ○ Desire to help others • Positive perception about transplant recipients' behaviour • Emotional appeal • Anticipated regret if not registered • Sense of obligation or responsibility to donate	**Psychological motivation** • Negative perceptions about transplant recipients' behaviour • Perception that their own organs would be unusable • Perception that wealthy recipient could buy the organ and that this is a

• Personal experience of a friend or family member who needed an organ • View that they should have autonomy over decision made • Perception about the ease of the process of removing organs and transplanting it to recipient • Perception of sharing the same attribute as an organ donor, feeling like a good person and how others view organ donors (positive self-image) **Social/Societal factor** • Family are supportive of organ donation • Peers have registered and this has influenced the individual • Knowing that own religion does not object to organ donation **Benefits** • Self-benefits: feelings of pride and self-worth • Reciprocal benefit of both donor and recipient: it benefits the donor in that they feel positive about themselves and happy to be able to benefit the recipients as they improve their quality of life • Avoidance of waste of an unused organ after death **Knowledge/information**	disadvantage for poorer people on the organ donation waiting list • Fear of the loss of body integrity **Social/Societal factor** • Family are not supportive of organ donation • Perceived religious objection towards organ donation **Trust** • Mistrust of the system • Belief in black market **Insufficient knowledge**

2.3.8.1 Factors influencing organ donation registration or none registration

Psychological motivation

Thirteen of the 34 retrieved studies reported psychological motivation as a key influence on the decision to donate (Galanis *et al.*, 2008; Godin *et al.*, 2008; Morgan *et al.*, 2008a; Farsides, 2010; Studts *et al.*, 2010; Hyde and White, 2011; Joshi, 2011; O'Carroll *et al.*, 2011b; DuBay *et al.*, 2014; Feeley *et al.*, 2014; Hyde and White, 2014; Irving *et al.*, 2014; Webb *et al.*, 2015). These papers outline psychological motivations that influenced registration to become a donor as outlined in Table 2.6, Table 2.7, and Table 2.8.

Altruistic deeds were most influenced by the desire to voluntarily save life and help to improve the well-being of the recipient. An individual’s judgement (Hyde and White, 2011) with regards to whether the recipient deserves to receive a donation or not appears to be part of decision making, even though it is never certain who will receive an organ at the point of registering one’s intention to donate. Emotional appeals (Studts *et al.*, 2010; Joshi, 2011) are reported as stimulating registration and appear to influence by providing narrative information about a patient waiting for a transplant, which stimulates an individual to register. This could work in stimulating more organ donation registration because emotional appeal is intended to sway a person's feelings towards pity, upset, or sympathy for others in need of an organ. The end goal of emotional appeal is to create strong empathy through feelings of pity, upset, or sympathy that later lead to organ donation registration.

Also, anticipated regret manipulation led to a significant increase in organ donor registrations as not signing makes the respondent feel bad (O'Carroll *et al.*, 2011b). This means that when anticipated regret is in play, a person’s intention or action towards something is altered because they want to avoid negative outcomes of failing to perform an action. The negative outcomes could be the feeling of fear that one day they may be in need of an organ donor and realize that they have never registered themselves, or it could also be being pressured by social surroundings for not registering as an organ donor. Similarly, if individuals know someone who is waiting for a transplant this knowledge may prompt registration (Galanis *et al.*, 2008; Joshi, 2011; Feeley *et al.*, 2014).

Autonomy over registering a decision to be an organ donor is important, with individuals believing family members cannot veto this decision (Irving *et al.*, 2014). When a person is able to make their own informed decision, it helps to satisfy their psychological needs. In the context of organ donation registration, a person meets their need for psychological autonomy when they are able to make non coerced decisions, which are meaningful decisions made willingly. The psychological need for autonomy includes the need to believe that others will respect and accept the decision made.

The retrieved studies report how psychological factors can influence the decision to donate (Galanis *et al.*, 2008; Godin *et al.*, 2008; Morgan *et al.*, 2008a; Farsides, 2010; Studts *et al.*, 2010; Hyde and White, 2011; Joshi, 2011; O'Carroll *et al.*, 2011b; DuBay *et al.*, 2014; Feeley *et al.*, 2014; Hyde and White, 2014; Irving *et al.*, 2014; Webb *et al.*, 2015), but also how psychological reasoning can influence non-registration. For example: negative perceptions about transplant recipients’ behaviour and the deservingness issues (Hyde and White, 2011 and Morgan et. all, 2008), perception that their own organs would be unusable (DuBay et al., 2014), fear it will disfigure the body and impact on the funeral (Salim et al., 2010) and perception that wealthy recipients could buy the organ and that this disadvantages poorer people on the organ donation waiting list (Salim et al., 2010). Developing a negative evaluation about transplant recipients suggests that people have preconceived notions about transplant recipients’ behaviour prior to transplantation, and among the negative evaluations is that the recipients could be alcoholics, drug users, smokers, criminals, or those with other undesirable behaviours. These negative thoughts stop people from registering. Similarly, the reflection of the conservation of the disfigured body's image plays a significant role in registration decision.

Social/societal factors

Social/societal factors were identified in eight out of the 32 studies (Morgan, 2006; Galanis *et al.*, 2008; Morgan *et al.*, 2008a; Salim *et al.*, 2010; Robinson *et al.*, 2012; Karim, Jandu and Sharif, 2013; Murray *et al.*, 2013; Irving *et al.*, 2014). Social motivation appears to refer to the influence of the community at large and/or the people around individuals who influence the decision to register as a donor. Examples of social motivation influences include familial and peer influence whereby if the family holds a positive view of donation that positive view supports the decision to register as a donor, or peer pressure whereby an individual with a family member or friend who is registered as a donor is likely to sign-up to the donation register as well.

Religion was reported as a potential influence in two papers (Morgan *et al.*, 2008a; Robinson *et al.*, 2012) where it positively influenced the registration decision (Morgan *et al.*, 2008a) and intention to donate (Robinson *et al.*, 2012). This seems to contradict survey studies as religious belief is often reported as a barrier to donation in these (Lam and McCullough, 2000; Morse *et al.*, 2009; Wakefield *et al.*, 2010). An included survey paper by Salim *et al.* (2012) also reported religion as an obstacle to donation intention as the respondents fear delay to the funeral, fear body mutilation and fear for the afterlife. This is consistent with previous studies (Karim, Jandu and Sharif, 2013; Tumin *et al.*, 2014) where a barrier to organ donation among Muslims is the belief that our body is owned by God, thus burial rituals require the body to be treated respectfully and the burial carried out as soon after death as possible. But in Morgan *et al.* (2008a) and Robinson *et al.* (2012), religious influences such as Islam, Buddism, and Christianity support organ donation as it reflects the importance of helping others.

Of note is that the terms 'cultural', 'spiritual' and 'religious' beliefs were often used interchangeably. Quantitative empirical work carried out by Bresnahan *et al.* (2007) looked at the influence of spiritual belief on willingness or reluctance to register as an organ donor in three different countries, namely Korea, Japan, and the United States. Results found in the three countries are remarkably similar, where respondents exhibiting spiritual connection with potential organ recipients exhibited a positive attitude towards donation while those who demonstrated spiritual concerns were more fearful about organ donation and were less likely to indicate an intention to become an organ donor.

Data from 11 out of 32 studies reported that family communication and opinion about organ donation are important prior to registration as a donor (Smith *et al.*, 2004; Afifi *et al.*, 2006; Galanis *et al.*, 2008; Hyde and White, 2009b; Hyde and White, 2009a; Hyde and White, 2010; Newton *et al.*, 2010; Long *et al.*, 2012; Hyde and White, 2013; Murray *et al.*, 2013; Irving *et al.*, 2014). A family that has a positive view of donation would positively influence the decision to register as a donor but family who are not supportive of organ donation would negatively influence the registration decision. Four out of the 11 papers that discuss family communication identify the following factors as being influential: outcome expectancy (Afifi *et al.*, 2006), higher income (Newton *et al.*, 2010), donor prototype (Hyde and White, 2009b), reading and perceiving organ donation messages as credible, and having a family member to witness the signing of an organ donor card (Smith *et al.*, 2004).

Outcome expectancy proposes that a person is more likely to discuss the issue of organ donation with their family if they expect that the outcome will be a positive response from the family, interaction with the family is likely to be less if the person expects a negative outcome to the conversation about organ donation (Afifi *et al.*, 2006). Individuals with higher annual incomes were more likely to communicate about organ donation with family compared to individuals with lower incomes, and this difference is attributed to the level of health-related knowledge (Newton *et al.*, 2010). Individuals of a low income group may be less willing to discuss sensitive health issues such as organ donation because they have less extensive health related information (Newton *et al.*, 2010). Donor prototypes theory proposes that a person has a socially shared view of a typical person who donates their organs upon death, and that image is informed by an altruistic stance and a wish to do good by giving (Hyde and White, 2009b). The perceived credibility of the organ donation messages read by individuals also influences family communication about organ donation intention and signing the organ donor card in front of a family member may also lead to family discussion (Smith *et al.*, 2004).

Benefits

It is interesting to note that most persons who reported altruism as the reason to sign the register also expressed certain other benefits linked to registration, such as: self-benefit, expressed as a feeling of pride and satisfaction after registering as a donor; reciprocal benefits, expressed as the donor gaining a positive feeling from the potential for a recipient to enjoy improved quality of life, and avoidance of waste, expressed as a desire to avoid wasting viable organs that could be used for transplantation to another ill person.

Knowledge/Information

This review suggested that knowledge influences the organ donation registration decision both positively and negatively (Morgan, 2006; Morgan et. all, 2008; Robinson et. all, 2012). Positive view of organ donation is very much influenced by an improved knowledge and having the right information. On the contrary, limited knowledge or not having the right information always leads towards non-registration as people do not have sufficient information to form a correct understanding of organ donation.

Knowledge about organ donation also influences discussion around this topic with family members. Lack of understanding about organ donation and not being well informed about the beneficial impact of organ donation and transplantation stops people from sharing their organ donation intention with family. Empirical research by Hyde and White (2010) explored whether people's decision to discuss organ donation with their family occurred via a reasoned or reactive pathway. A reasoned pathway leads to a discussion about organ donation after a process of individual thought, whereas in a reactive pathway discussion is spontaneous, in response to a trigger such as a television commercial.

Whilst findings from the 32 reviewed studies have provided some information about factors that might influence a family discussion about organ donation, none of the studies discuss the experience of communicating with the family about organ donation and none explore the type of information that potential donors share with their family members before and after registration, therefore it is unclear as to whether the family are aware of the final decision. Very little is known about the predictors of family discussion regarding organ donation and there is even less information about the type of information shared with family, and the implications of the discussion are unknown. It is important to uncover this in order to improve education efforts surrounding organ donation.

Trust

It is noteworthy that based on a qualitative study by Morgan et al. (2008), one of the reasons mentioned for not wanting to register as an organ donor was mistrust of doctors, hospitals, and the organ allocation system. Another issue raised in the same study was participants' belief that organs are being sold on the black market. Medical mistrust and a belief in a black market for organs have long been noted as real barriers to the willingness to donate organs. Compared with belief in a black market in organs, a smaller number of people mistrust medical professionals because they think that the medical staff would not treat, or would not do everything they can to save, a patient who is a registered organ donor. Thus, fear of mistreatment by the medical profession caused people to not register as an organ donor.

2.4 Summary of gaps in the knowledge base

Following a systematic search across a range of significant databases (Table 2.5), included studies were selected in line with preset inclusion criteria, were mapped and described to provide an overall picture of the current state of the evidence in the field. This scoping review has also allowed the researcher to identify knowledge gaps in the area of organ donation particularly in relation to organ donation intention registration. The results of the scoping review illustrate several research gaps; including the lack of studies conducted outside of western societies, the lack of knowledge around registration as a donor from the qualitative research convention which possibly limiting understanding of why people hold particular views and engage in certain actions in response to organ donation registration, as well as a lack of evidence regarding how student-based sample may be a representative of the general public view.

Current evidence relating to organ donation reported how psychological factors can influence the decision to donate but also how psychological reasoning can influence non-registration. There is less evidence if these psychological factors would similarly influence registration motives and behaviours from a broader cultural perspective particularly from the Southeast Asian region. There is an obvious need for research to uncover this gap in order to improve education efforts surrounding organ donation.

2.5 How the scoping review has informed the thesis

This scoping review is useful in establishing baseline data about the availability of research on organ donation registration and it has informed the decision made regarding methodology employed in this study. The scoping process also permits researcher to describe the extent, range, and nature of research questions, making it useful for determining this study overall research aim and specific research objectives. Thus, the research aim was to understand individual lived experiences in deciding to register as an organ donor in Malaysia.

Scoping review also has uncovered a weakness in previous research based on its design, as in quantitative research it is not able to capture broader narratives embedded in any specific contexts, thus not able to offer explanations of why people engage or refuse to engage in organ donation registration. This justifies the choice of phenomenological methodology engaged in this study. Furthermore, qualitative research, particularly phenomenology highlights how and why individual decides to register organ donation intention.

2.6 Chapter summary

In summary, and in response to each of the review objectives: i) there is a small amount of literature examining registration as a donor from non-westernised countries, particularly from the Southeast Asian region including Malaysia, ii) there is no literature that has offered any evidence regarding the type of information referred to in making a decision to register for organ donation (refer Appendix A, Table 2.6, Table 2.7, Table 2.8), iii) minimal yet contradictory literature examines religious and cultural perspectives, and iv) there is a broader literature base in relation to family influence, however little attention has been given to the predictors of family discussion concerning organ donation, and the sort of information shared with family remains unknown.

Thus, very little is known about how the intention to donate an organ becomes a decision and an act of registering, and it remains poorly understood. There is a need to carry out research into registration motives and behaviours from a broader cultural perspective, particularly for countries such as Malaysia. This lack of knowledge is the driver for the study outlined in the chapters that follow.

Chapter 3 Methodology

3.1 Introduction

Chapter 3 presents the methodology and methods applied to undertake this research study. The choice of methodology was informed by the broad aim of the research, which is to explore individual experiences of deciding to register as an organ donor, to describe the motivation driving registration and to explain how the intention to become an organ donor results in the action of registration. The chapter also presents briefly the method of data analysis, the quality assessment criteria, and the ethical considerations relevant to this study.

3.2 Aim and research objectives

This study aimed to understand individual lived experiences in deciding to register as an organ donor in Malaysia.

3.2.1 Research objectives

The specific research objectives were:

1. To explore the reasons why individuals in Malaysia decide to register as potential organ donors.
2. To explore whether religious and cultural beliefs play a role in the decision to register as a potential organ donor in Malaysia.
3. To identify what information individuals in Malaysia seek prior to registering as a potential organ donor.
4. To explore whether family communication about a decision to register as a potential organ donor takes place, and to determine the information discussed with the family.

3.3 Paradigm of inquiry

The term paradigm implies a pattern, structure, values and assumptions regarding the nature and conduct of research (Guba and Lincoln, 1994; Crotty, 1996; Creswell, 2007; Denzin and Lincoln, 2011). In simple terms, it is an approach to thinking about and doing research. Some of the most common paradigms are positivism, constructivism, and pragmatism, among others. Different paradigms support differing ontological and epistemological viewpoints and these underpinning assumptions about reality and knowledge must be considered when choosing a research methodology.

In conducting this research and in view of the objectives, a paradigm provides a framework which helps in understanding the human experience and to answer the "how" and "why" of the phenomenon of organ donation registration. The reason a person decides to register as an organ donor varies, and is socially constructed and ever-changing depending on their social context and interactions: this is a reflection of a constructivist paradigm. This paradigm is alternatively known as a naturalistic (Guba and Lincoln, 1994) and interpretive paradigm (Guba and Lincoln, 1994; Merriam and Tisdell, 2016). Guba and Lincoln (1994) state that a research paradigm is fundamentally associated with philosophical assumptions concerning ontology, epistemology and methodology.

Creswell (2007) argued that ontological assumptions are concerned with what constitutes reality. Researchers need to take a position regarding their perceptions of how things really are and how things really work, and this position differs between, for example, a positivist paradigm and a constructivist paradigm. The positivist paradigm seeks to generalize, thus a positivist researcher claims that there is one single truth or reality which can be observed and measured; while the constructivist paradigm seeks to understand, thus a constructivist view is that there is no single reality, as each individual views reality through the lens of his or her prior experience and knowledge (Guba and Lincoln, 1994). In understanding the 'why' factor in organ donation registration, it means different things to different people depending partly on social and cultural context. It is therefore appropriate for this study to adopt a constructivist approach embracing the idea of multiple realities; the view that reality is subjective and differs from person to person.

Epistemological assumptions are concerned with how knowledge is created, acquired and communicated. In constructing knowledge within qualitative inquiry, researchers need to recognise the importance of the participant's context, as the primary objective is to gather information from the interviewee's world view. In qualitative research, researchers need to remind themselves that in understanding a phenomenon, people construct meaning in different ways depending on the individual's perspective, and on the historical and cultural contexts in which they have lived. This leads the researcher in choosing the paradigms of enquiry.

On that note, and in view of the aims and objectives of this study, an approach from the constructivist paradigm of inquiry has been selected so that the "how" and "why" of the phenomenon under investigation can be explored (Green and Thorogood, 2009). A principle of the constructivist paradigm is that events or phenomena cannot be isolated from the context within which they occur, as these are inextricably linked. The ontological position of constructivism is relativist: reality is viewed as subjective, differing from person to person (Guba and Lincoln, 1994). For example, in this research, in deciding to register an organ donation intention, each individual's decision may be influenced by factors including social and cultural contexts. Therefore, the experience of making the decision to register as an organ donor may vary greatly among individuals, potentially leading to the construction of multiple perspectives of the same phenomena. It is therefore appropriate that this study adopted a constructivist stance whereby reality is considered as subjective, yet situated within historical, social and cultural dimensions.

From an epistemological standpoint on the processes of obtaining valid knowledge, a constructivist stance accepts that reality is constructed, interpreted, and experienced by people in their interactions with each other and with wider social systems (Guba and Lincoln, 1994; Merriam, 2002; Maxwell, 2005). In line with this epistemological stance, the choice of methodology - the why, what, from where, when and how data is collected and analysed - must support these philosophical assumptions.

3.4 Methodology

As stated, the selection of a research methodology is underpinned by ontological and epistemological assumptions. The constructivist ontology and interpretivist epistemology underpinning the constructivist paradigm requires a research methodology that enables the researcher to explore meaning that is embedded in the participant's experiences. In view of the research question guiding this study, and in order to gain an understanding of the organ donation registration phenomenon in real-life situations, a phenomenological methodology was chosen with the expectation that it would facilitate an in-depth examination aimed at understanding social phenomena in the natural world (Moustakas, 1994). Furthermore, phenomenology is particularly useful for exploring a problem or situations about which relatively little is known (Morse and Field, 1996). The intention behind adopting a phenomenological methodology was to move beyond simply describing surface views and preferences, thereby facilitating the description of the feelings, experiences and reasons behind the act of deciding to register as an organ donor.

3.5 Phenomenology: descriptive phenomenology

There are various operational definitions of phenomenology including an in-depth investigation of the lived experience (Moustakas, 1994; Crotty, 1996; Merriam, 2002; Creswell, 2007) in order to be able to describe in detail and make sense of a phenomenon of interest (Patton, 2002). In general, when conducting a phenomenological study, the focus is on the way things appear to us through experience or in our consciousness, where the phenomenological researcher aims to provide a rich textured description of a lived experience (Finlay, 2013). Scholarly work on phenomenology began in the early 20th century in the works of several scholars associated with the methodological framework of phenomenology. Phenomenology has been applied in a number of professional practices such as psychology (Wertz, 2005; Todres, 2007; Giorgi, 2010), nursing (Rose, Beeby and Parker, 1995; Lawler, 1998; Todres and Galvin, 2006), and education (van Manen, 1990).

The foundations of phenomenology are credited to the work of German philosophers such as Edmund Husserl (1859-1938), who is viewed as being the founder of the phenomenological movement. The phenomenological movement was advanced by Martin Heidegger (1889-1976), Husserl's student, who in turn influenced the work of French philosophers Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1907-1961). Husserl and Heidegger proposed different schools of phenomenological thought, with Husserl's approach being referred to as descriptive phenomenology (Giorgi, 1970; Giorgi, 2007) and Heidegger's approach being referred to as interpretative phenomenology (Koch, 1995).

3.5.1 Husserl's philosophy of phenomenology: descriptive phenomenology

Husserl's approach to phenomenology emphasized the scientific study of the essential structures or essences of phenomena as they appear in consciousness (Giorgi, 1985; Moustakas, 1994; Giorgi, 1997; De Castro, 2003; Giorgi, 2010;2012). Authors define being conscious as being aware of a phenomenon, aware of our life experience, or aware of an object (Mohanty, 1954; Costello, 2006; Finlay, 2009). Objects as defined by Husserl may be physical objects, events, or abstract objects such as intentions and anything else that we conceive with our minds (Mohanty, 1954; Costello, 2006). This consciousness of mind about something (an object) is intentional in so much as that whenever we are conscious, we are conscious of 'something'. In the context of the study undertaken, I aimed to identify the structures underpinning the intention to register as an organ donor (the phenomena), which also became the object of analysis.

Husserl's central idea of intentionality is that in doing something we do it consciously and deliberately (McIntyre, 1982), therefore all conscious awareness is intentional awareness. The term intentionality indicates the orientation of the mind toward the object or event (McIntyre, 1982; Moustakas, 1994). In other words, intentionality has to do with the directedness or reference of mind to things, objects, or events. Therefore, analysis sought to understand what the conscious and deliberate intention to register/not register as an organ donor was based on.

Additionally, Husserl's phenomenology acts as the basis from which the other strands of phenomenology originate (Moran, 2000). Husserl emphasized the importance of carefully describing the essence of the phenomenon, arguing that at its core, phenomenology is descriptive, but that this does not rule out interpretations (Giorgi, 2012). For Husserl, interpretation is when the researcher reflexively analyses the participant's descriptions and offers a synthesized account, for example, general themes about the essence of the phenomenon (Giorgi, 2007; Finlay, 2009).

To understand the phenomenon being explored, Husserl recommended that phenomenologists suspend all suppositions of their own experience of the phenomenon (Creswell, 2007). This suspension is achieved by bracketing (discussed in detail in section 3.5.2), which involves putting aside what the researcher already knows about the experience being investigated, and approaching the data with no preconceptions about the phenomenon (Dowling, 2004; Lopez and Willis, 2004). However, Heidegger, building on the work of Husserl, modifies Husserl's theories developing interpretative phenomenology, also known as hermeneutic phenomenology. Primarily, Heidegger eliminated bracketing, asserting that impartiality or neutrality is impossible because researchers are as much a part of the research as the participant, and that their ability to interpret the data is reliant on previous knowledge and experience (Lopez and Willis, 2004). Heidegger suggests that it is impossible to free the mind from preconceptions, ideas or biases and approach something in a completely unbiased or neutral way. The building of our knowledge of a phenomenon should therefore start with conscious awareness of the person experiencing it (Giorgi, 1985; Koch, 1995). The way to study conscious experience is by asking the person who is experiencing it to reflect on their experiences.

3.5.2 Justification for choosing Husserl's descriptive phenomenology

The selection of descriptive phenomenology was driven by the principal aim of this study, which is to understand the phenomenon of registering as an organ donor, but also as the process of bracketing was seen as a strength because it requires the researchers to reflect on and articulate their own previous knowledge and/or experiences, so that the focus of analytical thinking is on the participant's story.

Bracketing is a key concept in Husserl's phenomenological philosophy where it is used to refer to suspending judgement about a natural world (Gearing, 2004; Christensen, Welch and Barr, 2017). The aim of bracketing is to assist the researchers to detach themselves from what they already know, so that they can encounter the phenomenon being studied whilst setting aside prior assumptions. Bracketing is done by means of entering into an attitude of phenomenological reduction (Giorgi, 1997). To enter into the reductive attitude by means of bracketing, the writing of memos and a reflective diary were utilised in this study. A reflective diary was used to make assumptions and biases explicit before setting them aside at the beginning of the research process, to clarify thinking on a research topic, and to provide a mechanism for me to express assumptions and subjective perspectives about organ donation registration. Analytic memoing was employed throughout data collection and analysis, which enabled me to engage with the raw data and question it from a unique perspective that otherwise may not have been possible. Analytic memoing was done by asking questions such as “what is actually going on here with the data?”

For Husserl, the bracketing processes described above are key in facilitating the researcher’s move away from scientific and other knowledge to gain access to what Husserl refers to as ‘the things themselves’ (Wertz, 2005). By bracketing scientific preconceptions, for example theories of unconscious behaviour in relationship to organ donation registration, Husserl argues that an epoché of natural attitude can be achieved. However, this process involves more than simply purifying oneself of bias and prejudice, instead it involves entering a new way of looking at the phenomena of interest. The epoché of natural attitude is now commonly referred to as eidetic reduction, a cognitive process through which patterns of meaning related to the phenomenon of interest are identified. Eidetic reduction is the process by which the researcher attempts to describe meaning or the essences of the phenomenon.

Eidetic reduction poses some challenges to me as a novice researcher, as the process by which it is achieved is not something that Husserl made explicit in his writing. Phenomenologists around the globe agree that putting something in ‘brackets’ and in a ‘reduction’ to achieve an open attitude is of value but what it involves specifically is still unclear (Finlay, 2009). In fact, the analytical process in descriptive phenomenology is one that has generated discussion in view of the fact that Husserl’s approach to phenomenology does not articulate a clear framework for undertaking analysis (Wertz, 2005; Costello, 2006; Giorgi, 2007;2012). Some researchers believe that bracketing only occurs during data collection and analysis (Ahern, 1999; Hamill and Sinclair, 2010; Zenobia C.Y. Chan, Yuen-ling Fung and Chien, 2013). However, I believe it should occur throughout the study, even at the development of research objectives as discussed earlier. The lack of framework to provide guidance particularly around analysis led to a review of what phenomenologists who developed Husserl’s ideas have done. Three frequently used methods for phenomenological analysis are the methods of Colaizzi (1978), Giorgi (1985), and Van Kaam (1966), which the data analysis method was based on Husserl’s descriptive phenomenology (Dowling, 2007); Reiners, 2012).

Colaizzi, Giorgi, and Van Kaam formulated three different methods of data analysis (Reiners, 2012), and each method employs a similar series of steps (Dowling (2007). All three methods involve a search for common patterns to describe the meaning of an experience. However, there are differences among these approaches; for example in Colaizzi's final step which involves the researcher to validate the findings by returning to participants, while Giorgi's analysis relies solely on researchers and he disapproves of validation by the participants as he argues that asking the participants to evaluate the findings is inappropriate, since they had described their experiences from the perspective of everyday life, whereas Van Kaam's method requires that inter subjectivity be confirmed with other expert judges (Dowling, 2007; Giorgi, 2008; Reiners, 2012; Morrow *et al.*, 2015). Additionally, Van Kaam uses the concept of 'co-researcher' to describe how the researcher and participant come together to explore the lived experience of the phenomena under phenomenological investigation. Giorgi commented from the perspective of practicality on both Colaizzi and Van Kaam's analytical techniques, that these were time consuming and unnecessary, and defeated the purpose of bracketed analysis from the perspective of psychology. Therefore, based on these differences and due to practical reason, it has led to the choice of the analytic framework developed by Amedeo Giorgi (1985).

Giorgi's framework evolved by bringing together four characteristics aligned to Husserl's philosophy; it is rigorously descriptive, it uses reduction, it focuses on intentionality, and it searches for essences (Giorgi, 1985; De Castro, 2003). Giorgi emphasizes that the operative word in phenomenological research is to carefully describe the experiences being lived, refraining from any pre-given framework while remaining true to the facts obtained from raw data. Giorgi advocates that descriptions of an experience are gained from others, rather than undertaking a personal philosophical reflection on experience.

Furthermore Giorgi, who has a natural sciences (field of vision) background, was highly motivated to understand the whole human person (Giorgi, 2012). Thus in his early career as a researcher, after engaging with the approach to phenomenology as described by Husserl, Giorgi began to develop a frame of reference for studying human experiential and behavioural phenomena (Giorgi, 2012). Thus, Giorgi developed a practical analytical process for application in descriptive phenomenological research, which comprises five steps (Table 3.1). The systematic framework that Giorgi developed has been widely used in the field of psychology and in recent years it has been applied in health sciences research as a means of understanding the experiences of illness and nursing care (Koch, 1995; Crotty, 1996; Finlay, 2009).

A further factor informing my choice of Giorgi's framework is that I am a novice researcher whose previous experience with research has been quantitative, therefore I recognised the benefits to me as a learner of having a framework that facilitates the process of analysis by following a step-by-step approach. In Giorgi's perspective analysis is performed from the phenomenological perspective as well as from a disciplinary perspective (e.g.; psychology). Giorgi's phenomenological psychological method appeared understandable and applicable to this study. Central to Giorgi's phenomenological psychological is the lived experience of the individual as it is recalled to consciousness (Giorgi, 2007;2010). Since the focus of this research is to specifically look at the factors that underpinned the experience of deciding to register or not register as an organ donor and this process stimulates both cognitive and emotional processes; and in view of the fact that Giorgi's informing theoretical lens is psychology, it is argued here that Giorgi's framework was the most appropriate phenomenological analytic approach for this study.

3.5.3 Giorgi's analytical process

As a follower of Husserl, Amedeo Giorgi (1970;1985; 1997;2007;2010;2012) argues that there should be a systematic process by which data is analysed so that the process can be replicated, generating robust findings. Giorgi's work commenced in the 1970s when he began the development of a rigorous analytical framework which combined philosophical, scientific and psychological approaches and is heavily dependent on the thoughts of Husserl (Giorgi 2010). Giorgi situates himself within four principal characteristics of phenomenology, similar to Husserl; it is descriptive, it uses bracketing, it searches for essences, and it is focused on intentionality (Giorgi, 1985; De Castro, 2003; Giorgi, 2012). The first characteristic refers to the idea that analysis has to follow the naïve description given by participants instead of giving an explanation from a theoretical standpoint, this then links to the secondary characteristic, whereby Giorgi uses bracketing. The third characteristic is the search for essences, in which Giorgi looks for unchangeable characteristics of the particular phenomenon under study. The fourth characteristic is intentionality, which refers to the intentional act by which every human being is related to the objects or event.

It is important to remember that central to Husserl's approach to phenomenology, is the uncovering of true meanings, and this emphasises the importance of being true to the original source. This study sought to describe the meaning and fundamental elements of the organ donation registration decision as perceived by the registered organ donor, rather than the interpretation of experience by the researcher. This linked to Giorgi's position (1997) on bracketing where he demands that the phenomenological researcher must be able to conduct analysis within the reductive attitude, otherwise no phenomenological claims for the analysis could be made. Thus, the phenomenological claim can be made when the researcher adopts the attitude of phenomenological reduction via bracketing, by withholding past knowledge about the phenomenon of enquiry in order to be fully present to the true meaning of the phenomenon as presented by the participant.

However, Giorgi's approach to the analysis of phenomenological data has been contested because it relies exclusively on the participant's description, and many phenomenologists deny that it is possible to bracket the researchers' own experience (Halling, *et al*, 2006; Finlay, 2009; Davidsen, 2013). They argued that in order for the researcher to reach a greater understanding of phenomena, researchers need to be sensitive of their pre-existing beliefs, which then makes it possible to examine those beliefs in a more complex and sensitive way of thinking which allows some interpretation. Still, Giorgi indicates that this issue is not problematic to phenomenological research as he argues that if a researcher reads the participants descriptions without bias and refrain from postulating, this permit the researcher to describe the transcript from the participant's perspective. Thus, the quality of the findings is not compromised (Giorgi, 1997) as bracketing is a ways of signifying the validity of the data collection and analysis process (Giorgi, 1997; Ahern, 1999) as researchers put aside their knowledge and experiences in order to truthfully describe participants' experiences.

Thus, the adoption of descriptive phenomenological psychology determined the most appropriate approaches to data collection and analysis. The adoption of Giorgi's five-step framework (Table 3.1) appeared practical for this study and based on the aim of the research, which was to understand the individual lived experiences in deciding to register as an organ donor in Malaysia. As decision-making is a fundamentally psychological process and Giorgi's focus is the analysis of the condition of human experience and how meaning is composed of experiences, the approach was a fit with the ontological and epistemological stance of the study (Applebaum, 2010; Applebaum, 2011; Applebaum, 2012). Thus, Giorgi's framework was chosen to guide analysis in this study (Chapter 5).

Table 3.1 Giorgi's framework: Five steps of data analysis

Steps	**Description**
Step 1:	Gaining a sense of the whole
Step 2:	Discrimination of meaning units within a psychological perspective focused on the phenomenon being studied
Step 3:	Transformation of subjects' everyday expressions into psychological language with emphasis on the phenomenon being investigated
Step 4:	Synthesis of transformed meaning units into a consistent statement of the structure of the experience
Step 5:	Final synthesis

Therefore, the methodology of descriptive phenomenological psychology applying Giorgi's five-step analytic framework was adopted to undertake this research study, which seeks to understand the act of registering as an organ donor in Malaysia.

3.6 Ethical considerations

There are ethical considerations when carrying out any research. In preparation for the ethical application (Ethics ID: 21312), the following ethical principles outlined by The Royal College of Nursing (2009) were addressed; informed consent, confidentiality and anonymity, autonomy, and nonmaleficence.

3.6.1 Informed Consent

Informed consent is central to ethical practice and this means that every participant must be fully informed of the research aim and potential benefits and harms of the research carried out. Therefore, as part of the recruitment process, participants received detailed written information about the study in the form of a participant information sheet (PIS) (Appendix G and H). Outlined in the PIS are the following; the purpose of the study, method of information gathering, level of participant involvement, assurances of confidentiality and anonymity, level of risk, and their right to withdraw from the study without prejudice. Furthermore, prior to interview, participants were given the opportunity to ask questions about the research and gain answers directly from the researcher in a language that the participant could understand.

3.6.2 Confidentiality and anonymity

After the participants were fully informed and had agreed to participate, they were asked to sign a consent form (Appendix I). By signing, participants agreed to audio recording of the interview, material from the interviews being anonymised and then used in subsequent dissemination activities including publications, and for secondary analysis of the transcripts to be undertaken by the researcher in the future, and their right to withdraw at any time was made known to them. Participants were asked to keep one copy of the consent form and the researcher retained the other copy. In keeping with the established standards for confidentiality, no information that may lead to the identification of any participant is included in the thesis. Anonymity of the participants' identity is ensured by the use of pseudonyms. The only person to have access to the audio recording and transcripts was the researcher, while two supervisors had access to the translated transcripts for the purpose of guiding the researcher in the analysis process and monitoring the rigour of the analysis.

3.6.3 Autonomy

Every researcher should respect and protect the rights, dignity and autonomy of their participants. Therefore, participants were given the right to withdraw from the study at any time without providing a reason for doing so. This right was stated in the participant information sheet and the consent form and it was discussed with participants before and after interview. In the information sheet, the purpose of the study and the use to which the data would be put was made clear to participants. These statements, the study design and the seeking of informed consent set up the relationship between the interviewer and interviewee, shaping expectations.

3.6.4 Nonmaleficence

Research must not cause harm to the potential participants in particular, and to people in general. Thus, risks to participants must be minimized and justified by the potential benefits. Possible harm can include physical, emotional, social and financial harm. In the context of this study, there was no risk of physical harm, but potential for emotional harm was considered.

To facilitate participant discussions and emotional comfort I undertook training in interview methods before commencing data collection. The skills acquired have enabled me to respond to participants' needs and recognise potential emotional changes, for example, there were two participants who disclosed personal and sensitive matters which caused them to become upset (discussion of death and dying etc.). When this occurred, the interview was paused to provide time for the participants to consider whether they wanted to continue. In both interviews, the participants consented for the interview to continue.

In preparation for the interviews, as outlined in the participant information sheet, participants were prompted to identify a person who they felt could support them during and after the interview if needed. After the interview, a thank you letter (Appendix M) was sent out to participants to show appreciation for their participation in the research.

3.7 Quality in qualitative studies

When conducting any research study the issue of quality is an important consideration. Seale (1999) claims that quality in qualitative research can be assessed in terms of validity and reliability, where validity refers to the appropriateness of methodology, design, sampling and the data analysis process to answering the research question, and reliability refers to the transparency and documentation of decision-making in relation to methodology, methods and the data analysis process. Commonly in qualitative research, the concepts of validity and reliability are assessed by the following four criteria: credibility, transferability, confirmability, and dependability (Denzin and Lincoln, 2011; Seale, 2012). These criteria to establish the rigour and trustworthiness of qualitative studies are recommended by Guba and Lincoln (1994) and these same criteria facilitate the evaluation of data trustworthiness in a descriptive phenomenological psychological study (Giorgi, 2008). These criteria were applied to this study to ensure rigour in the research undertaken (Table 3.2).

Table 3.2 Criteria to assess rigour of qualitative study adapted from Lincoln and Guba (1994)

Criteria for judging	**Strategies applied in this study to achieve the criteria**
Credibility Establishing that the results of qualitative research are credible or believable from the perspective of the participant in the research or the reader of the research.	• *Triangulation* Triangulation involves using either two or more different methods, researchers, and data sources. The two main sources of information concerning the decision to register organ donation intention were; registered potential organ donor and non-registered potential organ donor. • *Reflexivity* Transparency of method is facilitated by documentation of the detailed process of data collection and analysis including the use of field notes and any reflective notes. • *Negative case analysis* Negative case analysis improves the credibility of the study because the researcher accounts for the alternative and varied perspectives that are generated during analysis as opposed to ignoring them. The non-registrants were beneficial as it provided a negative case analysis in this research.
Transferability Results of the research study can be applicable to similar situations or individuals.	• *Thick description* A very detailed or thick description of a setting can give a reader of a research report the indirect experience of 'being there' and the reader can then assess the similarity of the setting described in the report to settings in which she or he has personal experience (Seale, 2012).
Confirmability The extent to which the results could be confirmed or validated by others.	• *Reflexivity* Transparency of method is facilitated by documentation of the detailed process of data collection and analysis including the use of field notes and any reflective notes. • *Audit trail* An audit trail is a transparent description of the conduct of the research from the start of the project to the development and reporting of findings (Koch, 2006). An audit trail facilitates quality judgements about the conduct of the research process. This involves documentation of data, methods and the rationale of decisions made during a project (Seale, 2012).

Dependability To ensure the findings are repeatable if the inquiry occurred within the same cohort of participants, coders and context.	• *Audit Trail* An audit trail is a transparent description of the conduct of the research from the start of the project to the development and reporting of findings (Koch, 2006). An audit trail facilitates quality judgements about the conduct of the research process. This involves documentation of data, methods and the rationale of decisions made during a project (Seale, 2012).

Five strategies were applied in this study to achieve the criteria for judging rigour (Table 3.2). The strategies were triangulation, reflexivity, negative case analysis*,* thick description, and audit trail, some of the strategies facilitated assessing more than one criterion.

Triangulation was particularly helpful in order to increase credibility of this research. It involves using different sources of information in order to increase the validity of the study. The two main sources of information concerning the decision to register organ donation intention were registered potential organ donors and non-registered potential organ donors. The non-registered potential organ donors were beneficial as they provided a negative case analysis in this research. However, the literature as well as inputs from supervisors during supervision becomes additional sources of information to inform this study as whole.

Negative case analysis was undertaken when initial ideas in the developing analysis appeared to be contradicted or questioned by ongoing analysis. By focusing on the 'negative case' for example, an alternative perspective, or views that was in sharp contrast to those reported by participants and exploring these alternatives explanations the credibility of the findings are increased. Negative analysis is only achievable if the data collected is of sufficient depth and provides, what is referred to as 'thick descriptions'.

Thick description is important when writing up the results of a study as the researcher need to provide wide-ranging of information about; the participants of the study, location and methods of data collection, the quality of the interview questions, and other aspects of data collection that help provide a richer and fuller understanding of the research setting. To have a thick description and a robust data researcher need to constantly return to the transcripts. A thick description of methods and findings is important because it allows readers to make an informed judgment if they can transfer the findings to their own situation. If a thick description is not available, it is difficult for the reader to determine the extent to which the overall finding is true. Therefore, to ensure transferability of qualitative study the researcher must be able to write thick descriptive data, which allows comparison of this context to other possible contexts to which transfer might be contemplated.

The dependability of any research cannot be assumed it must be demonstrated by making the processes undertaken in the study transparent. An audit trail was employed to demonstrate a transparent description of the research steps taken from the start of this study to the reporting of findings. An audit trail is a qualitative strategy to establish the confirmability, dependability and credibility of a research study. This transparency was achieved in this thesis by the use of field notes and reflective notes (see Section 4.2.4.2, page 64) provided a description, explanation or justification of key points of decision making and research processes, for example; who and how to recruit participants, how data were collected, how long the data collection period would last, the settings in which data were collected, how data were transcribed and analyzed, how biases were acknowledged to minimise their impact and the comprehensiveness of the categories developed from the data.

In summary, the use of field notes and reflective notes were critical to the trustworthiness, confirmability, and transferability of the study findings.

3.8 Chapter summary

Chapter 3 has presented the methodology of descriptive phenomenology that underpinned the research undertaken and presented in this thesis. Chapter 3 has discussed the philosophical assumptions, ontological and epistemological perspectives informing the generation of knowledge in the presented research and outlines how the quality of the research process was assessed. Chapter 4 presents the design of, and the methods adopted, in carrying out the research.

Chapter 4 Design and methods

4.1 Introduction

Chapter 4 presents the study design, participants, sample size, recruitment, and the method of data collection applied to undertake this research study. In addition, the chapter also addresses the data management and storage of data relevant to this study.

4.2 Recruitment process

As this study aimed to explore the experience of deciding whether to register or not to register as an organ donor, and to understand the motives behind the decision-making process in Malaysia, the first step was to establish viable routes to recruitment and confirm that the proposed number of participants invited to participate in the study was feasible.

The recruitment process started with making contact with the National Transplant Resource Centre (NTRC) in Malaysia. The NTRC provided the following data. The total population of registered organ donors in Malaysia = 310, 391 individuals with the following distribution by ethnic group: Chinese = 141, 992 (45.7%), Malay = 80, 561 (26%), Indian = 74, 330 (24%), and other minority races = 13, 443 (4.3%). The largest proportion of registered organ donors, about 80 thousand (26%) is based in Kuala Lumpur, the capital city of Malaysia and therefore this was the target location for recruitment.

In order to assess potential participant numbers prior to commencing the study, an informational flyer (Appendix B) was developed and circulated to the public during Organ Donation Awareness Week, which ran from the 3rd – 10th of October 2015 in Kuala Lumpur. The flyer was also distributed by the staff at the NTRC to potential registrants who walked-in to the NTRC office during Organ Donation Awareness Week to discuss organ donor registration or to register their organ donation intention. Flyers were handed out to individuals who fulfilled the inclusion criteria as in Table 4.1. Among the criteria were that they were over the age of 18 and able to speak Malay or English. The NTRC staff explained that this study would be taking place in the future and sought the person’s agreement to be contacted by the researcher to discuss participation in the study.

Throughout the distribution timeframe of the flyer (during Organ Donation Awareness Week, 3rd – 10th of October 2015) where NTRC staff approached individuals who attended the one-week event, but the number of individuals that NTRC approached and given a flyer was not collected by NTRC and that this was omission. There is also no evidence of whether the individuals approached by NTRC were all over 18 and it's unclear if those approached could actually speak either Malay or English.

However, during the distribution timeframe of the flyer, if potential participants that were approached and given a flyer by NTRC agreed to be contacted, they were asked to sign the agreement for contact section on the flyer (Appendix B). After one week, a total of 28 individuals had agreed to be contacted by me to discuss participation in the research study. The Head of NTRC agreed to store these contact details until ethical approval for the study had been granted (Appendix C).

Participant inclusion criteria (Table 4.1) were developed not just to inform discussions with NTRC staff, but also to guide the final selection of participants once the contact details from the NTRC were available to the researcher. The inclusion criteria underpinned the purposeful sampling technique utilised to identify and recruit individuals who had registered as organ donors. Purposeful sampling facilitated the selection of information-rich cases with the potential to provide an insight as well as an in depth understanding (Ritchie and Lewis, 2003). Since this study also aimed to trace individuals who might have the intention to donate but who decided not to register as an organ donor, a snowballing technique was employed, where a participant is asked to recommend others (anyone that had expressed an interest in organ donation but had decided not to register) to interview (Creswell, 2007).

Table 4.1 Participant's Inclusion criteria

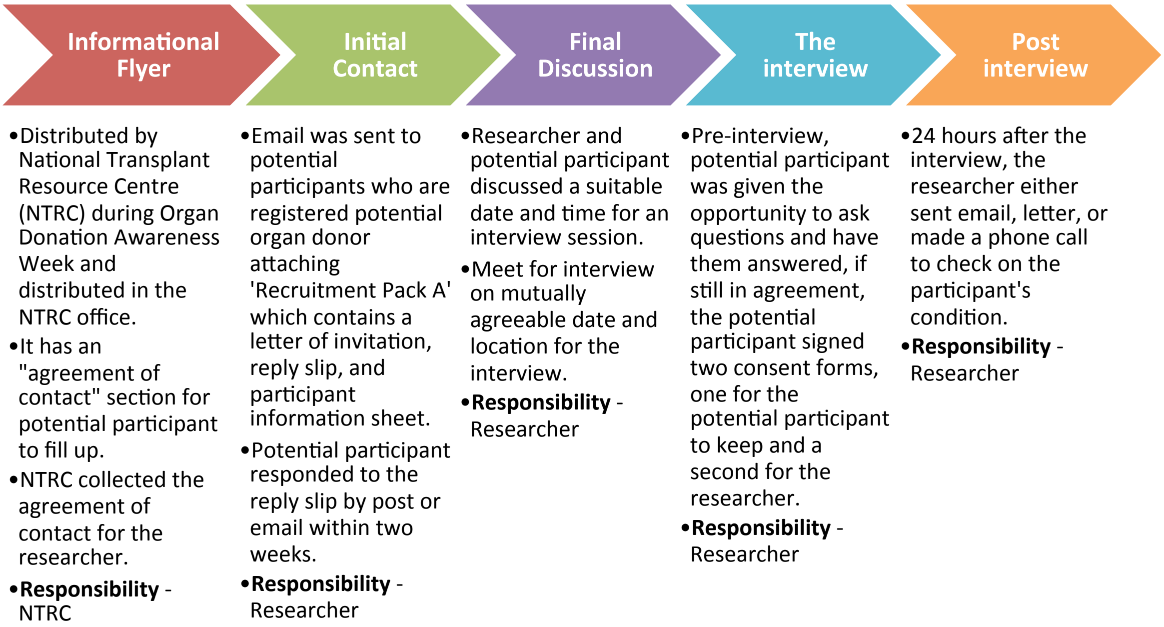
Inclusion Criteria	**Rationale**
Registered organ donor	Potential participants must be registered organ donors as the main aim of this study is to explore their experience in deciding to register as an organ donor.
Not registered as an organ donor	Potential participants who are not registered may also be included in this study in order to understand their decision in deciding not to register as an organ donor.
Malay or English speaking	The researcher can speak Malay and English thus this study is limited to those who are able to speak either Malay or English languages.
Socio-demographic criteria: 18 years and above	Participants must be 18 years old and above as that is the minimum age to register as an organ donor in Malaysia.

4.2.1 Recruitment process: registered organ donors

Post ethical approval (Ethics ID: 21312), which was a process required by the University of Southampton before embarking on fieldwork, the Head of NTRC provided the contact details of 28 potential participants who had agreed to be contacted by the researcher.

Initial contact with all 28 potential participants was made via personalised email with attachments including a letter of invitation, reply slip and participant information sheet (PIS) (see Appendix D, F, G). The PIS outlined the purpose and conduct of the research. Contact details were provided so that participants could make contact with the researcher. Upon receipt of the email and the necessary information, potential participants were asked to respond via the reply slip or email to discuss a suitable date, time and location for an interview. All 28 potential participants responded and agreed to an interview. Figure 4.1 illustrates the recruitment process for registered potential participants.

Figure 4.1 Recruitment process for registered potential participants



Informational Flyer

- Distributed by National Transplant Resource Centre (NTRC) during Organ Donation Awareness Week and distributed in the NTRC office.
- It has an "agreement of contact" section for potential participant to fill up.
- NTRC collected the agreement of contact for the researcher.
- **Responsibility** - NTRC

Initial Contact

- Email was sent to potential participants who are registered potential organ donor attaching 'Recruitment Pack A' which contains a letter of invitation, reply slip, and participant information sheet.
- Potential participant responded to the reply slip by post or email within two weeks.
- **Responsibility** - Researcher

Final Discussion

- Researcher and potential participant discussed a suitable date and time for an interview session.
- Meet for interview on mutually agreeable date and location for the interview.
- **Responsibility** - Researcher

The interview

- Pre-interview, potential participant was given the opportunity to ask questions and have them answered, if still in agreement, the potential participant signed two consent forms, one for the potential participant to keep and a second for the researcher.
- **Responsibility** - Researcher

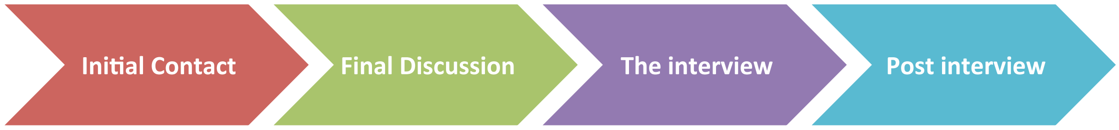
Post interview

- 24 hours after the interview, the researcher either sent email, letter, or made a phone call to check on the participant's condition.
- **Responsibility** - Researcher

4.2.2 Recruitment process: non registered

This study also aimed to trace individuals who might have had the intention to donate but had decided not to register as an organ donor (Figure 4.2). These potential participants were sought using a snowballing technique whereby all participants who were a registered organ donor were asked if they knew of anyone that had expressed an interest in organ donation but had decided not to register. If participants were in agreement to facilitating recruitment they were provided with Recruitment Pack B, which include a letter of invitation for non-registered organ donor, reply slip and participant information sheet (PIS) for non-registered organ donor (see Appendix E, F, H) to pass on. A total of 7 participants who were a registered organ donor agreed to assist, thus they were given Recruitment Pack B to pass on to individuals who were non-registrants. Potential participants who are non-registrants could then make an informed decision to make contact with the researcher themselves by returning the reply slip that was included in the 'Recruitment Pack B'. Upon receipt of the reply slip via email, potential participants who are non-registrants were asked to suggest a suitable date, time and location for an interview. A total of three potential non-registrant participants responded and agreed to an interview. Figure 4.2 illustrates the recruitment process for non-registered potential participants.

Figure 4.2 Recruitment process for non-registered potential participants



Initial Contact

- Participants who are registered potential organ donors who have been interviewed helped researcher to locate this group of participants by passing a 'Recruitment pack B' which contains a letter of invitation, reply slip, and participant information sheet to anyone they think might be interested.
- Potential participant responded to the reply slip by email.
- **Responsibility** - Researcher

Final Discussion

- Researcher and potential participant discussed a suitable date and time for an interview session.
- Meet for interview on mutually agreeable date and location for the interview.
- **Responsibility** - Researcher

The interview

- Pre-interview, potential participants were given the opportunity to ask questions and have them answered, if still in agreement, the potential participants signed two consent forms, one for the potential participant to keep and a second for the researcher.
- **Responsibility** - Researcher

Post interview

- 24 hours after the interview, the researcher either sent email, letter, or made a phone call to check on the participant's condition.
- **Responsibility** - Researcher

4.2.3 Outcome of recruitment

Recruitment strategies resulted in 31 potential participants (Table 4.2). A total of 28 registered organ donors and 3 non-registered from the three main ethnic groups in Malaysia: Malay, Chinese, and Indian. After contact with all 31 potential participants all agreed to undertake an interview either face-to-face, by telephone or by Skype.

After discussion with the 28 registered participants, five potential participants could not participate in an interview due to geographical location and lack of landline access or Skype facilities. As these potential participants had already logged their interest in the study, an amendment was made to the Ethics and Research Governance Online (ERGO), requesting agreement for these five potential participants to be offered an e-mail interveiw. Following ERGO approval (22 November 2016), these potential participants were recontacted via e-mail (Appendix J) requesting their agreement to participate in an interview via e-mail. Participants were asked to respond within one week by sending the completed consent form back. None of the five potential participants responded after one week and one further e-mail.

Of the remaining 23 registered donors who had agreed to undertake a face-to-face or Skype/telephone interview, 16 participants completed interviews. Due to the window for data collection ending, the remaining seven participants were contacted and an apology and thanks for their interest in the study was extended (appendix K). These seven participants were offered a summary of the completed study; however none communicated any interest in the summary.

While for the three non-registrant participants who had been in contact by returning the reply slip via email and had agreed to undertake a face-to-face or Skype/telephone interview, all three of them completed interviews.

Table 4.2 Summary of sample post recruitment

Registration status	**Outcome**	**Number of potential participants**	**Total= N**
Registered donors	Contact by e-mail, N = 28 Failed contact with, N = 5 Agreed to participate via face-to-face, telephone or Skype interview, N = 23 Insufficient time due to window for data collection ending, N = 7 Completed interviews, N = 16	28	16
Non-registered donor	Completed interviews N = 3	3	3
TOTAL		31	19

4.2.3.1 Demographic data

Overall participant ages ranged from 23 to 47 years with a mean age of 32. There were 16 females and three males recruited. Ten participants were from urban areas as they lived in close proximity to Kuala Lumpur, and the other nine lived in sub-urban/rural areas. Two participants were educated to Diploma level, 10 participants held a Bachelor degree, and seven participants held a Master's (Table 4.3).

In comparison of the two groups; registrants and non-registrants, all three non-registrant participants were female while for the registrant participants it is a combination of both male and female with three and 13 respectively. The age range of the registrant participants was much wider which stretched from 26 to 47 in comparison to non-registrant participants where they age just between 23 to 25 years. Another key differences between these two groups are; the non-registrant participants are all not married and live with parents while the registrant participants are a blend of married and not married status. The only similarity observed between registrants and non-registrants participants is that they all have attended tertiary education. Provision of detailed demographic data about participants allows researcher to recognizes the psychological processes and how it could influence the findings.

In total, 19 interviews were completed, 16 with registered organ donors and three interviews with individuals who had the intention to donate but decided not to register as an organ donor.

Table 4.3 Participant demographic data

Participant (pseudonym)	**Gender**	**Age**	**Marital status**	**Living with**	**Highest level of education**	**Location**
Registered organ donor						
D/1: Amira	Female	32	Married	Spouse and children	Masters	Urban
D/2: Balkis	Female	47	Married	Spouse and children	Masters	Urban
D/3:Chadia	Female	34	Married	Spouse and children	Bachelor degree	Urban
D/4 Darleene	Female	34	Single	Alone	Bachelor degree	Rural
D/5 Ediline	Female	28	Married	Spouse and children	Bachelor degree	Urban
D/6 Fatimah	Female	34	Single	Parents	Diploma	Urban
D/7 Ghufran	Male	37	Single	Alone	Masters	Sub-urban
D/8 Haris	Male	33	Married	Spouse and children	Diploma	Sub-urban
D/9 Imran	Male	40	Married	Spouse and children	Bachelor degree	Sub-urban
D/10 Jaslin	Female	29	Married	Spouse and no children	Masters	Sub-urban
D/11 Khairiah	Female	27	Single	Parents	Bachelor degree	Sub-urban
D/12 Liana	Female	26	Single	Parents	Bachelor degree	Sub-urban

Participant (pseudonym)	Gender	Age	Marital status	Living with	Highest level of education	Location
D/13 Madhu	Female	34	Married	Spouse and no children	Masters	Urban
D/14 Nina	Female	39	Married	Spouse and children	Bachelor degree	Sub-urban
D/15 Olina	Female	36	Single	Alone	Masters	Urban
D/16 Pauline	Female	31	Married	Spouse and children	Masters	Urban
Non-registered organ donor						
ND/1 Zita	Female	23	Single	Parents	Bachelor degree	Urban
ND/2 Yani	Female	23	Single	Parents	Bachelor degree	Sub-urban
ND/3 Wana	Female	25	Single	Parents	Bachelor degree	Urban

4.2.4 Data collection methods: Interviews, field notes, reflective diary

4.2.4.1 Preparation for Interviews

The adoption of semi-structured interviews as the data collection method is recommended in phenomenological research (van Manen, 1990; Moustakas, 1994; Kvale, 1996; Seidman, 1998; Merriam, 2002; Giorgi, 2012). This form of interviewing facilitates a dialogue whereby the researcher is able to probe the interviewee's responses as a means of following up on the issues that arise and thereby gain clarification and in-depth data (Morse, 1994; Ritchie and Lewis, 2003; Seale, 2012).

Semi-structured interviews were guided by an interview schedule (Appendix L) developed in line with the research aim. This alignment is crucial so as to ensure that the interview questions conform to the research purpose and eliminate unnecessary questions. The questions in the interview schedule were broad to facilitate participants to speak freely about their registration decision-making. Conversation flow was stimulated by the use of probing questions.

4.2.4.2 Field notes and reflective diary

Taking field notes and writing a reflective diary is an integral part in qualitative research as it functions as an audit trail. The purpose of a field notes and reflective diary is to provide researcher a venue for reflection and enhanced the interpretation of findings. It contributes to the overall quality of a qualitative research as discussed in earlier chapter (see Section 3.7, page

54) as it provide a description, explanation or justification of key points of decision making and research processes.

At the completion of each interview, I set aside time to complete field notes. Field notes are a way of recording important information about the interview, for example, commentary on a participant's behaviour, activities, events, and other features of observation during or after the interview. Field notes were written after each interview so that vital details of the interview were recorded immediately. Field notes are useful in generating new ideas for inclusion in later interviews (Ritchie and Lewis, 2003).

A reflective diary was used to record my thoughts over the period of data collection and analysis. The reflective diary was also used to record ideas, questions, and concerns that arose while conducting the interviews, for example, I recorded that my role in the interviews was to probe in order to encourage the participant to provide further explanations which would contribute to my understanding. I also recorded what I did during the interview that appeared to be helpful to the participant. For example, two of the nine participants who were registered organ donors found some of their personal experience emotionally challenging, in particular when talking about the death of their family members. I felt that it was important to allow this expression of emotion by not interrupting, therefore after a moment of reflective time I asked if they wanted to continue and after they expressed their wish to go on, I continued with the interview. In early interviews some questions seemed inappropriate and after reflection these questions were amended. Thus, keeping a record of my thoughts and feelings associated with the reflective process, helped to develop self-awareness and improve attentiveness on the issue of interest.

4.2.4.3 Location of interviews

Of the 16 completed interviews with registrants, three were conducted at a coffee shop, two were undertaken at the participant's home, one at the participant's work place and ten via skype utility. Interviews lasted approximately 45 minutes (Table 4.4).

Interviews with individuals who had the intention to donate but decided not to register as organ donors (n = 3) were conducted at the participant's home and lasted approximately 30 minutes. (Table 4.4).

Table 4.4 Summary of interviews conducted

Description	**Location/means**	**Number (N)**
Interview with registered organ donor	Coffee shop	3
	Participant's home	2
	Participant's work place	1
	Skype	10
Total		**16**
Interview with non-registered organ donor	Participant's home	3
Total		**3**
Total interviews		**19**

4.3 Data management

4.3.1 Data management and storage of data

All participants were given a study pseudonym and identifier. Participants who were registered organ donors were assigned code 'D', non-registered organ donors were assigned code 'ND'. All interviews were audio recorded with the audio recordings undergoing a full transcription process. The interview recordings, transcripts, field notes, and reflective diary were stored in a locked cabinet when these materials were not in use. All electronic data files were backed up to a USB external hard drive that was stored in a locked cabinet. All data will be kept for at least 10 years after the conclusion of this study in line with the Faculty of Health Sciences and University of Southampton Research Data Management regulations.

4.3.2 Translation of interview transcripts

Each interview was transcribed immediately after the interview was completed: the language of interviews was Malay. The transcribed interviews were translated from Malay to English for sharing with supervisors and analysis. In order to ensure that the results of the study were accurate, the quality of translation of the interview data played an important role in the study's credibility. The application of a rigorous approach to the process of translation ensured that the findings of the study were reflective of the participants' lived world and not a distortion of their experiences owing to poor translation. Translated transcripts were checked by two other postgraduate students who were bilingual in Malay and English. All possible identifying data was removed from the transcripts, such as the interviewee's job. This was to ensure the participants' privacy was protected as required by the University of Southampton ethics committee.

4.4 Chapter summary

Chapter 4 has presented justification of the decisions made in relationship to participant selection, recruitment, data collection and data management. Chapter 5 provides an overview of the analysis undertaken, applying Giorgi's five-step framework.

Chapter 5 Data Analysis

5.1 Introduction

The purpose of Chapter 5 is to illustrate the process of data analysis, to provide transparency on how the researcher reaches final findings and to assure the reader of the trustworthiness of the findings. The process of analysing phenomenological data is complex, nonlinear, challenging and time-consuming, requiring various skills as well as the integrity of the researcher. To complete this process, Giorgi's five-step data analysis framework was utilised. The analysis process is illustrated using examples of quotes, meaning units, and memos, which are offered as an illustration of how the developed categories were derived from the data.

As indicated in Giorgi's framework, the aim of analysis was to develop meaning units. As the selection of the meaning unit is dependent on, and determined by myself as the researcher, and could be influenced by my assumptions, biases, and personal factors, such as age, gender, ethnicity, education and professional background, it is imperative to reflect upon these personal influences. During the analysis, I noted my own 'taken for granted thoughts' in the margins of transcripts aiming to 'bracket' my thinking in line with Husserl's phenomenological approach. Bracketing is not a process restricted to data analysis, as I was conscious of bracketing findings from the scoping review as these could influence my interpretation of participant data.

As elaborated in Chapter 3, bracketing is done in order to enter into a phenomenologically reductive attitude, which is achieved by the writing of memos throughout data analysis. Memoing enabled me to examine and reflect upon my engagement with the data. This is clearly demonstrated in Appendix O, entitled 'Meaning Units, Initial Ideas, and Memos'. Being in a phenomenologically reductive attitude assisted in the separation of the researcher from the expressed experience of participants.

As a novice researcher, particularly in qualitative research, the process of analyzing data based on Giorgi's framework was rather challenging and time consuming. There were times where I got frustrated, as it was a lengthy process ensuring all meaning units were demarcated correctly, as per the aim of this research. Some transcripts took fewer attempts at separating the meaning units than others. In addition to focusing on the aim of the study when identifying meaning units, I also took notes on the transcript regarding anything that I felt was of emerging importance about the experience of registering as an organ donor. Again, I faced difficulty in continuously bracketing my thoughts completely. I was concerned that I would make early tentative interpretations rather than sticking to description. To counter this issue, I made an effort to return to the transcript with delineated meaning units and re-justify my selection of meaning units.

5.2 Orientation of Giorgi’s framework in data analysis

To present the entire process employed in analysing data in a clear and complete way, Giorgi’s five steps of data analysis are illustrated with the associated actions or processes involved (Table 5.1).

Table 5.1 Giorgi’s five step analytic framework

Steps	**Process/Action**
Step 1: Gaining a sense of the whole	All transcripts were read while listening to the audio recording with the aim of gaining an overview of the phenomena. Generation of initial ideas and codes for review during on-going analysis. **Output** – immersion in the data, initial ideas and codes
Step 2: Discrimination of meaning units within a psychological perspective focused on the phenomenon being studied	On a transcript-by-transcript basis, the data was broken down into “meaning units”. For example, a meaning unit ends when participants move from one topic (or focus) to another. The meaning units were developed from a psychological perspective. Each meaning unit was highlighted. Generation of memos as part of analytical audit trail. **Output –** Meaning units, initial ideas, and memos
Step 3: Transformation of the subjects’ everyday expressions into psychological language with emphasis on the phenomenon being investigated	Review of meaning units, and language used by the participants, begin comparing initial ideas from individual transcripts from one to the other. The meaning units are transformed into psychologically descriptive expressions via a process of comparison as a means of grouping meaning units under categories and then into psychological concepts. **Output** – Grouped meaning units transformed into psychological language.
Step 4: Synthesis of transformed meaning units into a consistent statement of the structure of the experience	Grouping of meaning units based on similarity or difference (negative case analysis) and construction of an interpretation of the lived experience of registering as an organ donor from each interview. **Output** – interpretative statements from across the data set.
Step 5: Final synthesis	Comparison of meaning units and interpretive statements from one transcript to the next with generation of a description of the essence of the phenomenon of registering as an organ donor in Malaysia. **Output –** Synthesis of interpretive statements and a descriptive rendering of the lived experience.

5.2.1 Preparation for analysis

While conducting the interview and prior to reading the interview transcript, I made several attempts to suspend pre-existing knowledge and judgements. Bracketing involves a self-reflective process whereby I needed to acknowledge but set aside prior knowledge and assumptions in order to allow myself to analyse the participant's description with an open mind. One method of bracketing that was utilised was writing memos throughout the data analysis as a means of examining and reflecting upon my engagement with the data. The writing up of commentary memos during analysis are illustrated in Appendix O.

5.2.2 Step one - Gaining a sense of the whole

Transcripts were read several times while listening to the audio recording with the aim of becoming immersed in the data. The idea here is to obtain an overview of the phenomena. According to Giorgi (1997), in step one, one does not try to thematise any aspect of the description based upon the global reading. Here I was reading to gain a general sense of the content so that I became familiar with the transcript and immersed in the data.

Immersion in the data allows the generation of initial ideas and codes for review during on-going analysis. Codes facilitated the development of meaning units, and categorisation of meaning units facilitated the development of the psychological concepts, which are the intended outcome of analysis applying Giorgi's framework.

When re-reading the scripts, I constantly ask, "What is this participant saying?" and label the single words or phrases that contain information relating to every particular point being made. A code represents a single idea of what is being said. Some of the words or phrases may be attributed to more than one code. As I work through the transcripts, more information about the topic is learned and more codes are added, and the meaning of each code could be refined. When this process occurs, earlier coded transcripts are revisited in order to verify that the code still applies, or whether the older transcript may need re-coding.

5.2.2.1 Output – Immersion in the data, initial ideas and codes

Following the process of moving forward and back through the transcripts in order to immerse in the data, a total of 35 codes were finalized. Table 5.2 illustrates the final 35 codes that were generated during on-going analysis.

Table 5.2 The codes developed in analysis

No	Codes	Explanation of the Code
1	Being certain that the action does not violate religious principles	This code shows the importance of knowing for sure that the action of donating an organ does not violate religion, and this is important to overcome the feeling of uncertainty.
2	Belief in the continuous reward in the afterlife	This code expresses participant belief in continuous reward even after death, which is in the life hereafter.
3	Belief that nothing belongs to us but to God	This code demonstrates faith in the fact that everything we own belongs to none but God, including all the organs that we have belonging to God.
4	Belief that their afterlife journey is less of a burden, with lighter punishment if they donate organs	This code illustrates that donating an organ becomes part of a long term charitable work where the donor will continuously be rewarded, and one type of reward that the donor foresees is a lighter form of punishment.
5	Belief that organs are not useful anymore after death and can be given to others	This codes shows belief that once a person dies, the organs are no longer beneficial to the deceased, but could still be valuable for others who are still alive.
6	Belief that religion teaches donation as a form of charity even after death.	This code demonstrates that religion encourages charitable acts such as organ donation by a deceased person, as this act of helping others would benefit the organ receiver.
7	Benefit for ourselves (double reward) when the recipient contributes to society.	This code describes that participants think that if the organ receiver does good things in life after being given a second chance to continue living, not only the receiver will be rewarded, but the donor too. So here the donor gets rewarded twice; first for donating and then for as long as the receiver does good things, the donor is also getting the reward.
8	Satisfaction in being able to help and do good for others	This code illustrates a donor's personal fulfilment in being able to do something good by helping and contributing to others.
9	Belief in sharing and giving	This code illustrates views about the importance of sharing and giving as part of a humanitarian act for others in need.
10	Sense of responsibility towards society, and fulfilment in benefitting society as a whole	This code describes an individual's personal views about the importance of benefiting society as part of carrying out social responsibilities. Participants see it as an opportunity to benefit society indirectly, when the receiver returns to society and does good things for the community.
11	Fulfilment in improving quality of life for others	This code demonstrates the desire to help sick people and wanting them to have a good quality of life like other healthy people.
12	Belief in individual autonomy	This code describes the feeling of autonomy in that the decision to register was made regardless of anyone else's opinion or suggestion, and that everyone else should respect it.
13	Feeling of sadness when considering	This code exhibits the key emotions of unhappiness when listening to, reading about, or watching sad stories of a sick or

No	Codes	Explanation of the Code
	people waiting for an organ donation	less able person needing and waiting for an organ donor.
14	Feels disturbed when listening to personal experience of the organ recipient	This code exhibits the key emotions of feeling disturbed when listening to the experience of those who have received an organ, and how receiving an organ has impacted or changed their life.
15	Fear if the removal process would hurt the dead body.	This code describes the key emotions of fear that the organ removal process would hurt the dead body.
16	Worry if the body would not be in the normal state and unrecognizable	This code describes the key emotions of worry if the deceased body would not be in a normal state and it is not identifiable anymore.
17	What if one day I need a donor?	This code demonstrates the key emotion that has driven a donor toward registration, which was fear of not being able to find an organ donor if they themselves needed an organ.
18	What if one day my children, parents, siblings or extended family needed a donor?	Similar to above, this code exhibits the key emotion that has driven a donor toward registration, which was fear for other important people in their life, if they needed an organ but were unable to find an organ donor.
19	Confidence in trusted online resources	This code describes the significant role of an authorized body as a trusted unit/entity in providing the necessary information via online resources such as through a website.
20	Confidence in official religious body's online resources	This code describes the significant role of an authorized religious body as a trusted party in providing the necessary religious information via online resources such as through a website.
21	Confidence in social media	This code explains the significant role of social media, particularly Facebook and Instagram, in sharing organ donation and transplantation information.
22	Confidence in the organ donation governing body	This code demonstrates the important role of the National Transplant Resource Centre, as the governing body that oversees the operation of organ donation and transplantation.
23	Confidence in a talk, seminar, or booth set up by governing body	This code explains the importance of choosing the right representative (which must come from the National Transplant Resource Centre) in giving a talk at seminars or booths.
24	Confidence in an official statement from a Mufti	This code describes the importance of having Mufti, as a qualified Islamic jurist, to issue a fatwa from the Sharia (Islamic law) point of view with regards to organ donation.
25	Confidence in the information shared in a newspaper	This code demonstrates the important role that newspapers play, sharing written information, about organ donation and transplantation.
26	Confidence in TV advertisements	This code shows the important role that TV advertisement play, in conveying and disseminating messages about organ donation and transplantation.
27	Confidence in information shared by	This code illustrates the influence of a friend in information sharing and updating about organ donation and

No	Codes	Explanation of the Code
	friends	transplantation.
28	Knowledge of the donation and transplantation process	This code demonstrates the importance of knowing the process involved prior to making the registration decision, particularly the donation process itself as well as the surgical removal process.
29	Knowledge of the process involved in registration	This code describes the influence of knowing how and where to register organ donation intention, as well as the ease of the registration process (e.g.: via online or at the exhibition booth) provided that the participant felt that the registration process was easy.
30	Knowing of the need for different organs	This code shows that knowledge of the types of organ that can be donated has influence on the organ donation registration decision.
31	Favourite artist	This code illustrates that an awareness of someone famous who has signed up as a registered organ donor has somehow driven registration decision.
32	Well-known religious person	Similarly, this code describes how a well-known individual such as a respectable religious person could influence organ donation registering decision.
33	Healthcare practitioner	This code demonstrates the need to seek the opinion of an expert who has the relevant knowledge, particularly on the organ removal and transplantation process. Certainty of the process involved helps in making the registration decision.
34	A teacher or a lecturer	This illustrates the influence of a teacher or lecturer, who is a prominent figure in building confidence and certainty with regards to organ donation information.
35	Mother or father as the leading role or the decision maker in the family	This code demonstrates the powerful influence of a leading figure in the family. If there is support from either one of the parents, the registrant feels comfortable with the decision made.

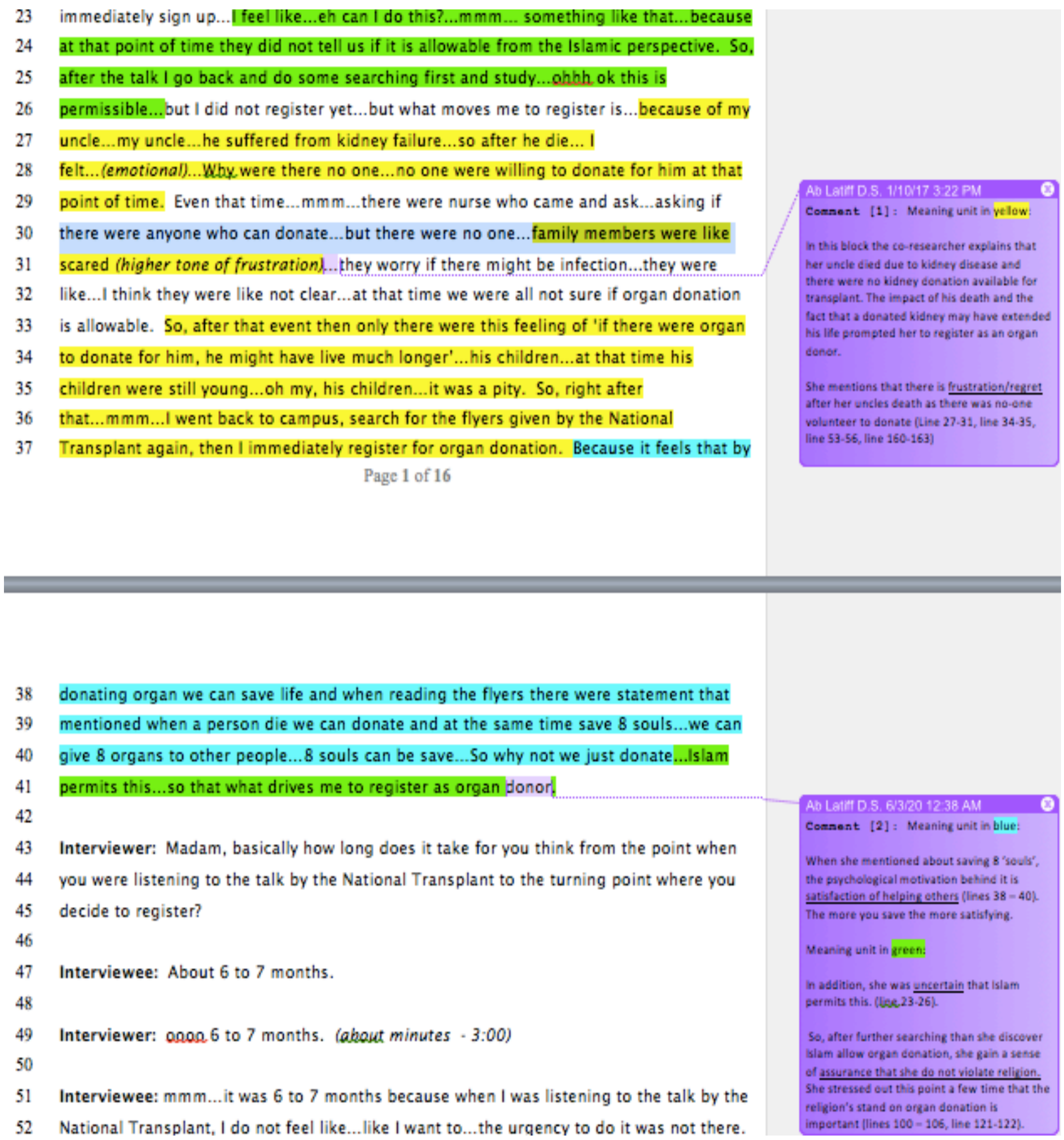
5.2.3 Step two - Discrimination of meaning units within a psychological perspective focused on the phenomenon being studied

In line with Giorgi's framework, on a transcript-by-transcript basis, the data were broken down into "meaning units". Meaning units are defined as complex strings of words, sentences, or a series of sentences in the text that convey ideas, perspectives, or perceptions relating to a similar phenomenon. In identifying meaning units, it is necessary for the researcher to be aware of the changes in topics and meanings in the description generated by the participant. Meaning units are developed by the researcher through a process of clarification and decision making. In this research the focus is on the factors behind registering or not registering as an organ donor. Therefore, any sentence, or series of sentences in the text, which conveyed ideas, perspectives, or participants' perceptions of what informed their decision, was initially highlighted. Each time there was a significant shift in the meaning, it was highlighted on the transcript.

Operationally, all the meaning units were formed through a slower re-reading of the description where I re-read it a few times until I was clear of the participant's intended meaning. Figure 5.1 offers examples of the development of meaning units in Transcript 1. This example illustrates how meaning units are developed by linking instances related to a topic or focus that may be spread across the individual transcript. The outcome of this step is a series of meaning units expressed in the participant's own everyday language.

Meaning units are differentiated by use of a colour code. (Appendix N presents the colour code). For example, the meaning unit illustrated in Figure 5.1 focused on the topic of religion and was highlighted in green (line 23-26, and 41-42), yellow illustrates the participant's emotions and feeling sad when seeing those left behind (line 26-37).

Figure 5.1 Example: an identification of a meaning unit within Block 23-52 in Transcript 1



immediately sign up...I feel like...eh can I do this?...mmm... something like that...because at that point of time they did not tell us if it is allowable from the Islamic perspective. So, after the talk I go back and do some searching first and study...ohhh ok this is permissible...but I did not register yet...but what moves me to register is...because of my uncle...my uncle...he suffered from kidney failure...so after he die... I felt...*(emotional)*...Why were there no one...no one were willing to donate for him at that point of time. Even that time...mmm...there were nurse who came and ask...asking if there were anyone who can donate...but there were no one...family members were like scared *(higher tone of frustration)*...they worry if there might be infection...they were like...I think they were like not clear...at that time we were all not sure if organ donation is allowable. So, after that event then only there were this feeling of 'if there were organ to donate for him, he might have live much longer'...his children...at that time his children were still young...oh my, his children...it was a pity. So, right after that...mmm...I went back to campus, search for the flyers given by the National Transplant again, then I immediately register for organ donation. Because it feels that by

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donating organ we can save life and when reading the flyers there were statement that mentioned when a person die we can donate and at the same time save 8 souls...we can give 8 organs to other people...8 souls can be save...So why not we just donate...Islam permits this...so that what drives me to register as organ donor.

Interviewer: Madam, basically how long does it take for you think from the point when you were listening to the talk by the National Transplant to the turning point where you decide to register?

Interviewee: About 6 to 7 months.

Interviewer: oooo 6 to 7 months. *(about minutes - 3:00)*

Interviewee: mmm...it was 6 to 7 months because when I was listening to the talk by the National Transplant, I do not feel like...like I want to...the urgency to do it was not there.

Ab Latiff D.S. 1/10/17 3:22 PM

Comment [1]: Meaning unit in yellow:

In this block the co-researcher explains that her uncle died due to kidney disease and there were no kidney donation available for transplant. The impact of his death and the fact that a donated kidney may have extended his life prompted her to register as an organ donor.

She mentions that there is frustration/regret after her uncles death as there was no-one volunteer to donate (Line 27-31, line 34-35, line 53-56, line 160-163)

Ab Latiff D.S. 6/3/20 12:38 AM

Comment [2]: Meaning unit in blue:

When she mentioned about saving 8 'souls', the psychological motivation behind it is satisfaction of helping others (lines 38 – 40). The more you save the more satisfying.

Meaning unit in green:

In addition, she was uncertain that Islam permits this. (line 23-26).

So, after further searching than she discover Islam allow organ donation, she gain a sense of assurance that she do not violate religion. She stressed out this point a few time that the religion's stand on organ donation is important (lines 100 – 106, line 121-122).

As participants may raise an issue early on in the interview (in response to a question), which they returned to at a later point in the interview, it was essential that initial meaning units be flexible, as they would ultimately expand if the issue or idea, is stated on more than one occasion. As indicated in Giorgi's framework, stage two necessitates the generation of memos as part of the analytical audit trail; this is needed to confirm the research findings and to demonstrate the density of evidence. Commentary memos illustrate my initial thoughts and reflections (Table 5.3).

Meaning units were developed for each transcript and similar meaning units were grouped. These grouped meaning units were given a category heading. For example, in relation to the initial idea that participants held a view that Islamic law may prohibit organ donation, commentary and reflexive memos were generated as a means to show the iterative cycle articulating the participant's data and researcher's interpretation (Table 5.3 and Table 5.4).

Table 5.3 Example: Meaning units and initial ideas arising from transcript 1.

Meaning units Transcript 1	**Initial ideas (i.e. the issue which dominates the unit)**	**Category**
For us as Muslims, we will only do something if it is outlined in the Sharia. Because when I first heard about organ donation, the idea was still new in Malaysia. For me I was still young as I was doing my First Degree…still very young. I was like hesitating and thinking if organ donation is allowable. So a discussion took place with friends. I had to do research from the perspective of Islamic law. If Islam permits it, only then would I do it. For as long as it was not clear yet from the Islamic perspective, then I could not do it. (Block 100-106) I think an organ is the one thing that we can give, where we cannot give it away when we are still alive, but when we die it becomes a lifelong charity. (Block 396-398) Basically all that is in us belongs to Allah, it is not ours. When the time comes our organs may become someone else's. Right? So we have to give. When the time has come then it is no longer ours. Just like our money, sometimes we have saved a lot of money but then suddenly our car broke down! Just look at it, it is not meant for us, it is not ours, God can take it away from us. (Block 411-415)	Is organ donation allowed? Does Islamic law permit donation? Commentary Memo: In this meaning unit, the role of religion is expressed. What Islam allows is important to this participant and she would not register to be an organ donor if Islam prohibited donation. Her view is that her organs are not hers but belong to Allah and she has a belief in sharing them with others when she dies. Reflexive commentary: It appears that she is a strong believer in her faith. Therefore, donating organs after death appears to be part of a lifelong charity.	Religion and Culture

Table 5.4 Example: Meaning units and initial ideas arising from transcript 2.

Meaning units Transcript 1	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Category**
I will be rewarded, and when rewarded I feel that it would help me when resurrected to face God in the hereafter. (Block 40 – 41) One of them is affected by my religious belief because I believe that my religion says that you must do something good and you will be rewarded, and the more rewards you have, it helps you to go to heaven. So, at least when I die I would continuously be rewarded by God, from Allah SWT to ease the journey to face Him. Which I think is one of the religious reasons. (Block 63 – 67) When I first heard about organ donation, I was already a very strong religious believer. That is why I wanted to do something good, up to the point of registering I was very sure because of strong religious belief. That is my main reason, if you were to ask between wanting to contribute to society and religion, religion has more influence. (Block 87 – 91) I knew it from the very beginning. I have read somewhere that states that organ donation is permissible from the Islamic point of view. I am sure of that. So, from that perspective, from religious perspectives, and as I am a Muslim, and knowing that it can be done, so why not? I just registered as an organ donor. (Block 96 – 99)	Religious stance is important. What is the religious benefit for me? Commentary Memo: In this meaning unit the role of religion is expressed. The participant is saying that she was assured that Islam permits organ donation, as it is an act of doing good, as it is a form of sharing and giving. This participant went on to link her religious beliefs to her belief in doing good and her belief in sharing and giving. At an earlier point in the interview the participant had indicated that her decision to register would help her to be continuously rewarded by God in the afterlife for as long as the organs that she had donated were still being used by someone else. This reward is believed to help the journey in the afterlife, which eases her journey to heaven. Reflexive commentary: Religion appears to play a central role in the decision-making of these two participants albeit from slightly different perspectives.	Religion and Culture

5.2.3.1 Output – Meaning units, initial ideas, and memos

Following step two, a total of 521 meaning units were recognized and it leads to the development of 9 initial categories. Meaning units, initial ideas, commentary, reflexive memos, and categories generated during on-going analysis across all 19 transcripts are available in Appendix O.

5.2.4 Step three – Transformation of subjects' everyday expressions into psychological language with emphasis on the phenomenon being investigated

In step three the meaning units developed in step two are reviewed. The aim is to begin comparing initial ideas from individual transcripts, from one to the other. At this stage of the data analysis, what happen is the separation of "meaning units" within the participants' story, so that the data can be dealt with in manageable portions (Giorgi, 1985; Giorgi, 2010). At this point the meaning units are transformed into psychologically descriptive expressions via a process of comparison, as a means of grouping meaning units under psychological concepts.

Operationally, I went through the narrative text in a subsequent reading(s) with the purpose of identifying places where the meaning or focus changes. I personally think that how or where the meaning units are demarcated is not absolute, as a different researcher may demarcate the meaning units in different places in the same data. However, (Giorgi, 2010) has stated that even if there is a slight difference in the meaning units identified among researchers, it is the end results (categories) that are important to the overall quality of the analysis. Category is the output of Giorgi's analysis process, where similar meaning units are grouped and given a category heading. In this process, other researchers have commented that the use of the terms category and theme are sometimes used almost interchangeably in completed research (Gale *et al.*, 2013). However, 'theme' is intended to indicate interpretive thoughts or ideas that explain aspects of the data, while categories are closely linked to the raw data. Developing categories is a way to start the process of abstraction of the data which lead to the development of concepts (Heath *et al.*, 2012).

To illustrate this, Table 5.5 highlights an example of the transformation process that was undertaken for this study. Column one illustrates the meaning unit from transcribed data, column two illustrates transformation of the interview data (meaning unit) into everyday language with the use of the third person. Column three illustrates the psychologically descriptive expressions developed from this step-in analysis.

Table 5.5 An example of meaning units' psychologically descriptive expressions from Transcript 1

Meaning units	**Transformation 1 – using everyday language and use of the third person**	**Transformation 2 – using psychological language**
I feel like..eh can I do this..mmm..something like that..because at that point in time they did not tell us if it is permissible from the Islamic perspective. So, after the talk I went back and did some searching first, and study…ohhh ok this is permissible. (Block 23-26)	The participant was curious whether her religion allows organ donation. In deciding to register she needed to be certain that it was OK so she did some research on it in order to know that is it permissible.	Psychological transformation: *Code - Being certain that the action does not violate religious principles* *Category – Religion and culture* *Psychological concept – Belief and attitude* Religion is a key driver for decision-making, however this is only one part of an individual's belief system.
For us as Muslims, what is outlined in the Sharia then only we do it. Because when I first heard about organ donation, the idea was still new in Malaysia. For me I was still young as I was doing my First Degree…still very young. I was like hesitating and thinking if organ donation is allowable. So discussion took place with friends. I had to do research from the perspective of Islamic law. If Islam permits it, only then I would do it. For as long as it was not clear yet from the Islamic perspective, then I could not do it. (Block 100-106)	At the beginning, the participant has some hesitation as to whether Islam allowed organ donation. For her, she would only proceed with the decision to register if it was not contrary to Sharia law.	
Basically all that is in us belongs to Allah, it is not ours, when the time comes our organs may become someone else's. Right? So we have to give. When the time has come then it is no longer ours. Just like our money, sometimes we have saved a lot of money but then suddenly our car broke down! Just look at it, it is not meant for us, it is not ours, God can take it away from us. (Block 411-415)	The participant's view is that everything that she has belongs to God be it her money, organs, or other things. She believes that God can give it to her temporarily and take it away from her. So, she decided to register, as she believed in giving her organs to someone else when the time came.	Psychological transformation: *Code - Belief that nothing belongs to us but to God,* Belief in sharing and giving *Category – Religion and culture, Humanitarianism* *Psychological concept – Belief and attitude* An individual's belief system is informed by personal views about the importance of sharing and giving as part of lifelong charity and an act humanitarianism for others in need.
I think organs are the one thing we can give, where we cannot give it away when we are still alive but when we die they become a lifelong charity. (Block 396-398)	The participant's opinion is that giving away an organ after death is an enduring donation, which she is not able to do when alive.	

Meaning units	**Transformation 1 – using everyday language and use of the third person**	**Transformation 2 – using psychological language**
When I was listening to the talk…mmmm…I felt like this thing needed to be done but we just choose not take one more step ahead, which is to register…we just keep the flyers. I just do not know why... (giggling). Maybe it is the attitude. The intention was there, the awareness was obviously there, but, maybe it's our attitude, our attitude, 'eh its ok, this can wait'. We feel like it's not important to register. (Block 67 – 71)	The participant's intention to become a registered organ donor does not translate into registration immediately. Her attitude has influenced her registration decision. She prefers to hold back on some action that she feels is not urgent such as registering as an organ donor.	<u>Psychological transformation</u>: *Code - Feeling of sadness when considering people waiting for an organ donation* *Category – Emotional responses* *Psychological concept – feelings and emotions* Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of urgency, frustration and regret when the issue of a lack of organs became personal
Maybe it feels like we are not desperate to donate at that time, but when there is a triggering event, only then you will feel there is a need to do it. (Block 84 - 85)	The participant's view is that there needs to be an external push factor which leads to the feeling of urgency only then can registration happen.	
Because of my uncle…my uncle…he suffered from kidney failure…so after he died… I felt…(emotional)…Why was there no one…no one was willing to donate for him at that point in time. (Block 26 - 29)	The participant needed to be emotionally touched by an event such as death of family member.	

5.2.4.1 Output – Grouped meaning units transformed into psychological language.

As Giorgi (1985) described, the outcome of step three is the transformation of the meaning units into psychological language, which is illustrated in Table 5.5 (see Appendix O for full transformation of all 19 transcripts). To illustrate the on going analytic development

Table 5.6 illustrates the nine categories and four psychological concepts. In Appendix P, there is an illustration of all 35 final codes and how it is organize into categories and later the progress of categories into psychological concepts that represents the data.

Table 5.6 The categories and psychological concepts developed in analysis

Categories	**Psychological concepts**
Religion and Culture	Belief and Attitudes
Humanitarianism	
Autonomy	
Emotional responses	Feelings and Emotions
Fear for self and those close	
Confidence with information resources	Cognitive readiness
Information needs	
Valued Social networks	External influence
Motivated by respected individuals	

5.2.5 Step four - Synthesis of transformed meaning units into a consistent statement of the structure of the experience

In step four, after transforming the participant's meaning units into psychological concepts, initial concepts are then compared, with the researcher seeking negative cases to develop statements articulating the lived experience of registering, or not registering as an organ donor across the dataset. Step four requires a twostep process: i) the production of an individual structural description (specific description) for each participant and ii) a general structural description (general description) of the experience (Giorgi, 1985).

5.2.5.1 Individual specific structural descriptions

Individual specific structural descriptions for each participant were developed illustrating the particular and specific characteristics of each participant related to their lived experience.

5.2.5.1.1 Registered Participant 1

Amira decided to register as an organ donor when she was in her mid-20s. At that time, she was still at the local university in Malaysia pursuing her bachelor's degree. She first heard about organ donation from a talk held on the campus, which was organized by the Malaysia National Transplant Centre. The talk sparked some interest in becoming an organ donor but she put her intention on hold because of uncertainty about whether her religion permitted organ donation. It was important to her that she did not commit herself to something that was against her religion. For her, religious belief was a key driver towards her registration decision. In the midst of contemplating the registration decision, an emotional event happened. The death of her uncle who was waiting for an organ transplant stimulated strong emotions prompting distress at his death, and reflections on her lack of action regarding registration in view of her research that her religion permitted organ donation. This emotional response to death of a family member who required an organ was a driver to registration. .

5.2.5.1.2 Registered Participant 2

Balqis first heard about organ donation when she attended a seminar/talk whilst completing undergraduate studies but did not take any action. Later in life she attended another organ donation talk by the Malaysia National Transplant Centre and was very much influenced and driven to register after the talk. A key factor that influenced her motivation to register was when the speaker shared a fatwa that states organ donation is acceptable in Islam. To her, it's important to hold on to the teaching of her religion and to practice good conduct in her life that does not violate religious belief. Other evidence relevant to Balqis' registration decision was the ease of the registration process. She was able to register immediately at the venue and did not have to go elsewhere. Therefore, motivation towards registration was influenced by her religious belief as well as by the knowledge of the registration process.

5.2.5.1.3 Registered Participant 3

Chadia works as a biologist and also a Mercy (NGO) volunteer. Chadia's interest in organ donation was stimulated when she first saw an article in a newspaper about a child who was in need of a liver donor. She was emotionally disturbed and this motivated her to donate her liver. She also developed fears for herself as she started to think of the possibility that she needed one and there was no one willing to help. However, her parents objected to her intention and she listened to them. Later in her life, as she began doing volunteering work and her role gave her so much exposure to sick people, this again stimulated her intention to become an organ donor. As a result of her humanitarian activities with the NGO, and in-line with her priority of, and passion for, helping others, she decided to register her intention to be an organ donor. Prior to registering, she was also certain that her decision did not violate her religious principles. She also knew that donating an organ is a humanitarian act of being responsible towards society by helping, which is in line with her religious teaching of charity work even after death. Therefore, key factors that motivated her towards registration were her emotional response, humanitarianism, and most importantly her religious belief.

5.2.5.1.4 Registered Participant 4

Darlene decided to register as an organ donor right after attending a talk by the Kidney Foundation. The current scenario and the lack of donors available in the donor pool disturbed her emotionally, as she felt sad considering people waiting for an organ donor. Darlene has a high sense of humanity as she even intends to donate by giving her kidney now, before death. She likes the idea of giving, sharing and benefiting others. Darlene loves the feeling of fulfilment from benefitting society, which in this context means benefitting the organ recipient. It would also satisfy her if she could see the organ recipient's quality of life improve as they get healthier and live a normal life. Furthermore, Darlene was also motivated as she believes that the afterlife journey will be less of a burden, with lighter punishment, if she donates organs. She was also confident about her decision, as she knew that it did not violate her religious belief. Moreover, she believes in practicing her autonomy as she strongly thinks the decision to donate an organ is solely hers, and thus she does not need time to consult her family. She also worried that if one day she needed an organ donor, there would be no-one willing to donate. Thus, she hoped that there would be someone willing to donate for her too. Therefore, Darlene's motivation towards registration was driven by many factors, and the key factor was religion and attitude.

5.2.5.1.5 Registered Participant 5

Ediline is a health care professional who described herself as someone who is not pious and not culturally oriented. Ediline's work environment has given her exposure to organ donation. Her role allows her to encounter many sick people, which has influenced her emotionally. Ediline has come across many disturbing and sad stories at work as well as from her reading about people who donate organs or about other people who survived after organ donation. The stories inspired her in many ways that make her want to be an organ donor too. Furthermore, she started thinking about not wasting her organ after death, as when it is no longer useful to her it can be utilised by others. In addition, this is in line with her Catholic belief, where her religion encourages the believer to share with those in need. As a Catholic, she was taught that when she dies her body is not needed any longer, but only her soul. Thus, her motivation towards registration was religious belief and emotional response.

5.2.5.1.6 Registered Participant 6

Fatimah is a single lady who runs her own company. During her free time, she browses through social media accounts and she always reads links shared by others that she thinks are interesting, including links on organ donation. Her confidence in the information resources drives Fatimah's intention towards organ donation. Her confidence in social media is not only limited to links shared, but she has also been reading blogs written by a prominent religious figure who discusses organ donation. She also browses trusted online resources such as the National Transplant Resource Centre website and does further research. Reflecting on her reading closely a blog written by a prominent religious figure that deliberates about organ donation, has influenced her certainty that her religion accepts organ donation. Thus, she decided to register as an organ donor after she was sure that it does not violate her religious beliefs. Furthermore, what made it easier was the fact that Fatimah thinks that the registration process was easy, as she could just click on the link she saw in the blog she was reading. Hence, her motivation towards registration was very much due to her religious belief and cognitive readiness; her confidence in the information resources and knowing the registration process.

5.2.5.1.7 Registered Participant 7

Ghufran was stimulated to register as an organ donor after a talk, as he was emotionally touched by sad stories shared and the alarming figures of people on the organ waiting list. But that was not sufficient for him, as he needed to be certain that if he registered as a potential organ donor, his action would not violate his religious principles. After the talk he personally spoke to the speaker who further elaborated to him that the majority of religions allow organ donation, and this motivated him to register. Ghufran was also moved by the fact that registering opened up a way of engaging in a humanitarian act, as through donating organs he could help save people's lives, and not only by saving one person, but saving up to eight lives. Therefore, Ghufran's motivation towards registration was driven by his belief and attitude as well as his emotions.

5.2.5.1.8 Registered Participant 8

Haris decided to register as an organ donor after he had undergone surgery not long since. That episode in his life stimulated fear for himself, as during his stay in the ward he was troubled by the thought of 'what if' one day he needed a blood or organ donor but there were none available. This stimulated the idea of registering as an organ donor. Then he began doing some research prior to making the registration decision. It was important for him to know that organ donation is in line with his religious belief. Haris also needed to know about the registration process (how and where to go to register as an organ donor) and he was interested to know about the organ removal process. However, after all the information searching, registration did not take place immediately. Only when he attended an organ donation talk, and there was an NTRC booth, which allowed people to register, did he actually do so. Thus, the stimulus for him towards registration was his feelings and emotions, but key factors were religious belief and ease of registration process.

5.2.5.1.9 Registered Participant 9

Imran is a 42-year-old male, registered as an organ donor after he passed by an NTRC booth when he attended a regular medical check-up at a hospital. He is a type of person who enjoys helping and is always wanting to benefit others as part of his humanitarian work, thus when being approached by an NTRC representative he immediately signed up as an organ donor. Imran believes that by signing up as an organ donor he would be able to help sick people to live longer, and enjoy an improved quality of life and that the organ receiver will be able to continue contributing to the family and society. However, despite his pleasure in humanitarian activities, one key factor for him is that organ donation must not violate his religious belief. Since he was confident after listening to the NTRC, an authorized representative explaining about Islam's view on organ donation, he straightaway made the decision to register as an organ donor. Therefore, the stimuli towards his registration decision were; religious belief, humanitarianism, and confidence in the booth set up by the governing body.

5.2.5.1.10 Registered Participant 10

Jaslin has had the intention to register as an organ donor since her university days. Her cognitive readiness has been influenced by her confidence in information shared by friends about organ donation. She was also motivated by a respected individual, as discussion surrounding organ donation also extended to one of her lecturers in which they deliberated about the religious aspect. Her lecturer has very much influenced her registration decision as the lecturer was able to convince her that organ donation is legal from a religious standpoint, and that her religion teaches donation as a form of charity for as long as it protects human interests and does not harm or damage other people. She feels that by registering she is playing a humanitarian role in helping and benefiting other people. Thus, her motivation towards registration was religious belief, cognitive readiness, humanitarianism and motivation by respected individuals.

5.2.5.1.11 Registered Participant 11

Khairiah holds an administrative role in a health care setting and her work environment had exposed her to organ donation. This instilled an intention to be an organ donor during a considerable period of time. As a person, she is someone who easily gets emotionally touched when listening, reading, or watching an ill person waiting for an organ donor. However, registration never took place even though the intention was there, until one day she came across an NTRC booth where a representative from the governing body was present, and she immediately signed up as she thought that the registration process was easier at that time. Therefore, her motivation towards registration was knowing how easy the registration process is, and feelings and emotions also had driven her decision.

5.2.5.1.12 Registered Participant 12

Liana registered as an organ donor right after a talk as she was very much disturbed when listening to personal stories from an organ receiver and a donor. As a person who appreciates humanitarianism and utilitarianism, she thinks that sharing and giving is a good thing for as long as it benefits a lot of people. Besides, prior to attending the talk and registering, she had heard about organ donation and had had the intention, but she needed assurance that organ donation would not be violating her religious stance. Thus, Liana had been researching on online resources and consulting a religious person and a doctor. She spoke to a respected religious man about the religious perspective, while she spoke to a doctor to understand about the organ removal process prior to transplant. Thus, the stimulus towards registration was religious belief, emotional responses, humanitarianism, and knowledge of both the registration and the removal process.

5.2.5.1.13 Registered Participant 13

Madhu decided to be a registered organ donor after listening to her mother's suggestion. Both her parents are highly educated, and her mother works in the healthcare industry. Madhu has seen and come across many campaigns on organ donation since she was a little girl as she often accompanied her mother to the workplace during school holidays. Thus, when Madhu got older and when her mother told her to sign-up as an organ donor, she did so without hesitation as her mother often plays a leading role as the decision maker in the family. Madhu has no doubt about her religion's stance on organ donation as to her, her mother would not do anything that is against her religion. Thus, her motivation towards registration was solely due to the influence of a respected individual.

5.2.5.1.14 Registered Participant 14

Nina is someone with a positive attitude and strongly believes in humanitarianism; thus she decided to register as an organ donor as she believes in doing good things for others and had faith that good things would come her way. Nina also thinks that her decision to register is beneficial to many; it benefits the receiver, and benefits society as a whole, especially when the receiver returns to society and contributes. She was also motivated to register as an organ donor as she has a fear for herself that she may need an organ donation in the future, thus she hopes that one day if her family members or herself needed an organ donor, there would be someone who would come forward and voluntarily donate an organ for them as well. This also links with her religious philosophy, where Muslims believe that if they do a good thing, God (Allah) will reward them. Therefore, two factors that led her towards registration were; belief and attitudes towards humanitarianism and her emotional responses (fear).

5.2.5.1.15 Registered Participant 15

Olina decided to register her organ donation intention after confirming from her research activities that organ donation does not violate religious principles. She has been exploring and reading from resources that she has confidence in, such as online resources, pamphlets and brochures when she sees one in healthcare facilities. Indirectly from her reading while searching for information, she gets very emotionally disturbed by the fact that there is a very low registration rate, thus making her feel sad thinking of people waiting for an organ donation. This was the key driver that moved her to register, as she wanted to help in increasing the number of people on the organ donor register. Hence, her motivation towards registration was due to her religious belief, cognitive readiness, and emotional responses when considering people waiting for an organ donation.

5.2.5.1.16 Registered Participant 16

Paulina first heard about organ donation during her tertiary education in Australia. She had the intention to register as an organ donor back then for the reason of wanting to contribute to medical education and research, as campaigned widely in Australia. What was holding her back was the fact that she was in doubt as to whether it's acceptable to donate an organ from the perspective of her religion. Only when she was certain that organ donation does not violate religious principles, did she decide to register. The sources of information with regards to the religious view were also important, as the information must come from trusted resources. She was only certain that she was making the right decision when she gained confidence from an official statement from a Mufti as well as after reading around it in the newspaper. At the point of making that decision, her donation intention was no longer for medical education, but to help sick people, as later in her life she began to develop a passion for humanitarian work. Paulina registered her intention online via a link that she saw on social media, as she thought it easier to do it virtually. Thus, religious belief, humanitarianism, and being cognitively ready motivated her to register her organ donation intention.

5.2.5.1.17 Non-Registered Participant 17

Zita has had the intention to be a registered organ donor as she knows that her religion allows organ donation. However, she decided not to register because she failed to overcome her fear of the pain that she thinks her dead body might feel during the organ removal process. This links to the argument made by (Sanner, 2006), which found that unwillingness towards organ donation was most commonly due to the discomfort which is the "Illusion of lingering life," meaning that it is hard to visualize a difference between being still alive and being dead, and that procedures with a corpse are perceived as being conducted on a living body. Another factor leading to Zita's decision not to register was due to a misunderstanding that rich people who are in the waiting list would be prioritized to get an organ over poor people. Zita also pointed out that right now there is no personal event in her life which required or demanded an organ donor. Hence, negative emotional response, no sense of urgency and misconception has discouraged registration for Zita.

5.2.5.1.18 Non-Registered Participant 18

Yani has decided to put aside her thought of being a registered organ donor as she does not know what the process for registration is, therefore there is a lack of knowledge acting as a barrier to registration. Furthermore, Yani is lacking the motivation to investigate how to register and indicated that she ‘might’ do this if she bumped into someone from the NTRC who was seeking immediate registration. Another evidenced barrier relevant to Yani, is that her family are discouraging her from registering. Therefore, motivation and lack of family support are key factors discouraging registration for Yani.

5.2.5.1.19 Non-Registered Participant 19

Wan has had the intention to be a registered organ donor but did not register her intention. She decided to not register because she failed to overcome her fear of pain. This cognitive state is similar to Participant 17, where she thinks that her corpse might feel pain during the organ removal process. She is also very much influenced by her cultural belief that a deceased body needs to be in its original condition when returning to God.

Although there were many similarities between participants’ journeys in making the registration decision, it cannot be denied that each journey was unique. To check my thinking and concepts I looked back at both the registrants’ and the non-registrants’ journey. I generated interpretive statements from across the data set and linked to psychological concepts explaining the statements. Examples of some interpretative statements are available in Table 5.7.

Table 5.7 An example of interpretive statements and psychological concepts

Interpretive statements (across data set)	**Psychological concepts**
Religion is a key driver in decision-making, however this is only one part of an individual’s belief system. An individual’s belief system is informed by personal views about the importance of sharing and giving as part of enduring charity. In addition, religion links to the concept of humanitarianism. Religion acts as both facilitator and barrier to registration depending on the information in the hands of the person making the decision.	Concept: Belief and attitudes Categories: Religion and culture, humanitarianism
Emotions as triggers stimulating differing responses; a sense of urgency in taking action to register as an organ donor or feelings of urgency, frustration and regret when the issue of a lack of organs became personal, sadness when considering people waiting for an organ donation, and fear for self and those close. Emotions act as both facilitators and barriers to registration. Emotion becomes a barrier when it stimulates fear of pain from the removal process and fear that the dead body would be unrecognizable.	Concept: Feelings and emotions Categories: Emotional responses, fear for self and those close

Interpretive statements (across data set)	**Psychological concepts**
Cognitive readiness is a person's mental preparation, which includes equipping oneself with knowledge about organ donation. Fulfilling individual needs of certain information motivates registration decision. This psychological concept is more prevalent in discussing motivations of those who decide to register, but it is a little difficult to discuss this concept with regard to a non-registrant because they don't do it.	Concept: Cognitive readiness Categories: Confidence with information resources, information needs
An individual feeling of being similar to someone that he/she adores or respects, for example; a well-known religious person, a teacher, or a favourite artist. This concerns the feeling that the decision made to register organ donation intention is in line with a valued or respected character. External influence could affect organ donation either positively or negatively. When a person looks up to someone who accepts the idea of organ donation, this can positively influence the organ donation decision, and vice versa.	Concept: External influence Categories: Valued Social networks, motivated by respected individuals

Based on the interpretive statements from across the data set and the psychological concepts presented in Table 5.7, the experience of making the decision to register as an organ donor is described as a complex, multi-faceted process, which is affected directly by internal elements related to the experience (belief and attitude, feelings and emotions, and cognitive readiness) as well as impacted indirectly by external elements related to the experience.

5.2.6 Step Five - Final synthesis

The final step in Giorgi's framework involves the synthesis of interpretive statements and a descriptive rendering of the lived experience of the essence of the phenomenon of registering as an organ donor in Malaysia from the psychological perspective. This step is vital as it enables the phenomenon and not the participant to be the focus of analysis (Giorgi, 2012).

For this final step, the psychological concepts from across the dataset have been drawn together to describe the general structure of the experience of registering, or not registering, as an organ donor in Malaysia. This final step in Giorgi's framework is illustrated in Chapter 6.

5.3 Chapter summary

Chapter 5 has outlined the data analysis process using Giorgi's five steps of data analysis framework. Each of the steps has been discussed and elaborated in detail. At each of the steps, there is an output presentation so that the reader can visualize an example.

Chapter 6 Findings and Discussion

6.1 Introduction

Chapter 6 presents the outcome of analysis as a synthesis of interpretative statements delivering a general structural description of the experience of registering or not registering to be an organ donor in Malaysia. As directed by Giorgi (1985) this general structural description forms a synthesis of the meaning units generated from each participant's individual description from across the dataset, from a psychological perspective.

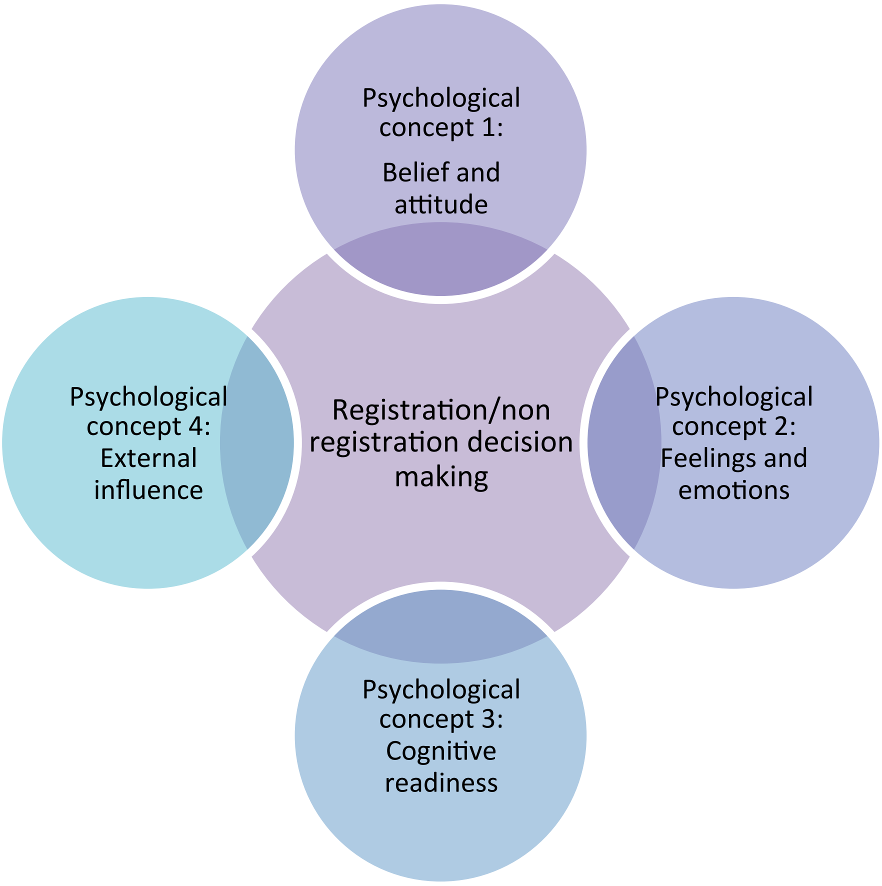
This chapter is focused entirely on reflecting the aim of this study, which was to explore the experiences of deciding to register or not to register as an organ donor and to describe the motivations driving a participant's registration of their intention to become an organ donor. From the psychological perspective, I attempt to explain the gap of knowledge concerning the change of behaviour from having an intention to donate organs and the actual action of registering as an organ donor. The focus is on the decision-making process and experience. The participants' descriptions are kept as faithful as possible to the actual phenomenon under investigation (Giorgi, 2010).

Figure 6.1 illustrates the four psychological concepts developed from 521 meaning units and, 9 categories during analysis. The findings from this analysis is integrated with a discussion of findings supported by participant exemplar quotes.

6.2 Findings

The nature of making the decision to register or not to register as an organ donor is to involve a complex mix of factors, with variation in the way that the participants experience the factors. Giorgi (1985, 2007, 2012) explains that these variations are pertinent and important and therefore are incorporated into the presentation of findings that follows.

Figure 6.1 The four psychological concepts underpinning participant decision making related to registration or non-registration as a potential organ donor in Malaysia.



6.2.1 Psychological concept 1: Belief and attitude

Beliefs and attitudes in this study were underpinned by religious and cultural beliefs, views of what it is to be a humanitarian, as well as views of practicing human rights.

A belief is an idea that a person holds about what is right and wrong or what is true and false. This belief system may derive from various sources such as a person's own experiences, religion, culture, or even educational background. A belief system is embedded within ourselves, and shapes our attitudes (Fishbein and Ajzen, 1975). According to scientists in social psychology, attitude is a significant concept in the study of human behaviour. Attitude plays a key role in various mechanisms such as the construction of psychological and emotional representation (Fazio, 2007), or behaviour (Ajzen, 1991). Thus, attitudes are the psychological dispositions people have towards others and the current situation prior to making decisions that result in certain behaviours. In the context of this research, belief is powerful enough to influence the attitude and response of the community at large towards accepting and consenting to organ transplantation and donation activities. All participants, both registered and non-registered organ donor participants, discussed their beliefs and attitudes.

6.2.1.1 Religion and Culture

During interviews all participants raised the issue of religion, with religion being a key influence on registration or non-registration decision-making. Prior to making a registration or non-registration decision, most participants expressed some uncertainty about whether their religion permitted organ donation. A personal interpretation of religious guidance could be a facilitator and driver to registration or a barrier leading to non-registration. For all participants of this study, religion as a component of a belief system was a deal breaker in the decision making process, as their religious stance on organ donation was important in deciding to register or not.

> *"For us as Muslims, we only do what is outlined in the Sharia. Because when I first heard about organ donation, the idea was still new in Malaysia. For me I was still young as I was doing my First Degree…still very young. I was like hesitating and thinking if organ donation is allowable. So discussion took place with friends. I had to do research from the perspective of Islamic law. If Islam permits it, only then would I do it. For as long as it was not clear yet from the Islamic perspective, then I could not do it yet." (Registered Participant 1, Line 100-106)*

> *"But, another main contributing reason that impedes me from registering as of now, is because of religion. I am uncertain of religious views surrounding this. There are many here who say… Some say Islam permits organ donation, and some say no." (Non-registered Participant 19, Line 109-112)*

Most participants who registered checked with some authoritative source either in person or online, even if their initial motivation was to register.

> *"Honestly if up to this point the church that I go to has not discussed about organ donation and shared with us about it from the bible's point of view, and they cannot say for sure that it is permissible from the Christian point of view, then I would not have registered. But, since the church has made it official, that is why I decided to just go ahead." (Registered Participant 4, Line 141-143)*

> *"Religion is an important factor to me. I want to be sure what religion says about organ donation. I wanted to know if it is permissible. After knowing that Islam permits organ donation it somehow gives me certainty and assurance that I am doing the right thing that is in line with my religious belief. This gives me strength in making the decision to go and sign up myself as a registered organ donor. I became more confident after the talk in my workplace as the speaker also discussed the religious stance" (Registered Participant 8, Line 175-181)*

Another important point related to religion articulated by some participants was their perception of the idea of 'continuous reward in the life hereafter': that the journey to the afterlife would be less of a burden if they donated an organ. Continuous reward from God seemed possible as long as the organ recipient was still alive and kept using the organ. Furthermore, this idea of continuous reward would be sustained if the organ recipient did good things in their life after being given a second chance. Then not only would the recipient be rewarded, but the donor who donated the organ would be rewarded too.

> *" I believe that my religion says that you must do something good and you will be rewarded, and the more rewards you have, it helps you to go to heaven. So, at least when I die I would continuously be rewarded by God, and it will ease the journey to face Him. Which I think it is one of the religious reasons." (Registered Participant 2, Line 63-67)*

> *"First, I will be rewarded by God for donating my organ to someone. For the second reward, I look at it this way, when the recipient does good in his or her community, God will reward him and I feel that God will also reward me. That's double reward. I will be happy to be getting a lot of reward even after I am dead. You know how it feels, when you are not doing anything anymore in this world, but you are still reaping the reward. Can you imagine how it would ease my life in the hereafter? Who would not want that?" (Registered Participant 10, Line 200-206)*

This idea of continuous reward may be in parallel with the literature postulating organ donation as a charitable act (Kuddus, 2014; Lukow, 2020; Padela and Auda, 2020) that enhances the life of the donor as well as the recipient. From an Islamic stance charity is one of the Five Pillars of Islam and is best known as zakat or almsgiving, which teaches the sharing of wealth for the needs of others and to help the less fortunate. In general charity is a voluntary donation of money or other means to help those in need. This study reveals that donation registration is influenced by individual beliefs that religion views donation as charity work and therefore it shaped followers' attitude towards doing good and supports followers to help and benefit others by registering an intention to donate organs for use in transplant operations:

> *"To me what's important is that I wanted to save the lives of sick and dying people. So, the main driver was not only about doing charity work, but also saving other people's lives, saving sick people who are in need is also what drives me to register." (Registered Participant 6, Line 74-76)*

> *"There is one quote from our beloved prophet Muhamad stating that "whoever helps others will be granted help from Allah in the life hereafter. When we die, there are only three things that we bring with us, which are ongoing charity, science/knowledge left for others to use, and a good child. So registering as an organ donor is one of the acts of continuous charity because the organ that we give to others brings a whole lot of benefits to its receiver." (Registered Participant 7, Line 73-78)*

It is worthwhile to note that even participants who decided not to register their donation intention expressed their awareness that organ donation is taught to be the best form of charity.

> *"I was like feeling confused because earlier on I have heard other people says that in Islam this action is not encouraged. But I just got to know that in Islam, organ donation is the best form of charity. I now understand that its OK to donate organ as it help to save life. It is good to be able to help. But I am still sceptical when the thought that of organ donation is painful when dead came back into my mind." (Non-registered Participant 17, Line 42-47)*

Despite the fact that both registered and non-registered participants believe, that organ donation is a form of charity work and is encouraged by their religion, for those participants who had considered registration but had not registered these motivations were inhibited. For example: non-registrants feared that the removal process would hurt the dead body.

> *"But honestly the issue of taboo, you know, it still possesses me, it is in my mind. I always think that it is going to be painful. So my unconscious mind is more powerful and it's always in the mind and it influences me more that the fact that many people need it and if I register it is beneficial to many people, as I was able to help others. But, I am scared if it will hurt me." (Non-registered Participant 17, Line 226-230)*

Authors (Wong, 2010a; Randhawa, 2012; Tumin *et al.*, 2014) described how individuals who reject organ donation often discussed the feeling of fear together with the belief that organs must be kept and body wholeness must be maintained after death in order for the deceased to successfully enter the next life. This is reported in studies investigating rejection to organ donation by general public as well as by family members for a deceased person, however, the same justification may have surface as a factor for non-registration.

The idea that once dead the living no longer has 'ownership' of their organs, that the organs belong to God, and therefore the individual cannot make decisions about their use, informed decision making.

> *"Basically all that is in us belongs to Allah, it is not ours. When the time comes our organs may become someone's else. Right? So we have to give. When the time has come then it is no longer ours. Just like our money, sometimes we have saved a lot of money but then suddenly our car broke down! Just look at it, it is not meant for us, it is not ours, God can take it away from us." (Registered Participant 1, Line 411-415)*

> *"You see, when you are in that situation, there's nothing, I believe that there is nothing else you can do. You basically are dead if the hospital pronounces you are brain dead. You are literally gone. So, the last thing that I can do on earth to be nice to other people is probably by helping by giving whatever is left and functioning in me. Give it to those who need it. I don't need it anymore." (Registered Participant 5, Line 60-64)*

Discussion:

Generally, religion is both a barrier and a facilitator to donation registration behaviours. Ambiguity led to 'seeking information behaviours' by those who went on to register, or inertia for those who did not register. Ambiguity was due to receiving mixed messages about religious tenets regarding organ donation, for example, grey areas in religious texts and religious leaders in churches or mosques not discussing the topic of organ donation. The lack of discussion was perceived as a signal that organ donation was not supported by faith leaders.

Although participants show gaps in understanding about their religion's viewpoint on organ donation, participants' religion was the key issue discussed when considering organ donation registration for both the registered and non-registered organ donor. Whenever participants became aware or were given information about organ donation, the first question on their minds centred on religion. This also extended to their family members whose primary concern was also the religious perspective when discussion on organ donation took place. In Malaysia, the main faiths of its citizens are Islam, Christianity, Buddhism, and Hinduism with the majority of participants in this study being Muslims.

Muslims conform to Sharia law which dictates what medical treatments should be undertaken, therefore the development of organ donation and transplantation triggered questions about whether it was allowed under Sharia teachings (Paladin, 1998; Wong, 2011; Ismail, 2012). None of the monotheistic faiths reject organ donation in principle (Bruzzone, 2008), in fact the Quran, acknowledges and accepts removal of organs, but only in specific situations: that it is the only way of treating the ailment; that the success of the transplant is highly probable; that donor or the family must have consented to donation and if possible transplantation must be between Muslims only. Therefore whilst Sharia law supports organ donation and transplantation how that law is interpreted will influence organ donation registration rates in Malaysia.

Whilst the main religions in Malaysia accept organ donation, there is evidence that suggests that members of the public are still not enthusiastic about organ donation (Wong, 2010a; Tumin *et al.*, 2014). It may be understood that this is because many families practice a range of rituals that are carried out at the time of death. For example, an Islamic requirement for burial is that it should take place as soon as possible after death without delaying it and the body must be untampered, as delay and tempered body is not good for the soul of the deceased. Additionally, in a study conducted in Malaysia, it was found that Muslims particularly fear that the organ removal process will hurt the deceased body, and fear becoming unrecognisable as a result (Andy, *et al.*, 2015). Similarly, research has demonstrated (Ashkenazi, *et al.* 2015; Loch *et al.*, 2010; Wakefield *et al.*, 2010; Wong, 2010a) unresponsiveness towards organ donation as due to fears and concerns about being dissected after death and the body being potentially disfigured.

Some Muslim scholars further interpret this as; human body is a trust given by God and that there is no permissibility for the transplantation or donation of organs. This links to empirical research by Sanner, 1994 who explains that organ donation objection was due to what she refers to as 'the Illusion of lingering life', the perception that even though death has occurred there still may be and in which he further describes the difficulty of imagining a difference between being still alive and being dead.

Findings have demonstrated that although religion is a key driver for decision-making, it is only one part of an individual's belief system. Indeed, data demonstrated a link between those who hold strongly to religion, and those who also believed in humanitarian work such as doing good, sharing and giving to other people.

6.2.1.2 Humanitarianism

Belief in humanity was widely commented on by participants. In this context humanitarianism symbolizes a helpful and responsible gesture, not only to the person in need of an organ but also towards society as a whole. As organ donation is considered (by religious texts) as a charitable contribution to the community, this may be a driver to registration as by donating an organ the individual is able to help others, encouraging a feeling of belonging to a greater community.

> *"All that I can think right now about the reason for registering was only because I just wanted to help. Because my religion taught me to be good and help others". (Registered Participant 10, Line 50-52)*

Participants who registered to be an organ donor reported feelings of satisfaction of helping others. This reflected the view that on the whole organ donation is a way to make a charitable act by reaching out and giving back to the community.

> *"I attended an event on kidneys. It was an event by the Kidney Foundation where they were sharing information about the current scenario on kidney diseases. There are many chronic kidney problems where the patient is very young but yet they are already in need of kidney transplant. But there is no donor available in the donor pool. I think that was the point where I started thinking about becoming an organ donor and decided to be one." (Registered Participant 4, Line 41-46)*

> *"To me what is important is that I wanted to save the lives of sick and dying people. So, the main driver was not only about doing charity work, but also saving other people's lives, saving sick people who are in need is also what drives me to register." (Registered Participant 6, Line 74-76)*

In general, data demonstrated strong opinions supporting organ donation as a humanitarian act, promoting sharing and giving, in line with all religious beliefs. This indirectly reflects that saving lives through organ donation is a noble and altruistic act. A strong potential motivator to donate organs was the idea that such organs are no longer needed in death and will be useful to help someone else live. Similarly, participants who decided not to register their donation intention expressed their belief that organ donation is part of a humanitarian act.

> *"I was like feeling confused because earlier on I have heard other people says that in Islam this action is not encouraged. But I just got to know that in Islam, organ donation is the best form of charity. I now understand that its OK to donate organ as it help to save life. It is good to be able to help. But I am still sceptical when the thought that of organ donation is painful when dead came back into my mind." (Non-registered Participant 17, Line 42-47)*

Discussion:

Organ donation is a noble and honorable act that benefits society in many ways as it affects more that the donors and recipients. It also touches the families, friends, colleagues, and acquaintances of those in need of organ, and upon receiving an organ it would benefit the receiver with renewed life and better health after transplant (Moritsugu, 2013). The recipient would enjoy an improved quality of life which permits them to return to normal daily activities, spend more time with family and friends, and do more physical activities they could not enjoy while ill. Thus, organ donation is the right thing to do, as it is an act of humanitarian and altruistic deed. The bigger picture is when altruism is inculcated in individuals it then promotes humane spirit in the society.

Although, altruism or humanitarianism is a component of individual's belief system which is informed by personal views about the importance of sharing and giving as part of charity, an individual's belief system is also influenced by the views of society at large and people that are important to them. This is transparent with non-registrant participants who shows understanding and acceptance on the benefit of saving life of others thru donating organ, but decided not register as they were concern what others in the society think about the decision to become an organ donor. Therefore whilst organ donation is seen as an act of humanitarian work that benefits individuals and the overall society, but whether this altruistic deed translates into actual behaviour of giving is still very much influence by the society at large. Thus organ donation registration rates in Malaysia remain stagnant as individuals, who have had the intention to donate organs, are bothered by the society's opinion and this lead to non-registration.

On the contrary, findings from the registrant participants who have demonstrated positive attitude in humanitarian work such as doing good and giving to other people, also demonstrated strong believe in autonomy, their ability to practice their right to make own decision.

6.2.1.3 Autonomy

The findings of this study established that all of the registered participants believed that the decision to register as an organ donor was their own, and that their wishes to be an organ donor should be supported by their family members if they were to die in such a way that they could become an organ donor.

> *"It is the autonomy…your own right and it feels like it's solely your own decision. Without referring to anyone." (Registered Participant 2, Line 179-180)*
>
> *"In your life, you must make your own decision and not let others decide for you, as it is your life. You will be the one living it." (Registered Participant 3, Line 226-228)*
>
> *"I have made up my mind. It is my personal life, I have the right to decide. Why give it to other people to decide?" (Registered Participant 9, Line 199-200)*

A key finding here is that none of the registered participants had discussed their decision to register with family members before they had completed the registration process, possibly in case the family were opposed to their decision.

> *"I signed up first. Because I was already in Kuala Lumpur. I took the flyer, filled it in and sent it back. Then I received the card: they posted it to my house. So when the card arrived, I told mom 'mom…aaa I am now a registered organ donor, if I die, I will donate my organs for other people'. So, I did inform her, I told her about the benefit and everything." (Registered Participant 1, Line 315-319)*
>
> *"I remember that after registration, I texted my husband just to inform him of my decision to become an organ donor. That was it. It is just a matter of informing him and not of getting his permission. To me it is totally my own decision. By the way this is my organ, my body that we are talking about." (Registered Participant 4, Line 113-116)*

On an opposing note, the three non-registered donor participants explained that when they were considering registration they had a discussion with family members. All three non-registrants reported strong objections from family members, therefore these individuals chose to obey their family's opinion and not continue with their registration intention.

> *"The first discussion that took place, where the topics were more driven towards the issue of body pain, the discussions were between me and my parents. Then later on, I also talked with my housemates regarding organ donation as they too have heard about organ donation and they too believe that when we die, the body should be*

> *handled gently so that it would not hurt the body." (Non-registered Participant 17, Line 80-84)*
>
> *"I think I wanted to be on the same side, same stance with my friends and family too, where they don't agree to becoming an organ donor due to the first reason as I mentioned earlier." (Non-registered Participant 17, Line 153-155)*
>
> *"And my dad said that 'oh there is no need for you to do that'. I don't know why, I don't understand why. My dad kept emphasising there is no need for me to register even though I kept stressing my point that I wanted to register. He kept saying, 'its ok for us not to do it, its ok, it is not necessary, it does not matter, it is not like you are in need of something right?' He said just don't trouble yourself. It would be easier for the family to manage our dead body without having to go through many procedures." (Non-registered Participant 18, Line 95-101)*

Discussion:

Autonomy as a component of a belief system is the ability to make decisions over one's own body and the belief that others should respect the decision made. A further feature of autonomy is holding independent views as opposed to identifying with group norms and mentalities. When choosing to register as a potential organ donor it can be seen as an important decision of how an autonomous individual wants to live their life or end their life. The decision is consistent with their belief towards humanitarianism attitude, act of altruism instilled with a strong sense of wanting to help other people in life and after death. People who hold strongly on individual autonomy are not afraid of what their family and others thought about their decision to register as organ donor.

In a society that does not embrace personal autonomy on matters like organ donation, it nonetheless necessary to be recognized that social and cultural factors will influence the extent to which people choose to exercise their autonomy. Making a positive choice towards organ donation is challenging, as this entails resolving questions of faith, cultural taboo and respecting your family and community whilst valuing individual autonomy. All 16 registrant participants expressed that they were aware of the taboo within the society that relates to organ donation process, such as body needs to be 'whole' for burial, however, they hoped that their decision would be fulfilled and respected by their family.

The non-registered participants, who decided to set aside their organ donation intention, anticipated family resistance. The strong family resistance against organ donation made them say no to donation. This is in line with collectivist society, which emphasizes respect and taking care of family relationships as well as conforming to social rules. A research study that looked into attitudes and beliefs about deceased organ donation in the Arabic-speaking community in

Australia found that many potential registrants were concerned about negative evaluation by their family and community, and expected family resistance and conflict if they registered as an organ donor (Ralph *et al.*, 2016). Conflict is noted in this study as the non-registered organ donor participants reported feeling of conflict between the religious values of being charitable by helping people and not being 'allowed to donate' for religious reasons, such as the need to avoid cutting the body after death. Equally, for the non-registered participants, it was difficult to differentiate between religious values and perceived societal norms. They expressed the need to conform to family opinion, which also abides by societal norms of rejecting organ donation (Ralph *et al.*, 2016; Knox *et al.*, 2017). Thus, communication between potential organ donors and their families should attend sensitively to the possible welfare benefits of religion as well as cultural belief.

6.2.2 Psychological concept 2: Feelings and Emotions

In the context of this study, feelings and emotions influenced individual decision-making processes around registration. Participants reported that emotions stimulated their registration decisions, particularly in response to some triggering event: as an example one participant's decision was triggered by the death of her uncle from kidney disease, as he did not receive a donated kidney in a transplant operation. Direct experience of the need for organs such as this stimulate the feeling of frustration and regret as there was no volunteer available to donate, and this motivated her to register.

Participant data clearly indicated that there was some form of trigger event that stimulated action to registration. These trigger events stimulated emotional responses related to sadness when considering people waiting for an organ donor. Participants expressed empathy toward those needing an organ, and this emotional response triggered donation registration behaviours, which were reported as altruistic.

> *"It touches my heart seeing the number of patients waiting for a donor and the number of patients that die every single day waiting for an organ. I don't remember the figure exactly, but I was really shocked to hear that fact. It is alarming." (Registered Participant 7, Line 45-47)*

Fear was also an emotional trigger to registration as some participants made the decision to register in view of a fear that, if needed, organs may not be available to them or to their family member:

> "It all started when I had to undergo a surgery. After the surgery when I had been transferred to the ward, I suddenly thought what if at that point of time there was no one who came forward to donate, or not enough blood supply in the blood bank, I would have died. So, that was the time that I started to think about donation." (*Registered* Participant 8, Line 35-39*)*

> *"Because of my uncle…my uncle…he suffered from kidney failure…so after he died… I felt…(emotional)…why was there no one…no one was willing to donate for him at that point in time. So, after that event, then only, there was this feeling of 'if there was an organ to donate for him, he might have lived much longer'…his children…at that time his children were still young…oh my, his children…it was a pity. So, right after that…mmm…I went back to campus, searched for the flyers given by the National Transplant again, and then I immediately registered for organ donation." (Registered Participant 1, line 26- - 37)*

So, a stimulus to donate may be focussed on a potential personal need, or the needs of close family members, and whilst being informed by religious teaching, was nevertheless self-serving: there was a personal motivation to register.

> *"Well, I also was imagining what if it was me? Or my mother, my sisters, or my kids? I would be hopeful that there would be someone donating for us. I don't want to die waiting. It is really sad to see your loved one dying and waiting. So, I don't want that to happen to me. I hope that if I give mine, God will help me, by helping me and my family members too if needed. In whatever situation, I believe if we always help others, things will be easier for us too." (Registered Participant 11, Line 192-197)*

As noted in this study, feelings of sympathy, regret and fear were triggers to registration for participants who registered. For non-registrants, whilst they fear death, they are more accepting of their fate. They report being resigned to God's provisions and will not fight the destiny of death despite the fact that they believe that organ donation is a form of charity work and is encouraged by their religion. Furthermore, the non-registered participants expressed fear of the organ retrieval process, expressing concerns that this would cause pain and that the body would not be recognizable.

> *"So I was not sure if I am ready to experience that pain they were talking about. I fear pain. Because I am sure that our bodies has to be cut open so that the organ can be remove, our bodies will be cut into pieces, then prior to the burial, I think people would not be able to wrapped the body perfectly." (Non-registered Participant 17, Line 37-41)*

> *"Even I have heard a very strong argument that says organ donation is the best form charitable work, because we are giving our organ for other people to go on and live or if not they will just die. But, I am contemplating when I also hear people say it is any form of torture to the deceased as the body will get hurt. So I then feel sorry for the deceased, I mean it is my dead body, so I have this fear in me." (Non-registered Participant 19, Line 112-117)*

This finding is supported by a survey conducted by Tumin *et al.* (2013; 2014) in Malaysia which reported that respondents were not willing to become donors because they fear of the pain during organ removal process and fear of by donating organs they would be buried as an incomplete person. The global literature also discusses the impact of emotions and feelings towards individual decisions on organ donation, as well as the reasoning of family members declining donation by a deceased loved one, and this included fear of mutilation and fear of suffering in the donation process (Sque *et al.* 2005; Sanner 2006; Morgan *et al.*, 2008a; Siminoff *et al.*, 2010; Wakefield *et al.*, 2010; O'Carroll *et al.*, 2011b; Irving *et al.*, 2014; Febrero *et al.*, 2019).

Discussion:

Feelings and emotions play an important role in registration decision making. Feelings and emotions are reported to focus attention and stimulate action, and are considered to be short-lived, intense phenomena that usually have clear cognitive content that is accessible to the person experiencing the emotion (Angie *et al.*, 2011). A key point here is the comment 'short-lived', which could account for why some participants were triggered to empathise with those waiting, but delayed registration until they had dealt with the questions and concerns they may have about registration, for example, whether their religion supported organ donation. Past studies have articulated that organ donation campaigns geared toward religious content (Karim, Jandu and Sharif, 2013; Irving *et al.*, 2014) and focused on emotional appeal (Irving *et al.*, 2014; Lin *et al.*, 2014; Sun, 2015) would increase registrations on the organ donor register (McGlade and Pierscionek, 2013).

Emotional appeal produce a feeling of pity, upset, or sympathy for others in need of an organ which then influence the conduct towards the registration behavior. While focusing on emotional appeals reinforced a sense of urgency to take action (Irving *et al.*, 2014; Sun, 2015) as registered participants in this study demonstrated, they were likely to experience personal distress when imagining themselves in the sufferers' place, thus leading to the pro-social behaviour of supporting organ donation to relieve their personal discomfort. During the donation decision-making process, an individual may reference their current feelings toward the organ donation scenario, or they may be moved by a particular emotion felt at the time concerning the real organ donation situation in Malaysia. In view of this finding 'emotional triggers' such as framing an individual case studies of people waiting for transplants and hoping for a donor could be a strategy for use by campaign organisations such as the NTRC. However, due to the suggested short-lived nature of responses towards emotional triggers, this emotion can move quickly towards emotional barriers that deter a potential organ donor from registering. As mentioned earlier, among the emotional barriers are fears of body disfiguration and fear that the organ removal process will hurt the deceased body (Sque *et al.*, 2005; Sanner, 2006; Morgan *et al.*, 2008a; Siminoff *et al.*, 2010; Wakefield *et al.*, 2010; O'Carroll *et al.*, 2011b; Irving *et al.*, 2014).

On another note, fear of body disfigurement and pain are challenging to dispel and are heightened by harmful depictions of organ donation in the media, such as in the TV series, Grey's Anatomy (Quick et al., 2014). Misrepresentations about organ donation in Grey's Anatomy series such as medical practitioner early announcement of death and corruption in the organ allocation system where people with money could have access to organ first when it's available have increased negative images of organ donation and discourage potential registrants. Similarly, dissemination of negative material on organ donation on social media such as information relating to organ trading particularly in the black market and false information that says organ donation violate religious belief may disrupt positive images of organ donation and neutralize the emotional triggers developed by individual potential donors.

Therefore, feelings and emotions, positive and negative have a role to play (Galanis *et al.*, 2008; Studts *et al.*, 2010; Joshi, 2011; O'Carroll *et al.*, 2011b; Feeley *et al.*, 2014) in individuals being cognitively ready to consider organ donation per sae and making a decision to register or not to register specifically.

6.2.3 Psychological Concept 3: Cognitive Readiness

Cognition is "the use of conscious mental processes" in acquiring knowledge and understanding through thought, experience, and the senses (Cambridge University Press, 2020). Findings from this study indicate that participants had informational needs and made choices around whether they would seek information or not, and if they did, how and where to gain that information.

6.2.3.1 Informational needs

Participants discussed their need to know and to understand how the process of organ donation works. A lack of knowledge was a barrier to donation registration, as knowledge deficits were usually linked to key concerns and feelings of anxiety.

> *"I would like to get all sorts of Information. Information about benefit, about what organ can we donate, and… what else? Mmm… maybe on the processes involved. The process of how the transplant will take place…whether…I thought that when they…like when we die because of an accident…during the post-mortem they would*

> *straight away take my organ if I were a registered organ donor. Whereas, in the website it mentioned that post-mortem and transplant is a separate process. Therefore, it is a different process. It is not what I thought, that during the post-mortem the doctor could remove an organ for donation purposes. Moreover, only from reading on the website, I knew that the doctor would I have to ask the permission of the family and it is not only based on our decision. Right? Even if we had signed up as a registered organ donor, when we die, the family will be asked first, and if the family does not allow it then it will not happen. From reading, I also know that we can either donate all organs, or we also get to choose which part to donate. Yes, that is it. These was all sorts of information I needed." (Registered Participant 1, Line 263-274)*

Overall participants were poorly informed about key donation actions, for example: how organ removal is performed, and how the dead body is handled after the removal process.

> *"I was actually referring to the way they perform the surgery at the time when health care personnel are removing the organ from the deceased body. I was also interested to know how they put it back together after the removal of an organ. I was really worried about it, maybe because my mom has put it in my mind, that organ removal for donation is painful and the healthcare personnel will do it carelessly as they would not bother to sew together the remains neatly." (Registered Participant 8, Line 95-100)*

> *"All this information is necessary for me to know prior to making the decision to register. I was curious, as I really wanted to know what our religion's stance about it is and how the removal process would take place. And what would happen to my body after the organs were removed?" (Registered Participant 12, Line 192-194)*

How the dead body is treated post donation is a concern discussed in the global literature (Sque *et al.*, 2005; Sanner, 2006; Morgan *et al.*, 2008a; Salim *et al.*, 2010; Siminoff *et al.*, 2010; Wakefield *et al.*, 2010; O'Carroll *et al.*, 2011b; Irving *et al.*, 2014; Andy *et al.*, 2015; Ashkenaz *et al.*, 2015; Sun, 2015; Cotrau *et al.*, 2019; Febrero *et al.*, 2019). A lack of knowledge or a misconception of bodily integrity, particularly on the organ donation operation and treatment of the body post organ removal procedure, was a factor in registration decisions in this study and is reported elsewhere (Wong, 2011; Riyanti *et al*., 2014; Tumin *et al*. 2014). Misconception arises because of a lack of correct information about organ donation processes. The informational needs of participants in this study were reported as needing to know whether or not religious teaching supported organ donation, but also the detail of what actually happens when you become a donor. These informational needs led to participants seeking information from varied sources, both traditional and contemporary.

6.2.3.2 Confidence with information resources

Where participants had questions regarding religious support or lack of support for organ donation, a key information resource was electronic resources. Electronic resources played a key role in providing the necessary information to guide decision making:

> *"Only from the websites. First, I looked and read from the pamphlet I received from the talk. However, since I would like to know more, I did further reading from online resources. I started goggling and reading about the fatwa/dalil from JAKIM as obviously religious information is from JAKIM website only. Then, I went into their website too, the National Transplant's website. I read again in the National Transplant's website, mmm…I was curious and I would like to know what you can do while you are still alive, and what are the benefits of organ donation." (Registered Participant 1, 243-248)*

> "I don't think it was necessary to do that because I felt that the National Transplant is the right source to refer to. Because they have the authority, I guess. I mean they are the authorised body that overlooks organ donation activities in Malaysia. So I don't think I should look from elsewhere." (*Registered* Participant *6, Line 123-126)*

As well as religious or donation specific resources, social media including blogs and Facebook was influential in not only supplying information but stimulating cognitive readiness toward organ donation.

> *"In many social media, especially Facebook, there were a lot of discussions surrounding the issue of whether it is illegal or not to donate organs. Thus, this fatwa council has made a statement that organ donation is not harmful to the deceased. So, when I read it, I was like 'oh, ok, organ donation is legal then'. So to me, by right, if the religious man or the pious says it is not violating Islamic rules, then it should not be a problem for me to go on with donating organs after death." (Registered Participant 3, Line 103-108)*

> *"I kept seeing in the FB wall where people shared the link on the awareness & campaign about organ donation… Plus I can also recall, I think in the last few years there were also official statements by the mufti." (Registered Participant 16, Line 39-42)*

Information gained from social media such as Facebook is now a key influencing factor and yet it is unclear exactly what information was being shared and if the information provided was robust. Notably, none of the non-registrant participants stated that they sought any information via social media. This might be due to their lack of interest to know more as they might have already decided to pause organ donation intention registration.

Furthermore, information appeared to have a 'social media life span', which was usually short:

> *"Talking about the sources of information, as far as I can remember there were no other websites that I searched. Most of my reading, not most, maybe all, I read about organ donation from links that other people shared in their Facebook. Usually, these links go viral for a certain period of time and people will be talking about it in that moment, if you get what I mean. It goes viral for maybe 1-2 weeks, and then no one talks about it anymore. Yeah, I am pretty sure there were no specific websites that I referred to other than the one I saw on Facebook." (Registered Participant 11, Line 170-176)*

Whilst social media and electronic resources were drawn on by participants, traditional mass media also played a role in influencing the decision to register. Examples of traditional mass media are newspapers, television and radio. Mass media has the ability to reach wide audiences with strong and influential messages (Wakefield *et al.*, 2010; Happer and Philo, 2013).

Participants reported reading newspapers, listening to items on the radio, or watching TV. The overriding impact of sources of information for those participants who registered was that the media triggered an emotional reaction that stimulated information seeking behaviours or the act of registration.

> *"I have been reading about organ donation from articles in newspapers. However, usually information shared in a newspaper is statistical figures. Therefore, I wanted to know more. I also browsed through sites looking for Islamic perspectives on this. I also obtained brochures and pamphlets." (Registered Participant 15, Line 72-75)*

> *"When I was listening to their story, suddenly there was a feeling in my heart that I wanted to donate mine when I die. So listening to their true stories has given me this feeling, which I don't know how to describe it, but it drives me to sign up." (Registered Participant 12, Line 35-38)*

> *"I was really impressed when I heard the story or the experience of one of the organ donors. He has donated one of his kidneys to a child. Before that the child was in a very critical condition. He is not as active as other children of that age are. When there was someone who was willing to donate an organ to him, now the boy can live the life he could have like other children." (Registered Participant 12, Line 46-50)*

A concern raised in relationship to TV is that it can raise (and even confirm) concerns that potential registrants may have, and may lead to non-registration:

> *"It was a local drama. Actually only one drama. It was a TV series. But from this TV series I came to know that those in need of organs or waiting for an organ donor, they have to wait in a long waiting list, it's a long queue until an organ becomes available. If there is an available organ and you are next in the queue, you will have the chance to get it as long as it matches. However, in the drama it also gives an impression that if you have the money, you can overtake the waiting line. I don't know if that is right since this is all in a TV drama." (Non- registered Participant 17, Line 254-260)*

If potential registrants have concerns that, for example, organs can be purchased by the wealthy, and that person sees this as in conflict with their personal views of altruism, continuous reward, and an act of contributing to society (Abate, 2015), then if they choose not to check this information, registration is unlikely.

Additionally, when deciding to register as a potential organ donor, the reliability and trustworthiness of sources of information was reported by participants as influential. For example, participants believed that online resources must be governed by the organization that oversees organ donation registration in Malaysia, the National Transplant Resource Centre (NTRC):

> *"The National Transplant Resource Centre was the organizer itself, thus we believed that it is a trusted body which looks after organ donation, and they should know better and the information shared…was accurate…so it convinced us, so that was why I made the decision to immediately sign up. There is no need to refer to anything else. I believed the information shared." (Registered Participant 2, Line 186-190)*

NTRC staffs were perceived to be 'experts' and that the information they provided could be trusted. As representatives from a governing body, they are potential resources for communicating information about organ donation to the public and they should be taking up the role as opinion leaders by building trust with potential registrants to increase the number of intention registration in the organ donation register. Overall, NTRC is the authorized body that oversees organ donation throughout Malaysia: they act as a continuous information centre for the community on organ donation and transplantation. The NTRC coordinates donor registration and runs organ donation and transplantation awareness programs.

> *"The speaker from NTRC did mention about organ donation from the perspectives of Islam. Before this I really thought that organ donation is prohibited and against our belief. But after listening to the talk then I understood it is not wrong in my religion." (Registered Participant 7, Line 48-51)*

Participants expressed the importance of information dissemination by a trusted governing body such as NTRC, but also the need for such bodies to support the discussion around religion. This is a key issue due to the important role a participant's belief system has in deciding to register as an organ donor.

Trusted sources therefore included the mosque, church, and Jabatan Kemajuan Islam Malaysia (JAKIM). JAKIM is a body that oversees Islamic development, ensuring standardization of the legal and administrative aspects relating to Islamic affairs, law and education throughout Malaysia. To reach a decision as important as donating an organ after death, it is vital for a person to have complete information and that information should come from a reliable source, especially when it involves religious matters. Dependability of JAKIM was mentioned by most participants and this corresponded to the importance of religion in making the organ donation registration decision.

Discussion:

Findings from this study indicate that making important decisions requires relevant and accurate knowledge, as this knowledge would serve as a basis for managing uncertainty and ambiguity. Cognitive readiness required that participants acknowledged the gaps in their knowledge, which stimulated a motivation that led to information seeking behaviours (Wilson, 2000; Fletcher, 2004). Information seeking behaviour is a feature of being cognitively ready to engage in the registration or non-registration decision. A study conducted in Iran where 85 students from various universities in Hamadan city were interviewed found that cognitive readiness influenced registration decisions (positively or negatively) and that cognitive readiness was directly related to the quality of knowledge available and the level of understanding of participants (Parsa *et al.*, 2019).

In the course of seeking information, participants may have interacted with different information sources, and the key sources discussed were computer based (the Internet) and manual information system (newspaper, pamphlet, television). The availability of Internet has allowed social media to be a powerful tool to spread awareness and encourage action (Cameron *et al.*, 2013). Nevertheless, social media can also influence unethical practices by disseminating incorrect information (Miller *et al.*, 2016), such as myth and taboo in the territory of organ donation activities. The availability of information and access to knowledge supports autonomous decision making as individuals can seek out information supporting their goals in life (Wilson, 2000; Hofstede, 2001; Fletcher, 2004). Whilst use of the Internet and traditional media was clearly a way in which participants gained access to the questions and concerns they may have about organ donation, there was an internal driver to seek information, and there were also pertinent external influences that influenced participants' decision-making.

6.2.4 Psychological Concept 4: External influences

Participants in this study expressed the power of their social network in influencing their choices and decision to register their organ donation intention. Social networks included: friends, family, community, employers and other valued and respected individuals. Social networks induced information exchange, thus it indirectly influenced choices, opinions, and actions in various ways (Kwon, Stefanone and Barnett, 2014; Kim, Rasouli and Timmermans, 2018), some of which can be seen explicitly when an individual wants to gain social approval and some subtly for impression management.

> *"If I can recall, it was just a general discussion with friends, with my classmates actually. One of my friends brought up this issue and we started talking about it. We also went on discussing this with our lecturers and asking for their opinion. On a few occasions in the discussion, the focus was more about digging for information about religious fatwa on organ donation. Then, I also did a lot of Internet searching." (Registered Participant 10, Line 83-88)*

> *"Then my boss continued saying that we are similar and she will continuously update me on the latest activities done by the National Transplant. Which I felt like, I am at a different level, as me and my boss we share the interest and it is more about doing something that is good for the community. I felt I had a different kind of relationship." (Registered Participant 3, Line 204-208)*

For non-registrants, they too seek social approval and communication surrounding organ donation does not encourage registration. Misunderstanding about cultural belief and taboo towards organ donation has surrounds the communication.

> *"I think I wanted to be on the same side, same stance with my friends and family too, where they don't agree into becoming an organ donor due to the first reason as I mentioned earlier." (*Non-* registered *Participant 17*, Line 153-155)*

Social approval was valued by both registrant and non-registrant participants who sought this from friends and others. To be part of social networks individuals engage in specific behaviours as a means of 'fitting in' and this can include mimicking other actions and thereby gaining approval for the decision being taken.

Participants in this study also indicated that they were inspired or motivated to register because of an influential person. In this study influential people included: a famous artist, a well-known religious person, parents, and other respected individuals such as University Lecturers.

> *"After reading around organ donation, I began to develop the intention to pledge. In addition, through that reading process, I came to know there is some artist who either had donated or had pledged, and one of them is my favourite artist. That has driven me a little more." (Registered Participant 8, Line 40-42)*

> *"I was reading a blog, an Islamic based blog by a pious man, if I am not mistaken his name is Ustaz Saiful Islam. He wrote something about organ donation. have no doubt. Because the blog looks reliable. I have been following that blog by Ustaz Saiful Islam and read other stuff as well that he wrote. So, yaaa, I trusted his blog." (Registered Participant 6, Line 35-66)*

> *"I was certain about it after discussion with my lecturer. What is important to me was that he was able to give evidence of a dalil. He was elaborating on a Hadith Riwayat by Ibn Majah that goes like this 'la dororo wala dhiror' which means that in whatever we do, Islam is concerned about human interest regardless of religion, race and ethnicity as well as not to cause harm and damage others." (Registered Participant 10, Line 105-109)*

On the opposing note, all three non-registrants reported strong objections from family members, therefore these individuals chose to obey their family's opinion and decided not to register organ donation intention.

> *"The first discussion that took place, where the topics were more driven towards the issue of body pain, the discussions were between me and my parents. Then later on, I also talked with my housemates regarding organ donation as they too have heard about organ donation and they too believe that when we die, the body should be handled gently so that it would not hurt the body." (Non-registered Participant 17, Line 80-84)*
>
> *"And my dad said that 'oh there is no need for you to do that'. I don't know why, I don't understand why. My dad keep emphasising there is no need for me to register even though I keep stressing my point that I wanted to register. He kept saying, 'its ok for us not to do it, its ok, it is not necessary, it does not matter, it is not like you are in need of something right?' He said just don't trouble our self. It would be easier for the family to manage our dead body without having to go through many procedure." (Non-registered Participant 18, Line 95-101)*
>
> *"So, in some way I think my parents opinion has actually stop me from looking or searching for the platform. I just don't bother about it any longer." (Non-registered Participant 18, Line 111-113)*

Family and peers has somehow influenced the non-registrant participant's decision to not register. They have had discussion around organ donation, however, it discourage intention registration.

Discussion:

Opinions and decisions regarding organ donation registration are often shaped and influenced by a prominent, respected, and important figure around the person making the registration decision. Most participants of this study talk about the importance of social approval and impression management within their network. The influence could be positive or negative, but for some participants gaining assurances and even agreement from individuals that they look up to was a key influencing factor in moving from an intention to register to an act of registration.

Social approval occurs when individuals conform to the expectations of other people in their social network and this links to subjective norms; one of the predictors in the Theory of Planned

Behaviour (TPB), which refers to the perceived social pressure to perform or not to perform the behaviour (Ajzen, 1991). Impression management refers to the behavioural strategies that people use to create desired social images or identities (Colwell *et al.*, 2006; Hines *et al.*, 2010), with the objective of fitting into the group. Individuals change positions and make decisions to the most preferred choice in order to conform to the group they belong to.

Past research suggests that those who we perceive to be influential in others' decision making processes have a power to stimulate both registration and non-registration (Ghorbani *et al.*, 2011; Scott and Quick, 2012; Murray *et al.*, 2013; Ralph *et al.*, 2014). Although an old source of information, the work of French and Raven (1959) can help in understanding how influential individuals influence decision-making. French and Raven (1959) propose five sources of power, which are; expert power, referent power, legitimate power, rewards power, and coercive power, with three of these sources of power being specifically relevant to this study and the related context. These are expert power, referent power, legitimate power.

In this study participants' decision making was mostly influenced by personal power (referent and expert) or formal power (legitimate). Expert power was reported in relationship to individuals from the NTRC and the specific healthcare professionals who were perceived to be knowledgeable and trustworthy. Typically, past organ donation research suggested that using trained and experienced individuals to make requests for organ donation increased consent rates (Kress *et al.*, 2009; Baughn, *et al.*, 2010) as these individuals are seen as experts. Talking to and spending more time with a trained member of staff or the organ procurement coordinator before being asked to make a decision were both strongly associated with donation, and this has been one of the reasons why it is proposed that hospitals particularly in Malaysia should have organ procurement coordinators, as they often lead to a positive outcome in relationship to organ donation (Simpkin *et al.*, 2009).

Referent power refers to the ability of a person to influence others in response to feelings of loyalty, respect, or admiration. Over the past years, icons have become more influential with the existence of social media, and they are more visible in their activities. Their influence was reported by participants who were stimulated to register in view of the comments or perceived agreement with organ donation shared with them, usually via social media, of influential people who they admired. In a study by Hou (2019) that examined social media celebrity by focusing on YouTube channels, many home-grown stars were considered by publicity practitioners as social media influencers whose media visibility can be leveraged to promote, engage and educate target audience on various brand messages. This is also evident in the area of organ donation, as

YouTube has been used to promote organ donation (Tian, 2010; Connor, *et al.*, 2014; Vanderknyff, *et al.*, 2015).

Legitimate power was represented by religious leaders, religious tenets and teachings, the professional organisation tasked with overseeing organ donation (NTRC) and the family as a social institution (Cernea, 1975; Waite, 2000). Typically, formal relationships within a family exist between parents and children, where parents impose legitimate power in enforcing certain rules and specifying expectations. This legitimate power was clearly indicated by the need of participants (both registered and non registered), to seek the views of their parents.

Malaysian family bonds are often strong and important in every family institution; it appears unforgiving to put aside a family's opinion especially when it implicates end-of-life matters. It is common for Malaysians to consult their families' views particularly in matters that affect the whole family. It is of utmost important for Malaysians to show respect for elderly members of the family, and conventionally parents act as gatekeepers who make important decisions, such as organ donation. This was clear for non-donor registrants who may have had an intention to register, but cast the intention aside after taking their families' opinions into account. Past empirical research has shown that families often reject or interfere in organ donation either by discouraging the family member from pursuing the intention to register or in the situation where a registered donor dies and their recorded wish to be an organ donor is vetoed by the family (Smith *et al.*, 2004; Afifi *et al.*, 2006; Galanis *et al.*, 2008; Hyde and White, 2009b; Hyde and White, 2009a; Hyde and White, 2010; Newton *et al.*, 2010; Long *et al.*, 2012; Hyde and White, 2013; Murray *et al.*, 2013; Irving *et al.*, 2014).

Malaysians is seen as a collectivist society (Hofstede, 1980;2001; Hofstede, 2007; Hofstede Insights, 2020) whose members focus on family and community, place a high degree of importance on personal relationships and keeping harmony within the group (Beitin and Allen, 2005; Ralph *et al.*, 2016), and members of the group take care of each other like a family, in exchange for loyalty. Nevertheless belief in autonomy in decision-making was evident as the registered participants pursued their organ donation intentions. In order to avoid a negative outcome of a registration decision, some registered participants expressed the idea that registration process took place prior to family communication with the expectation that family members would respect that decision. This contradicts what was mentioned earlier, that Malaysian society is collectivist in nature where family opinion is important to maintain a harmonious relationship. Correspondingly, news reported that currently Malaysians who live in urban areas in particular, are becoming more individualistic (Edward and Edwards, 2018) and this is in line with research findings that reported a global phenomenon of increasing individualism

(Santos, *et al.*, 2017). Nonetheless, collectivist or individualist, either culture indirectly impact and influence human behaviour in a particular society (Hofstede, 1980;2001; Schultz, 2002; Hofstede, 2007; Gammoh *et al.*, 2019).

6.3 Answering the research question and meeting the study objectives.

The final discussion aims to illustrate how the research that has been undertaken has answered the research question posed at the start of the research journey and met the research objectives. The research question guiding the research outlined in this thesis was: *What individual factors influence organ donation registration in Malaysia?* The following sections will respond to this question and respond to the study objectives, which were: *To explore the reasons why individuals in Malaysia decide to register as potential organ donors. To explore whether religious and cultural beliefs play a role in the decision to register as a potential organ donor in Malaysia. To identify what information individuals in Malaysia seek prior to registering as a potential organ donor and to explore whether family communication about a decision to register as a potential organ donor takes place and to determine the information discussed with the family.* To limit repetition of findings in the following sections objectives 1 and 2 have been integrated.

6.3.1 Why do individuals in Malaysia decide to register as potential organ donors and does religious and cultural belief play a role in the decision to register as a potential organ donor in Malaysia?

Beliefs and attitudes toward organ donation were key drivers to action or inaction for registration as religious beliefs and cultural attitudes were discussed by all participants, both registrants and non-registrants. Religion was the pivotal influence on decision making for all participants and whilst their knowledge base about religious tenets regarding organ donation may be lacking, this was a motivation for information seeking behaviours by those who went on to register, but not for those who did not register. For non-registrants although religion (and whether it supported organ donation or not) was factor in decision-making, fear and external influences were much more influential to their decision making.

Registrants talked about the good that can be achieved (either in this life or the next), an alignment with charitable acts and humanitarianism. The perception of organ donation as ‘continuous reward in the life hereafter’: that the journey to the afterlife would be less of a burden if they donated an organ was a key commentary. This idea of continuous reward from God seemed was conditional on: the organ recipient continuing to live, and that the recipient continued doing good things in their life after being given a second chance. In this case not only would the recipient be rewarded, but the person who donated the organ would be rewarded too. Continuous reward aligns with the literature suggesting organ donation as a charitable act (Kuddus, 2014; Lukow, 2020; Padela and Auda, 2020) that enhances the life of the donor as well as the recipient. Non-registrant participants expressed their understanding that religion views organ donation as the best form of charity, but as they fear that the removal process will hurt the dead body and hold the belief that bodily wholeness must be maintained after death in order for the deceased to successfully enter the next life, registration did not take place.

Feelings of altruism and humanitarianism underpinned registration behaviors. The stimulus for feelings of altruism was empathy for people on the waiting list for an organ transplant. Work dating back to the early 90's proposes the 'empathy-altruism hypothesis' (Batson, 1991; Batson and Shaw, 1991; Batson, 2011; Batson, Lishner and Stocks, 2015), which claims that feelings of empathy for another person produce an altruistic motivation to improve that person's welfare. The empathy-altruism hypothesis predicts that those having high levels of empathy for a person in need will be more prone to help than will those feeling less empathy. As findings from this study suggest, feelings and emotions stimulated organ donation registration consideration. This is clear when donor registrant participants reference their current feelings towards the need for organ donation, and they may be moved by their feelings at the time of the decision making process. However, non-donor registrants of this study have stronger feelings and emotions about threats and fear associated with thinking about the treatment of the body during organ removal process. This feeling of anxiety negatively affects the organ donation registration decision as they decide to withhold their intention to be an organ donor.

Furthermore, participants may have experienced a triggering event that stimulated action to register. These trigger events stimulated emotional responses related to wanting to help other people, or to visualizing themselves in the position of needing an organ. Being open to the idea of organ donation (cognitive readiness) was the first step in an intentional trajectory which was supported by confidence in the available informational resources and supported by influential others.

External influence stimulated and often supported organ donation registration. External influences included those who were perceived to be: valued, prominent, respected, and important figures who were part of the individual's social network. Social networks induced information exchange, thus it indirectly influenced choices, opinions, and actions in various ways (Kwon, Stefanone and Barnett, 2014; Kim, Rasouli and Timmermans, 2018). Most participants of this study talk about the importance of social approval, in terms of gaining assurances and even agreement from individuals that they look up to within their social network.

It was key for the participants to gain approval from their social network, in moving from an intention to register to an act of registration. However, for non-registrants the only influential external influence they mentioned was their direct family. As their family was not supportive of the idea of organ donation, often citing their own discomfort in the idea of organ donation, non-registration was the outcome.

Religious belief is the most important factor influencing registration decision making as it not only shaped individual actions but forms the cultural framework within which individuals make decisions. The expression by registered participants was that religion allows organ donation, while non-registrant participants considered that religion prohibits organ donation. Malaysians generally have a strong sense of religious and cultural norms (Wong, 2010; Tumin *et al.,* 2014), and so do the participants in this study. All participants brought up and debated the importance of recognizing values and principles with respect to organ donation from a religious point of view.

6.3.2 What information do individuals in Malaysia seek prior to registering as a potential organ donor?

The most important information needed by participants concerned whether deceased organ donation is permissible by their religion. There was a high level of concern expressed by non-registrant participants about perceived mistreatment of the deceased's body in the organ removal process, and whilst concern was also expressed by registrant participants, this usually led to information seeking behaviours to resolve concerns, but this was not the case for non-registrants where knowledge deficits were clearly linked to feelings of anxiety. Varied sources both traditional and contemporary were referred to, with key sources being reported as the Internet (Social media), newspapers, pamphlets, and television. Most participants expressed the importance of accessing information from reliable and trustworthy sources, for example, that the online resources must be governed by the organization that oversees organ donation registration in Malaysia, the National Transplant Resource Centre.

Findings from the study reported in this thesis suggest that misunderstandings about religious tenets and teachings due to lack of information, having incorrect information prior to making the registration decision, or lack of trust towards the sources of information are the key issues in relationship to religion as a barrier. Having access to information that answers the key questions and concerns of the potential donor registrant is essential in facilitating registration in a country where religion is so influential in promoting pro-social norms and values that lead to altruistic and humanitarian deeds (Bennett and Einolf, 2017).

Informational sources were essential in the decision-making process with participants appearing to select informational sources aligned with their key concerns and questions. For example, Muslims exclusively accessed JAKIM's (a religious body) website and Islamic religious blogs. Information seeking behaviours included contemporary and traditional media with most religious clarification being sought via online sources including online religious lectures on Youtube (Hirschkind, 2012). Authors suggest that the Internet has become a virtual archive for Islamic information and that it has now become a major source for religious information (Hoover, *et al.*, 2004; Kort, 2005; Rahman, *et al.*, 2015). Furthermore, evidence reports an increasing number of online 'religion seekers' using the Internet to supplement their religious life practices (Hoover, Clark and Rainie, 2004).

The development and growth of the Internet has provided an effective means of religious statement and engagement due to its interactivity, simplicity of use, and interactive media affordability (Tian, 2010; Rahman, *et al.*, 2015; Mohd Azmi, *et al.*, 2019). Despite the advancement of information dissemination online, organ donation acceptance among Muslims as well as other religions is rather slow. As findings from this study suggest that feelings and emotions stimulated by considering organ donation registration led to informational seeking behaviours and underpinned a state of cognitive readiness, the important role that information and knowledge has in supporting decision making is clear. Whatever route is taken to access information, the credibility of information sources is vital. As the findings of this study demonstrated, information pertaining to organ donation registration must come from reliable and trusted sources so that concerns generated by individual attitudes and beliefs toward, for example, what their religion permits, are resolved

6.3.3 Does family communication about a decision to register as a potential organ donor takes place, and what information is discussed with the family?

There are differing comments made by registrant and non-registrant participants around communication with family members about donation registration. The global literature indicates that family members are a key influence for decision making, and that families often reject or interfere in organ donation, either by discouraging the family member from pursuing his or her intention to register or in the situation where a registered donor dies and their recorded wish to be an organ donor is vetoed by the family (Smith *et al.*, 2004; Afifi *et al.*, 2006; Galanis *et al.*, 2008; Hyde and White, 2009b; Hyde and White, 2009a; Hyde and White, 2010; Newton *et al.*, 2010; Long *et al.*, 2012; Hyde and White, 2013; Murray *et al.*, 2013; Irving *et al.*, 2014). Findings from the study reported in this thesis indicate that most registrant participants indicated that they chose to avoid discussing their intentions with family members as they expected a negative response to initiating the discussion. Registrants belief was that they are practicing their autonomous right to register and that they expected family members to respect that decision.

On the contrary, the non-registrant participants reported that family discussion had taken place and that this discussion had impacted their decision to put on hold their organ donation intention, as a means of showing respect for their family's opinion. When discussing organ donation, the primary concern was the religious perspective as discussed earlier, and values regarding the protection, integrity, and respect for the body, however, the suggestion that Malaysian society is collectivist in nature (Hofstede, 1980, 2001, 2007, 2020), and that the family's opinion needs to be respected in order to maintain a harmonious relationship. It may be that until a larger proportion of Malaysians view individualism as more important than collectivism in line with global change (Santos *et al.*, 2017), significant change will not be achievable.

6.4 Chapter Summary

Chapter 6 has presented the outcome of analysis as a synthesis of interpretative statements delivering a general structural description of the experience of registering or not registering to be an organ donor in Malaysia by focusing on four psychological concepts (Figure 6.1). Chapter 6 discussion was centred around the aim of this study which was to explore the experiences of making the decision and to describe the motivations driving a participant's registration of their intention to become an organ donor. The focus is on the experience of decision-making process.

Chapter 7 Conclusions, recommendations and limitations

7.1 Introduction

Chapter 7 commences by situating the findings from the research presented within the wider literature as a means of supporting the outlined recommendations. Recommendations for public engagement campaigns, practice, policy and future research based on the findings are outlined. Chapter 7 concludes with a reflection on undertaking this study as well as on its strengths and limitations.

7.2 Implications of findings for future donor registration campaigns planning and future research

To date, no study has explored the lived experience of the registration decision making of Malaysians, and specifically how an intention to register becomes an action of registration or non-registration. Applying a phenomenological methodology and a psychological lens to analyse findings clearly indicates that psychological based factors combine to stimulate action or inaction in relationship to donation registration. Findings indicate that a state of cognitive readiness to donate can stimulate some individuals and this state is a product of beliefs and attitude, feelings and emotions and external forces. As indicated in this study, religious beliefs were positive drivers for registrant participants whereas other research has reported religious beliefs as barriers (Bruzzone, 2008; Wong, 2010a; Riyanti *et al.*, 2014; Andy, Abdul Rahim and Lyndon, 2015; Ralph *et al.*, 2016; Knox *et al.*, 2017; Parsa *et al.*, 2019; Akbulut *et al.*, 2020). While, the non-registrant participants' decision were very much influence by the external forces particularly family's opinion had stronger influence towards non-registration decision.

Making a decision to register as an organ donor in Malaysia has started to received attention in the literature, but the designs used did not provide the opportunity to explore the competing and varied factors that interlink to facilitate or obstruct registration. How an intention to register becomes an act of registration is primarily a psychological process, and therefore the application of a qualitative methodology applying a psychological lens to analysis has enabled this work to illustrate this complex phenomenon (see Figure 6.1). The study has generated a rigorous, high quality evidence base grounded in the Malaysian perspective that is focused on four useful psychological concepts in which is a complex mix of factors, with variation in the way that the participants experience the factors. This would influence the conduct as well as content of future organ donation campaign, which would be a great input to NTRC.

This study, being of an exploratory and descriptive in nature, raises a number of opportunities for future research, both in terms of theory development and concept validation. More research will in fact be necessary to refine and further elaborate this novel finding.

7.3 Recommendations

7.3.1 Implications for the design of registration campaigns by NTRC.

Empirical research within the Malaysian context tells us that the current organ donation campaigns run by NTRC in Malaysia is not influencing societal change in organ donation registration rates (Loch *et al.*, 2010; Wong, 2010; Tumin *et al.,* 2013; Riyanti *et al.*, 2014; Tumin *et al.*, 2014), and this suggests that best practice has not yet been identified. The findings from this thesis indicates that awareness campaigns need a collaborative approach necessitating partnership working between government organizations such as the Ministry of Health and the National Transplant Resource Centre, religious scholars and academic institutions to provide consistent messaging that all religion in Malaysia supports organ donation. Past research suggests that those who we perceive to be influential in others' decision making processes have a power to stimulate registration (Ghorbani *et al.*, 2011; Scott and Quick, 2012; Murray *et al.*, 2013; Ralph *et al.*, 2014). The work of French and Raven (1959) can help in understanding how influential individuals or bodies influence decision-making. French and Raven (1959) propose five sources of power, which are; legitimate power, referent power, expert power, rewards power, and coercive power, with three of these sources of power being specifically relevant to this study and the related context. These are legitimate power, expert power, and referent power. Thus, collaboration with Ministry of Health, National Transplant Resource Centre, and religious scholars would supports organ donation.

Evidence reports that Malaysians are aware of organ donation, particularly through the campaigns run by the National Transplant Resource Centre (Wong, 2010b; Tumin et al., 2013b). Key information sharing is via TV, radio, newspapers, brochures, roadshows and internet, but these sources do not necessarily include the depth of information or the content that people need. Traditional organ donation campaigns are aimed at attracting donors by providing statistics of people on organ donor waiting lists, however, these messages do not connect the view of the campaign with 'a person', thereby stimulating an emotional connection between potential organ donors and those people on the organ donor waiting list. Findings from this study indicated that such stimuli triggered feelings of empathy and altruism towards those needing an organ and moved individuals from a position of intending to register to actual registration.

Furthermore, participants expressed the importance of information dissemination by a trusted governing body such as NTRC and also the need for such bodies to support the discussion around religion. This is a key issue due to the important role a participant's belief system has in deciding to register as an organ donor. This findings suggest that campaigns may be more effective in stimulating donation registration if they included information about, for example, macro issues such as religious and cultural guidance regarding organ donation, the number of organs needed, and the benefits of organ donation, but also micro issues such as what is entailed in the donation process, and how to register as an organ donor. Findings from non-registrant participants indicate general concern about the mistreatment of the deceased's body during the organ removal process. Therefore, an essential element in campaign resources must be reassurance that the deceased body would be treated with respect and care, and that the handling of the body would follow the rules and regulations of their religious belief. There is the potential to address existing myths circulating within the Malaysian community with use of culturally and religiously sensitive messages about organ donation. A well-planned campaign would function as an intervention educating, persuading, and enabling individuals to translate intention to the desired behaviour (Michie et al, 2011). The Behaviour Change Technique (BCT) (Mitchie et al, 2011) emphasizes that any planned intervention should commence robustly and systematically order to determine what needs to change in order for the behavioural target to be achieved. Therefore the findings from this study should be able provide useful information and can contribute ideas in designing an intervention, particularly in education aspect of organ donation registration. Contribution of ideas on which new thinking could be based informed by this study accepting it is a first step, exploratory study that needs to enlarge.

7.3.2 Implications for public awareness raising strategies

Following the BCT framework (Michie et al, 2011) and based on findings from this thesis education and persuasion strategies should take advantage of social media. The use of social media to stimulate organ donation registration has received empirical investigation. A study in Malaysia by Yusop and Sumari (2013), investigating youth engagement with social media, reporting that 88% of Malaysian youth are actively engaged, therefore campaigns should take advantage of social media platforms. However, findings indicate that emotion-based stimuli presented on social media appear to have a short life span in triggering action, therefore the presentation of information must be linked to easily accessible routes to gain answers to concerns (re religion etc) followed by a link to the registration process that needs to be followed. For example, during streamed information campaigns individuals could be triggered to use a mobile phone to link to collaboratively generated information specifically designed to reduce personal fears that are evidenced in this study as driving non-registration.

Collaboratively generated information should be agreed by the key stakeholders and influential sources identified in this study: NTRC and religious facilities such as mosques, churches, and temples. A key point is that information sources need to provide consistent information from credible experts, delivered to different segments of the community, for example, school/university audiences, religious communities, health care communities, as these are sources specified by participants. As the media landscape has changed, with more age groups using social media (Miller et al., 2016; Valkenburg and Piotrowski, 2017) campaigns need to change. As much as television and radio has reached large audiences and influenced people's daily lives and routines, the use of websites and social media is reported as more effective in fulfilling information needs in the context of organ donation registration (Morgan et al., 2005; Hussen et al., 2017; Jiang et al., 2019; Ruck et al., 2019).

The outcomes from the research presented in this thesis clearly highlight the psychological concepts influencing how an intention to register as an organ donor can be stimulated, and what factors need to be in place for this intention to become an act of registration. This research will be disseminated via presentation of findings in a meeting to the transplant authority in Malaysia, the National Transplant Resource Centre (NTRC) team who supported participant recruitment and have expressed their interest in seeing the results of this study. Therefore, post submission and successful completion of the PhD, a presentation session of the findings with NTRC will be arranged. It is also a plus point to highlight that this research has already stimulated interest as a paper published outputs prior to viva have reach over 900 reads on research gate and therefore there is interest in this work due to it being one of the few studies carried out in Malaysia.

7.4 Reflection on strengths of the research undertaken

In choosing the paradigm of inquiry guiding this study, the fact that people construct meaning in different ways depending on the individual's perspective, and the historical and cultural contexts in which they live led me to choose a constructivist paradigm of inquiry so that the 'how' and 'why' of the phenomenon of organ donation registration could be explored from the perspective of the individual. A principle of the constructivist paradigm is that events or phenomena cannot be isolated from the context within which they occur as reality as viewed is subjective, differing from person to person (Guba and Lincoln, 1994). For example, in the study presented in this thesis, findings indicate that deciding to register an organ donation intention was influenced by factors including social and cultural contexts, and that therefore the experience of making the decision to register as an organ donor varied between each individual, who had a different perspective on the same phenomena.

A successful outcome of the methodology and methods chosen and applied has been the rich textured description of participants lived experience (Finlay, 2013) as they construct meaning from their interactions with each other and with wider social systems that impact on their donation registration decision making. In choosing Husserl’s approach to phenomenology the central concept of intentionality was key. The term intentionality indicates the orientation of the mind toward the object or event (McIntyre, 1982; Moustakas, 1994). In other words, intentionality has to do with the directedness or reference of mind to things, objects, or events and is clearly indicated in the concept of cognitive readiness identified in this work. Husserl emphasises the importance of carefully describing the essence of the phenomenon, arguing that at its core phenomenology is descriptive and balanced with researcher reflexivity, which offers a synthesized account, in this thesis, of the psychological concepts identified in analysis, illustrating the essence of the phenomenon (Giorgi, 2007; Finlay, 2009).

It is worthwhile to highlight other strengths of this research; i) it utilised triangulation of data sources from donor and non-donor registrants and the extent literature have underpinned the credibility of findings, ii) use of audit trail is a mechanism to track and confirm the sources, and as this study utilized an audit trail, anyone who is independent of the research processes such as recruitment, interviewing, data analysis, and other activities should be able to repeat these processes and arrive at similar findings, interpretations, and conclusions about the data.

Beside, to ensure transferability of qualitative study, a thick description is important when writing up the results of a study as the researcher need to provide wide-ranging of information about; the participants of the study, location and methods of data collection, the quality of the interview questions, and other aspects of data collection that help provide a richer and fuller understanding of the research setting. A thick description of findings is also important, as readers need to make an informed judgment if they can transfer the findings to their own situation.

Confirmability of this study is enhanced by using an audit trail and reflexive notes, which was helpful to ensure that the researcher is aware of how she could have influenced the data. Bracketing has also allowed the researcher to separate the lived experience of participants from the researcher’s experience of a phenomenon throughout the study, particularly in the analysis stage.

Whilst the choice of methodology and methods is strength of this research there are limitations to the study, and these are outlined in the following sections.

7.4.1 Limitations

The final sample of donor registrants was more similar (homogeneous) than dissimilar in regard to age, gender and educational level. Therefore, findings represent the views of a well-educated, female sample only and whilst the inclusion of non-registrants was invaluable from a methodological perspective (negative case analysis) the low number of participants limits the discussion that can be presented regarding their lived experience. A key learning point was that the chosen recruitment strategy has limited potential to recruit a non-registrant population due to the fact that access to non-registrants is dependent of facilitation by other stakeholders. Similarly, researchers all over the world have found recruiting people who did not register, or who declined donation of a family members organs problematic. One way to overcome this limitation if there is possibility of conducting this study again is to have a better recruitment strategies such as; use social media to attract more potential participants and could offer some incentives so that people would voluntarily come forward.

A further limitation was that the sample was predominantly Muslims, which was a result of the sample being self-selecting. Whilst this study is not able to report the variety of views held by those members of the population belonging to other major religions, the findings are valuable because the main religion in Malaysia is Islam.

It is also seen as limitation as the participants of this study were only interviewed once, in compliance of Giorgi's framework, which disallowed follow-ups to seek clarification of any concerns if required. If there were more than one interview with each participant of this study, it may have resulted in greater clarity of some of the descriptions of the experience of the organ donation registration decision.

Plus, another limitation that is worth highlighting is that, since this was a PhD study and undertaken by a solo novice researcher, this may have affected the quality of the research and its outcomes. This limitation was sought to be overcome by regular meetings and discussions with the research supervisors.

7.5 Future research

This study has been the first in-depth exploration of the organ donation registration decision in Malaysia, and as such provides a valuable contribution to knowledge and understanding of this phenomenon. In order to have a strong evidence base to benefit the Malaysian healthcare system and specifically the critically ill patient waiting for an organ donor, further research is required.

For future research, it is deemed necessary to test the psychological concept illustrated in Figure 6.1. This was not done in this study as the primary goal of this thesis was to first explore organ donation registration decision in Malaysia and no attempt examine or test it in the field. To do so, design proposed would be a mixed method study; qualitative component is important to develop construct or item for each of the concepts in a survey, and quantitative is to actually test the survey instrument.

Since the sample was biased toward the view of women and of a well-educated group, it is recommended that further research should be expanded towards different socioeconomic groups of people, for example men, those without tertiary education, or those who live in rural areas. Plus, since this study was the first in Malaysia looking at why and what stimulate the decision to register as an organ donor, a bigger size of registrant's participant is needed to improve understanding and enhance the current psychological concepts (Figure 6.1) developed in the study. Although these groups of people are hard to reach communities and could be only a minority group of registered organ donors, it is significant for us to understand the motives towards organ donation registration. This can be achieve by initiating collaborative effort with the NTRC, the authorized body that oversees organ donation in Malaysia.

7.6 Concluding Remarks

The study has applied a phenomenological approach in a rigorous manner, to generate findings from a Malaysian perspective focused on the individual lived experience of deciding to register as an organ donor.

Currently, the waiting list in Malaysia recorded a total number of 21, 826 individuals (National Transplant Resource Centre 2018 per communication). In the effort to reduce the number of ill people in the waiting list in Malaysia, a donor register was developed in 1997, handled by National Transplant Resource Centre (NTRC) and was seen to facilitate individual choice regarding organ donation so that donation intention can be recorded on a central database. However, to date, the number of deceased donors is only 0.53 p.m.p for every one million population (IRODAT, 2020). In comparison to other neighbouring countries; Indian has 0.65 p.m.p, Japan has 0.75 p.m.p, Thailand has 3.66 p.m.p, China has 4.43 p.m.p, and South Korea has 8.68 p.m.p (IRODAT, 2020).

Thus, it is very clear that there is low donation rate from deceased donor in Malaysia, despite on going campaign by NTRC and this has raised concerns about the national ability to increase the number of potential organ donors and reduce the organ transplant waiting list. This research has addressed just one component of organ donation, that of intentional registration behaviour. However, more research is needed, which should then focus specifically on the shortage of donated organs in Malaysia.

Appendix A Systematic Literature Search

STAGE 01

QUESTION: What are the reasons/factors that stimulate the decision to register as a potential organ donor?	
Keywords	**Synonyms and alternative spellings**
Factors	Factors OR Determinants OR Drivers OR Influences OR Motivates OR Perception OR Stimulates OR Thought
Decision	Decision OR decide OR decision making OR Choice
Register	Register OR Sign up OR “Signing up” OR Record
Organ Donor	“Organ donor”
Search Term: **Factor*** OR Determin* OR Drive* OR Influence* OR Motivate* OR Perception* OR Stimulate* OR Thought* AND **Decision*** OR decid* OR “decision making” OR Choice* AND **Register*** OR “Sign* up” OR record* AND **“Organ Donor”**	

Appendix A

STAGE 01 - SEARCH STRATEGIES

Databases	**Access Date**	**Retrieved**	**Accepted**	**Rejected**	**Reason for rejection**
Cochrane	28/05/2015 22/07/2015 17/09/2015 14/04/2020	23	1	22	• Unrelated non-clinical intervention - 2 • Clinical intervention – 11 • Presumed consent – 1 • Non target population – 3 • Economic study - 5
Medline		38 **(+1 in 2020)**	14	25	• Unrelated non-clinical intervention - 2 • Clinical intervention – 6 • Presumed consent – 2 • Non target population – 10 • Body donation – 3 • Systematic Review – 1 • Pilot study - 1
CINAHL		1	0	1	• Duplicate - 1
Embase		1	0	1	• Non target population – 1
PsycINFO		19	7	12	• Unrelated non-clinical intervention - 1 • Presumed consent – 2 • Non target population – 5 • Body donation – 2 • Duplicate - 2
W.O.S		19	0	19	• Unrelated non-clinical intervention - 3 • Non target population – 4 • Duplicate - 12
Scopus		21	1	20	• Unrelated non-clinical intervention - 3 • Clinical intervention – 5 • Presumed consent – 1 • Non target population – 9 • Duplicate - 2
TOTAL		**123**	**23**	**100**	

STAGE 02:

QUESTION: What information do individuals refer to prior to registering as a potential organ donor?	
Keywords	**Synonyms and alternative spellings**
Information	Information OR data OR evidence OR fact
Decision	Decision OR decide OR decision making OR Choice
Register	Register OR Sign up OR “Signing up” OR Record
Organ Donor	“Organ donor”
Search Term: **Information** OR data OR evidence OR fact* AND **Decision*** OR decid* OR “decision making” OR Choice* AND **Register*** OR “Sign* up” OR Record* AND **“Organ Donor”**	

Appendix A

STAGE 02 - SEARCH STRATEGIES

Databases	Access Date	Retrieved	Accepted	Rejected	Reason for rejection
Cochrane	28/05/2015 22/07/2015 17/09/2015 14/04/2020	24	0	24	• Unrelated non-clinical intervention - 2 • Clinical intervention – 10 • Presumed consent – 1 • Non target population – 3 • Economic study – 7 • Duplicate - 1
Medline		38	02	36	• Unrelated non-clinical intervention - 2 • Clinical intervention – 2 • Presumed consent – 1 • Non target population – 3 • Body donation - 3 • Duplicate - 25
CINAHL		3	0	3	• Duplicate - 3
Embase		1	0	1	• Duplicate - 1
PsycINFO		23	0	23	• Unrelated non-clinical intervention - 3 • Non target population – 1 • Duplicate - 19
W.O.S		24	0	24	• Non target population – 1 • Economic study - 2 • Duplicate - 21
Scopus		23	0	23	• Unrelated non-clinical intervention - 2 • Clinical intervention – 5 • Presumed consent – 1 • Non target population – 9 • Duplicate - 6
TOTAL		**136**	**02**	**134**	

STAGE 03:

QUESTION: What role do religious and cultural beliefs play in the decision making to register as a potential organ donor?	
Keywords	**Synonyms and alternative spellings**
Religious belief	“Religious belief” OR “spiritual belief” OR faith OR religion OR religiosity OR spirituality
Cultural belief	“Cultural belief” OR culture
Decision	Decision OR decide OR decision making OR Choice
Register	Register OR Sign up OR “Signing up” OR Record
Organ Donor	“Organ donor”
Search Term: “**Religious belief***” OR “spiritual belief*” OR faith OR religion OR religio* OR spiritual* OR “**Cultural belief***” OR culture* AND **Decision*** OR decid* OR “decision making” OR Choice* AND **Register*** OR “Sign* up” OR Record* AND **“Organ Donor”**	

STAGE 03 - SEARCH STRATEGIES

Databases	**Access Date**	**Retrieved**	**Accepted**	**Rejected**	**Reason for rejection**
Cochrane	28/05/2015 22/07/2015 17/09/2015 14/04/2020	3	0	3	• Clinical intervention –2 • Presumed consent – 1
Medline		11	01	10	• Duplicate - 10
CINAHL		1	0	1	• Duplicate - 1
Embase		1	0	1	• Duplicate - 1
PsycINFO		7	0	7	• Duplicate - 7
W.O.S		9	02	7	• Non target population – 1 • Duplicate - 6
Scopus		4	0	4	• Clinical intervention – 1 • Non target population – 2 • Duplicate - 1
TOTAL		36	03	33	

STAGE 04:

Databases	**Access Date**	**Retrieved**	**Accepted**	**Rejected**	**Reason for rejection**
Cochrane	28/05/2015 22/07/2015 17/09/2015 14/04/2020	3	0	3	• Clinical intervention –2 • Presumed consent – 1
Medline		11	01	10	• Duplicate - 10
CINAHL		1	0	1	• Duplicate - 1
Embase		1	0	1	• Duplicate - 1
PsycINFO		7	0	7	• Duplicate - 7
W.O.S		9	02	7	• Non target population – 1 • Duplicate - 6
Scopus		4	0	4	• Clinical intervention – 1 • Non target population – 2 • Duplicate - 1
TOTAL		36	03	33	

STAGE 04 - SEARCH STRATEGIES

Databases	**Access Date**	**Retrieved**	**Accepted**	**Rejected**	**Reason for rejection**
Cochrane	28/05/2015 22/07/2015 17/09/2015 14/04/2020	23	0	23	• Unrelated non-clinical intervention - 2 • Clinical intervention – 9 • Presumed consent – 1 • Non target population – 1 • Economic study – 5 • Duplicate - 5
Medline		40	0	40	• Non target population – 2 • Duplicate - 38
CINAHL		7	0	7	• Non target population – 1 • Duplicate - 6
Embase		1	0	1	• Duplicate - 1
PsycINFO		21	0	21	• Non target population – 1 • Duplicate - 20
W.O.S		34	0	34	• Unrelated non-clinical intervention – 5 • Clinical intervention - 1 • Non target population – 6 • Duplicate - 22
Scopus		37	0	37	• Unrelated non-clinical intervention - 2 • Clinical intervention – 6 • Presumed consent – 1 • Non target population – 4 • Body donation - 1 • Duplicate - 23
TOTAL		**163**	**0**	**163**	

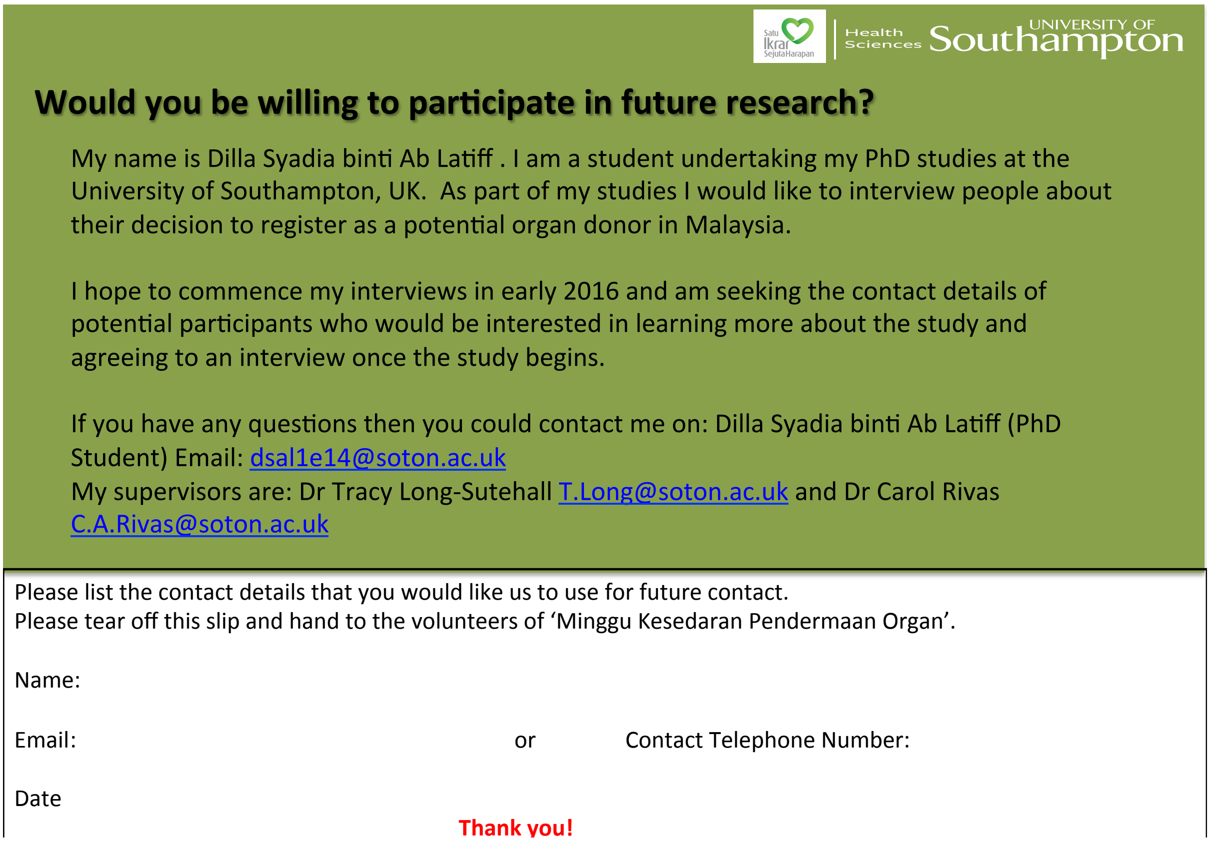
TOTAL NUMBER OF JOURNAL ARTICLES FOUND IN ALL FOUR STAGES OF LITERATURE SEARCHING:

STAGE	RETRIEVED	ACCEPTED	REJECTED
1	123	23	100
2	136	02	134
3	36	03	33
4	163	0	163
TOTAL	**458**	**28**	**430**

SUMMARY OF REASON FOR REJECTION

Description	Frequency
Body donation	9
Presumed consent	12
Unrelated non-clinical intervention	29
Unrelated clinical intervention	58
Non target population	67
Economic study	19
Systematic review	1
Pilot study	1
Duplicate	234
TOTAL	**430**

Appendix B Informational flyer



Would you be willing to participate in future research?

My name is Dilla Syadia binti Ab Latiff . I am a student undertaking my PhD studies at the University of Southampton, UK. As part of my studies I would like to interview people about their decision to register as a potential organ donor in Malaysia.

I hope to commence my interviews in early 2016 and am seeking the contact details of potential participants who would be interested in learning more about the study and agreeing to an interview once the study begins.

If you have any questions then you could contact me on: Dilla Syadia binti Ab Latiff (PhD Student) Email: dsal1e14@soton.ac.uk
My supervisors are: Dr Tracy Long-Sutehall T.Long@soton.ac.uk and Dr Carol Rivas C.A.Rivas@soton.ac.uk

Please list the contact details that you would like us to use for future contact.
Please tear off this slip and hand to the volunteers of 'Minggu Kesedaran Pendermaan Organ'.

Name:

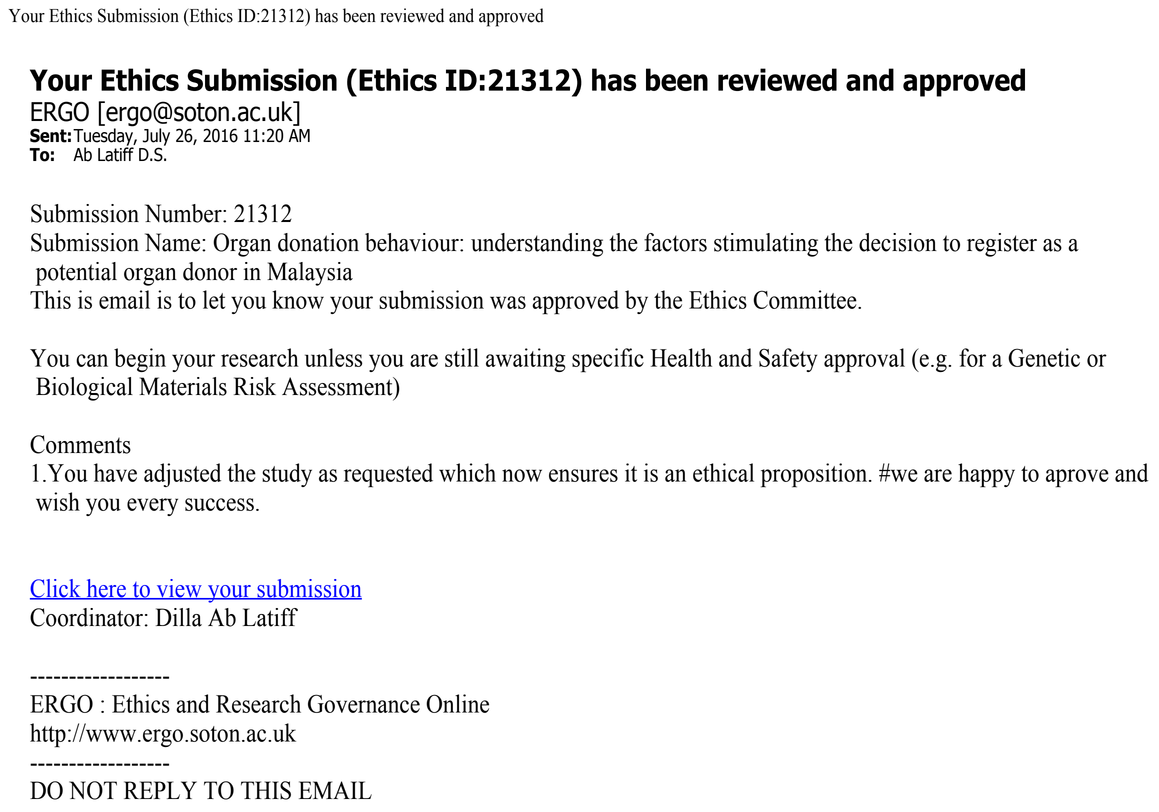
Email: or Contact Telephone Number:

Date

Thank you!

Note: This is a smaller scale. The original flyer was printed on A4 size paper.

Appendix C Ethics (ID: 21312)



Your Ethics Submission (Ethics ID:21312) has been reviewed and approved

Your Ethics Submission (Ethics ID:21312) has been reviewed and approved

ERGO [ergo@soton.ac.uk]
Sent: Tuesday, July 26, 2016 11:20 AM
To: Ab Latiff D.S.

Submission Number: 21312
Submission Name: Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia
This is email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments
1.You have adjusted the study as requested which now ensures it is an ethical proposition. #we are happy to aprove and wish you every success.

Click here to view your submission
Coordinator: Dilla Ab Latiff

ERGO : Ethics and Research Governance Online
http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

Appendix D **Letter of invitation for registered organ donor**

UNIVERSITY OF Southampton

Study title: Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia

Dear Potential Participant,

My name is Dilla Syadia Ab Latiff and currently I am a second year PhD Student at the University of Southampton, United Kingdom.

This letter is an invitation to take part in a research study which is seeking to understand how a decision to register to become an organ donor is made. I am approaching you as you have registered your intention to be an organ donor with the National Transplant Resource Centre, Malaysia.

Included with this letter is an Information Sheet that will give you details about the study. If after reading the information sheet you are willing to be involved in the study, please complete the attached reply slip and I will contact you to arrange a time for an interview. If you have any questions please do not hesitate to contact me, or my supervisor and you can find our details at the end of our information sheet.

Thank you very much for taking the time to read this letter.

Yours sincerely,

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ.
Email: dsal1e14@soton.ac.uk; Tel: +447708302657

Date: June 2016 Version number: 01 Ethics number: 21312

Appendix E Letter of invitation for non-registered organ donor

Study title: Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia

Dear Potential Participant,

My name is Dilla Syadia Ab Latiff and currently I am a second year PhD Student at the University of Southampton, United Kingdom.

This letter is an invitation to take part in a research study which is seeking to understand how a decision not to register as an organ donor is made. I am approaching you as you have an intention to become an organ donor but decided not to register your intention to be an organ donor with the National Transplant Resource Centre, Malaysia.

Included with this letter is an Information Sheet that will give you details about the study. If after reading the information sheet you are willing to be involved in the study, please complete the attached reply slip and I will contact you to arrange a time for an interview. If you have any questions please do not hesitate to contact me, or my supervisor and you can find our details at the end of our information sheet.

Thank you very much for taking the time to read this letter.

Yours sincerely,

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ.
Email: dsal1e14@soton.ac.uk; Tel: +447708302657

Date: June 2016 Version number: 01 Ethics number: 21312

Appendix F **Reply slip**

UNIVERSITY OF Southampton

REPLY SLIP (Version number: 01)

Study title: **Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia**

Researcher name: Dilla Syadia Ab Latiff
Ethics reference: 21312

I am/am not interested in taking part in the study.

By completing this form I understand that the researcher will contact me to discuss the study outlined in the Participant Information Sheet.

Name (print name) : ______________________

Your preferred contact details:

Telephone number : ______________________

Email : ______________________

Signature : ______________________

Date : ______________________

Appendix G **Participant information sheet for registered organ donor**

Participant Information Sheet (Version number: 01)
(Registered Potential Organ Donor)

Study Title: **Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia**

Researcher: Dilla Syadia Ab Latiff
Ethics Number: 21312

You are being invited to take part in a research study. Before you decide it is important for you to understand the purpose of the research and what it will involve. Please read this information carefully before deciding to take part in this research.

What is the research about?

This study intends to explore how an intention to be an organ donor becomes a decision to sign a donor register, as the process of this decision making is not well understood. Currently, there is a continuing low registration rate for organ donation in Malaysia, with an increasing gap between the number of organs needed for life saving transplantation and the number of organs available. To date, only 291,311 people which is less than 1% of the approximately 30 million population in Malaysia is registered as a potential organ donor, which is the lowest rate in the Asia-Oceania region.

Findings from this study are intended to inform future National campaigns aimed at increasing the number of people registered to donate in Malaysia.

Why have I been chosen?

You have received this information because you have registered your intention to be an organ donor.

Do I have to take part?

No, you do not have to take part, however your participation would help in gaining an understanding of why people register to donate organs. A decision not to take part will have no impact on your registration status.

What will happen to me if I take part?

If you agree to participate in this study, you will be asked to undertake an interview with the researcher. The interview can be conducted face-to-face, via telephone or Skype (whichever is your preference). If face to face, the researcher will meet you at a mutually convenient location and time. Before the interview begins you will have the opportunity to ask questions of the researcher before you are asked to sign an interview consent form.

You will be asked to talk about your experiences in deciding to become an organ donor. To ensure that your views are captured accurately the interviews will be audio-recorded and later transcribed for analysis. The estimated duration for each interview is approximately 60 minutes. You have the right to withdraw from this study at any time without giving any reason, even in the middle of an interview.

What are the possible benefits of taking part?
There are no direct benefits for you personally in taking part in this study. The information you provide will help us understand the experience and the motives of registering as an organ donor.

What are the possible disadvantages and risks of taking part?
There are no anticipated risks from taking part in this study.

Will my participation be confidential?
All information will be kept strictly confidential according to the Data Protection Act/University policy. Your anonymity will be preserved, as your name will be replaced with a participant identifier (number) that will be used throughout the study. Any direct quotes extracted from your interview for use in the final document or future publications will have been anonymised. All study information will be stored on a password-protected personal computer and the hard copy data will be stored in a locked cupboard within the university. Your confidential information particularly contact details are only accessible by the researcher where it will be kept for future use if necessary (e.g.: to send a summary of findings).

Collection of data on audio

Only the researcher and her supervisors will have access to the audio-recordings. The audio recordings and /or certified transcripts of the audio recordings and raw data will be retained securely for 10 years as per the University of Southampton archive policy.

What happens after the interview?

The researcher will contact you 24 hours after the interview to answer any questions that you may have post interview. You will receive a thank you letter from the researcher and you will be asked if you would like to receive a summary of the research findings.

What happens if I want to make a complaint?
If have a complaint or concern about any aspect of the study , you can contact the Research Governance Manager, Research Governance Office, Building 37, University of Southampton, Highfield, Southampton, SO17 1BJ (Tel: +44 (0)2380 595058; Email: rgoinfo@soton.ac.uk). The Research Governance Manager is completely independent of this study and will be happy to deal with any problems or concerns that may arise and can provide you with an official complaints form.

What will happen to the results of the research study?
The results of the study will be incorporated into a PhD Thesis and may be published in academic journals or presented at conferences. We may share the fully anonymised transcripts with other certified researchers so they can do further (secondary) analyses of the data.

Who has reviewed the study?
The study has been peer reviewed by the Faculty of Health Sciences and ethically reviewed by the University of Southampton Research Ethics Committee (Ethics number: 21312).

Where can I get more information?
If you would like further information you can call or write to:

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton
Highfield, Southampton, SO17 1BJ
Telephone: +447708302657
Email: dsal1e14@soton.ac.uk

Associate Professor Dr. Tracy Long-Sutehall
Main Supervisor
Faculty of Health Sciences
University of Southampton
Highfield, Southampton, SO17 1BJ
Email: T.Long@soton.ac.uk

Appendix H Participant information sheet for non-registered organ donor

Participant Information Sheet for non-registered organ donor (Version number: 01)

Study Title: **Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia**

Researcher: Dilla Syadia Ab Latiff
Ethics Number: 21312

You are being invited to take part in a research study. Before you decide it is important for you to understand the purpose of the research and what it will involve. Please read this information carefully before deciding to take part in this research.

What is the research about?

This study intends to explore how an intention to be an organ donor becomes a decision to sign or not to sign a donor register, as the process of this decision making is not well understood. Currently, there is a continuing low registration rate for organ donation in Malaysia, with an increasing gap between the number of organs needed for life saving transplantation and the number of organs available. To date, only 291,311 people which is less than 1% of the approximately 30 million population in Malaysia is registered as a potential organ donor, which is the lowest rate in the Asia-Oceania region.

Findings from this study are intended to inform future National campaigns aimed at increasing the number of people registered to donate in Malaysia.

Why have I been chosen?
You have received this information because you have the intention to become an organ donor but you have not register your intention to be an organ donor.

Do I have to take part?
No, you do not have to take part, however your participation would help in gaining an understanding of why people who has the intention to donate organs have not register their intention in the organ donor register. A decision not to take part will have no impact on your registration status.

What will happen to me if I take part?
If you agree to participate in this study, you will be asked to undertake an interview with the researcher. The interview can be conducted face-to-face, via telephone or Skype (whichever is your preference). If face to face, the researcher will meet you at a mutually convenient location and time. Before the interview begins you will have the opportunity to ask questions of the researcher before you are asked to sign an interview consent form.
You will be asked to talk about your experiences in deciding not to register your intention to become an organ donor in the register held by National Transplant Resource Centre, Malaysia. To

ensure that your views are captured accurately the interviews will be audio-recorded and later transcribed for analysis. The estimated duration for each interview is approximately 60 minutes. You have the right to withdraw from this study at any time without giving any reason, even in the middle of an interview.

What are the possible benefits of taking part?
There are no direct benefits for you personally in taking part in this study. The information you provide will help us understand non-registration decision as an organ donor.

What are the possible disadvantages and risks of taking part?
There are no anticipated risks from taking part in this study.

Will my participation be confidential?
All information will be kept strictly confidential according to the Data Protection Act/University policy. Your anonymity will be preserved, as your name will be replaced with a participant identifier (number) that will be used throughout the study. Any direct quotes extracted from your interview for use in the final document or future publications will have been anonymised. All study information will be stored on a password-protected personal computer and the hard copy data will be stored in a locked cupboard within the university. Your confidential information particularly contact details are only accessible by the researcher where it will be kept for future use if necessary (e.g.: to send a summary of findings).

Collection of data on audio

Only the researcher and her supervisors will have access to the audio-recordings. The audio recordings and /or certified transcripts of the audio recordings and raw data will be retained securely for 10 years as per the University of Southampton archive policy.

What happens after the interview?

The researcher will contact you 24 hours after the interview to answer any questions that you may have post interview. You will receive a thank you letter from the researcher and you will be asked if you would like to receive a summary of the research findings.

What happens if I want to make a complaint?
If have a complaint or concern about any aspect of the study , you can contact the Research Governance Manager, Research Governance Office, Building 37, University of Southampton, Highfield, Southampton, SO17 1BJ (Tel: +44 (0)2380 595058; Email: rgoinfo@soton.ac.uk). The Research Governance Manager is completely independent of this study and will be happy to deal with any problems or concerns that may arise and can provide you with an official complaints form.

What will happen to the results of the research study?
The results of the study will be incorporated into a PhD Thesis and may be published in academic journals or presented at conferences. We may share the fully anonymised transcripts with other certified researchers so they can do further (secondary) analyses of the data.

Who has reviewed the study?
The study has been peer reviewed by the Faculty of Health Sciences and ethically reviewed by the University of Southampton Research Ethics Committee (Ethics number: 21312).

Where can I get more information?
If you would like further information you can call or write to:

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton
Highfield, Southampton, SO17 1BJ
Telephone: +447708302657
Email: dsal1e14@soton.ac.uk

Associate Professor Dr. Tracy Long-Sutehall
Main Supervisor
Faculty of Health Sciences
University of Southampton
Highfield, Southampton, SO17 1BJ
Email: T.Long@soton.ac.uk

Appendix I **Consent form**

UNIVERSITY OF Southampton

CONSENT FORM (Version: 01)

Study title: **Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia**

Researcher name: Dilla Syadia Ab Latiff
Ethics reference: 21312

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (insert date /version no. of participant information sheet) and have had the opportunity to ask questions about the study.	☐
I agree to take part in an interview and for the interview to be audio-recorded and to be used for the purpose of this study and for future secondary analysis.	☐
I agree for my data to be used for the purpose of this study and for future secondary analysis. I agree to anonymised quotes being used in reports and publications.	☐
I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected.	☐
I agree to take part in this study	☐

	Participant	**Researcher**
Name (print name) :	______________________	______________________
Signature :	______________________	______________________
Date :	______________________	______________________

Appendix J Email invitation for email interview

To: Participant's email address

Email subject: Invitation for email interview

Study title: Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia

Dear Potential Participant,

My name is Dilla Syadia Ab Latiff and currently I am a second year PhD Student at the University of Southampton, United Kingdom.

Sometimes between January to July 2016 you responded to a flyer circulated by the Malaysia National Transplant Resource Centre inviting you to participate in a research study which is seeking to understand how a decision to register to become an organ donor is made. I am emailing you now to ask if you would be willing to respond (via e-mail) to three short questions.

Attached to this email is the Participant Information Sheet that will give you details about the study. If after reading the information sheet you are willing to be involved in the study by having an email interview, please complete the attached consent form and return to me within one week. After receiving your consent form I will email you the questions and ask that you respond to them within two weeks from receipt. I will send an e-mail reminder after one week.

If you have any questions please do not hesitate to contact me. My details are included in this e-mail.

Thank you very much for taking the time to read this email.

Yours sincerely,

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ.

Email: dsal1e14@soton.ac.uk; Tel: +447708302657

Date: June 2016 Version number: 01 Ethics number: 21312

Appendix K **Email to cancel an email interview**

Dear Participant,

Some time ago you received information about a study that I was undertaking as part of my PhD training at the University of Southampton. The title of the study was ‘Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia’.

You responded indicating that you would be willing to talk to me as part of this study. Thank you very much for your interest in the study. I am contacting you to explain that data collection has now ended for this study and so I will not be contacting you for participation.

I am very grateful for your interest and sorry that I could not include you. I would like to offer you a copy of the summary of the completed work in thanks for your interest. If you would like to receive this, please let me know via e-mail.

Thank you again for your interest.

Yours sincerely,

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ.
Email: desal1e14@soton.ac.uk; Tel: +447708302657

Appendix L **Interview schedule**

Development of interview schedule

Questions for the interview of registered organ donor:	
Question	Prompt topics
Could you tell me about your decision to become a registered organ donor?	• What motivated you to register? • How long ago did you begin to think about it? • How long have you been on the organ donor register? • Can you tell me more about the time between thinking about it and registering? • What information did you access that may have influenced your decision? • What information influenced your decision the most? • What were your feelings about your decision? (e.g. was it easy, did you feel good about it, was it stressful?) • Were other people involved in your decision making? (Link with 'who do you live with?' • Did you share your decision with anyone else? • How did they respond? • Were their views influential? • Have you considered changing your mind about registration?
Would you tell me about your view of organ donation in general?	• What do you know about organ donation in Malaysia? • What expectations do you have about organ donation? • Why is it important to you?
Is there anything else you would like to say that has not been covered in today's interview?	

Questions for the interview of a person not registered as an organ donor:	
Question	Prompt topics
Could you tell me about your decision not to become a registered organ donor?	• Have you ever considered registering? Can you tell me more? • What made you decide not to register? • Did you access any information in reaching your decision? Can you tell me more about it? • Did you discuss your decision with anyone else? • How did they respond? • Do you think your decision might change? Can

	you explain this more?
Would you tell me your view of organ donation?	• What feelings do you have about it?? • What do you know about organ donation in Malaysia? • What expectations do you have about organ donation?
Is there anything else you would like to say that has not been covered in today's interview?	

Appendix M **Thank you letter**

UNIVERSITY OF Southampton

Study title: Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor in Malaysia

Dear Participant,

Thank you very much for meeting with me to discuss the registration decision to become an organ donor or not. I appreciate the time you took to spend with me. The information you shared with me concerning the decision making on registering as a potential organ donor will be very helpful.

If you would like to receive a summary of the research findings, please do not hesitate to contact me and you can find my details at the end of this letter.

Thank you again for your assistance.

Yours sincerely,

Dilla Syadia Ab Latiff
MPhil/PhD student
Faculty of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ.
Email: dsal1e14@soton.ac.uk; Tel: +447708302657

Appendix N **Coding for Codes, Categories and Psychological Concepts**

COLOR CODING FOR DONOR PARTICIPANTS:

Psychological Concept 1 – Belief and attitudes

Category – Religion and Culture

Codes:

1. Being certain that the action does not violate religious principles
2. Belief in the continuous reward in the afterlife
3. Belief that nothing belongs to us but God
4. Belief that their afterlife journey is less of a burden, with lighter punishment if they donate organs
5. Belief that organs are not useful anymore after death and can be given to others
6. Belief that religion teaches donation as a form of charity even after death.
7. Benefit for ourselves (double reward) when the recipient contributes to society.

Category – Humanitarianism

Codes:

8. Feeling of satisfaction being able to help and do good for others
9. Belief in sharing and giving
10. Sense of responsibility towards society, and fulfilment of benefitting society as a whole
11. Fulfilment of improving quality of life of others

Category – Autonomy

Codes:

12. Belief in individual autonomy

Psychological Concept 2 – Feelings and emotions

Category – Emotional Responses

Codes:

13. Feeling of sadness when considering people waiting for an organ donation
14. Feels disturbed when listening to personal experience of the organ recipient

Category – Fear for self and those close

Codes:

15. What if one day I need a donor?
16. What if one day my children, parents or siblings need a donor?

Psychological Concept 3 – Cognitive Readiness

Category - Information resources

Codes:

17. Confidence in trusted online resources
18. Confidence in official religious body online resources
19. Confidence with social media
20. Confidence with the organ donation governing body

21. Confidence with the talk, seminar, or booth set up by governing body
22. Confidence with an official statement from a Mufti
23. Confidence with the information shared in the newspaper
24. Confidence in TV advertisement
25. Confidence with information shared by friends.

Category - Information needs

Codes:

26. Knowledge of the donation and transplantation process
27. Knowledge of the process involved in registration
28. Knowledge of the need for different organs

Psychological Concept 4 – External influence

Category – Valued social networks

Codes:

29. Favourite artist
30. Well-known religious person

Category – Respected individuals

Codes:

31. Healthcare practitioner
32. A teacher or a lecturer
33. Mother or father as the leading role or the decision maker in the family

Appendix N

CODING FOR NON-DONOR PARTICIPANTS:

Psychological Concept 1 – Belief and attitudes

Category – Misconception about Religion and Culture

Codes:

1. Uncertain if religion allow organ donation
2. Taboo has stopped registration of intention to donate organ

Category – Nothing urgent attitude

Codes:

3. It is not important as there is no triggering event in life
4. The influence of 'similar to me effect', no different than the rest

Psychological Concept 2 – Feelings and emotions

Category – Emotional Responses

Codes:

5. Fear if the removal process would hurt her dead body
6. Worry if the body would not be in the normal state and unrecognizable

Psychological Concept 3 – Cognitive Readiness

Category - Absence of information

Codes:

7. Lack of right information about organ donation
8. Misunderstand that only the rich one will receive organ
9. No attempt to search on information about organ donation
10. Difficulty of the registration process

Psychological Concept 4 – External influence

Category – Respected individuals

Codes:

11. The influence of cultural belief in society has influence the way family think
12. Family communication led to organ donation rejection as child don't want to be disobedient

Appendix O **Meaning unit, Initial Ideas, and Memos**

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 1

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I feel like…eh can I do this?…mmm… something like that…because at that point of time they did not tell us if it is allowable from the Islamic perspective. So, after the talk I go back and do some searching first and study…ohhh ok this is permissible… (line 23-26) …Islam permits this…so that what drives me to register as organ donor. (Line 40-41) for us as a Muslim, what is outline in the Sharia then only we do it. Because when first heard about organ donation, the idea was still new in Malaysia. For me I was still young as I was doing my First Degree…still very young. I was like hesitating and thinking if organ donation is allowable. So discussion took place with friends. I have to do research from the perspective of Islamic law. If Islam permits it then only I would do it. For as long as it was not clear yet from the Islamic perspective, then I cannot do it yet. (Line 100-106) religion is important… what the religion stand on organ donation is. (Line 121-122) I discovered there is a fatwa/dalil from the national religious body where it confirms Islam allow this. Even it says it is a must…in order to save other people's life. Yes that is it. (Line 138-140)	Is organ donation allowed? Does Islamic law permit donation? Commentary Memo: In this meaning unit the role of religion is expressed. The co-researcher is telling us that she was stimulated to think about organ donation by a discussion about it but that she needed to explore the issue more as she had questions (uncertainty) about whether it was permissible from a religious perspective. What Islam allows is important to this participant and she would not register to be an organ donor if Islam prohibited donation. So, after further searching than she discover Islam allow organ donation, she gain a sense of assurance that she do not violate religion. She stressed out this point a few time that the religion's stand on organ donation is important. Her view is that her organs are not hers, but belong to Allah and belief in sharing it with others when she die. Here the co-researcher thinks that donating organ is something that is not doable while alive thus giving it away after death is a lifetime benefit for her as god will continuously reward her. She belief that it's an easy form of lifelong charity.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system. What it tells me of the reason of registration is that religion is the key driver. The participant expressed that it is important to feel assured that action does not violate religion, to overcome the feeling of uncertainty. Besides the participants also feels that nothing belongs to us but God and the participant belief in the continuous reward in the life hereafter.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Certain that action does not violate religion • Beliefs that nothing belongs to us but God • Belief in the continuous reward in the life hereafter

Appendix O

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
In order to make the decision, it's the religious body, because to proceed or not to proceed. It is obvious that in deciding whether I should or should not proceed, I must first looked into the fatwa that explains the Islamic perspective. (Line 256-258) plus it is not wrongdoing from religion point of view, even religion encourages us to help people. (Line 391-393) we have to start giving too, and whatever that we give, Allah's reward is even better for us. Right? That is the basis of our religion. (Line 402-404) basically all that is in us belong to Allah, it is not ours, when the time comes our organs may become someone's else. Right? So we have to give. When the time has come then it is no longer ours. Just like our money, sometimes we have saved a lot of money but then suddenly our car broke down! Just look at it, it is not meant for us, it is not ours, God can take it away from us. (Line 411-415) we have to, have to let it go. In Islam we even believe that the reward is greater when we give away something that is very valuable to us. (Line 419-421) Culture is on the factor that shape our behavior. The culture in the Malay community has been like 'while you are not desperate, mmm…things can wait'. (Line 505-506)	Reflexive commentary: It appears that she is a strong believer to her faith. Therefore, donating organs after death appears to be part of a lifelong charity, and she registered as she was certain that it is allowable. Since it's a lifelong charity, she belief in the continuous reward the life hereafter.		

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
because of my uncle…my uncle…he suffered from kidney failure…so after he die… I felt…*(emotional)*…Why were there no one…no one were willing to donate for him at that point of time. (line 26-29 So, after that event then only there were this feeling of 'if there were organ to donate for him, he might have live much longer'…his children…at that time his children were still young…oh my, his children…it was a pity. So, right after that…mmm…I went back to campus, search for the flyers given by the National Transplant again, then I immediately register for organ donation. (Line 33-37). But when something happens in the family and losing someone…when we look at his children we even feel sorry for them *(very emotional)*…why were there no one…why we did not give it when he needed it the most? After he is no longer with us, then only we started thinking 'what if' *(sound regretful)*…haaa now only there is regret. So…that's it… (Line 53-56) The thing is the doctor could check if anyone is fit to donate, so there were a few in the family who were actually fit, but they were reluctant to donate. So, that what makes me upset. It was so sad, because there were people who could have done it because they are fit to do it but they just don't until …. *(Sad facial expression - death)*. (Line 160-163)	Not taking action to register. Sense of urgency in taking action. Triggering event stimulated registration. Commentary Memo: In this meaning unit the participant suggests that whilst organ donation was important the act of registration was not seen as urgent. Later in the transcript she goes on to explain that a triggering event may be needed to stimulate registration, in her case the death of her uncle from kidney disease as he did not receive a donated kidney in a transplant operation. Her uncle died due to kidney disease and there were no kidney donor available for transplant. The impact of his death and the fact that a donated kidney may have extended his life prompted her to register as an organ donor. Reflexive commentary: It appears that only when she had direct experience of the need for organs, when there is frustration/regret after her uncles death as there was no-one volunteer to donate and this has stimulated her to register.	Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of desperation, frustration and regret when the issue of a lack of organs became personal. Emotionally disturbed when losing loved ones or seeing someone lose their loved ones.	**Concepts:** Feelings and emotions **Categories:** Emotional responses **Codes** 34. Feeling of sadness when considering people waiting for an organ donation **Concepts:** Feelings and emotions **Categories:** Fear for self and those close **Codes** • What if one day my children, parents, siblings need a donor?

Appendix O

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
When I was listening to the talk…mmmm…I feel like this thing need to be done but we just choose not take a one more step ahead, which is to register…we just keep the flyers. I just do not know why… *(giggling).* Maybe is the attitude. The intention was there, the awareness was obviously there, but, maybe it's our attitude, our attitude, 'eh its ok, this can wait'. We feel like it's not important to register. We know the needs of organ donor, but to take an additional step of registering…it's our attitude. (Line 67-73) so there were this feeling of doing it so I took the flyers…but I just keep it …*(laughed) (Line 79-80)* Maybe it feels like we are not desperate to donate at that time, but when there is a triggering event, then only you will feel there is a need to do it. (Line 84-85) It is our attitude, where we are not concerned… we like to take things for granted…things like…things that we do not see in front of our eyes… we would say…we would feel like 'its ok this can wait'…it's our attitude in delaying things *(stressing out this point)*…delaying things…leave it first, when we have the time, then we will look into it. (Line 90-93) Until my uncle passed away then only…mmm…I think it links with attitude…my attitude. (Line 141-142)	Delaying registration. Sense of urgency in taking action. Satisfaction of helping others. A lifelong charity. Commentary Memo: When she mentioned about saving 8 'souls', the psychological motivation behind it is satisfaction of helping others. The more you save the more satisfying. However, the co-researcher is explaining that whilst she was interested (she took a flyer) , and that she was aware of the need for donation, but after the talk she did not take any further action. The sense of urgency in taking action is not there until a triggering event was 'in front of her eyes'. It took a trigger event for her to act (the death of her uncle). The co-researcher is telling us that when something bad happen in the family then it triggers her to take action. So, in this case after losing someone she immediately register. Reflexive commentary: She talk about behavioural changes in time of desperation. Thus, the feeling of desperation is also a driver to registering as donor.		

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Because it feels that by donating organ we can save life and when reading the flyers there were statement that mentioned when a person die we can donate and at the same time save 8 souls…we can give 8 organs to other people…8 souls can be save…So why not we just donate (Line 37-40) sense of humanity to other people. We have this feeling of humanity to other people. But basically when we talk about helping other people, obviously it's a good thing… I think organ is the one thing that we can give, where we cannot give it away when we are still alive, but when we die it becomes a lifelong charity. (Line 396-398)		An individual's belief system is informed by personal views about the importance of sharing and giving as part of lifelong charity. As well as when a person have a sense of humanity.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others
At that time I do not know, I do not know if organ donation is permissible. Plus, during the talk by National Transplant they did not mention anything from religion point of view. (Line 111-113) Only from the websites. First, I looked and read from the pamphlet received from the talk. But, since I would like to know more, I do further reading from online resources. I start googling and reading about the fatwa/dalil from JAKIM so obviously this information is from JAKIM website only. Then, I went into their website too, the National Transplant's website. I read again in the National Transplant's website, mmm…what to do when you are still alive, and what the benefits of organ donation are. (243-248) Information about benefit, about what organ can we donate, and… what else?...mmm…maybe on the proseses involved. The process of how the transplant will take place…whether…I thought that when they…like when we die	The information searching behaviour. The influence of information gained. Commentary Memo: The online resources plays a significant role in providing the necessary information as the co-researcher only refer to the websites for additional information. It's important for her to gain information on; first the religious fatwa from JAKIM website, then followed with NTRC website looking at the process she has to go through in registration, the benefit of registration, organ that we can donate, the role of family member.	Certainty and confidence with the information gain about organ donation. These feelings include; confidence with online resources, confidence on religious body resources.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence in trusted online resources • Confidence in official religious body online resources

Appendix O

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
because of accident…during the postmortem they will straight away take it if we are a registered organ donor. Whereas, in the website it mentioned that postmortem and transplant is a separate process. So, it's a different process. It is not as I thought that during the postmortem, the doctor can remove the organ for donation purposes. Plus, from reading on the website, I only got to know that the doctor will have to ask the permission of the family and it is not only based on our decision. Right? Even if we had sign up as a registered organ donor but when we die, the family will be ask first, and if the family does not allow then it won't happen. From reading, I also know that we can either donate all organs, or we also get to choose which part to donate. Yes, that is it. These kind of information. (Line 263-274)	Reflexive commentary: She talks about the influence of an online resource developed or controlled by an authorized body.		
There is no point we make a pledge but at the end the family can still overrule. Whereas, I think family should respect our decision. They themselves are not donor, so, they should follow which is just like the will, yes the will, as if we had put it down in the will that we want to donate our organ, whatever that we want to donate, its all written down, when we die, they should respect our wish despite the fact they are still grieving. It is our will. (Line 285-290) I signed up first. Because I was already in KL. I took the flyers, filled it up and send it back. Then I receive the card, they post it to my house. So when the card arrived, I told mom 'mom…aaaa I am now a registered organ donor, if I die, I will donate my organ for other people'. So, I did informed her, I told her about the benefit and everything. (Line 315-319)	When does family communication take place? Has family communication influence donation decision? Commentary Memo: She belief that family member cannot override the decision to donate organ after death and belief that family should respect the decision. Registration has taken place prior to family communication. Thus, communication that proceed next is just to inform the family. The co-researcher informed her parents and later when she got married she informed her husband. All of her family member that she talked to has no objection. It was easier for the mother to accept, maybe because the participant linked her decision to her Uncle's death. Types of information shared were centred around religious information and the benefit of organ donation. Again, even her family member was	Belief in having the autonomy in making the registration decision. This include the feeling where family will not object the decision made	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** • Belief in individual autonomy

Meaning units Transcript 1	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
surely all mother will ask, 'does Islam permits this', she even asked 'have checked on the Islamic laws, what does it says?'…so I said 'yes yes I have checked and even do some study on this, it certainly can do this. (Line 324-326) Yes, that was good. Because I told her that I have studied about this. Then, I mentioned about us losing my Uncle which is her brother, no one wants to donate, if we were to give maybe we can safe more life. So she accept. (Line 341-343)	concerned about religious stand. Reflexive commentary: She talks about how she belief in the autonomy to make the decision on her own. Communication with family were solely to inform of registration decision.		

Appendix O

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 2

Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
When I register as an organ donor, at least when I die I feel that I can still do something that would benefit other people. (Line 39-40) Would also benefit other people as they can survive because of the organ that I donated. (Line 49-50)	Why is it important to register? Commentary memo: Here what the co-researcher is saying is that, even after her death she could still continue benefitting other people by donating her organ to those in need. In line 49-50 she keep on stressing out this point. Reflexive commentary: It somehow demonstrates her fulfilment of benefitting others.	Personal views and satisfaction of benefitting others.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Fulfilment of improving quality of life of others
I will be rewarded, which when rewarded I feel that it would ease me when resurrected to face God in the hereafter. I want to do something good even though I am no longer in this world (Line 40-43) I will be rewarded from Allah because I did something good (Line 48-49) One of them is affected by my religious belief because I belief that my religion says that you must do something good and you will be rewarded, and the more rewards you have it helps you to go to heaven. So, at least when I die I would continuously be rewarded by God, from Allah SWT to ease the journey to face Him. Which I think it is one of religious reason. (Line 63-67) when I first heard about organ donation, I am already a very strong religious believer, that is why I want to do something good, until the point of registering I am very sure because of strong religious belief. That is my main reason if you were	Not only that her action of doing good would benefit others but also lead to herself being continuously rewarded by God in the life hereafter for as long as the organs that she donated is still being utilized by someone else. This reward is believe to help the journey in the afterlife, which it ease her journey to heaven. This point is repeatedly mentioned in line 48-49, 63-67, 137-138, 147-148, 152-154. In line 320-321, she mentioned again about continuous reward after death. Even when in the condition where if her organ were not remove for donation for whatever reason, she believed that she will still be rewarded on the day of her death as she has already expressed her intention. In Islam we believe that God will always reward us even we only have the intention and we have not perform the good action we intent to do.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Belief that their afterlife journey is less burden, with lighter punishment if they donate organ • Belief in the continuous reward in the life hereafter • Belief that nothing belongs to us but God • Certain that action does not violate religion

Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
to asked between wanting to contribute to society and religion, religion has more influence. (Line 87-91) I knew it from the very beginning. I have read somewhere that states organ donation is permissible from the Islamic point of view. I am sure of that. So, from that perspectives, from religion perspectives, and as I am a Muslim, and knowing it that it can be done, so why not? I just register as an organ donor. (Line 96-99) that is the starting point where I get information about organ donation, and that is the time where they shared a fatwa stating that it is acceptable from the point of Islam. So, that is the turning point, that was the time. (Line 106-108) I want to go to heaven, I want to do this, when I die I would continuously be rewarded'. (Line 137-138) I think its more because of my religious belief, to do good, to do good so that I will be rewarded. (Line 146-147) At that time I was sure that when we do good things, InsyaAllah, we will be rewarded. That was the only principle, if you ask about organ donation then yes religion is the answer. That's how I register. (Line 152-154) When asked what if family rejected, Just accept it, but in the first place I already register. At least I already have the intention. So, I belief having a good intention is already good enough in my religion as will still get some kind reward in the life hereafter. (Line 319-322) Because when we die, there is nothing left anymore. But, my intention was to donate all of my organs. (Line 344-345)	Here, the co-researcher is saying that she was rest assured that Islam permits organ donation, as it is an act of doing good, as it is a form of sharing and giving. This link with her point in line 48. Thus this point, shows a linkage between those who hold strongly to religion would also belief in doing good, belief and sharing and giving		

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Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
if it were my parents or my child, I would just allow it. Because they are no longer with us, I am returning them to Allah, so just donate. (Line 371-373) Right now if we don't donate, they will still be buried underground (Line 374)	Here when she say nothing left, it means that all the organs that own now is no longer hers. It belong to God, Thus, this link to her thinking of to just donate all of her organ to other (belief in sharing/giving) and it then links to doing good and benefitting others (line 350-352, 371-374.		
I want to do something good even though I am no longer in this world. (Line 42-43) So they held the campaign there. Back then when I heard it I feel 'oh ok I can do something good (Line 136-137) No. At that particular time, no fear at all, like I said, we wanted to do something good. (Line 351-352) Even we are no longer in this world, we are facing our God Allah SWT. So, for whatever that we have now, we try to do good as much as possible. So, just do it. (Line 352-353) I still hold on to my opinion and principle that it is important to do something good. Right now if we don't donate, they will still be buried underground. So why not you do something good. (Line 373-375)	This point which portraits that she belief in doing good links with the previous point where by doing good which it can came in many forms, but here her action of doing good is by taking an action that benefits other. Belief in doing good and link this behaviour with her religious belief.	Personal views about the importance of doing good to others. As well as when a person have a sense of humanity.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others
Plus, an added point is that they have a representative at their booth that handle registration straight away. So, it was easy. You don't have to go elsewhere to do it. (Line 110-112)	In this block the co-researcher is saying that, eventhough she was already rest-assured that religion permits organ donation, registration took place when there was an event that promotes organ donation in her university and she attended it.	The availability of information about how and where registration takes place is crucial for it can ensure registration to	**Concepts:** Cognitive readiness **Categories:** Information needs

Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
The problem is I don't know where to go to register my interest. That was what holding me back. (Line 118-119) . I think it is so simple, you fill it up then either you return it by posting it or like what I did was that I return it by hand at the booth. But I think this process is not that complicated. Just fill up the form, then you just post it. This thing is so simple. So, if they do open up a booth anywhere, even not in the university, we still can register. (Line 455-458) If it's from the radio then it's possible, difficult to register. But if there is a booth, they often give out flyers and there are details on how to register. But, if they heard about this from TV or radio then maybe it's difficult to register. (Line 465-467)	Only at this point she decided to register her intention because there was a booth with representative from National Transplant Centre who handle organ donation registration. She stress out that the registration process was easier since she can do it straight away at the booth and she don't have to travel elsewhere to do it. So, ease of registration process plays a role in her registration experience. Line 118-119, line 136, line 455-458, line 464-466 stressed out this point. Not knowing where to go to register has hold her back from registering in the past. This link to point she made when she mentioned that having a booth at an event or a talk session is important factor that lead her to straight away register.	take place.	**Codes** - Knowledge of the process involved in registration
It is solely my own decision. Right after the talk, it's like, it feels like 'ohhh it feels good to be an organ donor' so I straight away signed up. (Line 174-175) It is the autonomy…your own right and it feels like it's solely your own decision. Without referring to anyone. (Line 179-180) I did not even tell my family member. Maybe because of the time is not right. Because when we were university student, we often concentrate on our study… aaa… something like that. I did not tell my parents. I did not tell them at all. (Line 247-249)	Here the co-researcher describe her feeling of autonomy in that the decision to register was made on her own. In line 179-180 she go on talking about her right in making this decision. She do not require anyone else opinion on this matter. Thus, she did not seek her family or peer's suggestion.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** - Belief in individual autonomy

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Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
only a moment ago I just tell my husband. I just told him because of this interview session today as he was questioning how I got myself involve. So, I told him that I am a registered organ donor. So, he only got to know about it today. I meant that it was only recently. When you started contacting me about this interview, so that was the time when I told my husband that I am an organ donor. One thing maybe it's been a long time that I discussed about organ donation…it's been 12 years, it has been quite some time. I had already forgotten it. (Line 258-264) He was happy. He said 'Thank God because you do something good'. Yes, that was it. (Line 269-270) He was happy. He said 'OK, you registered. That's good as you do something good'. He accepted it. There was no problem. (Line 274-275) I know that without family consent, donation cant take place, but at that particular time I just don't share it. I was solely my decision. Until recently I told my husband. (Line 296-298) But, really, it did not cross my mind about telling my family. At the back of my mind, let it be, when the time comes…mmm…but the National Transplant did advise us to share but…i don't know. Maybe I was not mature enough at that time, I was just in year 2 or year 3. I just register as organ donor like it is not a big thing. I made my own decision. It's like doing something good. (Line 304-309) Because I studied far away from hometown I seldomly go	In this block and in line 258-264, 401-408, the co-researcher is saying that she never think that it's necessary to inform her family about her registration decision. She never inform her parents, nor her siblings. She knew from the talk that she should inform them about the decision made, but she never did and this was due to distance, as she is not staying with her family. But, when she does go back home to see her family, it never cross her mind to tell them about it. Additionally, after her marriage (line 258-264) she did not even bother to tell her husband, until the day of the interview then she told her husband as she has got to get his permission to have this interview at their home. This link, with the feeling of autonomy where she thinks it's her decision and family should respect it. The National Transplant Resource Centre should play a role by sending a reminder about it. She herself even forgot that she is a registered organ donor.		

Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
back to my hometown. So, I tend to forget about it. It is just that I don't know if the society didn't discuss, maybe, there could be family who is against it, it all depend, that is why I said it all depend on the family. So if you asked me, I don't know. I don't know why no discussion. Like I said, we were away from family and we seldom meet during the university years. Sometimes you remember and at time you forgot about it. This thing has never become a topic and no has ever bring this up in the family. No reason to discuss. It just passed by. (Line 402-409) Maybe there are parents who are closed minded and cannot accept changes even though they know that there are fatwa that says it is allowable. So maybe the children don't dare to discuss this topics with their parents. (Line 416-418) that they refuse to accept new things. I know someone who is also an organ donor, where his parents has doubt with current religious scholars. To them the new released fatwa is vague. That is the reason why they reject this idea of organ donation on the ground that religion supposedly being spread at the time of the prophet never perform any form of organ donation. (Line 422-426)	She thinks that whether communication takes place in the family depends on the parents. Line 401-408 discuss about this as well. Maybe communication will only occur if the child believe that the parents can accept the idea but it would not happens if they believe that their parents would not welcome this idea.		
the National Transplant were the organizer itself, thus we believed that it is a trusted body which look after organ donation, and they should know better and the information shared…were accurate…so it convinced us, so that was why I made the decision to immediately signed up. There is no need to refer to anything else. I believed with the information shared. (Line 186-190)	The co-researcher is explaining that organ donation information should come from the trusted governing body. In this case, she trusted the National Transplant resource center and she go on mentioning that 'who' the speaker is what his role is in the National Transplant office is not important. This point can be seen in line 206-208, 213.	Certainty and confidence with the information gain about organ donation. The participant's feelings focus towards the confidence with the authorized body.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence with the organ donation

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Meaning units Transcript 2	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
What influenced me was the representative from National Transplant itself. They even put on the National Transplant uniform so we automatically know they are from the National Transplant(Line 206-208) But it has been sometimes that I did not came across it, there might be in other places or perhaps I did not coincidentally passing by it. They often open up a booth in big events only, and I don't live in Kuala Lumpur which is where it is often held as National Transplant is in Kuala Lumpur. I live in Kelantan which is quite far, so I don't know but to me what they did when I was in university was one of National Transplant's good effort. (Line 437-442) For as long as I worked in the hospital, there were no emphasis on organ donation. There's nothing about it. Nothing. There was no one who came over to hospital to campaign about it. (Line 523-525) Since I started working, there was none. None. (Line 534)	This is her opinion on how the National Transplant can improve on their organ donation campaign.		governing body • Confidence with the talk, seminar, or booth set up by governing body

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MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 3

Meaning units Transcript 3	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I saw an article in a section of a newspaper. I was about a little kid who was in need and searching for a liver donor. So at that point in time, it triggered me to think 'what if this were to happen to us, who would be willing to help us? Surely there will be no one volunteering to help'. (Line 30-33)	Emotionally disturbed with the needy. Satisfaction of helping others. A lifelong charity. Commentary Memo: At this point, the participant is thinking about the future. She foresees the future and worries if she could be in the same shoe as the kids in the newspaper. Further, it worries her if there were no one volunteering to donate for her. This has triggered her intention to donate for the kids.	An individual's belief system is informed by personal views about the importance of sharing and giving as part of lifelong charity. As well as when a person have a sense of humanity. The nature of work has stimulate intention as well as the decision to register as an organ donor.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others
But, when I started getting involve with the NGO and started going into forest, I was also active with MERCY Malaysia, I see a lot of cases which all this while I only read it in the newspaper. But now I can see it for myself, in person, there was this Aborigines family which comprise of the parents who are actually sibling and because of inbreeding most of the children are not really well. Some of the children has got cataract, spina bifida and the kid cannot walk, and the most crucial is that one of the kid was deaf and blind. So it triggered me to think 'is there anyone willing to donate their eye?'. Then when we did a fundraising activity and Hospital Kuala Lumpur informed us that to be an eye donor it is necessarily from human donor. There is this material which I am not sure the name of the material, but they can form a new eye to help replace the little kid's cornea. So, right after this incident, I said to myself 'Ok, I want to do this, I want to become a donor'. (Line 41-52)	Her attitude towards other, her passion in helping others has again triggered her intention to be an organ donor. She just wanted to help deceased people and wants them to have a good quality of life like other people. She always relate other people condition to herself and imagine what if she was in that person shoe. Her volunteering work has again open her eyes about need to be a registered organ donor.		
But, after some time I felt like I am being selfish if I did not donate my organs upon death. (Line 70-71)	Here she emphasis her stand that she really believes in donating organ as a good deed and she is the type of person who think of others, she is not a self-centered person.		

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Meaning units Transcript 3	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think she can see that I am always busy with my NGO activities, thus she understands where my heart is. (Line 77-78) We just want to donate to help save other people live. (Line 109) There was this one time where a little kid was in need of kidney, so we were looking for kidney donor, towards the end we failed to get the kidney donor. In the end the kid die. This is among the thing that I feel that if there are many people who volunteer to sign up to become an organ donor it would turn out better. I try to donate for the little kid, but the result of the blood test shows that my kidney is incompatible for the baby. The situation was indeed very sad. (Line 147-153) it was influence from what I saw and if it was not because of the aborigine kid that I saw maybe I could not feel this, you know having this feeling…where you are emotional disturbed, and you feel sad. (Line 214-216) yes I signed up not because of campaign conducted by NTRC but I signed up because I see cases where if the ill person did not get a donor then death is the answer. So things like this is when you know….what your eyes can see your heart can feel. When I directly see death due to no organ donor, this trigger me thinking 'eh why didn't I register as a donor'. (Line 188-192) I remember the parents to the child told me that they are OK with the death of their child as the belief they can bear more children but this is a life that we are talking about. The child were so small and you know, all little children they	In line 77-78, talk about her parent's view after she informed them of her registration decision. Her mother in particular, accepted her decision knowing the participant's interest and passion in helping others. So, she respected her decision to be an organ donor. It is embedded in her as portrayed in line 147-153), the attitude of helping other people. She is very passionate to give to other. Willing to share what is hers. She gets emotional disturbed if she were not able to help in any way to make the sick person feels better. Her role and her involvement in volunteering work has very much stimulate her into registering as an organ donor. She came across many people who are need well and need help. Commentary memo: She was emotionally disturbing when she sees someone sick and she were not able to help. It upset her more if the person dies. It's her heart, she has a high sense of humanity for other.		

Meaning units Transcript 3	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
are all so cute and adorable. But, it was really upsetting to look at him go and leave us just because there were no one wanted to donate organ that he need. (Line 243-248)	She has a high sense of humanity. This links a lot to her attitude as someone who like to give and share with others for the sake of benefitting other people. She appreciates life.		
I wanted to go, but my family did not allow me to do so. Because they said it was illegal. (Line 34-35) they thought it is illegal from religious point of view. They said Islam forbid organ donation because we have to remove our body parts after death which then the parts/organs are to be given to someone else. (Line 92-94) in many social media there were a lot of discussion surrounding the issue of whether it is illegal or not to donate organs. Thus, this fatwa council has made a statement that organ donation is not harmful to the deceased. So, when I read it, I was like 'oh, ok, organ donation is legal then'. So to me, by right, if the religious man or the pious says it is not violating Islamic rules, then it should not be a problem for me to go on donating organs after death. (Line 103-108) Yes, that is one of the point. Additionally, from the religious perspective, I can confidently say that it is not illegal as our intention was just to help others. (Line 116-117)	Commentary memo: Family has influence her donation decision as her family think that religion does not permit O.D. In line 39-41 she talks about respecting parents and her maturity in making decision which lead her to listen to her parents. In line 69- 70, again she mentions about obeying her parent's decision. Social media plays a major role in her information gained. She came across and issue about organ donation in the social media where people were discussing if its legal or illegal. Then, an authorize religious body came forward by responding towards the issue on social media. So, this has change her understand about her religion's stand about organ donation. Religion always teach us to do go by always helping other people who are in need.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Certain that action does not violate religion
my parents were concern or more of scared that I might fall sick after I donate mine and who will then take care of me. (Line 35-36)	Commentary memo: This is a misconception, as the family think that after donation their children could be unwell and unfit. So, they disagree with donation as they do not want any bad effect after donation.	Family discussion were hinder because of family's view is very much influence by the community's opinion.	Cultural misconception in the society

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Meaning units Transcript 3	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Before this I did not sign because at that time I was just obeying my parents. Since they say NO, then it cannot be done. But, after some time I felt like I am being selfish if I did not donate my organs upon death. (Line 69-71) is it culture or it's just the way we were being brought up? I am not sure about other races, but we the Malay, most of us are Muslims. So, it's common to hear the Muslims Malay that says organ donation is prohibited. So, straight away people would have some sort of mental block and in our community and this impedes them from doing it. (Line 261-265) that there is taboo in our society especially among the Muslims that believe it would actually torture the deceased body. Even if you look in the Malay community they would not agree to postmortem as the strongly believe it would only hurt the body of the deceased. (Line 411-414)	When she first had the intention she did not go on registering, as in the Malay society, young adult who still study usually listen to the parent's order. It's a culturally and religiously accepted behaviour. This link to, how strong the influence of religion in her decision making. When she talked about culture, it is leading to the idea that a religion can colour a culture. Culture is a way of life while religion is a belief system. The culture in Malaysia is very much influence or shaped by religion. Taboo in the community		
I always hang out with her and she often said to me that she is an organ donor too. She was telling me of her father's case which was the one that open up her mind and heart into donating organs. We shared a lot in common. Then, I told her that I think, I can confirm that I want to be an organ donor. (line 53-57) In many social media, especially Facebook, there were a lot of discussion surrounding the issue of whether it is illegal or not to donate organs. Thus, this fatwa council has made a statement that organ donation is not harmful to the	Commentary memo: Sharing of information with peer, contribute to her certainty that she is doing the right thing. This encourage her to continue with her intention. Social media plays a major role in her information gained. She came across and issue about organ donation in the social media where people were discussing if its legal or illegal.	Certainty and confidence with the information gain about organ donation. These feelings include; confidence with information shared by peers, confidence with online resources, and confidence with the authorized body.	**Concepts:** Cognitive readinesss **Categories:** Information resources **Codes** • Confidence with information shared by friends. • Confidence with the organ donation governing body

Meaning units Transcript 3	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
deceased. So, when I read it, I was like 'oh, ok, organ donation is legal then'. So to me, by right, if the religious man or the pious says it is not violating Islamic rules, then it should not be a problem for me to go on donating organs after death. (Line 103-108) literally I visited the National Transplant Resource Centre (NTRC) because my friend worked there. Along the way, I also subscribed to the NTRC newsletter. (Line 132-133) The one performing the surgery is a medical doctor, and it is not me who have to think of all the medical terms and medical requirement'. So just trust the doctor to do his job. But the point is now, for as long as there is no donor, how would doctor continue to do transplantation procedure. So I thought and told myself 'Ok, I should just register'. (Line 428-432) So, regardless of races, you cannot choose the person receiving it. Well to me I can accept it. (Line 467-468) I think they will be a bit reluctant to actually see my organ to be inside someone of different races or even of someone other than Muslim. But, to me, I really hold on that all religion want their followers to be a good person. So, even though a person may not be of the same religion, but this is about their life, so why should this issue becomes a hiccup to continue with transplantation. (Line 468-473) Well maybe it's just me. The way I think may not be the same as other Malay does. In other words, let's say it's us who need an organ from someone, and all that we know an available organ is from an Indian donor, of course we would just accept it. Right? (Line 474-477)	Then, an authorize religious body came forward by responding towards the issue on social media. So, this has change her understand about her religion's stand about organ donation. The influence of friend keeps her updated about the progress of organ donation. This friend as a trusted source to her, plus, this friend of her work with an authorized body. Continues newsletter from authorized body also keep her informed about organ donation. The removal procedure did not bother her. Why should it? She trusted the surgical procedure as she knows it is performed by a doctor. The donation is process is fair to her. It does not bother her who would receive her organ. She belief that donation process in Malaysia is transparent and fair.		• Confidence in official religious body online resources

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Meaning units Transcript 3	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Then my boss continue saying that we are similar and she will continuously update me on the latest activities done by the National Transplant. Which I felt like, I am at a different level, as me and my boss we share the interest and it is more of doing something that is good for the community. I felt I have a different kind of relationship. (Line 204-208)	Commentary memo: Feeling proud as she sees similarity between her boss and herself. She felt that she had a different kind of relationship with her superior since they both like to do good deed for the community.	The similar to me effect with superior	**Concepts:** External influence **Categories:** Valued social networks **Codes:** Superior or employer is an organ donor
In your life you must make your own decision and not let others decide for you as it is your life. You will be the one living it. (Line 226-228)	Commentary memo: She believes in autonomy and her right so make her life decision on her own. She take charge of her life.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy
to me the idea is fairly simple, someone is in need, so why not we give some. But, honestly speaking, I think in Malaysia we are not there yet. I think maybe consciousness or exposure level is not there. Or maybe because in Malaysia, majority are still struggling to obtain work life balance. Everyone is still working hard to stabilize its own economic position. So we are have not been in the direction in which we think, OK I have everything and now I am willing to give. Now we are still in the stage of receiving our basic needs. We want our children to have enough to eat, we want to have a comfortable home, we want our children get the best of education. So we are still struggling to fulfil our basic need. Many of them the low-incomers still rushed for stable economic position. If we look at the developed countries such as in England we can see they have fulfil all their basic need and so they are more willing to give. Therefore sometimes a campaign of this kind, such as awareness on cancer, awareness on recycling too, are more exposed to those with high incomes. (Line 273-285)	Commentary memo: SES influence our attitude. It often shaped how we do things, how we view it. The less able or lower income group of people are less expose as they have other priority to attend to. They are still thinking about fulfilling their basic needs. Those from higher SES group, they have fulfilled all their basic needs, so helping others becomes something they may be thinking about.		Recommendations

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 4

Meaning units Transcript 4	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think it is because of humanity. As the statistic itself shows that they are many people who require or in need of an organ but they are not getting it just yet. (Line 40-41) Because to me, I see it this way. When we are alive we were not able to give to others. We cannot donate organs which is I think to give an organ is a good deed. So why not when you have the chance to donate (Line 87-89)	Commentary memo: She sees that donating organ after death is a way to contribute something after death. Particularly she sees it as an opportunity to donate organ which most people won't be able to give during their lifetime. What she is saying her links to point in line 40-41.	The sense humanity is embedded within the person as she expressed willingness to donate even while still alive.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others • Belief in sharing and giving
I attended an event on kidney. It was and event by the Kidney Foundation that they are sharing information about the current scenario on kidney diseases. There are many chronic kidney problem whom the patient are very young but yet they already in need of kidney transplant. But there is no donor available in the donor pool. I think that was the point where I start thinking about becoming an organ donor and decided to be one. (Line 41-46) I made my decision to register as an organ donor after death. But, if in need I don't mind donating say for example my kidney while still alive if it is necessary. (Line 57-59) By the way we are not on the losing side. We do not lose anything. We are dead by the time they remove our organ so it be of no use to us any longer. So we don't lose anything actually by (Line 144-146) But let say if it happens that when they grow up and decide to be one like me, then I would not mind. I would not stop the hospital from removing organs. I will just let it be as their wishes. I will be a proud mom. (Line 188-191)	Commentary memo: The participant has registered to be an organ donor after death. But she don't mind giving or donating organ that is viable while she is still alive. This link with her point in line 57-59. I think it is just her attitude, who like to share and give to other people. Her sense of humanity is great as she don't mind donating organ while still alive. She felt that there is nothing to lose by giving away her organ after death. Since it would not be utilize by us anymore so she see no harm to let it be used by others. It is the participant's attitude that is embedded in her. She even doesn't mind but welcome if her children would want to be an organ donor too. She is more than happy to just agree with it.		

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Meaning units Transcript 4	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Emm there were booth for registration. I think it was a collaboration program between a few agencies. Because as far as I can remember there were Mufti (religious man) which I think is from the Islamic Department, there were people from the Nephrology Department, and I think there were NTRC booth. (Line 76-79) . I remember at the end of the session I straight away registered. (Line 104-105) He accepted my decision. I think he is also aware that our religion and the church also has said that it is not illegal to become an organ donor. So, it did not bother him. I assumed that, to him he would not interfere or bother with my doing or any decision I made for as long as it is not against religion. (Line 128-131) I was really interested to know about the procedure after death especially the process involving family member. I want to know what family member should do once the doctor declare death upon me. Thru my searching, I know that family member should tell the hospital that I am a registered organ donor. (Line 161-164) He accepted my decision. I think he is also aware that our religion and the church also has said that it is not illegal to become an organ donor. So, it did not bother him. I assumed that, to him he would not interfere or bother with my doing or any decision I made for as long as it is not against religion. (Line 128-131)	Commentary memo: Ease of registration process is crucial in the registration of donation intention. The ease of the registration process play a role in her decision. Since in line 76-79 also mentioned about the presence of NTRC booth which ease the registration process. Commentary memo: The participant and her spouse were well informed that their religion allow organ donation. Her husband was curtained about it as he has heard it from the church he attended.	The availability of information about how and where registration takes place is crucial for it can ensure registration to take place. Certainty and confidence with the information gain about organ donation. These feelings include; confidence with information shared by religious body, confidence with online resources, and confidence with the authorized body.	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes** • Knowledge of the process involved in registration • Knowledge of the donation and transplantation process **Categories:** Information resources **Codes** • Confidence with the organ donation governing body • Confidence in trusted online resources

Meaning units Transcript 4	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I was really interested to know about the procedure after death especially the process involving family member. I want to know what family member should do once the doctor declare death upon me. Thru my searching, I know that family member should tell the hospital that I am a registered organ donor. (Line 161-164)			
Great reward after death, we not just donate. It is a way to be rewarded too. (Line 89-90) So, it did not bother him. I assumed that, to him he would not interfere or bother with my doing or any decision I made for as long as it is not against religion. (Line 129-131) honestly if up to this point the church that I go to has not discuss about organ donation and share with us about it from th(e bible point of view, and they cannot say it for sure that it is permissible from the Christian point of view, then I would not have register. But, since the church has made it official, that is why I decided to just go ahead. (Line 141-143) Plus, I also believe that if the person do something good, at least indirectly I will also be rewarded because a part of me is in that person. The best part is that the benefit to myself because I get to enjoy the benefit after death as well because God will make my journey in the life hereafter easier, (Line 208-211)	Commentary memo: Even a Chinese participant believe in being rewarded after death. The see the benefit of donating organ after death is something that could help them in the journey in afterlife. This link to line 197-199. So to him, for as long as the wife (the participant) is not doing anything that is against the religion, he is fine with the participant's decision to register as an organ donor. Religion is a contributor as well for the Chinese. Her religion, Christianity is significantly important of whether she will go on with her registration decision. She will not do it if it's not allowed.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Belief that their afterlife journey is less burden, with lighter punishment if they donate • Certain that action does not violate religion

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Meaning units Transcript 4	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I remember that after registration, I texted my husband just to inform him of my decision becoming an organ donor. That was it. It is just a matter of informing him and not for getting his permission. To me it is totally my own decision. By the way this is my organ, my body that we are talking about. (Line 113-116) He just responded 'OK' (laughing). Just that. Just 'OK'. (Line 122) I am certain that I have already informed my husband and my both my parents. But, honestly, I am not sure if they will just let the hospital proceed with whatever necessary for them to do. But, I am sure I have talked to them about this and also explained that it's permissible. But I am not sure what will happen when the time comes. All I know I have given them enough information, gave them relevant flyers, and they seems to just agree at that point of time. (Line 173-178)	Commentary memo: Family communication took place after her registration with a purpose to inform the spouse. The intention was not to get her husband permission, as to her the decision made was solely hers and only she has the right of her body. Family communication was easy. I personally think that the background of the family member as well as their attitude play a role of whether or not a person will go on registering without any prior discussion. Maybe, there could be no discussion at all if the registrant think that the family will object or will not even try to listen to their justification. Here the participant expect that her family would agree with her decision. As she has shared sufficient information with her spouse and parents by sharing flyers, and they seem in agreement. But, she cannot be certain that when the time comes, the family will let the hospital carry on with the removal of her organ. She is just making assumption.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy
Well I look at it this way. It's as if you enrolled yourself into a membership club or something. But, this one it's a once in a lifetime enrolment but you get to enjoy a lot of benefit. Benefit to you and others as well. (Line 197-199)	Commentary memo: She sees donating organ as something that she could enjoy a lot of benefit. Like joining a club, you get a lot of benefit.	Personal views and satisfaction of benefitting others.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes**

Meaning units Transcript 4	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Obviously we can see the benefit. Its tangible benefit when we talk about saving other people's life. Somebody would benefit. You will see someone alive and still living his live as before. Even healthier. (Line 206-208) Plus, I also believe that if the person do something good, at least indirectly I will also be rewarded because a part of me is in that person. The best part is that the benefit to myself because I get to enjoy the benefit after death as well because God will make my journey in the life hereafter easier, (Line 208-211)	By having her registering as a donor, the potential recipient would benefit after receiving her organ, and she would benefit by being rewarded in the life hereafter. This link to line 89-90.		• Sense of responsibility towards society, and fulfilment of benefitting the society as a whole • Fulfilment of improving quality of life of others
Oh one more thing I was also hoping that when I do something good like this, you know having this intention to donate organs to others, I hope that there will also be other people out there who would do the same for me or my children when we are in need. (Line 230-233)	Commentary memo: She has hope that if she is in the position of in need of an organ donor, there will be someone who is ready to donate. Be it for herself or for her children.	Expectation of getting something in return if one day he or she would need an organ donor. Need to overcome the fear if one day will be in need for one.	**Concepts:** Feelings and emotions **Categories:** Fear for self and those close **Codes** • What if one day I need a donor? • What if one day my children, parents, and siblings need a donor?

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MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 5

Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
You see, when you are in that situation, there's nothing, I believe that there is nothing else you can do. You basically are dead if the hospital pronounce you are brain dead. You are literally gone. So, the last thing that I can do on earth and be nice to other people is by probably help by giving whatever is left and functioning in you. Give it to those who need it. I don't need it anymore. (Line 60-64) I am aware that it is not wrong religiously, so why not we do something good to help other. It is morally right. (Line 260-261) I will not stop them. If that's the choice that they make, I will not stop it. Because again I think…yaaa.. It's the same thing, it's just that I believe if there is a way for this person to do something good and benefit other people before her time to go, just let her do it. Yes, that's my opinion. So, I will not stop anyone from donating organ. (Line 272-276) I really want to do this. I feel like some kind of satisfaction to help other people you know. (Line 290-291) But I do insist though, I said when the time comes, when it happen I said it will be good to be able to do something good and just insist them to let me do it. (Line 431-433) rather than just waste it might as well donate the organs. (Line 450)	Commentary memo: She think that rather than wasting it (the organ), she prefer to still utilise it even after her death. How? By donating all viable organ to those in need. Here, I think that the attitude of helping others and doing good to other people, link very much with the teaching of most religion. All religion preach us to do the same. Here it strengthen the point that she is someone who loves doing good and benefitting other people. Her passion in doing something good. Don't like wasting. But prefer sharing. Note: The participant's work environment has exposed her into organ donation. As she is working in the hospital, she came across many cases of ill people. It has indirectly stimulated her intention of wanting to do something with her organ when she no longer need it.	The sense humanity is embedded within the person as she expressed willingness to donate even while still alive.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes:** • Belief in sharing and giving • Feeling of satisfaction being able to help and do good for others

Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Since I am a Catholic, I know that when I die, I don't need that organ anymore, probable give it to someone else who need it. (Line 64-66) it's more to my faith. Since I am a Catholic, when you are dead you don't need your body anymore. What's important in the life hereafter is just your soul. That's what I believe. So, whatever is still valuable at that time just leave it on earth for somebody who needs it. Because the one to go is just your spirit (Line 74-76) I thought this is something good and it suits my faith as well and in is in line with what I believe. (Line 85-86) I was pretty sure that it is coincide with my faith. (Line 125) I would say that firstly they are lack of awareness, second thing would be if culture, mmmm…culture is pretty hard to say, but I think maybe, mmmm I don't know how culture blend with it though. Seriously. On one note, I am not a very cultural person as well you see. But I cannot link of any culture to donating organ. I have not known any. (Line 208-212) I think it is something, how do I say this, organ donation is something that is beyond the community to understand, why, how, when, question like this you know. Then, I don't think they know about it, if there are people who knows or heard about it, it's just a very small number, and even if they know, it's not much. They would not really understand, how it's going to happen, when it's supposed to happen, or what happen to the family when it happen. You know those kind of questions. It is not answered to the community so they don't talk about it. But when you relate to culture,	Commentary memo: Her religious belief also has taught her to give and share with other people who are in need. Link to line 125. Her religion has taught her that, when the Catholic believer died, their body is no longer useful but what's important is their soul and spirit. This link to point in line 229 – 235. When asked about the influence of culture in organ donation in general, the participant think that, culture do not have much influence in the decision making or acceptance. Maybe this link to her character itself, as she claimed that she is not a very cultural person nor not really a pious person (line 247 – 252). But in line 220 – 235, she go on saying that she think culture has no influence because in general the community especially those in Sarawak they are not aware about the existence of organ donation thus	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Belief that body is not useful anymore after death and can be given to others • Certain that action does not violate religion

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Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
mmm..because Malaysia has diverse ethinicity, Malay has different culture, Chinese has different culture, the native people of Sarawak has different culture. Like me I am a mixture of Chinese and native Sarawak. When I think about the ritual of death in both Chinese and native Sarawak culture, I don't see any issue that would inhibit organ donating, or I don't feel that donating organ would interfere with the death ritual. You know what I mean. I don't really know about other culture like the Malays or Indian. I am talking on behalf of my background as a Chinese, as a Catholic and also as native Sarawakian. I am talking as being a Christian, I don't see any problem. (Line 220-235) No. I don't think so because. Emmmm from what I understand, you see me myself, I am not very pious you know, from my Catholic teaching that I have attended to, from my understanding when we are dead our body just disposed, I mean decomposed wherever we are. Our tissue will just decompose and what remains is our spirit, our soul will go up, something like that. So nothing like our body will be painful or what not. To me this should not appear to mind. That's not in my faith. (Line 247-252) No. I think my decision has nothing to do with my faith or culture. It is just that I am aware of the problem, I am aware that it is not wrong religiously, so why not we do something good to help other. It is morally right. (Line 259-261) But, to me, as far as what I understand organ donation is not an issue in any other religion too. (Line 448-449)	there is nothing to discuss. They are not in the know. Information is not well disseminated and not even in the hospital. So, if people don't know, then there is nothing to talked about in general or culturally (Line 220-226). Here, I think that the attitude of helping others and doing good to other people, link very much with the teaching of most religion. All religion preach us to do the same.		

Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I read newspaper, I saw somebody promoting it in the hospital, holding a green colour card with a white colour ribbon. That person actually triggered me read further more. (Line 83-85) I was reading why do people decided to do this, I was reading a few inspiration stories. It's a story told by the family member of the donor. So, I thought it was a brave thing to do. To me it's a noble thing to do by ordinary human being like us, who is giving part of their body or organ to another person just to give them a chance to live. For me it is a very magnificent and unique thing to happen. So after reading those stories I kept thinking that if I were in that situation I would not hesitate to do it. (Line 107-113) Because it is not common. There is not much happening surrounding this matter that when trigger other to be talking about it. Maybe if it's happening also, it is not broadcast, and it is not well known. Plus, in recent years, especially since in Sarawak, I have been working in Sarawak for 10 years, I don't even see the organ donor promotion. There is no awareness campaign that is on-going here in Sarawak. (Line 174-179) Not in the hospital what more if you ask me outside of healthcare premises. You would not see even one organ donation campaign. So, when there is no awareness, of course we would not discuss about it. So, we cannot expect the majority of people in the community to be communicating about this. (Line 185 – 188) First, they are not aware about this at all. So they do not think about it. Well, to be honest there is nothing for them to think about. Right? I can't really answer you this question because me myself, I never discuss with my friend	Commentary memo: She a lot of information thru her newspaper reading. Besides this also link with line 39-42 and line 44-46 that discussed the importance of her work environment towards her decision to register as an organ donor. Working in a hospital has given her a lot of opportunity to learn about organ donation as there were events or talk about it in hospital. She used this inspirational stories to persuade her family especially her parents so that they could accept her donation decision. Inspirational stories about others who has donated an organ/organs has inspired her to become one as well. She wanted to be inspiration by doing something noble too. Here the participant is suggesting that the society is not well informed or best said not aware about organ donation. She has never seen any sort of campaign on organ donation in Sarawak and not even in the hospital she works since the last 10 years. Which she only came across about it when she travelled to Kuala Lumpur for work purpose. This link to point in line 188-185, line 195 – 198, and line 199-201. Lacked information dissemination so the community are not aware.	Certainty and confidence with the information gain about organ donation. These feelings include; confidence with information shared by religious body, confidence with online resources, and confidence with the authorized body.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence with the information shared in newspaper • Confidence with the talk, seminar, or booth set up by governing body

Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
about registering as an organ donor and what not. So it is not a very common topic to discuss even with patient in Sarawak, or even with my colleague in Sarawak. Basically the decision to become an organ donor is very personal for me. But not a very vast topic to discuss here in Sarawak or even in my place. Just look at my hospital, we don't talk about it a lot. So, I can tell you that not many people are aware about it(Line 194–201)	Lacked information dissemination so the community are not aware.		
In Malaysia, I don't visit Kuala Lumpur very often, but when I go, I don't see anything on organ donation in this recent years. Probably about 7 years I am working in the hospital, in the Columbia Asia, but I don't see anything. That's too bad. Maybe there are. But I don't see much. Even on television I don't see much awareness or people talking about it. I don't see much. Even in the hospital, in the environment that we are working, which I think play a bigger role in creating this awareness, I don't see it as well. (Line 305-311)	The participant thinks that the information dissemination in Malaysia is poor. Even she as someone who works in the hospital think that it is not widely known (link to line 320-322). So, if the healthcare professionals are not aware about it, what more the public.		
I don't think so, even the healthcare staff, they would not know about all this. Because it never make known. It is not something common or it is not something that is ongoing. (Line 320-322)			
when somebody donating organ, probably once a year, then it just came out on the newspaper, but then after that it just die off like that. So there is no continuity or no continuous effort I would say. (Line 324-326)	Organ donation is not even seen in the media such as TV or radio.		
Well, then to me I think the information about their event is not well disseminated. If you look at Sarawak, there is nothing going on here in Sarawak. I don't see it happening. (Line 373-375)	Lacked information dissemination especially in areas further away from the capital city.		

Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I did not discuss at all actually. I did not even think that I was necessary to discuss this with another person. I made the decision on my own. After I register, then only I told my parent. (Line 131-133) They do not know what it is. They would not know what it is. They definitely do not know what it is. Plus, until today they still do not know what it is. (Line 139-140) But, I told them I am an organ donor. So I told them that if that situation happen, if I happen to be in that situation you can donate my organ that is possible to be donated. I also did told them that you and doctor can decide which organ to donate. I told my family that. I remember telling them about all this. Then, they….of course they will feel a bit weird. They were feeling like 'why?', 'why you want to do that'. I told them the same thing like I told you. Anyway to	Commentary memo: Decision was made on her own without consulting with anyone else. She believes that its her right to make that decision on her own. This link to line 198-199. She mentioned that this decision making is very personal to her. Communication with family only happens because just wanted to inform her decision to be a registered organ donor. Not as asking for their opinion or permission. The participant seems quite confident that her family don't understand what organ donation is. This link to line no 155, 161 - 166 as she said her family did not argue as they think it might not happen. They ignore the conversation. So, this is something to worry, because even though family communication takes place, it did not guarantee that donation will take place as for this participant its really obvious the parents don't accept it. When she informed her family about her donation registration, she tried to psycho her parents so that they can accept her decision. I think there is a different way of conveying the message to parent in urban or in rural area. I think their SES play a role.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

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Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
make them feel better, what I did was I tried to play with their psychology, I said to them that when a person is dead you actually chuck them into the coffin, and then nobody even can see what is inside there. So, what's the big deal? (Line 140-149) Of course nobody argue with me as maybe they think it would not happen. (Line 155) my parents they don't really like this topic, so they choose to just ignore it. Then, I think they keep on praying that it does not happen. I think at that point when we were discussion about my decision, it all stop as my parents purposely stop the conversation, and then just ignore what I said, and then I guess in their heart it's like 'no impossible, it's not going to happen'. I don't think they are very supportive of it. I really don't think so. (Line 161-166) Basically the decision to become an organ donor is very personal for me. (Line 198-199) Maybe I can tell you, how I actually tell my parents. I gave them example. I said, look when somebody die in our Catholic church, normally in the Catholic church when we die our dead body will just be put in a coffin, so normally there will be somebody who would handle our body and lay our body nicely in the coffin, and put us on a very nice dress, just like how we are dressing up now, so if I donate any organ from my body let say my lung or my heart or whatever, you would not know, I said, because I will just look normal, I just look like who I am, I am still who I am, it's just that I will be covered up by the cloth, and I will be in the coffin, and eventually I will end up in the graveyard. So that's what I told my parents. There is nothing that's going to be different and you don't even have to see the whole	This link to her point in line 131-133 when she mentioned that its her right in making this decision and she don't think it's important to consult her family.		

Meaning units Transcript 5	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
process of donating. That's what I told them. They are just…you just have to think that they are taking some part of my body for somebody and then they will just close me up nicely and then it will just be the same after that. That's what I told my parent. They kind of like listen to me and then Ok, change the topic. You know what I mean. So I hope I reassured them and tell them the correct thing. But I know that at the end, when the time comes, it really is their decision that will determine if the donation will takes place or not. But I do insist though, I said when the time comes, when it happen I said it will be good to be able to do something good and just insist them to let me do it. I think that was in another harsh way for me insisting my parents, I told them it's my body so just let me do it. Let me decide what I want to do with it. You know what I mean? I also said to them, you just bring me out to this world but it's my body and I took care of it so I decide what I want to do with it. Normally it works very well when I talk like that to my parents, like giving them the ultimatum. (Line 415-438)	Family communication. How she persuades her parents.		

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MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 6

Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I was reading a blog, an Islamic based blog by a pious man, if I am not mistaken his name is Ustaz Saiful Islam. He wrote something about organ donation. In his writing, he explains about the advantages of organ donation, especially for Muslims. So it attracts me and has sparks interest in me to be a registered organ donor so that when I die I can donate organs to others. As the Ustaz did mentioned that this is also a form of doing charity work after our death. (Line 35-40) I don't think it bothered me in anyway. Because I was certain that Islam permits all Muslims to donate organs because I have had proper reading about it from the Ustaz Saiful's blog. In that blog he clearly explains concerning the law on organ donation from the view of Islam. Additionally, I saw on television program called 'Pencetuh Ummah', it's a shows bringing the concept of the spread of Islam. In that show a young Imam gave an explanation regarding organ donation law. So, I was not so concern of whether or not Islam permits it because I was certain that it is not illegal. (Line 135-142)	Commentary memo: <u>About religion</u> Information seeking behaviour. The participant was very much involved into reading and searching about organ donation particularly focusing on the religion aspect. The influence of internet and social media is very strong as he seeks clarification about Islam and organ donation from Islamic blogs, particular a blog written by a prominent figure. Link to line 137-140, 148. The participant look at it as something that would benefit her if she could donate her organ after death. In line 39-40, she go on saying that relate to gaining advantage were by donating organ, she could gain something in the life hereafter. Religion teaches her to do good thing like charitable work. So, doing charity work is closely related to the teaching of her religion. This link to point in line 35-36, 64-66 Here, the participant emphasizes again on how confident she was that religion permits OD after reading a prominent figure's blog. It did not bother her despite the fact that many doubted on religion's stance towards OD. Emphasize was given on the influence of social media such as blog and TV series.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Belief that religion teaches donation as a form of charity work even after death. • Certain that action does not violate religion • Belief in the continuous reward in the life hereafter • Belief that organs are not useful anymore after death and can be given to others • Benefit for our self (double reward of pahala) when the recipient contributes to the society

Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I look at it as a chance for me to get Allah's blessing even after death and I will continuously receive rewards from God after death. As we all know that once we die, all the good practice that we have been doing in this work stops. So you will no longer be rewarded. So, I presume that by donating organ to others after death will be the last charity that we can do to increase our deeds in the hereafter. (Line 155-159)	Here, the participant is telling me that by donating organ after death, she will be rewarded continuously from God for as long as the organ receiver is still alive and keep utilising the organ. Double reward.		
I really think that giving our organs to sick people with the intention to save them so that they can live longer and it is hopeful that if the person also continue doing good thing, we will too be rewarded (Line 159-162)	The participant also thinks that if the organ receiver does good things in his/her life after given the second chance to continue living, not only the receiver will be rewarded with pahala, but the donor too! So, here the donor gets rewarded for donating and for as long as the receiver do good thing, the donor also will be getting the pahala.		
Afterall, the 'body', our 'body' does not belong to us but Allah. I also understand that in the life hereafter, our body don't stay together with us, it's just our spirit that will be there. I believed that Allah only lend the body to us, and He lend it to us in order for us to do good deeds in the world. After the death of the body we have no purpose, so what's the harm we give some parts of our body to those in need. (Line 163-168)	The participant believes that nothing belongs to us but God, so why not give it to someone else too. So, that other people can use it, use something that belongs to God.		
I think they are all aware about organ donation. But the only problem is I think this mind-set in our community where we are difficult to accept changes and we are not open to something like this as it involve death. There like a negative connotation when we talk about it. So to donate organ is not common to see or hear in our society. So I think my mom's she is that type of person who do things based on what others would say or comment. (Line 368-374)	Commentary memo: Cultural influence. What others would say about it. Link to point in 380-382.		
I think she is the sort of person who care what other people like aunties, uncles, other relatives or neighbours think. She just don't dare to do things differently. (Line 381-383)	Conforming to the culture.		

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Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think it is maybe because in general people are still scared of the idea of removing organ from their body and to give it away. Maybe because this is not a tradition or culture of our society. So even though people knows of the advantages of organ donation, many do not want to donate theirs because they fear. (line 409-413)	Link to point in 367-373.		
I really think that giving our organs to sick people with the intention to save them so that they can live longer and it is hopeful that if the person also continue doing good thing, we will too be rewarded (Line 159-162)	The participant thinks that after donating organs upon death, there is possibilities where the recipient will live longer and do good thing to the society, which the participant believe he will be rewarded too as his organ is in the recipient's body.	Personal views and satisfaction of benefitting other and the benefits gain for own self.	
I was reading a blog, an Islamic based blog by a pious man, if I am not mistaken his name is Ustaz Saiful Islam. He wrote something about organ donation. (Line 35- 37) So it attracts me and has sparks interest in me to be a registered organ donor so that when I die I can donate organs to others. As the Ustaz did mentioned that this is also a form of doing charity work after our death. (Line 38-40) It is properly written by Ustaz Saiful Islam where he explained about where to go if reader wanted to register, and he even provide a link of the National Transplant website. (Line 49-51)	Commentary memo: <u>About Information</u> Someone prominent in her religious belief who shared information about organ donation has influence her intention. The participant was very much involved into reading and searching about organ donation particularly focusing on the religion aspect. The influence of internet and social media is very strong as he seeks clarification about Islam and organ donation from Islamic blogs. The information shared on the blog that she was reading provide sufficient information which make her aware of how and where to register her donation intention.	Certainty and confidence with the information gain about organ donation. These feelings include; confidence with information shared by religious body, confidence with online resources, and confidence with the authorized body.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence in trusted online resources • Confidence in TV advertisement, • Confidence with information shared by friends.

Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I do have some questions in mind. I really wanted to know more what organs can be donated. I also wanted to get opinion from my close friends and family too about this issue. Most of my friends there were in agreement with me, it's just that my family member they don't really agree with me. My family, they were so concerned with the deceased body if donation were to take place. (Line 100-104) I read a lot on the National Transplant website. (Line 115) I don't think it was necessary to do that because I felt that the National Transplant is the right source to refer to. Because they have the authority I guess. I mean they are the authorised body that overlooked on organ donation activities in Malaysia. So I don't think I should look elsewhere. (Line 123-126) I was certain that Islam permits all Muslims to donate organs because I have had proper reading about it from the Ustaz Saiful's blog. In that blog he clearly explains concerning the law on organ donation from the view of Islam. (Line 135-138) Additionally, I saw on television program called 'Pencetuh Ummah', it's a shows bringing the concept of the spread of Islam. In that show a young Imam gave an explanation regarding organ donation law. (Line 138-140) after reading the blog I don't have any doubt. (Line 148) Maybe the fear of I don't know what, but this fear is lingering in their mind, their thought, they fear of something that makes them reluctant to accept organ donation. They maybe fear they would hurt the body even after death. Maybe this is all because they don't have much knowledge	Before she decided to sign up as an organ donor, she chose to consult her friends and family about her donation intention. Which, her circle of friends (relate to SES-young), were in agreement with her intention but not her family. She referred to a trustable website in order to know more about organ donation. In line 123-126, she emphasize this point again. The influence of internet and social media is very strong as she was really certain that OD is permitted in Islam. This link to point in line 35-40, 148 Again, this strengthen the point that she was very much influenced by the social media like blogs and television particularly Islamic TV series. This answer to why the participant's friends, even though in agree about the registration decision but		

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Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
about this matter, not much exposure to this topic. They don't understand the many benefit of organ donation. (Line 202-207) I think it is for the same reason as my friends. It is the thought that it would torture the decease body. In general it's the same way of thinking in the community. (Line 213-214) Maybe there are not much awareness given in our community with regards to organ donation. Perhaps it was seen as something alien in our society. Although it has long ago be an option for sick people in other parts of the world. (Line 220-223) Maybe it is because there is less exposure or campaign or program going on in our society. (Line 231-232) No doubt that sometimes you would came across advertisement in the television, it was not until a few minutes, very short advertisement. Thus, the information provided is not comprehensive. (Line 233-235) I feel like their campaign is very superficial and they did not go in depth on the content that they delivered to the public. So to me there are many grey areas. It leaves a lot of question to the public. Even worst, with the question in mind, they don't know who to ask or what to read to answer the questions in their mind. (Line 251-254) The speaker should have elaborated more on the topic about religion. They should provide more evidence from the Quran or hadith the demonstrate to us and make us feel confident to go on and register as an organ donor. A lot of Muslims people have this wrong connotation and they have	they themselves don't register, because of fear they would hurt the body. This is due to lack of understanding about organ donation. They are aware but don't totally understand. The misconception in the community where they think that it would hurt the deceased, it's like a taboo in the society. This link to misunderstanding due to poor information dissemination. This is supported as the participant continue arguing that there is lack of information being shared in the community. She takes note that there are TV commercials available, but the messages in the commercial is not comprehensive, taking into consideration that it is aired for a short period. So, she is suggesting that the message did not reach the audience as much as it was intended too. Information shared with the public were not able to penetrate the public's interest to register. Maybe the information shared is very limited thus it does not open up the public's heart to at least have the intention to be one. Since insufficient information were made available, this leaves the public with many more unanswered questions in their mind.		

Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
heard same religious man that argues organ donation is not permissible. So this conflicting argument from well-known religious man has influence the public to have hesitation in donating organ. (Line 262-267) it would be much better if it was a collaboration or a joined effort with people from the Department of Religion. (Line 275-277) So the culture in the Malay society is very much influence by their religion which is most Malays they are Muslims too. So, here we are talking about organ donation, which issues like this, these people would stress out the importance of complying with the religious law. It is really important for Malay Muslims to be certain of Islam's stance or view on organ donation. So, if programs such as this is accompanied by a religious expert group, it would be better. (Line 278-283) I think she is aware that our religion permits organ donation, as I have explain to her about it and the way she responded as if as she knew or has heard somewhere from someone, probably went she went to the mosque. I just strongly believe that her rejection was because of fear. (Line 346-349) It is properly written by Ustaz Saiful Islam where he explained about where to go if reader wanted to register, and he even provide a link of the National Transplant website. (Line 49-51)	The lack of information that becomes concerned of the public is more centred around religion. As, overall, religion is key in making decision of registering as an organ donor. So, if they really understand and were rest assured that organ donation is permissible then they would continue with registration. But, somehow that is the key problem here , where people are not certain of their religion stance about OD. This strengthen the point in line 262-267. It demonstrates that religion is key. This strengthen the point in line 262-267. It demonstrates that religion is key.		
Well since I don't have to go elsewhere to register, plus I don't have to do extra work like googling about it, you know the registration process, so I just click on the link and register. It was easy. (Line 57-59)	Commentary memo: The registration process itself has influence her to register. To her it was easy as she can do it online and the link for registration was also available on the blog she has been reading.	The availability of information about how and where registration takes place is crucial for it can ensure registration to take	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes**

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Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
	The information shared on the blog that she was reading provide sufficient information which make her aware of how and where to register her donation intention.	place.	Knowledge of the process involved in registration
To me what's important is that I wanted to save the lives of sick and dying people. So, the main driver was not only about doing charity work, but also saving other people's lives, saving sick people who are in need is also what drives me to register. (Line 74-76) I think I'm more useful as at least there is a small contribution from me to the people. (Line 301-302)	Commentary memo: Other than doing charitable work through donation, the participant sees it as way of demonstrating the act of humanity. To portray loves and care for other human being . She felt good for being able to do something good in contributing to others.	An individual's belief system is informed by personal views about the importance of sharing and giving as part of lifelong charity. As well as when a person have a sense of humanity.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others • Sense of responsibility towards public, and fulfilment of benefitting the society as a whole
I also wanted to get opinion from my close friends and family too about this issue. Most of my friends there were in agreement with me, it's just that my family member they don't really agree with me. My family, they were so concerned with the deceased body if donation were to take place. (Line 101-104) As for my friends, they agreed and gave support to me so that I register my intention to be an organ donor. But that's not the case for them as they don't see themselves registering as well. My friends do understand the benefit of donating organ and they are aware of our religion's stance about it, but they just don't have the intention to donate as they are scared of this idea of donating organ. Maybe they were visualizing and think too much of the physical	Commentary memo: Her family, they objected her intention as they questioned about what would happen to the body after death. I think, it's more of a taboo, they worry how the dead body will be handle, might it hurt the body etc. Link to point in line 101-104. Her circle of friends (relate to SES-young), were in agreement with her intention. Maybe because they are more exposed with information available from online resources. They are in the loop and aware	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
condition of their dead body after the transplantation process takes place. (Line 186-192)	about it. But, still they don't have the intention to register like what the participant is doing.		
As for my family's opinion, they rejected it at the beginning. But, after I explained to them about all the benefits of donating organ as well as Islam's stance on organ donation, at the end they change their mind about it. (Line 192-195)	This participant is the only participant who decided to talk about donation intention with family prior to registration. Not like the five previous participants who chose to register first and only talk to the family about donation register for the purpose of informing. Not to get their consent.		
Before I register, I talk to my father about it. I explained to him what is the rules or stand of our religion with regards to organ donation. Plus, I also share with him of the good thing or benefit when we become and organ donor. So, my father granted permission for me to go on with my decision to register as a potential organ donor. So, I straight away register my intention. (Line 290-294)	Link to line 311-317, 326-330, 348-350.		
Actualy my mom disagree with my decision. She was really objecting it because she said she was afraid to see the remains have stitches all over the body. My mother is not working anymore, and now she was much involved with activities at the mosque. So, among the roles is that she have to cleanse the corpse. I think that is why my mom disagree. But my dad he was really Ok with this issue. So, I just proceed with my registration decision since my dad agree with my decision. (Line 312-318)	This point supported the point discussed in line 290-294.		
Most of the time I will try to talk to her about the benefit of donating organ. I think I will continue to persuade her slowly and gently and I hope someday she will open her heart to accept my decision. But, no doubt I worry she keep grudges in her hurt but to me what I am doing is right plus I have got my dad's permission. (Line 327-331)			

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Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
maybe she just surrender with my decision because he knew my father had agreed to it. She can't say much as a wife. In my religion the wife place is to obey the husband all the time. (Line 349-351) I am very sure and confident with my decision since I have got my dad's support on it. (Line 392-393)	This point supported the point discussed in line 290-294. This point supported the point discussed in line 290-294.		
I was reading a blog, an Islamic based blog by a pious man, if I am not mistaken his name is Ustaz Saiful Islam. He wrote something about organ donation. (Line 35-37) . I have no doubt. Because the blog looks reliable. I have been following that blog by Ustaz Saiful Islam and read other stuff as well that he wrote. So, yaaa, I trusted his blog. (Line 64-66) I was certain that Islam permits all Muslims to donate organs because I have had proper reading about it from the Ustaz Saiful's blog. (Line 135-137)	Commentary memo: Someone prominent in her religious belief who shared information about organ donation has influence her intention. Since the blogger was a prominent figure, she has no doubt on the information that he shared on the blog. This link to point in line 35-36, 136-137	The confidence and certainty with the information gain from reading a blog written by a pious man who is a prominent figure.	**Concepts:** External influence **Categories:** Valued social networks **Codes:** Well-known religious person
Before I register, I talk to my father about it. I explained to him what is the rules or stand of our religion with regards to organ donation. Plus, I also share with him of the good thing or benefit when we become and organ donor. So, my father granted permission for me to go on with my decision to register as a potential organ donor. So, I straight away register my intention. (Line 290-294) Actualy my mom disagree with my decision. She was really objecting it because she said she was afraid to see the remains have stitches all over the body. My mother is not	Commentary memo: Another prominent figure, as someone who makes decision in the family. When the father granted permission, she continues with registration. Thus, it is important for us to know who should we go to in order to discuss about our donation intention. It should be someone with power to persuade others. POWER!	The powerful influence of a prominent figure in the family. If there is supports from either one of the parents, the registrant feels right with the decision made.	**Categories:** Respected individuals **Codes:** • Mother or father as the leading role or the decision maker in the family

Meaning units Transcript 6	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
working anymore, and now she was much involved with activities at the mosque. So, among the roles is that she have to cleanse the corpse. I think that is why my mom disagree. But my dad he was really Ok with this issue. So, I just proceed with my registration decision since my dad agree with my decision. (Line 312-318) Most of the time I will try to talk to her about the benefit of donating organ. I think I will continue to persuade her slowly and gently and I hope someday she will open her heart to accept my decision. But, no doubt I worry she keep grudges in her hurt but to me what I am doing is right plus I have got my dad's permission. (Line 327-331) maybe she just surrender with my decision because he knew my father had agreed to it. She can't say much as a wife. In my religion the wife place is to obey the husband all the time. (Line 349-351) I am very sure and confident with my decision since I have got my dad's support on it. (Line 392-393)			

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MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 7

Meaning units Transcript 7	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
After I attended a seminar on organ donation organized by my students. The speaker not only touch my heart but my thought and feelings that day. (Line 34-36) the speaker did mention about organ donation from the perspectives of Islam. Before this I really thought that organ donation is prohibited and against our belief. But after listening to the talk then I understand it is not wrong in my religion. (Line 48-51) The speaker also shared a video where there are a few organ receivers who share their experiences on how organ donation has save their lives. That is another triggering point which stimulate me to register. (Line 59-61) While in the talk, I have my hand phone with me and I started to google more information regarding this issues before making decisions. Once I'm sure with the "hukum" of organ donation, then only I register. (Line 94-96) I just typed organ donation and Islam and found many sources such as websites and articles. They also discussed other religions view on organ donation. But, as usual for other matters as well, I always go to the relevant website to read more. I don't really prefer reading articles or newspaper. It is an easy access medium by just going into the relevant websites. (Line 112-116)	Commentary memo: He attended an organ donation talk conducted at his workplace. That was the time were he decided to register as an OD as was very much influence by the speaker on that day. The speaker has touch his feelings and moves him to register. From the talk, he knew that all this while he was wrong to think that Islam prohibits OD. What changes his mind was that when he heard the speaker said that Islam allow OD. A video was shared during the talk, which has emotionally touched his heart, it is about an organ receivers sharing about how receiving an organ has change their life. It has inspire him to register too. What the participant is saying is that, while he was still in the talk, he uses his mobile phone to do extra searching on the internet about organ donation. He googled about Islamic views on organ donation as it's important for him to know and be certain about the 'hukum' of donating organ in Islam. The key point here is that, when he searching for more information on the internet, the main keywords were organ donation and Islam. On the result page appeared, his first preference for further reading were from relevant websites such Jakim, Jom Ikrar, and NTRC. This is supported in line 122-123. Even, during the talk itself, I think he was very much	Certainty and confidence with the information gain about organ donation. These feelings include; confidence with the authorized body, confidence with online resources, and confidence with information shared by religious body.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence with the organ donation governing body • Confidence in trusted online resources • Confidence in official religious body online resources

Meaning units Transcript 7	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think it was Jakim website and I think I also read a little bit from the 'Jom Ikrar, derma organ' website. (Line 122-123) I have never notice any advertisement. But, sometimes I think I saw this issue being discuss in a talk show on television. (Line 278-279)	influenced by it because the speaker was a representative from the NTRC (Line 134). So, to me, conducting talk or a seminar like, is a good platform to share information about organ donation. It is good to create awareness and makes people in the know about the need or an organ donor.		
It touches my heart seeing the number of patient waiting for a donor and the number of patient that die every single day waiting for an organ. I don't remember the figure exactly, but I was really shocked to hear that fact. It is alarming. (Line 45-47) The speaker also shared a video where there are a few organ receivers who share their experiences on how organ donation has save their lives. That is another triggering point which stimulate me to register. (Line 59-61)	Commentary memo: The alarming figures of those waiting for an organ donor, has touch his heart. This link to point in line 35-36. He was also emotionally touched when during the talk, he saw a video of organ receivers sharing about how receiving an organ has change their life. It has inspire him to register too.	Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of frustration and regret to know the number of people waiting for an organ donor is alarming, and emotionally touched watching videos and listening to stories from organ recipient.	**Concepts:** Feelings and emotions **Categories:** Emotional responses **Codes** • Feels disturbed when listening to personal experience of the organ recipient • Feels of sadness when considering people waiting for an organ donation
Another factor that drives me stronger to decide to register was due to the fact that one organ donor can help to save eight lives. This has also really influence my decision to register. (Line 62-64) I want a light punishment from Allah, if you can let God reduce the penalties on us, hopefully with good practices such as organ donation can help reduce the punishment. (Line 84-86)	Commentary memo: He was also moved by the fact that when you become an organ donor, you are not only saving a person, instead you could be saving the life of 8 persons. This charitable work will benefit him in the long term as he thinks he will continuously be rewarded. He foresees the reward would be in a form where he will be lightly punish.	Personal views and satisfaction of benefitting others.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Fulfilment of improving quality of life of others

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Meaning units Transcript 7	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
There is one quote from our beloved prophet Muhamad stating that "whoever help others will be granted help from Allah in the life hereafter. When we die, there are only three things that we bring with us which are ongoing charity, science/knowledge left for others to use, and a good child. So registering as an organ donor is one of the act of continuous charity because the organ that we give to others bring a whole lot of benefits to its receiver. (Line 73-78) In the life hereafter, I want a light punishment from Allah, if you can let God reduce the penalties on us, hopefully with good practices such as organ donation can help reduce the punishment. (Line 84-86) Religion is also one of the factor. But Islam's stance is crucial, as I just have to be certain if it's ok to go on with my decision to register. If Islam don't permit it then I won't do it. (Line 103-105) Talking about organ donation, I think it's the norms where we have to respect the deceased body. This also I relate to religious belief. (Line 217-218)	Commentary memo: He is a person who is a strong believer of his religion. His decision to register was very much influence by his religious belief that when a Muslim die, you only bring three things with you which are: ongoing charity, knowledge left for others to utilise, and a good child. Thus, his beliefs that donating organ is a form of continuous charity. This point link to point in line 73-78. Through donating organ, it becomes the long term charitable work where he thinks he will continuously be rewarded. He foresees the reward would be in a form where he will be lightly punish. There are many other drivers that has somehow moves him to register, by his religious stand is most crucial, it is the key to his registration decision. If Islam does not permit organ donation, he would not register as an organ donor. These two concepts are used interchangeably. But, I would say religious belief often shaped a the culture of a community.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Certain that action does not violate religion • Belief that religion teaches donation as a form of charity work even after death. • Belief that their afterlife journey is less burden, with lighter punishment if they donate organ
before this we all have thoughts that it is not ok to harm a deceased body, we have this belief that any invasive process would harm our dead body and this will only tortured the dead person's body.(Line 204-207) I think it's because we were brought up with this way of thinking. It's embedded within us. I think majority of	Commentary memo: Cultural beliefs has also shaped up this family. Similar to all previous participants. The taboo that it would hurt the dead body is strong in the family. Even the participant himself belief that before this. Usually people in a community stick to the stigmas that often go unsaid in a community. We comply to		

Meaning units Transcript 7	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Malaysian have this stigma in their mind. The same goes to me, before this I believed that all deceased body will feel hurt and tortured. I heard this every time I attended a funeral so I believed it back then too. I guess it's the norms in the society where we look at something the same way. We don't often disagree. Talking about organ donation, I think it's the norms where we have to respect the deceased body. This also I relate to religious belief. (Line 212-218) The other day I saw on news on the television that where reporting about the accident involving a group of young cyclist who were hit by a car. Right now the all the parents involved are still discussing about whether or not they would want to continue with a post-mortem. Their main concern is that whether or not the procedure would only torture the body. (Line 225-229) Well, I think it's not clearly written in the Quran, but it's the practice, whenever there is death, the people from the mosque would clean the remain gently. I think it's more of showing respect to the deceased body. (Line 238-240)	the norms. These two concepts are used interchangeably. But, I would say religious belief often shaped a the culture of a community.		
I decided on my own. No one influence my decision at that point of time when I was deciding it. (Line 157-158) I just have hope that my family would just respect my decision. I also hope that one day the policy would change where the family don't have the right to stop. (Line 167-168)	Commentary memo: He beliefs in his right to make his own decision. He beliefs in practicing his autonomy. In making the registration decision he did not consult anyone before reaching to the final decision. He expects that his family will respect his decision.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

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Meaning units Transcript 7	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I just assumed that my mother especially, she would not agree for me to donate any part of me to anyone else after death. I think she totally cannot accept it. I can surely say that everyone in her family, her siblings, they are all against organ donation. So I did not straight talk to her about this. When the time comes and I told her that I have registered myself as an organ donor, I remember she said to me "Why are you doing this? You cannot wait any longer to die? Are you ready to die?" From that point, I understand that she is the person who is against my decision.(Line 176-183) My dad and all my sisters and brother they are OK with my decision to register as an organ donor. The leave it up to me as they always respect my decision. The only problem is my mom. But, I don't worry that much as my dad's agree with my decision. I think whenever needed, I think my dad will be able to talk over with my mom. I think she won't be able to change my decision and if the time comes and I were to die first, I think my mom won't be able to influence the hospital from removing my organ. For as long as my dad is still around and he will be able to control her. (Line 190-197) I just ignore her and I go on with my decision to be a registered organ donor. In the family and among friends I am well known as a stubborn person, and it is very difficult for others to influence me in any decision making that takes place and it is not easy to make me change my mind after I made any decision. (Line 256-259)	Family communication did not take place prior to registration. Nor, it did not happen immediately after he registered. He waited for the right time to communicate about his registration with his family. This link to point 169-171, where he mentioned he wanted to talk to the family, especially his mother at a suitable for example if there were a suitable advertisement on TV of if they might cross about it in the newspaper. Then, he would use that point to open up the topic. But, he could remember that his mother were really upset about the news and she is still against his decision. His dad and siblings were OK and accepted his donation registration decision. This makes him feel confident that the father's role has more authority in the final say of any issues in the family. Again, this link to the factor of a prominent figure role. He thinks that his father should be able to talk to his mother about this matter.		
No, I stop talking to her about organ donation after the first attempt talking to her about it and hearing her negative response. I think I should just wait for a more suitable time, like for example if we came across organ donation issues in	The participant chose not to continue persuading his mother about his organ donation registration. As, he don't want to get into argument and end up listening to negative comments from his mother.		

Meaning units Transcript 7	**Initial ideas** **(i.e. the issue which dominates the unit)**	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
the newspaper or television. (Line 269-271) When I inform her, all she said was 'it is up to you' but by the look on her face, it is so obvious she gave me an unhappy face. But whoever knows me, would have known that I don't care, as I am very stubborn. I would not change my mind. (Line 294-296)			
I don't worry that much as my dad's agree with my decision. I think whenever needed, I think my dad will be able to talk over with my mom. I think she won't be able to change my decision and if the time comes and I were to die first, I think my mom won't be able to influence the hospital from removing my organ. For as long as my dad is still around and he will be able to control her. (Line 192-197)	Commentary memo: He feels confident that the father's role has more authority in the final say of any issues in the family. Again, this link to the factor of a prominent figure role. He thinks that his father should be able to talk to his mother about this matter.	The powerful influence of a prominent figure in the family. If there is supports from either one of the parents, the registrant feels right with the decision made.	**Concepts:** External influence **Categories:** Respected individuals **Codes:** • Mother or father as the leading role or the decision maker in the family

Appendix O

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 8

Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
when I did some reading I was actually reading on the halal and haram law on organ donation. (Line 76-77) I needed time as I need to search for more information particularly on the religious view about organ donation. (Line 86-87) I did some reading around what does my religion says about about organ donation. I wanted to know more if it's permissible (Line 116-117) religion is an important factor to me. I want to be sure what religion says about organ donation. I wanted to know if it's permissible. After knowing that Islam permits organ donation it somehow gives me certainty and assurance that I am doing the right thing that is in line with my religious belief. This give me strength in making the decision to go and sign up myself as a registered organ donor. I became more confident after the talk in my workplace as the speaker also discuss about religious stand (Line 175-181)	Is organ donation allowed? Does Islamic law permit donation? Commentary Memo: The most important factor of registration decision is whether or not Islam permits OD. If it does not, then registration will not take place. Again, in this meaning unit the role of religion is expressed. The co-researcher is telling us that he was stimulated to think about organ donation when he was warded and he worry if he might need an organ one day. But he needed to explore the issue more as he had questions (uncertainty) about whether it was permissible from a religious perspective. What Islam allows is important to this participant and he would not register to be an organ donor if Islam prohibited donation. Reflexive commentary: It appears that he is a strong believer to his faith and he registered as he was certain that it is allowable.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Being certain that action does not violate religion
It all started when I was warded, I had to undergo a surgery, after the surgery when I had been transferred to the ward, I suddenly thought what if at that point of time there were no one who came forward to donate, or not enough blood supply in the blood bank, I would have die. So, that was the time that I started to think about donation. (Line 35-39)	Triggering event stimulated registration. What if there were no donor? Commentary Memo: In this meaning unit the participant suggests that there was a triggering event in her life. What triggered the intention to donate was that, the fact that he was worried if during the surgical procedure there were no enough blood, or if he needed an organ, there were no one volunteering to donate.	The key emotion that has driven him was his fear of not being able to find an organ donor if he needed one in the future.	**Concepts:** Feelings and emotions **Categories:** Fear for self and those close **Codes** • What if one day I need a donor?

Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
	Reflexive commentary: It appears that only when he had direct experience of medical need which was blood, this has made him thinking or what if one day he needed an organ but there were no donor. This has stimulated him to register.		
It is some sort of satisfaction. It felt like I was able to contribute something to the public or someone out there you know. I may not know who, obviously I would not know I guess, but I felt satisfaction knowing that my organ can still be useful for someone else after I am not around. (Line 197-200) So what's wrong with donating, rather than wasting it, let's just give our organs to those in need. (Line 478-479)	Satisfaction of helping others. Commentary Memo: He felt happy after registration as he feels satisfied as he knows he is able to help other people in the future. He doesn't like wasting something that can be utilized by someone else, as he feels satisfied helping others. Reflexive commentary: He talks about satisfaction for being able to gives something to others. Thus, the feeling of satisfaction after being able to contribute is a driver to registering as donor.	An individual's belief system is informed by personal views about the importance of sharing and giving as part of contributing to society. As well as when a person has a sense of humanity.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others
After reading around it, I began to feel more eager to pledge. Plus, thru that reading process, I came to know there are some artiste who had either donated or had pledged. (Line 40-42) there were a representative from National Transplant who came over to my office and started giving a talk about organ donation. Immediately after the talk, I straight away go and register myself as a potential organ donor. But I would not exactly say that I was really motivated to register because of the talk, as to me the talk held by the National Transplant were just a channel for me to register, because before attending the talk, I was already highly motivated after I had	The information searching behavior. The influence of information gained. Commentary Memo: After having the intention to be an organ donor, he did not immediately sign up as he do not how and where to do. Only when he attended a talk at his workplace, he straight away register as there were booth that allow people to sign up. The gap between having the intention and attending the talk, he did some online searching, and online resources plays a significant role in providing the necessary information as the co-	Certainty and confidence with the information gain about organ donation. These feelings include; confidence with random online resources like blogs.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence with the talk, seminar, or booth set up by governing body • Confidence in trusted online resources

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Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
the surgery. The only problem after the surgery was just that I don't know how to register and I don't have the effort to go to the National Transplant to register. But, when I attended the talk I felt like, it's a waste if I did not just proceed with registration now since the representative from the National Transplant was already right in front of eyes. So I just decided to register after the talk. (Line 44-55) it was solely because at that time I do not know how or where to go to register. (Line 66-67) when I did some reading I was actually reading on the halal and haram law on organ donation. Then I was also interested to know more about how they do it, so I start reading around it. (Line 76-78) I was actually referring to the way they perform the surgery at the time the health care personnel were removing the organ from deceased body. I was also interested to know how they put it back together after the removal of organ. I was really worry about it maybe because my mom has put it in my head/mind, that organ removal for donation is painful and the healthcare personnel will do it carelessly as they would not bother to sew together the remains neatly. (Line 95-100) I think I read about the organ removal procedure from blogs. Yes, I think it was a blog. I don't directly go to the National Transplant website. I was just googling and I read whatever comes up on the first page option. (Line 107-109) I did some reading around what does my religion says about about organ donation. I wanted to know more if it's permissible. So I went into religious website and again I read blogs from religious man. Additionally, I also watch	researcher only refer to the websites for additional information. It's important for him to gain information; first the religious fatwa, then followed with information on the benefit of registration, how surgery is performed, and how the dead body is handle after the removal process. Reading on his own about the information that he was interested to know more did somehow increase his level of assurance of the removal process. He understands how dead body is handle and this has somehow eliminated the taboo or misconception in his mind but not in total. He did not read from any specific websites. But more whatever that hit the top list after he googled. He remembers he has been reading from blogs. Reading from a reliable or trusted source is not a main concern for her in the information searching process. Reflexive commentary: He talks about the influence of an online resource which are not from an authorized body. He trusted grey materials like blogs. All this information was important to him as he need to be sure that he has been listening from his mother is not right. The taboo in the society has somehow shaped the way his mother thinks which has indirectly influence the rest of the family member as well.		• Confidence in official religious body online resources

Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
video on YouTube to see others opinion on organ donation particularly from the point of view of pious man. (Line 116-120) When I read it, I do not really read in detail, just glance through whatever reading materials that I came across. Until I attended a program held in my office. There were an event which they invited the National Transplant Centre from Kuala Lumpur to give a talk in promoting organ donation. From that talk, then only I became very sure of the processes involved in the removal of organ and I was certain of how our body will be handle after removal of organ. (Line 128-134) There were no specific website. All i did was just type the keyword on Google. As far as I can remember there were no specific website. I just read anything that I came across. (Line 154-156) but i think it was from a blog. I do not go reading journal articles as that is really academic I would say. That is so not me. But, honestly i do not specifically search on any particular websites, I just search in Google. When i was googling, I will just read whatever appeared on the first page of the search result. Maybe there are websites like JAKIM or goverment link websites like the National Transplant, i would just go through once to read whatever is there. (Line 163-168)			
there were no one who had the capacity to influence me when I was making the decision. Only after that, after pledging, then only I told my wife and my mother about my	When does family communication take place? Has family communication influence donation decision?	Feeling of autonomy in making the registration decision. This include	**Concepts:** Belief and attitude **Categories:**

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Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
registration decision. (Line 207-209) Well, after I signed up, on the same day, I go back home and I told my wife about it. I told her that I had pledge as an organ donor. Not long after that, when I go back to my hometown to visit my mom, then I also told her of my action. (Line 216-218) actually before telling her at home about my decision of registering, I had texted her immediately after registration, which I was still in the office at that time. In the very first instant, she immediately shows his disagreement. She even said that when the time comes, which means when I die, she will not allow the hospital to go on removing my organ for donation. To be honest, from reading the text messages that she replied, I think she was angry. (Line 224-229) I just ignore her comments. I just let go of the topic and did not bring it up again. I just keep quiet.(Line 235-236) ! This is another big problem. She was really angry when I told her that I have actually registered myself as an organ donor. Like really angry with me. She said I ignore her and make my own decisions without consulting her opinion first. She says I ignore her. (Line 262-265) My mother was angry I think because she is worry, or I guess she was afraid if my dead body will be badly managed. (Line 271-272) I think my mother was afraid, after the procedure for removing my organs from my body, the doctors might just you know, did not sew my body back to its best condition.	Commentary Memo: Family communication only takes place for the sake of informing his family member after he registered, not to get their consent before registration. **B**oth the wife and mother objected his registration decision. His wife disagrees, and even the mother was really mad with his decision. His mother thinks that he was rude as he did not even ask for her opinion before registering. To him walking away and to remain silent as well as not bringing up the topic again is the best solution. As he does not want to get into argument with both his wife and mother. Presumably, this is normal among male as usually they walk away from problem. Compare to women, we tend to try to explain again and again until the registration decision is accepted. Walking away is not a good thing since, family member can stop the donation from taking place. Reflexive commentary: His communication with family were solely to inform of registration decision. Since, both his wife and mother disagree with his registration decision, he never bring up the topic again.	the feeling where family will not object the decision made	Autonomy **Codes** Belief in individual autonomy

Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
She is worry if I would not look the same physically. (Line 279-281) She worried if during the removal process, they did not handle my body gently which then I will be in pain and after that, they did not sew my body back to the normal physical look. I guess it is both. (Line 288-290) No. after the first time that I told them of my decision, I would never again try to talk to my wife or my mother about this. I just choose not to discuss or prolong this topic with them because I'm afraid I will be scolded again. (Line 304-306) I remembered telling them that I just signed up myself as an organ donor, I told them that I have checked and read that our religion has no objection of this matter and even it is encouraging to help others in need. I also explained to them that I have read about the removal procedure where I am sure and I know that my dead body will be handle gently. They will not manage remains roughly. But after all the explanation, like I said earlier, my mom was the most difficult person to talk to if I were to compare to my wife, she obviously disagrees like I said earlier. So I stopped explaining. I just keep silent after that. (Line 334-341) she's still with her old beliefs, she is an old lady, the way she think I do thing is still very much old-fashion. It's like a taboo passed on from generation to generation. I think you yourself must have heard others saying, particularly those of older generation, they said that when we die, our body will still feel the pain and that why before the burial service, which is during the cleansing of the dead body, it need to be done slowly and gently so that they deceased would not feel hurt. (Line 376-382)			

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Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
she still thought that dead body would not be handle with care after removal organ. The doctors would not do it gently since it's a dead body so why would they care. So, she think the doctor would not do it properly. Because that was what she said when I informed her. She repeat it a few thing. I think that was what bothering her very much. She worry if my dead body will be in pain as well. (Line 391-396)			
But I would not exactly say that I was really motivated to register because of the talk, as to me the talk held by the National Transplant were just a channel for me to register, because before attending the talk, I was already highly motivated after I had the surgery. (Line 47-50) But, when I attended the talk I felt like, it's a waste if I did not just proceed with registration now since the representative from the National Transplant was already right in front of eyes. So I just decided to register after the talk. (Line 52-55) as at the same time they had a booth set up, which allow people to register straight away. So that makes it easier since I dont have to do it online or go to other places to register. (line 182-184)	How to register? Where do you register? Commentary Memo: There was no information available or at least easily art for him to find out about the place or medium of registration. Until one day he attended organ donation talk in his workplace. So, since at the talk there were representative from NTRC who open a booth that allow people to register organ donation intention. He decided to register as this has ease the registration process. Reflexive commentary: Ease of the registration process has also drives her to register. As he do not have to put extra effort to go elsewhere to register.	An individual preference, where he don't want to feel troublesome having to search about the platform of registering. So, he takes the advantage that he feels has ease his registration process.	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes** • Knowledge of the process involved in registration
After reading around it, I began to feel more eager to pledge. Plus, thru that reading process, I came to know there are some artiste who had either donated or had	Who else did it? Commentary Memo:	An individual feeling of similar to someone that he adores or referred	**Concepts:** External influence **Categories:**

Meaning units Transcript 8	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
pledged. (Line 40-42) So I went into religious website and again I read blogs from religious man. Additionally, I also watch video on YouTube to see others opinion on organ donation particularly from the point of view of pious man. (Line 116-120)	A well-known person has catch his attention about registering as an organ donor. Besides, a respectable person in his religion also has influence him. Reflexive commentary: A famous person also has somehow makes her wanted to do it.	to. He feels that his decision is in line with a trustable character.	Valued social networks **Codes:** • Favorite artist • Well-known religious person

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MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 9

Meaning units Transcript 9	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I remember that when I decided to register, all I had in mind was because I wanted to help others after my death. (Line 34-35) Yes. At the same time, when I help others, I will be able to give new life for others. They can have a second chance to live longer with improve quality of life. The person could contribute to his family, contribute to the society. Even the children won't be losing someone they love, someone they need. (Line 41-44) There were a request from WhatsApp group to test blood that match with one of leukaemia patient. This patient is someone that I know, a long-distance relative. So, I wanted to help. Then I went to the hospital, for that, to donate blood. Coincidently, someone there explain to me about organ donation too while I was in the hospital for blood testing. You know being me, I don't see a problem about it, why not? All I wanted to do is help for as much as I can. So, I accept it immediately. (Line 51-57) After making the decision to register as an organ donor, I just wondered have I make the right decision. But then after some time I just think and tell myself that I am doing this because I want to help others. (Line 129-131) I will be able to give new life for others. They can have a second chance to live longer with improve quality of life.	Commentary memo: PERSONAL CHARACTERISTICS: Helping others He is a good person with a good attitude as in his heart I wanted to help other people. It's his personal characteristic, something that is within himself wanting to contribute and benefiting others and society. As the participant continue saying in line 41-44, 51-57, 292-295 helping other thru donating organs, he is able to let sick people to live longer. Thus, from there the receiver will be able to continue contributing to the family and society. That the satisfaction for the participant as well, contribution to the society. Additionally, he also registered as deep down his heart he do not want small children to lose a mother or a father, someone they love. He feels sad, emotional, thinking about it. Link to line 43-44, 93-94. This is key, the availability of information, this was a key event in the registration process to become an organ donor for him. The participant is someone with good characteristic who likes helping others, so when being approach by a representative from NTRC, he easily decided to sign up after listening to some explanation that could capture his heart and emotion.	An individual's belief system is informed by personal views about the importance of helping others as part of lifelong charity as the receivers' could improve their quality of life. There is a sense humanity embedded within him as a person as he expressed willingness to donate was also influence by the fact that the receiver could benefit the community as a whole.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others • Sense of responsibility towards public, and fulfilment of benefitting the society as a whole

Meaning units Transcript 9	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
The person could contribute to his family, contribute to the society. (Line 41-43) Whatever that I am doing right now is for the benefit of the society. I am giving back to the people. Whoever receive my organs after my death is benefiting from my decision today. Look at it as for the advantage of the community as a whole. (Line 292-295)	Commentary memo: PERSONAL CHARACTERISTICS: Benefit to others and society Something that is within himself wanting to contribute and benefiting others and society.		
Even the children won't be losing someone they love, someone they need. (Line 43-44) At that time it was more feeling empathy for sick people and I just want to help. (Line 93-94)	Commentary memo: He also registered as deep down his heart he do not want small children to lose a mother or a father, someone they love. He feels sad, emotional, thinking about it..	Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of sad knowing that there will be children losing their parents, and emotionally touched looking at sick people.	**Concepts:** Feelings and Emotions **Categories:** Emotional responses **Codes** • Feels of sadness when considering people waiting for an organ donation
I went to the hospital, for that, to donate blood. Coincidently, someone there explain to me about organ donation too while I was in the hospital for blood testing. (Line 53-55) The person promoting it, I think they were someone from an authorize department of the Ministry. They had a booth there in the hospital. The person promoting it, she explained to me what is organ donation, what your right is after registering, what they will do to you when removal of organ, and what sort of organ they will take from you. (Line 80-84)	Commentary memo: This is key, the availability of information, this was a key event in the registration process to become an organ donor for him. The sort of information shared might have influence his decision as well as the representative explained to him about OD, his right after registering, the surgical removal process, and they organs that can be remove from dead body. As he continues saying, he immediately made his decision to register and he don't need more time to research about organ donation as I think because the information provided were sufficient. Plus, the representative at the booth	The availability of information from authorize body is key driver towards registration. The information shared such as about registrants' right after registration, types of organ that can be donated, organ removal process, and religious view has influence him to straight away register.	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes** • Knowledge of the need for different organs • Knowledge of the donation and transplantation process

Meaning units Transcript 9	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
As for me it was an immediate decision. At that time I just made my decision straight away. I don't feel like I need to do some thinking or do any further research. (Line 91-93)	were from an authorize body, NTRC. When ask what makes him certain about it, he said that he has doubt with NTRC as an authorized body, thus he belief with the information shared by NTRC.		
Yes. I trusted them as they were a representative, like a booth, and yeah its from an authorize body. So I did not hesitate at all. (Line 109-110)			**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** Confidence with the talk, seminar, or booth set up by governing body
Well at that time the people at the booth did explained too about religion perspective. So, I was make known of my religion's stance. I have no doubt about it after listening to them. (Line 100-102) Yes. I trusted them as they were a representative form an authorize body. So I did not hesitate at all. (Line 109-110) Well there were many information that they shared with me. But I would say the point when they were explaining to me about religion has influence me the most. Since my religion allow its believer to donate organ after death, so I confidently register. If the promoter was not able to assure me on this, then I think I would need some time to make certain about my religion's stance. I don't want to do something that is wrong. (Line 117-122)	Commentary memo: He was rest assured that his religious belief is not against organ donation. Because of his certainty on this matter he straight away made the decision to register as an organ donor. To him religion was the key factor that make him continue with registration. If Islam does not permit OD then he would not register. He just do not want to do something that is wrong from his religious view.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Certain that action does not violate religion

Meaning units Transcript 9	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think it might be that they have this imagination that all my organs will be remove from my body and that process of removal will only hurt me although I am dead. (Line 228-229) Because the people in our community, they believe that even though the person is dead, but still the spirit can still feel like the human feels. If we feel hurt or not comfortable after surgery, the same goes to the dead body. (Line 238-240) Yes, it is the cultural factor. It's like a taboo that most races like Malay in Indian, we believe in all sort of taboos. Plus, our society we easily trust someone and when we have high level of trust usually we highly respect this someone and whatever he or she said we just believe it without thinking or considering if what was said is right or wrong. (Line 246-250)	In general, this participant express the same view experienced by his family members, and it is similar to other previous participant. He thinks that his parents will not accept his registration decision as they worry if it might hurt the deceased body. His parents' way of thinking is very much influence by the taboo/misconception in the society. Most people be it Malay, Chinese or Indian believes that even the dead person can still feel whats going to his or her body even after death.		
Sort of. We like to comply with the community expectation. We worry a lot of what others think of us, and we are always afraid to do something different then what the majority believes in. Even though we do not know if what we believe in is right or wrong. It's just a taboo in the community. One more thing, we always listen to our grandparents, or even great grandparents, we just accept whatever the ancestors believe. We hear things and hear all the believes of older generation without finding out the truth. This sort of things in our community has influence in our daily life, the way we do things that we do, the way we think and make decision. This is the effect to our society as our old man has trained us to just follow our previous generation way of life. (Line 257-266)	Again, religion is key factor of whether or not registration will take place.		

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Meaning units Transcript 9	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I can surely say that the most important factor is religion. If it is not permissible. Then I surely will not proceed. (Line 282-283)			
I hope that in return, if one day any of my children needed an organ donor, there will be someone volunteering. (Line 131-132)	Commentary memo: He has fear of the uncertainty if one day if he were in need of an organ donor be it for himself or his children, but there are non-available. Thus, he somehow feel good that once he become a registered organ donor, he is hopeful that when he needed one, there will be a volunteer or a donor.	Expectation of getting something in return if one day he or she would need an organ donor. Need to overcome the fear if one day will be in need for one.	**Concepts:** Feelings and emotions **Categories:** Fear for self and those close **Codes** What if one day my children, parents, and siblings need a donor?
I did not tell anyone after my registration decision. I was not ready. It took me sometimes to tell them about it and the first person that I told was my wife. (Line 158-159) Of course as what I expected. She did not agree at all. Obviously, she was angry with my decision. We did not talk for a few days. (Line 165-166) I don't really know for sure why she disagree with my decision. She did not say it clearly why I can't donate. After that I don't dare to open up about this issue again with her. I don't want to get into a fight. (Line 172-174) I try explaining to her based on religious perspective which it is allowable and it is also a good deed because we give hope to others to live their life longer and healthier. I also try to persuade her, I think I beg her to accept this decision because if she refuse, the team in the hospital can stop to take organ from me. (Line 180-183)	Commentary memo: It takes him sometimes to decide to discuss his registration decision with his spouse and family. He did not straight away inform them as he presume that all his family member would not accept his decision. But, later he did inform his wife and as expected his wife was agree. They get into argument, and since that they never discuss about it anymore. From there onwards, he also decided not to share his registration decision with his parents as he think that it will lead to another argument, just like what happen between him and his wife. Plus, he thinks that it is his right to decide what to do with his body. It's his right to make the decision. AUTONOMY.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

Meaning units Transcript 9	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Yes, she knows that she has that right. That's why I beg her to accept my decision as I don't want her to stop the removal of organ when the time comes. I told her to respect my last request. (Line 190-192) I have made up my mind. It is my personal life, I have the right to decide. Why give it to other people to decide? (Line 199-200) No, I did not tell them. As I think once we are married. We only discuss things or any other arising matter with our partner and no longer to our parents. (Line 209-210) Yes, it is the same issue. It's all because I am quite sure they will not allow me to go on with my intention to donate organs after I die. I can imagine if I told my parents, they will start ask me so many questions which will then make me feel very uncomfortable. Personally, I think that I am old enough to make my own decision. After all it's my life, my body that we are talking about. (Line 217-221)	This is the main problem; family members are aware that they can stop the removal process when the time come. So, it is important for the NTRC or the Ministry of Health to do something to address this.		

Appendix O

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 10

Meaning units Transcript 10	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think it was from my reading. I am not so sure. I think I read somewhere and I know that the rate of organ donors in Malaysia is very few. So, knowing that the number of organ donors very low, I felt like I just need to help. I would say that I do it as part of my social responsibility. (Line 34-37) If I can recall, it was just a general discussion with friends, with my classmates actually. One of my friend brought up this issue and we start talking about it. We also go on discussing this with our lecturer and asking for their opinion. In few occasion of the discussion, the main focus was more about digging information about religious fatwa on organ donation. Then, I also do a lot of internet searching. (Line 83-88) Basically my discussion and my information searching activities were focused around the ruling or fatwa with regards to organ donation in Islam. I read a lot on why Muslim have no interest in organ donation. I was a bit interested to know more on how we as the Muslim sister should be promoting organ donation to Malaysia. (Line 127-129) Well I think since religion's stance is most important in deciding if I should proceed with registration decision, so I browse on websites particularly JAKIM websites. I was actually looking for articles or any write up on the website with regards to fatwa that covers about organ donation. I seriously want to know more particularly of whether or not organ donation is Sharia compliance. (Line 136-140)	Commentary memo: Reading around organ donation has triggered her to become a registered organ donor. The one information that stimulate her was the fact that the number of organ donor is very low in Malaysia if compared to the number of people in the waiting list who is waiting for an organ donor. In the university days, exchange of information among peers has trigger her intention of wanting to know more about organ donation. The discussion with her friends were surrounded around the topic of religion. She started talking about organ donation with her lecturer too about religious view on OD. In the process of information searching, other that discussion with her lecturer and friends, she also did a lot of googling on the internet. I assumed she wanted to be certain with all the information that she gets thus she went online to confirm it. Other than the communication with her lecturer about Islamic perspective on organ donation, she did a lot of information searched using the internet too. In line 136 - 139, she mentioned the use of JAKIM website in her searching process. Which means, other looking up at a prominent character, she utilised a reliable and trustable website to know more about organ donation. Above all, she need to certain that organ donation is Syariah Compliance.	Certainty and confidence with the information gain about organ donation. These feelings include; Confidence with information share through discussion with friends and lecturers, confidence with random online resources like blogs.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes:** • Confidence with information shared by friends. • Confidence in trusted online resources • Confidence in official religious body online resources

Meaning units Transcript 10	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
So, knowing that the number of organ donors very low, I felt like I just need to help. I would say that I do it as part of my social responsibility. (Line 35-37) All that I can think right now on the reason of registering was only because I just wanted to help. Because my religion taught me to be good n help others. (Line 50-52) For as long as I had good intention, I wanted to help others to live longer, I am happy. I just want other people to have the second chance to live when I am not able to get that chance. (Line 186-188)	Commentary memo: The fact that the number of organ donor is very low in Malaysia if compared to the number of people in the waiting list has made her felt that it is her responsibility to help other people by offering help to those in need. She wants to do good thing in life by helping others in need.	An individual's belief system is informed by personal views and religious view about the importance of helping other people. She was also influence by the thought of carrying out her social responsibilities.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others • Sense of responsibility towards public, and fulfilment of benefitting the society as a whole • Fulfilment of improving quality of life of others
Our religion, Islam promotes all Muslims to do good and benefit others too. I see that donating organ as one of the good deeds. (Line 37-39) Who knows, the person who survive and continue living with my organ, is someone who is beneficial to the community. I will be grateful to know that. As if as I am not only saving a person's life, but I am also contributing to the community. I am making his or her family happy, and in return the person is also doing some good stuff in the community, maybe he is a teacher, a volunteer, or whatever. So,I think it's a double reward for me. (Line189-194)	Commentary memo: Other than believes in helping others, she believes in doing good thing to do good to others and to benefit not only herself but others as well. She looks forward to gain the benefit for herself after donating her organ to sick people when she die. Other that being rewarded with pahala donating organ itself, she sees it will benefit her with pahala when the receiver do good thing for the community. That is double reward for her. This would ease her life in the hereafter. This links to point in line 200-206.	Personal views and satisfaction of benefitting others. This believe is very much influence by her religious teaching.	

Meaning units Transcript 10	Initial ideas (i.e. the issue which dominates the unit)	Meaning unit transformed into psychological language	Concepts, Categories, and Codes
Our religion, Islam promotes all Muslims to do good and benefit others too. I see that donating organ as one of the good deeds. (Line 37-39) we Muslims hold on to one of the Prophet hood tradition which is to benefit others regardless of their background and differences. There is also a hadith that says: "The best of you is to benefit of others" (Line 41-44) All that I can think right now on the reason of registering was only because I just wanted to help. Because my religion taught me to be good n help others. (Line 50-52) Yes, of course. As a Muslim, before we make any decision on any matter, be it small or big matter, the decision must be made base on religious ruling. We hold on to religious fatwa and hadith. We do not want to do anything that does not comply with our religious belief. (Line 95-98) Religion is the first priority, then helping others would just follow through. (Line 116-117) I seriously want to know more particularly of whether or not organ donation is Sharia compliance. If it is not, as a good Muslim, obviously me or you, we would not proceed. You know we do not want to do something that God does not grant us to do. We just don't want to be sinful. Like stealing, god forbid it, so a good and a religious person would not commit that wrong doing. We only do something that is religiously and morally accepted. (Line 139-144) Who knows, the person who survive and continue living	Commentary memo: She also holds on to her religious teaching where her religion and her Prophet teach her to do good to others. How? To do good to others is by helping and benefitting them in any way that we could. This link with Muslim's belief system where Muslims belief that if we always do good and benefit others, Allah will help simplify our daily affairs. Thus, doing good, helping others, and benefiting others link to religion's teaching. Above all the other factors that she mentioned earlier that has driven her into registering, her religious stance is the key factor of whether registration will take place or not. This is the same with all other participants interviewed earlier. Link to line 116, 136-139.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Being certain that action does not violate religion • Benefit for our self (double reward of pahala) when the receiver contributes to the society • Belief that their afterlife journey is less burden, with lighter punishment if they donate organ

Meaning units Transcript 10	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
with my organ, is someone who is beneficial to the community. I will be grateful to know that. As if as I am not only saving a person's life, but I am also contributing to the community. I am making his or her family happy, and in return the person is also doing some good stuff in the community, maybe he is a teacher, a volunteer, or whatever. So, I think it's a double reward for me. (Line 189-194) First, I will be rewarded by God for donating my organ to someone. For the second reward, I look at it this way, when the receiver do good in his or her community, God will reward him and I feel that God will also reward me. That's double reward. I will be happy to be getting a lot of reward even after I am dead. You know how it feels, when you are not doing anything anymore in this world, but you are still reaping the reward. Can you imagine how it would ease my life in the hereafter? Who would not want that? (Line 200-206) If I can recall properly, at the time when I was about to decide, I was scared, scared of the process, would it hurt your body. You know those kind of sceptical thinking. But I guess I just overcome that feeling by saying to myself, oh this is OK. You would not feel anything when you are dead. You know those kind of thing. You are no longer breathing, how can you feel the pain? (Line 150-154) very much influence by the culture within the society they lived in. I think generally that is the case for us in Malaysia. We worry so much of what other people say about us. We are busy worrying about things that are not significant as what people are talking about us. We are afraid to do things that other people never do. Because we are afraid of others	Commentary memo: She first had misconception about organ donation, she thinks it would hurt her dead body and what not. But after further reading and talking to other knowledgeable people, her perception about it changed. This is normal in the society. The cultural influence has very much shape the way individual think and accept thing. We worry too much of what others think of us, and we try to comply as much as possible with the norms in the society. So , we chose not to talk about it and not to do it.		

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Meaning units Transcript 10	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
insulting us. I think the situation became such because of the lack of exposure regarding organ donation. People do not know, so this has cause people having little understand with regards to this topic. (Line 279-285)			
We also go on discussing this with our lecturer and asking for their opinion. In few occasion of the discussion, the main focus was more about digging information about religious fatwa on organ donation (Line 84-87) I was certain about it after discussion with my lecturer. What's important to me was that he was able to give evidence of a dalil. He was elaborating on a Hadith Riwayat by Ibn Majah that goes like this 'la dororo wala dhiror' which means this phrase means in whatever we do, Islams is so concerned about human interest regardless of religion, race and ethnicity as well as not to cause harm and damage others. (Line 105-109)	Commentary memo: She started talking about organ donation with her lecturer and there is this one lecturer that she look up to and they have talking a lot about organ donation particularly from the point of religion. So, the role of a lecturer as a figure that she referred to play a role here. Information assurance from someone superior/knowledgeable. Having a discussion with her lecturer, she was more into finding evidence that Islam permits organ donation. The lecturer explained to her of a hadith, that says as a Muslim, whatever we do, it should be for the interest of other human being and not to cause damage or harm.	The confidence and certainty with the information gain from her lecturer who is a prominent figure.	**Concepts:** External influence **Categories:** Respected individuals **Codes:** • A teacher or a lecturer
No, I did not share with them immediately. I decided to just keep it to myself. I'm afraid they will disagree with me. That is why at the beginning I did not discuss this with them or even anybody else. As far as I can remember, I think none of my family members know about my decision to become an organ donor right after I registered. (Line 232-236)	Commentary memo: At the time after she made that registration decision, none of her family member knows of her registration decision. She did not inform any of them. She made the decision to register on her own, without the influence of her family. I presume she believes it is her right, she has the autonomy to decide on her own.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

Meaning units Transcript 10	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I actually do not want to waste time and energy to explain at length to them about organ donation. I see as a tough job as it is not a small issue where you can discuss overnight. I strongly believe, in order to make my family, especially both my parents, I will have to educate them slowly. To do that I will need to have enough information and be mentally prepare to open up the topic to them. Maybe after this, I will start by explaining the ruling about organ donation to both of my parents in respect the view of Islam. Islamic stance is the most crucial point when explaining this to elderly. Probably I can show them the JAKIM websites that explains Islam's stance on organ donation. From there, I will want to stimulate them to think about it, to look at it as something doable and it is not sinful. Once they show some positive attitude about it, then only I think I will be ready to tell them of my registration decision. I think it's better that way. (Line 244-255)	She was not ready to share the registration decision as she belief that it is not an easy job trying to explain and persuade her parents about it. In preparation to tell her parents, she educates them slowly about OD, like trying to bring in the topic when she came across something that allow her to bring up the topic. She needed more time to gather all relevant information particularly from religious point of view prior to communicating about her decision to her parents.		
Now, both my parents already know about my decision. I told them only after sometimes. If I can recall, it was not even during the first year after registration. As I mentioned earlier, I wanted to educate them first. After I believe they are already open to this idea, then I told them. Of course in the 1st place both of them disagree, but after I proved to them again that the religious body has issued a statement formally declaring it permissible in Islam, I also explained about the importance of organ donation, how it can help other to pursue life and how it will consider our good deeds till the day of judgement, both my parents looks calmer and accept my decision. They respect the decision I have taken. By the way it's a good deed. So both of them have no objection now. But now I am already married. But, I have not yet discussed about this with my husband. (Line 261-271)	When she did inform her parents about it, as expected they were angry and totally disagree with her decision. But after she explained and provided evidence that their religion allows organ donation, outlining the benefits and advantages of it, the parents seems to accept her registration decision.		

Appendix O

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 11

Meaning units Transcript 11	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I guess it just came from my heart. (Line 42) This then lead to loving to help others in need. It's just me. (Line 114) I just want to do it. This is something good. (Line 204)	Commentary memo: Care about helping other people.	The sense humanity is embedded within the person as she expressed her love to help other which comes naturally from her heart.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others
At the time when I registered myself, there were like a sport carnival and there were a few booth open for visitor to pay a visit. One of the booth were I think from the Ministry of Health which were promoting on organ donation. I read a pamphlet that they were distributing and I straight away registered myself as an organ donor. (Line 49-52) It's just a coincidence that there was an exhibition about organ donation, so I just straight away register. (Line 64-65) as I once work in the hospital premises, so I often heard about organ donation. Sometimes in hospital, I would came across booth on organ donation, and passing by those booth has actually moved me. (Line 74-76) So, when I started working in the hospital, then only I was exposed to the idea that we can donate part of us when we die. So, when I stopped at booth, it is just the medium for	Commentary memo: The availability of NTRC's booth and information. The existence of booth at a carnival is one of the driver that makes her register. At the booth the representative was sharing information about organ donation, so this stimulate her as well. She was triggered by the sad stories of sick people who are waiting for organ donor. It touches her as well knowing the alarming figure of those in the waiting list. This reaction very much relates to her character as someone who have a soft spot in her heart especially looking at needy people. This link to the fact she gets emotionally touch just by reading novel about a blind person. Her nature of work has also exposed her about organ donation. Since she work in a hospital, she has come across booth on OD.	The availability of information in public area (booth) from authorize body is key driver towards registration. The information shared such as about the number of people waiting for organ donor, and religious view has influence her to straight away register. Information goes viral on social media also play a role. Other than that advertisement and movie played on TV also has reminded her of her intention to donate organ which was originated from her hobby of reading novels.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes** • Confidence with the talk, seminar, or booth set up by governing body • Confidence with social media • Confidence in TV advertisement

Meaning units Transcript 11	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
me to register, plus the strength to register is there when the representative the booth started telling me stories about other people who is waiting in the line for a donor. Talking to you, I think it rings a bell, my intention to be an organ donor started because I read books/novel about it, then the turning point to register is when I listen to stories at the booth. (Line 88-94)			
It is just that each and every time I came across advertisement or movie, which reminded me on my intention to become an organ donor. (Line 101-103)	Advertisement and movies also has play a role in triggering her intention and indirectly to register as an organ donor.		
I think I did some reading around religion as I was curious of whether or not religion allow organ donation. In between the time that I had the intention up to the point I registered, I did a little bit of reading on this. I would not say I read a lot, but I did read articles especially those popping out through links in the FB. (Line 144-148)	Information seeking were particularly surrounded around religion only, nothing else bothers. The medium used in searching of information were mainly through the use of social media, which is FB. She rely on the links attached on the FB wall, on trusted the sources without referring to any other website of an authorised body.		
Talking about the sources of information, as far as I can remember there were no other website that I search into. Most of my reading, not most, maybe all, I read about organ donation from links that other people share in their Facebook. Usually, this links goes viral at certain period of time and people will be talking about it in that moment, if you get what I mean. It goes viral for maybe 1-2 weeks, then no one talk about it anymore. Yeah, I am pretty sure there were no specific website that I refer to other than the one I saw on Facebook. (Line 170-176)			
I guess, in general we are less exposed to such topics. When I was in school, I have never heard of this matter being discussed. Maybe when we entered college or university			

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Meaning units Transcript 11	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
then only we hear and know about this. This topic is a more foreign topic for people in rural areas. (Line 341-344)	The real scenario.		
There was an exhibition about organ donation, so I just straight away register. (Line 64-65) So, when I stopped at booth, it is just the medium for me to register, (Line 89-90) Back then it was because I felt it's easier to do it now rather that you have to search for the platform of registration. From the point of having the intention to register, I don't really know where to go to register. I don't know where the National Transplant office is or headquarter. Plus, I think I just don't put extra effort to try to search online about where or how to register. (Line 122-126)	Commentary memo: She already had the intention for quite sometimes but have never register her intention as she do not how or where to register. She does not have the effort to even learn about registration. However, when she came across a booth at a sports carnival, she thinks that it's easier to register at that time as there were representative form the Ministry. So, she don't have search about how or where to go in order to register her donation intention.	An individual preference, where he don't want to feel troublesome having to search about the platform of registering. So, he takes the advantage that he feels has ease his registration process.	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes** • Knowledge of the process involved in registration
The thing is that I personally think that I am soft hearted. Before I talked to someone at the booth, I always read novel. It often touches my heart when there is a character of a blind person in the novel. From there I started to think and have the intention to donate my cornea. (Line 85-88) I think it's more of feeling sorry and pity for those waiting for an organ donor. The concept is the same, as when I was reading the novel. I easily get emotional about sick people. This then lead to loving to help others in need. It's just me. (Line 112-114)	Commentary memo: She is a person who easily get touched emotionally when listening, reading, or watching a sad stories of a sick o less able people. Her heart melt away easily and gets emotionally disturbed. Points in line 91-94 links.	Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of sad imagining ill people needing an organ donor, and fear for self and others close.	**Concepts:** Feelings and Emotions **Categories:** Emotional response **Codes:** • Feels of sadness when considering people waiting for an organ donation

Meaning units Transcript 11	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think when I was reading links of Facebook, it touches my heart looking at the long waiting list. It was such a big number you know. And I was imagining, if that was the number of people waiting, and knowing that not many people become a donor, then how many people would die waiting? It is sad. (Line 183-186) Well, I also imagining what if it was me? Or my mother, my sisters, or my kids? I would be hopeful that there will be someone donating for us. I don't want to die waiting. It is really sad to see your loves one dying and waiting. So, I don't want that to happen to me. I hope that if I give mine, God will help me, by helping me and my family member too if needed. It whatever situation, I believe if we always help others, things would be easier for us too. (Line 192-197) If we do good thing, other good thing will come our way. (Line 204-205)	Commentary memo: She also thinks of her future. She hopes that by registering her donation intention, there will be someone, a donor who would donate for her or her family if ever they are in need.		**Categories:** Fear for self and those close **Codes** • What if one day I need a donor? • What if one day my children, parents, and siblings need a donor too?
I was only interested to know more on religion's stance. I think there were no other issues that were really of my concern other than religion. Yes, as far as I can recall, there were no other issues that bothers me at all. My concern was totally on religion. I think you would understand, in everything that we do, we just want to make sure that it is Sharia compliance. We don't want to do anything that is against it. (Line 157-162)	Commentary memo: She is a person who strongly practice her religious teaching. She doesn't want to do something that is against her religion's view. She need to be certain that organ donation is Shariah compliance.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Certain that action does not violate religion

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Meaning units Transcript 11	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
The fear is as if one of, how do I say this yeah, I think it's like a taboo in our society. (Line 301) I think you might have hear this, certain people would say that they are scared, they are afraid because they were worried when thinking that the body function will be reduced if an organ is remove for donation. If they were to donate while they are still alive. (Line 308-311) Yes. In our community, we are still afraid to give organs after death in Islam, especially because they thought it would punish the bodies.(Line 321-322) People in our community believe that after death the deceased body will still feel the pain. That's why during the cleansing process of the deceased body, we often hear the older generation people telling us to handle the body gently and not to hurt the body. So in terms of organ donation, when the organ is remove, and the body will need to be sew in order to ensure the deceased is still physically OK. This process becomes the main concern of our society, they worry this process is hurting the body. I think this has become a taboo in our society. (Line 328-334)	Commentary memo: Taboo/misconception.		
There were not even one person involved. I made the decision on my own. (Line 212) Nope. I did not ask them. As usually, whenever I ask them in anything that I would want to do, their response is usually 'it's up to you'. So, I decided not to discuss with them first. (Line 218-220)	Commentary memo: She made the registration decision on her own without even discussion about it with her family. She believes in practicing her right in making the decision of what to do with her body after death.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

Meaning units Transcript 11	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think I can recall telling them about my registration decision. But they don't take it seriously. (Line 226-227) When I informed them it felt like, everyone was busy doing other things. I did not like seat everyone together so that I can explain one by one of issues relating to organ donation. But as I recall, they were all engaged with all sorts of other activities, for example, my mother was cooking in the kitchen, and my father maybe was watching TV. So the thing that I have to say at that time was not the main focus. Their response seems like there were telling me 'it is up to you'. (Line 236-241) Not at all. I did not hear any negative comments or any sound of disagreement from both my parents. I think all this while, in anything that I do or I want to do, whenever I ask for their opinion, they really let me make my own decision. They don't force to do anything that do not want to. (Line 248-251) I somehow think that yeah my parents they are a little open minded. They have a lot of exposure and easily accept new ideas as long as no conflict of religious orders. But disclosures regarding organ donation has not been much. But I am sure that they can accept my decision when I got the chance to explain as well as possible. They will understand. (Line 276-280)	After registering, she did informed her family about it, and to my surprise her family member did not object her decision. Not like any other family members of the previous participant. Her family is a little open minded about organ donation, and the family what's important is that the decision is not against their religious teaching. It's really up to her if she wants to donate organ after death.		

Appendix O

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 12

Meaning units Transcript 12	Initial ideas (i.e. the issue which dominates the unit)	Meaning unit transformed into psychological language	Concepts, Categories, and Codes
It all started when attended a talk in my university when I was studying. At the talk, they invited an organ donor and organ receiver to share their donating related experience. (Line 33-35) I was so impressed when I hear the story or the experience of one of the organ donors. He has donated one of his kidney to a child. Before the child gets the person willing to donate organ, his condition is very critical. He is not as active as children of that age. So, when there is someone who is willing to donate an organ to him, now the boy can live the life he could have like other children. After that, the relationship between the two of them, the donor and the receiver, turns out to be very close to one another. In the past they did not even know each other. But now their relationship is like a member of their own family. The donor said he donated because he wanted to see the little kid grow up like other children. Because he thinks that everyone deserve a good life. So why not we share what we have with others. When we see other people happy, we will also be happy. The little boy also said that he wants to be healthy, so that he will be able to study hard in order to help and to please both his parents when he works later. In addition he also wanted to help other people because his parents were poor people. He did not want both his parents' gets any poorer because she often fall sick and his parents has got to fulfil his medication need (Line 46-61) And there is another story about a donor where the family did not allow him to be an organ donor. But, before he die	Commentary memo: An organ donation talk held in campuses, in her campus particularly has open up the opportunity for her to register as an organ donor. The one information that has influence to register straight away after the talk was the story from a receiver and a donor. This has touch her emotionally. So, if the content of the talk were able to touch peoples' heart, many more would register. To touch the family's heart, by thinking that if a part of	Certainty and confidence with the information gain about organ donation. Her confidence were very much influence by information shared from a donor who has donated one kidney other than information gained from internet reading. Internet searching were for the purpose of finding enough evidence that religion permits it and to use that evidence when family communication take place. Plus, talking to prominent figures or experts is also important towards making registration decision.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes:** • Confidence in trusted online resources • Confidence in official religious body online resources

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he wrote a will where he asked his family member to respect his wish because all he wanted was that his family would forever remember him even after his death as though he is still exist but in someone else's body. (Line 61-65)	the respondent's life is in another person's body, so that the family will always remember her. Inspired after listening to stories from donor and recipient.		
I even read from the internet sources like website which I read a lot about the pros and cons of organ donation. (Line 105-106)			
I think I need a lot more information before talking to them about it so that I am more confident and have extra courage when talking to them.(Line 157-159)			
I need more information on the topic of religion and the processes involved. So I can talk and at the same time I can show evidence of material I was reading to my parents. (Line 166-168)	Information is not only important in making the registration decision, but it very crucial, while the registrant is breaking the registration decision with his or her family. Would having a KIT helps?		
Removal process was important for me to really understand that we will know what happened during the process.(Line 181-182)			
All these information is necessary for me to know prior making the decision to register. I was really curious, I really wanted to know what is our religion's stance about it and how the removal process would take place. (Line 192-194)	This link to the taboo on how much the deceased body is hurt during the removal process.		
Basically I was searching a lot from the internet. But at the same time I also acknowledge that not all information from the internet is accurate. So I know that I have to double check all information that I was reading on the internet with someone else especially experts. (Line 202-205)	The main two important information that she needed prior making registration decision were on; religion, and removal process.		
	The two main sources were basically the internet and		

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I remember clearly that I read a lot on the JAKIM website when I was curious about religion's stance towards organ donation. (Line 213-214) I remember clearly that I read a lot on the JAKIM website when I was curious about religion's stance towards organ donation. (Line 220-221) As far as I can remember I think it was more of government website, maybe it was KKM website. But I think I also do read somewhere else, probably it was a link to a newspaper cutting. I also read papers from abroad to learn about the removal process. (Line 228-231) I was refereeing to doctors and it was a communication thru social media. (Line 237) . I followed doctors on twitter. So I did asked them some questions with regards to organ donation and particularly about the removal process. Additionally, I did attend a talk about organ donation, so I also had the chance to talk to the speaker who happen to be a doctor. So I got some explanation as well during the talk. (Line 246-249) I think it was both. As I said earlier, religion and the removal process was crucial information that I need to be clear off. So the web searching and talking to experts were really influential as from there I obtained information the makes me feel confident that I am making the right decision by registering as an organ donor. (Line 257-260) Probably at the time when I was reading, I think the decision	an expert. In using the internet, she referred to authorized and trustable website such as the KKM and JAKIM website. After reading from the internet sources, she already made up her mind about registration. However, she needs to reconfirm anything that she has read on the website with someone with relevant knowledge about it. She seeks expert opinion. She wants to make sure she is making the right decision. She communicate with doctor (a prominent character) to learn about the removal process. The medium of communication were thru social media where she communicate with doctors on twitter. She also talk in person with a religious man in order to be certain that her religion permits OD.		

Meaning units Transcript 12	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
was made after reading all the available material that I have at that time. So it was very much after reading, I was able to make up my mind. But, I just wanted to talk to someone else to be certain that I don't make the wrong choice. That's where I began talking to experts to see if the decision that I made is right. Just like confirming my decision. The feeling of certainty is there you know when you began talking to someone especially experts in the field.(Line 267-273) I was certain that Islam permits organ donation. Oh yeah I also remember that other than talking to the experts, I also asked a few religious person in respect to the Islamic perspective as I just wanted to be certain from what I was reading. And all I hear is that in Islam it is a acceptable. (Line 305-308)			
I need more information on the topic of religion and the processes involved. So I can talk and at the same time I can show evidence of material I was reading to my parents. (Line 166-168) Removal process was important for me to really understand that we will know what happened during the process.(Line 181-182) All these information is necessary for me to know prior making the decision to register. I was really curious, I really wanted to know what is our religion's stance about it and how the removal process would take place. (Line 192-194) As far as I can remember I think it was more of government website, maybe it was KKM website. But I think I also do read somewhere else, probably it was a link to a newspaper cutting. I also read papers from abroad to learn about the			**Concepts:** Cognitive readiness **Categories:** Information needs **Codes:** • Knowledge of the donation and transplantation process

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removal process. (Line 228-231) . I followed doctors on twitter. So I did asked them some questions with regards to organ donation and particularly about the removal process. Additionally, I did attend a talk about organ donation, so I also had the chance to talk to the speaker who happen to be a doctor. So I got some explanation as well during the talk. (Line 246-249) I think it was both. As I said earlier, religion and the removal process was crucial information that I need to be clear off. So the web searching and talking to experts were really influential as from there I obtained information the makes me feel confident that I am making the right decision by registering as an organ donor. (Line 257-260)			
So, when I was listening to their story, suddenly there is a feeling in my heart where I wanted to donate mine when I die. So listening to their trues stories, has given me this feeling, which I don't know how describe it, but it drives me to sign up (Line 35-38) I was so impressed when I hear the story or the experience of one of the organ donors. He has donated one of her kidney to a child. Before the child gets the person willing to donate organ, his condition is very critical. He is not as active as children of that age. So, when there is someone who is willing to donate an organ to him, now the boy can live the life he could have like other children(Line 46-50) The donor said he donated because he wanted to see the little kid grow up like other children. Because he thinks that everyone deserve a good life. So why not we share what we	Commentary memo: She is a person who easily get touched emotionally when listening go the experience of an organ donor. Her heart melt away easily and gets emotionally disturbed.		**Concepts:** Feelings and emotions **Categories:** Emotional responses **Codes** • Feels disturbed when listening to personal experience of the organ donor

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have with others. When we see other people happy, we will also be happy. The little boy also said that he wants to be healthy, so that he will be able to study hard in order to help and to please both his parents when he works later. In addition he also wanted to help other people because his parents were poor people. He did not want both his parents' gets any poorer because she often fall sick and his parents has got to fulfil his medication need(Line 53-61)			
Plus, by donating our organs we can save one's life so he or she can live a life like normal people do. (Line 38-39) I like to do good and beneficial thing, where it would bring goodness in people.(Line 81-82) So why not we share what we have with others. When we see other people happy, we will also be happy. The little boy also said that he wants to be healthy, so that he will be able to study hard in order to help and to please both his parents when he works later.	Commentary Memo: She felt that registration is a good thing as she has the opportunity to let other lives a normal lives. As she also feel satisfied as she knows that her organ can be utilized by someone else, as she feels the person could go back to the society and give back. Reflexive commentary: He talks about satisfaction for being able to gives something to others. Thus, the feeling of satisfaction after being able to contribute is a driver to registering as donor.	An individual's belief system is informed by personal views about the importance of sharing and giving as part of contributing to society. As well as when a person has a sense of humanity.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others • Sense of responsibility towards public, and fulfilment of benefitting the society as a whole
At the point of registration, I knew that from religious perspective, donating is a must, it is not something that is required as a Muslim, but it is a must for as long as we are able to give, So in order to save another human being, it is a must for us to donate an organ if we are able. (Line 90-94) I was quite certain that Islam permits organ donation. I was certain because I have speak to a few people, for example	Commentary memo: She has prior understanding that her religion permits organ donation. Donating is in line with her religious teaching which encourage its followers to help others be have a sense of humanity. Information seeking was more towards making sure	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Being certain that action does not violate religion

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Meaning units Transcript 12	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
one or two religious man, family member and my close friends. I even read from the internet sources like website which I read a lot about the pros and cons of organ donation. (Line 103-106) Obviously the information about religion is the most important factor. As we all adhere of a religion. So our belief in the principle of the religion established ourselves. So whatever was written in the Quran and hadith will be something that I hold on to. It is the same with the issue of organ donation, for as long as religion allows it, I will stand by my decision to donate. Because religion itself allow this. (Line 281-285) Hmm I will still proceed especially if I only read about it, about my religion does not allow organ donation from a questionable sources like blogs, then yes I will continue with my decision. I will only stop or not proceed with my decision if it is an official statement from an authorize religious body. I want to see a black & white document that explains about organ donation is not allowed. If there are, then obviously I will not decide to register.(Line 292-297) Well this I am not sure if I am right. I really do not know how to explain, but it's like a fear that you have in you, in your mind, when we process or do something to the body of a deceased, the action would only torture the dead body. We often hear people say 'do not torment the bodies'. Something like that. (Line 362-365) But, to both my parents, for as long as they are not convince that Islam permits organ donation, the answer will be a 'NO' from them. As of now, they never bring up this topic, even me myself, I don't talk about it anymore. I think they are just	that religion allow OD. Similar to other participants, religion is the key factor. Similar to other participants, religion is the key factor.		

Meaning units Transcript 12	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
ignoring the topic of organ donation and never brought up this topic again as I think it is of no interest to them. (Line 380-385)			
They do not like it when the dead body is being dissected and the organs are being "taken away". They have this perception of not punish their bodies or hurting it by cutting the body here and there. Plus, I heard some arguing that religion does not allow this. (Line 128-131) I think most Malay people way of thinking is a bit old fashion and is not open minded. They are a bit difficult to accept change. As for the Indian & Chinese, I think they are more open minded, but there might be a small group of the Indian and Chinese who very conservative too. (Line 138-141)	Commentary memo: Misconception in the community. This link to how her family perceived OD. Reluctant to accept change. Maybe this link with lack of information?		
I was quite certain that Islam permits organ donation. I was certain because I have speak to a few people, for example one or two religious man(Line 103-104) So I know that I have to double check all information that I was reading on the internet with someone else especially experts. (Line 203-205) I was refereeing to doctors and it was a communication thru social media. (Line 237) . I followed doctors on twitter(Line 246) So the web searching and talking to experts were really influential as from there I obtained information the makes	Commentary memo: She needs to reconfirm anything that she has read on the website with someone with relevant knowledge about it. She seeks expert opinion. She wants to make sure she is making the right decision. She communicate with doctor (a prominent character) to learn about the removal process. Plus, she speaks to religious man to ensure she is making the right decision.	The confidence and certainty with the information gain from communication with pious man. She also speaks to and follow a doctors on twitter.	**Concepts:** External influence **Categories:** Respected individuals **Codes:** • Healthcare practitioner **Categories:** Valued social networks **Codes:**

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Meaning units Transcript 12	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
me feel confident that I am making the right decision by registering as an organ donor. (Line 258-260) The feeling of certainty is there you know when you began talking to someone especially experts in the field. (Line 272-273) I also asked a few religious person in respect to the Islamic perspective as I just wanted to be certain from what I was reading. (Line 306-307)			- Well-known religious person
I just ask their opinion only. But in fact they did not even know that I register. I did not tell them about my decision. Just simply having a chat regarding organ donation. I just want to know what their views is like. That's all. From conversations with them, I know there are some who agreed and accepted the donation of organs, but there is also negative acceptance towards this idea. They cannot accept the idea of organ donation for several reasons. (Line 113-118) After knowing my family member's view on organ donation, which majority of them disagree, especially my parents, they view is totally the opposite of what I believe. So I don't dare to tell them yet of my decision. Maybe not now. (Line 148-150) As of now not yet. I am not ready. I think I need a lot more information before talking to them about it so that I am more confident and have extra courage when talking to them.(Line 157-159) I need more information on the topic of religion and the	Commentary memo: Communication was not for the purpose of getting their approval or to inform of her decision, but just to learn about their feelings and opinion about OD in general. From there she could assume what the reaction would be like when she tell her family of her registration decision. So, she needed more information before informing her family about her registration decision. She needed more information in hand so that she is ready to tell her parents about registration decision.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made. Communication did not take place as lack of confidence with information at hand.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes:** Belief in individual autonomy

Meaning units Transcript 12	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
processes involved. So I can talk and at the same time I can show evidence of material I was reading to my parents. So all my argument is supported with that evident.(Line 166-168)	She wants to be ready with all the evidence to answer all possible questions or arguments from her parents.		
Removal process was important for me to really understand that we will know what happened during the process. From A to Z. I want to transfer my doctor clearly how our organs to others... What if the operation goes wrong? What will they do to fix the problem? If I am clear about this whole process of organ removal, I think it would be easy for me to tell my parents. I will be able to explain to them easily how this thing work.(Line 181-186)	This link to the taboo on how much the deceased body is hurt during the removal process. She need to be sure of the process so that she will be able to convince her parents.		
It was very much because I was afraid of their acceptance after hearing about the decision that I have made. It worries me more is I did not consult their permission before I actually go and sign up. Both of my parents they are kind a conservative people especially especially when it comes to such topics. So I'm not ready to tell them.(Line 334-338)			
Well I'm afraid if they cannot accept my decision. Let's see if I was really ready to tell them. Maybe one day when the time is appropriate. Plus, I think I was not ready because I don't have enough information for me to use to justify my. Yeah I think so. Even before I register, I had try like initiating conversation with my parents about organ donation, but to them, they are not convinced and not confident if organ donation is okay or not. (Line 344-349)	Family communication did not take place as she worry of her parents rejection. She was never ready to share the news with them. Maybe she is not confident with the information that she already have.		

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MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 13

Meaning units Transcript 13	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think it was very much because of the fact that my mom is a nurse, and I see a lot of campaign going on in the clinics as well as hospitals that encouraging us to donate organ. (Line 34-37) Mama was the one who has been very encouraging. She who encourage me to register as an organ donor. (Line 44-45) My father was OK with this idea. He just accept the decision made by my mother and I. Actually, after all these years, most of the decisions that I make are influenced by my mother.(Line 52-54) Since I was being brough up in a family which I can say both my parents are highly educated plus my mother works in the healthcare industy. Thus, I feel that it has very much shaped who I am today and the way I look into the organ donation matter. So, when my mother suggested that I should also be an organ donar and she asked me to go and sign up, the topic is not alien to me. (Line 83-87) So, when my mother suggested that I should also be an organ donar and she asked me to go and sign up, the topic is not alien to me. (Line 86-87) There was no question in my mind. Maybe I trusted my mother, as she is a nurse, and I trust her decision. I am very sure she is well verse about it from our religious perspective. (Line 109-111)	Commentary memo: Her mother were the main influencer in her decision making since her mother is also an organ donor. Plus in the family her mother is more prominent and dominant in making decision on any matter, thus since her mother is also an organ donor and has ask her to sign up, she just continue with it. She was certain her mother has researched about religious perspective on organ donation, otherwise she would not do things that's against religious teaching The participant's background (SES) has influence her registration decision. Both her parents are highly educated. Since she was brought up in a family where her parents (mother) works in the healthcare industry as a nurse, she has seen and has come across many campaign on organ donation when she followed her mother to work. SES has an influence on OD acceptance, what more towards registration. .	The powerful influence of a prominent figure in the family. If there is supports from either one of the parents, the registrant feels right with the decision made. Plus, the nature of her mother's work has stimulate intention as well as the decision to register as an organ donor.	**Concepts:** External influence **Categories:** Respected individuals **Codes:** Mother or father as the leading role or the decision maker in the family.

Meaning units Transcript 13	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
and I see a lot of campaign going on in the clinics as well as hospitals (Line 34-35) Unless you came across something, maybe an advertisement on tv or newspaper, then maybe it would trigger me to tell him. But it never did. Yes, never talk to him about it. (Line 148-150) Now I am trying to imagine, let say if I was in the car with him and there is a radio advertisement about organ donation, maybe it would remind me that I am a registered organ donor and indirectly I must think that this is the time to update my husband about this. (Line 150-154) Additionally before I register, I did not do any addition information searching as I was certain that my mom's decision is right for me. Thus, I don't bother to look elsewhere if my religion allow this. Plus, there were no other concern before I decide to register, for example I don't bother to know more maybe about the organ removal process or I also don't bother to know about how hospital handle our dead body after removing the organ. (Line 285-290)	Commentary memo: Information gain from pamphlets in hospital compound when she goes to hospital where her mother works. Information is not available most of the time to trigger communication.	The availability of information is key. She has come across campaign while accompanying mom to workplace which happen to be a hospital.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes:** Confidence with the talk, seminar, or booth set up by governing body

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Meaning units Transcript 13	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I always hear that in Malaysia there are many people who are in need of organ. So, I feel like this is good for me to contribute something. (Line 36-37) I like it, I think I like the feeling when I know that I am able to help other people after death (Line 71-72) I am happy to be able to make someone else lives longer when me myself is no longer in this world. (Line 75-76) I really like helping others. And by registering as a donor, I really hope that there will be people who can use my organ later. I hope there will be a match with my organ. I am sure I will be satisfied even if I have nothing in the world. (Line 97-99) In the context of organ donation, I just want to be beneficial to people who are really in need. Help sick people to live healthily and able to live longer. Plus, donating my organ after death is not going to be harmful to me as I no longer need the organ. (Line 231-234)	Commentary memo: From the information that she gained, be it from the hospital or pamphlet, she is aware of the alarming number of people in need of an organ donor, thus it makes her feels good to share with those in need. She is passionate in helping those in need. She will be very happy to be able to help others. Commentary memo: She don't like to waste. Rather than wasting, she wants her organ to be beneficial to others.	The sense humanity is embedded within the person as she expressed her love to help other which comes naturally from her heart. Personal views and satisfaction of benefitting others.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Belief in sharing and giving • Feeling of satisfaction being able to help and do good for others
Since he knew about our registration decision, he has be OK about our idea to donate organ after death. (Line 63-64) He just got to know about it. I just told him since I was telling him about this interview. So he just knew.	Commentary memo: There were no need of family discussion before or after registration decision, as the decision made were due to her mother's suggestion. Plus the father's role is seen as not important in this decision making process. As I think the father agree with the mother's decision as he would think that the mother knows better. Issues surrounding family communication are: Participant choose not to talk, they think its ok for as long as either one of the parents are aware.	There were no need for family communication, as the points above has overrule the need for one. The mother has bigger influence in the family.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

Meaning units Transcript 13	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
He did not say anything. Nothing at all. Maybe he was not feeling well when I told him. But, I think he is OK about me being an organ donor. Knowing him, if the did not comment anything, or when he remained silent, it means he agrees. Looking at his body language he seems to agree. It did not show any disagreement.(Line 137-140) No. I totally forgot about it. Or maybe I just think that it is not necessary. It did not occur to me that it was important to tell him plus being a potential organ donor did not cross my mind everyday. (Line 146-148) let say if I was in the car with him and there is a radio advertisement about organ donation, maybe it would remind me that I am a registered organ donor and indirectly I must think that this is the time to update my husband about this. (Line 150-154) if anyone, any of my close family member who is also a registered organ donor, I will just let the procedure go on. It's a good deed. I would respect their decision as much as I want them to respect mine. (Line 266-269)	Once married, they tend not to discuss about it. So the new family member is unaware. But the role of a husband is very significant in every family. After first, discussion, they never prolong the discussion. Choose to be on the safe side. Unless, coincidently they came across advertisement on newspaper, TV or radio that could be the point where she share information with her husband. She expects her family member would respect her decision.		
I like to think that a part of me will be in someone's else, don't you think its nice? Imagine that when your are gone, you still leave something behind for your family member to keep remembering you, cos you are around, its just in someone else's body. (Line 72-75) I feel sorry for the sick people whose waiting for organs that they needed. Just imagine how difficult for them to find	Commentary memo: Wanting family member to continuously remember us after death. To remain connected.	Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of sad imagining ill people needing an organ	**Concepts:** Feelings and Emotions **Categories:** Emotional response **Codes:** Feels of sadness when considering people waiting for an organ donation

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Meaning units Transcript 13	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
organ donors and it is more burdensome as they have to find a matchy clinical characteristics between the organ donor and them. (Line 243-246)	She gets emotional thinking of sick people who are waiting for an organ donor.	donor.	
When it comes to this, religion is not an issue. Because, when my mama said 'let's register to be a donor', I think straight away agree with her opinion and I did not ask much, nothing at all. I just did it and I am OK about it. There was no question in my mind. Maybe I trusted my mother, as she is a nurse, and I trust her decision. I am very sure she is well verse about it from our religious perspective. She would not do somehting that is against our religious belief. (Line 107-112)	Commentary memo: She was certain religion allow organ donation because if it is prohibited, her mother would not have registered as an organ donor and obviously would not persuade her to register as well. She was certain her mother has researched about religious perspective on organ donation, otherwise she would not do things that's against religious teaching.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Being certain that action does not violate religion

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 14

Meaning units Transcript 14	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
The first reason was mainly because I wanted to help other people. At the back of my mind, I have this thought where we must do something good to other people if you want other people to do good things to you as well. (Line 34-36) Plus, another reason for registering is because I want to do good deeds. I want to help those in need especially people who are very frail but still young and you know, can still contribute to the society. (Line 46-48) They will be able to still do good thing too for the society. It's as if as I am donating twice, one for individuals and the other one is indirect contribution to the public.(Line 48-50)	Commentary memo: Its herself, with positive attitude within her inner self. She believes in doing good thing and believe that what goes around comes around. When you do good things to others then others will do the same for you. She really wants to help those in need especially the young ones so that they still have more time to return to the society and benefit others. Commentary memo: She sees that her did of registering is beneficial to many. First, it benefits the receiver, and then benefitting the society as whole, especially when the receiver go back to the society and contributes.	The sense humanity is embedded within the person as she expressed her love to help other which comes naturally from her heart. Personal views and satisfaction of benefitting others.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others • Sense of responsibility towards public, and fulfilment of benefitting the society as a whole
So, whenever I am ill and I am in need, there will be someone who is willing to help me. Not just me, for my family too. If my husband or my children, they are in need of help, I hope there will always be someone there during difficult time to give a hand. (Line 36-39)	Commentary memo: This link to the point above where, by registering she hopes that one day if her family members or herself needed an organ donor, there will be someone who would come forward and voluntarily donate organ for them as well. This also link with religious teaching where we believed that if we do good thing, god will reward the same.	Expectation of getting something in return if one day he or she would need an organ donor. Need to overcome the fear if one day will be in need for one.	**Concepts:** Feelings and emotions **Categories:** Fear for self and those close **Codes** • What if one day I need a donor? • What if one day my children, parents, and siblings need a donor?

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Meaning units Transcript 14	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
right after I knew about the organ donation program, I just wanted to register. Even, before I came across organ donation campaign, I have thought about signing up but the only problem was that I do not know the channel to do so. (Line 75-78) I just did not go and register because I do not know where to go to sign up. (Line 96-97) I used the time to read more about organ donation, especially I when on to check if whether or not it is allowable in Islam. That's all. (Line 104-105) Since I was so interested to know if Islam's permits this, so I have been reading the e-fatwa from the JAKIM and some other relevant websites. I think that was the only relevant and trustable website to look into for information related to our religious belief. I don't go into blogs or I reading from social media like Facebook. As I doubt the sources of information that they share in the blogs or the social media. So, basically I have been reading from the JAKIM website. (Line 113-118) As I was only interested to know about Islam's stand on organ donation. So as far as I can remember, I only refer to JAKIM. (Line 124-125) The only important matter to me is whether or not Islam's permit organ donation. Since I have found the answer from my googling activity and particularly from reading the JAKIM website, I do not bother to know more about other things related to organ donation. (Line 142-145)	Commentary memo: She has had the intention to be an organ donor for sometimes, but she don't know (LACK OF INFORMATION) where to go to register her interest. Until she attended a program on organ donation, she instantly signs up. So, in between the time after having the intention and registering, she has used the time to research about organ donation particularly from Islamic point of view. Online resources were key in her information searching activities. She surfed and read a lot from a trustable website particularly website developed by authorized organization that look into religious matter. Other information is not important or not necessary for her to know. All that matter is her religious stance towards organ donation.	The availability of information online is crucial for her. The type information that she searched for was primarily focusing on religious view.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes:** • Confidence in trusted online resources • Confidence in official religious body online resources

Meaning units Transcript 14	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I know only basic information, for example, I know I need to get the family consent. But the process concerning family want to ask for approval or even want to remove the process of organ, I do not even care.(Line 145-147) I am not really sure about advertisement. But, I remember I think I have seen on TV. Yeah…I think it was on the awareness campaign on TV or maybe in drama. But, in general not much has been don't in terms of promotion. There is no wide coverage. (Line 274-277)	This is important for future research or activities by NTRC. As most are aware that it's important to get family's consent about organ donation, but they just don't bother about it. This usually lead to why organ removal process don't proceed.		
especially I when on to check if whether or not it is allowable in Islam. That's all. (Line 104-105) Yes, in anything that I do, I always make sure I abide to my religious ruling. I do not want to do something that will only invite the anger of God. Whatever the rules of the religion, it is important for me to obey and I want to be a good Muslim.(Line 132-134)	Commentary memo: So, in between the time after having the intention and registering, she has used the time to research about organ donation particularly from Islamic point of view. Again, this is key in her decision-making process. Registration would not take place if organ donation is against her religion.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Being certain that action does not violate religion
I guess older people or older generation they are not use to the idea of donating your organ or maybe they have never heard of organ donation all their life. So, to hear their own child giving away organs is like the biggest strike in their life you know. No one else has ever do it. (Line 162-165)	Commentary memo: Here she talks about the influence of culture in her family particularly her parents. Both her parents keey saying that 'no one has ever do this'. So the parents want to stick to what's normal. The usual practice. They don't want people to talk about it.		

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Meaning units Transcript 14	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I think, somehow it must have influenced their way thinking and how they look into things. Because it is common if we hear people in our society will be a bit reluctant to allow for post-mortem because they believe it would hurt the body of the deceased. So the concept applied to removal of organs, the concept or the taboo is the same where they don't want to hurt the body. I guess all this taboo in society is because there is lack of awareness particularly about organ donation. (Line 235-240) I have never read in the Quran or even hadith that says the body will be in pain if you do anything or when you are not gently while handling the dead body. But, this perception or maybe some kind of belief has been passed down from time to time and between generations. So, I think this belief is embedded in society and become something that they hold on to. I don't think its religious influence. People say its religion but I would say it's like a misinterpretation and I would say it's more of cultural influence. (Line 246-252)	Misconception or taboo in the society is mainly I think because of reluctant to change or accept new idea. This is indirectly due to lack of understanding, not enough access to the right information.		
No I did not. It was solely my own decision. I just sign up without informing my parents. After registration then only I informed my parents.(Line 154-155) They were surprised and quiet upset. And of course this was because they disagree that I wanted to donate my organs upon my death. (Line 161-162) I think that both of my parents disagree because they are not use to the idea of donating organ. They are a little old-fashioned I would say. (Line 213-214)	Commentary memo: Registration decision was solely hers. She doesn't ask for family consent prior to registration. She only informed her family of her decision. Which means she believes in practicing her right, her autonomy towards her own body. The parents are from a different generation. They are older. They are not very much expose about it.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 15

Meaning units Transcript 15	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
What saddened me the fact that less Malays are registering compared to other races specifically Chinese. Where the reality is the Malays are at the top the waiting list, the Malays are the group of people that needed organ donation the most. But not Malays become a registered organ donor. Its very sad you know. So, I decided to be one. (Line 34-38)	Commentary memo: The participant was very much emotionally disturbed by the fact that there was very low registration of people from her race. She registered as she wanted to help improve the number of Malays in the organ donor register to help other Malays who are at the top of the list.	Key emotions underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: feelings of frustration and regret to know the number Malays who registered is very low despite the Malays are highest in the waiting list.	**Concepts:** Feelings and emotions **Categories:** Emotional responses **Codes:** 1. Feels of sadness when considering people waiting for an organ donation
I feel that this one way of how I could help.(Line 49)	Commentary memo: Care about helping other people.	The sense humanity is embedded within the person as she expressed her love to help other which comes naturally from her heart.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes** • Feeling of satisfaction being able to help and do good for others
I was determined to register after reading the article. And decided there and then. but I don't know how to register and would like to talk with someone in person to gather more information. (Line 64-64) I have been reading about organ donation from article in	Commentary memo: She has been gaining information from newspapers and	The availability of information in the newspaper and online from authorize body is key driver towards registration. The information shared such as statistical	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes:** • Confidence with the information shared in

Meaning units Transcript 15	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
newspaper. But usually information shared in newspaper are statistical figures. So, I wanted to know more. I also browsed through sites looking for Islamic perspectives on this. I also obtained brochures and pamphlets. (Line 72-75)	this has triggered her to dig more from the websites especially on Islamic view on organ donation. She browses the net about it. Plus, she also read through pamphlet and brochures.	figure, and religious view has influence her registering decision.	newspaper - Confidence with official religious body online resources
a campaign came to the campus where I work, they have a registration counter. I immediately sign up.(Line 64-65)	Commentary memo: After the intention to be a registered organ donor, she did not immediately register because she did not know of how and where to go to register her interest. Until one day she attended a campaign/talk in her workplace and she immediately register there as there were representative who set up a booth for people to do so. So, it has ease her registration process.	An individual preference, where he don't want to feel troublesome having to search about the platform of registering. So, he takes the advantage that he feels has ease his registration process.	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes** - Knowledge of the process involved in registration
No. it was my decision alone.(Line 91) I shared my decision with my best friend who turn out to be very interested as well and have also registered. I told my family only after I made the registration as to inform them. and they understood and respected that. Some of them have also registered. (Line 97-100)	Commentary memo: She communicates with her family about her decision for the sake of informing them only. Prior to registering she did not consult their opinion because she thinks its her right to make decision of what to do with her body after her death. Plus, I think that her family is a bit open minded about it so she trusted her family will not object, plus some has also register.	There were no need for family communication, as the points above has overrule the need for one. The mother has bigger influence in the family.	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 16

Meaning units Transcript 16	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
I always wanted to be one but not so sure about is it ok in Islam or not...(Line 34)	Commentary memo: Since she first had the intention, she has doubted if Islam permits organ donation. So, she did not straight away register even though she had always enjoy benefitting other people, but to go on with this decision, her religious stand is key.	Religion is a key driver for decision-making, however this is only one part of an individual's belief system.	**Concepts:** Belief and attitude **Categories:** Religion and culture **Codes** • Being certain that action does not violate religion
but I put my intention on hold as I want to talk to someone else like maybe a religious man but then I as time passed by I forgot about it. Until recently, I kept seeing in the FB wall where people share the link on the awareness & campaign about organ donation… Plus I can also recall, I think last few years there were also official statements by the mufti about organ donation.(Line 37-42)			
after I came across few articles and fatwa or something.. because all this while I always that then when we die, our body get sensitive, our body get hurt easily if you don't handle it gently. So all this while I didn't know that organ donation was ok..(Line 61-64)			
but above all, if our religion do not allow organ donation, i wouldn't register. (Line 90-91)	Religion play a role in her decision making.		
I need to be sure first that Islam permits organ donation. (Line 117-118)			
Yes, certainly. Right after I am assured, I am certain of Islamic point of view, then I decided to go on registering. (Line 127-128)			

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Meaning units Transcript 16	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
Because I dont want them to sort of interfere with my decision. Can you just imagine if after I mentioned to them especially my husband and all you hear is his objection, he says NO, obviously I cant do it right..I think you are also aware that a wife has got to obey what the husband says. (Line 144-147)	Her action is very much influence by her religious stand. This portrays the importance of Islam view towards organ donation.		
I think what's important to our parents is that they wanted to preserve the body. Maybe? I am not so sure. I think it is like, prior to the burial process, it is better to have our body in one full body. But, somehow I am pretty sure the hospital will take care of this. After they take out our organs, I don't think they will just leave it like that. Another reason that I can think of right now is that you know how the Malay and Muslims, you know what they always say…when we die, our body becomes sensitive and get hurts easily. That is why during the cleansing of corpse, we have to do very gently so that it won't hurt the dead. Maybe they have this same idea towards organ donation, you the know, the removal of organs involve cutting here and there on your body, so the knife or the process is seen as something that is hurting the dead body. (Line 213-223) there will be people who disagree to go on with post-mortem as they worry it might hurt the deceased. I think, maybe the same thing applies to organ donation?(Line 236-238)	Commentary memo: Discusses about cultural belief in the society (family).		

Meaning units Transcript 16	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
There was an event in the campus for alumni and students to sign up to donate organ for learning purposes... At that time, I think it was interesting... I came to think that it will benefit others... (Line 35-38) I think organ donation is beneficial especially at time I was more keen of donating for medical education so that other people, the future student can gain knowledge from my body, or my part of my body…but actually at that time I didn’t take it seriously about donating... but I was serious about organ donation for medical purpose, for helping sick people in hospital, for the past 1-2 years... (Line 57-61) i would choose for medical purpose, which is to help others to have better health.(Line 80-81) yes true.. that’s the main driver why I registered. I want to benefit others (Line 90)	Commentary memo: From the beginning when she first had the intention to become an organ donor but did not proceed with registration just yet, it was because she sees it something that would bring benefits to others. To benefits others. This point is in line with her justification when asked what was the factors that lead to registration, she likes to benefit other people. So, at the point of registration, she wanted to help others who are in medical need, to improve their health condition.	Personal views and satisfaction of benefitting others. This believe is very much influence by her religious teaching. The sense humanity is embedded within the person as she expressed her love to help other which comes naturally from her heart.	**Concepts:** Belief and attitude **Categories:** Humanitarianism **Codes:** • Sense of responsibility towards public, and fulfilment of benefitting the society as a whole • Feeling of satisfaction being able to help and do good for others
an event in the campus for alumni and students to sign up to donate organ for learning purposes (Line 35-36) , I kept seeing in the FB wall where people share the link on the awareness & campaign about organ donation… Plus I can also recall, I think last few years there were also official statements by the mufti (Line 39-42) during my 1st and 2nd year we had anatomy subject.. where we used real cadaver to learn.. so the awareness and event was on this... its like giving back to UQ and students. :) it	Commentary memo: Information from social media (Facebook) was the contributing factor that lead her to understand and improve her knowledge about organ donation and then registered herself in the organ donor database. I think social media has a lot of influence on the youngster. Information from authorized body or person (mufti) has a big impact on her decision making as well. As mufti as a big role in Islamic dept.	The availability of information in public area (booth) and online resources is key driver towards registration. The information shared particularly on religious view has influence her registration decision. Information goes viral on social media also play a role.	**Concepts:** Cognitive readiness **Categories:** Information resources **Codes:** • Confidence with official statement from Mufti • Confidence with social media

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Meaning units Transcript 16	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
was my first time hearing about organ donation… (Line 51-53) Really! I never knew that. Seriously I don't know that…. This is new to me! But I feel like they need to respect my wish n decision. (Line 160-161) I think I remember they asked us to inform and discuss with family members but I really dont know they can stop the donation process. ermmm…How can this be, you see, during emotional time of losing someone, they wait for final say from family member even though the deceased has decided to donate? i really don't know the process can be stopped by our family member. (Line 171-175) … I registered because I found them through online. (Line 246)	The importance of family communication was not properly delivered to registrant. So she were not aware that her decision can be object when the time come.		
So basically I registered, as there was this one day I saw a link… a direct link to register online.. I straight away signed up myself.. Make it easy for me. If not… I will still procrastinate. (Line 42-44) But I would say the whole easy process of registration and all really make it easy for me to register.(Line 104-106)	Commentary memo: Ease in the registration process. She did not wait long to register, as she found a link on the social media that she browsing so she thinks that it eases her registration process.	An individual preference, where she don't want to feel troublesome having to search about the platform of registering. So, she takes the advantage thats he feels has ease her registration process through online.	**Concepts:** Cognitive readiness **Categories:** Information needs **Codes** • Knowledge of the process involved in registration

Meaning units Transcript 16	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
at that time I did not even ask the opinion of anyone of my family members. Not at all. Until I got my card and showed it to them and the first thing that they asked me was, is this permissible in our religion? I think, at first my husband did not approve of my registration decision. But, I think later on he has learned to just accept it. Maybe he just have too. Hehehehe.(Line 106-110) Because I dont want them to sort of interfere with my decision. Can you just imagine if after I mentioned to them especially my husband and all you hear is his objection, he says NO, obviously I cant do it right..I think you are also aware that a wife has got to obey what the husband says. So I decided not to discuss or share my opinion before I register because I seriously think that whatever we do with our body after we die is our business. Its between us and our God. It doesnt really involve them. Our family member has to only take care of our physical, our dead body, make sure it is buried, that's all. So that's why I decide on my own. only after registration I shared my decision with them. Just for the sake of informing them. Both my husband and my parents.(Line 144-153) Really! I never knew that. Seriously I don't know that.... This is new to me! But I feel like they need to respect my wish n decision. (Line 160-161) They asked me. Is it permissible in Islam? So after explaining to them.. there is a fatwa that confirms organ donation is permissable.. they just kept quiet.(Line 181-182) .. i didnt really ask much about their opinion, whether they agree or not. But now since u mentioned they have the final say, I think I have to go back I discuss this again and make	Commentary memo: Family communication one takes place for the purpose of informing the husband and parents. She decided to not to share or discuss with family member before registration as she worry they especially the husband would interfere with her registration decision. As she mentioned, our religion teach us to obey our husband once we are married, so if she hear objection from her husband, she can't go on with registration. So, she decided not to discuss but only to inform.	Feeling of autonomy in making the registration decision. This include the feeling where family will not object the decision made. Plus, there were no sharing about registration decision as she worry they would interfere with her registration decision. • Communication did not take place because worry of having to obey towards objection	**Concepts:** Belief and attitude **Categories:** Autonomy **Codes** Belief in individual autonomy

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Meaning units Transcript 16	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**Concepts, Categories, and Codes**
sure they totally accept my decision. I mean they should respect my decision. (Line 189-192) First, they were not happy about it. From their body language, I can see that they actually opposed my decision. However, the discussion was just for a little while. I did not continue any longer when I think they will show some disagreement. I just walk away. (Line 197-200)			

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 17 – Non Donor

Meaning units Transcript 17 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
when we, my friends and I we were talking about organ donation, and a group of them were saying that when we die and we donated or organ, it would only hurt our body. Which they continue saying that usually before we bury the body we have to clean the corpse, and while cleaning it we have to do it slowly and gently so that we are not hurting the deceases. (Line 33-37)	Commentary memo: Here, the participant describes the misconceptions about organ donation. Her circle of friends and herself belief that the organ removal process would hurt the deceased body.	Misunderstanding about cultural belief towards organ donation which is known as taboo in the society is a key driver for decision-making.	**Concepts:** Belief and attitude **Categories:** Misconception on religion and culture **Code**: • Taboo has stopped registration of intention to donate organ
So I was not sure if I am ready to experience that pain they were talking about. Because I am sure that our bodies has to be cut open so that the organ can be remove, our bodies will be cut into pieces, then prior to the burial, I think people would not be able to wrapped the body perfectly. (Line 37-41)	This point strengthens her misconceptions about OD. I think because of misunderstanding and lack of information she thinks that the deceased body will not be handle properly after the removal process. So she worries if the body will not look the same.		
I was like feeling confused because earlier on I have heard other people says that in Islam this action is not encouraged. But I just got to know that in Islam, organ donation is the best form of charity. But I am still sceptical when the thought that of organ donation is painful when dead came back into my mind.(Line 42-46)	Even though she has heard that in Islam, OD is acceptable, however, she still cannot overcome the misconception about OD in her mind. She fears of the pain that she thought she could feel after death.		
I was worry if by donating it would hurt my body. It is more like a taboo in my mind. I was just worry if my deceased body would be in pain prior to burial.(Line 151-153)			
But honestly the issue of taboo, you know, it still possess me, it is in my mind. I always think that 'oh it's going to be painful', you know what I mean. (Line 226-227)			

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Meaning units Transcript 17 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
But fear still lingers deep down inside my heart, I think the first reason is that I was a little bit old-fashioned, a bit narrow minded I would say.(Line 62-64) I have this thought that whoever wants to be an organ donor, it is a good deed, but just not me. I was influenced of people says and worry if it hurts. It was the most important concern. (Line 126-128) I was worry if by donating it would hurt my body. It is more like a taboo in my mind. I was just worry if my deceased body would be in pain prior to burial.(Line 151-153) Because I am kind of afraid when I think about the pain. (Line 202) But honestly the issue of taboo, you know, it still possess me, it is in my mind. I always think that it is going to be painful. So my unconscious mind is more powerful and it's always in the mind and it influence me more that the fact that many people need it and if I register it is beneficial to many people, as I was able to help others. But, I am scared if it will hurt me. (Line 226-230)	Commentary memo: Even though she knows that Islam permits OD, she is still sceptical and fear that the process of removing organ from her deceased body would hurt her. The feeling of fear of pain is possessing her mind in making the decision of not to register her donation intention.	Key emotions underpinned a sense of fear in taking action to register as an organ donor. These feelings included: feeling worry if the dead body would be in pain.	**Concepts:** Feelings and emotions **Categories:** Emotional responses **Code**: • Fear if the removal process would hurt her dead body.
Yes, I have not yet really open my mind and heart to go register my intention. I was not exactly sure. There is still doubt 'am I doing this'? (Line 73-74)	Commentary memo: There were no attempt to look or search about organ donation information. She don't bother to know more about OD. So basically, its lack of awareness, which means she don't have the right understanding.	The unavailability of information and not accessing the right information has led her to have inaccurate facts about organ	**Concepts:** Cognitive readiness **Categories:** Absence of information

Meaning units Transcript 17 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
Basically it was just a discussion with my friends. I did not go further by doing extra research in order to know more. I did not. Yeah as of now not yet. I never google or that sort of thing you know. But, it was just more of a discussion among friends as well as discussion with my family. (Line 172-175) It was local drama. Actually only one drama. It was a TV series. Only on series. But from this TV series I came to know that those in in need or organ or waiting for an organ donor, they have to wait in que, it's a long que until an organ becomes available. If there is an available organ and you are next in que, you will have the chance to get it for as long as it matches. Plus, in the drama it also gives an impression that if you have the money, you can overtake the waiting line. I don't know if that is right since this is all in a TV drama.(Line 254-260)	Misunderstand about OD. From watching movie series, she wrongly understand that only the rich one will received organ.	donation.	**Code**: • Lack of right information about organ donation • Misunderstand that only the rich one will received organ
The first discussion that took place where the topic were more driven towards the issue of body pain, the discussion were between me and my parents. Then later on, I also talked with my housemates regarding organ donation as they too have heard about organ donation and they too believe that when we die, the body should be handle gently so that it would not hurt the body. (Line 80-84) But, from tall the discussion I can summarize that all of them had this idea where donation organ would only hurt the deceased body. To them, even though we are dead, the body would even feel hurt more than when they were alive. (Line 94-97)	Commentary memo: Family and peers has somehow influence the participant's decision not to register. They have had discussion around OD and they believe that the organ removal process would hurt the deceased body. So, the participants think the same.	Family communication does not encourage registration. Misunderstanding about cultural belief and taboo towards organ donation has surrounds the communication.	**Concepts:** External influence **Categories:** Respected individuals **Code**: • The influence of cultural belief in society has influence the way family think. • Family communication led to organ donation rejection as child don't want to be disobedient.

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Meaning units Transcript 17 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
I think I wanted to be on the same side, same stance with my friends and family too, where they don't agree into becoming an organ donor due to the first reason as I mentioned earlier.(Line 153-155) . With my parents I just want to please them, I don't what to do things that they disagree. I just don't want to trigger them to be angry at me. That's all. As of now, I just want to remain the way things are. (Line 161-164)	As a child, she wants to be good child who are obedient to her parent by not going against them.		
I just don't want to be different particularly among friends (Line 161) But maybe, if something were to happen in the future, where if there are others who help us when we are in distress and need, like maybe something happen to our family or maybe to our self where we need the help of other people, so maybe incident like this will be the point for us realized that we should also be giving. (Line 204-208) We often need something to happen first then only we take action to correct things.(Line 216-217) But if it involves sibling then I thing I do things differently. Because you know when it comes to family, we respond to things differently. I guess I will try to donate. I think anyone else would do the same when we talk about family member who are in need. (Line 237-240)	Commentary memo: Want to be accepted as the same as others in the community. Will only react if there is a triggering event that affected her personally.	There were lack in the emotions that underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: lack of feelings of desperation.	**Concepts:** Belief and attitudes **Categories:** Nothing urgent attitude **Code**: • The influence of 'similar to me effect'. • It is not important as there is no triggering event in life

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 18 – Non Donor

Meaning units Transcript 18 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
. Majority don't know that we can register to be an organ donor. It never cross my mind that we can do that. I do not even know where to go to register, how do we register, you know that sort of thing. (Line 34-37) it did cross my mind the idea of donating organ, you know to give my organ to someone else after death. So, I have given a thought to register, I don't see anything wrong about it, it does not do any harm if you register. So why not? But then, I do not see the platform of registering. I don't know how or where to go. (Line 37-41) So it is the same for organ donation, you know that you can do something about it but you just do not know where is the platform. So, basically I just have the idea of donating m organs after my death but honestly I don't know where to register. (Line 59-62) So since you mentioned there is a fatwa issued by JAKIM about this organ donation thing, that it is doable and it is not wrong, plus it becomes another form of charity, then I think for me and for all Muslim, this should not be a problem. Why would it be a problem if it is something good? As good as giving and doing charity. By the way we will all be dead one day, and we no longer utilizing the organ, so just give it to someone else who can still use it. (Line 191-196)	Commentary memo: What the participant is saying is that, she has thought of donating organ, HOWEVER, she never knew that there is a platform where she can register her donation intention. So, since the topic of registering donation intention is an alien to her, is not surprising when she go on saying that she don't know how and where to register. Points in line 34-41, 59-62 links. This is the main problem. She doesn't even know that it is possible to register to become an organ donor. Obviously this would not lead to registration. She was not in the know that Islam permits organ donation. Lack of information may have lead her not to register.	The absence of information about organ donation has led her not even knowing there is a mechanism to register intention. Thus, this lead to not knowing how and where to register. The participant also have not heard to Islam permits organ donation.	**Concepts:** Cognitive readiness **Categories:** Absence of information **Code**: • Lack of right information about organ donation • No attempt to search on information about organ donation. • Difficulty of the registration process

Appendix O

Meaning units Transcript 18 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
Honestly, not much. Or maybe I should say that I know nothing at all. I think because there is not much awareness. So I don't know what's going on. For me, so far, I did not come across anything like maybe an advertisement or what not. Not even banner or brochures that being distributed which invites people to be an organ donor. Not at my place. (Line 232-236) Yes, I don't know where to go and things get more complicated because I am not the one who purely has the intention, I want to, but not really you know, I am not so serious with this idea so I guess the push factor is not there. So I don't go looking around or searching about where to go to register. (Line 72-75) Maybe if one day, at a mall there is a booth or counter then allow people to register, then probably I would do so. Since the platform is just right there, there is not for you to trouble yourself in searching for the platform. So to me, it is easy, if it is available right in front of you then I would do it, but if it not accessible, I won't be looking around. (Line 75-79) I am not the kind of person who would go and look for the platform to register, I think it's the same of everyone else in general, it's like this, even if you wanted to donate blood, you would just wait until you come across a booth at an event, you know, you would do it if you see there is a booth being set up for blood donation. There is no such thing as you go to hospital to set an appointment for you to do blood donation. There is no such thing right. So basically, if I am being approach then I will do it. Just like at a blood donation campaign, you will be approached by someone asking you to donate blood and they will offer you	She demonstrates lack of information. So, this could be a suggestion. Commentary memo: What the participant is saying is that, she could have register if she has come across a booth that would ease the registration process. She don't want to trouble herself looking for the platform. Ease of registration.	An individual preference, where she doesn't want to feel troublesome having to search about the platform of registering. Would be easier if the participant might come across a booth that allow immediate registration.	

Meaning units Transcript 18 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
something in return, like pack of food, or voucher for you to eat somewhere. (Line 210-218)			
Yes, I don't know where to go and things get more complicated because I am not the one who purely has the intention, I want to, but not really you know, I am not so serious with this idea so I guess the push factor is not there. So I don't go looking around or searching about where to go to register. (Line 72-75)	Commentary memo: Here the participant is saying that even though that she has the intention to donate, but she was not really serious about the idea, so she put it on hold. I think this is because there were no other external factors that pushes her to register or to look for information about how to register.	There were lack in the emotions that underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: lack of feelings of desperation.	**Concepts:** Belief and attitudes **Categories:** Nothing urgent attitude **Code**: • It is not important as there is no triggering event in life
And my dad said that 'oh there is no need for you to do that'. I don't know why, I don't understand why. My dad keep emphasising there is no need for me to register even though I keep stressing my point that I wanted to register. He kept saying, 'its ok for us not to do it, its ok, it is not necessary, it does not matter, it is not like you are in need of something right?' He said just don't trouble our self. It would be easier for the family to manage our dead body without having to go through many procedure. (Line 95-101) So, in some way I think my parents opinion has actually stop me from looking or searching for the platform. I just don't bother about it any longer. (Line 111-113) About my parents, I think I can speak to them slowly. I believe I can still convince them and ask them to respect my decision. From the last experience talking to them, they were not really hard on me, it's just we don't look at it from the same perspective I guess. But the conversation ended nicely and maybe because I was not really pushing them to accept my idea. Maybe I could not really persuade them at that them as me myself I don't even know where to register.	Commentary memo: She has also discussed about organ donation with her family and the objected this idea. So she was very much influence by her family's opinion thus she decided not to register. 95-101, 111-113	Family communication does not encourage registration. They belief they are not in need of one.	**Concepts:** External influence **Categories:** Respected individuals **Code**: • Family communication led to organ donation rejection as child don't want to be disobedient.

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Meaning units Transcript 18 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
So I don't bother persuading them you see. I am not yet an organ donor. Plus I don't even have the effort to go search on how to register. So, coming back to your question, I will sign up if I see booth somewhere someday. I think my parents will learn to accept it. I can also expect that by that time I may have more information so that I can use it to influence my parents. They are not old-fashioned by the way. But, at the moment we have different understanding and different perspective. (Line 128-139)			

MEANING UNITS, INITIAL IDEAS, AND MEMOS TRANSCRIPT 19 – Non Donor

Meaning units Transcript 19 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
I my organ is successfully donated to someone else, I am really worry, I am afraid if the recipient would use my organ but then commits into sinful behaviour for example, using my cornea but to watch pornographic video which is our religion it is not right. (Line) I have this feeling that maybe if the organ receiver commit into unlawful activity, I felt that I contributed to it. I was worried that, since I am the donor, I will also have to bear their sin. But now, I understand that as a donor I am not responsible for their sin. (Line) Oh not only because I was not in the know about the platform of registration. But, another main contributing reason that impede me from registering as of now, is because of religion. I am uncertain of religious view surrounding this. There are many here say. Some says Islam permit organ donation, and some says no. (Line 109-112) . Even I have heard a very strong argument that says organ donation is the best form charitable work, because we are giving our organ for other people to go on and live or if not they will just die. But, I am contemplating when I also hear people say it is any form of torture to the deceased as the body will get hurt. So I then feel sorry for the deceased, I mean it is my dead body, so I have this fear in me. (Line 112-117)	Commentary memo: Negative case analysis. This is as if as the non-donor's response. Above all the factors that she has mentioned as the reason for not registering, RELIGION is the main factor, as she described her uncertainty if her religion allows organ donation. She has some conflicting information in hand, some says it's the best from of charity, but there is also opinion that says it is hurting the deceased body which generally, this taboo is widely spread in Malaysia. So, she is confuse of what would be the right decision. She wanted to do something good by donating however she fear if it would hurt her dead body. Religion – taboo – fear.	One part of her belief system which is religion has stop her from registering. Uncertain if religion allow organ donation and this align with the belief that it would hurt the deceased body. Cultural belief and religious belief intersects with one another.	**Concepts:** Belief and attitude **Categories:** Misconception on religion and culture **Code**: • Uncertain if religion allow organ donation. • Taboo has stopped registration of intention to donate organ

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Meaning units Transcript 19 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
because I really doubt about whether Islam permits organ donation or not. I'm not sure of how true is the information I've heard from conversations with friends. So issues like this made me think 'should I proceed with it or not'. If I were to just follow my guts feeling, yes, I can only continue with my intention, but then I still have some hesitation if this is OK.(Line 124-129) As of now I think it is still a mixed feeling. If you can understand what I am trying to say. But, I recently heard that this is the best form of donation. After hearing so, I was more inclined to 'oh religion permits it'. But, on the other side I also heard that we are in pain if you touch or do anything to the body, we also are not in the capacity to be able to make sure that 'oh right, body remains is in pain'. You know. Because we know that dead cannot tell us that. Yes, that's the main reason why I am still contemplating.(Line 136-142) basically on the taboo part, it's more like I think that even though I have good intention to donate so that it can save other people's live, but at the same time I don't want it to harm me just because I am the one donating. In a way I see it as harming myself if only the removal procedure would hurt my dead body. I don't want that. That is what I am worried of. (Line 210-214)	Why does this happen, because of lack of the right understanding on this matter. The taboo that she holds on too, has led to fear in her where she is scared if the surgery which very much hurt her body.		
I am not sure how to register, and then, mmm how do I say this yeah. Well, basically I am not sure how to register, where to register, and all other details you know. (Line 33-35)	Commentary memo: She doesn't have the information in hand of how and where to go to register her intention of becoming an organ donor. Thus, her intention was put on hold. This means there was lack of information dissemination on the platform of registering.	The absence of information about organ donation has led her not knowing how and where to register. The participant also have limited	**Concepts:** Cognitive readiness **Categories:** Absence of information **Code**:

Meaning units Transcript 19 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
, it does not become like my priority to go and find out about it and I don't feel like putting extra initiative to find out. (Line 36-38)	Since she sees in as not important to do it anytime soon, she did not put any extra effort to learn about the where and about of the registration.	understanding about the overall picture of organ donation.	- Lack of right information about organ donation - No attempt to search on information about organ donation.
I don't know what is the platform for me to register. I don't know if I can do it online or I have to go somewhere like an office or something you know. (Line 48-49)			
But to me I think there is no promotion or campaign going on about organ donation so that from there it could be informative for people like me.(Line 51-52)			
. It all started from a TV series that I was watching on TV. I think you would know Grey's Anatomy. From that TV series, I can see how much struggle the hospital have to go through in order to find an organ donor. You know. Emmm I don't know if this is not logical or valid but it is this TV series that triggered me to have the intention to become an organ donor. (Line 67-71)	Her intention was triggered when keep coming across organ donation issues in the TV Series that she watched. This is where she gained some knowledge or at least has the idea about organ donation. WHAT DRIVES HER INTENTION.		
Maybe I need more details before I can do so. I do not know what kind of information I need to know more. But if you were to tell me to register now, I guess I do not quite understand yet. Yeah that is it. I feel like I want to register now, but do not quite understand about this issue. (Line 308-311)	Basically she says, she need more information, she need to have more details that might be helpful to overcome her fear about donating organ. So, basically it goes back to lack of information.		

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Meaning units Transcript 19 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
I know about organ donation and I wanted to be one, but since I don't know how and where, it does not become like my priority to go and find out about it and I…(Line 35-37) I don't think that registering is a main thing that I have to do right now. It's not my priority or responsibility. I do understand this is a good deed, but I don't have to urge of having to do it. (Line 228-230) As of now, it has not really trigger me to go and sign up because I am not affected. So, if there happened to me personally, I believe it will trigger and indirectly encouraged me to continue to register. As of now, this is the kind of thing that would change my decision(Line 326-329)	Commentary memo: Even though she has the intention, but there was no additional push factor or no triggering event that would really drives her to register so, I think she sees registering her intention as not an important action.	There were lack in the emotions that underpinned a sense of urgency in taking action to register as an organ donor. These feelings included: lack of feelings of desperation.	**Concepts:** Belief and attitudes **Categories:** Nothing urgent attitude **Code**: • It is not important as there is no triggering event in life
Well in that TV series, you will see many cases of terminally ill people, emergency cases and what not. Some are dying as they cannot be save. Some can be save if there were organ donor but there were not easily available. So it makes me feel sad you know, to see the ill person faces. And then you will see the family members there, waiting with hopes, their faces, it's all very sad. So I was very much disturbed with it, I feel sad. (Line 92-97) Ok, now to be honest, after sometimes, you know, after making that decision, I think now I know that this is not haram in our religion. So it's ok for me to just go and sign-up. But still I have this fear in me, as what people has been saying, I fear that my body will be in pain when organs are being remove from my body. It really scare me you know, I keep imagining at the time of the surgical removal, how my body can bare the pain. You know. Or maybe it's just me, I think too much. (Line 175-180)	Commentary memo: From the TV series that she watched, she was touch by the content in drama, she feels sad looking at ill people and the relatives. WHAT DRIVES HER INTENTION. When the participant was asked, if one day she become certain that Islam permits organ donation from an authorized body, would she register. She said that, at the point of the interview, she somehow was pretty sure that Islam permits organ donation, but she just failed to overcome the fear that the organ removal process will hurt the body. This is the main reason why she did not register. This taboo is always in her mind when she thinks about registering.	Key emotions underpinned a sense of fear in taking action to register as an organ donor. These feelings included: feeling worry if the dead body would be in pain.	**Concepts:** Feelings and emotions **Categories:** Emotional responses **Code**: • Fear if the removal process would hurt her dead body. • Worry if the body would not be in the normal state and unrecognizable.

Meaning units Transcript 19 – Non Donor	**Initial ideas** (i.e. the issue which dominates the unit)	**Meaning unit transformed into psychological language**	**what it tells me of the reason of non-registration**
I would say this is just like a taboo. This fear where people think if you harshly touch the dead body, it will feel hurt. But, it is in my mind. What if it's true?(Line 188-189) Because to me what's important is that I want my body to still be in its original form and recognizable. If not I just could not imagine what my family feels like seeing me in …you would know… In such a condition. (Line 199-201) if only I have enough information, to give me more strength or courage in me to confidently make decisions until I can say 'ok, now I'm going to register'. The important thing now, I have to overcome the fear to do this thing. Yes, I want to get rid of fear in me first (Line 305-308)	Because of her belief and fear that the organ removal process would hurt her body, this has also lead her to have fear if after the surgery, her body would not be recognizable by others. Basically she says, she need more information, she need to have more details that might be helpful to overcome her fear about donating organ. So, basically it goes back to lack of information.		
They were encouraging but even though they showed positive reaction there is thing going on at the back of our mind that make us wonder. Everyone were like 'uh … can we do this?' you know, the same question on their mind 'is it permissible in our religion'. Things like that. There is also the word 'nice eh, that's good … mm but you are not afraid to' … something like that (Line 262-266)		Family communication does not encourage registration. They belief they are not in need of one.	**Concepts:** External influence **Categories:** Respected individuals **Code**: • The influence of cultural belief in society has influence the way family think.

Appendix P **The codes, categories, and psychological concepts developed in analysis**

Codes	**Categories**	**Psycholog concepts**
1. Being certain that the action does not violate religious principles 2. Belief in continuous reward in the afterlife 3. Belief that nothing belongs to us but to God 4. Belief that their afterlife journey is less of a burden, with lighter punishment if they donate organs 5. Belief that the body is not useful anymore after death and can be given to others 6. Belief that religion teaches donation as a form of charity even after death. 7. Benefit for ourselves (double reward) when the recipient contributes to society.	Religion and Culture	Belief anc Attitudes
8. Satisfaction in being able to help and do good for others 9. Belief in sharing and giving 10. Sense of responsibility towards society, and fulfilment in benefitting society as a whole 11. Fulfilment in improving quality of life of others	Humanitarianism	
12. Belief in individual autonomy	Autonomy	
13. Feeling of sadness when considering people waiting for an organ donation 14. Feels disturbed when listening to personal experience of the organ recipient 15. Fear if the removal process would hurt the dead body. 16. Worry if the body would not be in the normal state and unrecognizable	Emotional responses	Feelings a Emotions
17. What if one day I need a donor? 18. What if one day my children, parents, siblings or extended family needed a donor?	Fear for self and those close	
19. Confidence in trusted online resources 20. Confidence in official religious body's online resources 21. Confidence in social media 22. Confidence in the organ donation governing body 23. Confidence in the talk, seminar, or booth set up by the governing body 24. Confidence in an official statement from a Mufti 25. Confidence in the information shared in the newspaper 26. Confidence in TV advertisements 27. Confidence in information shared by friends	Confidence with information resources	Cognitive readiness

Codes	**Categories**	**Psychological concepts**
28. Knowledge of the donation and transplantation process 29. Knowledge of the process involved in registration 30. Knowing of the need for different organs	Information needs	
31. Favourite artist 32. Well-known religious person 33. Healthcare practitioner 34. A teacher or a lecturer 35. Mother or father as the leading role or the decision maker in the family	Valued Social networks	External influence
	Motivated by respected individuals	

Accompanying Information

Published outputs prior to viva:

Ab Latiff, D S, Rivas, C, Long-Sutehall T (2016) Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor: a scoping review in completion of Milestone Two of Mphil/PhD pathway. Working Papers in the Health Sciences 1:15 Spring 2016 ISSN 2051-6266 / 20150090

Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor: a scoping review in completion of Milestone Two of Mphil/PhD pathway

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Abstract

Background: The demand for organ donors has risen as there is greater improvement in organ transplantation outcome. However, low donation rates have led to a scarcity of organs worldwide. Among potential barriers to organ donation are family rejection when they are not aware of the deceased's preferences regarding organ donation. To overcome this, countries around the world have developed registers in order to provide a platform for potential donors to record their donation intention. Nevertheless, the process by which an intention to donate an organ becomes a decision and an act of registering has received little attention in the organ donation literature and remains poorly understood.

Objectives: To conduct a scoping review and comprehensively systematically map the literature available to identify factors that influence individual decision making in relation to registering as a potential organ donor and identify key concepts, theories, evidence, or research gaps.

Method: Arksey and O'Malley (2005) five step framework for scoping reviews was applied. The sources searched between May – August 2015 were the Cochrane database for systematic reviews? MEDLINE, CINAHL, EMBASE, PsychINFO, World of Science (W.O.S), and Scopus. The reference lists of relevant articles were also searched.

Results: A total of 457 titles were retrieved with 32 papers meeting the criteria for inclusion in the final review. After discussions with supervisors 10 papers were reviewed to inform the findings section of the Milestone. Analysis of the findings from the 10 papers reviewed showed that factors influencing willingness to register included: altruism, personal benefits, social motivation, and psychological motivation, process of organ donation, religion, and trust.

Conclusion: There is limited literature examining registration as an organ donor particularly from non-westernised countries such as the Southeast Asian region. This suggests that research that explores registration motives and behaviours from a broader cultural perspective is needed, supporting the authors' intention to complete a study exploring individual donor registration decision- making in Malaysia.

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Introduction

Organ transplantation has become a viable and effective treatment for patients with end-stage organ failure (Siminoff et al. 2001). Since 1954 when the first kidney transplant was successfully performed, the demand for organs has escalated rapidly (Ehrle 2008). Currently, many countries have a deficit

Keywords
Organ donor, registration, factors, religious belief, cultural belief, family communication

Accompanying Information

in the number of organs available for use in transplant operations. Low donation rates have been linked to: a lack of public awareness and knowledge about organ donation and transplantation (Siminoff and Mercer 2001); misleading interpretation of religious fatwas or decrees in relation to organ donation (Wakefield et al. 2010); cultural concerns about how the dead body will be treated (Ashkenazi et al. 2015); and mistrust of the healthcare system (Anwar Naqvi et al. 2014). A consistent finding from studies investigating barriers to increasing the number of organs available for transplantation is that family members are more likely to reject the option to donate (when asked) if they do not know the deceased's preferences or wishes regarding organ donation (Siminoff et al. 2001, 2010; Coppen et al. 2010; Anker and Feeley 2011; Ghorbani et al. 2011; Wang 2011; Hyde and White 2013; Ralph et al. 2014). Therefore, as a means of gathering individual views about posthumous organ donation, countries around the world have developed registers in order to provide a platform for members of the public to record during their lifetime their wishes or intention to become an organ donor after their death (World Health Organization 2009).

This information is recorded on a central database which is usually situated within the organisation responsible for overseeing donation activities within each country (Gomez et al. 2012), for example, NHS Blood and Transplant (NHS BT) in the UK and the National Transplant Resource Centre (NTRC) in Malaysia. This central resource can then be accessed by health care professionals who are intending to raise the potential of organ donation with next of kin so that if the registration is not known to the family, this information can be shared.

However, the process by which the intention to donate an organ becomes a decision and an act of registering has received little attention in the organ donation literature and remains poorly understood. Of particular interest to the first author is the situation in Malaysia where both the organ donation and registration rates are very low. To date, less than 1% of a population of approximately 30 million is registered as a potential organ donor, which is the lowest deceased donation rate in the Asia-Oceania region (see Figure 1).

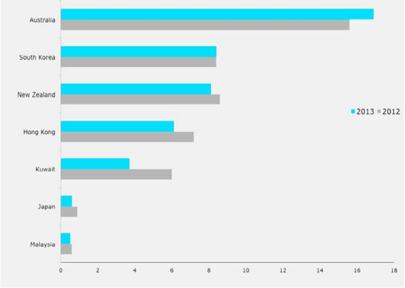

Figure 1. Asia-Oceania Actual Deceased Organ Donors 2012 - 2013 (per million population), (International Registry of Organ Donation and Transplantation 2014)

Therefore in preparation for undertaking a study exploring the factors that influence organ donor registration in Malaysia the current knowledge base available in the published literature will be scoped.

Choice of Review Methodology

In reviewing published literature, there are various systematic approaches that are available. Each type of review has a different purpose and choosing which review format is appropriate depends on a number of factors including the needs of the writer and the aim of the review. Is the aim to identify theory, review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology is particularly useful for examining a broadly covered topic to comprehensively and systematically map the literature and identify key concepts, theories, evidence, or research gaps (Arksey and O'Malley 2005; Anderson et al. 2008; Davis et al. 2009; Levac et al. 2010; Daudt et al. 2013). Therefore the aim of this scoping review is to map the literature and identify the evidenced factors that influence individual decision making in relation to registering as a potential organ donor.

Search procedure

In designing the protocol for this review, Arksey and O'Malley (2005) scoping review framework was utilized where the framework outlines a five steps approach as follow:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising, and reporting the result

Step 1: Identifying the research question

The research question guiding this review was developed in Milestone One: What are the factors that stimulate the decision to register as a potential organ donor?

However, reading broadly around this topic to inform Milestone One prompted development of four objectives to provide further structure to the review. The objectives were:

1. To explore the reasons why individuals decide to register as a potential organ donor.
2. To identify what information individuals refer to prior to registering as a potential organ donor.
3. To explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.
4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine type of information discussed with the family.

Step 2: Identifying relevant studies

Developing search terms

From a practical point of view, a search strategy commences with the identification of specific search terms. In order to develop specific search terms for each stage of the search, the PEO format (Bettany-Saltikov 2012) was applied (see Table 1).

Table 1. PEO Format

P	Population and problems
E/I	Exposure / Issue
O	Outcomes and themes

As four objectives had been developed in support of the research question, four stages of searches were carried out using the search terms identified (Table 2). The key words and related synonyms were combined using Boolean operators AND/OR, and truncation '* (Table 2).

Table 2. Core search terms for each objective and Boolean Operators

Stage	Objectives	Keywords	Boolean Operators
First	1. To explore the reasons why individuals decide to register as a potential organ donor.	P – organ donor E/I – register O - factors, decision	"organ donor" AND register* OR "sign* up" OR record* AND factor* OR determin* OR drive* OR influence* OR motivate* OR perception* OR stimulate* OR thought* AND decision* OR decid* OR "decision making" OR choice*
Second	2. To identify what information individuals refer to prior to registering as a potential organ donor.	P – organ donor E/I – register O – information, decision	"organ donor" AND register* OR "sign* up" OR record* AND information OR data OR evidence OR fact* AND decision* OR decid* OR "decision making" OR choice*
Third	3. To explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.	P – organ donor E/I – register O – religious belief, cultural belief, decision	"organ donor" AND register* OR "sign* up" OR record* AND "religious belief*" OR "spiritual be-lief*" OR faith OR religion OR religio* OR spiritual* OR "cultural belief*" OR culture* AND decision* OR decid* OR "decision making" OR choice*
Fourth	4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine type of information discussed with the family.	P – organ donor E/I – register O – family communication, decision	"organ donor" AND register* OR "sign* up" OR record* AND "family communication*" OR "family discussion*" OR famil* OR "next of kin" OR relative* OR sibling* OR parent* OR spouse* OR partner* OR wife OR wives OR husband OR communicat* OR discuss* OR talk* AND decision* OR decid* OR "decision making" OR choice*

Setting inclusion/exclusion criteria

In order to maximise the potential to identify relevant material for review, inclusion and exclusion criteria were established at the beginning of the search process (Table 3). Defining the inclusion and exclusion criteria prior to searching helps improve both the transparency and the rigour of the review by ensuring screening is conducted in a consistent and relatively unbiased manner. The start date for the search was set at 1978 as the focus of this review is to look at registering behaviour and the first register was established by Israel in 1978 (Rosenblum et al. 2012). Whilst the minimum age to register as a potential organ donor in most countries is 16 and above (Rosenblum et al. 2012), France and the Netherlands have a minimum age requirement of 12 and 13 respectively. This review will set the minimum registrants' age at 16 years in line with registration requirements in most countries. Inclusion criteria also include the most common registration methods; e.g. via a donor card, electronic registration, as well as driving licence and passport renewal. Exclusion criteria include: whole body donation, presumed consent and prisoners' registration.

Database selection

The following databases related to health, social care, psychology and sociology accessed via the University of Southampton library were searched: Cochrane, MEDLINE, CINAHL, EMBASE, PsychINFO, World of Science (W.O.S), and Scopus (Table 4).

Searched procedure

The search terms (Table 2) were conducted on 'All field'. Applying 'All Field' is important in a scoping review as the whole point of scoping the field is to be as inclusive as possible in identifying primary studies for answering the central research question.

Table 3. Inclusion and Exclusion Criteria

Inclusion	Exclusion
Those who register as: Organ donation Tissue donation Kidney donation Blood donation Egg/sperm donation Deceased organ donation Participant age – above 16 years old Time line to search – 1978 to current	Body donation Presumed consent Prisoner
Routes to registration: Electronic register Donor card Driving licence passport	-
Language – Malay, English	Other language

Table 4. Database

Database	Selection criteria
Cochrane Library	The availability of systematic reviews, technology assessments, economic evaluations and individual clinical trials.
MEDLINE	Medline is the largest and most widely used database in the health sciences. It covers journal articles and other reference types in medicine, dentistry and nursing, including biomedicine, medicine, nursing, dentistry, allied health, pre-clinical sciences and psychology.
CINAHL	Offers comprehensive coverage of journals in nursing, midwifery and allied health.
EMBASE	Offers a range of journal articles in biomedicine
PsychINFO	Contains journal articles, books, dissertations and theses in core psychology disciplines, behavioral sciences and mental health.
World of Science (W.O.S)	Provides access to a wide range of field particularly covering science, health, social science, humanities.
Scopus	Is the largest abstract and citation database of peer-reviewed literature. It comprises the world's research in the fields of medicine, social sciences, and arts and humanities.

Step 3: Study selection

The four stage search strategy resulted in a total of 457 hits (see box A and B of Figure 2). Using the inclusion and exclusion criteria (Table 3) all the 457 titles and abstracts were screened and duplicates removed (see box C, D and E Figure 2). A total of 27 full papers were retrieved and read to check for relevance and further citations. The reference lists of these 27 full papers were reviewed for other relevant publications (using the inclusion

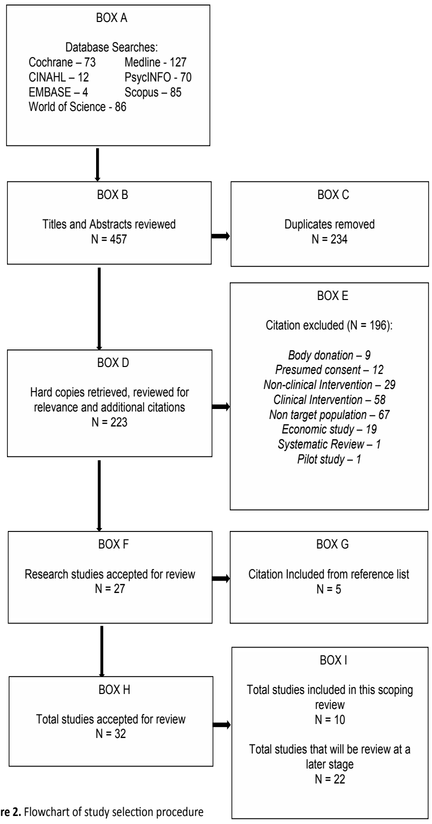

Figure 2. Flowchart of study selection procedure

and exclusion criteria as in Table 3) which resulted in an additional 5 citations to be included (see box G of Figure 2). A total of 32 papers met the criteria for inclusion in the final review however, after discussion between the authors regarding the number and focus of papers gained and the necessary limited word count for Milestone Two, only those papers which report on the central aim of participant reported reasons influencing registration/non-registration were reported in Milestone Two. The remaining 22 papers will be reviewed during development of the research proposal (Milestone Three) as they focus on the use of theoretical frameworks proposed for predicting registration behaviours.

Step 4: Charting the data

According to the Arksey & O'Malley's framework for conducting a scoping review, the data charting process involves extraction of information from individual articles. Therefore the following data was entered into an Excel spreadsheet: author(s), year of publication, study location, aims of the study, methodology/ study design, and method of data collection, sample/participant, and key findings (Appendix 1).

Step 5: Collating, summarizing, and reporting the result

Unlike a systematic review, scoping reviews do not strive for synthesis of evidence from different studies but for a thematic construction that presents a narrative or description of the existing literature (Arksey and O'Malley 2005). As stated by Arksey and O'Malley (2005) scoping reviews should help the reader quickly get a flavour of the main areas of interest and consequently identify where the significant gaps are.

With the aim of informing Milestone Three the literature will be collated in the following sections in relation to: the country in which the study was completed, the methodology applied and the populations sampled. The findings section will summarize the reported factors or concepts underpinning the decision to register as a donor. The findings section is structured using the objectives for this review which were to: explore the reasons why individuals decide to register as a donor, identify the information individuals refer to prior to registering as a donor, explore the role of religious and cultural beliefs in registering as a donor, and the role of family communication in registering to be a donor.

Collating the studies: country of origin

All of the selected papers were written and published after 2008 as countries across the globe have sought to understand the factors that influence the continuing gap between supply and demand. From the 10 papers reviewed, five studies were carried out in the USA, two in the UK, one in Greece and two in Australia. Thus, there is limited literature examining registration as a donor from non-westernised cultures and no research found from the Southeast Asian region. This suggests that research that explores registration motives and behaviours from a broader cultural perspective is needed.

Collating the studies: design, method, and data collection

The dominant research design applied in the retrieved studies was quantitative with six surveys and one intervention study. Two studies applied qualitative approaches. Of the six surveys, two (Cohen and Hoffner 2013; Murray et al. 2013) employed a standardized tool for data collection, the Organ Donation Attitude Scale (ODAS) (Parisi and Katz 1986). Four studies (Galanis et al. 2008; Hyde and White 2011; Joshi 2011; Feeley et al. 2014) employed questionnaires that were either self-constructed or developed in collaboration with clinical experts. The two studies that adopted qualitative approaches collected data via interviews (Morgan et al. 2008) and nominal group technique (Irving et al. 2014). Thus, there is limited literature examining registration as a donor from a naturalistic perspective which limits our knowledge base regarding individual understanding, values, and views.

Collating the studies: participants

The participants identified in the reviewed studies were from the following populations: university students (Morgan et al. 2008; Studts et al. 2010; Hyde and White 2011; Joshi 2011; Cohen and Hoffner 2013; Murray et al. 2013), customers exiting the Department of Motor Vehicles (DMV) offices in state of New York (Feeley et al. 2014), and the general public (Galanis et al. 2008; Irving et al. 2014; Webb et al. 2015). Seeking public participation in donation studies is justifiable because it is the public who are going to register and become a donor. However there may be limitations in seeking a student only sample as this group falls within the age range least likely to register.

Main findings

Objective 1: to explore the reasons why individuals decide to register as a donor.

The aim of this study was to map out the reported reasons behind registering a decision to become a potential organ donor. Therefore the 10 selected papers were read and factors that were reported as influencing respondents' willingness to register or not register as a donor were identified and categorised under the headings: reasons for registering and reasons for not registering and then subcategorised into concept groups, for example altruism, benefits etc (see Table 5).

Table 5. Factors that influence the decision to register or not register as donor

Factors for registering:	Factor for not registering:
1. Altruism a. Saving lives b. Desire to help others 2. Benefits a. Self-benefits b. Reciprocal benefit c. Avoidance of waste 3. Social/Societal motivation a. Family support b. Peer pressure c. Religion 4. Psychological factor a. Perception about transplant recipients' behaviour b. Emotional appeal c. Personal experience d. Own decision to donate e. Process of organ donation	1. Psychological factor a. Perception about transplant recipients' behaviour 2. Trust a. Mistrust of the system b. Belief in black market 3. No reason

Four of the 10 retrieved studies reported altruistic behaviour as a key influence on the decision to donate (Morgan et al. 2008; Feeley et al. 2014; Irving et al. 2014; Webb et al. 2015). Altruistic deeds were most influenced by the desire to voluntarily save life and help to improve the well-being of the recipient.

It is interesting to note that most persons who reported altruism as the reason to sign the registry also expressed certain benefits linked to registration, such as: i) self-benefit expressed as feeling pride and satisfaction after registering as a donor; ii) reciprocal benefits expressed as the registrant feeling proud of their intention to donate with the outcome that the recipient would enjoy improved quality of life; iii) avoidance of waste expressed as the view that it was wasteful if organs were not utilised for transplantation.

Social/societal motivational factors were reported in four out of the 10 studies (Galanis et al. 2008; Morgan et al. 2008; Murray et al. 2013; Irving et al. 2014). Social motivation appears to refer to the influence of the community at large and/ or the people around us that influence the decision to register as a donor. Examples include: familial and peer influence whereby if the family holds a positive view of donation, that positive view supports the decision to register as a donor; or peer pressure whereby an individual with a family member or friend who is registered as a donor is likely to sign up to the donation register as well.

Psychological motivation was linked to both positive and negative perceptions of recipients' pre donation behaviour, for example whether the recipient deserves to receive an organ or not was linked to their responsibility to illness such as someone with lung complication were likely perceived as smoker and this appears to be part of decision making (Hyde and White 2011). Interestingly, emotional appeal, which provides a narrative story about an organ donor and a recipient who had underwent transplantation stimulates the decision to register (Studts et al. 2010) as does if individuals knew someone who was waiting for a transplant, own decision to donate, and process of organ donation were also outlined as factors that influenced registration to become a donor (Galanis et al. 2008; Joshi 2011; Feeley et al. 2014; Irving et al. 2014).

Objective 2: to identify what information individuals refer to prior to registering as a potential organ donor.

None of the 10 studies reviewed provided any information regarding what formal or informal information people refer to in making a decision to register for donation. This is a gap in the knowledge base.

Objective 3: to explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.

Religious belief is reported as a barrier to donation (Lam and McCullough 2000; Morse et al. 2009; Wakefield et al. 2010) but in Morgan et al. (2008), religious belief is reported to support organ donation and was derived from the perception of the importance of helping others. Of note is that none of the 10 references discussed the influence of culture.

Objective 4: to explore whether family communication about a decision to register as a potential organ donor takes place and to determine type of information discussed with the family.

As indicated in findings above, views regarding organ donation were often shaped by the participants' families and such views could have either a positive or, more often, negative influence on individuals' decisions. Data from three out of 10 studies reported family communication and opinion about organ donation as important prior to registration as a donor (Galanis et al. 2008; Murray et al. 2013; Irving et al. 2014). However, none of the 10 studies discuss the type of information that potential donors share with their family member before and after registration therefore it is unclear as to whether the decision to register is shared with family members.

Summary

This scoping review was conducted to comprehensively and systematically map the literature, identify key concepts, and research gaps in relationship to the factors that stimulate the decision to register as a potential organ donor.

Findings from the papers reported have provided some insights into the factors that influence respondents' willingness or unwillingness to register as a donor; however none of the studies reviewed provided any information on two of the specific objectives, thereby we have identified a gap in the knowledge base in relationship to: what type of information is referred to by individuals prior to making a decision to register as a donor, and whether the family are aware of the decision of their family member to be a donor.

The outcome of this review also points to a need to explore further the role of religion and culture in the decision to register as a donor, and due to the small amount of literature examining registration as a donor from non-westernised countries, particularly from the Southeast Asian region, a need for research that explores registration motives and behaviours from a broader cultural perspective. These deficits in the current knowledge base support the first author's intention to undertake a study exploring the factors that stimulate the decision to register as a potential organ donor in Malaysia.

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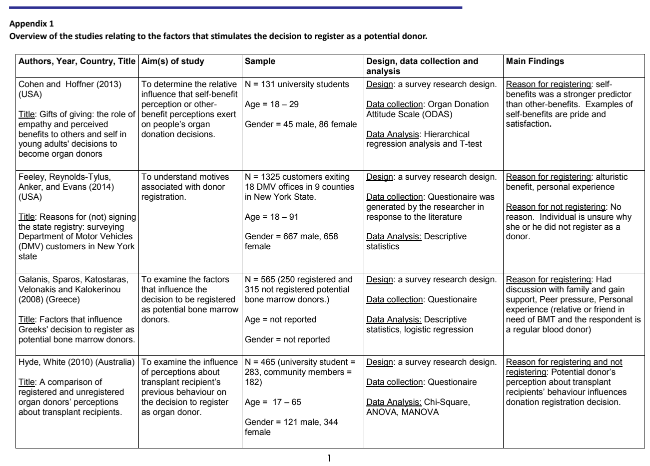
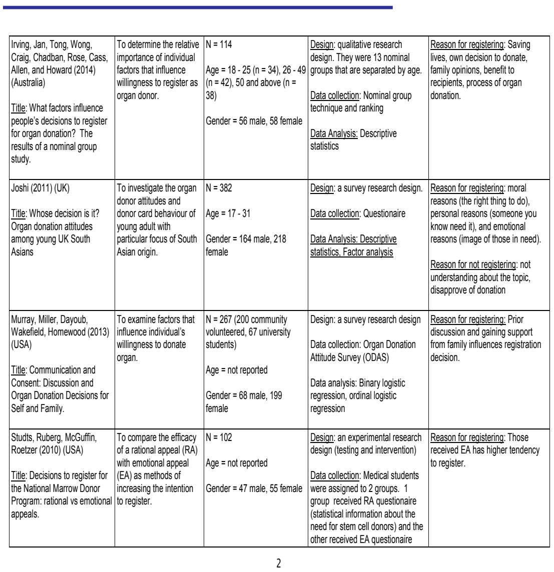
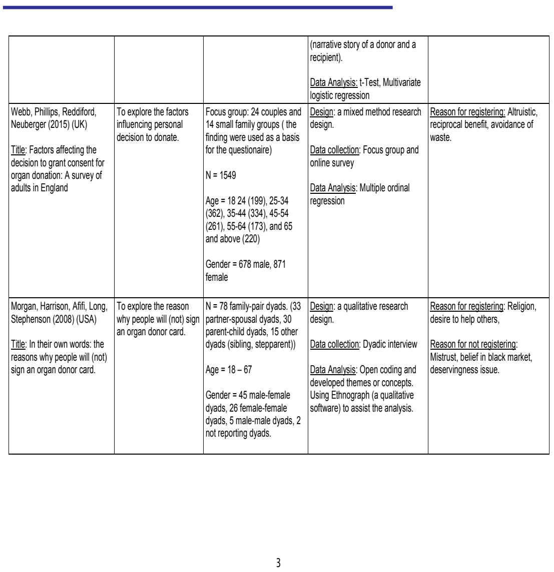


Appendix 1
Overview of the studies relating to the factors that stimulates the decision to register as a potential donor.

Authors, Year, Country, Title	Aim(s) of study	Sample	Design, data collection and analysis	Main Findings
Cohen and Hoffner (2013) (USA) Title: Gifts of giving: the role of empathy and perceived benefits to others and self in young adults' decisions to become organ donors	To determine the relative influence that self-benefit perception or other-benefit perceptions exert on people's organ donation decisions.	N = 131 university students Age = 18 – 29 Gender = 45 male, 86 female	Design: a survey research design. Data collection: Organ Donation Attitude Scale (ODAS) Data Analysis: Hierarchical regression analysis and T-test	Reason for registering: self-benefits was a stronger predictor than other-benefits. Examples of self-benefits are pride and satisfaction.
Feeley, Reynolds-Tylus, Anker, and Evans (2014) (USA) Title: Reasons for (not) signing the state registry: surveying Department of Motor Vehicles (DMV) customers in New York state	To understand motives associated with donor registration.	N = 1325 customers exiting 18 DMV offices in 9 counties in New York State. Age = 18 – 91 Gender = 667 male, 658 female	Design: a survey research design. Data collection: Questionaire was generated by the researcher in response to the literature Data Analysis: Descriptive statistics	Reason for registering: alturistic benefit, personal experience Reason for not registering: No reason. Individual is unsure why she or he did not register as a donor.
Galanis, Sparos, Katostaras, Velonakis and Kalokerinou (2008) (Greece) Title: Factors that influence Greeks' decision to register as potential bone marrow donors.	To examine the factors that influence the decision to be registered as potential bone marrow donors.	N = 565 (250 registered and 315 not registered potential bone marrow donors.) Age = not reported Gender = not reported	Design: a survey research design. Data collection: Questionaire Data Analysis: Descriptive statistics, logistic regression	Reason for registering: Had discussion with family and gain support, Peer pressure, Personal experience (relative or friend in need of BMT and the respondent is a regular blood donor)
Hyde, White (2010) (Australia) Title: A comparison of registered and unregistered organ donors' perceptions about transplant recipients.	To examine the influence of perceptions about transplant recipient's previous behaviour on the decision to register as organ donor.	N = 465 (university student = 283, community members = 182) Age = 17 – 65 Gender = 121 male, 344 female	Design: a survey research design. Data collection: Questionaire Data Analysis: Chi-Square, ANOVA, MANOVA	Reason for registering and not registering: Potential donor's perception about transplant recipients' behaviour influences donation registration decision.



Irving, Jan, Tong, Wong, Craig, Chadban, Rose, Cass, Allen, and Howard (2014) (Australia) Title: What factors influence people's decisions to register for organ donation? The results of a nominal group study.	To determine the relative importance of individual factors that influence willingness to register as organ donor.	N = 114 Age = 18 - 25 (n = 34), 26 - 49 (n = 42), 50 and above (n = 38) Gender = 56 male, 58 female	Design: qualitative research design. They were 13 nominal groups that are separated by age. Data collection: Nominal group technique and ranking Data Analysis: Descriptive statistics	Reason for registering: Saving lives, own decision to donate, family opinions, benefit to recipients, process of organ donation.
Joshi (2011) (UK) Title: Whose decision is it? Organ donation attitudes among young UK South Asians	To investigate the organ donor attitudes and donor card behaviour of young adult with particular focus of South Asian origin.	N = 382 Age = 17 - 31 Gender = 164 male, 218 female	Design: a survey research design. Data collection: Questionaire Data Analysis: Descriptive statistics, Factor analysis	Reason for registering: moral reasons (the right thing to do), personal reasons (someone you know need it), and emotional reasons (image of those in need). Reason for not registering: not understanding about the topic, disapprove of donation
Murray, Miller, Dayoub, Wakefield, Homewood (2013) (USA) Title: Communication and Consent: Discussion and Organ Donation Decisions for Self and Family.	To examine factors that influence individual's willingness to donate organ.	N = 267 (200 community volunteered, 67 university students) Age = not reported Gender = 68 male, 199 female	Design: a survey research design Data collection: Organ Donation Attitude Survey (ODAS) Data analysis: Binary logistic regression, ordinal logistic regression	Reason for registering: Prior discussion and gaining support from family influences registration decision.
Studts, Ruberg, McGuffin, Roetzer (2010) (USA) Title: Decisions to register for the National Marrow Donor Program: rational vs emotional appeals.	To compare the efficacy of a rational appeal (RA) with emotional appeal (EA) as methods of increasing the intention to register.	N = 102 Age = not reported Gender = 47 male, 55 female	Design: an experimental research design (testing and intervention) Data collection: Medical students were assigned to 2 groups. 1 group received RA questionaire (statistical information about the need for stem cell donors) and the other received EA questionaire	Reason for registering: Those received EA has higher tendency to register.



			(narrative story of a donor and a recipient). Data Analysis: t-Test, Multivariate logistic regression	
Webb, Phillips, Reddiford, Neuberger (2015) (UK) Title: Factors affecting the decision to grant consent for organ donation: A survey of adults in England	To explore the factors influencing personal decision to donate.	Focus group: 24 couples and 14 small family groups (the finding were used as a basis for the questionaire) N = 1549 Age = 18 24 (199), 25-34 (362), 35-44 (334), 45-54 (261), 55-64 (173), and 65 and above (220) Gender = 678 male, 871 female	Design: a mixed method research design. Data collection: Focus group and online survey Data Analysis: Multiple ordinal regression	Reason for registering: Altruistic, reciprocal benefit, avoidance of waste.
Morgan, Harrison, Afifi, Long, Stephenson (2008) (USA) Title: In their own words: the reasons why people will (not) sign an organ donor card.	To explore the reason why people will (not) sign an organ donor card.	N = 78 family-pair dyads. (33 partner-spousal dyads, 30 parent-child dyads, 15 other dyads (sibling, stepparent)) Age = 18 – 67 Gender = 45 male-female dyads, 26 female-female dyads, 5 male-male dyads, 2 not reporting dyads.	Design: a qualitative research design. Data collection: Dyadic interview Data Analysis: Open coding and developed themes or concepts. Using Ethnograph (a qualitative software) to assist the analysis.	Reason for registering: Religion, desire to help others, Reason for not registering: Mistrust, belief in black market, deservingness issue.

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