Deceased Organ Donation and Health Literacy

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ETHICS STATEMENT

Ethics approval was obtained from the Medical Education Ethics Committee (Ref: MEEC 1516-07- see Appendix C) and the Research Ethics Committee of London-Hampstead (Ref: 16/LO/0664- see Appendix C)

ABSTRACT

Background: Organ shortage remains the biggest challenge in transplantation worldwide. Principles of health literacy (HL) are used to aid individuals make informed decisions about their health.

Methods: An observational, cross-cultural comparative, mixed-methods study design was employed involving three European countries (N=1111); The Netherlands (n=503), United Kingdom (n=312), Spain (n=296) consisting of patients, administrative staff and medical students. Empirical review of HL principles and each country's national transplant organisation website were used to construct a DOD-HL questionnaire (DHQ). The DHQ was used to measure and rank each parameter of HL with respect to supporter-registrant profiling using descriptive and predictive regression analyses. Qualitative data from focus group interviews (N=9) added context to the DHQ results.

Results: Support for DOD surpassed registration rates, in all three countries ($p < 0.001$***). Communication about DOD attitudes and wishes were generally positive and bidirectional. Willingness to grant consent was greater for close, compared to distant family members. Knowledge scores for DOD topics were negative in all three countries ($p < 0.001$). Participants were most knowledgeable on waiting lists and least knowledgeable on technical aspects and in-hospital protocols. Non-discussion behaviours, poor knowledge about common health related topics, older age and lower educational background were observed among non-supporters and non-registrants. Predictive modelling showed that the arrangement of top-ranking variables was different for 'support' and 'registration'. Focus group discussions revealed utilitarian values and social responsibility as primary motivational drivers.

Conclusion: The study validated that support for DOD does not directly translate into registration. Mapping individuals' values, background, communication patterns and knowledgeability provides a greater understanding of the interplay between these variables. Health campaigns should focus on extending the use of HL principles beyond the healthcare setting to create a better culture of social awareness on DOD through targeted informativity and guided interactivity and translate inaction into action.

GRAPHICAL ABSTRACT

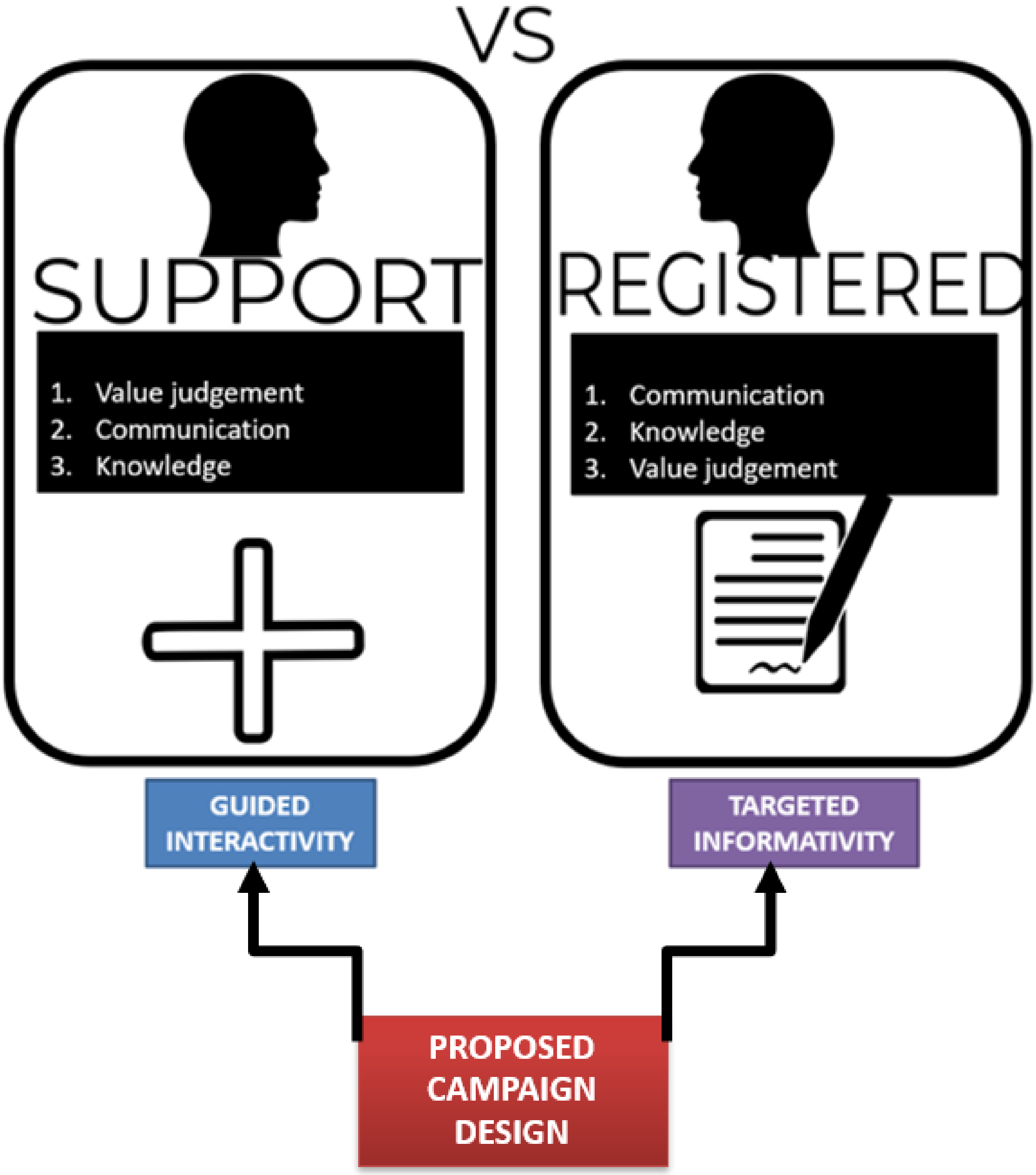

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TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER 1

CHAPTER 2

CHAPTER 3

CHAPTER 4

LIST OF TABLES

CHAPTER 2

CHAPTER 3

CHAPTER 4

LIST OF ACRONYMS

AALHS- All Aspects of Health Literacy Scale

AIC- Akaike Information Criterion

BAME- Black, Asian, Minority Ethnic Groups

CA- Correspondence Analysis

CKD- Chronic Kidney Disease

CS- Confidence Score

DBD- Deceased brain Death

DCD- Deceased circulator Death

DHQ- DOD Health Literacy Questionnaire

DOD- Deceased Organ Donation

EU- European Union

FGD- Focus Group Discussions

GLM- Generalised Linear Model

HL- Health Literacy

HLS-EU- European Health Literacy Survey

HLSI- Health Literacy Skills Instrument

HTA- Human Tissue Authority

IOM- Institute of Medicine

IRODaT- International Registry of Organ Donation and Transplantation

KWt- Kruskal-Wallis Test

MCA- Multiple Correspondence analysis

MEEC- Medical Education Ethics Committee

METER- Medical Term Recognition Test

NAOD- National Agencies for Organ Donation

NHSBT- National Health Blood and Transplant Service

NLmed- Netherlands Medical Students

NLpat-Netherlands Patients

NLsta- Netherlands Staff

NTS- Netherlands Transplant Society

NVS- Newest Vital Sign

ODTF- Organ Donation TaskForce

ONT- Organizacion Nacional de Trasplantes (National Transplant Organisation)

OPO- Organ Procurement Organisation

PCC- Pearson’s Correlation Coefficient

PHP-Retrospective post-hoc power

pmp- per million population

PSHE- Personal Social and Health Education

REALM- Rapid Estimate of Adult Literacy in Medicine

SAT- South Alliance for Transplants

SDV- Stichting Donorvoorlichting (Donor Information Foundation)

SLNS- Skills for Life National Strategy

SMT- Social Marketing Target Analysis

SN-OD- Specialist Nurse in Organ Donation

SPmed- Spanish Medical Student

SPpat- Spanish patients

SPsta- Spanish staff

s-TOFHLA- Short Test of Functional Health Literacy for Adults

TCs-Transplant Coordinators

TOFHLA- Test of Functional Health Literacy in Adults

UKmed- UK medical students

UKpat-UK patients

UKsta- UK staff

UN- United Nations

WHO- World Health Organisation

CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

This chapter provides the research context, thesis summary and structure. An overview of the current and international relevance of this issue is presented, alongside an outline of Health Literacy (HL) and Deceased Organ Donation (DOD). The chapter ends with insight into the researcher's background and motivations.

1.2 THESIS SUMMARY

The organ shortage issue is complex and multifactorial. Modelled at its simplest, it describes the mismatch between the organ supply to meet the needs of patients on waiting lists and the ability of healthcare institutions and society to accommodate this. Despite medical advancements, most transplants still occur following DOD. The size of this donor pool is affected by the willingness of the deceased's family to grant consent and the decisions made by the individual while they were alive. Therefore, DOD is both an institutional and social challenge that is affected by behaviours that occur at an individual level.

This thesis presents HL as a novel solution to this problem by considering its use as both an explanatory and exploratory tool to better target future health promotion campaigns. HL provides insight into how organisations respond to the populations' needs and into the ways in which this has a ripple effect on society and culture. At its core, health literacy enables access and understanding of the information required to make informed health decisions. At its best, it successfully facilitates health behaviour change.

DOD presents several challenges to the traditional relevance and meaning of conventional health literacy. The most crucial challenge is that while conventional health literacy refers mostly to technical competencies, HL in DOD requires emphasis on motivation. To this end, this thesis has developed a questionnaire on DOD-HL (DHQ) on the basis of core HL parameters and the DOD information health promotion agenda in order to map and predict supporter-registrant profiles in three European countries with low, intermediate and high DOD rates. This is complemented by qualitative analysis of focus groups discussions in the three countries with three predefined lay populations linked to the health care setting: patients, administrative staff and medical students. This thesis has constructed a supporter-registrant profiling which contributed the concepts of guided interactivity and targeted informativity to HL within DOD, predicting these strategies as instrumental to optimise campaigns, for support and registration for DOD respectively.

1.3 THESIS OVERVIEW

1.3.1 RESEARCH APPROACH

1.3.1.1 SELECTION OF THE TOPIC

Current opinion polls suggest that 9 out of 10 people support organ donation but fewer than 1 in 3 people are registered (NHSBT, 2016). The literature research at first was concentrated broadly at the topic of organ donation, live and deceased, which revealed several topics and trends, similarities and differences between the two. One important difference between the two kinds of organ donation is the willingness to donate organs when it comes to a live related transplant contrasted with the low rates of DOD. This contrast led to an increased interest in the causes of reluctance to donate organs after death. Multiple factors, such as knowledge gaps, cultural and religious beliefs, have been found to contribute to this reluctance. This line of research led to the exploration of the decision of organ donation as a personal and private decision, but also as a shared and social one.

The second stage was the research of literature about health literacy as a dynamic '*multiplier effect'* idea that *empowers* people (Kickbusch, 2001), drives *sustainable development* and equity in public health and *phronesis or 'practical wisd*om' (Schulz, Nakamoto, 2013) on both an individual and collective level.

In recent years, the territory of health literacy is getting more accurately mapped. The literature search ratified that current efforts to increase DOD rates focus on helping patients and the general public develop greater familiarity with health issues and resume the responsibility of making informed health decisions towards self-care management within a 'shared responsibility partnership' scheme that is neither 'doctor-centric' nor 'patient-centric' but relational and interactional (Sorensen et al, 2012). However, the topic of how people learn, what they feel they need to know, how they communicate their opinion on the matter, how they make informed decisions about themselves and others has not received visibility.

1.3.1.2 SELECTION OF PARTICIPATING COUNTRIES

This thesis aims to develop a holistic overview of health literacy practices, supporter-registrant behaviours and efficiency of campaign design. This is achieved through cross-cultural, sampling. Institutions within three countries participated in this research: the UK (intermediate DOD rates), the Netherlands (low DOD rates) and Spain (high DOD rates).

The first criterion for this selection was the difference in DOD rates, as defined by the International Registry for Organ Donation (IRODat) (IRODaT,2016), in order to obtain a holistic and cross-sectional overview of the topic. The second criterion was geographical position and potential for efficiency in cross-national collaborations. Thirdly, each country has a unique approach to the resolution of the DOD issue. The UK was selected as the Hammersmith Hospital of the Imperial College NHS Trust, operates a world class Transplant Program and is a Health Promoting Hospital that supports patients and their families through a regular and systematic program of patient seminars where it offers information to patients and their families about donation and organ transplantation. Furthermore, it is the country in which my doctoral studies take place.

The Netherlands is a member of the 'Eurotransransplant' collaboration, a non-profit organisation responsible for the cross-border allocation and distribution of organs and tissues among Austria, Belgium, Croatia, Germany, Hungary, Luxembourg, the Netherlands, and Slovenia.

Finally, Spain is the European country with the highest organ donation rate worldwide. It also participates in the South Alliance for Transplants (SAT) established in 2012, in which France, Italy, Portugal, Spain and Switzerland participate, and the Czech Republic is an observer.

1.3.1.3 SELECTION OF PARTICIPANT SUBGROUPS

As this is a new domain, which has never been studied before, it was believed that these complex parameters must be first examined from the perspective of lay participants that have some experience in the healthcare setting. Furthermore, the decision to distribute the surveys within hospitals and large academic centres has thematic relevance. This is because the highest proportion of potential donors is found in larger hospitals and the most resources are invested in this setting (Gostin et al, 2009) .

For this reason, patients, administrative staff and medical student subgroups were selected. This selection represents lay individuals closely linked to the healthcare system and each provides a unique and valuable perspective. All participants in the patient group had either already received a transplant or were on the waiting list. The hospital administrative staff were required to have a non-clinical role within the healthcare setting and to be current employees within their respective trusts. The medical student participants were required to be within the clinical years of their study (years 3-5+) or to have attended hospital placements within the past academic year. There were no limitations or specifications on age, gender or ethnicity so as to allow for a higher degree of randomisation and to provide a greater insight into the cross-sectional representation of these socio-demographic variables within each participating group and country.

Whilst clinicians were closely involved in the construction and validation of the questionnaire tool that was developed as part of this research, they were excluded from the study population on the basis of two criteria. Firstly, the thesis aims to explore the impact of HL in DOD from a lay perspective. Whilst the subgroup categories that were selected had some familiarity with the topic, they did not have specialist knowledge. To this end, the purposeful exclusion of clinicians from the research sample was on the assumption that it is reasonable to consider this population as sufficiently health literate on the topic and that their inclusion would significantly skew the results of the statistical analysis (Safeer and Keenan,2005).

1.3.2 RESEARCH AIMS AND OBJECTIVES

This dissertation aims to expand the definition and potential of HL as a driver for social change by extrapolating and instilling its key principles into a new explanatory approach for supporter-registrant profiling in DOD. Subsequently, a secondary aim is to further build research capacity in public and healthcare-based health promotion campaigns. This is deconstructed further into a series of aims and objectives:

Aim 1: Expand the theory and definition of HL to consider its wider role in society, beyond the healthcare setting.

Objectives:

- Review existing concepts, theories and definitions of HL
- Collect data on the content of DOD websites across the three participating countries, to derive the common appeals and parameters of the health literacy agenda, as presented by each respective national transplant organisation
- Develop a questionnaire tool to measure the impact of defined parameters on supporter-registrant profiling.

Aim 2: Measure the interaction and relative importance of defined core HL principles in the construction of supporter-registrant profiles

Objectives:

- Construct descriptive and predictive profiles for supporter-registrant categories of DOD, based on the individual, social and cognitive HL domains examined in the DHQ
    - Individual: Socio-demographic characteristics and personal values

    - Social: Family based DOD-conversation patterns
    - Cognitive: Topic-specific knowledgeability, general health topic knowledgeability, and self-perceived knowledge or confidence
- Map the interactions and relationships between these HL domains in the construction of supporter-registrant profiling
- Rank the parameters in order of importance and contribution to supporter-registrant profiling

Aim 3: Target and tailor campaign design to the intended audience, focusing on their perspectives and tendencies in order to develop a culture of informed decision making

Objectives:

- Devise campaigns that emphasise and enhance coordination between individuals, their immediate and wider social sphere using insight derived from focus group discussions
- Tailor DOD-HL campaigns to help better inform the public about the topic and their decision-making;

1.3.3 KEY OUTCOMES

The key outcomes of this thesis are:

- A thematic comparison of the DOD-HL information and agendas of three European countries with low, intermediate and high DOD registration rates
- An exploratory DOD-HL questionnaire (DHQ) tool for understanding the interplay between the HL domains in DOD supporter-registrant behaviours
- A descriptive model indicating the interaction between HL domains in supporter-registrant profiles
- A predictive model ranking HL domains in supporter-registrant behaviours
- A new proposal for DOD campaign design. This features separate approaches; guided interactivity and targeted informativity. Respectively, these are required for i) increasing DOD support rates and ii) promoting registrant behaviours.

1.3.4 STRUCTURE OF THESIS

Chapter 1 is introductory, presenting the purpose and premise of the thesis and an overview of the context, content and structure.

Chapter 2 presents the combination of theoretical frameworks and data collection used in the construction of the DOD-HL questionnaire (DHQ). This is structured in three sections. Section A collects information and produces a report on the current status of the DOD in the context of the three countries participating in this research. Section B explores HL as a concept, its evolution, multidisciplinary range of definitions, research interests and emerging trends in clinical and social health literacy. Finally, Section C addresses elements that relate and differentiate the three official national DOD information websites for the participating countries. In combination with Sections A and B, Section C outlines the development and validation of the DHQ.

Chapter 3 presents the quantitative analysis of the DHQ responses. Section A describes the statistical methods that were used. Section B presents the results of this statistical analysis. Both sections are split into Parts A-E. Each part relates to a different analytical parameter; Part A: Socio-demographics, Part B: Communication, Part C: Knowledge, Part D: Summary Descriptive Model Multiple Correspondence Analysis (MCA), Part E: Predictive Model.

Chapter 4 presents the qualitative analysis of this thesis, conducted through nine focus group discussions (FGD). Section A describes the methodology employed, including the selection of participants, the interview protocol and the transcription process. Section B presents the results of thematic analysis. This is compartmentalised with separate sections for each country and each participant subgroup. The thematic analysis for each group is split into five common themes, labelled Themes A-E; Theme A: Personal values and donation, Theme B: Facts on DOD process, Theme C: Registration Options, Theme D: Communication with Family Members, Theme E: Promotional Resources.

Chapter 5 presents the overall Discussion of this thesis. This is a synthesis of the results from the quantitative and qualitative analyses, discussing the role of HL in supporter-registrant profiling and campaign design. This is split into Section A: The pre-campaign environment, which considers the existing interaction of HL parameters (individual, social and cognitive) as observed in the supporter-registrant profiling and Section B: Campaign Design. Section B introduces two new approaches for campaigns addressing supporter and registrant behaviours in a customised fashion.

Chapter 6 presents the overall Conclusion of this thesis. This includes an overall thesis summary, a list of the key conclusions from the previous chapter. In addition, there is a summary of the challenges and limitations encountered in each chapter, as well as overall during the completion of the thesis.

Furthermore, there is an outline of the wider context of this research and suggestions for future areas of study. Finally, this chapter includes a personal reflection.

This thesis ends with a list of references that were used and an Appendix section. Appendix A contains additional information for the quantitative analysis, Appendix B contains additional information for the qualitative analysis and Appendix C contains the two ethics approvals from the Medical Education Ethics Committee (Ref. MEEC 1516-07) and the Research Ethics Committee of London-Hampstead (Ref: 16/LO/00664) and the researcher's publications on the subject can be found in Appendix D.

All chapters consist of an introduction and a conclusion. For Chapters 3 and 4, additional conclusions are provided for each part of the analysis. A summary diagram of the structure of this thesis is presented in **figure 1.1**.

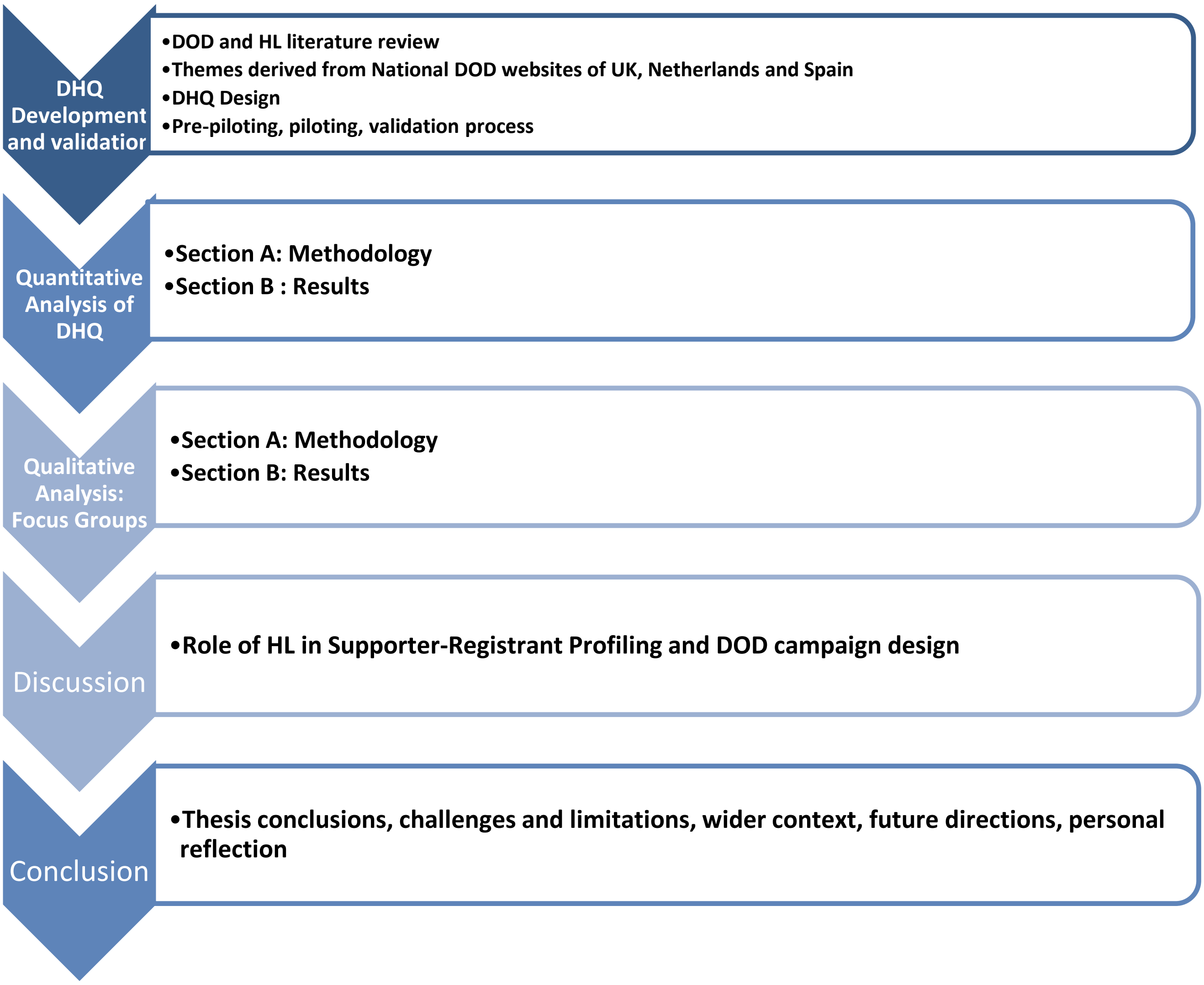


Figure 1. 1 Schematic of thesis structure and study development process. Content analysis was used to extract from the national websites for each respective European country and examined quantitatively (via the questionnaire) and qualitatively (via focus groups). Original diagram.

1.4 RESEARCHER'S BACKGROUND

My studies and experience in the field of Adult Education and Lifelong Learning for 10 years have taught me that any new or proposed educational activity must start from the point where people are, understanding their needs and acknowledging the knowledge and experiences they already have. One of the educators which deeply influenced my school of thought is the American adult educator Malcolm Knowles. His model of Andragogy expressed the core attributes of adult education, including the principles of self-directed learning, readiness to learn, and using knowledge to satisfy personal needs. This means studying the learning process which takes place outside of organised educational institutions.

Through my PhD in Lifelong Learning (completed in 2009 at the University of Athens, School of Philosophy: Department of Education), I saw the practical impact of this principle and how addressing the educational needs of adult learners requires placing emphasis on the individual being in control of the entire learning activity. This starts with self-diagnosing their learning needs, setting goals, selecting informal learning resources that they serve their learning goals and self-evaluating the outcomes.

Through my career in Adult Education at the Ministry of Education (in the department of continuing Professional Development and Lifelong Learning) in Greece, I studied the subjects of family learning and health education. I had the opportunity to experience first-hand the process of collaborating with families to create communication-centric environments. In addition, I studied the use of empathy as a tool in interviewing to transform negative behaviours and perspectives. I also realised that superficial understanding of health issues can lead to uninformed decisions and continuation of stereotypes.

My scientific interests in family learning and health education are harmoniously combined in the field of health literacy. Health literacy does not restrict the study of health issues within a medical context but embraces the whole spectrum of a person's experiences. On the topic of DOD, I was intrigued by the interaction between an individual's beliefs and their use of informal and formal learning channels, as well as understanding the family dynamics that are a core part of the organ shortage problem (See Appendix C for recent publications and abstracts on this topic (Theodosopoulou & Papalois 2016, Theodosopoulou et al, 2018)).

1.5 CHAPTER CONCLUSION

This chapter introduces the structure of the thesis. Furthermore, a brief introduction into the topic of DOD was given outlining the principles, process and problems it is currently facing in terms of organ shortage and waiting lists. Moreover, the topic of HL was introduced and how it is an integral tool to allow individuals to make informed and conscious decisions about their health and their general awareness of health topics. Finally, the researcher's background was outlined to emphasise their professional skills knowledge around this topic and that of Adult Education.

CHAPTER 2

DOD-HL OVERVIEW AND DHQ DEVELOPMENT

2.1 INTRODUCTION

This chapter is divided into three sections. Sections A and B review the literature and key principles of DOD and HL, respectively. Section C incorporates this information into a review of the DOD HL agenda, through a cross-comparative content analysis of each participating country's official website on DOD. This is used to inform the design, construction and validation of the DOD-HL questionnaire (DHQ). The ultimate purpose and intended outcome measures of the DHQ were guided by the research aims. Therefore, the design was oriented towards its use as a tool to explore the interaction of HL principles in the construction of supporter-registrant profiles.

2.2 SECTION A

2.2.1 DECEASED ORGAN DONATION

Transplantation is one of medicine's greatest achievements. Continuous medical advancements allow transplants to be lifesaving operations with high survival rates as well as provide major improvement to the quality of life of patients and their families.

Despite these major advancements, waiting lists continue to grow and every day, several patients die while awaiting a matched donor. These deaths occur despite estimates that the pool of potential donors is more than adequate to meet the current demand for transplantable organs (Mocan and Tekin, 2010).

2.2.3 THE ORGAN SHORTAGE ISSUE

Whilst this thesis studies DOD practices in three European countries, the long-lasting challenges associated with this life-giving act are observed world-wide. One of the core issues is the shortage of organs available for transplantation **(figure 2.1)**. This results in a critical mismatch between 'supply' and 'demand' and is evidenced by the ever-expanding waiting lists. According to data by the European Union (2014), 86,000 patients were registered in waiting lists for organ transplants and on average, three people die every day waiting for a transplant (Harper et al., 2013). Fundamentally, the factors contributing to the organ shortage issue are bound by two contexts; the in-hospital setting and the pre-hospital environment or the wider social milieu.

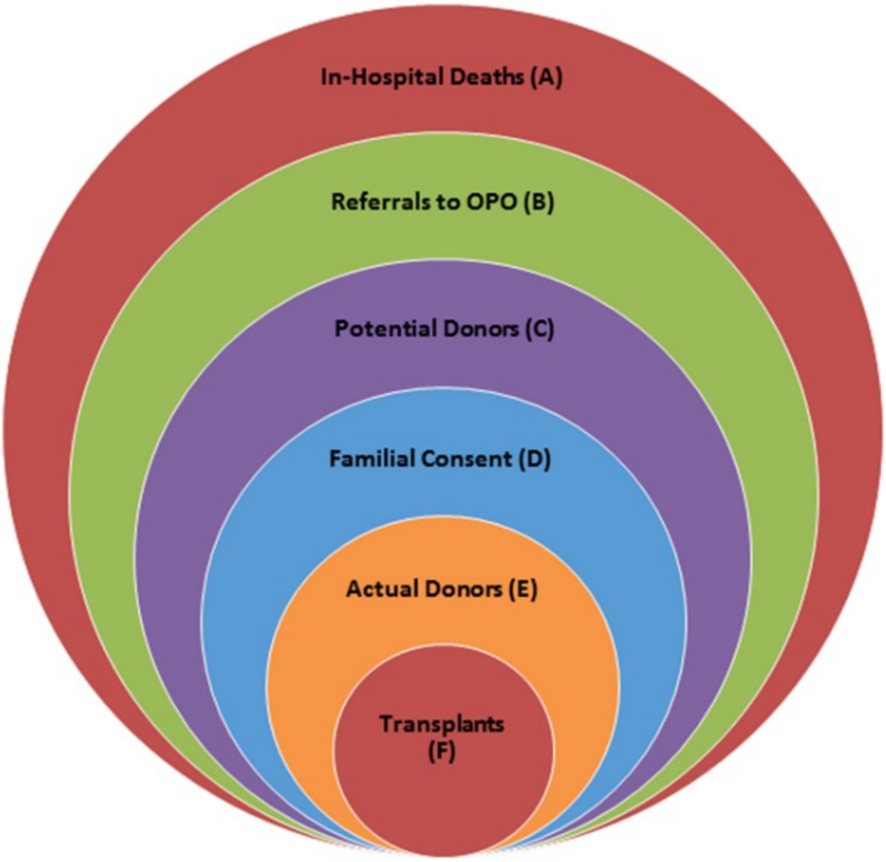


Figure 2. 1 Conceptual schematic (stacked Venn diagram) of potential and actual donors. (A)in rare instances out-of-hospital deaths result in organ donation. **(B)** In-hospital deaths are reported to the local organ procurement organisation (OPO). **(C)** The number of 'True' Potential Donors is yet to be defined. **(D)** Eligible deaths. **(E)** Actual Donors, not all of whom result in transplants. **(F)** Deceased donor transplants. Original Diagram.

The hospital setting is a time pressured environment, where critical decisions must be made by healthcare teams and patient families, to ensure that end of life procedures that ensue are compatible with the deceased's wishes, as expressed in life. This is also a tightly regulated and closely monitored environment. **Figure 2.1** demonstrates the processes and protocols that must be observed in this setting before DOD take place. The stepwise decrease in the circumference of each circle in the stacked Venn diagram illustrates the gradually decreasing number of potential donors at each level.

The first circle demonstrates that, in most cases, DOD follows in-hospital confirmation of death. Healthcare teams confirm death either on the basis of irreversible cessation of the cardiocirculatory system or the irreversible cessation of brain function. This results either in donation after cardiocirculatory death (DCD) or donation after brain death (DBD), respectively. Historically, healthcare teams made selections about potential donors solely on the basis of DBD (Bendor et al., 2013). This decision was based on criteria outlined by the Harvard Ad Hoc Committee in 1968, for increasing the number, quality and viability of transplantable organs (Bendor et al., 2013). However, during the past decade, in an effort to provide an additional pathway to increase the organs retrieved from deceased donors, several countries have worked to refine the protocols for DCD. This requires greater efficiency and coordination of the time of cardiocirculatory arrest and organ retrieval in order to preserve organ viability (Veatch, 2008). Subsequently, the individuals pronounced 'dead' by either criteria are referred to the organ procurement organisation (OPO) for further evaluation, before officially being considered as 'potential donors' (stages B and C).

After this stage, the deceased's family are approached. Several studies have identified this as the critical and rate limiting step in the conversion of the large potential donor pool to the considerably smaller pool of 'actual donors' (stages D and E) (Simpkin et al., 2008). According to the NHS Activity Report 2015-2016 only 4 in 10 families in the UK grant consent (NHSBT, 2016a). **Figure 2.2** presents a summary of some of the reasons indicated in the report about the causation of this issue, the most important of which were factors pertaining to communication and discussions about DOD while the patient was alive.

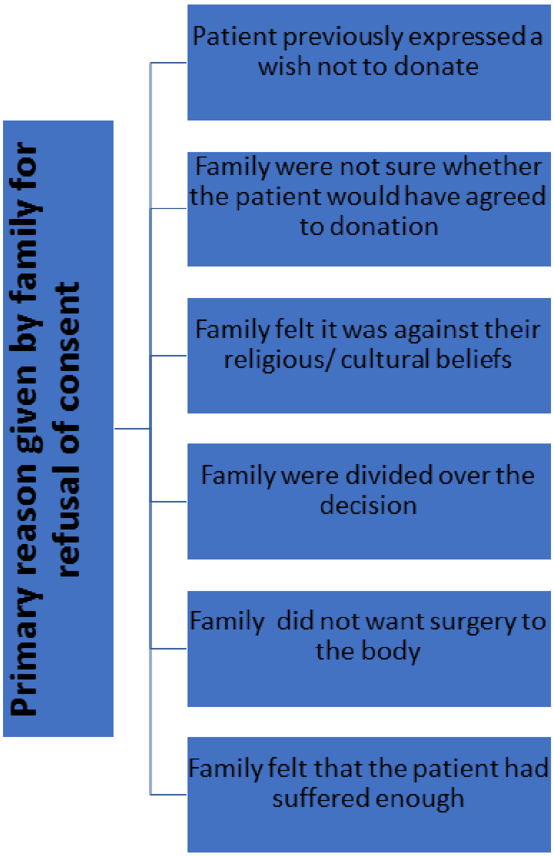


Figure 2. 2 NHS Activity Report, Hierarchy of reasons for family refusal rates. The data is based on survey data collected between 1 April 2016 and 31 March 2017. The survey was conducted on families consented after their relative was confirmed a potential donor following either brain death or circulatory death. The reasons are arranged hierarchically, with the most common response illustrated at the top.

These findings were corroborated by a systematic review_of the factors influencing the high familial refusal rates (Simpkin et al., 2008). Here, it was suggested that the primary cause is that in a time-pressured environment and emotionally burdened time, the deceased's family are required to process complex health information about brain death or circulatory death, organ procurement, organ allocation, as well as consider their own and their loved one's ethical, religious and cultural traditions.

The decision of families is also significantly influenced by the conditions in which they are called to give consent. Stahler et al. (2014) reported that 75% families are willing to grant consent when approached by both OPO and hospital staff together, compared to 67% when approached by OPO alone and 9% when approached by hospital staff alone. Furthermore, families who knew or were presented with registry evidence of their loved one's donation decisions, were more willing to respect that wish (Scandroglio et al., 2011). Subsequently, the communication strategy of asking the family to respect the patient's wishes, instead of asking for 'permission' appears to positively influence their willingness to authorise a donation request (Christmas et al., 2008).

Siminoff et al. (2001) observed different patterns of interaction between healthcare teams and families who were favourable and unfavourable to DOD. The encounters between healthcare teams and unfavourable families were characteristically brief and non-exploratory. In contrast, families who were favourable had longer and more detailed conversations with healthcare providers about the process of procurement and the funeral arrangements.

Finally, stage F of the schematic indicates that only a fraction of the organs from the actual donor population are used for transplantation purposes. This is because the organs that are retrieved from actual donors are subject to further quality checks by the hospital procurement team, who subsequently determine graft viability for transplantation (Barber et al., 2006).

2.2.4 POLICY DECISIONS AND CONSENT SYSTEMS

In reality, the challenge of organ procurement has started long before the confirmation of death. It has started with the wish of the individual about DOD and the communication of that wish to their family.

Ever since the possibility of DOD became a reality to be integrated into clinical practice, there has been on-going debate about the regulations and ethical considerations guiding the process. As outlined by the WHO (2010), '*the retrieval of organs, tissues and cells can be done after obtaining of consent, and in the absence of any evidence that the deceased objected to this removal*.' This statement presents a duality in the definition of 'consent'; considering both its active, declarative component and its passive or implicit component. This basis gives rise to the two policy frameworks, the 'opt-in' and the 'opt-out' systems.

The ‘opt-in’ system, also known as explicit consent, requires an individual to register their decision to become a donor on a national registry. The registration options also allow an individual to specify whether they are willing to donate their whole body or specific organs and tissues. In contrast, the ‘opt-out’ or presumed consent system, considers all citizens as organ donors unless they have specified otherwise. Ideologically, these two policies appear to embody different ethical judgements; for explicit consent, there is an emphasis on autonomy, whilst presumed consent prioritises utilitarian values and collective social welfare (Gevers et al, 2004).

Several assumptions are made about the pragmatic advantages offered by an opt-out approach. For instance, unlike opt-in, presumed consent does not depend on the unreliable transition of intention into action (Shepherd et al., 2014). This is justified by the fact that several polls report positive attitudes towards DOD, suggesting that as many as nine out of ten people support DOD, but fewer than one in three are registered (Harper et al, 2013).

However, the differences between these two systems seem to matter more in theory than in practice. Studies by Rosenblum et al. (2012) and Rithalia et al. (2009) demonstrated that regardless of the policy framework in place, the ultimate decisive influence on whether a donation request proceeds lies with the deceased’s family and their permission, referred to as a ‘soft opt-out’

An argument supporting the transition into presumed consent focuses on the successful increase in the organ donation rates that countries with opt-out system have achieved. Mossialos et al (2009) studied attitudes and the willingness to donate and grant consent in 15 European countries, finding that people in countries with presumed consent were more willing to donate in relation with participants from countries with opt-in consent systems. Nevertheless, additional factors may be important contributors to organ donation increase as a result of a systematic effort, in which legislation is only one part (Boyarsky et al, 2012; Rithalia et al., 2009).

The case study of default consent system change in Brazil, where the presumed consent system did not have the expected results, acting as a cautionary tale of the dangers of considering legal factors in isolation (Parsons, 2018). In 1997, the country changed from informed consent to presumed consent, adopting the hard line of not consulting the family or respecting any veto to the donation. This approach was received with mistrust by the society, and after less than two years the country changed back to opt-in.

2.2.5THE ROLE OF KNOWLEDGE IN DOD

To help raise awareness among the public, organ donation campaigns take place all over the world celebrating the 'gift of life' and informing people about medical facts, statistical data, and stories of patients. However, the impact of the campaigns in many cases does not meet the expected outcomes, as the direct publicity campaigns have a high cost-effectiveness ratio, without significantly changing the rates of willingness of people to donate (European Consensus Document, 2013; Matesanz and Miranda, 2002).

Individuals who are knowledgeable about organ donation are more likely to discuss the issue with their families (Volz Wenger and Szuks, 2011). This hypothesis was supported by evidence by Haustein and Sellers (2004), who also found that people who had recently been exposed to information about DOD and had discussed the issue with their families were more willing to donate.

Furthermore, in a study with interviews of 58 Indian and Pakistani medical and non-medical university students. Gauher et al. (2013) reported that students recognised that medical education played a positive role in their awareness, knowledge, and willingness to donate organs.

Mekahli et al (2009), in a study with first year medical students in France showed a high percentage (81.1%) willingness to become organ donors, but also revealed deficits among what they knew about transplantation. D' Alessandro et al (2012) refer to studies that show that only 23% of college students register as organ donors, attributing this resistance to a lack of knowledge about organ donation and the procedure of registering, as well as an attitude that is common among young people, which makes the topic not relevant to them.

2.2.6 THE ROLE OF ATTITUDES AND VALUE JUDGEMENTS

For some people, one of the barriers to consent decisions is lack of knowledge on their faith's official position on DOD, including compatibility with teachings about life after death, the sanctity of the body, and burial rituals with the practices of DOD (Oliver et al, 2011). Randhawa et al (2010) in their study with major faith and belief leaders in the UK raise awareness of the fact that organ donation is a novel and complex issue and as such, it is relatively undefined in official and traditional religious texts. This means that guidance is open to the interpretations of religious scholars and community figureheads. As a result, religious concerns can act as a factor for unwillingness to donate organs after death either because people are not aware of what their religion preaches or because they have misunderstood their religion's teachings regarding DOD (Rykhoff et al, 2010).

Bendorf et al (2013) in their comparison of organ donation registration factors in 53 countries examined the complex relationship between religion and organ donation. The study found that Christianity, Judaism, Islam, and Eastern religious faiths support the idea of organ donation, but also identify that in Catholic countries the percentage of live organ donation fall among the lowest in their study. Cantarovich et al (2007) in a survey conducted in European and South American countries showed that people largely ignore the positions of the major faiths, as 47% people believed the Catholic Church allowed organ donation, 24% believed Protestant Church allowed it, 17.3% thought Buddhism allowed it, 15.4% thought that for Judaism, and 4.1% thought that Islam allowed it. Nevertheless, as spirituality is still considered an integral parameter in organ donation decisions, one of the recommendations drawn in the Organ Donation Campaign (2010) is that the interaction between faith leaders, local communities and health organisations, could make awareness activities more inclusive, inform the faith leaders in depth about the medical aspects of the issue and also train the healthcare staff in intercultural understanding.

Gauher et al. (2013) discussed how the attitudes of the older generation, influenced by non-western culture, still have an impact on younger generations, although less significant than before. Both Indian and Pakistani university students considered that the decision to donate is a topic upon which the family is to be consulted, and for Pakistani students, religion was an important factor in their attitude towards organ donation.

Hyde and White (2011) studied the influence that the perception of the recipient's deservedness has on the decision to donate. The survey asked university students and community members to rate the types of persons who need an organ as responsible or not for their condition and evaluate the worthiness of smokers and alcohol dependent patients to receive an organ. Comparing participants that are not registered as donors and those that are, the non-registered respondents had more negative perceptions of the transplant patient, considering that it is most likely to be a smoker, alcohol dependent, responsible for the health condition, undeserving person.

A valuable and highly preferred source for getting informed about DOD are the media, particularly television. Stories in television convey cognitive and emotional messages, and at the same time act as agents of social modelling (Morgan et al., 2010). Studies about the messages conveyed in prime-time American medical dramas (Harbaugh et al, 2011; Quick, 2009) found that many messages were conflicting and myths about organ donation were reproduced, generating sentiments of mistrust towards the healthcare team. Morgan and Miller (2002), Morgan et al, (2005; 2007) also showed that negative messages had a strong impact on people, as they were memorable and reproduced in family discussions as a justification of people's unwillingness to become donors. Following this line of research Khalil and

Rintamaki (2014) showed that viewers of dramas were more likely to discuss DOD with other people, when the storylines were memorable.

2..2.7 DOD OVERVIEW IN THE UK, NETHERLANDS AND SPAIN

Legislature, registration options, in-hospital protocols and promotional efforts for DOD vary highly from country to country. This section presents a historical and contemporary overview of the practices and challenges of DOD in each of the three countries participating in this research.

The most recent data of the International Registry of Organ Donation and Transplantation (IRODaT , 2019) as published in March 2019, shows the organ donation rates worldwide **(figure 2.3)**. According to this registry, Spain has the highest rate among the three. This is approximately twice as high as the DOD rate in the UK , which had the second highest donation rate. The Netherlands had the lowest rates among the three

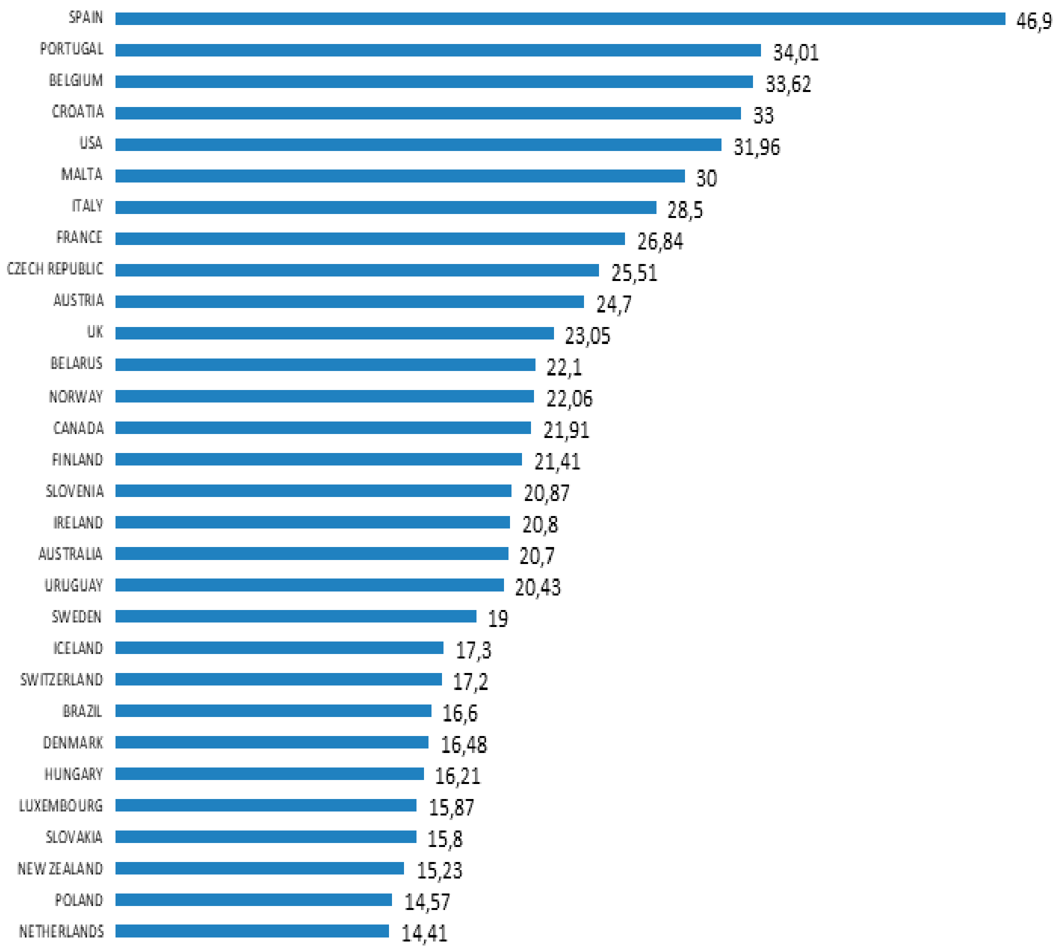


Figure 2. 3 National DOD rate comparison, Diagram adapted from IRODaT report, 2019 Numbers in parts per million (ppm).

2.2.8 OVERVIEW OF DOD IN THE UK

In 1961, the ‘Human Tissue Act’ enabled anyone who expressed a desire in the presence of witnesses for their organs to be used for therapeutic purposes after their demise, to do so. The UK’s official ‘opt-in’ donor registry was established in 1994, by Health Secretary Virginia Bottomley. This enabled people who wished to become an organ donor to formally register their decision within a national database. In 2004, the Human Tissue Act 1961 was repealed and enabled the person responsible for a deceased individual to give consent for the donation of organs; giving rise to the decisive influence of familial consent, regardless of the default consent system (Hall and Parkin, 2016).

Despite these legislative changes, donation and transplantation rates remained low. 7,000 people in the UK were added to the waiting list last year, while 1,300 people became too ill or died waiting for a transplant (Organ Donation Taskforce, 2010). In 2008, the Organ Donation Taskforce (ODTF) report investigated the factors contributing to this issue and identified two core obstacles; the in-hospital process of donor identification and referral by the transplant coordinator team and the high rates of family refusal. A follow-up report produced by ODTF in 2013 revealed an overall 50% increase in organ donation rates, alongside a 30.5% increase in the actual rates of transplantation (NHSBT,2013). This increase was attributed to enhanced coordination within the hospital taskforce, consisting of Specialist Nurses in Organ Donation (SN-ODs) and a more established organ retrieval service by NHSBT. However, the report emphasised that this rise must also be interpreted in the context of the expanded criteria for the confirmation of death. The identification of potential donors was not solely based on mainstay deceased brain death (DBD) but also on deceased circulatory death (DCD) criteria. The ODT also reported no improvement in overcoming the barrier of familial refusal, characterising these refusal rates as ‘*one of the highest in Europe, currently at 43%*’ (NHSBT, 2013). The refusal rates are especially high among Black, Asian and Minority Ethnic (BAME) populations, who also represent over a quarter of those on the waiting list, but only account for one twentieth of the population of potential donors (NHSBT, 2014).

England started a public consultation in 2015, which concluded that the country will move to an opt-out system in spring 2020. In Wales, the law changed to presumed consent in 2015 with moderate increases in DOD (Albertson, 2018). People who do not want to be considered donors or want to donate certain organs have to register in the NHS Organ Register. If they do not want to make this decision themselves, they can nominate up to 2 individuals who will decide on their behalf. These individuals can be family members, friends or anyone else is suitable to make this decision. In the rest of the UK, including Scotland and Northern Ireland, the default system is informed consent. Since June 2018 the Scottish Parliament has considered a change of the consent system. Northern Ireland will remain in the informed consent system (NHSBT, nd (a)).

Several initiatives have been proposed to increase DOD rates in the UK. The official NHS report, 'Taking Organ Transplantation to 2020' (NHSBT, 2016b) suggests a possible strategy, resting on four pillars. The first pillar attempts to increase consent rates through public awareness and health literacy on organ donation. This operates on the assumption that families are better prepared to address the donation request when they can expect it and have knowledge of their relative's wish. The initiative also intends to establish the closer cooperation and stronger engagement of the BAME community, educating these communities on the benefits of organ donation. The second pillar suggests improvements in clinical practices and infrastructure that would better monitor the performance of each NHS Trust and also support the donation of as many organs as possible by each donor. The third pillar focuses on achieving greater consistency in the organ selection criteria and offer more options for their optimal preservation. The last pillar places emphasis on the optimisation of resources and training programmes to increase clinicians' expertise in the identification of potential donors.

Increasing the number of deceased donors per million population (pmp) from 19.1pmp to 26pmp is also considered, by the report, a feasible target, only attainable realistically by the coordination of efforts by the government and healthcare professionals to improve public awareness and knowledge about organ donation. The report also reported a financial benefit to increasing DOD rates. An increase in the number of transplants and reduction in the number of patients on waiting lists could save the NHS over £316million (NHSBT, 2013). According to Hall et al in 2016, the NHS Health Development Agency in 2004 suggested that the use of mass media as a credible tool to increase public awareness on an issue. This was employed by NHSBT, by running annual campaigns such as National Transplant Week to inform those already or are interested in registering and their family and friends about organ donation through the use of multiple social media platforms (Hall and Parkin, 2016).

2.2.9 OVERVIEW OF DOD IN THE NETHERLANDS

Since 1998, DOD practices in the Netherlands operated under an informed consent system. After July 2020 the country will adopt the presumed consent system.

In 1991, the Dutch government identified two key issues hindering the supply of organs available for transplantation (Coppen, 2010). Firstly, there was a general consensus concerning a lack of trust in the healthcare team responsible for organ donation, and secondly, a lack of structure and organisation in the procedure of organ donation in hospitals. Uncertainty surrounding the new concept of organ donation and insufficient training of medical staff in identification of donors, obtaining consent and organ retrieval methods prompted the Dutch Government to develop the Dutch Organ Donation Act in 1998 (Coppen, 2010).

The 1998 Act operates on the grounds of explicit consent and is dually a part of Public Law (Coppen, 2010) to protect the public interest. This was designed to safeguard the donor's integrity, consistent with article 11 of the Dutch Constitution. The Act also sought, as its main aim, to increase the supply of organs and ensure fair allocation to recipients on the waiting list and to prevent illegal and commercialised organ donation. As an outreach effort to involve more people in organ donation, a form is sent to young people when they reach the age of 18 in which they can declare if they object to organ donation, if they want to donate all or parts of their organs, or if they want to nominate a family member to make this decision for them (Gevers et al, 2004).

An additional requirement for all hospitals included having a donor protocol and donation committee which would provide the basic framework for additional policies to be implemented in the future. Following the 1998 Act, the Netherlands Transplant Society (NTS) was founded to ensure adequate implementation of the Act and create a network for consultation and information about the process and concept of organ donation. In order to increase the supply of organs, the NTS introduced specialised transplant coordination teams in hospitals and designated medical officers to increase public awareness of organ donation. In order to ensure the fair allocation of organs, the Act relegated the responsibility to the Eurotransplant International Foundation, reasoning that participating in cross border allocation schemes increases the overall donor pool (Coppen, 2010). The Netherlands is part of the Eurotransplant alliance, in which Austria, Belgium, Croatia, Germany, Luxembourg, and Slovenia also participate Oosterlee and Rahmel (2010). In 2009, approximately 1288 people were in need of an organ transplant, but only 200 deceased organ donors each year (Coppen, 2010).

With regard to donor education, the Donor Information Foundation, Stichting Donorvoorlichting (SDV), was established in 1976 to provide an introduction to the concept of organ donation. The main aims of the partnership focused on increasing the numbers of people on the donor register, increasing public awareness and knowledge on organs donation, especially targeting groups such as next of kin, or religious groups. Religious leaders had been approached to explain their faith's stand on the issue, information packs for churches and mosques to inform their followers, as well as people encouraged to talk about their wishes with their families.

Family refusal continues to be a serious barrier to organ donation. Jansen et al (2010) reviewed medical records in 64 Dutch hospitals, between the years 2005-2008 and found that family objection to organ donation accounted for about 60% of the organ donation losses.

Further developments are being considered to increase the supply of organs in the Netherlands. This includes stronger public health awareness campaigns, hospital training and education schemes to teach and better prepare the general public and hospital staff on the process of organ retrieval and obtaining consent (Coppen, 2010).

2.2.10 OVERVIEW OF DOD IN SPAIN

In recent years, Spain has been regarded as the ‘gold standard’ operational paradigm for DOD, steadily maintaining the highest donation and transplantation rates in the (Rodriguez-Arias et al, 2010). However, although the overall national rate is very high, there have been regional variations recorded, with rural rates as low as 17.4 donors pmp, compared to 74.2 donors pmp in urban areas (Matesanz et al, 2011).

In 1979, under the ‘Spanish Transplantation Law’, Spain adopted presumed consent policy, with familial decisive influence (Bramhall, 2011). Despite legislation being an integral component in Spain’s success, it only represents part of a wider infrastructure. A decade after the legislation of presumed consent was introduced, Spain’s national transplant organization, Organización Nacional de Trasplantes (ONT), was established by the Ministry of Health. The purpose of this organisation was to coordinate legal, medical and promotional efforts, with the end-goal of creating a self-perpetuating pro-donation culture (Matesanz, 1992).

At a hospital level, ONT oversees the teams of transplant coordinators (TCs) who are responsible for identifying potential donors and liaising with family members. These coordinators are mainly physicians and nurses who have received specialist training in the early identification of potential donors and family liaison services. Patients who enter the hospital with severe brain injuries are admitted to intensive care for potential DBD to be diagnosed. Their ultimate role is to conciliate the prospect of DOD within intensive care units and integrate it as part of standard end of life care (NICE, 2011). Over the recent years, the ONT has closely collaborated with medical societies, such as Critical Care Medicine, Coronary Units of Neurology and of Emergency Care to engage and train healthcare professionals of different specialties which are directly or indirectly involved in medical care leading up to organ donation (Matesanz et al, 2011).

Another aspect which contributes to the success of the Spanish model is the close collaboration with journalists and local networks. This has proven to be a critical component in establishing a general trustworthy and transparent attitude towards organ donation in Spain. Journalists are invited to attend and participate in seminars in order to be informed of the latest organ donation news and to accurately interpret developments regarding organ donation. This direct reporting to the media, has proven to be cost-effective as it reduces the need to spend large sums of money on awareness campaigns, but also links the local communities with the organ donation successes (Freeman, 2000; McMaster and Vadeyar, 1999).

Aspects of the Spanish Model such as the use of transplant coordinators, a central national transplant organisation with a role comparable to ONT and a close network of procurement hospitals have been adopted by other countries. The success in these cases depends on how these components fit into the national healthcare systems. In Croatia and Portugal, in the period 2006-2009, DOD rates successfully increased by 37% and 54% respectively through this strategy (Matesanz et al, 2011).

Nevertheless, there are areas for improvement and development. Spain recently unsuccessfully trialled an ‘old for old’ policy, which allocated organs from older donors, which were deemed ‘unusable’ by conventional criteria, to older recipients (Frei et al, 2008). This suggests that the next stage of evolution for the Spanish model involves the refinement protocols for older patients, patients with rare conditions and DCD (Matesanz et al, 2017)

2.3 SECTION B

2.3.1 HEALTH LITERACY

HL emerged as a technical term in the social sciences in 1974, in a discussion of health education as a policy issue affecting the health system (Ratzan, 2001). Above all, the purpose of HL defines an individual’s ability to make informed decisions about their health. The majority of studies discussing health literacy confine its uses exclusively in the context of the healthcare setting. Broader notions of HL extrapolate its principles and consider its capacity to allow individuals to interact with, pass judgement on and act upon messages in a wider context.

2.3.2 HL IN HEALTHCARE

Medical health literacy refers to the optimal use of medical services, doctor visits, compliance with medical information, specialised terminology, complex procedures, disease management and patient safety (Abel, 2008). The benefits of this approach are best seen in the context of the management of chronic conditions. A cross-sectional observation study of 131 patients in out-patient pain clinics demonstrated that patients with inadequate health literacy skills were older people, with increased comorbidities, poor disease-related knowledge and less likely to utilise health services (Mackey et al, 2019). From this study, it is evident that the individuals most lacking in health literacy skills are also those who are most in need of these skills. Furthermore, the Institute of Medicine (IOM, 2004) asserted that the health literacy demands of healthcare settings place a strong burden to people of all literacy levels, and as a result even highly literate people may be challenged.

Certain groups are at higher risk of limited health literacy. This includes senior citizens, migrants, ethnic minority groups and people from a low socio-economic background (Roberts, 2015; Kutner et al, 2006). Communication strategies to overcome conversational challenges will respect the needs of these individuals so that these patients are not excluded from the decision-making and design of the treatment system (Frosch and Elwyn , 2014).

Various studies have explored the HL skills of transplant patients, including their understanding of medical terms, compliance with medication and skills of self-management (Lora et al, 2011; Campbell & Duddle, 2010). Chisholm et al (2007) found that around 70% of the patients on renal dialysis had limited numeracy skills and consequently, had difficulties adhering to their immunosuppressive treatment. Devraj and Gordon (2009) developed a conceptual model of health literacy among patients with chronic kidney disease (CKD), reaching the conclusion that the best time to consider enhancing patients’ pre-existing health literacy requirements is at the earliest stages of disease progression.

2.3.3 HL MEASUREMENT

The majority of existing tools for measuring health literacy are considered limited in their use for successfully mapping health literacy and all the principles it encompasses by only focusing on measuring linguistic and numerical skills (Pleasant et al, 2011). Some examples of HL measurement tools include :

- The Test of Functional Health Literacy of Adults (TOFHLA) was developed as a tool for assessing patients' reading comprehension of instructions and informed consent forms with 50 items, as well as numeracy with 17 items. The scores assess HL as 'inadequate', 'marginal' and 'adequate'. A shorter version, S-TOFHLA, was developed, containing fewer items both in reading comprehension and numeracy (Pleasant et al, 2011).
- The Rapid Estimate of Adult Literacy in Medicine (REALM) measures reading comprehension and pronunciation of 66 common medical terms (Murphy et al, 1993). Among its advantages is the short time (3 minutes) in which it can be administered and scored. These scores are used to contribute to the retraining of administrative personnel.
- Medical Term Recognition Test (METER) is a self-administered and assesses the recognition of health terms (Rawson et al, 2009).
- Health Literacy Skills Instrument (HLSI) also a skills-based tool, which measures print literacy, numeracy, oral literacy and navigation on the Internet (Bann et al, 2012).
- Chinn & McCarthy (2013) developed the All Aspects of Health Literacy Scale (AALHS) to measure functional, communicative and critical health literacy. This tool adapted items of other scales and behaved as a self-reported questionnaire used within the primary health care setting.

2.3.4 HL IN UK, NETHERLANDS AND SPAIN

The European Health Literacy Survey (HLS-EU) focused on strengthening people's knowledge, motivation and competencies. This encouraged them to be active partners in managing their health and at the same time, the need to reduce the complex parts of the healthcare systems and society. The HLS-EU measured HL over four competencies. The first two; *accessing* and *understanding* are considered basic competencies; whilst the final two are more complex. These involve *appraising* and *acting* in three interrelated domains; healthcare, disease prevention and health promotion. This survey became the first comparative assessment of HL standards in Europe.

The distribution and completion took place in 2011 in eight European countries; Austria, Bulgaria, Germany, Greece, Spain, Ireland, the Netherlands and Poland (Sorensen et al 2012). The results revealed four levels of HL; 'inadequate, problematic, sufficient and excellent'. Across all countries, an average 12.4% of the European population demonstrated 'inadequate HL'. This varied between countries. The Netherlands population displayed the highest level of health literacy, with only 1.8% of the population falling into the ‘inadequate’ category, 26.9% was ‘problematic’, the majority, 46.3% were in the ‘sufficient’ category and approximately a quarter, 25.1%, possessed ‘excellent’ HL (van der Heide et al, 2013). Comparatively, in Spain, 7.5% of the population possessed ‘inadequate’ HL, whilst the majority, 50.8% fell into the ‘problematic’ category. No information was available for the United Kingdom, as it was not one of the participatory countries. The survey findings imply a different effect, perception and reception of health information among different cultures. This suggests the importance of taking into account the impact of social determinants on HL. Specifically, the HLS-EU identified financial status as the strongest predictor of low or inadequate HL. This was followed by social status, education and age.

In the United Kingdom, the Skills for Life National Survey (SLNS) (Department for Education, 2003) assessed the literacy skills of a sample of eight thousand people. The SLNS found that 75% of participants possessed literacy skills below the level needed to achieve their full potential (Protheroe et al, 2009). In another study by Rowlands et al (2015), the researchers assessed the participants’ comprehension of 64 real life health materials to determine the threshold level of literacy skills among 16-65-year-old participants. The survey found that 46% of the participants were unable to engage sufficiently with health promotion materials involving text only content and a 61% literacy skill deficiency when the materials incorporated both literacy and numeracy skills.

2.3.5. LIFELONG LEARNING AND SKILL DEVELOPMENT

The theory of lifelong learning outlines how an individual’s literary skills develop through the course of their life (Laal and Salamati, 2012). One proposed mechanism is that an individual must first acquire a core set of technical skills, such as reading and writing which then serve as a foundation for the development of higher cognitive and critical skills. Alternatively, literacy skills can be developed alongside non-literary skills, symbiotically. An example of this approach is embedding information about health issues in school reading comprehension materials. This technique was employed in the HIV/AIDS awareness campaign with considerable success, where informative material was placed in the curriculum in primary and secondary education (Murphy et al, 2010).

The development and maintenance of literacy skills are lifelong processes. Furthermore, progress is not necessarily linear. For instance, although the duration of schooling can serve as a predictor of skill level, other factors might mitigate this influence and cause a decline in literary skills, such as increasing age or migration to a country, which might require the acquisition of new literary skills. In the complex environments of today’s society, people’s skills require continuous updating. This is a necessity as individuals are constantly inundated with new sources and formats of information (Horrigan , 2016).

2.3.6 SOCIO-COGNITIVE DEVELOPMENT, QUALITY OF LIFE AND SOCIAL CHANGE

Within a social context, HL is 'the degree to which individuals and groups can obtain, process, understand, evaluate and act upon information needed to make public health decisions that benefit the community." (Freedman et al, 2009). This perspective explores the psychosocial factors that shape HL and its outcomes. Kickbush and Maag (2008) consider civic responsibility as an advanced stage of health literacy. This expands the applications of HL from an individual to a social level.

The World Health Organization's (WHO) Global Conference on Health Promotion, 2017 referred to health literacy as '*the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health for themselves, their families and their communities*" (WHO, 2016). Individuals must be empowered to navigate the often complex health systems and ask for change when health systems, community and governmental policies do not adequately serve their needs (WHO, 2016). This concept expanded the definition of Sorensen et al (2012), who emphasised the importance of 'literacy' in health literacy:

" Health Literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and make decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course."

The United Nations (UN) declared the Literacy Decade of 2003-2013, promoting literacy a cultural and socio-developmental goal with the potential to improve quality of life and drive social change; eradication of poverty, the reduction of child mortality, and as a catalyst for growth, equality and peace (UNESCO, 2005). Following this initiative, UNESCO perpetuated its mission with the 'Education for Sustainable Development Goals 2030' Agenda (UNESCO, 2017) **(figure 2.4).**

Figure 2. 4 UNESCO Education for Sustainable Development Goals 2030 agenda overview (UNESCO,nd)

Literacy is defined as a set of technical and neutral skills, required for the purposes of reading, writing and calculation, as well as independent contexts (UNESCO, 2005). It is a dynamic, multi-dimensional and longitudinal concept (Poureslami et al, 2016). This means it is both a concept and a science, without an exhaustive definition, that evolves over time and in different contexts. The most important aspect of literacy is that it is a transferable skill. In the 1970s, socially situated literacy was considered solely within a work-based context. The skills that were considered necessary were those which increased productivity (Freire, 1970) . Enhancing quality of life by means of supporting livelihood is still at the core of current literacy-promoting initiatives. However, this is now only considered one fraction of the plethora of ways in which literacy can enhance the quality of life.

During the 1990s, ethnographic research studied the role of literacy in social contexts and questioned the dichotomous distinction of populations as either literate or illiterate (Collins, 1995). The conclusion was that literacy is not a binary identity, either present or absent, but a continuum of skills, acquired within and beyond the classroom. Literacy is a tool that serves a functional purpose but also self-expression and cultural development (Papen, 2005). This gave rise to the notion of socially-situated literacy, which considers literacy in the context of broader social goals and interactions (Barton & Hamilton, 2000. The ideological aspects of literacy are examined through questions which examine power relations regarding those who control and distribute written communication, those who are benefited, strengthened or weakened by these communications (Tett et al 2012; Street,1984).

HL can also function as a source for empowerment and self-efficacy. Critical health literacy moves beyond the competencies of literacy with respect to health-related materials and instructions into looking at the causes of health inequalities. This is seen as an asset, putting into motion individual behaviours as well as social actions, serving to increase health outcomes (Nutbeam, 2008). Nutbeam considered adopting the principles of adult education and tailoring health education activities according to individuals' pre-existing knowledge, inviting interaction and critical analysis of information.

Individuals' must not only interpret medical knowledge but also see the personal relevance of information, change patterns of consumption and motivate social action in order to restore inequalities. Sykes et al (2013) underlined the need for collaboration among individuals, communities and health professionals for developing structural changes.

A radical perspective on the roles of learners and teachers was expressed by Brazilian educationalist Paolo Freire, who explored the distinction between narrative and transformative education (Freire, 1970). Freire opposed the concept of narrative education, which follows a top-down information processing and educator-centred approach. Instead, Freire suggested that literacy should be taught in a way that transforms people's lives through empowerment and encouraging them to take action. Transformative education encouraged people to define, analyse and reflect on how the political, social and economic forces shape their reality.

This evolved into the concept of 'critical literacy', discouraging the passive consumption of information and promoting the ability to question the source and content of the information itself so as to make personally relevant decisions. Critical literacy is considered the mechanism by which information can become action, or 'praxis' to change inequalities and transform society (Darwish et al, 2009). In the Persepolis Declaration (International Symposium of Literacy 1975) literacy contributes to the liberation of man, thus, becoming a tool of emancipation and empowerment of people, who become active literate citizens, both understanding their rights and becoming agents of change in their environment. Social structures are transformed when all participating actors reflect on their situation and act to change those situations. Green (2008), in his three-dimensional literacy model, tried to encompass functional and socially situated literacy with transformative action. HL theories consider micro and macro variables affecting people's decision in healthcare. Individual's views are considered alongside communication and their aptitude and knowledge on a subject. These socio-cognitive parameters have been explored through different practical concepts which are utilised to further explore the evolving field of HL. A summary of the key theories, concepts and broader socio-cognitive categories are outlined in **table 2.1.**

THEORY	CONCEPT	BROAD HL DOMAIN
Critical HL **-A**ssessing the personal motivation for HL , and investigating health inequalities (Nutbeam, 2008)	• Comorbidities and certain demographics related to low HL (Mackey et al, 2019) • Certain groups have shown to display low HL- (Kutner et al 2015) • **AIC-** self-reporting questionnaire assessing • **HSL-EU-** assessment on motivation for behaviour and attitudes	**INDIVIDUAL**
HL in the social context -Extraction of information from sources and subsequent use (Freedman et al, 2009)	• Communication strategies to reduce difficulties in communication Frosch and Elwyn (2014) • **TOFHLA-** comprehension of instruction- understanding and communicating informed consent • **HLSI-** understanding information conveyed via online websites and common medical terms	**SOCIAL**
Comprehension of Knowledge -Understanding medical terminology/processes (Campbell and Duddle, 2010)	• **REALM**- assesses understanding of common medical terms • **METER**- assessed recognition of health terms • **HSL-EU-** assessment of knowledge	**COGNITIVE**

Table 2. 1 Table summarising key HL theories, practical concepts and their broader HL domains. Original table.

2.4. SECTION C

2.4.1 DHQ DESIGN AND DEVELOPMENT

So far, Sections A and B of this chapter presented a review of the current status of DOD and HL, respectively. The outcomes of these sections generate the first iteration of broad frameworks that may be incorporated in the design of the DOD-HL Questionnaire (DHQ). This section aims to extrapolate, categorise and synthesise these concepts, using content analysis methodology to extract information from the national DOD websites for each of the countries participating in this research.

These websites present the official HL agenda in each country and function as an official reference point for top-down information processing, thereby connecting public health organisations and citizens. The thematic report and feature comparison chart derived from the content analysis inform the domain selection and DHQ design. This chapter ends with further detail on the questionnaire version history, the pre-piloting and pre-piloting processes, the validity and reliability testing.

2.4.2 BACKGROUND OF NATIONAL TRANSPLANT ORGANISATION DOD WEBSITES: ORIGINS AND AGENDA

In the European Union (EU), the National Agencies for Organ Donation (NAODs) provide the public with official information about DOD through their corresponding website. These websites present to the public the status of DOD in their country, arguments to support DOD and registration options. Historically, health information to the general public was almost exclusively through government provision. Since the late twentieth century, many countries have endorsed the use of consolidated information websites, whose purpose is to increase community access to high quality, evidence-based health related information (Bastian, 2008).

This decision is guided by the desire to promote education as a catalyst for informed decision making and empowerment, both of which serve and motivate service-user autonomy. To serve this function, the information that is provided must support individual decision making in accordance with people’s own values (Sackett et al, 2000), with content that is designed both to inform and direct the public (Glenton, Paulsen & Oxman, 2005).

2.4.3. METHODOLOGY

2.4.3.1. THEORETICAL FRAMEWORK

A qualitative cross-comparative content analysis was employed to extract the thematic patterning of the three websites. This is a flexible mixed-methods research technique, frequently utilised in social-science information studies and in the analysis of mass communication methods (White & Marsh, 2006). A humanistic and inductive process, "Content analysis is a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" (Krippendorff, 2004).

The theoretical basis for quantifying and recording HL through qualitative parameters is rooted in social marketing target analysis (SMT). This is an interdisciplinary approach adopted by the World Health Organisation for use in the analysis of health learning materials (Manoff, 1985). SMT provides observational information about service user tendencies, with the purpose of bridging the chasm between educational assumption and social reality.

2.4.3.2. DATA COLLECTION

The exploratory research initiated with a review of the national DOD websites for each of the participating countries to uncover what information is currently available on the topic of DOD and what national governments and public health organisations (National Health Service Blood and Transplant (NHSBT, n.d (b)) in the UK, Netherlands Transplantation Society (NTS, n.d) in the Netherlands and Organizacion Nacional de Trasplantes (ONT,n.d) in Spain consider relevant information in guiding decision making and motivating behaviours.

The objectives underpinned by the research aims guide the analytical constructs for the extraction of information. These explore the websites' functionality as tools for empowering health communication and informed-decision making on DOD (Kettunen et al, 2006).In the initial stage, emphasis was placed on making inferences based on qualitative analysis of identifiable and recurring manifest content. Subsequently, this analysis was broadened to include an assessment of the functional pragmatics of the content and its hermeneutic implications. This approach was flexible and allowances were made for inductive sampling of any emergent material and themes that were uncovered on closer inspection of the data. The second criterion for the purposive selection was reflection of good and poor cross-comparability among the three websites. There was no limitation or precept to the nature of the data that was considered (including semantic, pragmatic, textual and non-textual data).

2.4.3.3 DATA PROCESSING, LIMITATIONS AND CHALLENGES

Firstly, the Dutch NTS and Spanish ONT websites were translated into English using the convenient internet based automatic page translation. This was of considerable utility; aiding initial cross-comparability and reliability, avoiding human errors in downstream processing and potential interpretation bias. Furthermore, this simulates the navigation methods used by information-seekers, specifically those that require translation services. Finally, this reflects the notion that the English language is an international medium for web-based communication (Berland, Elliot & Morales, 2001). Nevertheless, internet-based translation presents challenges pertaining to word-sense disambiguation and accuracy. This has the potential to generate limitations in the inferential and hermeneutic analysis, as it is more difficult for a computer based translation algorithm to convey the essence of the original text.

For this reason, in order to validate the suitability of these translated versions, the Dutch and Spanish collaborators (Dr. Frank Dor and Professor Daniel Casanova) checked the translations and provide clarifications or modifications where necessary.

2.4.4. RESULTS: WEBSITE CROSS COMPARATIVE CONTENT ANALYSIS

2.4.4.1 FEATURES: AUDIENCE, LINGUISTIC AND STYLISTIC ELEMENTS

All three websites feature separate sections for citizens and medical professionals. This content analysis focuses solely on the information that is directed towards the former group of information seekers, as this group will be issued with the DHQ.

A comparison of the language style of the translated version of each website indicates a strong consideration for audiences with a range of health literacy abilities. The question and answer format adopted by all three websites ensured that information seekers can directly access answers to their questions. As a corollary, this format ensures a low textual density, aiding readability. Furthermore, the register is colloquial, clear and ambiguous, with an avoidance of jargon.

Audio-visual content complements textual narratives and illustrates complex points. This approach was best utilised in the NHSBT website, wherein a video animation, rather than text, is used to introduce key concepts in organ donation. The use of infographics is frequently employed where subsections address particularly technical or complex aspects of the DOD process. The NHSBT website also incorporates several photographs and videos of transplant recipients into every subsection. This has the effect of generating a personable connection and optimises the emotive appeal of the website and the topic. By comparison, the ONT website features the most visually and stylistically homogeneous content, with a greater emphasis on textual tools of information conveyance.

2.4.5 THEMATIC ANALYSIS

Below is a list of the five themes that were consistent among all three national DOD websites:

- Theme 1: Personal values for Donation
- Theme 2: Facts on the DOD process
- Theme 3: Registration Options
- Theme 4: Communication with Family Members
- Theme 5: Promotional Resources

Figure 2.5 summarises how these themes on DOD were further compartmentalised into HL principle domains and used to determine the conceptual framework of the DHQ. A detailed description of the content covered by each theme will now be discussed.

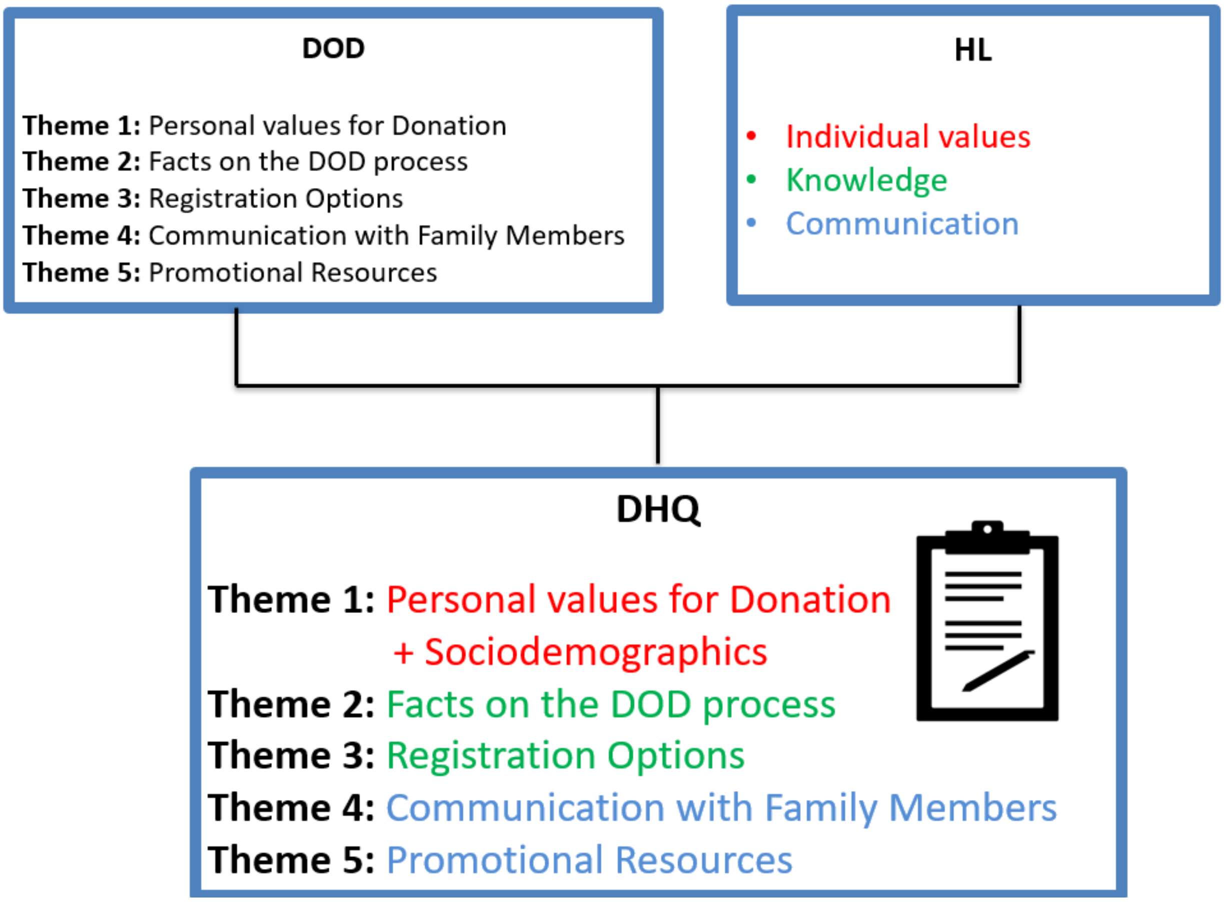


Figure 2. 5 Schematic outlining the combination of DOD themes identified from UK,NL,SP websites and their incorporation into DOD domains for DHQ construction. Original diagram.

2.4.6. PERSONAL VALUES FOR DONATION

The NHSBT homepage opens with a question, ‘if you needed an organ transplant would you have one?’ This makes the organ shortage issue a personal issue and introduces the theme of reciprocity and shared social responsibility, both of which are presented as core principles of the National Health Service. Furthermore, both the NHSBT and NTS websites presents a separate subsection about the compatibility of DOD with spiritual and religious beliefs. An overarching statement asserts that all the major religious groups endorse the act and support the autonomy of the individuals within their congregations. Further information for each specific religion is provided in the form of hyperlinks.

The NTS website addresses the concerns of sceptical information seekers. This includes a wide representation of positive, negative and neutral perspectives from lay people, with direct quotations that delineate each speaker’s rationale. This caters to the need of information seekers to establish personal connections with the topic and to identify with others. Furthermore, this de-emphasises DOD as socially responsible behaviour and focuses on individuals, their values and concerns, thereby promoting autonomy. By presenting decision making as a spectrum, allowance is made for indecisiveness and ambiguity. This allows the visitor to assess their own information needs and to customise their research experience. In terms of pro-donation values, the NTS website endorses the ethical arguments of utility, reciprocity and justice, as presented in the NHSBT website.

The ONT website shares these values and adds the theme of social ‘solidarity’, to which the success of the Spanish model is accredited. Beyond this, there is a strong emphasis on the absence of financial or other remunerative incentives for potential donors, asserting that donation must be an entirely altruistic act. In contrast to the NHSBT and NTS websites, there is no allocated subsection discussing the position of main religions. However, the ONT website fortifies utilitarian pro-donation arguments by stating explicitly that there is no alternative cure for patients on the waiting list with irreversible end organ damage.

2.4.7 FACTS ON THE DOD PROCESS

2.4.7.1 THE ORGAN SHORTAGE ISSUE

The urgency, scale and severity of the organ shortage issue is framed either in the context of how many patients are saved by the gift of transplantation or as how many die patients waiting for a transplant. In the NHSBT and the NTS websites, this is represented with statistics and graphical data. The ONT website’s omission of such detail implies that visitors are already aware of the issue’s existence. Instead, there is a brief reference to the discernible success of Spain in increasing organ donation rates, compared to other countries, within 'The Spanish, an imitated example'.

In the NHSBT website, there is an additional emphasis on the impact of the organ shortage among black, Asian and minority ethnic groups. Whilst these groups are most at risk of medical conditions such as diabetes and high blood pressure that increase their chances of requiring a transplant, they are the least likely to register as organ donors. This is evidenced with statistics. The 'Organ donation and ethnicity' section that is featured directly addresses these communities. It avoids accusatory statements and instead provides explanatory guidance, suggesting that donors from the same ethnic background are more likely to receive a match, based on their blood and tissue type.

2.4.7.2 WAITING LISTS

All three websites specify that waiting list ranking is solely based on medical criteria, as there are equal healthcare rights for all citizens. This means that there are no advancement privileges for individuals who register as donors. Further evidence of waiting list regulation, including procedures determining the eligibility of patients to enter the waiting lists is provided in the NHSBT website. This specifies lifestyle modifications, such as six month abstinence from alcohol and smoking cessation and weight loss, to ensure recipient deservedness and increase the likelihood of successful outcomes following transplantation.

The ONT website explains that patients on waiting lists are evaluated as individual cases by transplant coordinators on the basis of three organ allocation criteria. The first is the territorial criterion, wherein n patients in the same geographical region, as the ischemia time is reduced. The second criterion considers the severity of a recipient, which is prioritised on a national level. The third criterion is based on clinical tests, which assess the match between donor and recipient.

The NTS website provides statistical information for each of the potentially transplantable organs and tissues.

2.4.7.3 ELIGIBILITY CRITERIA

The NHSBT website lists eligibility criteria reference medical conditions such as cancer and HIV/AIDS. In the case of HIV/AIDS, potential donors can offer organs to patients having the same condition. The age criterion can be defined from the upper and lower limits. Regarding the upper limits the UK website sets only two conditions about tissue donation, and more specifically 80 years old for cornea donation and 60 years old for heart valves and tendons, but none for organ donations.

However, the website also claims that the final decision on donation eligibility rests with the clinical judgement of the medical team. Therefore, there are no guidelines that are universally applicable. The lower limit refers to children, acknowledging that although children can register as donors, their parents or guardians have to give consent if they die. NTS also sets 12 years old as the minimum age of registration, and also sets mental competency as a criterion for registering.

2.4.7.4 IN-HOSPITAL PROTOCOLS

All three websites emphasise the protocols and strict regulatory standards followed by the medical team and transplant coordinators for the protection of potential donors. To corroborate these statements, the NHSBT, NTS and ONT websites all reference the appropriate legislature and external regulatory bodies, such as the Human Tissue Authority (HTA). The NHSBT website provides the most information on this, with external links detailing relevant laws and providing information. Furthermore, all three websites explain that patients are entitled to the same duty of care, whether they are potential donors or not.

All three websites explain that only patients dying in intensive care hospital units can become donors, as tests must be run to establish if the patient can donate and which organs. The NTS website provides the most detail about the manner in which a donation request is processed. This includes both a written account and an infographic timeline about the procedure that follows after the identification of a potential donor and every stage of the retrieval surgeries.

2.4.7.5 DEATH

All websites discuss the concept of death in relation to DOD. In NSHBT and ONT websites this is presented in the form of definitions of who is regarded as a donor and relevant inclusion/exclusion criteria of what constitutes a donor. However, the Netherlands have a section on their websites entitled ‘How does organ donation work’, the differences between brain death and donation after circulatory death as emphasised. Moreover, there is a separate subsection on ‘saying goodbye after donation’. This discusses the time-frames between the medical team obtaining consent for donation, letting the family say goodbye before organs are harvested and the body is returned and detail on funeral arrangement is also given. Overall, all countries mention the concept of death in relation to organ donation albeit the NTS website contains more detail on the types of death qualifying for DOD , family’s role and funeral arrangements after the donation process.

2.4.8. REGISTRATION OPTIONS

2.4.8.1 FORMAL REGISTRATION

Information seekers are provided with clear and bold hyperlinks that take them directly to electronic donation registers. In most cases, this subsection is presented chronologically and logically, after the subsections designed to facilitate decision making. This design guides the reader in a logical sequence through pre-contemplation, contemplation and action. The implication is that one's decision is a product of information and personal evaluation of the preceding evidence. The aim is to bridge the gap between passive positive 'supporter' status and the active positive 'registrant' status. All three websites adopt this sequence, with the exception of the NHSBT website, which also presents the registration choices at the homepage and at the margins of all subsequent pages. This consideration addresses a special cohort of individuals that have reached their personal decision prior to visiting the website and solely seek an official platform to formally register their commitment.

2.4.8.2 DECISION AMENDMENT

All three websites present the option to amend registered decisions, however, only the NHSBT and NTS websites provide a direct hyperlink to facilitate this process. The ONT website suggests that registrants who wish to change their decision must inform their family, who should then transmit this information during the donation request. This protocol follows the explanation that donor card holder information is not stored in an official registry.

2.4.8.3 SELECTIVE AND LIVE DONATION

All three websites provide an exhaustive list of organs and tissues that can be donated. The ONT website suggests that while it is possible for individuals to select which organs they wish to donate, given the organ shortage issue, best practise guidelines suggest maximising the utility and contribution each organ donor. Nevertheless, a partial contribution is still preferable to no contribution and any individuals should state their preferences to their families. It is also specified that organs and tissues that are not suitable for donation may be used for scientific research. Furthermore, whilst all three websites provide information on live donation and links to separate websites, only the ONT and NHSBT websites provide information on specialised tissue donation, bone marrow transplantation and the donation of umbilical cord fetal stem cells.

2.4.8.4 LEGISLATURE AND DEFAULT CONSENT SYSTEMS

The national websites for organ donation in the UK, Netherlands and Spain all had designated sections regarding legislature surrounding organ donation. However each country presented this information in a different manner. NHSBT included a subsection on UK laws under the heading of ‘helping you decide’ reiterating the concept and the importance of informed consent. In contrast the NTS website presented this information in the form of a question and answer format under ‘frequently asked questions’ making information more accessible and digestible to the reader. The ONT website for Spain addressed this topic under a specialised information section outlining basic, national and international legislation on the topic of organ donation giving individuals a holistic view of the organ donation process around the world. In each of the websites the differences between opt-in and opt-out were highlighted as well as the steps needed in order for people to officially register their views and refer their questions if they needed clarification on a topic. Any upcoming/potential changes to legislation were also addressed in all three websites.

2.4.9 COMMUNICATION WITH FAMILY MEMBERS

2.4.9.1 IMPORTANCE AND ADVICE

All three websites emphasise the prospective importance of familial discussions. Information seekers are encouraged to personally initiate these conversations and act as sources of information within their social circle. The NHSBT website sets the ‘Tell your family and friends’ section in context, framing this request in shocking figures about family refusal rates. An effective indication of the transformative potential of this act is presented with a juxtaposition of consent statistics when the deceased’s wishes are known, compared to when they are not. This simple anastrophe ensures that visitors understand that donation rates are limited by not only their decisions, but those of their family.

The NHSBT website also provides information regarding the content of conversations. Information-seekers are encouraged to hold a two-way discussion, rather than a one-way discussion wherein they take the time to learn the wishes of their family. The website acknowledges that DOD is a difficult topic to discuss and suggests that different families consider different topics ‘off-limits’. As a solution, a broad and universal template to structure the discussion is offered. This consists of a triad of steps. The first refers to triggers that can initiate the discussion, such as sharing a specific story or news article. The second step involves sharing general information about the positive impact of DOD. Finally, the discussion should become specific once more, wherein individuals discuss their personal reasons for reaching that decision. Throughout this section, there is an underlying encouragement to base this discussion on facts and rational arguments, as these are most easily understood by others and generate the least conflict. Primary narratives and personal experiences are used to demonstrate that conversations can take place between any family members and at any age, such as between parents and young children or grandparents and grandchildren.

The NTS website presents the ‘Donation and Family’ topic in relation to in-hospital protocols. In contrast to the NHSBT and the ONT information, the NTS website states that is is not possible for family members to overturn the individual’s decision. In cases of conflict, the patient’s doctor is responsible for reaching a decision that is based on medical criteria. In addition to this, there is a larger section entitled ‘Talk about Donation at Home’. Similarly to the NHSBT website, it is acknowledged that some people prefer not to discuss difficult topics with their family. However, in contrast to the NHSBT website, an appropriate minimum age for participating in discussions about DOD is suggested as twelve years old. Specialised electronic resources are offered to introduce the topic to younger children.

By comparison, the ONT website has a smaller section dedicated to this topic. Familial consent is a subsection of the general information about DOD and is placed alongside information about transplant laws in Spain. The website emphasises that regardless of the opt-out system, the family’s decision is always respected. There is no explicit appeal for information seekers to initiate discussions with their families, as this need is considered self-evident. Furthermore, the website underplays the need for lengthy discussion by assuming that families would not contradict the wishes of their loved one.

2.4.10. PROMOTIONAL RESOURCES

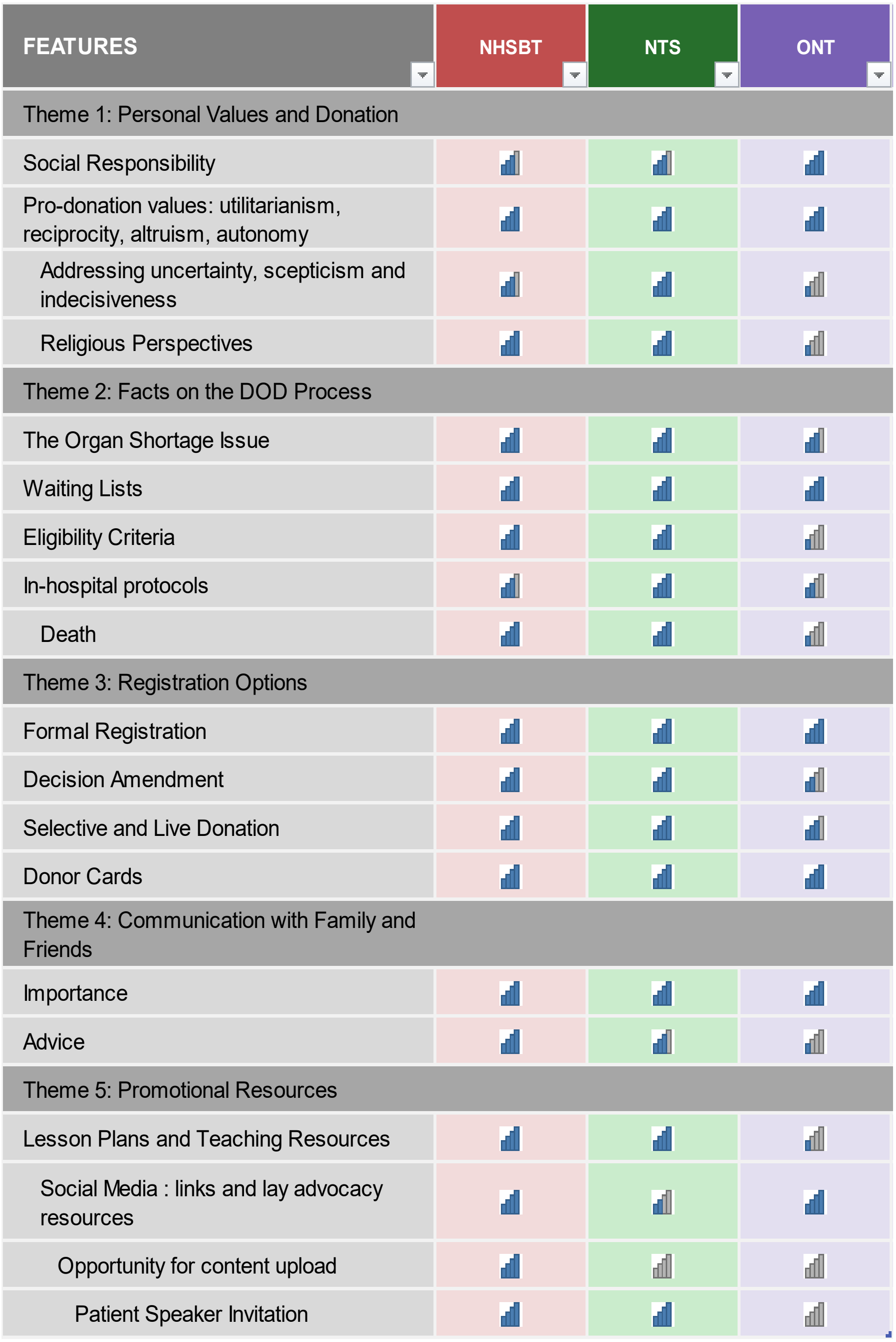
The NHSBT website comprises a ‘Get Involved’ section. This offers educational resources for secondary school students, addressing students aged 11-16 years-old. This consists of a condensed lesson plan, as well as detailed, three part lesson plan for both Personal, Social Health Education (PSHE) and Science curricula, as approved by the National Curriculum agency. The objectives of this activity are to encourage discussion and reflection among young people, who may proceed to engage in discussion with their family. In addition, information seekers are encouraged to become lay advocates, through sharing graphics, videos and electronic registers on social media and within their community. The website also offers visitors the opportunity to upload their own personal experiences on the website.

The ONT website consists of a similar ‘Donation Promotion’ section. This encompasses video resources from official advertising agencies, as well as a collection of relevant films that cover the topic. These resources emphasise the ONT website’s emphasis on the emotional appeal of DOD. In addition, there is a downloadable and shareable calendar, featuring key national and international days of interest. This collection of resources is contained within the ‘Citizen Information’ category. Beyond this, there is an additional category, entitled ‘Press Area’. Herein, the ONT organisation delineates its close and permanent collaboration with the media and the Press Office, to transmit pertinent information. This is described as ‘proactive communication’. The organisation expresses its gratitude to the media, whose contribution in the creation of a positive and pro-donation culture is considered ‘incalculable’.

The NTS website promotion section, ‘Talk about Donating’ is structured in a similar manner to the NHSBT website, with resources for both lay people and teachers. However, the NTS lesson plans are available for both primary and secondary school students within social and science curricula. The website also offers the option of inviting a guest speaker to the classroom. Finally, the NTS website’s ‘Donor Dialogue’ scheme aims to assist citizens who experience language barriers. This initiative matches individuals of the same ethnic background and invites them to discuss the topic and inform each other.

2.4.11 NATIONAL DOD WEBSITE CROSS COMPARISON CHART

The relative representation of these qualitative features within each website are presented in **table 2.2**.



FEATURES	NHSBT	NTS	ONT
Theme 1: Personal Values and Donation			
Social Responsibility	▮▮▮▯	▮▮▮▯	▮▮▮▮
Pro-donation values: utilitarianism, reciprocity, altruism, autonomy	▮▮▮▮	▮▮▮▮	▮▮▮▮
Addressing uncertainty, scepticism and indecisiveness	▮▮▮▯	▮▮▮▮	▮▯▯▯
Religious Perspectives	▮▮▮▮	▮▮▮▮	▮▯▯▯
Theme 2: Facts on the DOD Process			
The Organ Shortage Issue	▮▮▮▮	▮▮▮▮	▮▮▮▯
Waiting Lists	▮▮▮▮	▮▮▮▮	▮▮▮▮
Eligibility Criteria	▮▮▮▮	▮▮▮▮	▮▯▯▯
In-hospital protocols	▮▮▮▯	▮▮▮▮	▮▮▯▯
Death	▮▮▮▮	▮▮▮▮	▮▯▯▯
Theme 3: Registration Options			
Formal Registration	▮▮▮▮	▮▮▮▮	▮▮▮▮
Decision Amendment	▮▮▮▮	▮▮▮▮	▮▮▯▯
Selective and Live Donation	▮▮▮▮	▮▮▮▮	▮▮▮▯
Donor Cards	▮▮▮▮	▮▮▮▮	▮▮▮▮
Theme 4: Communication with Family and Friends			
Importance	▮▮▮▮	▮▮▮▮	▮▮▮▮
Advice	▮▮▮▮	▮▮▮▯	▮▯▯▯
Theme 5: Promotional Resources			
Lesson Plans and Teaching Resources	▮▮▮▮	▮▮▮▮	▮▯▯▯
Social Media : links and lay advocacy resources	▮▮▮▮	▮▮▯▯	▮▮▮▮
Opportunity for content upload	▮▮▮▮	▯▯▯▯	▯▯▯▯
Patient Speaker Invitation	▮▮▮▮	▮▮▮▮	▯▯▯▯

Key	Relative representation of theme
▯▯▯▯	Not Present
▮▯▯▯	Sentence
▮▮▯▯	Paragraph
▮▮▮▯	Subsection
▮▮▮▮	Further Links

Table 2. 2 Cross-comparison table summarising the key themes and topics among the three National DOD websites. Pictogram indicates relative representation of content for each theme. Original table. The bars encode the relative coverage of information dedicated to each theme in each respective website. No highlighted bars indicates that a topic was not discussed (not the case for any), one bar indicates that a sentence was dedicated to the subject, two bars denotes that a paragraph was dedicated to a theme, three bars show that a distinct subsection covered a specific theme and four bars signifies that the all aforementioned conditions were covered and external links were added.

Figure 2.6, summarises the DHQ design process sequence, as outlined in this chapter. This combined design approach ensured that the topics covered in the survey respond to the research aims and be of interest and personal relevance to the potential respondents.

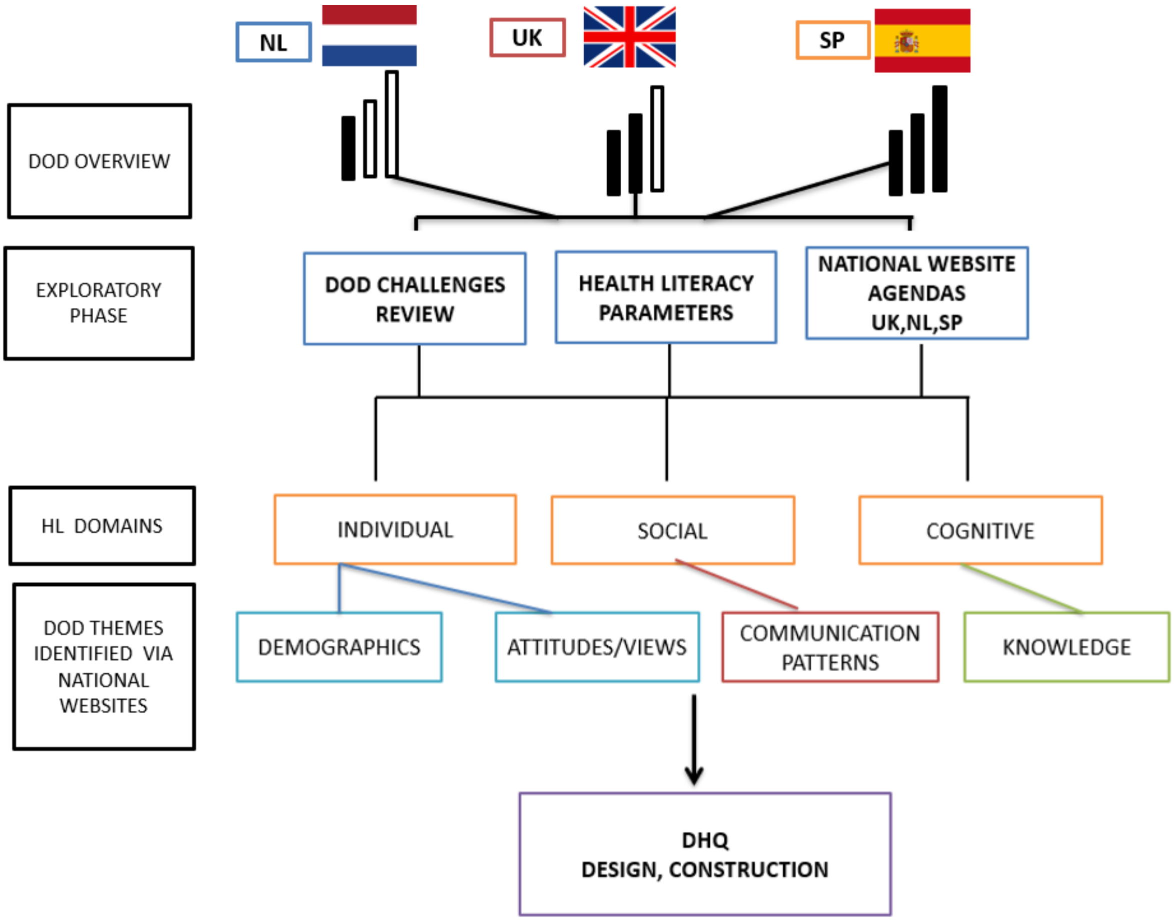


Figure 2. 6 Schematic diagram summarising the DHQ design and conceptual framework. Original diagram.

2.4.12 DHQ DRAFTING PROCESS

After identifying the topics of the questionnaire, the next step was to draft questions and answers. The respondents' task of filling in the questionnaire was facilitated in three ways, the logical progression, phrasing and specificity of questions. The layout order of the topics was considered at this stage, with the sequence of the topics guiding the respondents from more general to more specific questions.

2.4.12.1 PRIMARY OUTCOME MEASURES AND INTENTIONS

Each stage of the design process was guided by the requirement to explore research aims (1) and (2) of the thesis through the DHQ**.** To this end, the categories and questions selected were designed to consider:

- The potential role of HL as an exploratory tool for DOD supporter and registrant profiles
- The ranking of HL domains in exploring supporter-registrant profiling, with the purpose of targeting DOD campaigns

2.4.12.2 DHQ OUTLINE

The final DHQ was obtained after a refinement of the question wording and formatting from the original and revised versions (both in Appendix A), following the comments in the pre-piloting and piloting stages. Below is presented a summary of the question categories that provided the framework used in each version of the questionnaire:

1. Attitudes and Value Judgements
    a. Commitment: i) Support for DOD ii) Registration for DOD
    b. Reasons for (a)
2. Communication Patterns
    a. Expression of one's own wishes
    b. Knowledge of loved one's wishes
    c. Hypothetical Consent for loved one
3. Knowledge Patterns
    a. Source Usage
    b. Organ donation
    c. Health related topics
    d. Confidence
4. Respondent Demographics

2.4.13 DHQ VALIDATION PROCESS

2.4.13.1 PRE-PILOTING AND PILOTING

Pre-piloting and piloting stages were only conducted in the UK in order to optimise the DHQ question types before the translation into Dutch and Spanish. Piloting in the UK was easier to manage logistically in terms of organising feedback sessions, as well as reducing the need for the DHQ to be translated multiple times. A summary of the DHQ validation process is outlined in **figure 2.7.**

The first version of the questionnaire consisted of 66 questions (Appendix A). This was distributed to 12 individuals, consisting of clinicians, medical students and administrative staff at Hammersmith Hospital, London and patients from the West London Kidney Patient Association **(table 2.3)**

As indicated in **table 2.3**, clinicians were included only in the DHQ pre-piloting and piloting stages and were not part of the final sample composition. This is because their expertise was deemed a necessary part of the design process . Specifically, their feedback was particularly helpful in establishing how reliably the DHQ captured and presented topics and concepts in DOD. However, as specified in Chapter 1, this participant category would not be one of the three subgroups (patients, staff and medical students) issued with the final DHQ, which was designed to look at supporter-registrant profiling in three lay populations associated with the healthcare setting. For this reason, the final version of the DHQ was validated only among the three subgroups that would complete the questionnaire for the quantitative analysis of this study.

The same group took part in semi-structured interviews which were used to clarify the areas, topics and questions of the survey and gather general feedback. The discussions were one-to-one, lasted approximately 40 minutes and were structured through the same verbal probes **(table 2.4).** Two main points arose from the pre-piloting interviews. Firstly, while the participants found the questions easy to understand and answer, they would have preferred having more options to select from for their answers. Secondly, they wanted the questions to be organized under headed categories, so that each section of the questionnaire could become clearer for the respondents.

Once more, an inductive approach enabled further modification of the questionnaire on the basis of semi-structured interviews with participants both in the pre-piloting and piloting stages (**table 2.4**). This editing stage focused on refining the phrasing of the questions. The pilot groups' remarks helped locate words, which were difficult to understand or ambiguous, and phrases which needed further explanation. Following the pilot studies, the number of questions and answers was reduced. There was also an effort to word questions and answers in a neutral way, which would not lead respondents into selecting one answer over another or creating the impression that some behaviours were more socially desirable than others The number of question types in each version of the DHQ is outlined in (**table 2.6)**.

Following these comments, three answer format patterns were incorporated:

a) Selecting all the responses that applied to a statement
b) Selecting a rating from a Likert scale (e.g.1-5, 1= not very confident and 5= very confident)
c) Selecting 'True, False, Not Sure' in response to facts

Having incorporated all the remarks from the pre-piloting stage, a second version of the questionnaire was developed (Appendix A). This consisted of 72 questions which were once again piloted to the same individuals from the pre-piloting group, as well as additional volunteers **(see table 2.3)**.

Following this, a third and final version of the questionnaire was devised.

Having incorporated all the remarks made in the previous stages, the final layout of the questionnaire was piloted, so that the final comments could be taken into consideration, before the actual distribution of the questionnaire. Once again to prevent the DHQ versions being translated multiple times and for logistical reasons the piloting was only conducted in the UK albeit there was close collaboration with Dutch and Spanish colleagues at each stage of DHQ construction to inform them and obtain approval for any changes.

Their remarks led to the final proof-read of the questionnaire.

2.4.3.2. DHQ VALIDATION

Face validity was established during the pre-piloting and piloting stages through the one-to-one interviewing. This ensured that the DHQ order to evaluate whether there were any questions that they felt did not capture the topic under investigation.

Secondly, an independent validation group the questions included in the survey were officially validated by a statistical consultant of the Imperial College Office for Statistics. This was conducted by a psychometric and inferential statistical analysis; whereby inter-rater reliability was calculated using Cohen's kappa coefficient (κ) and percentage agreement.

Overall, there was an acceptably high reliability ($\kappa = 0.71$, indicating 'substantial' inter-rater agreement) and a high average percentage agreement (87.50%) ($p < 0.05$). Although both reliability measures are significant, κ coefficient is deemed superior to percentage agreement, as this accounts for the discrepancy between random agreement and perfect agreement (McHugh, 2012).

A full list of the modifications made in response to the pre-piloting and piloting groups' comments is summarised in **table 2.5**.

Participant Subgroup	**Pre-piloting**	**Piloting**	**Final Validation (independent group)**
Patients	5	6	4
Staff	3	5	2
Medical Students	2	5	2
Clinicians (Nephrologist (n= 1), Transplant surgeon (n=1)) ****Included only as expert advisors. Not part of the final sample composition***	2	2	0
Total N=	**12**	**18**	**8**

Table 2. 3 Table summarising the pre-piloting and piloting participant totals from each category.

Category	Verbal Probe
General Probes	'Tell me more', 'How easy or difficult was it to answer the question?'
Comprehension Probes	'How easy is it to understand this term?', 'What does this word mean to you?'
Paraphrasing Probes	'Can you repeat the question in your own words?'
Confidence Judgement Probes	'Why did you choose this answer?'

Table 2. 4 Table outlining the verbal probes used in one-to-one interviews to receive feedback on the DHQ content.

estion types and their frequency after each revised version
n pre-piloting and piloting stages.

Question Format	Example	Version 1 (numbers of q. types)	Pre-Piloting Comments	Version 2 (numbers of q.types)	Piloting Comments	Final Version 3 (numbers of q.types)
Yes/No	Are waiting lists long?	40	Reduce the number of dichotomous responses	15	Reduce the number of dichotomous questions	5
True/false	An organ donor is registered as a tissue donor as well T/F?	0	-	0	-	5
Agree/Disagree	I need my family's consent about my decisions Agree/Disagree?	7	Assess knowledge by including clearer true/false answers to calculate knowledge score	0	-	0
Free text	Until what age can patients receive organs?	11	Options would better enable the reader to answer more accurately	4	Reduce free text answers and guide participants with options	0
Select one/all that apply	Which of these statement would better reflect your thinking	6	Add more value judgement statement	15	Include more questions	19
Likert	How confident do you feel explaining the meaning of these words to a family/friends	2	Include more graded response scales	38	Include less questions on Likert scales	3
Total		**66**		**72**		**32**
ADDITIONAL COMMENTS FOR QUESTIONNAIRE MODIFICATION						
Rephrase technical terms	e.g. Change DOD to donation after death		**15**		**12**	
Correct Neutrality issues	Organ donation is an altruistic act		**6**		**4**	
Structure	Attitudes, Communication, Knowledge	**Continuous questions**	**Structure the questionnaire in themes**	**3 Themes: Attitudes Knowledge Communication**	**Structure the questionnaire in parts and consider subthemes**	**Questionnaire structured in Parts A-E with Themes1-5 explored**

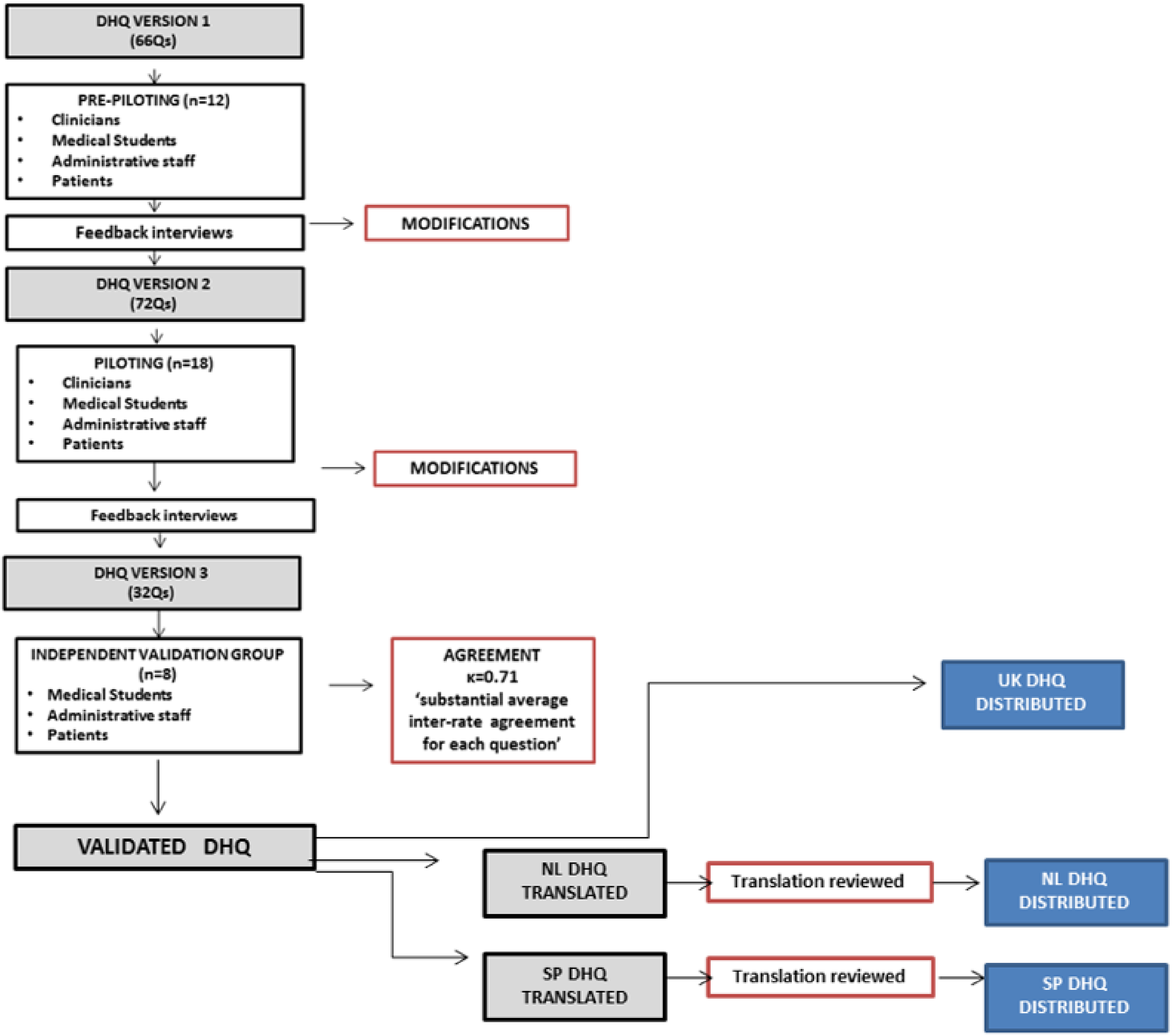


Figure 2. 7 Flow chart outlining the pre-piloting and piloting stages of the DHQ. Original diagram

CHAPTER CONCLUSION

This chapter outlined the use of the literature review of DOD and HL and the official DOD websites in the UK, Netherlands and Spain to aid in the construction of the DHQ used in the study. The websites were compared and common themes were identified which were used to explore different parameters regarding views and general knowledge surrounding DOD. The pre-piloting and piloting stages in the UK implemented modification of the DHQ question types and number to construct the final version of the questionnaire. The development of the DHQ was intended to address the research aims outlined in Chapter 1 and ultimately help construct DOD supporter and registrant profiles and rank specific HL domains within those profiles to help inform DOD campaigns.

CHAPTER 3

DHQ
QUANTITATIVE ANALYSIS: METHODS AND RESULTS

3.1. INTRODUCTION

The previous chapter presented the theoretical framework and validation process used in the development of the DHQ. This chapter presents the DHQ data collection process, analytical methods and results. The methodology and results are split into five parts. They consist of: Part A: Socio-demographics, Part B: Communication, Part C: Knowledge, Part D: Multiple Correspondence Analysis (MCA) and Part E: Predictive Modelling.

3.2 SECTION A: METHODOLOGY

3.2.1 DATA COLLECTION

Data collection took place between May 2016-May 2017. The questionnaires were distributed in each of the three countries involved within this collaboration and were completed by each of the three categories of participant; patients, staff and medical students (**table 3.1**). As mentioned in Chapter 1, ethics approval for the thesis was obtained from the MEEC and REC in the UK (Appendix A). In the Netherlands and Spain, the nature of the study did not require submission to an ethics committee. Oral consent was obtained by co-investigators Dr. Frank Dor (for the Netherlands), and Professor Daniel Casanova (for Spain).

Patients were informed of the opportunity to partake in the survey by members of their hospital healthcare team. The administrative staff and medical students in each country were informed electronically by their line managers and student union, respectively, as well as through face to face advertising methods, such as via announcement after lectures.

The survey was available through a link in the platform of Qualtrics. Qualtrics offers a survey tool, which allows to build, construct, distribute and receive instant feedback from surveys accessed through an anonymous internet link, so that no participant could be identified. By completing the survey, participants entered a prize draw for winning three electronic shopping gift cards, each worth £25 GBP.

3.2.2 DATA PREPARATION

3.2.2.1 SAMPLE RETROSPECTIVE POWER ANALYSIS

The minimum sample size required for each country was 259 participants. This size was selected because it represents a 90% power to detect the difference between the null hypothesis proportion of 0.50 and the alternative proportion of 0.60, given a $p= 0.05$ for two sided-significance level for a given variable (Kadam & Bhalerao, 2010). The advice by the statistical consultant of Imperial College was that separate sample size calculations were not required for each subgroup, and rather it was advised to consider all subgroups in all countries holistically to provide greater cross-sectional and cross-cultural comparability.

Power analysis is an integral part of social-science statistical interpretation. As sample sizes and proportions were different between the three countries and within the three group categories (patients, administrative staff, medical students), a retrospective post-hoc power (PHP) calculation was performed. This evaluates the retrospective power of an observed effect based on the sample size and parameter estimates (Lenth, 2007). In this case, the observed effect being considered was ‘support for DOD’.

Beyond minimising the effect of sample size variation, PHP is also used for verification in cases where results appear statistically nonsignificant ($p > 0.05$). PHP can discern whether this lack of significance is due to low power, owing to a smaller sample size, or if the observed effect is indeed insignificant. If the PHP value is high, then the non-significance is attributed to the effect itself.

3.2.2.2 INCLUSION CRITERIA

The inclusion criteria for all statistical analyses were:

i) All questionnaires in which question 1 was answered;

ii) Variables which have missing values less than 10% of the sample;

After removing all questionnaires that did not meet the required criteria, there total number of questionnaires included in the statistical analysis was N=1111 with UK n=312, Netherlands n=503, Spain n=296 (**table 3.1**).

The highest proportion of missing values were seen for socio-demographic variables. This is due to the fact that this category was the last section in the DHQ, which most participants did not complete in its entirety. For this reason, a separate sample size for this category was calculated, for use in the statistical analysis **(table 3.2)**.

In general, the data set from the Spanish sample had the lowest proportion of missing values. Even in the questions with the most missing values were answered by approximately half of the sample. The UK and Netherlands data sets had comparatively higher proportions of missing values. Notably, the spread of missing variables was different among the three countries. Nevertheless, a common theme was a reluctance to respond to questions indicating an unfavourable view towards DOD. Another category with a high proportion of missing values was ‘source material’. A full table of missing values can be found in Appendix A.

COUNTRY	SUBGROUP	(n)=	(N)=
UK	Patient	141	**312**
	Staff	49	
	Students	122	
Netherlands	Patient	97	**503**
	Staff	240	
	Students	166	
Spain	Patient	77	**296**
	Staff	50	
	Students	169	
TOTAL			**1,111**

Table 3. 1 Table of (n) values used for descriptive statistics. Breakdown of sample populations from the UK, Netherlands and Spain. Number of participant from each subgroup, after inclusion and exclusion criteria were applied. These values were used for all descriptive and analytical statistics, except for sociodemographics.

Country	Demographics (n)
UK	244
NL	119
SP	213

Table 3. 2 Table of (n) values used for sociodemographic analyses. Number of participants used for the sociodemographic descriptive and analytical statistics.

3.3. DATA ANALYSIS

The data analysis was split into 5 parts, each consisting of several non-parametric tests, summarised in **table 3.3**.

3.3.1 PART A: SOCIODEMOGRAPHICS

This is designed to assess the explanatory and confounding influence of individualistic and non-modifiable traits on support and registration for DOD. This is a crucial parameter, as all three national websites noted the requirement to achieve greater engagement with ethnic and religious minority groups.

Hypothesis testing was conducted using the chi-squared test to explore the significance of differences and dependence of support for organ donation and registration status on gender, age, ethnic background, marital status, educational background, religious beliefs and group category (i.e. patient, staff, student). The null hypothesis considered was that there is no statistically significant effect on supporter-registrant for DOD on the basis of sociodemographic characteristics.

3.3.2 PART B: COMMUNICATION

The national websites of all three countries reiterate the potential to overcome family refusal rates through discussion with one's family. Therefore, this is a crucial parameter in the assessment of HL. This parameter examines the occurrence and bidirectionality of DOD discussions between participants and members of their intimate and extended family. In this way, the DHQ maps participant tendencies not only as potential donors but also as family members to potential donors.

Descriptive statistics were used to delineate:

a) Preferential communication towards family members
b) Wishes expressed by participants
c) Wishes of family members expressed to participants
d) Participants' interpretation of (c), by willingness to grant consent

Hypothesis testing assessed whether communications with family members produce a statistically significant effect on decision making.

In defining how effective the communication is, it is necessary to define a distortion measure between the exchange process and the exchange output. For (d), the Cohen's kappa test of agreement was used to assess the participants' ability to accurately interpret the wishes of their loved ones with regard to DOD. In this context, 'agreement' is defined as correct interpretation of a family member's wishes i.e. the participant would grant consent for a family member who expressed a positive wish ($\kappa = 1.0$, 'perfect' agreement).

The following formula was imputed to Statistical Package of the Social Sciences (SPSS) platform:

$$\kappa = 1 - \frac{1 - p_0}{1 - p_e}$$

Where:

$$p_0 = \text{ the relative observed agreement among raters}$$

$$p_e = the\ hypothetical\ probability\ of\ chance\ agreement$$

The kappa statistic is ranked on a scale from 0-1 where:

- 0= chance agreement
- 0.10-0.20='slight' agreement

- 0.21-0.40= ‘fair’ agreement
- 0.41-0.60=‘moderate agreement’
- 0.61-0.80= ‘substantial agreement’
- 0.81-0.99=‘near perfect agreement’
- 1.0= perfect agreement

3.3.3 PART C: KNOWLEDGE

This parameter was designed to assesses the participants’ engagement with information sources and their content. As knowledge is not normally distributed, the non-parametric Kruskal-Wallis Test (KWt) was utilised for the hypothesis testing. This was performed under the null hypothesis of no difference in the knowledge distributions between supporter-registrant status for DOD.

A ‘knowledge score’ was calculated based on whether participants answered correctly, incorrectly or were unsure. This was quantified as +1 for a correct answer, -1 for an incorrect answer and 0 for a response indicating that the participant was not sure. This was calculated for DOD-specific topics and for other health issues. The DOD topics examined were: organ donation, waiting lists, medical care, family’s role and funeral arrangements.

The purpose of examining the participants’’ knowledge of other health issues was to establish a baseline level in which participants generally interact with health literacy campaigns was investigated by assessing knowledge scores in ‘basic’ (smoking, high blood pressure, diabetes) and ‘advanced’ health issues (Alzheimer’s disease, HIV/AIDS, mental illness).

In addition to the five domains, the usage of common sources to obtain information on DOD was explored. Relative usage was then determined through normalisation on a scale of -/+1 indicating proportion of participants selecting the source (-1 indicating few participants selected the source and +1 indicating a high proportion of participants selecting the source).

To gain insight into the respondents’ subjective or self-perceived knowledge, a confidence score (CS) was calculated. This was rated by the participants on a 5-point Likert scale, where 1 represents ‘not confident at all’ and 5 signified ‘feeling very confident’. Subsequently, the Pearson correlation coefficient (PCC) was used to measure the strength of linear regression between the variables ‘knowledge’ and ‘confidence’. The coefficient (r) was measured on a scale ranging from -1 to +1, indicating a perfect regression in the negative and positive direction, respectively.

3.3.4 PART D: MULTIPLE CORRESPONDENCE ANALYSIS (MCA)

The MCA was used to identify the relationships the variables examined in Parts A-C and construct supporter-registrant profiles. Two MCAs were conducted, one on sociodemographic and a second on value judgements, communication and knowledge. These are represented separately due to the higher proportion of missing values in the socio-demographics.

MCA is a multivariate graphical technique used to analyse frequency contingency tables, measuring correspondence between the rows and columns to graphically depict the numerical information as a single point (Costa, 2013). This is useful in understanding the data globally, as well as unveiling hidden inter-relationships between the various responses. As a statistical tool, it is distinguished by the fact that it is not a confirmatory technique; biased towards a specific hypothesis. Instead, it behaves in an exploratory manner, revealing true relationships within the data, summarising the profiles of DOD supporters and registrants and avoiding confirmatory bias (Greenacre, 1992). Furthermore, MCA preserves the categorical nature of variables (Benzecri, 1992).

MCA considers many variables and attempts to map these on a two-dimensional planar landscape. Dimensions are vectors which are combined in order to visually represent relative spatial relationships between multiple variables. For this reason, it is customary to select two adjacent dimensions. These vectors are given a quantified identity, described as the eigenvalue (**tables 3.5, 3.6**). The selected dimensions allow for the maximum amount of information and associations to be displayed. These dimensions were superimposed to demarcate quadrants in order to locate and examine four centroids; ‘support’, ‘no support’, ‘registered’ and ‘non registered’.

Owing to the high proportion of missing values for socio-demographics, it was necessary to feature a separate MCA map for this parameter. This is considered alongside the main MCA map, featuring all parameters.

3.3.5 PART E: PREDICTIVE MODEL FOR SUPPORTER-REGISTRANT STATUS

Predictive modelling analysis using GLM regression was used to consider the relative importance of HL domains in the construction of supporter-registrant profiling. Therefore, the output is presented as a priority-ranked synthesis of the variables within the individual, social and cognitive parameters assessed in the DHQ.

As in the MCA, the model is limited in accounting for socio-demographic variables owing to the low response rate in the DHQ. Therefore, these have been purposively excluded from the predictive regression for two reasons. Firstly, their inclusion would significantly reduce the predictive power of the model.

Secondly, the purpose of the predictive model is to rank HL domains for supporter and registrant profiles by considering only the modifiable variables that can be influenced by campaigns. By comparison, a large proportion of socio-demographic variables were considered non-modifiable. To compensate for this, the predictive regression accounts for the ‘individual’ domain of HL by considering the variables regarding value judgements instead.

For this mathematical model, a logistic linear regression analysis was performed, using the logit function as the link function, synthesising all the independent categorical variables in the questionnaire with the dependent variables of supporter-registrant status. This link function is advantageous, as no transformation of the dependent variables is required. In order to select the best model of fit, a backward step-wise selection was performed based on the Akaike-Information-Criterion (AIC).

AIC is a measure of quality assurance that favours the most parsimonious model. Parsimony is defined as the model with the lowest number of parameters, with the best fit, as assessed by the likelihood function. This serves to prevent over-fitting, which would mean that the model fits training data but does not have any generalisation ability. In the context of backwards step-wise selection, AIC was started with the full model containing all the variables and followed by a step-by-step removal of variables and recalculated AIC. The model with the lowest AIC was selected, as this has the greatest generalisation ability.

The selected model is represented as a confusion matrix, which compares the predictive model’s performance against the actual data, allowing for the calculation of ‘true positive’ (TP), ‘true negative’ (TN), ‘false positive’ (FP) and ‘false negative’ (FN) rates. This matrix is used to assess the predictive model’s performance quality using accuracy, sensitivity and specificity metrics. Accuracy considers the model’s ability to correctly distinguish between registered and non-registered participants. Sensitivity is the proportion of true positive assessments relatively to all positive assessments, and was therefore used to assess the model’s ability to correctly identify registered donors. Specificity considers the model’s ability to identify non-registered participants, as the proportion of true negative assessments relatively to all negative assessments.

PARAMETER	METHODOLOGY
PART A: SOCIO-DEMOGRAPHICS	**Chi-Squared Test** *Null Hypothesis:* There is no statistically significant impact of a participant's socio-demographic characteristics and their supporter-registrant status. (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$, for all hypothesis testing)
PART B: COMMUNICATION	**Chi-Squared Test** *Null Hypothesis:* There is no statistically significant impact of a participant's communication patterns and their supporter-registrant status **Cohen's Kappa Statistic Assessment of Agreement:** Agreement between a participant's consent decision for a particular family member and the wish expressed by that family member.
PART C: KNOWLEDGE	**Source Usage** Relative 'usage' of each source, standardised on a scale of -1 to 1, indicating selection by a low or high proportion of participants, respectively. **Knowledge Score** Standardised 'score' calculated from proportion of 'correct, incorrect and not sure' responses. *Kruskal-Wallis Test (KWt)* Dependence of supporter-registrant status on knowledge score for hypothesis testing of data that is not normally distributed. **Source Usage and Knowledge Score** Comparison of the calculated knowledge score obtained by participants who selected each source. **Confidence and Knowledge Score Pearson Correlation Coefficient (PCC)** Correlation gradient between participant's confidence (self-evaluation of knowledge, selected by participants on a Likert scale) and their calculated knowledge score (objective level of knowledge).
PART D: MULTIPLE CORRESPONDENCE ANALYSIS (MCA)	**Multiple Correspondence Analysis (MCA)** Descriptive factor map, synthesising all the categorical variables (Parts A-C) in relation to centroids for 'no support', 'support', 'not registered', 'registered' categories. Analysis of inter-variable relationships through spatial symmetry

	and co-localisation.
PART E: PREDICTIVE MODEL FOR SUPPORTER-REGISTRANT STATUS	**Generalised Linear Modelling (GLM)** Assessing whether independent categorical variables can be used to predict supporter and registrant status (each one in a separate predictive model). *Akaike-Information Criterion (AIC)* Quality assurance test ensuring parsimony. Performed using sequential elimination of categorical variables until the model with the lowest AIC score was found (indicating the model which best *'fits'* the data, and has the best generalization ability). **Performance Metrics:** p-value, sensitivity, specificity, accuracy

Table 3. 3 Table summarising the key statistical tests used in the quantitative analysis

3.4 SECTION B: DHQ RESULTS

3.4.1 PART A: SOCIO-DEMOGRAPHICS

3.4.1.2INTRODUCTION

Part A of the quantitative analysis presents the descriptive and analytical statistics relating supporter - registrant status to socio-demographic characteristics. Within each demographic parameter the key overall trends, and statistically significant results are emphasised. It must be reiterated that each country has a unique demographic sample composition. These differences create sample artefacts which can account for most of the disparities between countries. Full data on sample composition can be found in Appendix A.

3.4.1.3 GENDER AND SUPPORTER-REGISTRANT STATUS

Both in the total cohort sample and in the participating countries separately (**figures 3.1.A-D(i)**), gender was not a statistically significant descriptor of supporter status ($p > 0.05$). Furthermore, there was no clear trend, attributing pro-donation attitudes to one gender over the other. Nevertheless, there is a clear and strong trend of support for DOD in both groups (male and female >80%).

However, gender was a statistically significant descriptor of registrant status ($p < 0.01$**) (**figure 3.1.A(ii)**). More than half of the male participants were registered as organ donors compared to less than half of the female participants affirming the expectation that support for DOD does not always correlate with registration. This trend is also observed in all three countries separately (**figures 3.1. B-D(ii)**).

3.4.1.4 AGE AND SUPPORTER-REGISTRANT STATUS

Age was a statistically significant feature of supporter status in the total cohort and the Dutch sample ($p < 0.01$** and $p < 0.05$*, respectively) **(figures 3.2 A,C (i))**. There is a strong trend of support across all ages, with a slight decline in the 30-44 age group (nevertheless, > 75%, in all cases).

Age was also seen to be a significant discriminator for registration status ($p< 0.05$*) **(figure 3.2 A (ii))**. Pro-registrant behaviour is not as prominent as pro-supporter behaviour. Furthermore, registrant behaviour for DOD declines with age. This trend is displayed most clearly in the UK sample **(figure 3.2.A(ii))**, with the highest rates in the 18-29 age group **(figure 3.2. B(ii))**. Overall, the Dutch sample displayed the highest registration rates, with more than half of the participants registered across all age groups **(figure 3.2. C(ii))**. In contrast, the lowest registration rates were found in the Spanish cohort, with less than a quarter of the sample registered as donors **(figure 3.2 D(ii))**.

3.4.1.5 ETHNIC BACKGROUND AND SUPPORTER-REGISTRANT STATUS

Although not statistically significant ($p > 0.05$), there is evidence of strong pro-donation attitudes across all the ethnic backgrounds that were represented in the cohort **(figures 3.3 A-D(i)**. However, this support does not translate into registrant behaviour, with lower rates observed in the Asian and Black ethnic groups, especially in the UK sample **(figure 3.3 B(ii))**. The highest registration rates across all ethnic groups are demonstrated in the Netherlands sample ($p < 0.01$**). The effect of ethnicity was difficult to observe in Spain, owing to the homogeneity in the composition of the sample **(figure 3.3. D (i, ii))**

3.4.1.6 MARITAL STATUS AND SUPPORTER-REGISTRANT STATUS

Overall, marital status **(figure 3.4 A (i))** had no statistically significant impact on support for DOD ($p > 0.05$) albeit statistical significance was seen in relation to marital status and DOD registration ($p<0.001$***) **(figure 3.4 A (ii))**. In terms of DOD support, in all countries, those who are separated are less likely to express support for DOD compared to the rest of the categories **(figures 3.4 A-D) (i,ii)**. This trend was also seen in the UK and Spain, albeit in the Netherlands people who were separated were the ones most in support of DOD **(figures 3.4 A-D (i,ii)**.

3.4.1.7 RELIGION AND SUPPORTER-REGISTRANT STATUS

Religion was a statistically significant demographic factor in terms of support and registration **(figures 3.5.A-D (i, ii))** for DOD (both cases, $p < 0.001$***). Religious groups who did not support DOD were mostly, Buddhist, Jewish and Muslim populations. Registration for DOD was most popular among participants who reported ‘no religion’ ($p < 0.001$***) and Muslim participants were the least registered as organ donors **(figure 3.5 A (i)).**

3.4.1.8 EDUCATIONAL BACKGROUND AND SUPPORTER-REGISTRANT STATUS

Support for DOD correlated with higher levels of education in all three countries albeit this trend was non-significant **(figure 3.6 A-D (i))**. Conversely, registration for DOD was statistically significant for this parameter ($p<0.001$***) **(figures 3.6 A (ii))**. More specifically, registrants have high school level education or greater.

3.4.1.9 PARTICIPANT CATEGORY AND SUPPORTER-REGISTRANT STATUS

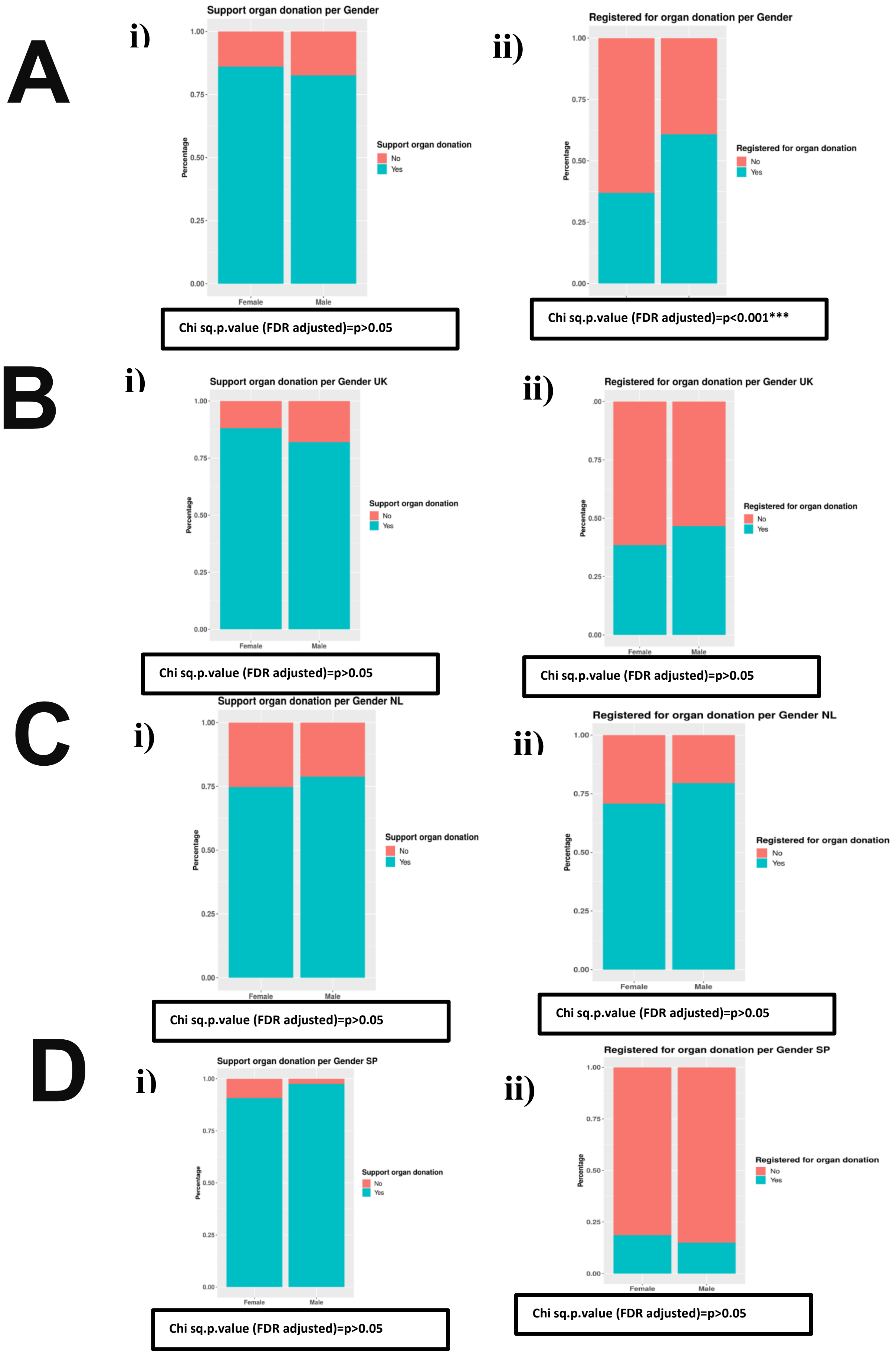
The medical student subgroup were most in support of DOD ($p < 0.001$***) followed by patients and staff **(figure 3.7 A (i))**. This trend was consistent amongst all three countries **(figures 3.7 A-D (i))**. With regard to DOD registration medical students were also the subgroup with highest percentage registration ($p < 0.001$***) followed by staff and patients **(figure 3.7 A (ii))**. Once again, this trend was observed in all countries **(figures 3.7 A-D (ii))**.

3.4.1.10 COUNTRY AND SUPPORTER-REGISTRANT STATUS

Overall, there was strong support for DOD in all three countries ($p < 0.01$**, >75% in all cases) **(figure 3.8 (i))**. Registrant behaviour was most prominent in the Dutch sample (>75%) **(figure 3.8. A(ii))**. This was followed by the UK sample, where just under half of the sample population were registered **(figure 3.8 B (ii))**. Spain had the lowest rates, (<25%) of the sample registered **(figure 3.8 D(ii))**. This trend was statistically significant ($p < 0.01$**).

3.4.1.11 PART A : CONCLUSION

This section of the quantitative results reinforces the common trend that DOD support far exceeds registration levels and this was seen in all countries. Supporter profiling trends were generally non-specific. However, for registrant status, all the demographic parameters were statistically significant, with distinct trends observed in the parameters of age, ethnicity, religion and educational background. Specifically, older age, lower educational background, Asian and Black ethnicity and Muslim religious groups displayed lower registrant behaviours. With regard to participant categories, the medical student group displayed the most prominent supporter-registrant behaviours, followed by patients and lastly by staff. Finally, in terms of country, the Spanish sample demonstrated the greatest supporter tendencies, while the Dutch sample comprised the greatest number of registrants.



Chi sq.p.value (FDR adjusted)=p>0.05

Chi sq.p.value (FDR adjusted)=p<0.001***

Chi sq.p.value (FDR adjusted)=p>0.05

Chi sq.p.value (FDR adjusted)=p>0.05

Chi sq.p.value (FDR adjusted)=p>0.05

Chi sq.p.value (FDR adjusted)=p>0.05

Chi sq.p.value (FDR adjusted)=p>0.05

Chi sq.p.value (FDR adjusted)=p>0.05

Figure 3. 1 Gender of participants expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A) (i)** Gender of volunteers who expressed support for DOD and those registered as DOD donors **(ii)** (pooled from all three countries). **(B) (i)** Gender of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C) (i)** Gender of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D) (i)** Gender of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

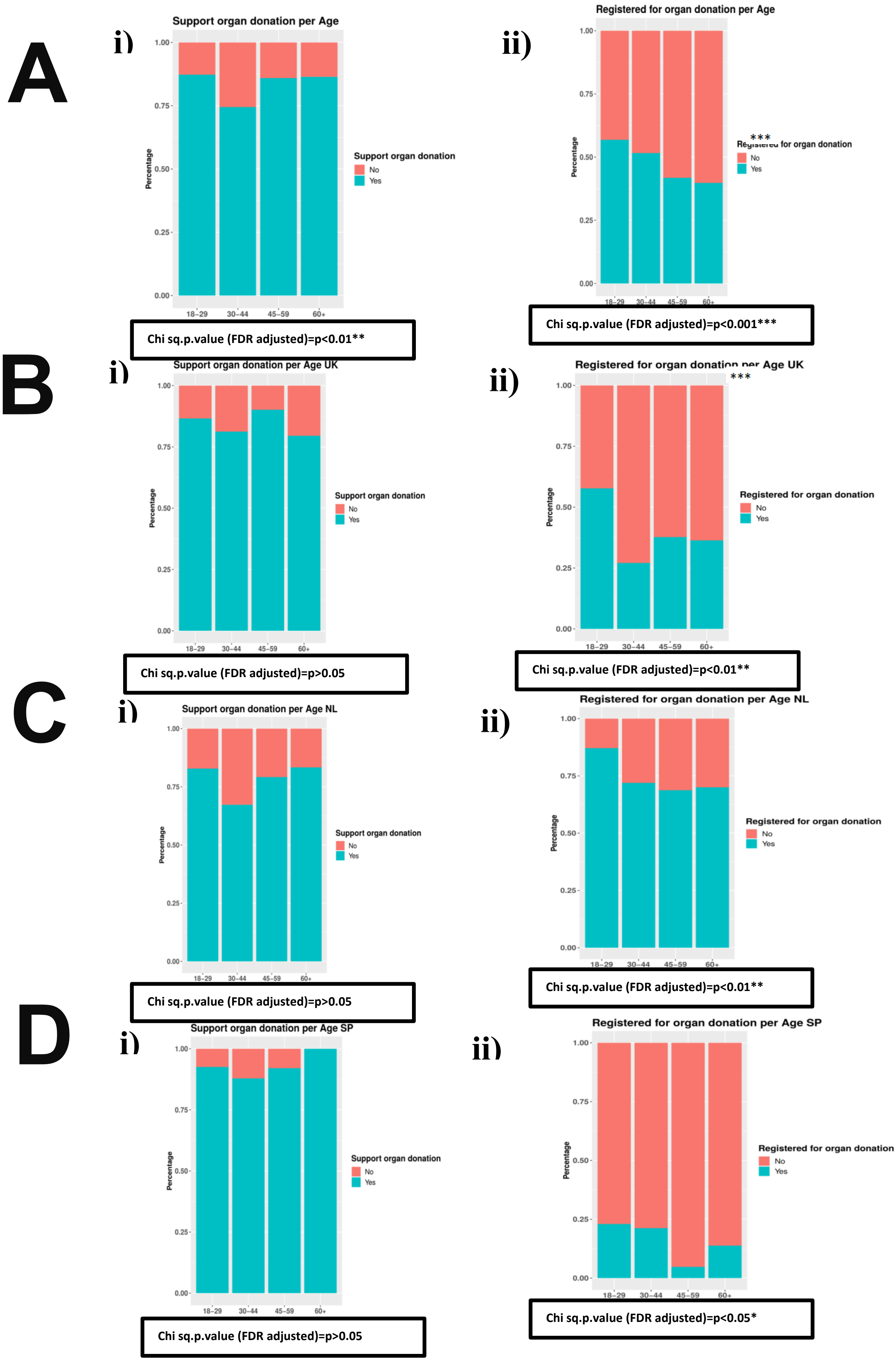


Figure 3. 2 Age of participants expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A)** **(i)** Age of volunteers who expressed support for DOD and **(ii)** registered as DOD donors (pooled from all three countries). **(B)** **(i)** Age of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C)** **(i)** Age of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D)** **(i)** Age of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

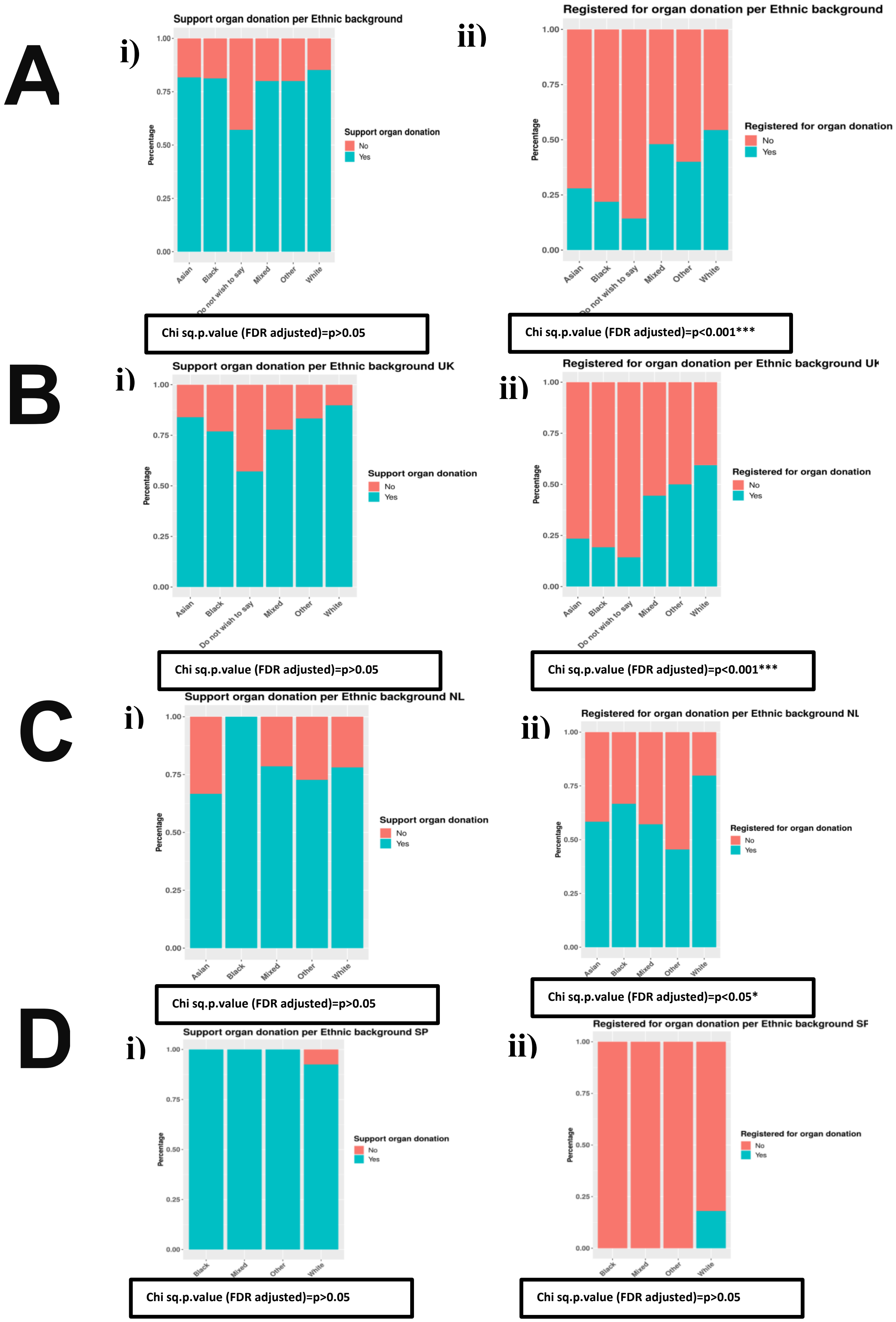


Figure 3. 3 Ethnic background of participants expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A) (i)** Ethnic background of volunteers who expressed support for DOD and **(ii)** registered as DOD donors (pooled from all three countries). **(B) (i)** Ethnic background of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C) (i)** Ethnic background of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D) (i)** Ethnic background of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

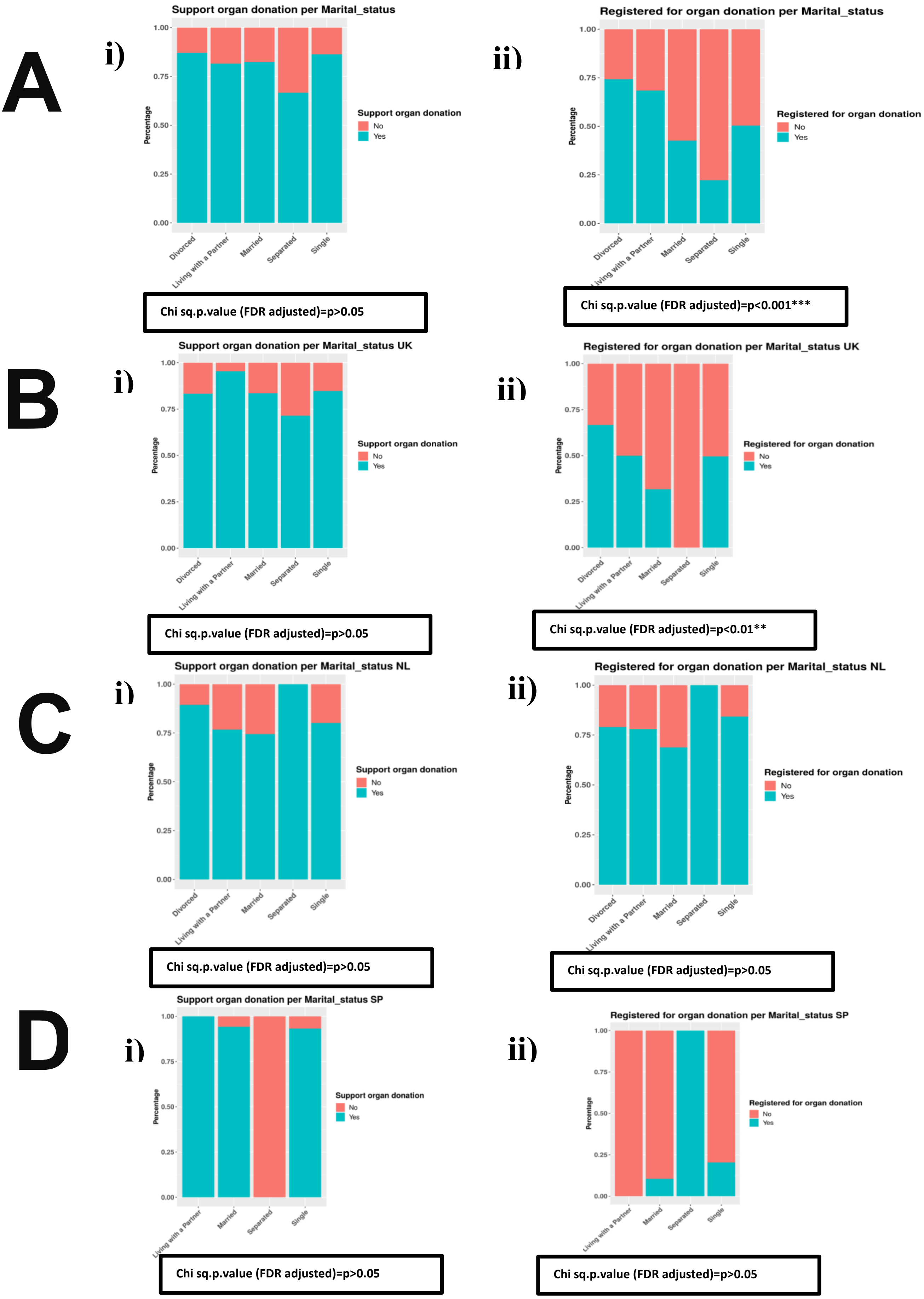


Figure 3. 4 Marital Status of participants expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A)** **(i)** Marital Status of volunteers who expressed support for DOD and **(ii)** registered as DOD donors (pooled from all three countries). **(B)** **(i)** Marital status of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C)** **(i)** Marital Status of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D)** **(i)** Marital status of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

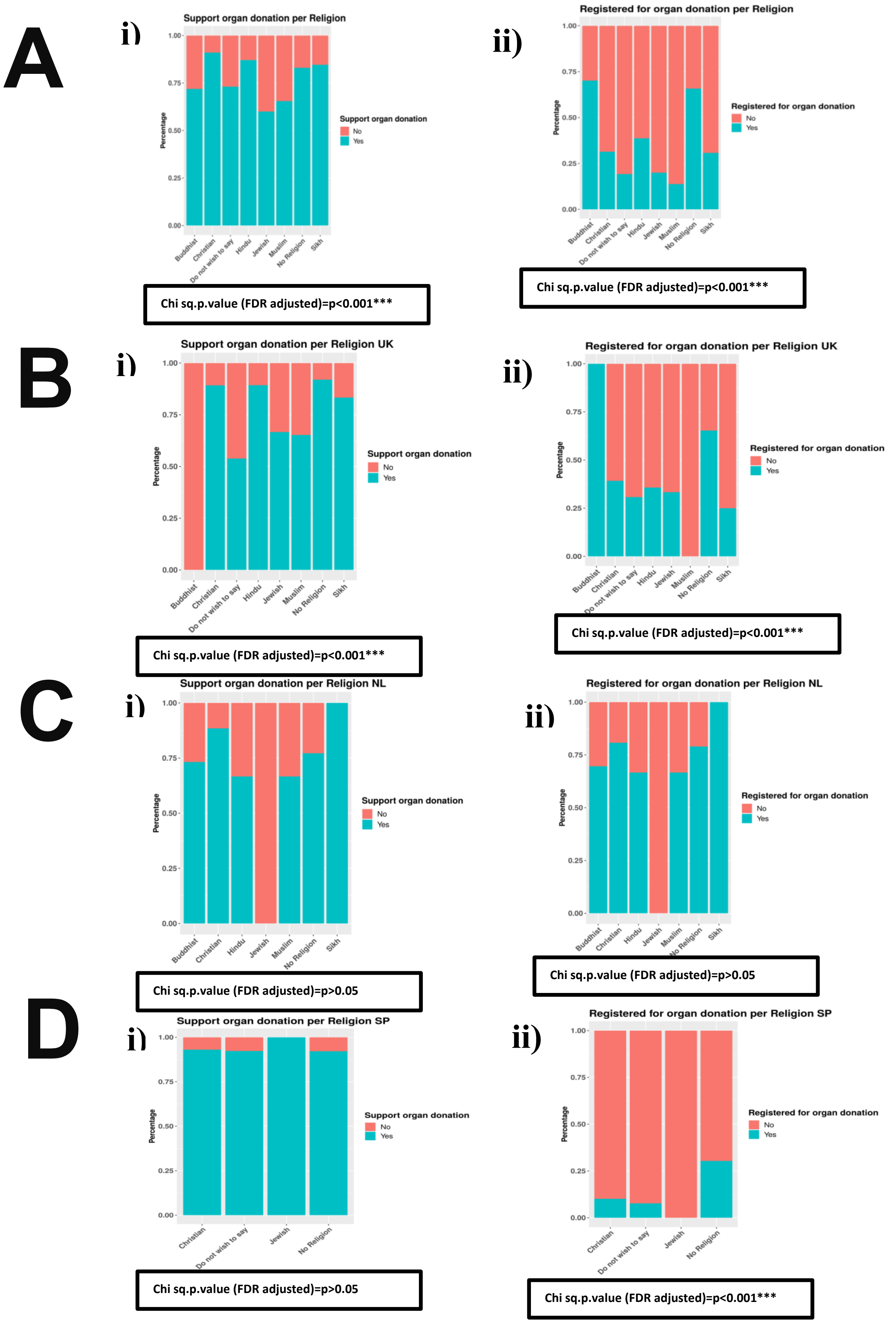


Figure 3. 5 Religious beliefs of participants expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A) (i)** Religious beliefs of volunteers who expressed support for DOD and **(ii)** registered as DOD donors (pooled from all three countries). **(B) (i)** Religious beliefs of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C) (i)** Religious beliefs of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D) (i)** Religious beliefs of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

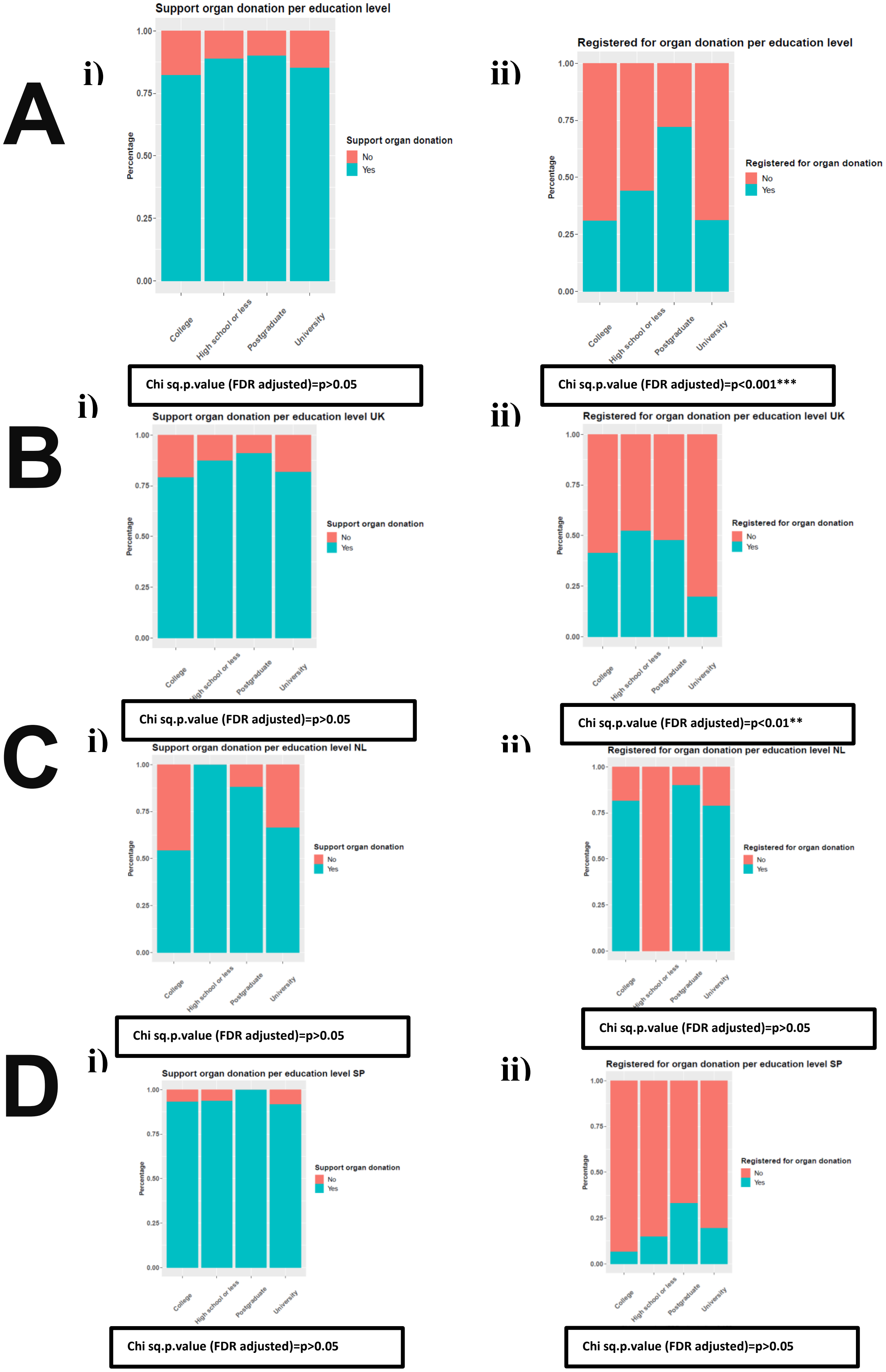


Figure 3. 6 Education of participants expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A) (i)** Education of volunteers who expressed support for DOD and **(ii)** registered as DOD donors (pooled from all three countries). **(B) (i)** Education of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C) (i)** Education of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D) (i)** Education of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

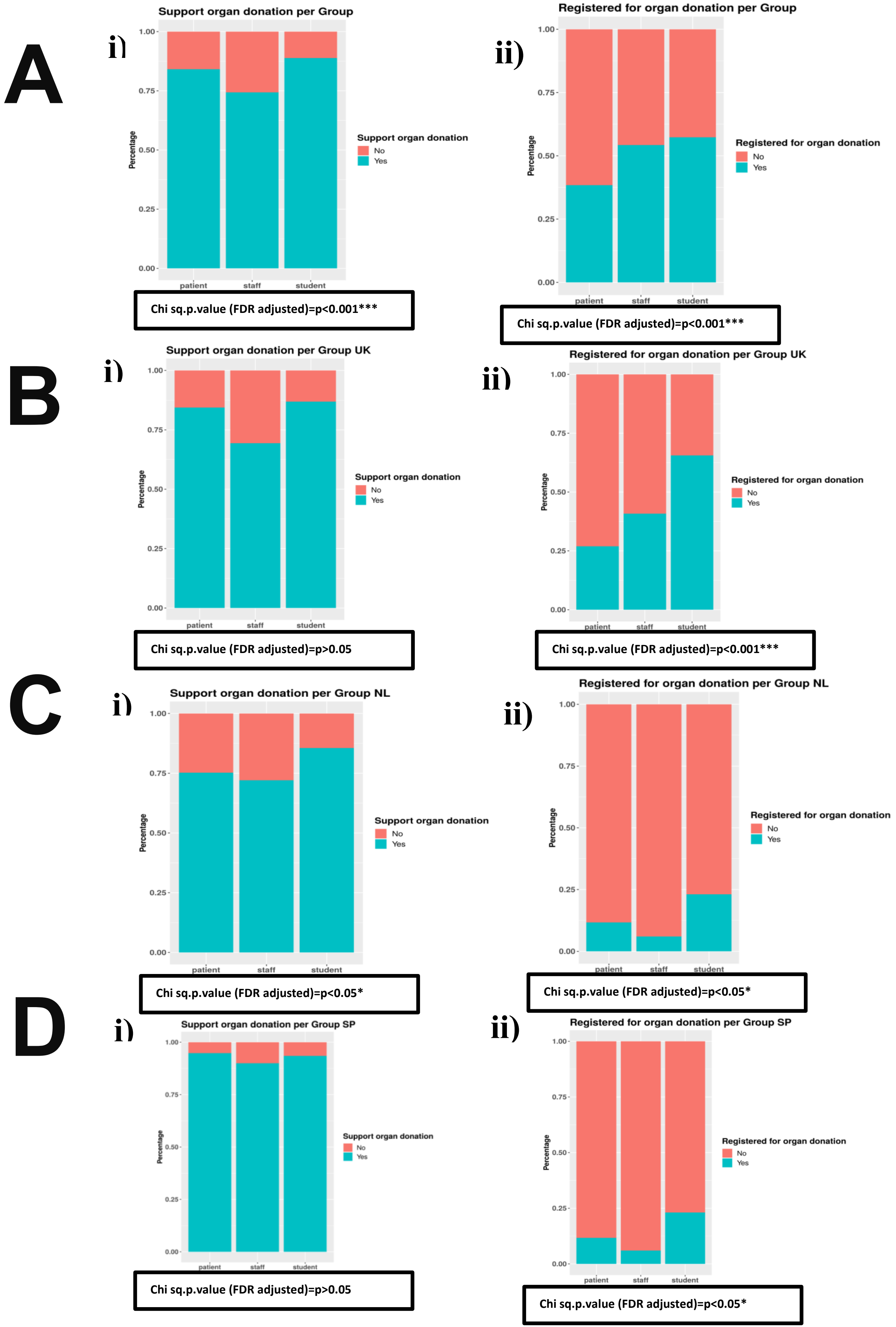


Figure 3. 7 Study groups expressing support for DOD and those registered as DOD donors in pooled sample and individual UK, Netherlands and Spain samples respectively. **(A)** **(i)** Study groups of volunteers who expressed support for DOD and **(ii)** registered as DOD donors (pooled from all three countries). **(B)** **(i)** Study groups of study participants from the UK who supported DOD and **(ii)** those registered as DOD donors. **(C)** **(i)** Study groups of participants who supported DOD in the Netherlands and **(ii)** those registered as DOD donors. **(D)** **(i)** Study groups of participants who supported DOD in Spain and **(ii)** those registered as DOD donors. **Chi sq p.value included. The key on the right denotes yes in blue and no in red.**

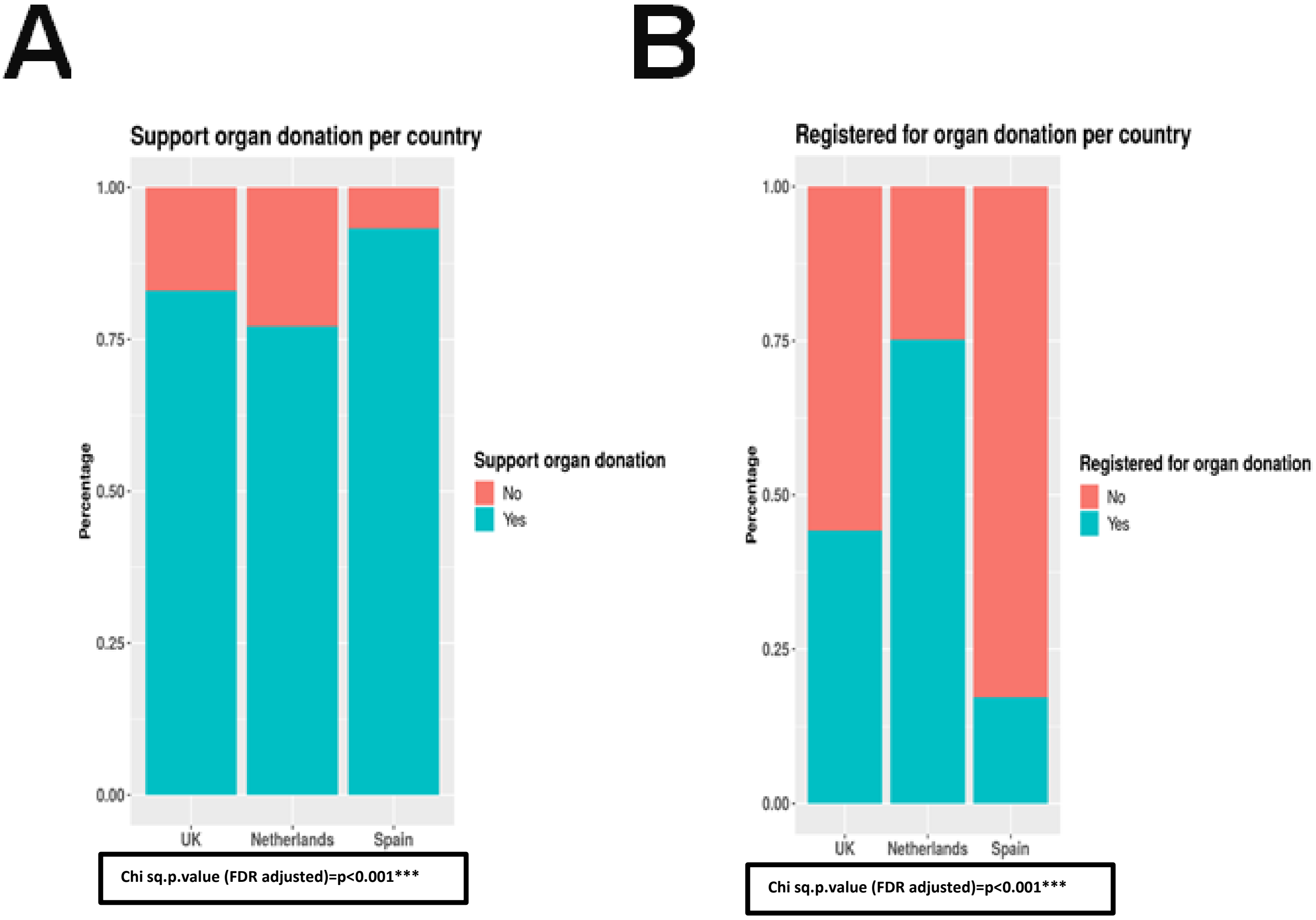


Figure 3. 8 Support and Registration for DOD per country in the study population.(A) Support for DOD in the UK, Netherlands and Spain expressed by the study population. **(B)** Registration for DOD in the UK, Netherlands and Spain expressed by the study population. **Chi sq p.value included.**

3.4.2 PART B: COMMUNICATION

3.4.2.1 INTRODUCTION

Part B presents the analytical statistics from the section of the questionnaire describing participant communication patterns, examining the expression of their own donation attitudes and consent decisions as well as those of their loved ones. The analysis compares the passive component of information reception and the active component of information appraisal. This is a crucial parameter because of the rate limiting role of familial consent in DOD.

3.4.2.2 COMMUNICATION WITH PARENTS

In all countries, participants reported that they were most likely to talk about DOD with their parents. Most participants from the UK, Netherlands and Spain expressed positive opinions on the subject and willingness to becoming organ donors to their parents ($p < 0.01$**) **(figure 3.9)**. In addition, a high proportion of participants across all countries were willing to grant consent for their parents.

3.4.2.3 COMMUNICATION WITH CHILDREN

Individuals generally expressed positive views on DOD to their children ($p < 0.01$**) **(figure 3.10)** and reported similar views expressed by their children. However, the majority of individuals stated that they had never discussed giving consent for organ donation on behalf of their children. In the Spanish sample, participants answered that they had personally only expressed and received positive opinions during conversations on the topic with their children (p-value < 0.001***). The proportion who would grant consent corresponded to the proportion of positive views received, with the remainder of answers reflecting the proportion that had not discussed the topic.

3.4.2.4 COMMUNICATION WITH PARTNER

The majority of participants reported expressing positive views in relation to DOD to their partner ($p<0.01$**) **(figure 3.11)**, and equally individuals reported that their partners also expressed positive views in similar proportions. Additionally, a similar proportion of those expressing positive views on DOD, stated that they would be willing to grant consent for DOD on behalf of their partners. Partners were the second highest cohort to which individuals expressed a positive wish for DOD.

3.4.2.5 COMMUNICATION WITH SIBLINGS

Participants reported that they had expressed opinions to their siblings (p<0.01**) **(figure 3.12)**. Similarly, most individuals reported that they would feel comfortable grant consent on behalf of their siblings. Despite the participants expressing a positive wish to their siblings, their siblings did not communicate their views on DOD in the same proportion. Siblings where the third highest cohort to which participants expressed positive views regarding DOD.

3.4.2.6 COMMUNICATION WITH COUSINS

Individuals were generally positive in expressing their views on DOD to their cousins (p<0.01**) **(figure 3.13)** and in similar proportion their cousins had expressed similar positive views to them. However in terms of willingness to grant consent for this group, most participants reported that they had never discussed the issue.

3.4.2.7 CONVERSATION OUTCOMES: AGREEMENT AND CONSENT

3.4.2.8 AGREEMENT: COHEN'S KAPPA COEFFICIENT

In the data for all countries **(table 3.4)**, there was a 'fair' agreement between participants' consent decisions and the wishes of close family members. This is true for parents (κ = 0.41, 95% CI: 0.36-0.46), children (κ =0.23, 95% CI: 0.18-0.27), partners (κ = 0.38, 95% CI: 0.32-0.43) and siblings (κ= 0.33, 95% CI: 0.28-0.38). By comparison, only 'slight' agreement was observed between participants and more distant family members, such as cousins (κ = 0.22, 95% CI: 0.15-0.28). This trend was preserved when the participating countries were considered separately **(tables 3.4**).

3.4.2.9 PART B CONCLUSION

Holistically, under all categories most participants expressed positive views about DOD to their families and reported receiving similar views in their exchanges. However, where in the UK there was a good spread of positive, negative and neutral opinions, the Dutch and Spanish groups was more homogenous. For these two samples, opinions were generally invariant and positively skewed. The Cohen's kappa test indicated that agreement was 'fair' for close family members (e.g. parents, children, partners and siblings) , and 'slight' for cousins or extended family. As a result, they were more willing to grant consent for immediate family members. The absence of 'perfect' agreement shows that even where loved ones had conveyed negative views about DOD, or where it had not been discussed at all, some participants were willing to grant consent

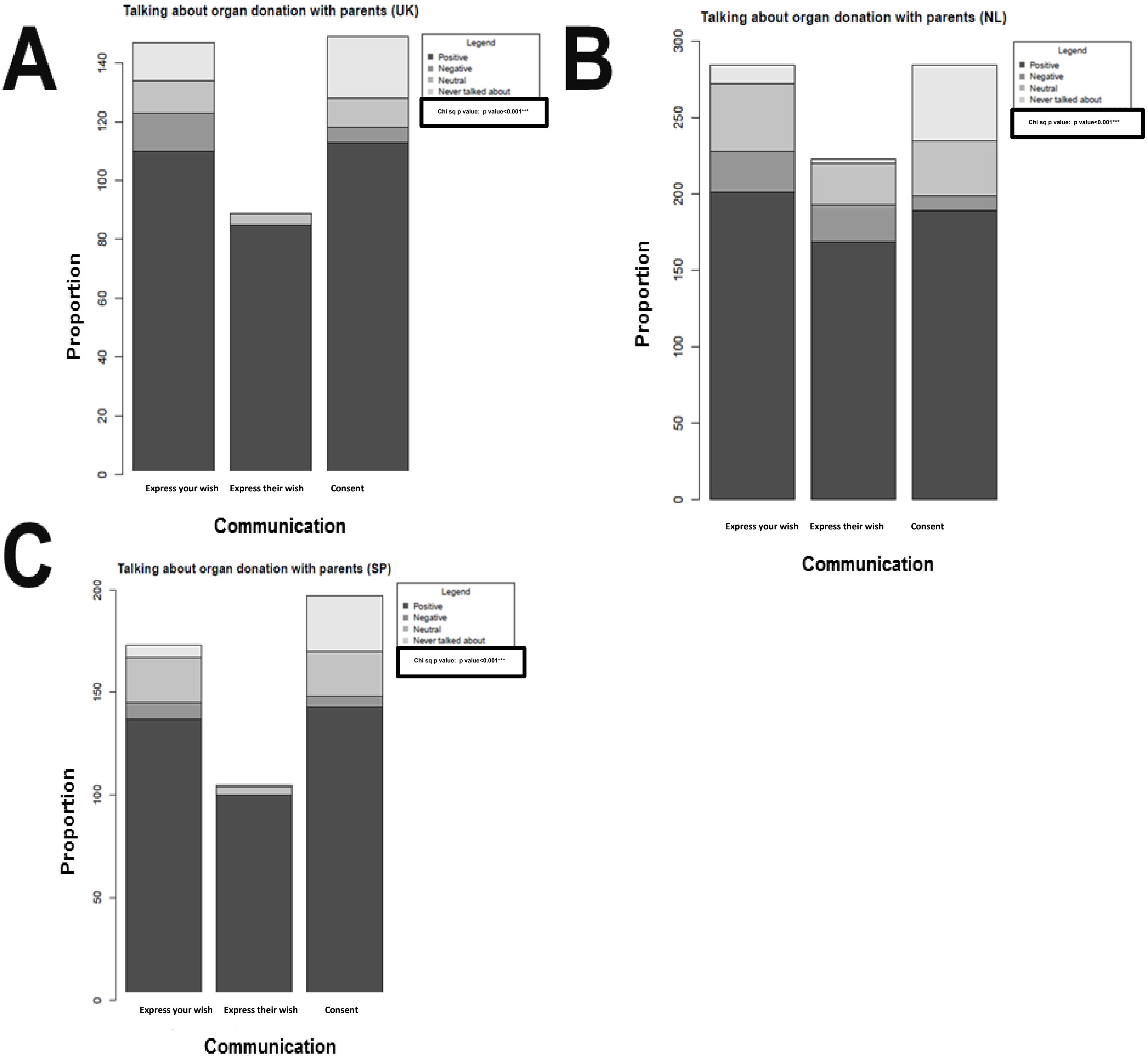


Figure 3. 9 Discussing DOD with parents. (A) Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions on DOD with their parents and the topic of organ donation consent (UK sample). **(B)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their parents and the topic of organ donation consent (Dutch sample). **(C)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their parents and the topic of organ donation consent (Spanish sample). Subgroups of patients, staff and medical students are included in each country, p values included.

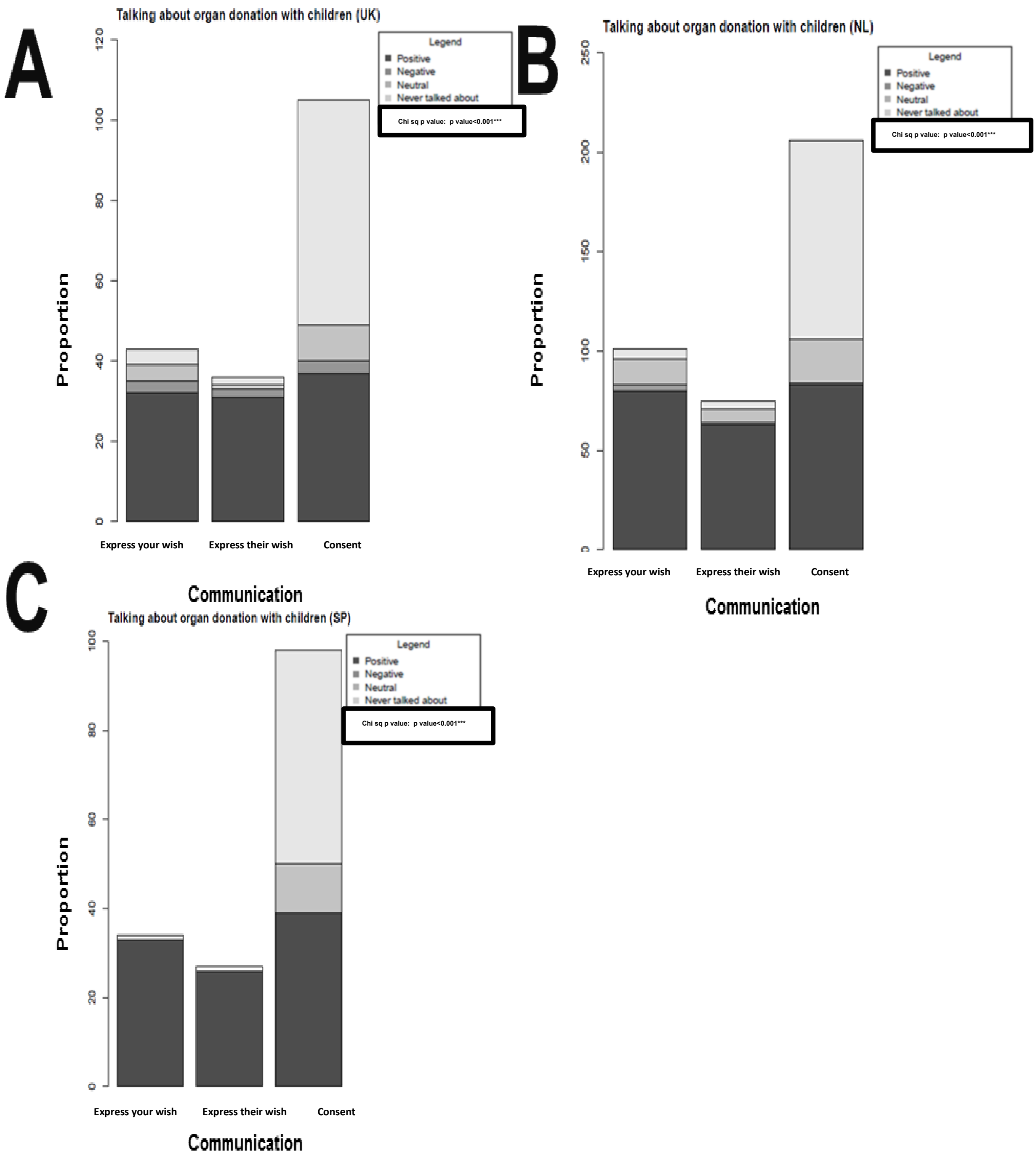


Figure 3. 10 Discussing DOD with children. (A) Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their children and the topic of organ donation consent in the UK sample. **(B)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their children and the topic of organ donation consent in the Dutch sample. **(C)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their children and the topic of organ donation consent in the Spanish sample. Subgroups of patients, staff and medical students are included in each country, p values included.

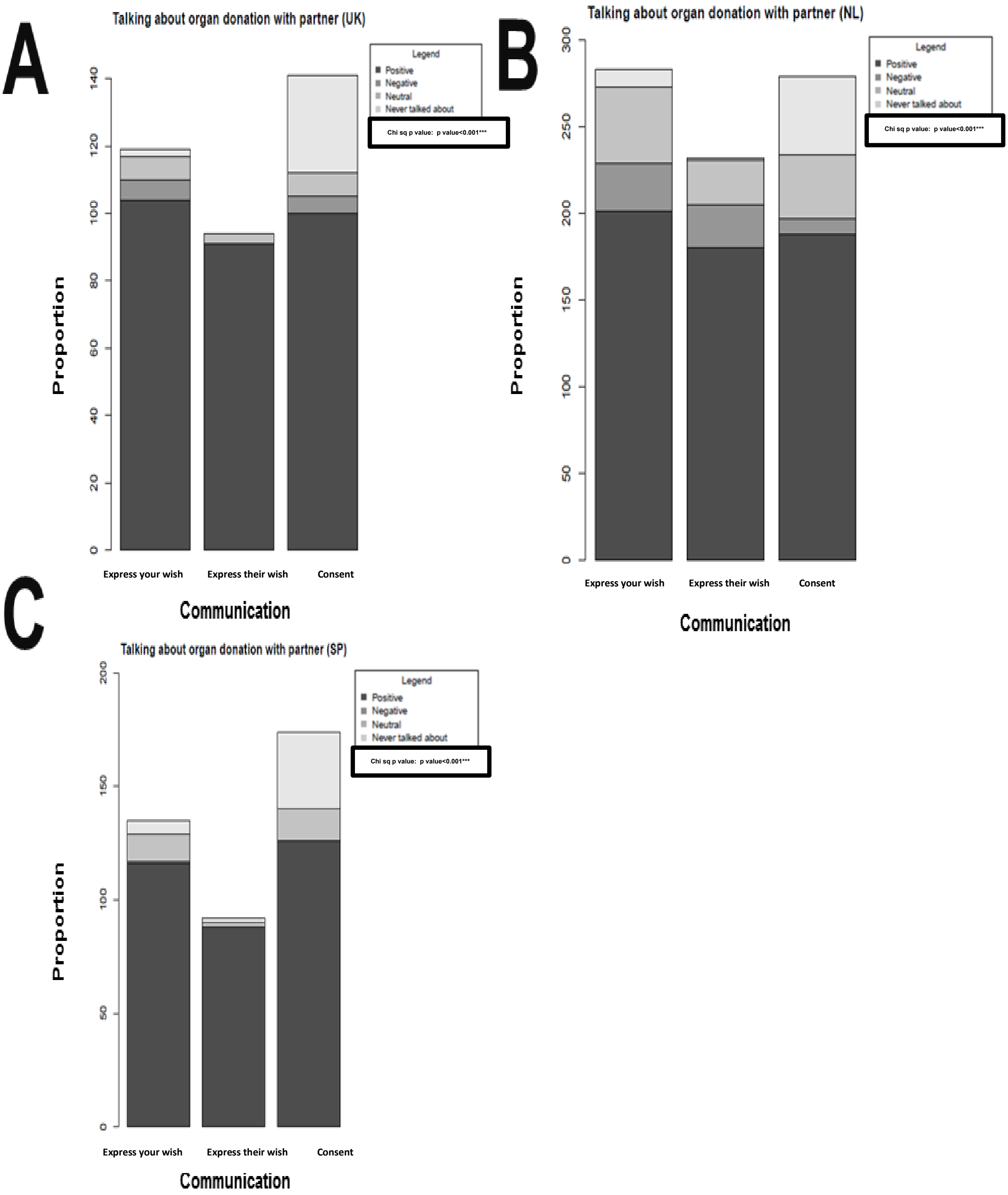


Figure 3. 11 Discussing DOD with partners . (A) Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their partners and the topic of organ donation consent in the UK sample. **(B)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their partners and the topic of organ donation consent in the Dutch sample. **(C)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their partners and the topic of organ donation consent in the Spanish sample. Subgroups of patients, staff and medical students are included in each country, p values included.

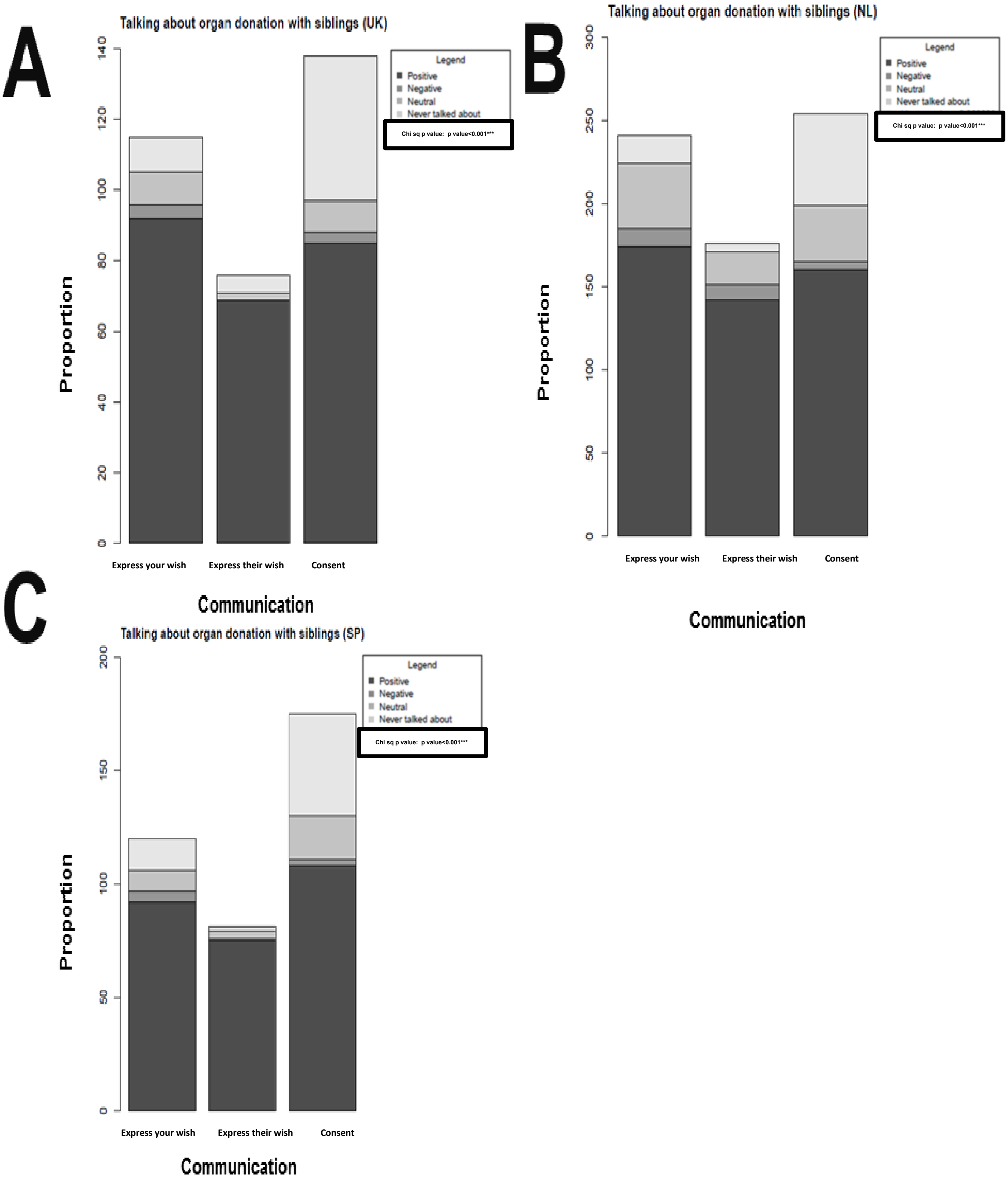


Figure 3. 12 Discussing DOD with siblings. (A) Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their siblings and the topic of organ donation consent (UK sample). **(B)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their siblings and the topic of organ donation consent (Dutch sample). **(C)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their siblings and the topic of organ donation consent (Spanish sample). Subgroups of patients, staff and medical students are included in each country, p values included.

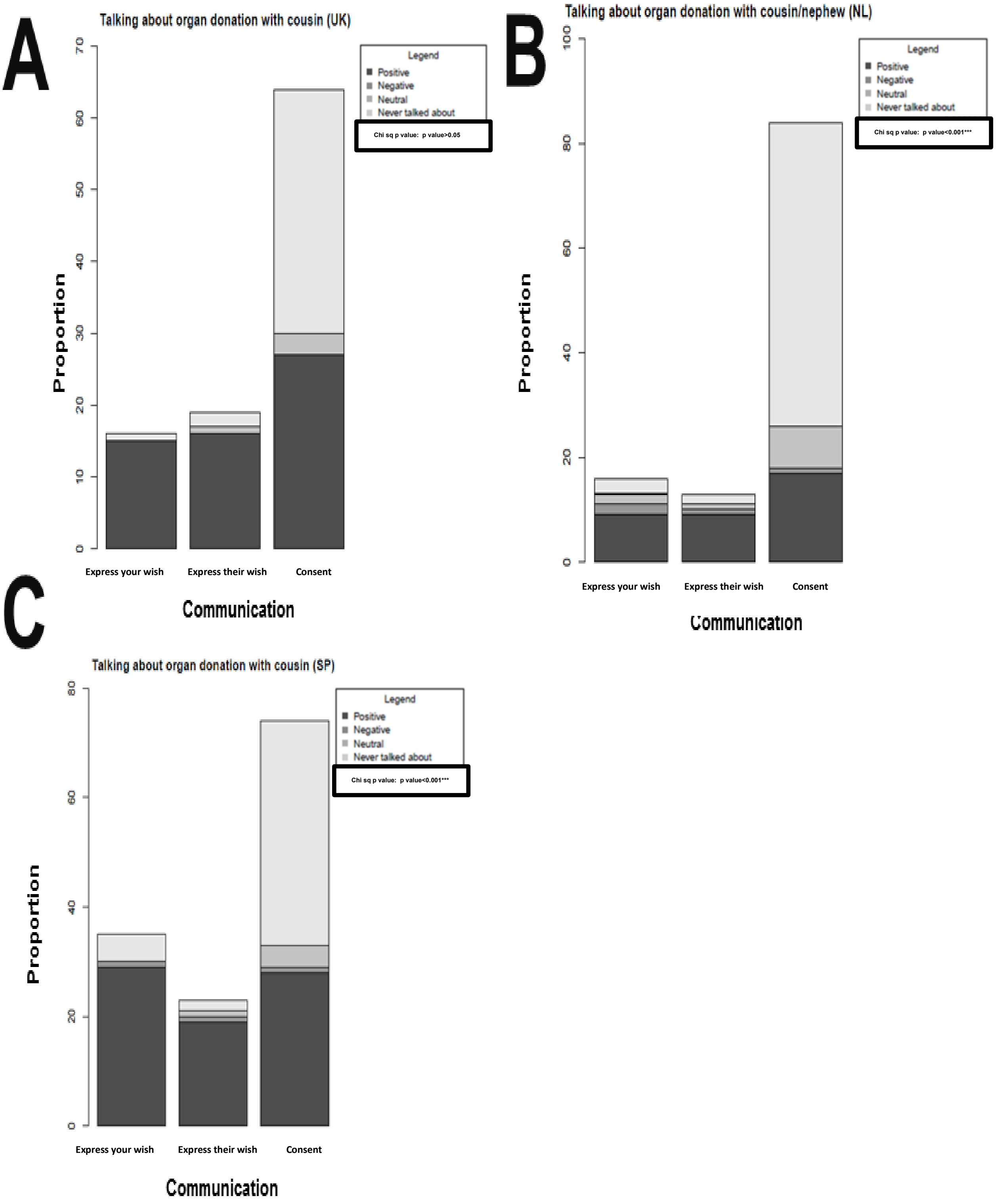


Figure 3. 13 Discussing DOD with cousins. (A) Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their cousins and the topic of organ donation consent (UK sample). **(B)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their cousins and the topic of organ donation consent (Dutch sample). **(C)** Graph showing the proportion of people who expressed positive, negative, neutral, or reported as never having interchanged opinions of DOD with their cousins and the topic of organ donation consent (Spanish sample). Subgroups of patients, staff and medical students are included in each country, p values included.

Family Member	COHEN'S KAPPA AGREEMENT (K) Agreement between participant's Consent Decision and wish expressed by family member			
	ALL COUNTRIES	UK	NL	SP
PARENTS	**K=0.410** (95% CI 0.358-0.462)	K=0.523 (95% CI 0.434-0.612)	K=0.354 (95% CI 0.272-0.436)	K=0.135 (95% CI 0.220-0.411)
SIBLINGS	**K=0.332** (95% CI0.280-0.384)	K=0.362 (95% CI 0.267-0.457)	K=0.326 (95% CI 0.246-0.407)	K=0.273 (95% CI 0.180-0.366)
PARTNERS	**K=0.376** (95% CI 0.322-0.429)	K=0.388 (95% CI 0.292-0.484)	K=0.396 (95% CI 0.314-0.478)	K=0.292 (95% CI 0.204-0.381)
CHILDREN	**K=0.226** (95% CI 0.178-0.273)	K=0.175 (95% CI 0.087-0.262)	K=0.265 (95% CI 0.193-0.338)	K= 0.206 (95% CI0.124-0.289)
COUSINS	**K=0.218** (95% CI 0.154-0.282)	K=0.269 (95% CI 0.150-0.389)	K=0.144 (95% CI 0.049-0.239)	K=0.202 (95% CI 0.088-0.316)

Table 3. 4 Table showing the Cohen's kappa agreement (K) between the consent decision vs the wish of loved ones. Agreement for this parameter is examined for parents, siblings, partners, children and cousins. The decreasing agreement trend is depicted in bold when data from all countries is considered (95% CI included). The ranges for Cohen's kappa interpretation indicating different levels of agreement: 0= chance agreement, 0.10-0.20 = 'slight', 0.21-0.40 = 'fair', 0.41-0.60 = 'moderate', 0.61-0.80 = 'substantial', 0.81-0.99= 'near perfect', 1.0 = 'perfect'.

3.4.3 PART C: KNOWLEDGE

3.4.3.1 INTRODUCTION

This section presents the areas of DOD and other health topics in which the survey participants were most knowledgeable. This is also related to the spectrum of sources used for information. The participant's confidence in their answers, as rated on a Likert scale, reflects the self-perceived level of knowledge. This is compared to the actual knowledge score, or the frequency of correct responses. The significance of these parameters on supporter-registrant status is appraised.

3.4.3.2 OVERALL KNOWLEDGE SCORE PER COUNTRY

Figure 3.14 compares the overall knowledge score in each of the three countries. The graph indicates that there is a statistically significant association between knowledge and participating country ($p < 0.001$***) **(figure 3.14 A)**. An inspection of the group medians reveals that across all three samples, the degree of overall health-related knowledge was poor, indicated by a negative median value. with the participants in the Spanish and Dutch samples performing marginally better than those in the UK sample. Furthermore, the similarity in the IQRs indicate similar group distributions. Even though knowledge scores between the three countries differed, there was no statistical significance observed relating knowledge with no support/support **(figure 3.14 B)**. This result was also observed in relation no registration/registration status **(figure 3.14 C)**.

3.4.3.3 SOURCE USAGE

The average source usage results are presented **(figure 3.15 A)**. Negative values on the standardised scale indicate low usage whilst positive values indicate popular sources. The preferred range of sources were as follows: family and friends, patient narratives and stories of organ donation, medical TV shows and films, newspapers and magazines, official national website, social media.

In contrast, the least popular sources were information from a place of worship, school, colleagues, family doctor, brochure from clinic/ pharmacy, transplant organisation, other healthcare website, awareness campaigns, local library, adult learning classes, none of these options, or other options. Higher knowledge scores suggest greater source credibility. Participants who utilised the following resources obtained the highest knowledge scores; family members, patient stories, GPs, medical documentaries, brochures in clinics and pharmacies, official website of national transplant organisation and awareness campaigns **(figure 3.15 B).**

3.4.3.4 OTHER HEALTH ISSUES AND SUPPORTER-REGISTRANT STATUS

The normalised knowledge scores for other health topics were all positive suggesting that the overall, participants had good awareness (**figure 3.16**). The topics in the selection generating the highest scores were Cancer, Diabetes, Heart Disease, High Blood Pressure, Obesity, Organ Donation and Smoking. By comparison, lower scores were obtained on more specialist topics, such as Alzheimer's Disease, HIV/AIDS and Mental Illness. Of the three participating countries, the Netherlands group obtained the highest median knowledge scores in this parameter ($p < 0.001$***) (**figure 3.17 A**). Knowledge about other health issues was not a statistically significant descriptor of non-supporter/ supporter status ($p > 0.05$) (**figure 3.17 B**). In contrast, this parameter was statistically significant for non-registrant/ registrant status ($p < 0.05$*) , with registrants obtaining higher median scores, compared to non-registrants (**figure 3.17C**).

3.4.3.5 DOD DOMAINS AND SUPPORTER-REGISTRANT STATUS

Overall, positive knowledge scores were obtained by participants in only in the domains of general knowledge about organ donation and waiting lists. In all other domains, including medical care, family's role and funeral arrangements, knowledge scores were negative, indicating a high proportion of incorrect answers (figure 3.18).

However, from the five topics tested, only the domain of funeral arrangements was a statistically significant determinant of registration status ($p < 0.001$***) (figure 3.19 E (ii)). For this topic, registrant participants obtained slightly higher median knowledge scores than non-registrant participants. None of the other four domains were statistically significant determinants of either supporter or registrant status ($p > 0.05$) and overall, non-supporters/ supporters and non-registrants/registrants obtained similar median knowledge scores (figures 3.19 A-D (i,ii)).

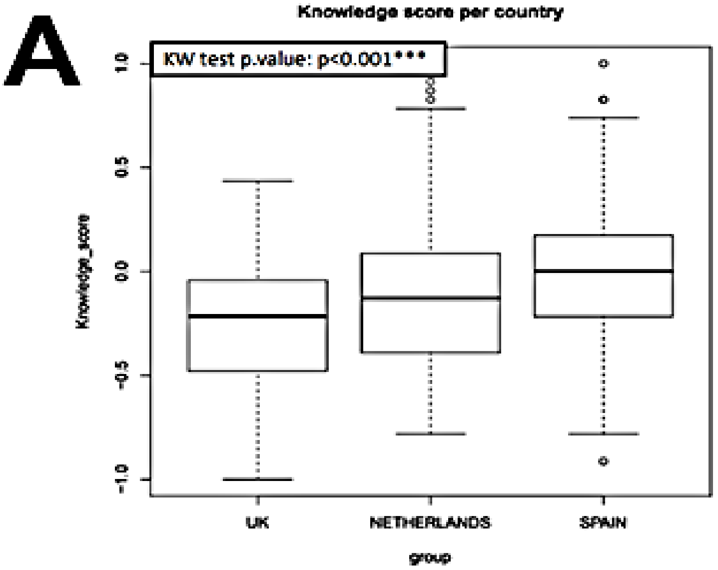
3.4.3.6 CONFIDENCE AND KNOWLEDGE SCORE CORRELATION

In all countries, there was a positive but weak correlation between knowledge score and confidence (PCC $r=0.27$, $p < 0.001$***) (**figure 3.20A**). The strongest positive correlation between these two variables was observed in the UK sample (PCC $r = 0.52$, $p < 0.001$**) **(figure 3.20 B)** indicating that participants were reliable assessors of their level of self-reported knowledge. In the Netherlands, the weakest correlation was observed (PCC $r=0.13$, $p < 0.01$**) (**figure 3.20 C**). A similar correlation to that observed in all countries together was seen in Spain (PCC $r =0.26$, $p < 0.01$**) (**figure 3.20 D**).

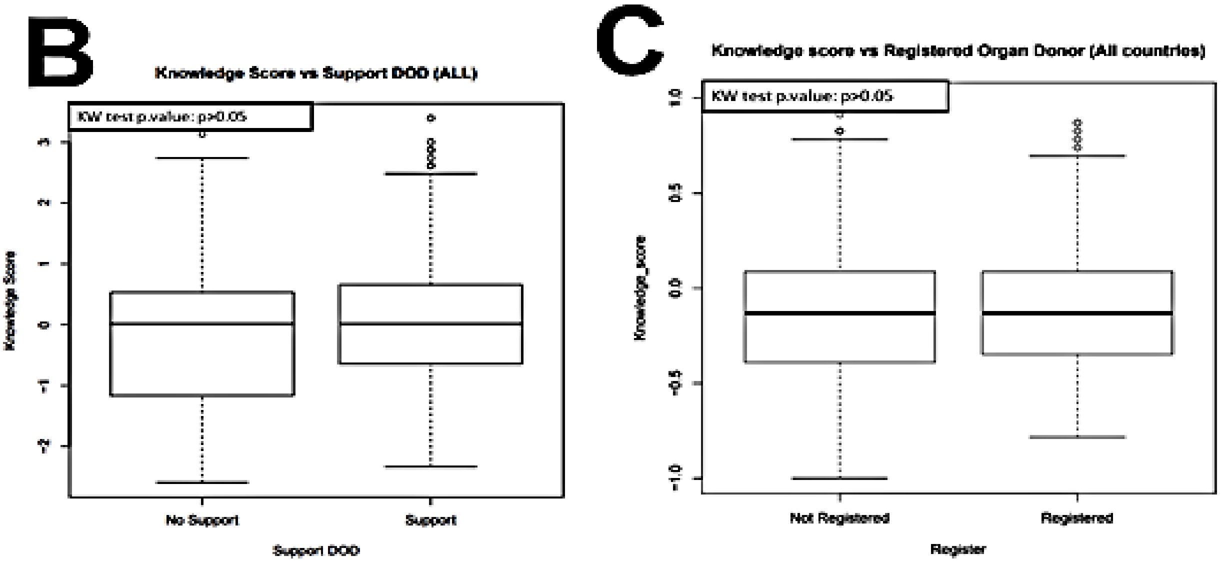
3.4.3.7 PART C CONCLUSION

The overall median knowledge scores in all three participating countries were low and in the negative range, with only minor variations between the groups. In terms of access to information, participants displayed preferences for narrative based resources, including patient stories and media sources. However, these sources were also associated with lower knowledge scores. Participants displayed good awareness of common health issues such as high blood pressure, diabetes and smoking and comparatively lower awareness of more specialised topics, such as Alzheimer's disease and mental illness. There was poor knowledgeability about DOD domains describing in-hospital processes, compared to better awareness of the organ shortage issue and waiting lists. Generally, there was a positive but weak correlation between objective knowledge score and the participants self-perceived knowledge, or confidence.

Although knowledge is an important parameter for improving understanding of the topic, and the above key trends were observed, overall, it did not significantly indicate supporter-registrant status in this sample.



Median	Q1	Mean	Q3
UK	-1.3	-0.34	0.44
NL	-0.83	-0.23	0.79
SP	-0.82	-0.0	0.64



	No support	Support
Median	0.0	0.00
Q1	-1.11	-0.83
Q3	0.53	0.62

	Non-registered	Registered
Median	-0.25	-0.26
Q1	-0.43	-0.41
Q3	0.15	0.16

Figure 3. 14 Knowledge scores per country. (A) Knowledge scores of participants from samples of all three countries. Positive values indicate correct responses and negative values indicate incorrect responses for particular domains. Kruskal-Wallis test and p-value included as well as lower, median and upper quartile range. **(B)** Knowledge scores in relation to no support/ support for DOD. **(C)** Knowledge scores in relation to non-registered/ registered participants.

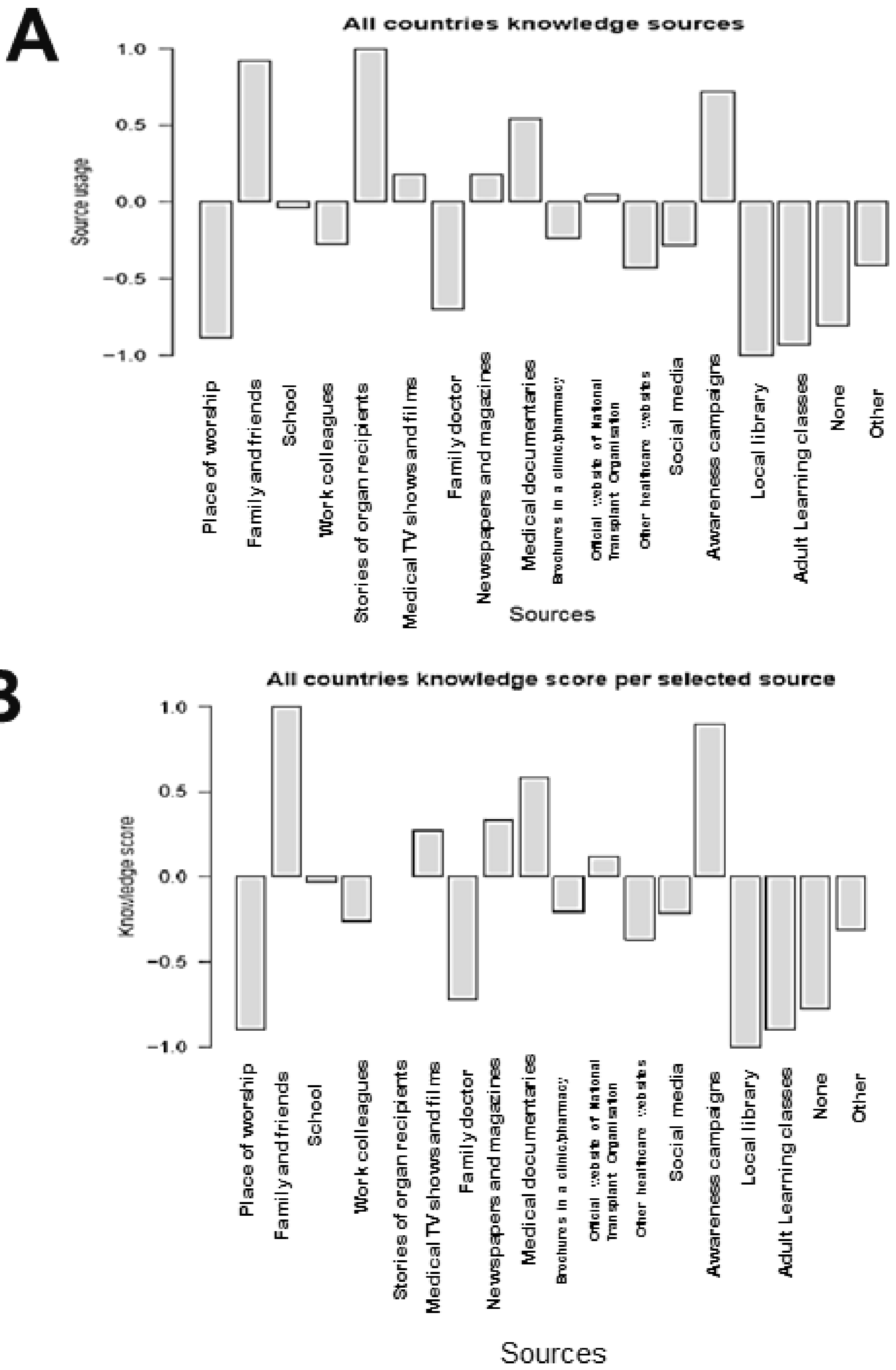


Figure 3. 15 Source usage and Knowledge Score. (A) Figure showing participant source preferences on a normalised scale indicating relative usage. **(B)** Figure showing normalised knowledge score, relative to each source.

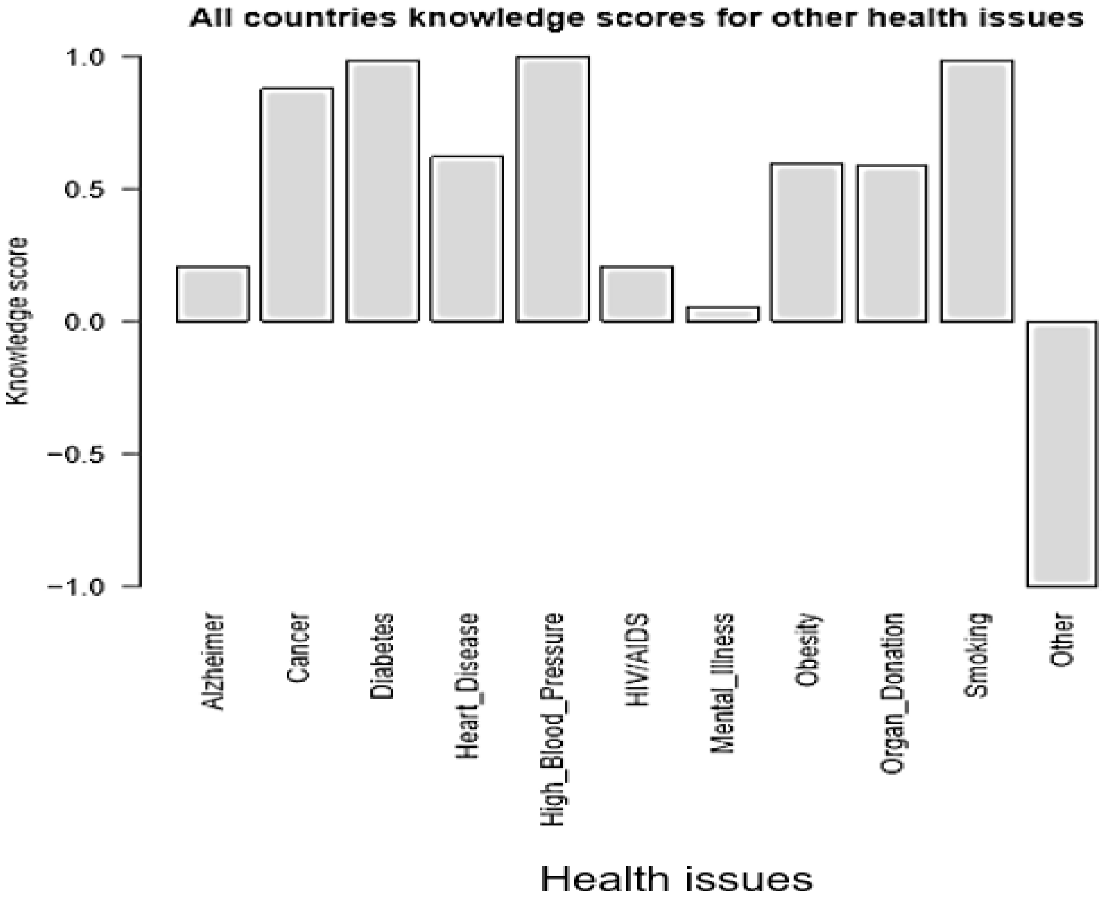
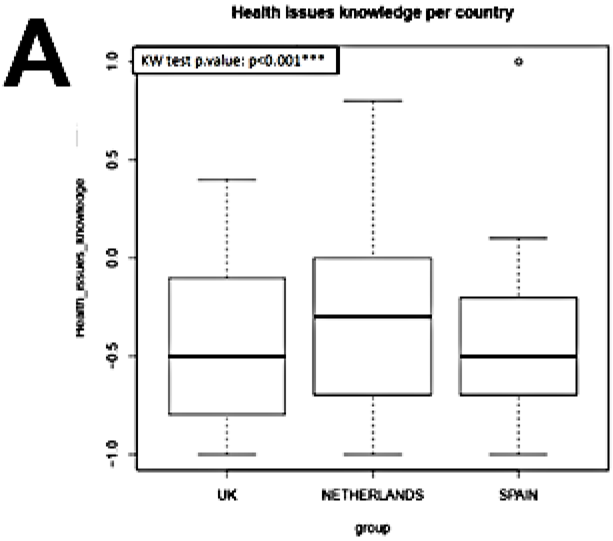
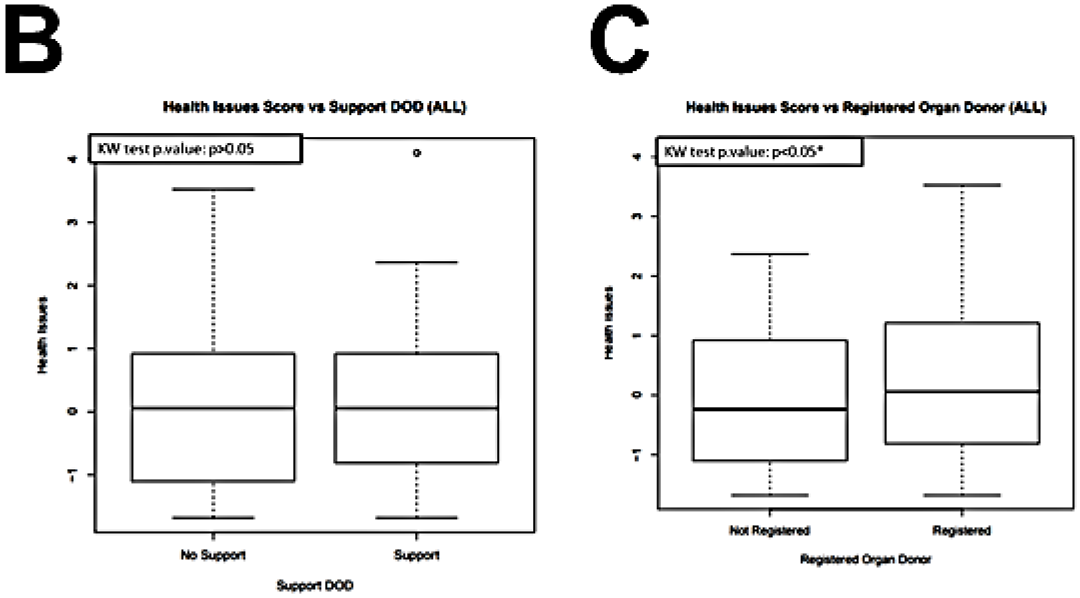


Figure 3. 16 Knowledge scores for other health issues . Knowledge scores of additional healthcare issues from sample populations of all three countries. Positive values indicate correct responses and negative values indicate incorrect responses for particular domains.



Median	Q1	Mean	Q3
UK	-0.84	-0.50	-0.12
NL	-0.62	-0.32	0.00
SP	-0.62	--0.51	-0.23



	No support	Support
Median	0.00	0.00
Q1	-1.10	-0.92
Q3	1.00	1.00

	Non-registered	Registered
Median	-0.24	-0.12
Q1	-1.00	-0.82
Q3	1.00	1.24

Figure 3. 17 Knowledge in other health issues and supporter-registrant status. Positive values indicate correct responses and negative values indicate incorrect responses. Kruskal-Wallis test p-value included as well as lower, median and upper quartile range **(A) Comparison of other health issue knowledge in UK, Netherlands, Spain (B) Other health issue knowledge and no support/ support status (C) Other health issue knowledge and non-registered/ registered status.**

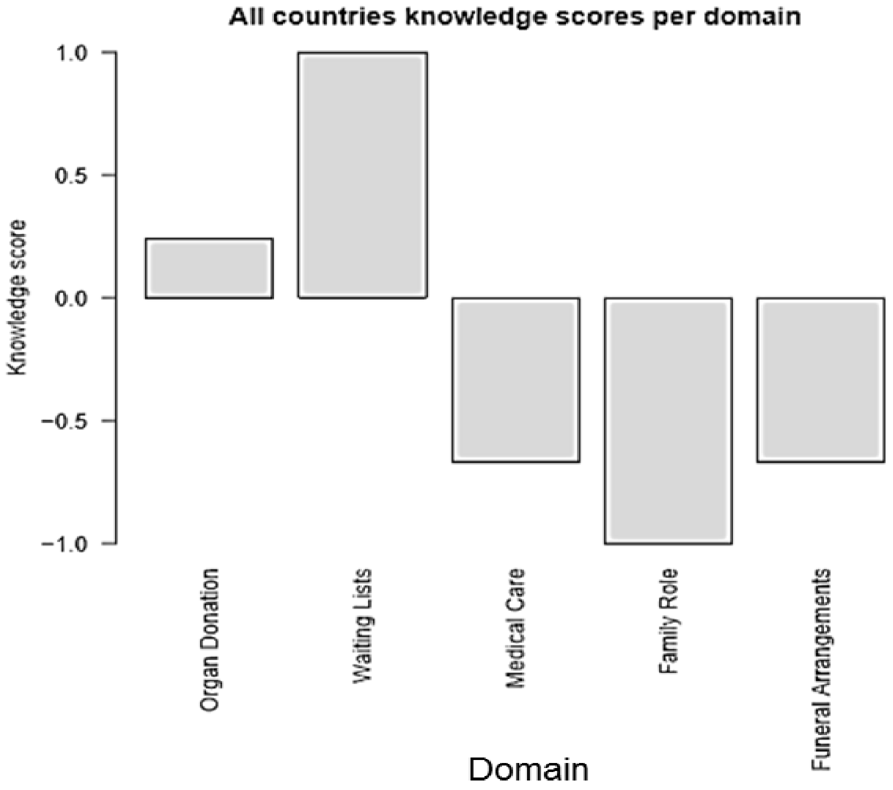
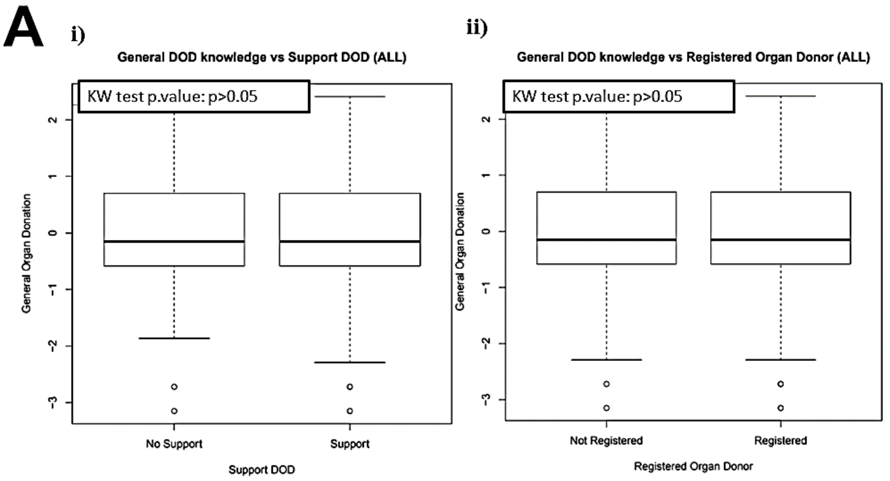
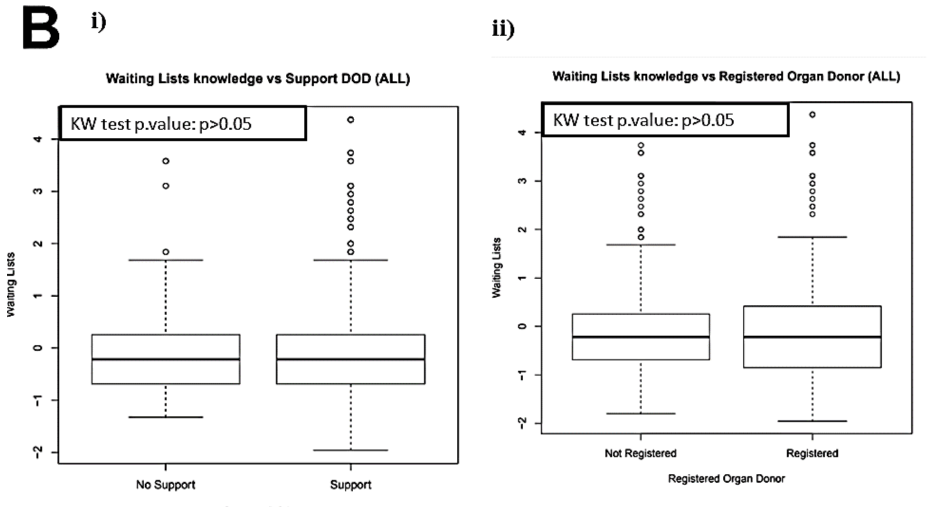


Figure 3. 18 Knowledge scores per domain. Knowledge scores of participants from samples of all three countries on the five main domains identified in the websites of NHSBT from the UK, NTS from the Netherlands and ONT from Spain. Positive values indicate correct responses and negative values indicate incorrect responses.



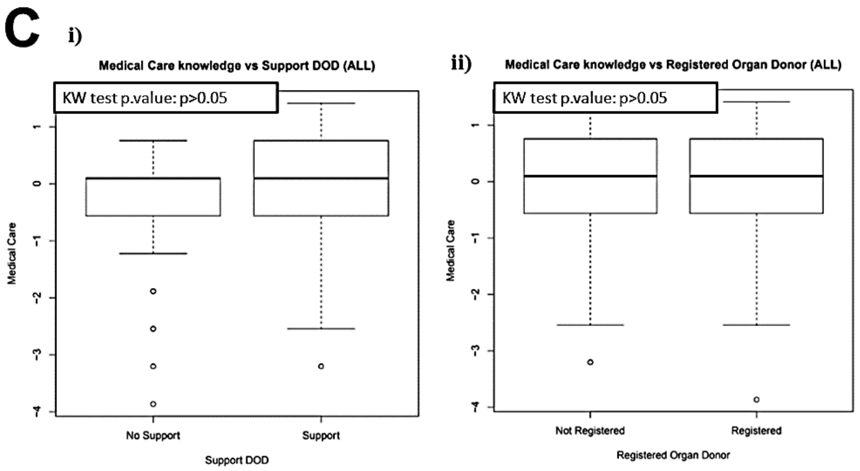
	No support	Support
Median	-0.15	-0.15
Q1	-0.58	-0.58
Q3	0.70	0.70

	Non-registered	Registered
Median	-0.15	-0.15
Q1	-0.58	-0.59
Q3	0.7	0.72



	No support	Support
Median	-0.22	-0.22
Q1	-0.69	-0.69
Q3	0.26	0.26

	Non-registered	Registered
Median	-0.22	-0.22
Q1	-0.69	-0.85
Q3	0.26	0.42



	No support	Support
Median	0.097	0.098
Q1	-0.56	-0.56
Q3	0.098	0.76

	Registered	Non-registered
Median	0.098	0.098
Q1	-0.56	-0.56
Q3	0.76	0.76

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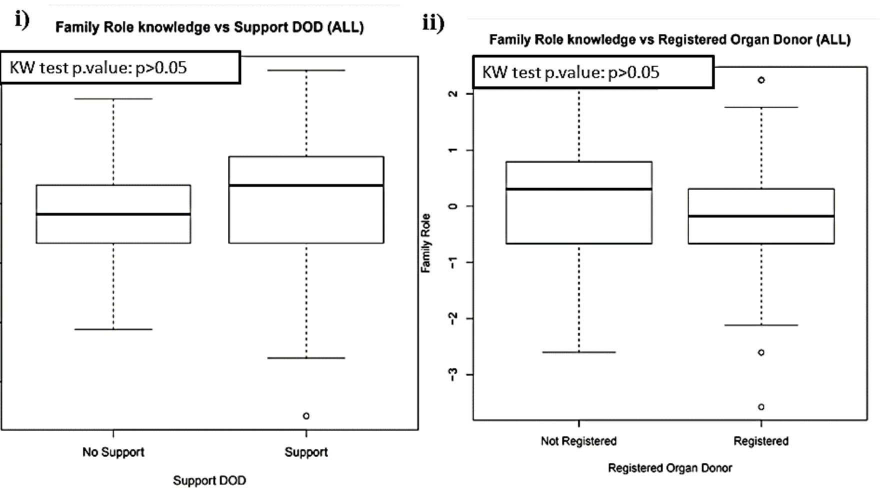
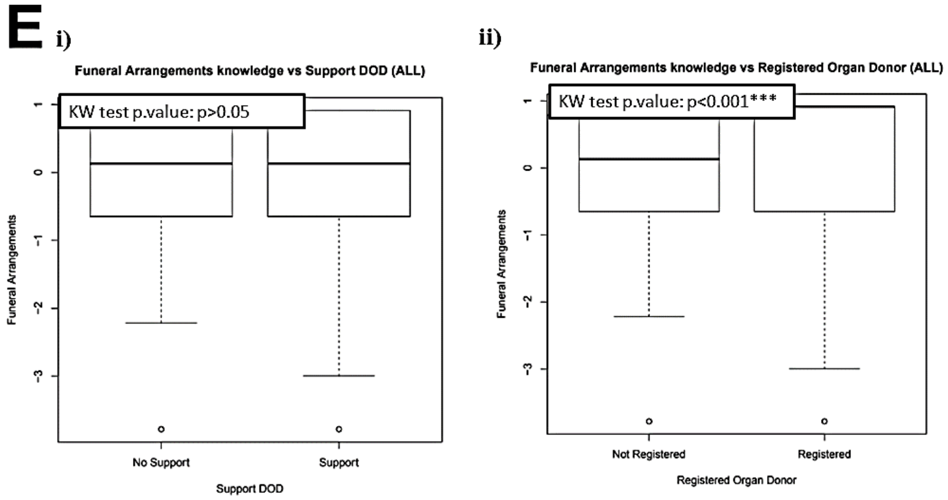


	No support	Support
Median	-0.18	0.31
Q1	-0.66	-0.66
Q3	0.31	0.79

	Non-registered	Registered
Median	0.31	-0.18
Q1	-0.66	-0.66
Q3	0.79	0.31

E



	No support	Support
Median	0.13	0.13
Q1	-0.65	-0.65
Q3	0.91	0.91

	Non-registered	Registered
Median	0.13	0.91
Q1	-0.65	-0.65
Q3	0.91	0.91

Figure 3. 19 Knowledge in DOD domains and supporter-registrant status. Positive values indicate correct responses and negative values indicate incorrect responses. Kruskal-Wallis test p-value included as well as lower, median and upper quartile range **(A) General DOD knowledge (i)** No support/ support **(ii)** Non-registered/ registered**. (B) Waiting list knowledge (i)** No support/ support **(ii)** Non-registered/ registered**. (C) Medical care knowledge (i)** No support/ support **(ii)** Non-registered/ registered**. (D) Family's role knowledge (i)** No support/ support **(ii)** Non-registered/ registered**. (E)Funeral arrangement knowledge (i)** No support/ support **(ii)** Non-registered/ registered**.**

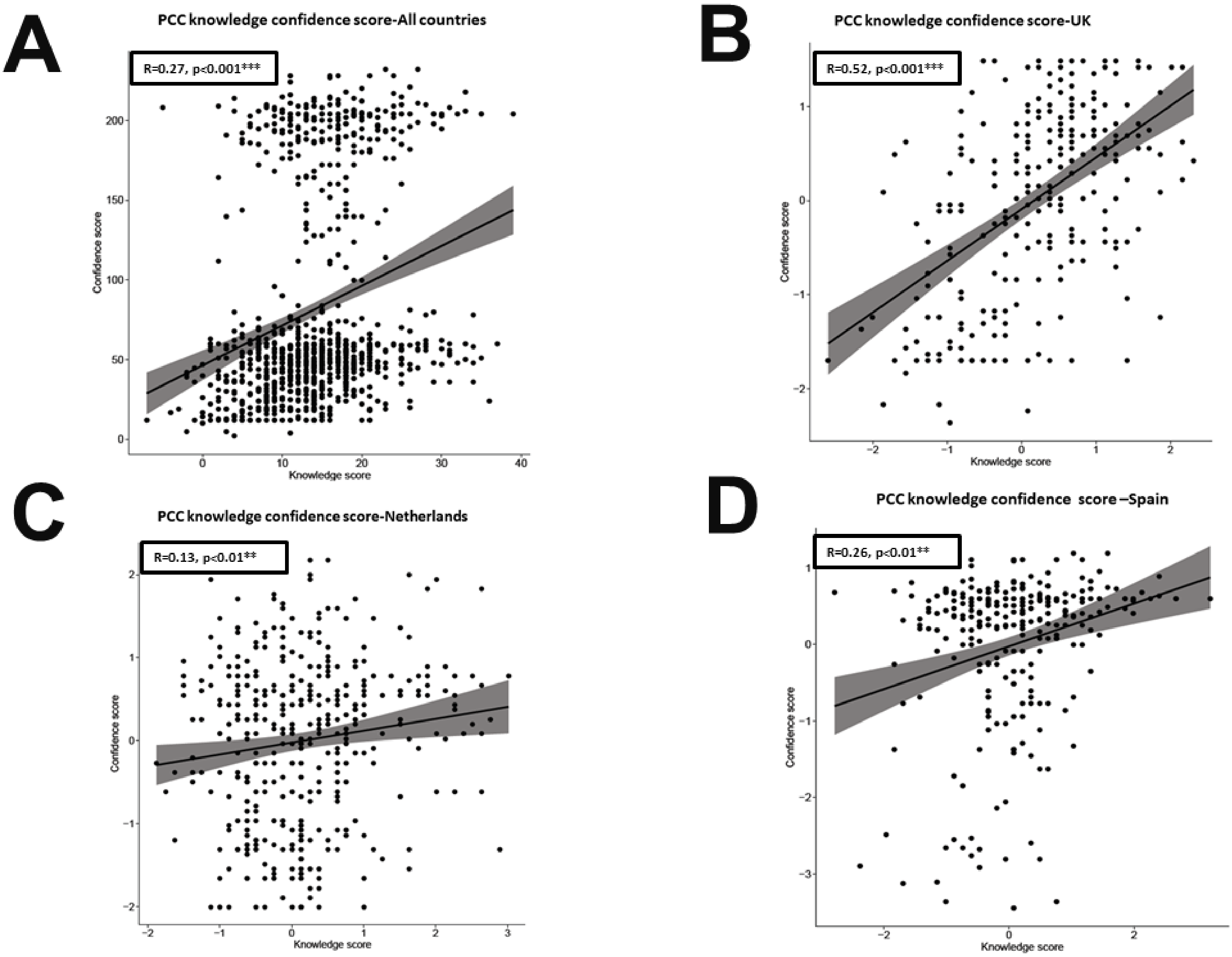


Figure 3. 20 Knowledge score confidence values. (A) Knowledge score confidence values of sample populations of all three countries. **(B)** Knowledge score confidence values of sample populations from the UK. **(C)** Knowledge scores confidence values of sample population from the Dutch samples. **(D)** Knowledge score confidence values of sample populations from Spain. **R and p values included.**

3.4.4 PART D: MCA AND EXPLORATORY FACTOR ANALYSIS

3.4.4.1 INTRODUCTION

This section combines and synthesises the parameters examined in Parts A-C. The purpose of this is to explore the interaction of these variables in the holistic construction of profiles for supporter-registrant status. As previously mentioned at the beginning of this chapter, owing to the high proportion of missing values for sociodemographic characteristics, it was necessary to create a separate MCA factor map for this analysis, alongside the factor map incorporating all the other variables (**see table 3.2**).

3.4.4.2CODING SCHEME FOR INTERPRETATION

As there is a limited amount of space on the MCA factor map, it was necessary to abbreviate some variables using a coding scheme. For ease of interpretation, this is included in the legend of figure 3.22. A complete table of the coding scheme can be found in Appendix A.

3.4.4.3 CONSTRUCTION OF THE PRINCIPAL DIMENSIONS

The fact that dimension 1 and dimension 2 account for similar percentage variance, generates a more symmetrical display. Cumulative percentage variance summarises the total variance accounted for by the two dimensions together **(tables 3.5; 3.6)**. In social sciences, the selected dimensions must account for a total of 60% or less of the minimum expected variance (Hair, 2014). The lower the total percentage variance, the closer the data points are to the mean and to other values within the data set.

Socio-demographic MCA: Construction of the Principal Dimensions			
	Eigenvalue	Percentage Variance (%)	Cumulative Percentage Variance (%)
Dim.1	0.4	9.6	9.6
Dim.2	0.3	8.1	17.7

Table 3. 5 Table on sociodemographic MCA principal dimensions.

Value Judgement, Communication and Knowledge: MCA Construction of the Principal Dimensions			
	Eigenvalue	Percentage Variance (%)	Cumulative Percentage Variance (%)
Dim.1	0.2	12.2	12.2
Dim.2	0.1	8.6	20.8

Table 3. 6 Table on value judgements, communication and knowledge MCA principal dimensions

3.4.4.4 MCA UK, NL, SP

Below are presented the two separate MCA factor maps; for 'Socio-demographics' (**figure 3.21**), and 'Value Judgement, Communication and Knowledge' **(figure 3.22**). Each map considers the four centroids, relating to supporter-registrant status among all three participating countries.

All four centroids are presented in dark blue on the factor map: 'support', 'no support', 'registered' and 'not registered'. The three participating countries are also depicted in dark blue, to aid in the interpretation of results. The gross, spatio-relational description is conducted with reference to the quadrants encompassing the relevant centroids. The counter-clockwise quadrant labelling follows the conventions of standard Cartesian graph interpretation (Leinhardt, 1990). This spatio-relational analysis is followed by a review of the variables' distances (chi ^{2}). A full list of the variable eigenvalues, interpoint distances and weights (Cos ^{2}) are included in Appendix A.

3.4.4.5 SUPPORTER/ NON-SUPPORTER EXPLORATORY FACTOR ANALYSIS

3.4.4.6 NON-SUPPORTER STATUS

a) SOCIO-DEMOGRAPHICS

The non-support centroid, depicted in Quadrant IV, indicates that non-supporters are mainly of black ethnic origin, male between the ages of (45-59), Christian and have an educational background of college or postgraduate studies. Marital status was variable as individuals in this group were either married or divorced **(figure 3.21)**.

b) VALUE JUDGEMENT, COMMUNICATION AND KNOWLEDGE

In **figure 3.22,** Quadrant I encompasses the 'no support' centroid. A lack of support for DOD correlates with poor knowledge about common health conditions (high blood pressure, diabetes and obesity), poor effort to communicate with the most members of one's social circle (parents, siblings, friends, cousins).

3.4.4.7 SUPPORTER STATUS

a) SOCIO-DEMOGRAPHICS

Supporter status was depicted in Quadrant II **(figure 3.21)**. Demographic characteristics of 'supporters' include being a student, being female, belonging in the 18-29 age group, a 'single' marital status and having a university level education.

b) VALUE JUDGEMENT, COMMUNICATION AND KNOWLEDGE

Quadrant III **(figure 3.22)** encompasses the 'support' centroid. DOD supporters demonstrate good engagement with information and expressed interaction with their immediate families. In terms of value judgement, this group was motivated by both moral value judgements and scientific facts. Specifically, the moral arguments that were endorsed were perception of DOD as the ultimate altruistic act, being convinced by scientific facts and figures, being remembered as a 'giving person', the belief that DOD allows some part of the deceased to stay alive. Individuals in this group were familiar with more advanced health related topics; including Alzheimer's disease, mental health, organ donation and HIV/AIDS. Beyond this, this cohort were unrestrained by religious and/or cultural objections. In terms of communication, this category is related to conveying a positive opinion about DOD to one's parents and friends.

3.4.4.8 REGISTRANT/NON-REGISTRANT EXPLORATORY FACTOR ANALYSIS

3.4.4.9 NON-REGISTRANT STATUS

a) SOCIO-DEMOGRAPHICS

The 'not registered' centroid is situated in Quadrant I **(figure 3.21)**. This is most closely associated with the UK group. This characteristic is also related to the 60+ age group, an education level at high school level or less, coming from a Black, Asian ethnic background and belonging to the Hindu, Muslim or Sikh religion.

c) VALUE JUDGEMENT, COMMUNICATION AND KNOWLEDGE

Quadrant IV **(figure 3.22)** contains the 'not registered' category centroid. This is associated with the UK and Spain country groups. This is related to a lack of knowledge about health issues, including cancer, Alzheimer's disease, heart disease, mental illness. This quadrant also contains inhibitory attitudinal beliefs. This includes the notion that potential donors receive poor treatment by the medical team and citing religious objections or cultural traditions are also situated in this quadrant.

3.4.4.10 REGISTRANT STATUS

a) SOCIO-DEMOGRPAHICS

The ‘registered’ centroid is situated in Quadrant III and associated with the Netherlands and Spain. Participants in this groups were also seen to be of white ethnic background and belonging to no religious group **(figure 3.21).**

b) VALUE JUDGEMENTS, COMMUNICATION, KNOWLEDGE

Quadrant Ⅱ **(figure 3.22)** encompasses the ‘registered’ category and the Netherlands group centroids. This suggests that the majority of the registered participants in the study were from the Dutch sample. In terms of knowledge, participants in this groups showed good knowledge about Alzheimer’s Disease, cancer, mental illness, heart disease. Furthermore, belonging to this group is associated with having no cultural traditions and no religious objections to DOD. In terms of communication patterns, individuals in this centroid, where seen to have discussed the topic of DOD with their close family covering neutral views and having non-discussions with their partners.

3.4.4.11 CONCLUSION

Overall the MCA has shown that, individual, social and cognitive variables interact with each other, in the construction of supporter/registrant profile. These interactions can be both dynamic and definitive as some traits are unique to each profile whilst others can overlap between categories.

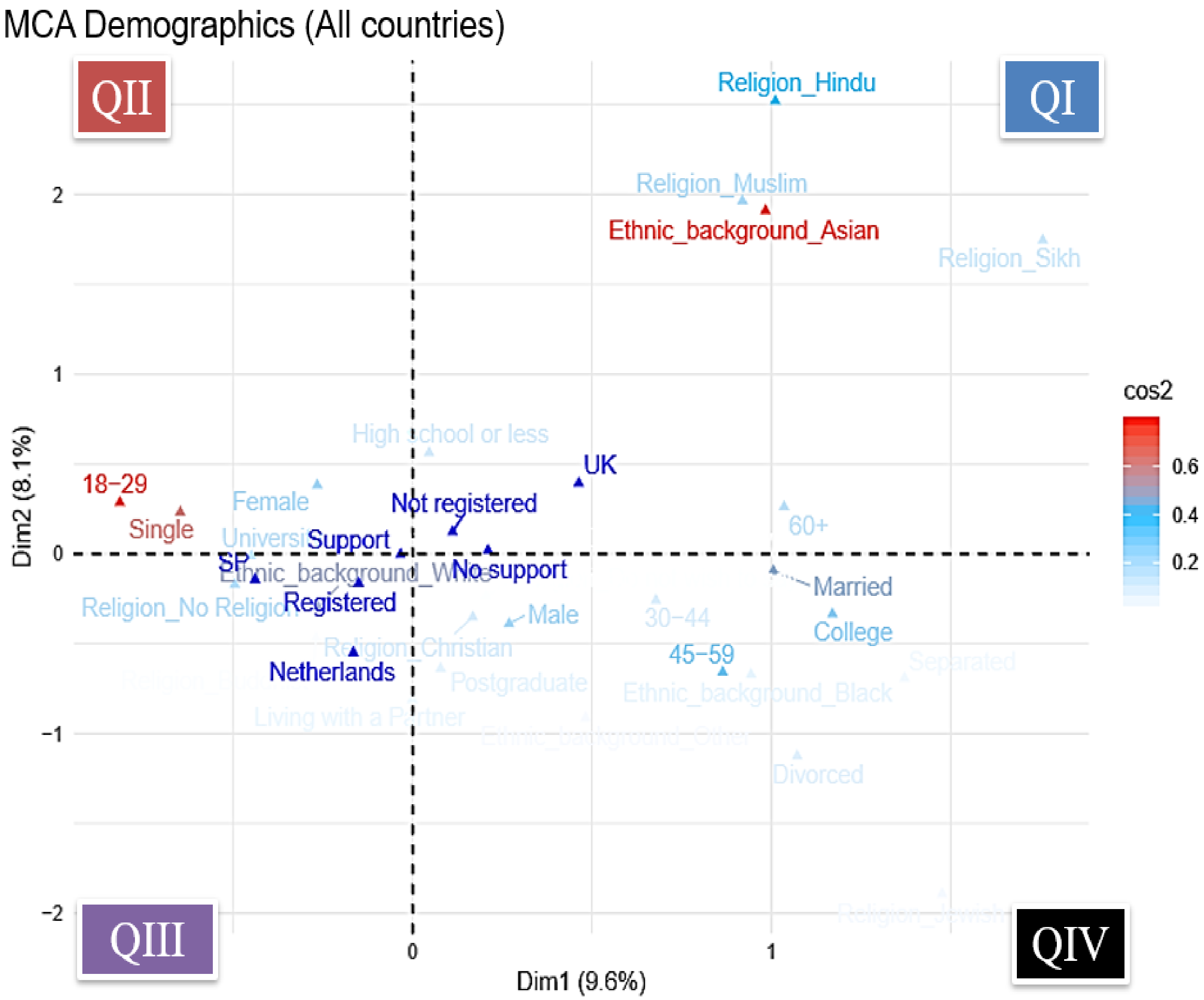


Figure 3. 21 Socio-demographic MCA. (QI) Quadrant I indicates characteristics of individuals not registered for DOD. **(QII)** Quadrant II indicates characteristics of individuals in support for DOD. **(QIII)** Quadrant III indicates characteristics of individuals registered as for DOD. **(QIV)** Quadrant IV indicates individuals not in support for DOD.

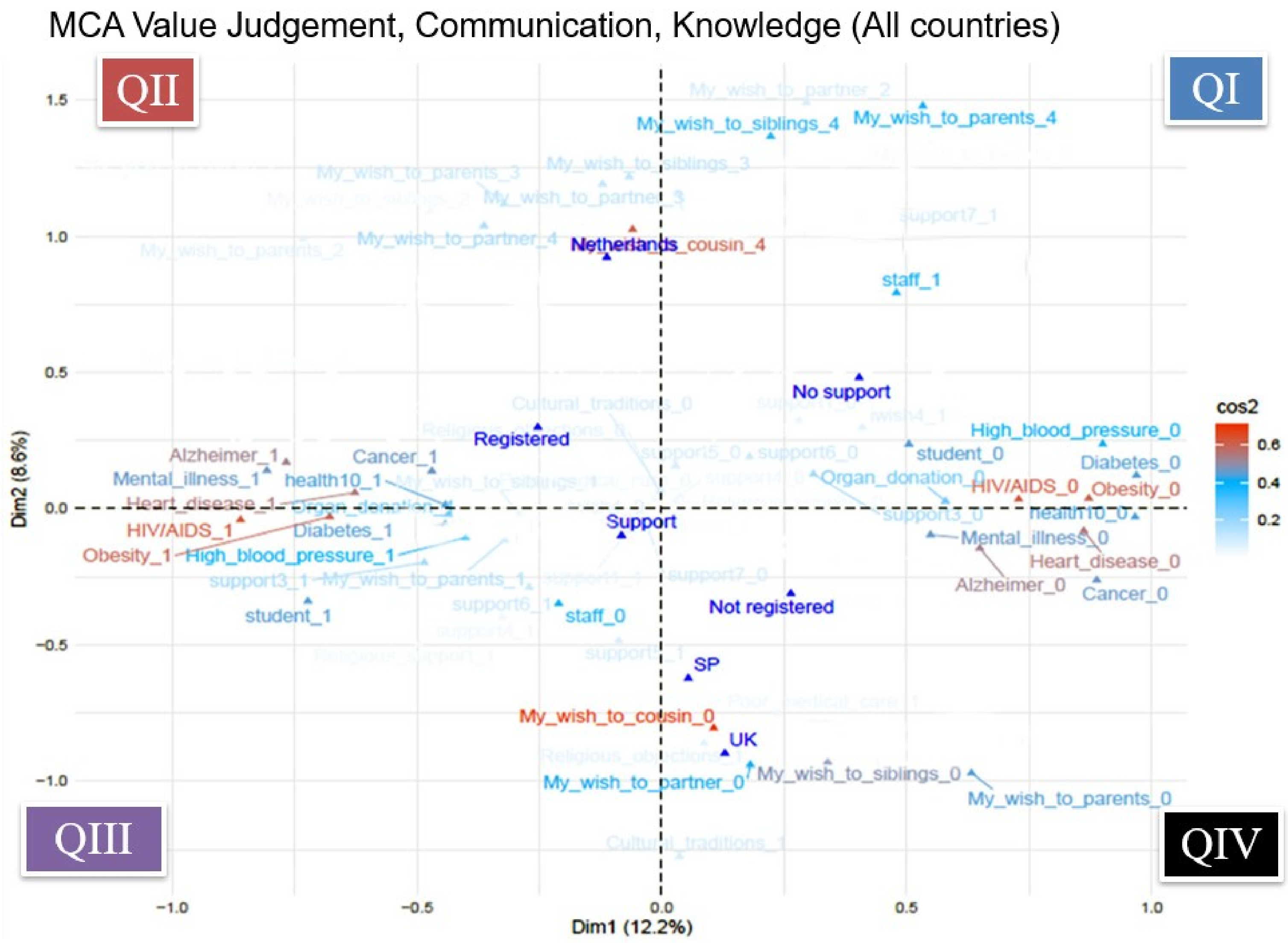


Figure 3. 22 Value Judgements, communication and knowledge MCA. MCA analysis based on value judgements, knowledge and communication) from sample populations of all three countries **(QI)** Quadrant i indicates characteristics of individuals not in support for DOD. **(QII)** Quadrant ii indicates characteristics of individuals registered for DOD. **(QIII)** Quadrant III indicates characteristics of individuals in support for DOD. **(QIV)** Quadrant IV indicates individuals not registered for DOD. Numbers next to the variables encode absence of the variable (0) or its presence (1) (e.g. Heart disease_1 means knowledge about heart disease). For communication variables, e.g. 'my wish to parents/siblings/ children etc_0/1/2/3/4 encoded as (0) no discussion, (1) negative, (2) + (3) positive, 4) neutral. Support(1-8)_0/1 encode various reasons for supporting DOD e.g. 1 (helping others), 2 (religious beliefs), 3 (scientific facts), 4 (remembered as giving person), 5 (relief), 6 (set an example), 7 (none), 8 (other). E.g. support1_1 means support DOD because of religious beliefs.

3.4.5. Part E: PREDICTIVE REGRESSION ANALYSIS

3.4.5.1 INTRODUCTION

This section presents the construction and outcomes of the predictive modelling analysis using GLM regression and assessing its performance. This is presented as a priority-ranked synthesis of the variables within the individual, social and cognitive parameters assessed in the DHQ.

3.4.5.2 SUPPORTER PREDICTIVE PROFILING

The funnel chart below presents with asterisks the variables which were statistically significant in predicting support status for DOD, in descending order of importance **(figure 3.23)**.

a) VALUE JUDGEMENTS

The top ranking socio-cognitive variable, was individual's value judgement. The first four variables in the funnel chart were related to the importance of values and attitudes (first three $p<0.01$**). Specifically, positive attitudes were to be reinforced by sound scientific evidence, personal attitudes focusing on the act of helping and encouraging others to do the same. In addition, having less personal reasons against DOD was seen to be important.

b) COMMUNICATION

The second highest ranking socio-cognitive dimension was communication. DOD discussion and expression of wishes to loved ones such as partners was a high ranking variable in relation to DOD supporter status ($p<0.05$*). In addition communication with close family members such as siblings and parents were seen to correlate with DOD supporter status albeit expression of wishes to children and extended relatives such as cousins were the lowest ranking communication elements.

c) KNOWLEDGE

Finally, knowledge was the parameter which ranked lowest in determining supporter status. Specifically, knowledge about common health issues such as obesity ($p<0.05$*) , diabetes and smoking were consistent with DOD support in comparison to more complex, specialist topics such as Alzheimer's Disease, which ranked lower.

d) SUPPORTER CLASSIFICATION MODEL PERFORMANCE

The accuracy of the supporter predictive model was very high, at 83% ($p < 0.01$**, 95% CI 0.77-0.88%) with lower specificity (0.24) but high sensitivity (0.95) **(table 3.7)**.

3.4.5.3 REGISTRANT PREDICTIVE PROFILING

The second funnel chart is a schematic representation of the top ranking variables which were identified as important in predicting registrant status in DOD **(figure 3.24)**, presented in descending order of importance. (Statistically significant results are denoted be asterisks).

a) COMMUNICATION

Communication was seen to be the most important socio-cognitive domain for registrant status. Similarly to support, expression of wishes to family members such as siblings and parents were seen to be statistically significant (p<0.01**). In contrast expression of wishes to partners ranked below extended family such as cousins.

b) KNOWLEDGE

The second highest domain seen to be significant in predicting DOD registrant status was knowledge. In contrast to the predictive model for DOD support, registrant predictive profiling ranked highly knowledge about complex health issues such as mental health, Alzheimer's disease and HIV/AIDS. General knowledge about DOD was the top ranking variable in this domain (p<0.05*).

c) VALUE JUDGEMENTS

Finally, value judgements were the lowest ranking socio-cognitive parameter, in contrast with supporter predictive profiling, where this parameter ranked highest. Nevertheless, value judgements were consistent amongst supporter and registrant DOD profiles. Primary values included the act of helping others and influencing others to follow by example. Generally, limited objections towards DOD and high agreement with reasons for support was found to be statistically significant (p<0.01**).

d) REGISTRANT CLASSIFICATION MODEL PERFOMANCE

The accuracy of the registrant predictive profiling was good, at 73%, (95% CI 67-79%). Sensitivity was calculated at 74% albeit the model had higher sensitivity that the predictive model for support at 72% **(table 3.8)**. However, in contrast to the supporter predictive profiling model, this model was not statistically significant (p > 0.05).

3.4.5.4 PART E CONCLUSION

Overall, the predictive modelling emphasised that different HL parameters are prioritised in terms of DOD support and registration. The top-ranking domain for support was individual's value judgement followed by communication and knowledge. In contrast registrant status was seen to be dependent on communication, followed by knowledge and lastly value judgements.

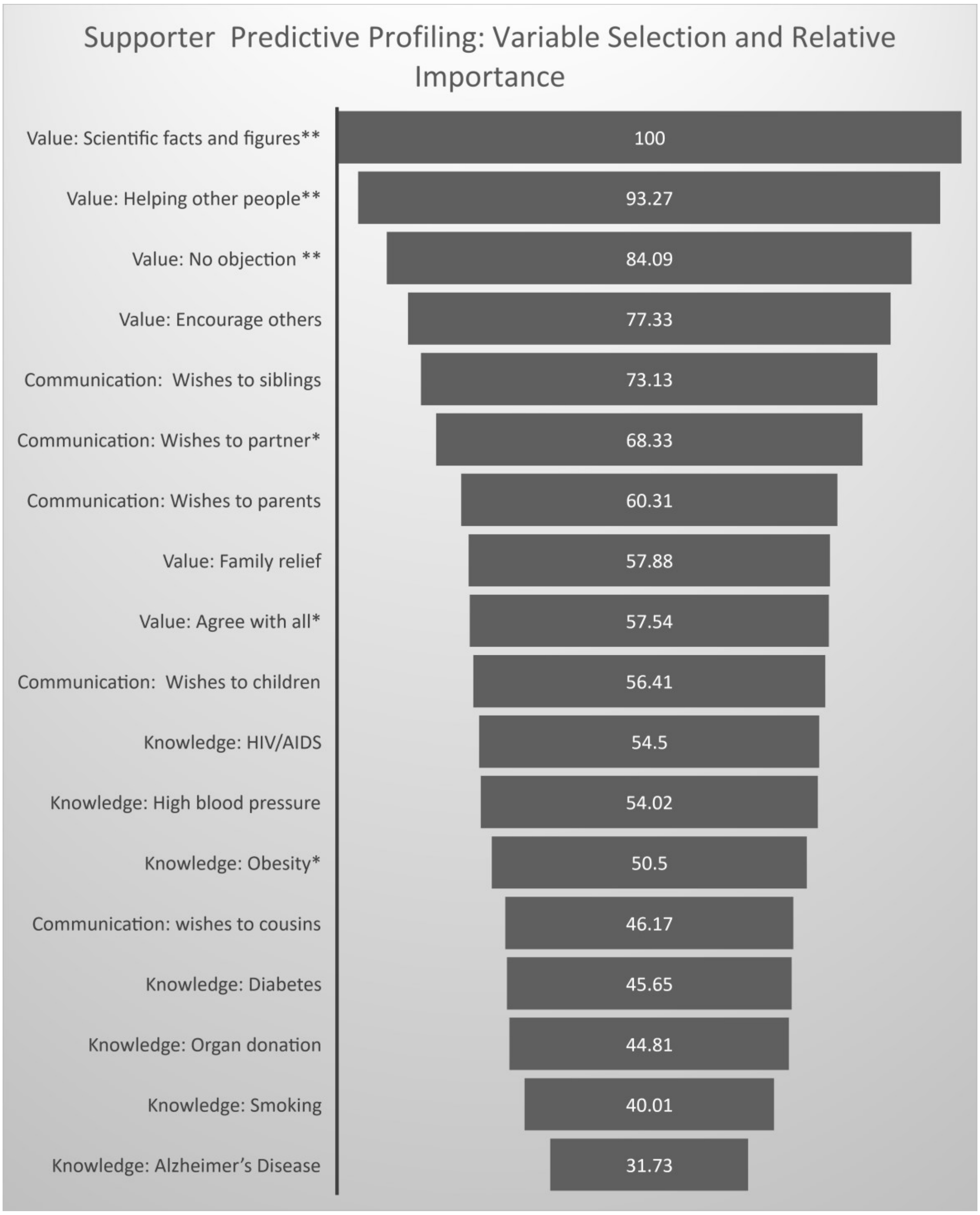
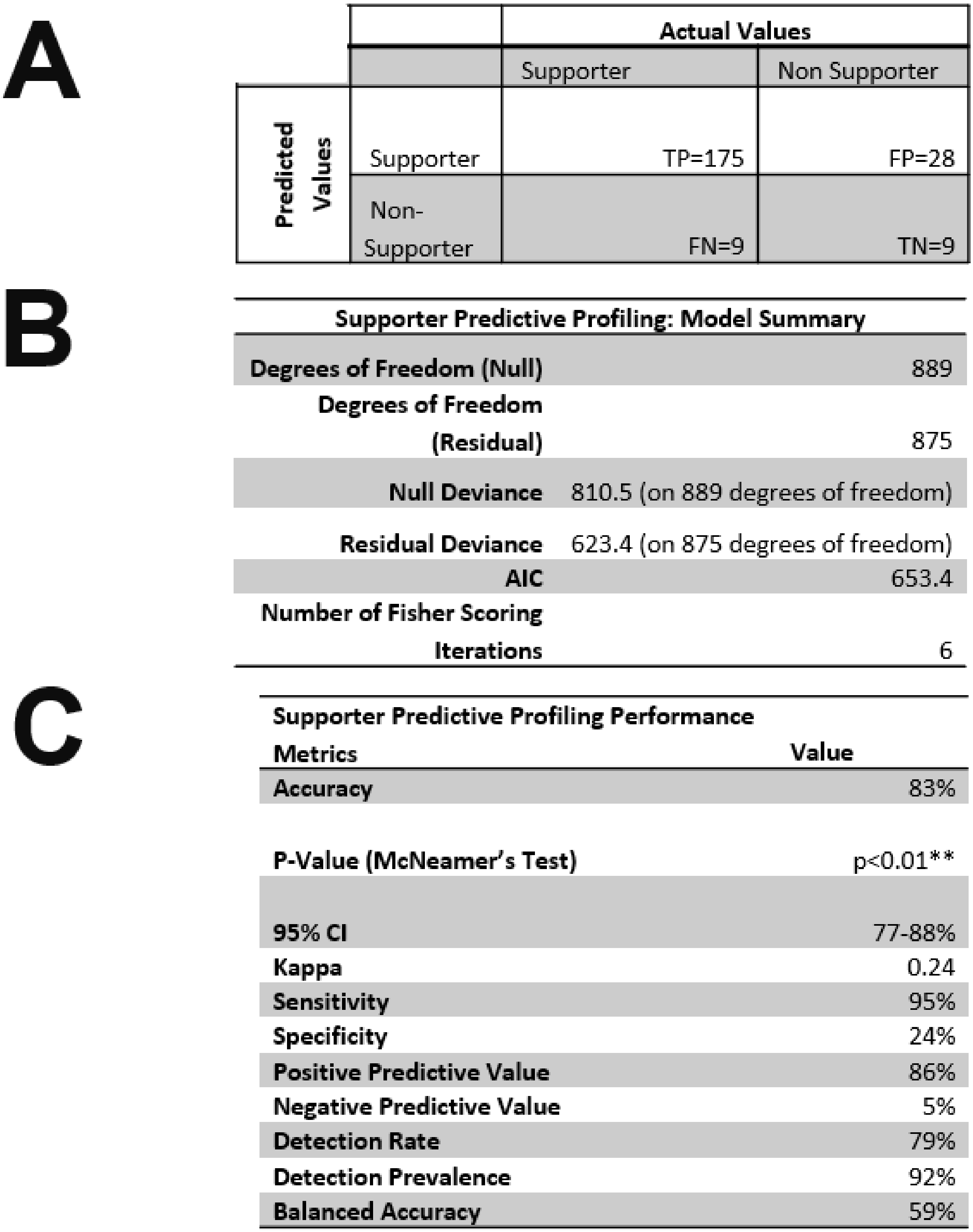


Figure 3. 23 Funnel chart summarising the key variables associated with predicted DOD support



A

		Actual Values	
		Supporter	Non Supporter
Predicted Values	Supporter	TP=175	FP=28
	Non-Supporter	FN=9	TN=9

B

Supporter Predictive Profiling: Model Summary	
Degrees of Freedom (Null)	889
Degrees of Freedom (Residual)	875
Null Deviance	810.5 (on 889 degrees of freedom)
Residual Deviance	623.4 (on 875 degrees of freedom)
AIC	653.4
Number of Fisher Scoring Iterations	6

C

Supporter Predictive Profiling Performance Metrics	Value
Accuracy	83%
P-Value (McNeamer's Test)	p<0.01**
95% CI	77-88%
Kappa	0.24
Sensitivity	95%
Specificity	24%
Positive Predictive Value	86%
Negative Predictive Value	5%
Detection Rate	79%
Detection Prevalence	92%
Balanced Accuracy	59%

Table 3. 7 Predictive model for DOD support statistical analysis. (A) Sample confusion matrix indicating the true positive, true negative, false positive, and false negative detection rates of the predictive model used to calculate the performance metrics including sensitivity and specificity. **(B)** Predictive model for DOD support summary. **(C)** Predictive model for DOD support performance metrics.

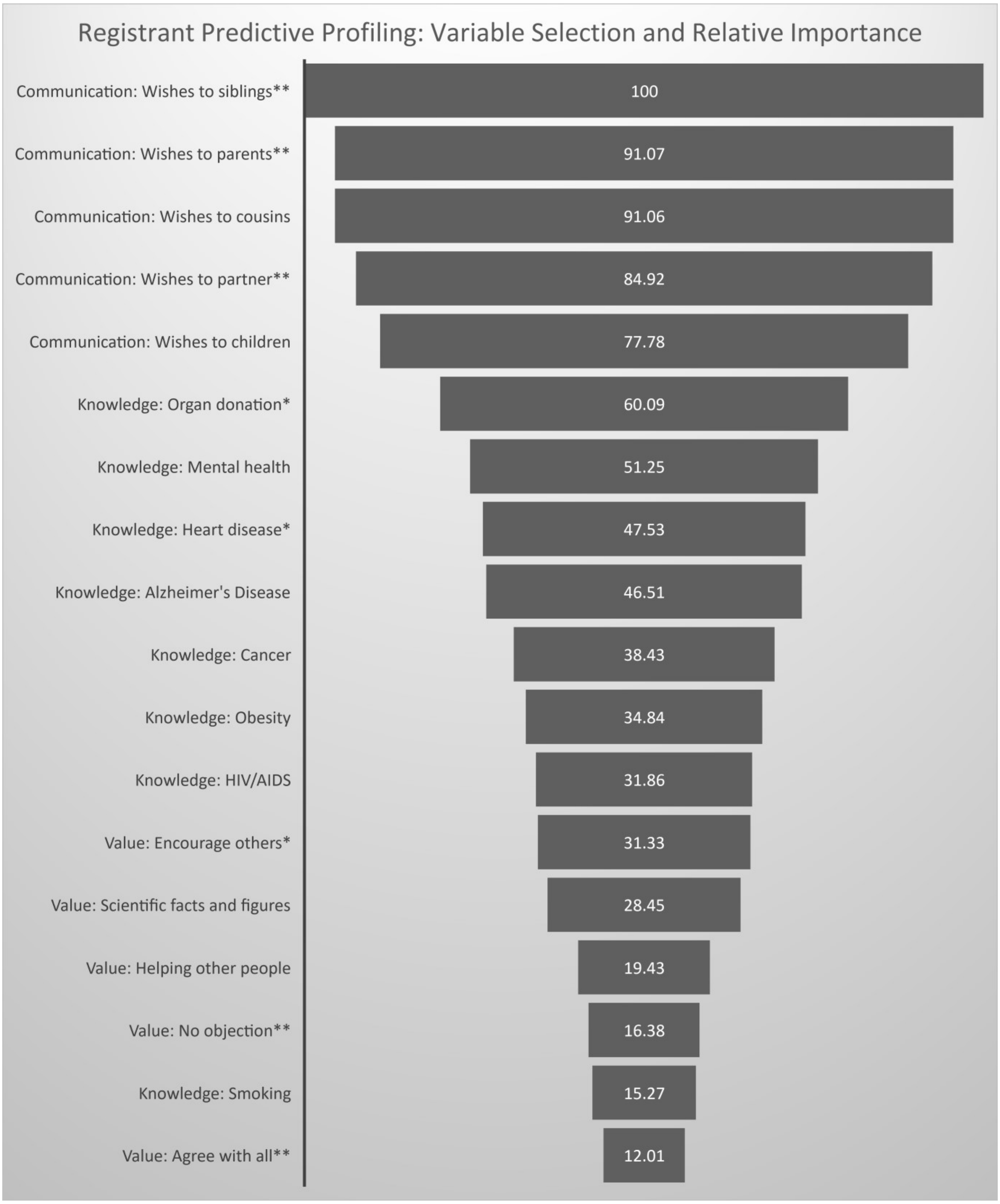


Figure 3. 24 Funnel chart summarising the key variables associated with predicting DOD registration

A

		Actual Values	
		Registrant	Non-Registrant
Predicted Values	Registrant	TP= 84	FP=30
	Non-Registrant	FN=29	TN=78

B

Registrant Predictive Profiling: Model Summary	
Degrees of Freedom (Null)	889
Degrees of Freedom (Residual)	865
Null Deviance	1233(on 889 degrees of freedom)
Residual Deviance	924.3(on 865 degrees of freedom)
AIC	974.3
Number of Fisher Scoring Iterations	12

C

Registrant Predictive Profiling Performance Metrics	Value
Accuracy	73%
P-Value	p>0.05
95% CI	67-79%
Kappa	0.47
Sensitivity	74%
Specificity	72%
Positive Predictive Value	74%
Negative Predictive Value	73%
Detection Rate	38%
Detection Prevalence	52%
Balanced Accuracy	73%

Table 3. 8 **Predictive model for DOD registration statistical analysis. (A)** Sample confusion matrix indicating the true positive, true negative, false positive, and false negative detection rates of the predictive model used to calculate the performance metrics including sensitivity and specificity. **(B)** Predictive model for DOD registration summary. **(C)** Predictive model for DOD registration performance metrics.

CHAPTER 4

FOCUS GROUPS QUALITATIVE ANALYSIS: METHODS AND RESULTS

4.1. INTRODUCTION

The previous chapter presented the quantitative analysis of the DHQ, including the methodology used and the results that were obtained. This chapter presents the qualitative component of this thesis, consisting of nine focus group discussions (FGDs). These discussions were conducted to complement and provide context to the quantitative results, with the purpose of achieving an iterative interpretation and a holistic understanding of the topic.

The chapter is structured in two sections: Section A describes the methodology and Section B describes the results and thematic analysis of each discussion. A flow chart summarising the methods used for qualitative analysis can be found in **figure 4.1.**

4.2. SECTION A: METHODS

4.2.1. THEORETICAL FRAMEWORK

The focus group experience encouraged members of each group to share and explain their own and collective phronesis or 'practical wisdom', as a lifetime socialization process, with regard to the topic of DOD (Krueger & Casey, 2009). This would establish what the participants already know and feel, what sources they used to reach these personal conclusions and what content and strategies they believe would be of potential benefit in future DOD health literacy campaigns. This rationale is rooted in the principles of empowering health communication in the sphere of health promotion (Kettunen, 2006). This approach is important in:

- Showing interest and respect for what individuals think about DOD
- Addressing what individuals want to know about DOD
- Respecting individuals' competence to make decisions and value judgements about DOD

4.2.2. SAMPLING

Owing to the international and cross-cultural case study design approach, the FGDs took place at the institutions of the three countries involved within this research; the Hammersmith Hospital of Imperial College NHS Trust, London in the UK (N= 18) ; the Erasmus University in Rotterdam, the Netherlands (N= 15) and the University of Cantabria in Santander, Spain (N=16). Further details on the composition of each group within the three countries are given in **table 4.1**.

Therefore, participant selection was a function of pragmatic convenience sampling, utilising the individuals that had already agreed to participate in the quantitative aspect of this research project by completing the DHQ.

Inclusion criteria were that all participants were aged over 18 years of age, able to understand and verbalise their responses; in English were possible or with the aid of a translator, able to give informed, written consent and were permanent or fixed constituents of the respective study sites.

All participants in the patient group had either already received a transplant or were on the waiting list. The hospital administrative staff were required to have a non-clinical role within the healthcare setting and to be current employees within their respective trusts. The medical student participants were required to be within the clinical years of their study (years 3-5+) or to have attended hospital placements within the past academic year. The purposeful exclusion of clinicians from the research sample was on the basis of bias avoidance, as it is reasonable to consider this population as sufficiently health literate on DOD. This would significantly skew the data.

There were no limitations or specifications on age, gender or ethnicity so as to allow for a higher degree of randomisation and to provide a greater insight into the cross-sectional representation of these socio-demographic variables within each participating group and country.

	UK	**NL**	**SP**
Patients	5	4	5
Staff	7	5	5
Medical Students	6	6	6
TOTAL	18	15	16

Table 4. 1 Table summarising the number of participants for each of the nine focus groups from all three subgroups in the UK,NL and Spain

4.3. DATA COLLECTION

Data collection took place between May 2016 – May 2017. The recruitment of the participants in the FGDs was conducted on an entirely voluntary basis. All of the participants who took part in the quantitative analysis in each country were invited to take part in the FGDs. The method of approach varied in relation to which category the participants were to be recruited. In the patient cohort, the primary method of approach was through bedside face-to-face invitation by members of their healthcare team. This gave rise to a higher degree of convenience sampling, in comparison with the other two participant groups. In contrast, the FGDs were mass-advertised through printed posters and lecture shout outs to the administrative staff and medical student groups, allowing for a greater degree of randomisation. All participants were offered a £25 shopping voucher to compensate for their time.

Participation was voluntary and participants were allowed to withdraw at any point without giving a reason. There were no such issues during the process.

It was not felt that there was a need or indication for repeat interviews to be conducted as:

- There were no adverse circumstances during the FGDs
- Topic coverage was deemed sufficient for cross-comparability in all nine interviews with no important thematic omissions identified during the transcription phase and in the coding phase.

4.4. DATA ORGANISATION

4.4.1. FOCUS GROUP PARTICIPANT GROUPING

The participants partook in the FGDs in their discrete, original and non-mixed categories. The rationale behind this was threefold. Firstly, due to the personal and sensitive nature of previous and/or current experience, patients would be only required to discuss and disclose details of their experiences and viewpoints to a group of their peers, in the absence of members of the hospital team. This would encourage unbiased and unreserved expression and patient engagement (Gallivan, 2012).

Additionally, the groups contained participants of the same group or discipline (e.g. patients, staff, students) to bypass any sense of inter-professional hierarchy that may hinder freedom of discussion.

Thirdly, this approach facilitates a mixed-methods purposive sampling, comprising both maximum variation or heterogeneous sampling and homogeneity or typical-case sampling simultaneously (Palinkas, 2015).

4.4.2. INTERVIEW CONDUCT

Topic guides for the FGDs were developed after a review of the literature, the official national websites on DOD available for each corresponding country, and using the thematic categories that were derived in Chapter 2 for the DHQ.

The topic guides were piloted in three interviews within the Hammersmith Hospital in London, UK; one with a patient, one with a member of the hospital's administrative team and one with two medical students (**table 4.3**) (full question guide in Appendix B).

Following the pilot studies, it was deemed that FGDs are superior to individual interviews, as the group dynamics assist in eliciting richer or more sensitive data (Morrison-Beedy, 2001). Additionally, the pilot studies were greatly beneficial in identifying various common patterns of conversational end points or knowledge deficits. This facilitated the process of refining the FGD interview guides so as to increase the likelihood of reaching data saturation (Fusch & Ness, 2015).

4.4.3 INTERVIEW PROTOCOL

Verbal confidentiality disclaimer and anonymity disclaimer were issued before the start of each FGD. Before the discussion took place, the researcher explained to the participants the aim of the project and the discussion, as well as that there were no right or wrong answers. It was also explained that the discussion did not rely on participants' factual knowledge, but on their individual life experiences, views and suggestions.

The aim was to encourage a naturalistic discussion between the participants upon the main questions set by the researcher instead of following an interview style format. Therefore, the researcher had a high threshold for intervention, doing so only when they felt the discussion was going off topic, during voice overlaps or in instances where several topics were raised simultaneously (Gukas et al, 2010). In such cases, prompt questions or clarifications were provided. The positive feedback from the pilot studies led to the retention of this interventional framework, suggesting that this did not significantly alter the potential for discourse analysis in the discussion, as no intended question was omitted, no objections or complaints were raised by group participants, and flow of conversation was preserved.

4.4.3 MODERATION CHALLENGES

The researcher acted as the primary moderator in all FGDs that took place in English (in the UK and the Netherlands) and as a second moderator in the two discussions that were moderated by the Spanish translator. A professional moderator without knowledge of the issue is considered the gold-standard of practice in FGD conduct. However, this is not appropriate in all cases.

Owing to the greater sensitivity associated with health-related issues, it is preferable for the moderator to have a greater familiarity with the topic. Given the researcher's expertise and background in adult learning, there was a specialist understanding of group processes and ability to put participants at ease by establishing rapport and mutual trust. Additionally, the researcher's role as the moderator is benefited by their intimate familiarity with the aims of the study.

This ensures that only the topics that are within the research scope are explored, thus avoiding subjecting the participants to reveal unnecessary levels of private and personal information (Morrison-Beedy, 2001). The following table depicts some of the precautions taken by the moderator to minimise neutrality issues (**table 4.2**).

Conceptual Techniques	Reinforcement
Strict withdrawal of the moderator's expression of personal opinions	Only contributing the exploratory questions to the discussion
Construction of topic guides that are directly and clearly outlining the aims and boundaries of the study	Controlling the discussion where it strayed beyond the scope of the research aims e.g. 'could we go back to the question?'
Emphasis on the non-requirement of homogeneity	Inviting contrasting viewpoints without challenging another participant's statement e.g. 'any other thoughts?' instead of 'does anyone agree/ disagree?'
Emphasis on opinion and experience over facts	Avoidance of confirmatory prompts, such as 'right', which imply that this is a correct response or a line of reasoning that the researcher condones

Table 4. 2 Neutrality techniques employed in focus group discussions by the researcher and collaborators.

4.5. DATA PREPARATION

4.5.1 INTERVIEW TRANSCRIPTION AND DATA ANALYSIS TECHNIQUE

All recordings were transcribed verbatim and a thematic analysis was conducted using ATLASti V.8 software, structured around the main areas of questioning. A deductive coding scheme was adopted, as the topics discussed were directly related to the pre-determined categories derived during the exploratory phase of the DHQ construction.

Thematic analysis was specifically selected as it is a simple to use and coherent method of qualitative data handling which offers research freedom and flexibility as it is suitable for interdisciplinary research and is not tied to any specific theoretical model. The nine focus group transcripts were initially integrated into a single data corpus. A set of codes for the text was initially generated; codes were then sorted in specific themes and sub-themes; all themes /sub-themes extracts were read and re-read a number of times until pattern coherence of themes/sub-themes was ensured (Braun & Clark, 2006; Pope & Mays, 2008).

ATLASti software was selected because of the multiple levels of data processing that are available. Firstly, the data was categorized under the highest and broadest possible taxonomic categories. This involved selection of quotations through highlighting selected pieces of data and annotating them using line by line coding. These quotations would then be sorted into homogenous categories to facilitate the subsequent coding. This initial segmental cross-comparative phase is mainly descriptive and non-informative. These first-level descriptive codes enable the subsequent higher level of analysis through thematic interpretation and analytical conceptualization. **Figure 4.2** demonstrates a descriptive word cloud of the common key words that arose among the nine discussions, generated by the Atlas.ti software.

Subsequently, constant comparison analysis was employed. This is a technique frequently utilised in comparative studies that feature numerous FGDs (Glaser, 1978, 1992; Glaser and Strauss, 1967, Strauss, 1987). The analysis of multiple focus groups confers numerous strengths. Most notably, it allows for a flexible and parallel inductive approach to coding. This allows for theoretical sampling of additional topics or themes that were generated by the discussion but were not originally considered in the deductive coding outline (Charmaz, 2000).

Structure	Question
Opening/ Debriefing	Outlining research aims, researcher/participant introductions
Introduction	What do you know about DOD?
Transition	What are your personal attitudes on DOD?
Key	Have you discussed DOD with your family or friends? What do you think of current DOD promotion campaigns? What would you recommend for future DOD promotion strategies?
Ending	Any further remarks, suggestions or additions?

Table 4. 3 Framework of questions to base discussions in focus groups

4.6. INTER-CODER AGREEMENT

One of the early and to a degree still commonly considered criticisms that qualitative research methods receive is its subjective nature. This criticism can be further distinguished to the researcher's bias and the lack of reproducibility (May & Pope, 1995). An additional challenge is that it is possible for a single quotation to be defined under more than one theme or category.

For this reason, after each of the nine focus groups were transcribed, and codes were applied to identify each theme, a second coder was used to validate the coding strategy. Dr. Lisa Aufegger (Postdoctoral Researcher Associate and Forum Fellow in the Patient Safety Group Institute of Global Health Innovation at Imperial College London) served as the second coder. Encrypted ATLAS. ti 8 files containing samples of each of the three subgroups from a participant country where taken (UK patients, NL staff, and SP students) and sent to the second coder along with the coding book. The second coder applied the codes to sections of the transcript and ATLAS.ti 8 quantified the level of inter-coder agreement. The parameters quantified were percentage agreement (assessing the frequency in which ratings agree divided by the number of observations rated) and Krippendorff measures **(table 4.4)**.

Country	**Percent agreement(%)**	**Krippendorff cα binary**
UK Patients	**89.3**	**0.91**
NL Staff	**88.2**	**0.88**
SP Students	**89.7**	**0.92**

Table 4. 4 Table summarising the inter-coder agreement parameters.

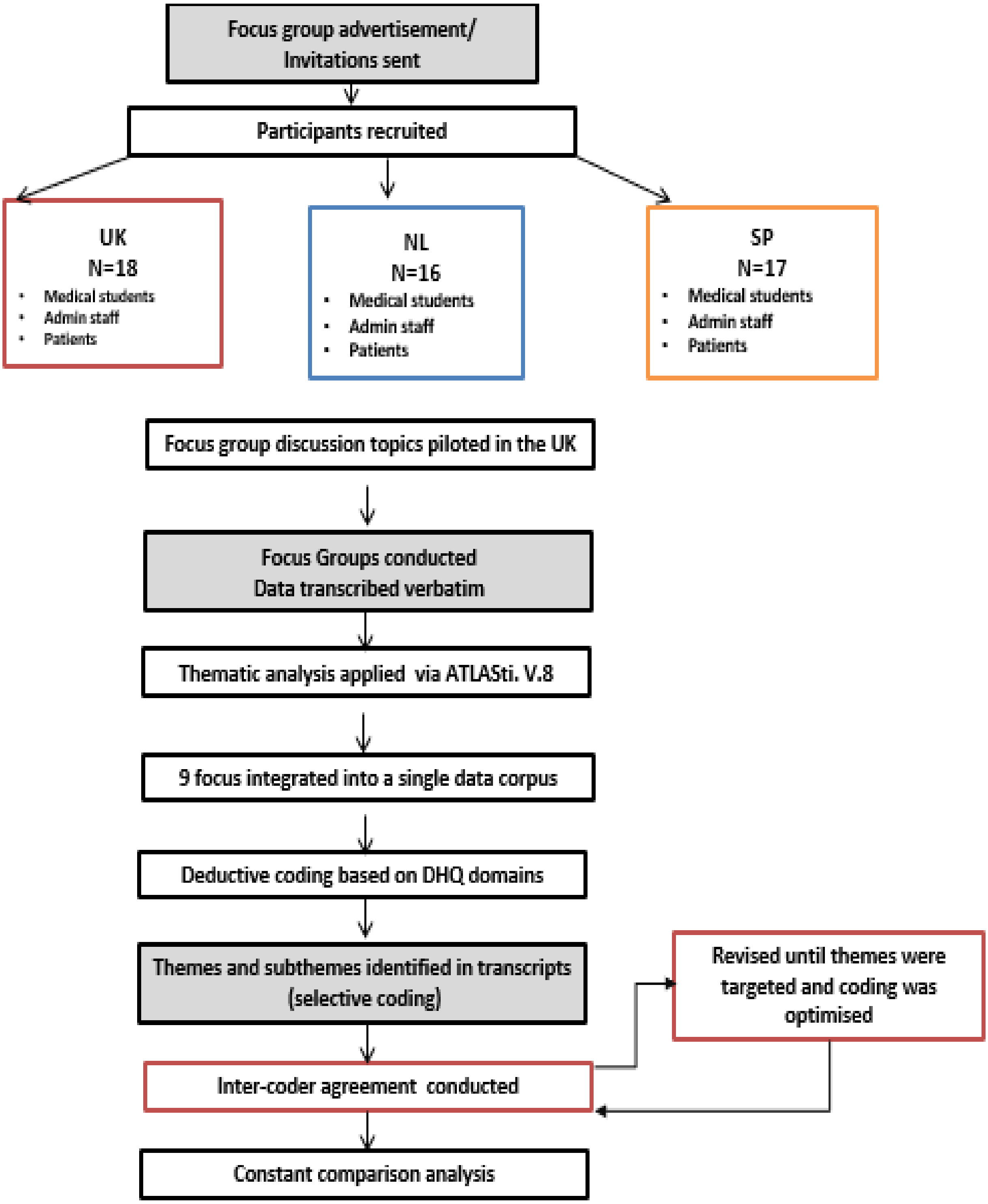


Figure 4. 1 Flow chart of Focus Group Methodology.

4.7 SECTION B: FOCUS GROUP RESULTS

4.7.1 INTRODUCTION

This section will report the qualitative focus group results examining the themes of the questionnaire on: Personal values and donation (Theme 1), Facts on DOD (Theme 2), Registration Options (Theme 3), Communication with Family and friends (Theme 4) and Promotional resources (Theme 5). Commentary and key points for each domain will be discussed for medical students (tables seen in blue), staff (tables seen in red) and patients (tables in green) from the UK, Netherlands and Spain (n=9 focus groups). Quotations are presented in tables for each focus group and are referenced in text with ID (doc. No: quotation sequence) as well as participant attributions of country (UK, NL,SP), subgroup (med =medical students, sta=staff, pat=patients), sex (m=male, f=female), and participant number.

4.7.2 UK

4.7.2.1 UK MEDICAL STUDENTS

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.5**.

a) THEME 1: PERSONAL VALUES AND DONATION

Medical students were extremely supportive of DOD, expressing positive attitudes and finding it difficult to express any negative or contrasting opinions (UKmedm3 3:4; UKmedw1 3:19). The study of Medicine confers a unique understanding of DOD processes and the privilege of access to first-hand information and patient stories. These factors made participants regard the issue pragmatically, rather than emotionally (UKmedw2 3:66). Most of the participants were keen to register for 'whole body donation'. Some made this decision in response to the opportunity to practice on cadavers that were donated for medical research, which they considered a privilege (UKmedw2 3:65). However, there was a small subset of students who raised the issue of selective donation, suggesting that there is increased sentimentality associated with certain tissues, such as corneas (UKmedw3 3:32; UKmedw2 3:71).

'Health' was understood as an unpredictable and fragile concept, since it is impossible to predict who will require a transplant and at what point in their life. The students considered this notion of 'reciprocity' as a catalytic motivational factor, suggesting that the public must consider society's best interest (UKmedm1 3:16). The group believed that the general public harbour neither strongly positive, nor strongly negative attitudes. Therefore, the majority would not be averse to becoming organ donors.

The main issue is that they are unaware of registration processes and this contributes strongly to the organ shortage issue (UKmedw1 3:45).

Participants believed that personal ‘hierarchies of values’ and religious beliefs are a key inhibitory factor for many people (UKmedm2 3:141; UKmedm1 3:148). Religious doctrines may often conflict with an individual’s individual morals. This dichotomy prevents them from forming concrete decisions on the topic (UKmedw1 3:150). However, in many cases, these beliefs are misplaced, and religious doctrines are misinterpreted, generating disparity between what the congregation believes and what the official guidance is (UKmedm2 3:219). Some religious communities were criticised as holding ‘double-standards’, willing to receive a transplant but not to donate (UKmedw1 3:145).

Participants were critical of altruistic donation, suggesting that these groups put themselves through unnecessary risk, not understanding why anyone would choose to undergo the donor surgery voluntarily (UKmedm3 3:79). One student attended a debate at the Board of Ethics, where it was proposed that past living organ donors should receive waiting list priority if they were in a position that meant they required a transplant. The proposal was rejected by the Board, a decision with which the students agreed (UKmedw2 3:82).

b) THEME 2: FACTS ON THE DOD PROCESS

The participants raised organ procurement as a medical legal issue. This implies that there are regulatory processes in place that prevent unethical or biased behaviours by the medical team. However, participants recognised that doctors are still susceptible to subjective decision making (UKmedm3-UKmedm1-UKmedm2 3:132).

There was some ambiguity about the processes governing the identification of potential donors both in hospital and the community (UKmedm1 3:133). Organ donor cards were considered secondary to the registration of one’s name and consent decisions on a national database, which medical professionals should have access to (UKmedm1 3:135).

As medical students, the participants discussed the presentation of DOD in their own curriculum. They understood the importance of being well-informed as future clinicians, so they can allow patients and their families to make informed and autonomous decisions (UKmedm2 3:13; UKmedw1 3:22). The students felt that they required less technical knowledge and more information on how to convey this information as part of the communication curriculum (UKmedm1 3:25; UKmedm2 3:26). They believed that more senior clinicians, such as consultant transplant surgeons and registrars should be responsible for addressing any logistical or specialist questions relating to treatment and medical protocol (UKmedm2 3:27).

Students who had experience in intensive care unit (ITU) placements supported this position, suggesting that the most important learning experience of their placement was developing interpersonal skills with patients' families (UKmedw1 3:20). The most important point in the conversation between the healthcare team and families is the clarity with which they communicate their loved one's health status as irreversible (UKmedw1 3:122). In addition, future medical practitioners must be better prepared to accommodate the needs of patients with lower levels of health literacy, such as children and those with disabilities (UKmedw2 3:124; UKmedw2 3:183). The optimum communication strategy is clarity, honesty and transparency (UKmedw2 3:124).

c) THEME 3: REGISTRATION OPTIONS

Some were registered as organ donors (UKmedm3 3:1; UKmedw1 3:86). In most cases, the participants took the opportunity to register when they obtained their driver's licence (UKmedw1 3:18). This was seen as an effective method, as individuals must be of a certain age in order to obtain a licence (3:185) Others wanted more time to contemplate the decision and had delayed completing the form (UKmedw5 3:35; UKmedw2 3:228). It was also recognised that people who do not have a driver's licence have to go out of their way to register their decision (UKmedm3 3:44). This is particularly an issue in cities (UKmedm3-UKmedw2 3:185).

There was some ambiguity on the default consent system as one participant noted that most of their social circle thought that their consent was presumed and therefore, did not take the initiative to register their support (UKmedw4 3:229).

GP practices were another pathway that was considered. One student recalled being on a clinical placement at a GP practice where a patient wanted to book a separate consultation to discuss organ donation options and to register their decision (UKmedm1 3:197). Others were unaware of this registration pathway, although they had attended several different practices both as a patient and as an observer (UKmedw2 3:159). One participant praised the infrastructure for registration in the UK and compared it to that of other European countries. They considered that there were fewer opportunities in countries with privatised healthcare, as there was less government involvement and therefore fewer public health promotional initiatives (UKmedm1 3:51). The students believed that it is easier for younger generations to donate, as they are able to use the internet search for pathways, or to register their decisions on the NHSBT website (UKmedw3 3:170).

Participants recognised the importance of familial consent. It was suggested that documentation, such as a donor card, have merit in evidencing the deceased's wishes and guiding the family (UKmedm2 3:137). Others believed that timing plays a crucial role in the families' decision to grant consent. One participant recalled how they had first-hand experience of family members changing their mind about refusing consent after they were given more time to consider their decision (UKmedm2-UKmedw1, UKmedw1 3:118, 3:123). Not all students agreed with this procedural step in the donation request. This group believed that familial consent contravenes the ethical principle of patient autonomy (UKmedw1-UKmedw4-UKmedw2 3:105; UKmedm2-UKmedw2 3:254).

There was some consideration of eligibility as a barrier to donation. Some participants were unaware of their own eligibility to become donors (UKmedw2 3:8). The participants agreed that the organ shortage issue was dependent on both donation quality and quantity. An increasingly ageing population with patients suffering from multiple comorbidities results in many organs being rejected due to poor quality (UKmedw2-UKmedm3-UKmedw2 3:154).

d) THEME4: COMMUNICATION WITH FAMILY AND FRIENDS

Experiences on medical placements strongly influenced participants and inspired them to discuss the topic with their own families (UKmedm2 3:216). Others were still hesitant to initiate the discussion, despite their knowledge of its importance (UKmedw3 3:31; UKmedw3 3:101). There was particular hesitation and emotional reaction when considering conversations with one’s parents (UKmedm3 3:176). Beyond the sentimental component, participants identified an intergenerational gap in attitudes, acting as a barrier discussion and requiring a specific subset of framing techniques to approach the subject (UKmedm3 3:126). Therefore, although there was no explicit opposition, there was an implicit resistance, leading to avoidance.

Family members who strongly supported DOD initiated the discussion themselves, wanting to ensure that there was no barrier to their decisions (UKmedw2 3:69). In certain cases, the conversations occurred in response to environmental triggers, such as obtaining a driver’s licence or reading a newspaper article (UKmedm3-UKmedw5-UKmedm3 3:36; UKmedw2 3:64). In both of these instances, there was consensus on values and some exchange of personal decisions. One participant noted that this homogeneity was a product of the family environment (UKmedw2 3:64).

e) THEME 5: PROMOTIONAL RESOURCES

Participants discussed the lack of promotional material for DOD. There appeared to be good awareness of other health related campaigns, such as blood donation (UKmedw5 3:57; UKmedw5 3:60). This is a campaign that was also endorsed by religious communities (UKmedm2 3:99; UKmedm2 3:259). The blood and bone marrow donation campaign were cited as particularly effective (UKmedw4-UKmedw20UKmedw4 3:203; UKmedw2 3:208). Concrete goals were set to actualise a potential donor’s decision, such as providing them with adequate follow up information, including locations where they could donate blood such as mobile blood banks. The blood donation campaign was also promoted in the community, with local mosques, as well as the London Central Mosque, dedicating a day to this particular health promotion. Such events help to clarify the faith's endorsement, making the community more receptive to these messages and those of future campaigns (UKmedm2 3:226).

The participants also described the emotional presentation of DOD in films; specifically addressing the notion that organ donation is a way of keeping a part of the deceased alive. The participants encouraged the use of emotionally provocative images in films, criticising their accuracy, but praising their memorability (UKmedm2-UKmedw2 3:76).

The participants noted that a good method of raising global awareness of the DOD issue would be promoting the topic on internet search engines, such as Google. This would also enable the public to search for website-based information about the topic simply by selecting the appropriate icon (UKmedw2- UKmedw3 3:242).

Participants discussed the notion that, in contrast to other health-related promotions, such as smoking cessation and cancer, which are present continually, DOD promotion only occurs intermittently. There was moderate awareness in the group of an allocated week dedicated to the national promotion of DOD (UKmedm2-R-UKmedm2-R-UKmedw2 3:206). Beyond this week, the students considered that any additional mention of this topic in the news is usually negative and in relation to hospital malpractice (UKmedw4-UKmedm3 3:87).

The participants agreed that social media is a valuable resource for health promotion, however, they also suggested that people are hesitant to initiate discussions about death on social networking sites (UKmedw4-UKmedm3 3:56; UKmedw2 3:257). Some participants suggested that consent decisions can be registered on Facebook upon the creation of a social media account (UKmedm3 3:241).

The participants endorsed the utilisation of local community leaders over public figures as sources of information, as they are considered to be more trustworthy and reliable (UKmedm2 3:223). Emphasis on socio-demographics and an understanding of how to target campaigns for specific groups is a key mechanism for optimising the reception of health promotion. The leaders of these communities can be recruited to customise the messages to suit these communities (UKmedm2 3:221).

A cost-benefit analysis comparing the financial burden of annual dialysis for one patient, compared to the cost of an organ transplant may help strengthen arguments for DOD and provide an additional, pragmatic perspective (UKmedm2-UKmedw3-UKmedm3 3:213).

GP practices were considered key and reliable sites for health promotion in the community. Practices could be both sources of information and offer registration opportunities, which can be directly noted on electronic patient records (EPR) (UKmedm1-UKmedw2 3:55). Participants suggested that practices should foster a mechanism similar to screening initiatives, whereby members of the community are invited to come to their practice to discuss their decisions through an alert or letter (UKmedw2 3:160; UKmedw2-UKmedm1-UKmedw4-UKmedw2-UKmedw4-UKmedm2 3:255). Some believed that, along with smoking cessation, diabetes management and blood pressure control, this could be an additional health promotion responsibility for specialist nurses and health care helpers (HCH) (UKmedmm1 3:198).

Some participants were informed about DOD in their first-aid related courses and extracurricular activities at school age (UKmedm1 3:92). Others recalled debating the issue in Biology lessons, although they did not believe that the opinions expressed were mature or lasting (UKmedm3 3:89).

It was proposed that the topic should be integrated into Personal Social Education (PSE) curricula instead, as this would increase awareness of the topic as an ethical and social issue, rather than a scientific issue (UKmedm1-UKmedw1-UKmedw3-UKmedm1-UKmedw2-UKmedm1 3:237). Furthermore, awareness should be raised as early as possible, before the age at which decisions can be registered, providing adequate time to discuss the topic with one's family and to reach a decision (UKmedm1-UKmedw1-UKmedm1-UKmedw1-UKmedm1 3:93).

Other students believed that the lessons and assemblies should be directed to students in their final years of secondary school, as they could be provided with the opportunity to actively register their decision immediately after these talks, while the information was still recent (UKmedw2 3:235). Some students had been involved in school-based health promotion campaigns for smoking and believed that DOD was a very complex topic which would be difficult to introduce (UKmedm2 3:175). Therefore, it was proposed that patient speakers should hold these talks in schools, as they would make the topic less technical and more personal (UKmedw4 3:90). For the medical students, this was the most important part of their own learning experiences, considering patient narratives superior to medical lectures (UKmedw2 3:91).

Table 4. 5 Table of focus group results from UK medical students discussing each of the five DHQ themes.

Participant attribution	I.D	Quotation Content	Reference
PERSONAL VALUES AND DONATION			
UKmedm3	**3:4**	**If I ever have an accident, people are free to have my organs. So, I honestly find a good thing to do. No question about it.**	**593-716**
UKmedw1	**3:19**	**I chose to be an organ donor, because I don't see any reason why not to be. And if you're dead and someone**	**2920-3182**

		else can benefit from your organ. I think I am very pro organ donation,	
UKmedw2	**3:66**	**An interest in medicine makes you doubly as pragmatic about donating organs and you become a lot less kind of emotional about the whole process.**	**15689-15927**
UKmedw2	**3:65**	**Especially, when you practiced at cadavers like we have at Imperial. So, you've seen other people who have donated their bodies to science, which is such an incredible thing to do.**	**15929-16327**
UKmedw3	**3:32**	**And there was a gentleman who was quite elderly and he said he wanted to have his corneas given to someone else after his death. And it was kind of grim. They took out both eyes. Yeah. And that's when I said I don't want to have my corneas ripped. They can have my other organs.**	**9212-9894**
UKmedw2- **UKmedm3-** **UKmedw5**	**3:71**	**And so (the eyes) are the most kind of relatable, is the most human part of them..** **UKmedm3-They don't put the whole eye** **UKmedw5-No, it's the cornea**	**17108-17646**
UKmedm1	**3:16**	**Health is unpredictable. You never really know whether anyone will need an organ at any point. So, it's in everyone's interest really to be on the register.**	**2639-2794**
UKmedw1- **UKmedw4-** **UKmedw1**	**3:45**	**UKmedw1- I feel there a lot of people who are indifferent. Not indifferent, but like wouldn't mind being a donor** **UKmedw4- Yeah** **UKmedw1-But don't care so strongly about to go out of their way and they are the people, like, who fall through the net**	**11217-11633**
UKmedm2	**3:141**	**When people bring their from subcontinent culture, or their middle-eastern culture, or whatever. Very long standing to a religion that's less consenting.**	**43559-43823**
UKmedm1	**3:148**	**Everybody has this hierarchy of values. And such complex things like organ donation, where so many values feed in.**	**45459-45716**
UKmedw1- **UKmedw4**	**3:150**	**UKmedw1- You have your religious values, but you also have your personal values and they don't necessarily agree**	**45774-46092**

		UKmedw4- everything clashes at the moment you are at a hospital, people you'd say murderers and you help them … as an extreme version	
UKmedm2	**3:219**	**And I went to him (the Imam) and I said 'is there any problem with donating organs in Islam?' And without hesitation he said 'no. Why would you think there is a problem with that?' And so I think there is a disparity between what the congregation might think and I think that has in large part has to do with their cultural backgrounds…**	**63593-64269**
UKmedw1- **UKmedw3**	**3:145**	**I know they say like Jehova's witnesses are very against receiving any blood products and would rather die. Like, would they receive an organ if they needed it?** **UKmedw3- it probably would be double standards**	**44432-44809**
UKmedm3	**3:79**	**like listening to people's stories, where they have just given it, like altruistically to whoever. In my mind, it's like 'what if it went wrong and you don't even know where it's going**	**20703-20886**
UKmedw2	**3:82**	**UKmedw2- The Head for kidney transplantation here went to speak to the Board of Ethics and they, the people that give, donate kidney donation, should be given priority to organ transplant, if anything went to happen to the remaining kidney. And that got vetoed … I think it's more in the sense that just because they did something good, it doesn't make them better**	**21000-21500**
FACTS ON THE DOD PROCESS			
UKmedw1	**3:123**	**It's that actually they have no chance of survival or coming back from this. And yeah, I like your question that the time of the initial reaction was 'no, we can't do that. No, we cannot donate their organs, blah, blah, blah'. And then, over the next few days, cause it wasn't a thing of like a few hours, it was over a few days that the decision was made, and withdrawn life support. Their organs were donated at the end.**	**34170-34740**
UKmedm1	**3:133**	**it brings out another question, you know. Is there any real benefit to having donor cards? Because, if it's going to, you know, impact the way people perceive the victim of an accident, you know, is there any real advantage? Sure, it's better to just have everyone on a central register that can be looked upon at the hospital**	**41007-41376**

UKmedm1	**3:135**	**Surely they have access to that on a database?**	**41572-41620**
UKmedm2	**3:13**	**in soon to be doctors, it's also important for us to know about the process and to be able to convince our patients, or to give them the right information really for them to make their own decision. But to tell them, it is available and it won't change your treatment plan, we won't think of you any different because you have an organ card.**	**1930-2446**
UKmedw1	**3:22**	**Cause obviously at that time it's really difficult. The family's getting ready to sort of lose their relatives, their loved one and I think the thought for a lot of families at that point about donating parts of that person is quite difficult to get the head around. But I think it's very important that doctors are able to have that discussion with patients, and sort of showing them that, I guess the positives and negatives of them. And talk through their feelings and what they think.**	**3609-4089**
UKmedm1	**3:25**	**Yeah, I think that's definitely an aspect of communication curriculum, which isn't really addressed well perhaps.**	**4876-6102**
UKmedm2	**3:26**	**So, I had a 3-weeks transplant attachment. And even there, I was focusing on surgical skills. I didn't really go to clinic. But that's probably the only time I'd actually be involved in discussions with the live donors for example.**	**6113-7215**
UKmedm2	**3:27**	**But I guess that's what the consultant transplant surgeon is there for, or the registrar to be doing that process. So, it's interesting to know how much of this, should understand ourselves. Because probably through the referral system anyway, they would get themselves into a position where they are in front of the doctor who knows enough about it to explain it.**	**7218-8455**
UKmedw1	**3:20**	**it is very important having I TU placements. I have been involved in family discussions about the donation of their loved ones' organs, when they have been diagnosed as officially brain dead.**	**3184-3459**
UKmedw1- UKmedw2- UKmedw1- UKmedm3- UKmedw1	**3:122**	**UKmedw1-Yeah, but like when that family member isn't dead yet. I mean they can't survive, but they are not dead** **UKmedw2- They are currently still alive in front of them**	**32448-34157**

		UKmedw1- Yes. So, I think, I think it's really difficult for families to get over that 'are they giving up on their relatives?', sort of **UKmedm3-They are not only giving up, but they are actively making it going past the point of no return by taking their organs** **UKmedw1- Yeah. So, I think it's really difficult from a doctor's point of view to be, to, I don't say convince, cause it's not 'convince', but like making clear to the families**	
UKmedw2	**3:124**	**I mean it's always difficult when it comes to kids. In ethics, it generally takes 50 shades of grey when it comes to kids. I think if I had a child and I knew from the offset that they were going to be unwell and potentially would have a chronic condition that would eventually cause them to pass away early, depending on how early that is obviously, I think the best thing regardless of whether or not it is a child or adult is honesty and transparency.**	**35307-36633**
UKmedw2	**3:183**	**or if there are some slight issues like competence, cause you get people who have learning disabilities, who can't make that autonomous decision to .. You might have to stratify who has a vote and then register the disabled, would have to vote in, whereas someone who has learning disabilities or … blind**	**51986-52292**
REGISTRATION OPTIONS			
UKmedm3	**3:1**	**I signed up to be an organ donor**	**526-557**
UKmedw1	**3:86**	**Like when we signed up for drivers licence, and that would be 15 -16, so that was like way pre the med school.**	**22566-22717**
UKmedw1	**3:18**	**In the driving licence its an option**	**2878-2915**
UKmedw5	**3:35**	**I just remembered while I was just filling in the licence form which was 'oh, do I do that?'... I didn't tick the box… cause I thought I'd have more time to think about what it would involve and whether it would be cornea, whether it would be different things.**	**10098-10189**
UKmedw2- **UKmedm2**	**3:228**	**UKmedw2-Not yet. But that's just because I am lazy, not because I don't have the intent** **UKmedm2- I think the same.**	**1749-1850**

UKmedm3	**3:44**	**Well I guess if you don’t drive you have to go out of your way to get a donor card**	**11116-11197**
UKmedm3-UKmedw2	**3:185**	**UKmedm3- In the driving licence works quite well, cause you’ve got to be at a certain** **UKmedw2-Yes, but in London so many people don’t drive**	**52299-52561**
UKmedw4	**3:229**	**None of my friends didn’t know they were in it automatically. So, you know, you have to tick the box. They want to be on it, they didn’t know they weren’t on it. So, I think it should be an opt-out. And they had to tick in the box. And they haven’t done it, but they want to.**	**10570-10844**
UKmedm1	**3:197**	**Want to be added to the organ donation?’ and the GP had this additional list of … 10 minutes. He was like, and his response at that time was ‘OK, will you let the receptionist know about it?’**	**57819-58214**
UKmedw2	**3:159**	**I also don’t think is very accessible. So, my GP has never mentioned it to me, and I’ve changed GPs three times now, and none of them has mentioned it to me. I’ve never had a letter to be invited**	**48296-48492**
UKmedm1	**3:51**	**UKmedm1- I think the opportunities here in the UK for opting into the register are very good… When I signed in to my GP practice, I was offered the opportunity to …. I just added my name on the register then. So, I think the infrastructure here in the UK, perhaps in comparison to other countries, is definitely out there, and it is very good.** **R- Compared to which countries?** **UKmedm1- So, I think for instance in Portugal, where I am from, where I was born and grew up the opportunities to get down to the register are fewer and harder to come by. You do, they do ask people at the point when they drive, but I haven’t heard, you know, people being asked when changing GP practice or when signing up to see a particular doctor. In part that’s due to the way the health system is organised. Because it relies on a greater extent to privatised care in Portugal, rather than in greater proportion of public–funded care, as it is the case here in the UK.**	**12144-13270**
UKmedw3	**3:170**	**I think it is quite easy if you are young, cause you kind of google it ‘I want to be an organ donor’. It’s quite simple to do it on the website. That’s how I did it. But, I think ……. That’s the thing to do**	**49794-49998**

UKmedm2	**3:137**	**if he kept in the wallet. And then the family saw your wallet. Well, he's keeping in his wallet, you are gonna see it every day**	**41627-41782**
UKmedw2- **UKmedw1-** **UKmedw2**	**3:118**	**UKmedw2-And it might also be that instant grief reaction** **UKmedw1-Yeah** **UKmedw2- And then once they've been given some more time to adjust**	**31648-32024**
UKmedm3- **UKmedm2**	**3:132**	**UKmedm3-I assume I am on a register somewhere, saying I am a donor. So, in that kind of mindfulness, I don't think about keeping an organ donor card on me…** **UKmedm2-But yeah, there are management protocols for patients. And if you seem to deviate from them, that's medically illegal… So, doctors should be objective and we assume that they are objective. But humans are not objective all the time… an audit trail might be interesting**	**39725-40866**
UKmedw1- **UKmedw4-** **UKmedw2-** **UKmedw4**	**3:105**	**UKmedw1- I think with transplant it is like, it's not a legally binding thing being on the register or not. It is more a discussion with the family type of thing. That's the impression I got from it. So, being on the organ donor register is like an expression of your wishes and then that sort of balanced up against the family's opinion and like** **UKmedw4- I think it should be only your opinion** **UKmedw2-Yeah, I don't think it should have anything to do with your family** **UKmedw4- It should be the person's choice**	**27894-29166**
UKmedm2	**3:254**	**It flies on the face of all the ethical principles we've been taught about…I can't think of circumstances in which it wouldn't be. If you have expressed a clear desire to be an organ donor, whether or not you've discussed it with the people closest to you, that is your desire. Your choices, your body**	**29184-30521**
UKmedw2	**3:8**	**I don't know if I can, cause I've got a blood condition. I haven't actually researched it. I know I can't give my spleen.**	**1426-1546**
UKmedw2- **UKmedm3-** **UKmedw2**	**3:154**	**UKmedw2 – They're older and they're getting more chronic conditions that affecting like, run to multiple organs, like are getting affected. And then, you've also got those people that, you know, probably pass away and**	**46648-47750**

		they are just so degraded inside, cause they are so much older, or they've been through so many different types of medication, that you can't really give that to someone. Or they have a chronic condition which could be transplanted to the other person. **UKmedm3 – So, there's a quantity over quality problem** **UKmedw2 – Yeah, quantity and quality**	
		COMMUNICATION WITH FAMILY AND FRIENDS	
UKmedm2	**3:216**	**When I was on my transplant attachment, I came home and I had never discussed transplant with my family before.**	**63477-63588**
UKmedw3	**3:31**	**I didn't really talk about it with my family. I know I should do, and I will do at some point. And it does say in the outline, obviously, you should talk with your family so that they know your wishes. I just kind of told to myself, that I am gonna get back to that.**	**8890-9155**
UKmedw3	**3:101**	**I still haven't told my family about it**	**27548-27587**
UKmedm3	**3:176**	**Can you tell your mother to give away her organs?**	**50938-50987**
UKmedm3	**3:126**	**It's just that they are not capable of making that decision themselves. They are probably still going to grow up with your principles**	**36847-37027**
UKmedw2	**3:69**	**And my parents are donors and they said, if anything were to happen to them, they would want to be donated. They said it themselves.**	**16822-16953**
UKmedm3- **UKmedw5-** **UKmedm3**	**3:36**	**UKmed3-Family discussion thing, I just remembered while I was just filling in the licence form which was 'oh, do I do that?', and my parents were 'yeah'** **UKmedw5 – Yeah** **UKmedm3 – And that was as far as the discussion went. It was like 'why wouldn't you?'**	**10073-10312**
UKmedw2	**3:64**	**It came up because it was, I think it was a story in the paper about someone getting a transplant. I think I asked my parents if they are on the transplant list. And then that opened a whole bag of worms around the dinner table I think it was. But, I mean, I've been raised by these people, so we have quite similar attitudes towards these things.**	**15337-15683**

PROMOTIONAL RESOURCES			
UKmedw5	3:57	I've had loads of things about blood donation, but nothing ever about organ donation.	13455- 13539
UKmedw5	3:60	the blood donation keeps really on top of that. Even when you change address and stuff, they know where you are and they send you stuff through Imperial, through GP I think, isn't it?	14377-14659
UKmedm2	3:99	So, I've seen in some of the mosques I've been to, they have blood drives. They'll go and give a talk and they'll organise days after congregational prayers on Fridays to have like the blood van outside	26461-26663
UKmedm2	3:259	And I also think that London Central Mosque as well and some of the other local ones in the area, which is in South London, and yeah, they had organised a day and had leaflets with the name of the mosque in them. And it was very much a community activity and everyone was going to donate blood	66419-66818
UKmedw4- UKmedw2- UKmedw4	3:203	UKmedw4- Something like 1.500.000 signed in for bone marrow transplants. UKmedw2-Very difficult, incredibly rare cancer, an incredible rare type of blood cancer …. and they got a match through UKmedw4-Through massive social media campaign	59473-60117
UKmedw2	3:208	I mean the amount of, like, …. blood donation adverts or cancer charity advert that you get on TV, I mean, you can't watch a TV show without having the adverts pop up at some point.	61522-61702
UKmedm2	3:226	And it doesn't need to be an immediate response. People don't need to donate then and there, but at least they know their mosque is advocating for blood donation. And so, they think then it is a normal part of their religion. So, that is education in itself and later on if the next campaign comes around and they are actually available, then they are more likely to be primed and ready to donate.	66899-68004
UKmedm2- UKmedw2	3:76	UKmedm2-They do have that scene looking into the eye UKmedw2-Which obviously it's completely not how it happens but that's how people will think of it. Cause films portray it	18899-19475
UKmedw2- UKmedw3	3:242	UKmedw2 – You know how Google changes its cover when it is an important day or week it changes how it UKmedw3- If you click on it, it tells you more about it	60521-60841
UKmedm2- R- UKmedm2- R-UKmedw2	3:206	UKmedm2- Is there an organ donation day? Or week? R-Week UKmedm2-What week is that? R- I think it is in September UKmedw2- I've never heard of it	60269-60400
UKmedw4- UKmedm3	3:87	UKmedw4-It's media as well. It's the newspaper stories that bring it up UKmedm3- And the stories in hospitals that bring it up, things like that	22724-22880
UKmedw4- UKmedm3	3:56	UKmedw4- There should be more in the social media, cause you don't get so much about organ transplant stuff in the social media.	13822 – 14131

		UKmedm3- It isn't very glamorous saying ' this is going to die	
UKmedw2	**3:257**	**You can probably roll that off into pretty much any country, can't you? Like talk to school age kids, come up with the social media campaign and each of these languages push it out to FB, push it out to Instagram, push it out to Twitter, TV, …. stories for adults.**	**61256-62222**
UKmedm3	**3:241**	**FB account, unless you make a decision about organ donation tick in a box when you sign in to FB, cause you can say no**	**60127 – 60262**
UKmedm2	**3:223**	**People might not necessarily value the opinion of the TV presenter very highly compared to somebody they have lived with and who has married their children for them, and who has been there when they were ill or visited them in funerals. So, you need to have two-pronged approach. One of them to create interest and another one to actually convert them to donors.**	**65691 – 66279**
UKmedm2	**3:221**	**The population is divided across the communities and those communities might be socio-economic groups and they might be professional groups. So, whenever you do any marketing campaign at public health you should always look at the different places that people congregate and look at the people that are their influences in those circles and target them to do the work for you.**	**64737-65325**
UKmedm2- UKmedw3- UKmedm3	**3:213**	**UKmedm2-There must be… an argument on how much money to spend on such campaigns. How much an organ transplant costs UKmedw3-And dialysis UKmedm3- Yeah, dialysis must cost a lot more. Dialysis for years compared to having an organ donation within a month.**	**62672-63035**
UKmedm1- UKmedw2	**3:55**	**UKmedm1- But maybe that would be one thing, you know, that could be done to improve the uptake of donors, ensuring that all GP practices have an option that allows people to opt in to the register when they sign up or when they choose practice UKmedw2 –Just like alert, GP alert**	**13545-13809**
UKmedw2	**3:160**	**That would be great, like they do with cervical screening. You get a letter to be invited.**	**48494-48584**
UKmedw2- UKmedm1- UKmedw4- UKmedw2- UKmedw4- UKmedm2	**3:255**	**UKmedw2- It would be quite good to have a GP alert UKmedm1- Yeah UKmedw4- The GP would … UKmedw2 –They would probably be the better equipped of the general community to give you a little bit of information about UKmedw4 –Cause a lot of people have year-like medical check-up. Just like the thing you just UKmedm2 – Like qof points**	**56553-56852**
UKmedm1	**3:198**	**But what they could do, is to delegate it to one of the … HCH, the practitioners, you know, the people that provide smoking cessation … and blood pressure monitoring. You know, have that as an additional thing that gets brought up**	**58243-58472**
UKmedm1	**3:92**	**So, during my school years I remember, when we had first aid delivered, using the St John's Ambulance curriculum. They brought it up briefly and passing. But, you know, it was an opportunity to think about it and discuss it.**	**24966-25189**

UKmedm3- UKmedw1- UKmedm3	**3:89**	**UKmedm3- I think in a biology lesson, they may have done like in an overview UKmedw1-Yeah UKmedm3-That might have sparked out a discussion out of your own head 'oh, I would. Would you?' Kids are like stupid, kids will give, kids will probably say 'no'. And give it just a … 'oh, it's weird or icky'. It's not like a point you can develop a strong opinion, and like rationale for whether you would or wouldn't**	**23062-2347**
UKmedm1- UKmedw1- UKmedw3- UKmedm1- UKmedw2- UKmedm1	**3:237**	**UKmedm1-Yeah, integrate into the curriculum UKmedw1-PSE UKmedw3- Look into the pros and cons UKmedm1-Just kind of …. UKmedw2- Increase, increase awareness basically UKmedm1- And even if it's before the age at which they can decide to become donors it's not a problem. Because, to be honest, that will have a lot of impact and the next person coming across, will go 'I remember that PHE lesson'. Some will say like a great idea, some will say not**	**58698-5917**
UKmedm1- UKmedw1- UKmedm1- UKmedw1- UKmedm1	**3:93**	**UKmedm1- So, I think bringing it up early is really important, and should probably be part of the, it should probably be integrated in some way into all school curriculums. And something you know can be touched on and passing, and it would probably make a big difference UKmedw1 – At your final year at school? UKmedm1 – Earlier than that really UKmedw1 – GCSE? UKmedm1 - like 8th year, 9th, you know, you are mature enough to understand what's going on essentially**	**25205-25694**
UKmedw2	**3:235**	**Have an assembly when, you know, at a secondary school, for like the senior years. Or if you feel you need to put a cap on it, GCSEs and above. Have a special assembly when you tell them about organ donor. And then, that lunch time, they can sign up, if they want to be an organ donor**	**51361-51760**
UKmedm2	**3:175**	**Yesterday I went to a primary school in Acton and was giving some talks to years 4s and 5s, about convincing their parents and their uncles to get eye checks ... telling them about the red spot blindness and like risk factors and like smoking, that kind of stuff. I guess that's a very benign kind of thing, an eye check, rather than telling your parents to sign in to the organ donation list**	**50541-50931**
UKmedw4- UKmedw2- UKmedw4	**3:90**	**UKmedw4- I think it would make a massive difference if people who had a transplant, would go at schools UKmedw2- Yeah UKmedw4- To be like 'I had a transplant, and now I am here"**	**23479-23638**
UKmedw2	**3:91**	**One of the best days in my first year at Imperial was when they brought in a kidney patient… It's the patients talking in front of you with the scars, with the symptoms, with the old fistulae, all this stuff**	**23645-24877**

4.7.2.2 UK: STAFF

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.6**.

a)THEME 1: PERSONAL VALUES AND DONATION

The participants expressed a mixture of values, which was often correlated with their level of knowledge on the topic. In general, participants who were less informed were more ambivalent (UKstaw2 5:5). In contrast, those who were aware of the topic and the different donation options available, such as live donation and donation for scientific research displayed strongly positive views (UKstaw1 5:1; UKstaw2 5:5). Some participants were already registered donors (UKstaw5 6:9).

The media was considered an influential force in the perception of DOD. In most cases, this topic was framed in a negative way. Reporting on cases of medical negligence and the treatment of donors contribute to the negative perception of organ donation. One participant described the historic issues in donor screening programmes with regard to blood donation and transfusion, contributing to the HIV epidemic of the 1980s (UKstaw2 5:146). Participants believed that evidence of good regulation, such as through protocols and legislation would update public perception (UKstaw2 5:70). Another participant discussed the high profile case of footballer, George Best who received a liver transplant which was destroyed following a return to the same lifestyle that contributed to his organ failure. This case raised wider ethical issues regarding self-inflicted illness, recipient accountability and transplant deservedness (UKstaw2 5:46; UKstaw7 6:62).

This led to a discussion of the ethics of reciprocity and justice. One participant raised the example of their experience with a family member, who refused multiple transplant opportunities, from both living and cadaveric donors. The patient offered several reasons for this, such as not wanting to put their children at risk and not wanting a stranger's organs in their body (UKstaw6-R-UKstaw6 6:52). Several members of the group agreed they would be reluctant to accept an organ from their families, although they would be keen to become living donors for their families (UKstaw4-UKstaw5-UKstaw4 6:55). The speaker believed that the underlying rationale for the rejection in their case was the patient's own opposition to organ donation, declining these offers to avoid hypocrisy, believing it would be unjust to receive a transplant, when they would be unwilling to donate (UKstaw6 6:149). Other participants agreed with this perspective, criticising the hypocrisy of readily accepting an organ but reluctance to donate. The group believed that many people are prepared to contravene their ethics when they are the ones in need (UKstaw6-UKstaw4-UKstaw6 6:150).

This attitude was discussed in relation to organ donation rates. Cultural factors impact organ donation rates, with emphasis on the shortage of organ donors among the Asian and Afro-Caribbean communities. These groups have increased susceptibility to conditions, such as sickle cell disease, that predispose them to end organ failure but are also among the groups least willing to donate (UKstaw4-UKstaw5-UKstaw4 6:101). One of the greatest barriers to donation is the belief that this will interfere with funeral arrangements and life after death (UKstaw5 6:15).

The group did not believe that their personal values were directly influenced by religion. There was some interest in exploring the topic through further discussion with religious figures of authority (UKstaw1 5:43). As a relatively recent innovation, many faiths have not yet developed an official position. This was considered responsible for generating ambiguity among many communities (UKstaw3 5:44).

There was admiration for altruistic donation, along with an attempt to deconstruct the rationale and a recognition of its rarity (R-UKstaw2 5:136; UKstaw5 6:93).

b) THEME 2: FACTS ON THE DOD PROCESS

Younger patients were considered more susceptible to victimisation and illegal organ retrieval, as their organs are considered to be more desirable for transplantation (UKstaw1-UKstaw2-UKstaw1-UKstaw2 5:32). Surgeons, from all of the members of the healthcare team, were the most negatively perceived with regard to adherence to ethical consideration (UKstaw4 6:29). The existence of waiting lists was a source of comfort to participants. These symbolised the protocols of regulation and priority that govern the NHS.

This reflected a general scepticism about the treatment of potential donors and donations both in the UK and internationally (UKstaw2 5:65; UKstaw3 5:177). Participants recommended that doctors and the healthcare teams should be held responsible for the strict regulation of donor and organ provenance (UKstaw3-UKstaw2-UKstaw3-UKstaw2 5:66). This sense of accountability and responsibility is heightened when considering the international exchange of organs and tissues. However, the group recognised that this may not always be logistically possible and this was a key deterrent against DOD. The duty to protect donor and recipient confidentiality were advocated as important measures to protect against selection bias based on personal prejudices (UKstaw2 5:50; UKstaw3 5:141).

The variation in organ selection criteria between transplant centres in the UK was considered evidence of the absence of universality and coherence in the standard of care offered by neighbouring hospitals (UKstaw5-UKstaw6-UKstaw4 6:152). For instance, one participant stated that it is common practice for an organ that was considered ‘poor quality’ and non-transplantable by one centre to be accepted and utilised for transplantation in a different centre only a few miles away.

The treatment of donors by the medical team was extended to consider the implications for posthumous arrangements. The inability to host an open-casket funeral following donor body disfigurement from the organ procurement was considered a common misconception (UKstaw4-UKstaw5 6:34). Several participants recalled a media controversy surrounding unauthorised organ retrieval from deceased neonates that took place in an NHS trust. The families of these patients were never informed of the procedure and in certain cases, the bodies were too heavily mutilated to be returned to their families for funerals to take place (UKstaw7 6:37; UKstaw7-R-UKstaw7 6:40).

The timing of the donation request is a catalytic factor for gaining familial consent. The relatives of potential donors are approached soon after the confirmation of death and this is one of the reasons for the high refusal rates (UKstaw4-UKstaw6-UKstaw5 6:23). Participants suggested that allowing the family sufficient time to grieve and process the loss of their loved one may lead to improved outcomes (UKstaw4 6:30).

Medical teams must be better prepared to answer the questions of the patient’s relatives, as well as explaining technical terms and consent systems, such as ‘opt-out’ in an unbiased and non-coercive manner. These discussions should also provide reassurance to the families that a donation request cannot proceed without indication of their wishes, or the wishes of their loved ones (UKstaw7 6:57).

However, the participants also recognised that there is a very brief window of opportunity for the healthcare team to perform tests for the confirmation of death, obtain consent and proceed with the retrieval (UKstaw5-UKstaw6 6:22). Therefore, this process would benefit from the early identification of potential donors.

c) THEME 3: REGISTRATION OPTIONS

The validity of registered consent decisions and the significance of donor cards was questioned (UKstaw3 5:119, UKstaw5 6:25). Some perceived these as futile, given the deciding influence of familial consent. This perception was particularly common among participants who had discussed the topic with family members and were aware that their loved ones would decline the donation request when it came (UKstaw5 6:10, 6:12).

In support of registering consent decisions, it was argued that this can be reassuring and guiding influence to families who are faced with the decision but have not had the discussion (UKstaw3 5:131). This is because it is hard evidence of the deceased's wishes, which one participant analogised as ‘a living will’, drawn while the person was of sound mind (UKstaw5 6:24). Additionally, there was some criticism of the binary framing of decisions as ‘opt-in/opt-out’. This no longer becomes a request or a question but a demand (UKstaw5 6:56).

Some participants were surprised and relieved to hear that it was possible to opt out or to change one’s consent decisions. (UKstaw1 5:118). Beyond the element of personal choice, some participants explained that there are practical instances which necessitate consent reversal. This includes a change in health status which compromises organ quality (UKstaw2 5:30; UKstaw3 5:35; UKstaw1-UKstaw2 5:117).

There was good awareness of the use of organs that are unsuitable for transplantation for medical research (UKstaw3 5:36). For some, this was their preference and the intention which motivated their donation decision (UKstaw3 5:9; UKstaw4 6:50). One participant discussed the impact which this type of donation had on medical education and health promotion, with university students learning from these specimens, even after several decades (UKstaw3 5:37). Another, praised the legal regulatory measures that protect and uphold the ethical integrity of research, offering the example of embryonic stem cells (UKstaw3 5:64). There was some advanced understanding of the topic of medical research. One participant explained to the rest of the group the curative potential of bone marrow transplantation for haematological malignancies (UKstaw3 5:63).

Participants strongly advocated live-related donation. Knowledge of the recipient’s identity was a particularly appealing prospect (UKstaw2 5:134; UKstaw5 6:51). In addition, the patient’s family feel more ‘useful’ in these cases, as they have the potential to be a donor and help their relative themselves (UKstaw3 5:54). However, there was some concern over the donor’s quality of life after the procedure (UKstaw2 5:25). One participant expressed concern over how this system may be abused, discussing the use of in-vitro fertilisation to create ‘saviour siblings’ (UKstaw2 5:62).

The selective donation of tissues was appealing to many participants, expressing particular reluctance to donate tissues such as their eyes and heart (UKstaw6 6:4; UKstaw6 6:6). Other members of the group disagreed with this concept, believing that DOD should be an all or nothing decision (UKstaw3 5:58).

d) THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS

A good portion of participants had expressed their wishes to their family, who agreed to honour them (UKstaw3 5:28, UKstaw3 5:55). These participants were often those who strongly supported DOD and understood the catalytic role of their families in fulfilling these wishes (UKstaw4 6:11). These conversations were sometimes, but not always two-way discussions. Some participants took this opportunity to learn the wishes of their family members, which often conciliated with their own (UKstaw3 5:57). There were some cases of conflict and resistance, which remained unresolved. In one instance, the participant was strongly in favour of DOD, while their partner was unsupportive, adamant in the opposite direction. Attempting to bypass this potential barrier to consent, the participant chose to resolve this issue by assigning the responsibility to their siblings (UKstaw4 6:81). In another case, there was a dispute over posthumous funeral arrangements. The participant chose to discuss this topic with their whole family, including the youngest member, their twelve-year-old son (UKstaw6 6:82). However, even in cases of conflicting views, the participants recognised the merit of holding these discussions as they may sometimes offer perspectives that may lead to re-evaluation (UKstaw7 6:18). The issues raised in the FGD made some participants more conscious of the need to discuss the matter with their relatives (UKstaw6 6:80).

e) THEME 5: PROMOTIONAL RESOURCES

Most of the participants had little exposure to the topic during their school years (UKstaw1 5:18). This is now changing, with the topic being gradually introduced into both Science and Religious Education curricula in secondary schools (UKstaw5 6:90). For some, there were variable degrees of information at higher education, during their time at university (UKstaw3 5:97). Participants discussed intergenerational differences in the perception of health promotion campaigns. Early exposure to information about DOD was proposed as a mechanism to overcome the fixed mindset that led to low organ donation rates in previous generations (UKstaw4 6:159). However, it was recognised that this may be difficult, as schools must ensure that the curricula are culturally sensitive (UKstaw4 6:88).

Some participants noted instances when DOD was promoted in their immediate social circle or communities. In both cases, this was in fundraising context. One participant cited that they recalled a member of their community asking for sponsors for a run she was doing to raise awareness about DOD (UKstaw2 5:40). Another participant recalled a money collection for DOD that took place at the Sikh temple they attend. The collection then prompted a discussion among the religious leaders and the congregation about the Asian community's predisposition to certain medical conditions, such as high blood pressure and diabetes, which may lead to increased risk of needing a kidney transplant (UKstaw5 6:96).

There was some discussion about the difficulty in making the topic relevant to lay members of the community. This was in contrast to other health promotion campaigns, such as those for smoking and weight loss. These are considered to be of greater personal relevance to the community, as a significant proportion of the population are smokers or are overweight (UKstaw4 6:121). As a result, the participants believed that people would be more likely to seek information, such as leaflets, on these topics.

Leaflets were described as a particularly ineffective way of conveying information (UKstaw3 5:104, UKstaw5 6:120). One of the main criticisms of this method was the passivity of the messages, which the participants considered inadequate to inspire action and memory retention (UKstaw5 6:126). However, this promotional method should not be discarded, as it is often preferred by senior citizens (UKstaw4 6:154). Participants described the antithesis with multi-media campaigns. One example was on the effectiveness of radio-based smoking cessation campaigns, whose message was simple enough to be retained and understood even by younger audiences (UKstaw6 6:129). Television adverts, interspersed between programmes, were also considered to be effective methods of embedding the topic in the social consciousness and prompting home-based discussion (UKstaw4 6:128). Graphic images depicting the harsh realities of life with end-stage renal failures were considered to be particularly memorable and emotionally appealing (UKstaw5 6:73).

The participants raised the issue of information accuracy with regard to internet-based health promotion and information sources (UKstaw1 5:154) . There was some suggestion that the content of this resource may be misleading and in some cases, contradicting (UKstaw3 5:96) . An additional criticism of internet based health promotion is the volume of information (UKstaw3 5:159). This makes it difficult to navigate through the pertinent information, leading to cognitive and information overload. There was moderate awareness of the NHSBT national DOD website. There was both praise and criticism for this resource. A major advantage was cited as the ease with which one can register consent decisions. However, the information was also considered biased in favour of registration (UKstaw3 5:113, UKstaw4 6:119). Social media was seen as a valuable resource to promote national awareness days, information and fundraising initiatives (UKstaw4 6:84). However, some felt uncomfortable sharing their personal views on social networking sites (UKstaw2 5:153).

Another aspect that future DOD promotional campaigns can focus on is the treatment of potential donors. The public may require reassurance of the protocols that regulate the organ procurement process while they are in hospital (UKstaw7 6:156). This could also include information about the number of patients that would benefit from one donation decision, as well as reassurance on the duty of care and confidentiality to potential donors and their families (UKstaw2 5:72).

Health promotion should be implemented in school education, with visits from patients, rather than healthcare professionals, to generate early awareness and discussion (UKstaw4 6:148). The participants agreed that it is comparatively more challenging to educate and change the attitudes of the adult population (UKstaw7 6:79).

One of the main weaknesses of current health promotional strategies is the dependence on public initiative and curiosity. Participants believed that campaigns are passive and people with the intention to donate are still unaware of how to proactively engage in the process (UKstaw4 6:127).

The group agreed that there should be diversity in the content of health promotion campaign, to cater to the different angles of the decision making process. This should include national and logistical details as well as provide an overview of organ donation around the world (UKstaw1 5:181). Furthermore, campaigns must provide contact information of organisations or professionals that can discuss the implications of the decision with people who are interested in further discussion (UKstaw7 6:118). GPs and other medical professionals should be better equipped to discuss the issue with their patients and to help them navigate through the complex information available (UKstaw3 5:103, UKstaw3 5:176).

Health promotion campaigns are expensive and they are underfunded. The current financial challenges faced by the NHS mean that such issues are not prioritized by the government (UKstaw2 5:184). However, participants agreed that a solution to this problem is the reallocation of funds from campaigns that are less beneficial to public health. More aggressive strategies must be employed to ensure the issue remains a priority in the health promotion agenda (UKstaw4 6:88, UKstaw4 6:165, 6:127).

Table 4. 6 Table of focus group results from UK staff discussing each of the five DHQ themes.

PERSONAL VALUES AND DONATION			
UKstaw2	**5:5**	**I don't know what to think about it. There's a little bit of doubt for me. I just don't know enough.**	**1038-1735**
UKstaw1	**5:1**	**I am not registered yet, but I'd like to register in the future. I am thinking about it right now**	**607-703**
UKstaw5	**6:9**	**I just ticked all of them, except my eyes.**	**1676-1788**
UKstaw2	**5:146**	**In the 80s people in transfusions picked up HIV, the screening wasn't proper. They were taking the blood from people who were donating blood and there weren't the proper tests.** **It's this kind of history of mistakes which has been uneasy.**	**46875-47447**
UKstaw2	**5:70**	**I want to know that there is good legislation in place and people will be protected**	**23409-23615**
UKstaw2	**5:46**	**I do remember that a few years back about George Best the footballer, he drank and drank and drank and then had a liver failure. And he got an organ. But then he started drinking again. And there was outrage about it. Like why was he given an organ?**	**11860-12490**
UKstaw7	**6:62**	**People should be responsible for their own health. And yes, if you have diabetes, you are in a bad position, but you shouldn't transfer this distress to someone else, by making their family opt-out**	**16913-17265**
UKstaw6- **R-** **UKstaw6**	**6:52**	**UKstaw6- I had, he is now deceased, a father-in-law who had kidney failure… but he refused to take a transplant from any of his kids… And also he was offered a transplant, twice, and he refused it.** **R- Why is that?**	**14355-14627**

		UKstaw6- He said he didn't want somebody else's body parts inside of him. And he didn't want to put his kids at risk if things didn't work.	
UKstaw4- UKstaw5- UKstaw4	**6:55**	**UKstaw4-I am not sure I'd accept from a family member UKstaw5- I wouldn't either UKstaw4- I'd give, but I am not sure I would accept**	**15300-15556**
UKstaw6	**6:149**	**And some people feel funny. I think he (father-in-law) gave up. Also, by the way he said it, he wouldn't have been a person who would have donated**	**54021-54278**
UKstaw6- UKstaw4- UKstaw6	**6:150**	**UKstaw6- That's it. They don't want, but when they go through it UKstaw4- They are like 'give me' UKstaw6- It's just like, I am not being funny, a lot atheists on their death bed, they talk to God**	**54443-54755**
UKstaw4- UKstaw5- UKstaw4	**6:101**	**UKstaw4-I think it's such a shame. Cause like you say the Asian community has such a vast problem UKstaw5- Huge, yeah UKstaw4- Yhings like kidney disease. But it can be cultural as well. Because I know like I am a blood donor and I have to donate my blood, they love my blood, because apparently it matches with sickle cell. But not a lot of the Black community donate.**	**28809-2916**
UKstaw5	**6:15**	**I think it's cultural as well in Hinduism they believe in after life, you don't mess with the body, you cremate the body very quickly afterwards.**	**2580-2724**
UKstaw1	**5:43**	**That question, I don't know about, because I haven't really asked any religious person. But that's something that I think I'll do. Yeah, I think I want to find out that**	**10785-11022**
UKstaw3	**5:44**	**I am not sure if any religion would necessarily explicitly go against or pro transplantation, for the simple reason that it is something fairly new and I haven't found any specific information in terms of my religious beliefs, how these will be supported. I have found a few discussions, but nothing explicit 'yes' that religion supports transplantation or not.**	**11028-11388**
R- UKstaw2	**5:136**	**R-There are campaigns that talk about recycling your organs UKstaw2-and it is kind like cleaning up the planet for future generations.**	**43467-44015**
UKstaw5	**6:93**	**Altruistic donors they'll basically I think 'I've got two, I only need one. We probably did last year six, seven… in a whole year. So, not huge numbers**	**25838-26126**
FACTS ON THE DOD PROCESS			
UKstaw1- UKstaw2- UKstaw1- UKstaw2	**5:32**	**UKstaw1-I thought maybe, if you are young, they will use your organs, even without your consent. Is that correct? Is that normally how it is? Ukstaw2-No UKstaw1-No? UKstaw2- I don't know**	**7774-8178**
UKstaw4	**6:29**	**All I know is that I suspect is that most our surgeons given half a chance would perhaps do that. But they obviously don't cause we've got a massive waiting list (giggles)**	**7108-7836**
UKstaw2	**5:65**	**I' ve heard of these people in China, there is organ donation, organ harvesting. People like, cause it's a communist country isn't it? It is not democracy**	**20302-20457**
UKstaw3	**5:177**	**So, that one is confident that if they don't die in this country, but they die elsewhere in Europe, their organs**	**35436-35757**

		will still be of use.	
UKstaw3- UKstaw2- Ukstaw3- UKstaw2	5:66	UKstaw3-There is a massive black market for organs, especially in China, Saudi Arabia… UKstaw2-And doctors don't ask where the organ is coming from. People have lost their lives, because they have been butchered… So regulation… where organs come from. I think there really needs to be some sort of database … UKstaw3-But it wouldn't be realistic, if it's a private clinic… you can't always track an organ. UKstaw2Tthat is my objection. People have been killed basically	20690-22064
UKstaw2	5:50	It could be an anonymous thing as well, an anonymous report, you know, something like that. Obviously, they are entitled to their privacy, as well.	14344-14729
UKstaw3	5:141	That's why I am happy it is anonymous on both sides. There's no judgement or prejudice passed on	45164-45267
UKstaw5- UKstaw6- UKstaw4- UKstaw5- UKstaw6- UKstaw5- UKstaw6- UKstaw5- UKstaw4	6:152	UKstaw5- Do you know how many kidneys we turn down compared say to Royal Free or Cambridge or someone else. How can we, if we cannot implement standards of what we will accept from one centre to another how can we do it from one country to another? UKstaw6- When you say turn down UKstaw4- The quality UKstaw5- The quality we don't offer it to our patients, so send it to the Unit that has the second-best match UKstaw6- That's interesting, wow UKstaw5- We turn them down but sometimes a kidney that maybe is not such good quality into an 85-year-old who we know doesn't have the life expectancy UKstaw6- Yeah UKstaw5- Yeah, so that's different. If that's not comparable and we are two miles away, how do we UKstaw4- That is absolutely true. We have completely different rules already here	55759-56777
UKstaw4- UKstaw5	6:34	UKstaw4-I think everyone thinks that they are going to see this chopped up body, but I don't believe it's like that at all... / UKstaw5-Your clothes, and everything's sewn up, you won't see a thing	9608-9855
UKstaw7	6:37	I have heard what was said about people not being asked what to do with their relative's dead body. I did hear on the news that something like this happened, but it was relating to babies, not adults	10054-10275
UKstaw7- R- UKstaw7	6:40	UKstaw7-And the families only found out that they didn't have a body to bury, when they tried to organize that, and they found that they were sent as part of a research trial, or they did some sort of post mortem as a research trial. So, they didn't have a person's full body. So, there was a big scandal, I heard about that R-Without the consent of the parents? UKstaw7- Yeah, they weren't consenting	10277-10665
UKstaw4- UKstaw6- UKstaw5	6:23	UKstaw4-But because you get asked that moment I think they are not quite ready to accept UKstaw6- To let go UKstaw5- Yeah. So, it's quite an odd time to make a really important decision.	4376-4543

UKstaw7	**6:30**	**I know that when you are grieving at that time and you have to make a decision, maybe you would say 'no', whereas if you waited for a while later you would really say 'yes'. But you can't really pressure someone in that situation**	**8052-8280**
UKstaw7	**6:57**	**They (family) disagree with the assumption that someone might have, that someone might put them in that position and to explain, explain themselves out of … opt-out. I think it might have to do with the way, I think people might need to demonstrate their ability to, the way they might behave in that situation, like the medical team, you know. That they would prepare to take their time or they wouldn't do anything until they could make sure that person was happy or that they might be patient.**	**15902-16388**
UKstaw5- UKstaw6	**6:22**	**UKstaw5-Maybe it's just the mechanics of no one can get to your organs till, that's almost admitting you are dead. Because that's when the machine goes off. That's when they take your organs out and turn the machine off. So, UKstaw6-So, they take them out just before they know you are gonna pass**	**4004-4370**
		REGISTRATION OPTIONS	
UKstaw3	**5:119**	**I thought it was enough as long they are aware that I am happy to do it. I thought it doesn't matter whether I am registered or not.**	**38549-38889**
UKstaw5	**6:25**	**Actually it's (donor card) not worth the paper it's written on**	**6096-6475**
UKstaw5	**6:10**	**I ticked them all, but my husband said, 'I don't know why you filled this form, because they are going to ask me anyway and I will say no'.**	**1812-2070**
UKstaw5	**6:12**	**my husband said, 'I don't know why you filled this form, because they are going to ask me anyway and I will say no'.**	**1834-2137**
UKstaw3	**5:131**	**And your family is more likely to be more comfortable with your decision as well**	**42210-42477**
UKstaw5	**6:24**	**Cause you fill up the card when you are sane, fine, in good mind and you think 'yeah, this is what I would want'. This is like having living wills.**	**4551-6090**
UKstaw5	**6:56**	**I think opting-in and opting-out is different from asking.**	**16484-16707**
UKstaw1	**5:118**	**It's good to know, at least you have a choice like that. So, it's not like, you're not, like, stuck.**	**39828-39985**
UKstaw2	**5:30**	**If you live to be elderly, like you die in your nineties, they are not going to take you organs…organs are also 90 years old**	**7506-7693**
UKstaw3	**5:35**	**Not every organ will be good, will be used for donation**	**8353-8518**
UKstaw1- UKstaw2	**5:117**	**UKstaw1-You can opt in and out whenever you want? UKstaw2-If you are healthy now and you go on to develop… some disease which affects your organs, or affects your blood or something like that, you need if you get cancer, you need to opt out.**	**38989-39536**
UKstaw3	**5:36**	**As far as I am aware though, if they are not deemed usable for donation, they can go to science and for research**	**8524-8773**
UKstaw3	**5:9**	**I am definitely strong for organ donation, whether it is for donating for recipient or for science.**	**2102-2285**
UKstaw4	**6:50**	**I just am a real believer in research, and you know giving up even organs for research, things like that**	**13960-14069**
UKstaw3	**5:37**	**And also my university had a whole body, which was**	**8821-9665**

		kindly donated by an anonymous person, so that students could try and mummify it. Also, there was a whole library of different organs with different pathologies, which were used by medical students in order to see how organs change with different diseases, for example cancer. These of course would be organs, that wouldn't be deemed usable for transplantation. And also, it was a library within the museum that could be used by any student.	
UKstaw3	**5:64**	**A lot of the European countries for example do have a strict regulation as to whether they allow or not the use of embryos for research.**	**19217-19755**
UKstaw3	**5:63**	**There is medical research which suggests bone marrow transplant can be used to cure some forms of blood cancer… still very much in experimental phases**	**19761-20262**
UKstaw2	**5:134**	**You are asking, like, people to donate an organ and then it goes to a complete stranger. And it's like 'why would you do that?'. Cause we don't care about strangers**	**42533-43382**
UKstaw5	**6:51**	**I'd do that (live donation). I'd definitely do that. That's different, cause you know where it's going**	**14130-14349**
UKstaw3	**5:54**	**And sometimes they can help, if that's live-related donation, a family member might feel more useful**	**16102-16398**
UKstaw2	**5:25**	**I think if you are giving away an organ, that might mean you won't be able to do stuff that you did before**	**5945-6144**
UKstaw2	**5:62**	**Some controversy or something like having another baby, like if one baby has a life limiting condition, then having another baby or a test tube baby, to provide tissues for a sibling, and the ethics behind that**	**18615-19132**
UKstaw6	**6:4**	**So, I wouldn't mind donating my organs after I die, but I would like to keep my heart. And my eyes also**	**1387-1489**
UKstaw6	**6:6**	**But they said to me, like they would donate all their organs except their heart, which I thought was interesting. And I kind of thought 'this is a good idea'**	**1059-1316**
UKstaw3	**5:58**	**Do I get a choice? (all giggle) just the left kidney and just the right lung (all giggle). It's all or nothing Once I am gone, I wouldn't need it anymore.**	**17446-17934**
COMMUNICATION WITH FAMILY AND FRIENDS			
UKstaw3	**5:28**	**I've made clear, sure that my family is aware that, I've told them whether I am registered or not, what my decision is.**	**6721-6918**
UKstaw3	**5:55**	**Well, they (parents) were very much supportive. Both of them are aware what it is and they are well informed, so**	**16408-16699**
UKstaw4	**6:11**	**Oh boy, they have to be told, because I will give everything**	**2191-2250**
UKstaw3	**5:57**	**Since none of them (parents) said they don't want to do it, when I brought up the topic. So, in my case it would be assumed consent**	**17088-17273**
UKstaw4	**6:81**	**I discussed it with my boyfriend who was 'no, no, no I don't like it'. And I said 'I warned you. This is what I want, this is what I absolutely want'. And you know, it's something that I absolutely want to talk about with my brothers and things like that**	**21506-22195**
UKstaw6	**6:82**	**I definitely want to be cremated and I told my partner and my son. I told my family this. But my son's like 'no, I won't cremate you'. And my son is like twelve, you know, but he's like 'no, I won't cremate you, no'**	**22403-22891**

UKstaw7	**6:18**	**When I first heard about it, I think I was quite young, maybe in early secondary school. And when I heard about it I was enthusiastic about the idea and I was really open. But I don't think I necessarily discussed it with any of my family. But recently when I mentioned it to my close family, there were a few people who were really against it and the idea really upset them. So, I would say perhaps for that, it would hold me back.**	**2997-3751**
UKstaw6	**6:80**	**I've never discussed it with my family actually, but I will tonight**	**21434-21500**

PROMOTIONAL RESOURCES			
UKstaw1	**5:18**	**I don't remember having a class or even a discussion about it in school or university.**	**4296-4427**
UKstaw5	**6:90**	**My daughter for her GCSE, dialysis was there as part of diffusion and as an example of diffusion osmosis… machine. But the RE had topics about abortion and donation of organs, and those more ethical issues rather than religion.**	**24806-2517**
UKstaw3	**5:97**	**I was mostly exposed to this information when I was already in University, in my 20s. I would have loved to have learnt more**	**32870-33021**
UKstaw4	**6:159**	**I am not saying we are too late for certain generations, but we need to start, there are a lot of minds to change. Whereas if you start them younger, it's just part of what they think about.**	**39262-3973**
UKstaw4	**6:88**	**I think nowadays it's probably, we are all a bit too politically correct. So, they might be afraid to approach the subject at schools. Because there are so many religious beliefs and people may find it offensive.**	**24370-24800**
UKstaw2	**5:40**	**But I did across once a campaign for a deceased, like, donation. Somebody was running, I think a community event to raise awareness… / people I know in the greater community, people that I live in, that I know of in London that I know of.**	**10021-10395**
UKstaw5	**6:96**	**In my temple, it's a Sikh temple that I go to, it was brought up more because at the end of every Sunday they'll have a collection. They did the kidney one, only because there's an idea within Asian communities that they have high occurrences of high blood pressure, diabetes.**	**27116-27671**
UKstaw4	**6:121**	**It's more, like the big campaigns are for smoking, cause a lot of people smoke and you know diet. Cause a lot of people do it. I don't know anyone who will pick up a kidney leaflet, if they are, you know, off the street.**	**37627-37984**
UKstaw3	**5:104**	**There are probably leaflets somewhere buried in the office… It's just a pile of information.**	**34808-34984**
UKstaw5	**6:120**	**They (leaflets) are all in the rack. I don't even look**	**37451-37609**
UKstaw5	**6:126**	**I don't know, I mean it's hard to tell. You've got like pictorial things that you think would trigger another action. So, those things are quite passive. So, you just look at them**	**40461-40691**

		and turn away and don't do anything, has no effect.	
UKstaw4	**6:154**	**But some people do though. You do. So, we've got to capture everybody. Do you see what I mean?**	**57671-57854**
UKstaw6	**6:129**	**My son then shouts out to me after the advert 'see mom, you can stop, you can get help'. And he's 3 years old, you know, so. And how come at 3 years old they know that smoking is bad? Because they have seen it at the telly**	**41534-42262**
UKstaw4	**6:128**	**If you think of that sort of adverts and things that you remember, funny ones like the 'You've been tango'd'? It's stuff like that that you remember. Who remembers adverts that are factual?**	**41338-41528**
UKstaw5	**6:73**	**I think if you had, you know, a person on dialysis and you saw they look grey. It almost would be a no brainer.**	**20275-20470**
UKstaw1	**5:154**	**And like you said earlier, everything is not always correct in the information. Are you looking more for answers being there. Or they might be there, but they are contradicting.**	**50060-50291**
UKstaw3	**5:96**	**Then Internet doesn't always have the right questions and sometimes there is a lot of misleading information.**	**32758-32868**
UKstaw3	**5:159**	**It can get buried in Internet with all this information.**	**50814-50869**
UKstaw3	**5:113**	**I was impressed that they have, when you opened the homepage (NHSBT), they have the question 'do you want to be an organ donor?' or something. And I pressed the 'no' out of curiosity and immediately it gave this page of why you should (giggles). Very persuasive. It's there if you want to be a donor, to register right away. That's easy**	**37909-38450**
UKstaw4	**6:119**	**The only thing I ever looked up (on NHSBT) was when I started donating blood to find out where I can do it. And obviously I registered online to be an organ donor.**	**36000-36779**
UKstaw4	**6:84**	**Sometimes see a few bits on Twitter when it's National Kidney Day or something like that. But I suspect I see that because of the field I am in and because of things I look at**	**22085-22356**
UKstaw2	**5:153**	**I wouldn't follow anything on Twitter or any kind of online thing. It's not my preferred means. Yeah, I just sit all day in front of a computer and I just don't want to follow that kind of social media.**	**49850-50054**
UKstaw7	**6:156**	**Just to display to them, that there are all these safeguards. You know, the safeguards of not feeling like they have to or there's going to be a pressure. Just to get that whole process of how it works in different situations. You know, if there is one, like if there is a kind of a protocol.**	**59297-60077**
UKstaw2	**5:72**	**So, you know, for example, what happens on the day of the transplant? I think this could really be a good approach** **Maybe where you can say how many donor organs were transplanted or something under the freedom of information act**	**23621-24187**
UKstaw4	**6:148**	**Someone who's 'I've been on dialysis. This is what's my life. This is now transplanted. This is what has changed in my life'. That's an actual impact on a human. I am not saying that we don't need doctors and nurses, but they come from a very technical point of view.**	**52502-53150**

UKstaw7	**6:79**	**I think maybe you need to do it through education, I don't know how far that would have affected people, because, you know, you can't make an adult who's going on, you know, with their own life, busy, how can you educate them?**	**21111-21337**
UKstaw5	**6:127**	**But I think if you want to make a difference and make things change, you've got to be a bit more forceful… it doesn't matter how good the website and the information they could go to.**	**40693-41332**
UKstaw1	**5:181**	**To see the figures how they vary from country to country.**	**37481-37904**
UKstaw7	**6:118**	**Indirect information, maybe some links to people you go, you feel assured, that there is someone who really has the knowledge to give you some information, yeah, for the people who are not, who are quite against it**	**34745-35995**
UKstaw3	**5:103**	**Also, speaking to a medical professional gives you confidence that they know what they're talking about. It's not just the massive amount of information out there, it is targeted towards you by someone who is already educated and trained**	**34129-3489**
UKstaw3	**5:176**	**If it is just for check-up, it is something that a lot of GPs might bring up, especially with healthy people. They know what your medical history is, they might as well, so actually it could be quite a good.**	**34985-35309**
UKstaw2	**5:184**	**where would you get the funding for the campaigns? Campaigns cost money. NHS doesn't have any money, so (giggles).**	**48781-49529**
UKstaw5	**6:165**	**There is rubbish being marketed to death, which is so bad for us and yet this is a positive thing that we hold back on , saying 'oh I don't want to offend anyone'... Because important things sometimes are upsetting**	**43670-44125**

4.7.2.3 UK: PATIENTS

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.7**.

a) THEME1: PERSONAL VALUES AND DONATION

Personal experience with the challenges of dialysis and end-organ failure personalised the issue of DOD for the participants. Prior to this, the majority were either unaware of the topic or had not insufficient information to develop strong opinions. One participant suggested that there is very little promotion of the topic outside of Europe (UKpatm2 4:4). As a consequence, some patients were unaware that organ donation and transplantation could be a lifeline, believing initially that their diagnosis was fatal (UKpatw1 4:58).

Utility is one of the greatest arguments in support of DOD. After death, the organs must be relocated to where they will have the greatest impact. This was analogised to the donation of clothing after they have been outgrown or are no longer required (UKpatm2 4:116). Participants believed that this pragmatic and utilitarian mindset must be implemented in wider life decisions. Some participants offered spiritual reasoning, with organ donation allowing some part of the deceased to live on after they are gone. This rationale was extended to consent decisions for family members, suggesting that framing the donation request in this way provides the donor's relatives with some comfort (UKpatm4-UKpatw-UKpatm4 4:118).

The patients were less optimistic about the general public's comprehension of DOD. They were perceived as 'selfish' and opportunistic, willing to receive an organ if they ever required one but unwilling to donate (UKpatm2 4:109). The public were also perceived as stubborn, with rigid belief systems that would not be influenced by more information or future campaigns. This was also believed to be the case among highly educated individuals (UKpatw1 4:147; UKpatm2 4:18).

Religious beliefs were discussed in depth by the participants, as they were believed to play a formative role in the creation of attitudes, particularly among older generations. A common spiritual belief was that the body must pass to the afterlife uncorrupted and in its entirety (UKpatm2 4:13; UKpatm2 4:163). This logic was considered flawed by some of the patients, who believed these spiritual inhibitions are based on technicalities and contradict the central dogma of all religions: the celebration and preservation of life. This belief in stewardship is common to all dominations and spiritual communities and should be the overarching belief influencing decisions about organ donation (UKpatm2 4:114). Deviation from time-honoured customs and traditions leads to criticism by the community of the deceased's family. One of the patients confirmed this narrative, describing their spouse's experience with their relatives in India following her husband's transplant in the UK (UKpatm1-UKpatm2 4:103). Certain religious groups, such as the Sikh community, are regarded as more open minded to DOD and constitute a large portion of the Asian donor population (UKpatm2 4:18). Some communities' resistance to DOD was viewed as an issue of practicality relating to burial practices. Two participants, one from Ireland and one from Kenya, described that organ donation is less common in rural areas in these countries. The reason for this is that the nearest hospital facilities are in the cities, which may be several miles away and as a result, most people die at home and are buried the same day (UKpatm4-UKpatm2 4:107).

This reflects the notion that conservative attitudes gradually diminish with time, with younger generations being less influenced by religious customs and traditions (UKpatm1 4:165). Furthermore, a patient described how members of his religious social circle were accepting and complimentary of his late father's decision to donate his body for medical research, with the condition that it would be returned to his family for burial at the end of two years (UKpatm2 4:97). The speaker believed that the community became more receptive to DOD once it became a personal issue that affected one of their members.

b) THEME 2: FACTS ON THE DOD PROCESS

Participants praised the care with which the healthcare team select organs for transplantation and defended this position to patients who were uncertain (UKpatm2 4:168). An understanding of the treatment of donors and the process of organ selection may help clarify the misunderstandings on procedural issues, which may serve as deterrents for some people (UKpatm1 4:148).

The healthcare team were seen as a good source of information. The patients recalled that they directed most of their questions regarding treatment to the nursing team, rather than their doctors, as they had greater contact with them (UKpatm4 4:36). The participants also praised the information seminar that was held for patients and their families, which covered a lot of details in the space of one day (UKpatm2 4:35).

However, some felt that there was an informational overload, which was too high to process. It was suggested that these conferences should cover less information with more detail. They still had gaps in knowledge following the seminar, such as understanding the different options for dialysis. Patient speakers were a perceived solution to this problem, as they have a unique understanding for what information is needed to navigate the healthcare system (UKpatm1 4:43). The Kidney Patients' Association also organises trips and newsletters for its members. These subscriptions allow their members to obtain up to date, current information (UKpatm2 4:139).

c) THEME 3: REGISTRATION OPTIONS

Some of the participants were registered as organ donors before they required a transplant (UKpatm1 4:2). Others discussed how their situation inspired members of their family to register as donors and obtain a donor card (UKpatw1 4:24; UKpatm1 4:76).

Following an informational seminar held for renal patients, participants became aware of the issue of familial consent as a barrier to donation decisions. The participants learned that the healthcare team are morally obliged to follow the families' wishes, even if they contravene the deceased's wishes (UKpatm2 4:90).

There was only moderate knowledge about factors affecting donor eligibility among transplant recipients. (UKpatm1 4:166). There was some debate among the patients, who suggested that all other organs and tissues, except for the allograft should be donatable (UKpatm2-UKpatm1-UKpatw1-

UKpatm2-UKpatm1-UKpatw1-UKpatm4-UKpatm1-UKpatm4-UKpatm2 4:167). One participant discussed eligibility criteria for live related donation which they learnt after they required a combined kidney and pancreas transplant. This excluded family members with systemic conditions such as hypertension and diabetes (UKpatm2 4:121).

Regardless of suitability for transplantation, several participants were eager to donate their body for medical research (UKpatw1 4:23; UKpatw1 4:86). In some cases, this was following the example of family members (UKpatm2 4:95; UKpatw1 4:101). There was some discussion of the recent implementation of the presumed consent system and people's reluctance to opt-out; an opportunity given when updating documentation, such as a driver's licence (UKpatm2 4:9).

d) THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS

The participants recalled being advised to hold discussions with their families about their attitudes and decisions by members of the healthcare team, in order to reduce the burden on their families at the critical moment (UKpatm2 4:90).

Despite their experiences, patients believed that their own families would be reluctant to grant consent for their decisions and therefore, in some cases, avoided this discussion (R-UKpatm1 4:33).

The participants believed that there is a particularly sensitive dynamic between parents and children (UKpatm1 4:31). Parents have a tendency to be protective and avoid discussing the topic of death with their children (R-UKpatw1-R-UKpatw1 4:34, UKpatw1 4:162).

One participant recalled how a family member who had experience learning with cadavers, tried to persuade them against donating their body for medical research. This did not change the participant's opinion (UKpatw1 4:92).

e)THEME 5:PROMOTIONAL RESOURCES

The participants discussed in detail the impact of the internet in DOD health promotion. There was universal agreement that this was a good source of audio-visual content, such as talks and videos for both patients and their families (UKpatm2 4:48). Several participants claimed that they used internet-based materials to obtain information about their conditions following their interactions with the healthcare team (UKpatm2 4:69; UKpatm2 4:71). Not all of the participants were aware that there was a national website, issued by NHSBT, covering key information on organ donation (R-UKpatm1 4:75).

Some participants raised the issue of health literacy and access to the internet, specifically among older members of the community and those diverse ethnic and cultural backgrounds, including those of Asian ethnic origin (UKpatm2 4:47; UKpatm2 4:54; UKpatm2 4:157). Other participants raised the idea of intergenerational support as a solution to this problem, where younger family members with greater technical literacy can assist their elders in obtaining information (UKpatm2 4:51).

Similar issues were raised with regard to print-based information sources. There was a general consensus among the participants that textual information is more difficult to understand and has higher literacy demands (UKpatm2 4:55). Consequently, it was considered significantly weaker at conveying key messages (UKpatw1 4:57). One suggestion for improving this method considered providing leaflets in clinical and GP settings different languages. Other sources of DOD advertisement mentioned were predominantly community based, including library posters (UKpatw1 4:134).

The participants acknowledged social media as a commonly utilised tool for health promotion. However, they suggested that this also suffers from similar limitations regarding memorability, as these are overcrowded advertising spaces (UKpatm1 4:135).

The local religious communities were considered a key area to focus future health promotions (UKpatm1 4:158). There was some evidence of effort to promote the issue in community organised events, such as health information fairs. These united communities from different parts of the country and were organised by national committees. The participants observed that while the younger generations are more supportive of DOD, the elder members of the community harbour more conservative views and will only be convinced if they receive information, verification and encouragement from their spiritual leaders.

This notion builds upon the belief that senior members of the community are less likely to use the internet for information, opting instead for face-to face teaching. Following their experience with transplantation, one of the participants encouraged their religious leader to promote the issue to the community, believing that the congregation views their leader as an extremely pious and saintly figure. The leader was hesitant to fulfil this request, unsure of how to instigate this process, and fearing resistance from the elder members of the community (UKpatm2 4:151). In addition, the group believed that such community-based information events would help to overcome language and health literacy barriers (4:151). Campaigns must provide the information that is necessary to convince certain socio-demographic groups, with an emphasis on the older generations (UKpatm2 4:155).

Patient narratives are a well utilised resource, with some participants having experience as speakers and as information seekers from these sources (UKpatm1 4:64).

Some believed that secondary school is the best time to introduce the topic (UKpatw1-UKpatm2-R-UKpatm2 4:80). Some participants based this viewpoint on their personal experience (UKpatm1 4:29; UKpatm1 4:30). Others believed in raising awareness as soon as possible. One participant described the criticism she received for showing an information video to her children, aged 11 and 12, prior to undergoing an operation. The participant stated that neither she, nor his children regretted this decision, as they were comforted knowing what the procedure involved (UKpatm2 4:53).

Table 4. 7 Table of focus group results from UK patients discussing each of the five DHQ themes.

PERSONAL VIEWS AND DONATION			
UKpatm2	4:4	I wasn't aware, because I lived most of my life in Kenya. I came here at the age of 21 and within about three, four years I was diagnosed with this issue	1629-1782
UKpatw1	4:58	I wasn't ready to take any kidney transplant. I thought 'if I go, I go'	15644-15713
UKpatm2	4:116	My one line is, when you explain to them that giving your clothes away that you will never see again, is the same as giving your heart away when you don't need it, they see a difference in that. There shouldn't be a difference	37986-38211
UKpatm4- UKpatw1- UKpatm4	4:118	UKpatm4- In that way, when one dies, like if I died and they took my heart, even if I am dead I still live on UKpatw1-Yeah, that is the way living in somebody UKpatm4 – After I've died, I could still live on. If one of my kids died and gave their heart to another child, my child would be still living on no matter who it is	38725-39030
UKpatm2	4:109	They are selfish that way… when the time of getting, they'll get it	35954-36131
UKpatw1	4:147	And they don't want to change that belief. That's what I think, they don't want to change that belief no matter what you do. Even the educated some of them, they don't want to give	51124-5104
UKpatm2	4:18	Different communities, like the Sikh community gives more, that's what the doctor told me at that time… I think it is a cultural thing that they don't want to give even with talks in the temples and all that. They just think 'that is not necessary' until family is affected. Then I think their views are changed, otherwise	4790-5284
UKpatm2	4:13	They've got some old religious beliefs, that the person should go whole	3419-3823
UKpatm2	4:163	They are scared of if they don't do the ceremonies, they will come back in a ghost	33457-33538
UKpatm2	4:114	They don't understand the point that they are giving life. In any religion that is always one thing that is there	37354-37605
UKpatm1- UKpatm2	4:103	UKpatm1-And they, my parents not so much, but my wife still worries about what people say, about her and us behind our backs UKpatm2- interference in other people's life, I call it	32146-3326
UKpatm4- UKpatm2	4:107	UKpatm4-If you die in the morning, in Ireland in the morning you go to graveyard, you get buried. It's not like waiting three weeks… the nearest hospital may be from Cork to Dublin, it's like a	34070-3592

		five-hour drive to take organs UKpatm2-Like in Kenya, the same situation. The facilities are not there.	
UKpatm1	**4:165**	**I think with the generations changing, time changing, it's definitely getting better**	**36901-3698**
UKpatm2	**4:97**	**Father's wish was for two years they take the body away, whatever they can take out, take out, research, do whatever research they want to do, tissue type whatever, and they return the body two years later. And they were happy with that. They did all the common things they do when people pass away except the ashes and all that.**	**30603-3108**
FACTS ON THE DOD PROCESS			
UKpatm2	**4:168**	**Somebody told me his kidney had cancer. I said to this person 'no, because these guys check that there's no way they give a defective kidney. They do check it. There is no way they give defective kidneys to anybody. They do check it as a general process, there is nothing to …kidney, otherwise they don't give. Because I know they call people in, as a general process, and they say, 'the kidney was not good, go back'. That has basically happened to some people**	**51614-52539**
UKpatm1	**4:148**	**Maybe some understanding of what happens when someone passes, the time frame between their organs being taken and donated, what is a good organ, what is a bad organ.**	**52546-52742**
UKpatm4	**4:36**	**Not so much the doctors. Like while I was on dialysis I got more information … nurses. I got more information out of them than doctors. You see a doctor once a month as far as seeing you nurses are more important than doctors**	**9245-9604**
UKpatm2	**4:35**	**I think they have a seminar, a conference in W12. Before I started dialysis I was approached to come. And that they explained to you and your family more. The seminar is every 3 or 4 months and that gives a lot of details both about transplant and everything, one day**	**8968-9235**
UKpatm1	**4:43**	**It is a balance you need to find and then make the right information available because it's still, I don't think there is enough information on different types of dialysis available and all that. There are still gap areas missing, information that people, that patients would want to acquire, which is why I was always keen to pass on my experiences, pass on my knowledge to help others get through this situation as easy as they can**	**11481-11914**
UKpatm2	**4:139**	**Mainly the people who were dialysing with, they are part of this. They've actually gone these summer trips. They organise summer trips to Margate and all that. So, that is a very good idea in that sense that keeps them up to date. Because I know in my group there were three or four who are regular members and they get newsletters directly sent to them and they were more educated. But that is after, you see. You only become or know about kidney Patients' Association.**	**47241-47786**

REGISTRATION OPTIONS			
UKpatm1	**4:2**	**I used to carry a donor card with me before I needed it. But I used to carry one before I actually got ill and actually required the service myself**	**1084-1230**
UKpatw1	**4:24**	**My family is there, they want to give anything. So, they are already carrying the donor card. Most of them.**	**6129-6235**
UKpatm1	**4:76**	**I think when I did it, it was just a form to fill in and send off. It came with a card on it already. So, you just registered to join the donor list**	**24539-24695**
UKpatm2	**4:90**	**In the seminar, they say, signed for the donor, the wife, he passes away, the wife says 'no'. The doctor says, 'we are morally obliged not to take it'.**	**28867-28914**
UKpatm1	**4:166**	**That's one thing I've always wanted to ask with doctors, what can we as transplant receivers give, what can we donate after we pass away. That's never been made clear to any of us**	**39145-39332**
UKpatm2- UKpatm1- UKpatw1- UKpatm4- UKpatm1- UKpatm4- UKpatm2	**4:167**	**UKpatm2-It's not clear. But my understanding is if you have a good heart, it should be made available, the kidneys got to be available UKpatm1- The kidney you'd understand, but then you have heart, lungs, you have liver, eyes UKpatw1-Just kidney won't UKpatm4-Kidney is no good UKpatm1-Skin UKpatm4-Kidney can't be UKpatm2-For heart patients the heart will be no good, no. Shame to put a weak heart in somebody just wanting it**	**39378-39775**
UKpatm2	**4:121**	**Because at the moment I was told, you can't have a live donor who is diabetic or high blood pressure. That excluded my entire family except my mom.**	**39835-40497**
UKpatw1	**4:23**	**Now I think even if you know, I get my organ donated I don't mind, giving anything for research, you know.**	**6017-6175**
UKpatw1	**4:86**	**I want to give my body to medical, all of it, whatever they can use. That's how I am feeling about, but I don't know how to go about it. So, I feel like doing that, yeah, giving my whole body, everything**	**28025-28230**
UKpatm2	**4:95**	**She mentioned giving her body for research. I only learnt that I could do that somewhere between 2000, where the guy I was working his father did that.**	**30448-30598**
UKpatw1	**4:101**	**A couple of years ago I got my cousin, she passed away with cancer. She gave her body to research, yeah.**	**31387- 31494**
UKpatm2	**4:9**	**Without it now they would become (a donor) because once you get your licence it's a compulsory thing unless you opt-out. But most are not opting-out.**	**2793-2984**
COMMUNICATION WITH FAMILY AND FRIENDS			
UKpatm2	**4:91**	**'tell your families that you are part of the donation list, because at that time it will be hard for them to lose you**	**289402-29546**

R-UKpatm1	**4:33**	**R- You signed as a donor without discussing it? UKpatm1-That's just the way my parents would have felt**	**7291-7386**
UKpatm1	**4:31**	**I never actually discussed with my parents**	**7240-7281**
R-Upatw1-R-UKpatw1	**4:34**	**R- Why would a parent worry about a child carrying a donor card? UKpatw1-I don't know, I don't know, but personally I do. Cause I don't want anything to happen to child, you know R-Do you think it is bad luck to think about? UKpatw1- not really. But I think I might change my mind, yet I am not focused on that sort of thing, you know, that after death or something, you know.**	**7705-8071**
UKpatw1	**4:162**	**Parents won't let (giggles). Me as a parent I wouldn't let my children donate. They get worried you know?**	**7392-7496**
UKpatw1	**4:92**	**I have a niece. She is a dentist. She told me that she doesn't want me to give my body to a thing. I said 'why?', she says because it looks frightening the face, everything. She is a dentist. She said 'I don't want you to do it'. I said 'why?'. Because she goes through all the organs and she doesn't want to see any relatives… But I told them I am going to donate**	**29740-30366**

PROMOTIONAL RESOURCES			
UKpatm2	**4:48**	**They don't know that and I told them that website, Imperial College whatever and ask. You need to ask you children to look at these videos. One seminar, they recorded it and they put it to their website. So, you need to look at that, all the options will be there, you are going to look at it at home, there are options.**	**12460-12779**
UKpatm2	**4:69**	**And that night obviously I went on the computer and I got a video of what they do, everything**	**21715-21807**
UKpatm2	**4:71**	**They said something to me, which I knew cause I had seen it in the video**	**22117-22189**
R-UKpatm1	**4:75**	**R- Did you visit the NHSBT website about organ donation? UKpatm1- I wasn't aware there was one**	**24340-24426**
UKpatm2	**4:47**	**And most of them had come from overseas. It was a lot of Asian community in that side, who had never studied, they don't know about Internet.**	**12114-12254**
UKpatm2	**4:54**	**But access to them, the general, the majority, most of them is because they don't know how to use that**	**14017-14118**
UKpatm2	**4:157**	**It is pretty much the older generation. Although they have Internet they won't bother looking at it.**	**49295-49394**

UKpatm2	4:51	And at that time, they didn't have knowledge of the …. Only some who are working, will have some idea. But the general, they don't. I know if my mom was in this situation. She wouldn't be able to use the computer. The youngest generation I think they can all read up and they do. If I came first time tomorrow, I went to YouTube to see what it is.	13100-13445
UKpatm2	4:55	And the paperwork is very weak I think. Because my mother doesn't know English at all. The moment I took that paperwork I was given to in transplant, she asked my niece to explain to her	14132-14556
UKpatw1	4:57	I think people will need to have more than a leaflet, because I wasn't ready to take any kidney transplant.	15557-15689
UKpatw1	4:134	If you go to library, you can see all these things there	45829-46068
UKpatm1	4:135	But sometimes the messages on social media once are shared and liked are forgotten	46501-46746
UKpatm1	4:158	Thinking religious beliefs I think, when it comes to India that's what's gonna influence	49049-49261
UKpatm2- R- UKpatm2	4:151	UKpatm2-I spoke to the local Temples committee members. And the feedback after a few weeks 'I don't think they will agree to that'. R- You believe that would make a difference UKpatm2-To the older generation. But now you talk to under thirty, they know about this, the internet. Some may be stubborn, too religious, but the majority are now thinking 'that's a good idea'. And they say, 'can we come one day and explain to your guys?'. In their language, it will be better. Over 50s now, every year it goes higher, but some of them are not educated. They don't know English and all that. Because they came to that country when they got an Indian education,	42913-45597
UKpatm2	4:155	In ten years time you will not have this conversation. Because most of the stubborn guys will have passed on. I think campaigning (this) specific age group.	46759-47036
UKpatm1	4:64	The guy who was in bed next to me… he was the one they did the documentary on. His wife donated to him. And it was only after that that I got a better idea of what to expect after the transplant.	19655-19864
UKpatm2- R- UKpatm2	4:80	UKpatm2-Not at a young age R-What is a young age? UKpatm2-I think after they go to high school is OK	25523-25769
UKpatm1	4:29	It was a talk I think. Someone came and gave a talk during an assembly. That was very odd to start with for me	7128-7239
UKpatm1	4:30	I learnt at high school which was actually when I did start carrying a card	6930-7011
UKpatm2	4:53	I showed it to my eldest son, he is only 12, he was only 11 at that time. People said, 'Don't show such things', but I said, 'Whenever I go, the night I go out of the house, it will be for this'…He was happy when the operation happened. He said, 'I know what will happen to you. I'll see you in a couple of days'	13640-14000

4.7.2.4 UK FOCUS GROUP CONCLUSION

In the UK model, the cross-comparative analysis indicated a strong emphasis on independence, diversity in values and engagement in discourse . Furthermore, participants displayed a tendency to root attitudinal assertions in a factual, evidentiary or anecdotal basis. This is consistent with good informational accessibility and potential for critical health literacy.

As a result, whilst the sample population were predominantly in favour of DOD, they were also sober of its realities and difficulties. This accounts for the comparatively lower proportion of pro-donation responses. Rather than framing supporter-registrant behaviours as a utilitarian imperative, campaigns promote informed decision making, suggesting that the 'best' choice is that which most tightly fits with one's personal values and preferences. This line of option framing is cohesive with the ethical foundation of autonomy in the public healthcare system in the UK.

Access to a high volume of information allows for a rapid conversion of precontemplation into contemplation. However, the contemplation phase becomes an extended period of quiescence. Here, access to a vast amount of information becomes inhibitory, leading to cognitive overload and a greater decision-making burden. This leads to stasis and behavioural inertia.

A possible transition to the presumed consent legislation is overall perceived negatively, seen as an infringement upon autonomy. A similar sentiment leads to a negative perception of familial consent protocols. This is perceived as an unnecessary step, conferring an inordinate amount of control onto family members, who have the potential to reverse the deceased's wishes.

Diversity is a unique and defining characteristic in the UK population and a key contributor to the observed multiplicity in beliefs and attitudes. As a result, the sample's sociodemographic character becomes a dominant formative operator on the process and product of social capital. As a recognised source of culturally specific and potentially conflicting attitudes, great effort is made to diminish the impact of these differences, ensuring inclusivity and a high standard of cultural competence on a national scale. The benefits of this methodological approach can be expanded through implementation of a more intimate and strategic collaboration with community specific figureheads.

There is a causative association between support for DOD and registration as an organ donor. However, the two variables do not demonstrate a linear relationship. The vast majority of supporters are unregistered. The quantitative analysis supported this sentiment, as higher degrees of both objective and subjective knowledge scores positively correlate with registration commitment but not with support. The latter is a function of emotional operators.

4.7.3NETHERLANDS

4.7.3.1 NETHERLANDS: MEDICAL STUDENTS

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.8**.

a) THEME 1: PERSONAL VALUES AND DONATION

The students recognised that organ donation is often perceived as a ‘scary’ topic, however, overall, the long-term advantages outweigh the temporary emotional discomfort. A pragmatic mindset, based on utility served as a motivational factor to overcome personal fears and inhibitions (NLmedw3 7:40; NLmedw3 7:72). Some viewed their social responsibility as an extension of their duty of care towards their family (NLmedm1 7:65). Others supported the notion of reciprocity and the ethical principle of justice, opting to register as organ donors in the hope that they would receive an organ if they ever required one (NLmedw3 7:14). In general, there was also a strong support for living donation, as it directly benefits friends or family members (NLmedw4 7:13).

b) THEME 2: FACTS ON THE DOD PROCESS

There was good awareness of the organ shortage issue and waiting lists. The participants discussed issues of patient prioritisation and the desperation of patients with renal failure who had been on waiting lists for a long time (NLmedw2 7:15; NLmedw2-NLmedw5 7:77). Some believed that the system had failed these patients, who felt they had no choice but to take upon the responsibility of finding a donor themselves, appealing to strangers through advertisements and social media (NLmedw1-NLmedw3-NLmedw2 7:129). The public must understand the significance of waiting lists for transplant patients. These are distinct from the waiting lists for other medical procedures, as for patients with end organ failure this is a matter of life and death (NLmedm1 7:84).

Ambiguity over posthumous arrangements contribute to the public’s concerns about DOD. These concerns arise mainly among religious groups and relate to bodily integrity and delay in funeral planning (NLmedw3 7:36; NLmedw3 7:37). Increased guidance from spiritual figures of authority and community discussions may help to resolve these (NLmedw5 7:26).

c)THEME 3: REGISTRATION OPTIONS

The registration of consent decisions should be made compulsory by the national government. From the age of 18, citizens should be informed of the requirement to declare their decision. A consensus was reached on this age limit, as this is legally the age at which one is considered an adult and obtains renewed documentation, such as an ID card, driver's licence and insurance number (NLmedw2 7:138). This suggestion was based on a pre-existing scheme that was trialed at a national level, in which a small fraction of the students took part (NLmedw3 7:8; NLmedw4 7:9). The group agreed that this was a successful strategy which should be enforced systematically.

Some suggested that this compulsory registration system should be accompanied with penalties and ramifications for those who fail to declare their decision (NLmedw5-NLmedw1 7:102).

This follows the participants' own experience with friends and family members, who required reinforcement as motivation to actively translate their intentions into their behaviours (NLmedw5 7:26; NLmedw3 7:82). In addition, this brings the issue of DOD to the attention of young people, who would otherwise not think about their death (NLmedw3 7:83).

There was a very good awareness of their families' values and consent decisions (NLmedw5 7:25) and their prospective importance (NLmedw2 7:78). The most active family members in these conversations were parents. In many cases, these conversations were initiated by the parents and subsequently played a formative role and influence on the participants' own attitudes (NLmedw2 7:5; NLmedw3 7:73; NLmedw2 7:76). Participants often adhered to their parents' viewpoints, with a desire to avoid conflict and reduce unnecessary distress (NLmedw5 7:68). One student described a debate with their mother on the selection of tissues to donate, which ended in disagreement (NLmedw3 7:71). Although students recognised the importance of knowing the decisions of friends and relatives, they maintained that personal consent decisions must not be the product of peer pressure (NLmedw5 7:91).

Several participants expressed reluctance to donate specific tissues, including their skin, eyes and lungs (NLmedm2 7:2; 7:68; 7:71). Skin and eyes were seen as personal tissues which hold sentimental value. Internal organs, such as the heart and lungs was viewed more practically, with a student expressing that their smoking history and past medical history would diminish the organs' suitability for transplantation (NLmedm2 7:42).

Students advocated selective donation, explaining that a misrepresentation of organ donation as an 'all or nothing' decision is a cause of people's reluctance to donate. A greater awareness of the element of choice and the potential to customize consent decisions may be beneficial in future campaigns (NLmedw1 7:39).

e) THEME 4: COMMUNICATION WITH FRIENDS AND FAMILY

Dutch medical students reported that they commonly exchanged views with their family and friends. It seems that most of the discussions took place amongst those who shared similar ideas, and so no conflicts or disagreements were apparent (NLmedw2 7:5). Family was described as a powerful influence in introducing the topic of DOD. Students described how they first learnt about the topic when their parents were registering as donors and that they were inspired to also register after becoming young adults (NLmedw2 7:76). Nevertheless, it was reiterated that DOD is a sensitive topic and can be quite intrusive to a family, especially if it has not been discussed. In these cases, participants suggested it would be safer to aid in the side of caution and refrain from granting consent (NLmedm1 7:94).

e) THEME 5: PROMOTIONAL RESOURCES

The students discussed how DOD is promoted in social networking sites, such as Facebook. The main issue with this promotional strategy was that it is intermittent and sporadic, rather than systematic. Consequently, awareness of and interest in the topic only occur in ‘waves’. The participants agreed that the same issues limit the effectiveness of national awareness weeks. One of the major advantages of social media was discussed as the ability to broadcast one’s personal values and consent decisions with their wider social circle. The role of social media was particularly important for younger generations, who were considered to be ‘easily influenced’ (NLmedw2-NLmedw1 7:124). Participants believed that adolescents would be more inclined to register as organ donors if they consider the action to be popular with their social circle.

The majority of the participants were Christian and discussed the under-promotion of DOD in their religious community. This was criticised as an avoidance behaviour from the Church, who appeared to be unequipped to support a position based on ecclesiastical evidence (NLmedm1 7:64). This places the burden of information seeking on the community, who must navigate through external, secular sources of information. One participant believed that this process is responsible for generating contradictory attitudes within the Islamic community. In the absence of authoritative guidance, there is subjective interpretation of religious doctrines (NLmedw5 7:61). Debates and discussions mediated by religious advisors and held within these communities may be helpful in resolving the conflict and confusion created by external information sources and generate greater support for DOD (NLmedw5 7:63).

The students believed that future promotional campaigns should create a greater sense of urgency. This can be achieved by highlighting the realities of the organ shortage issue on patients suffering from end stage organ failure (NLmedm1 7:20).

The responsibility of health promotion lies with the public health and education system (NLmedm1 7:123). These institutions must help to initiate local and national conversations on the topic. Regardless of how much information is provided, without adequate communication, people do not have the opportunity to address the topic and clarify their views (NLmedm1 7: 132). This is also important for the communication of consent decisions to one's family (NLmedm1 7:133).

For several participants, the first exposure to information on the topic and took place as early as primary school. Schools were seen as accommodating the need for awareness to varying degrees, through methods such as incorporating the topic into the Science curriculum, hosting student-led debates and organising special visits from official transplantation organisations (NLmedw3 7:48; NLmedw1-NLmedm2 7:49; NLmedw5 7:51).

Schools were recognised as important pastoral and formative influences. They are responsible for the development of social awareness among young people (NLmedw3 7:114). Secondary school was seen as the optimum time to introduce the topic to students. This would create a culture of knowledge and awareness (NLmedw1 7:86).

Debates and patient stories are the most effective way of health promotion. Debating the topic allows people to analyse the topic rationally, considering the pros and cons, learning the views of others and reaching a personal conclusion (NLmedw1 7:98; 7:132). Patient stories appeal to the humanistic component of the decision making (NLmedw5 7:116). Matching the patient speaker with the audience demographics may help increase relatability and generate greater empathy (NLmedw5-NLmedw4 7:117).

Table 4. 8 Table of focus group results from Dutch medical students discussing each of the five DHQ themes.

PERSONAL VALUES AND DOD			
NLmedw3	**7:40**	**I think it scares everyone, but, well, the fact that you can help people, and, like, you can see the effects that they have right now, if one has a transplantation, that, like, motivates me to just donate it.**	**8426-8903**
NLmedw3	**7:72**	**Why not, I am dead and if somebody can use it, like in need, I don't mind.**	**17357-17430**
NLmedm1	**7:65**	**for the people who have questions about it, it's altruism, and, yes, I think that's it. They say it's loving your next of kin and there's nothing wrong with that.**	**15905-16067**
NLmedw3	**7:14**	**Well, if one day I really need one I would be very, like, happy that I could get one, cause I've registered myself, so I would do it for someone else, so I would be happy if another one would do it to me. I mean, yeah, one day, if I need it**	**2608 - 2847**

NLmedw4	**7:13**	**I want to give my kidney to someone one day, I think that would be nice, probably family or friend, so I am holding on to it until someone needs it, close by. Then, hopefully, I can give one of my kidneys.**	**2337-2541**
FACTS ON THE DOD PROCESS			
NLmedw2	**7:15**	**It's also dependent on how ill you are, it's a huge waiting list, you get on top of the list when you are that sick that you can't live that much longer**	**2858-3009**
NLmedw2- NLmedw5	**7:77**	**There is a huge waiting list. You have to be really sick NLmedw5-the eyes not so much. It's like 3 or 4 months, all the other organs have very long lists**	**18157-18305**
NLmedw1- NLmedw3- NLmedw2	**7:129**	**NLmedw1-Like, you are searching for people you don't know to give a kidney to an advertisement, because you are in such need of a kidney NLmedw3-Yes, people just try to do it on their own to find a kidney, because like the government can't fix it NLmedw2-Yeah, you sometimes see it on Facebook 'I really need like a stem cell, donate it, cause'. Like everybody to share**	**35167-35888**
NLmedm1	**7:84**	**And things like waiting lists I don't think they really know the importance of such list, because most people see it as a waiting list for another operation, like well distressing. So, I don't think people see the importance of such life-giving operations and the need of organs for such operations**	**20469-20774**
NLmedw3	**7:36**	**I think many people fear that 'will they have a proper funeral? Would you get back the body? But I don't think everyone realises that. Like it's postponed, but you get it back, you can have any funeral you want.**	**7220-7556**
NLmedw3	**7:37**	**I think many people fear that 'will they have a proper funeral? Would you get back the body?**	**7220-7311**
NLmedw5	**7:26**	**Some religions, I don't know which ones any more (giggles), they have problems, and these problems are solved by going into discussion with the imam, and the priest, and all the higher people to take these away.**	**15025-15235**
REGISTRATION OPTIONS			
NLmedw2	**7:138**	**Maybe when you turn 18, you get your own insurance and there are a lot of things changing, and maybe it will be a good thing to add the donor profile with it.**	**21643-21955**
NLmedw3	**7:8**	**I became donor when I was 18 years old, I got from Government a letter at home, you could write yourself, yeah you could sign it in and post it**	**1341-1483**
NLmedw4	**7:9**	**But not everyone received it**	**1489-1517**
NLmedw5- NLmedw1	**7:102**	**NLmedw5-Maybe if the government forces everyone to fill in a form, you can always say no, but the system… If you want to register, you have to go online, search for yourself, where can I do this, and if you get the form at home that you MUST fill it in, or so. If your choice is no and if you don't send it back, then there are consequences, maybe something like that NLmedw1- Maybe we should put in the ID card and passport as well**	**24792-27641**
NLmedw5	**7:26**	**My parents do want to be donors, but they don't feel like filling in the form. They are lazy, but I printed it out for them, so 'fill it in, be a donor'. And it's like 'yeah, I will do it, maybe tomorrow, this weekend'. And it's going on for 3 years now, (giggles from others) and they still haven't filled it in.**	**4693-5005**
NLmedw3	**7:82**	**One of my roommates wanted to be a donor, was not registered**	**19738-2011**

		yet, and I said 'right, I can take information to you, they have at Erasmus MC, so I can bring it to you', and she said 'OK, OK', and then she thought 'yes, I want to become a donor', but she didn't register, so she wants it, but she's just too lazy to fill it in	
NLmedw3	7:83	Especially young people they don't expect to die, like, very soon. So, they think it's kind for later	20117-20462
NLmedw5	7:25	They do want to be donors, I know that, if they would have an accident or something, I would tell doctors but it's not filled in anywhere.	5124-5256
NLmedw2	7:78	If you are not aware of his wishes, it's really hard to make them yourself. … I wanted to do it for other people, but I don't want to pass the wishes of my mother.	18619-19402
NLmedw2	7:5	Well, I spread the word to my family and friends, but they are donors already	1205-1281
NLmedw3	7:73	It helped me that my parents were donors to donate myself I think	17436-17500
NLmedw2	7:76	I think my parents made me aware of it before I received the form. So, they really think the same as I do and they've made me aware of it	17694-18057
NLmedw5	7:68	My mother she couldn't live with the idea, if I would pass away right now, that they would take my eyeballs and my skin. She's alright with everything else, cause she knows me, I want to help other people, but just because for her sake I changed my donor profile.	16557-16917
NLmedw3	7:71	Before I signed, I asked my mother about it and she told me that she was a donor, but the only thing she doesn't donate is her eyes, and, well I thought about it and I thought 'why not?' she almost convinced me and I thought about it and I said 'why would I need my eyes in underground or somewhere.	16929-17349
NLmedw5	7:91	They can say no, register is not that you have to say yes. 'Oh, like, become a donor, because your friends are'. No, that is group pressure, you could say no as well, just make a choice	22865-23049
NLmedm2	7:2	Except my eyes and my lungs	719-745
NLmedm2	7:42	For me it was not really the disfigurement aspect, but more for medical reasons. Cause I smoke a lot, so my lungs are probably shut. Yeah, and my heart isn't built right, so I don't donate that.	8909-9277
NLmedw1	7:39	I think a lot of people aren't aware that you can choose what you can donate…they think they have to give everything.	8201-8395
		COMMUNICATION WITH FAMILY AND FRIENDS	
NLmedw2	7:5	Well, I spread the word to my family and friends, but they are donors	1205-1281
NLmedw2	7:76	I think my parents made me aware of it before I received the form. I don't know exactly how it went but I thought they were, like, busy filling in these forms and then they talked to me about it, so I was aware of it and at my 16th I knew that I wanted to become a donor at my 18th anniversary, so they really think the same as I do and they've made me aware of it	17694-18057
NLmedm1	7:94	…They say, 'I don't know, I haven't really spoken about it with the donor, so I want to be careful and I say no. I'd rather say no, tan give away an be maybe wrong about it'. then you have a big problem, I think. it also causes a lot of family grief and discussions, and even, yes, rows about inside the family whether to donate or not	23124-24246

PROMOTIONAL RESOURCES			
NLmedw2- NLmedw1	7:124	NLmedw2- Maybe you could see a hundred of your friends are already a donor, become one as well NLmedw1- They are easily influenced	22368-2286
NLmedm1	7:64	Christian church I've never heard about organ donation, as well. For the people who have questions about it and they leave it to society, to people in shows in television programmes to inform all those who go to church	15475-15892
NLmedw5	7:61	You know, you have to be WHOLE to go to heaven. And then the priest would say 'no, it's more important to do good for your fellow people. And because of these discussions more religious people, want to be donors.	14581-15009
NLmedw5	7:63	…the Head of the religious place, and there were some concerns and take the concerns away and that was better, easier for people to donate as well	15322-15469
NLmedm1	7:20	I think there would be more persons, who would become donor, if they were aware of the serious complications you can get from kidney failure, all the organ failures,	4115-4283
NLmedm1	7:123	It has to be an active role at schools, in government	32097-32264
NLmedm1	7:132	Yesterday we had a course about… and brain death and about donating and it didn't impress me as much as talking about it with my fellow students and asking the questions. I think it's more important to have a debate, a national conversation.	37115-37596
NLmedm1	7:133	Underline the problem you will give to your relatives when you pass away and you have not made a choice	23124-23228
NLmedw3	7:48	It was a debate and there were people from the Transplantation in Holland, Organisation, and you could be, register yourself there, and yeah a big day about it, transplantation at my primary school, high school	9820-10668
NLmedw1- NLmedm2	7:49	NLmedw1- I know they wanted to make all students aware of transplantation, like with few lessons and folders and that kind of stuff, but not as much as NLmedm2-My biology teacher once mentioned organ donation and that was it	10679-11100
NLmedw5	7:51	A couple of us watched the show, with the kidney transplantation a person was going to give the kidney away, and then we had sort of a debate with our biology class	11191-11481
NLmedw3	7:114	At high school I think this is a good age, if you are 16 or you're 18	29868-29975
NLmedw1	7:86	I think it should be integrated more in daily lives, like it becomes normal to have, to make high school students aware of transplantation and being a donor. Because if you start from there, everyone will eventually know about it	221405-21634
NLmedw1	7:98	Maybe a debate at every high school it has to be mandatory, because if you participate in a debate you are forced to think about it and think of the pros and cons and if you just read a pamphlet or see a TV show just for fun for 5 minutes you think about it for an hour and after that you forget it	24355-24782
NLmedw5	7:116	I talked to this lady and two months later she passed away. And if she had a heart in time, she would have lived and the idea that people died in those two months with a heart and just buried with the heart in them and if you talked to these people, how scared they are, and the lives they have, sometimes they are young people it impresses people.	30719-31140

NLmedw5-NLmedw4	**7:117**	**NLmedw5- Someone, 21 comes and tells you 'if I don't take a lung in 6 months, I'll be dead** **NLmedw4-That would work for them**	**31147-31322**

4.7.3.2. NETHERLANDS: STAFF

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.9**.

a) THEME 1: PERSONAL VALUES AND DONATION

For many participants, support for DOD was precautionary and dependent on their wish to receive an organ if they were ever in a position to require one (NLstaw2 9:1; NLstaw2 9:18). This sentiment of reciprocity was strong, with participants claiming it would be unjust to receive an organ if you would not be willing to provide one (NLstaw2 9:17; NLstaw2 9:19).

Some participants were critical of DOD and the donor's inability to determine the recipient's characteristics (NLstam2-NLstaw3-NLstam2 9:49). There was reluctance to donate organs among patients suffering from irreversible organ failure as a result of self-inflicted illness, such as in the case of lung damage and liver damage (NLstam1 9:11). This controversial statement was rejected on a moral and practical basis by the remainder of the group, who described the difficulty with which potential recipients and donors are matched based on medical criteria (NLstaw3-NLstam1-NLstaw3 9:50).

There was some awareness of the lack of support for DOD among certain ethnic and religious groups (NLstam1 9:15). One participant described the distinct difference of opinion among Christian denominations, with Catholics being more willing to donate than Protestants (NLstam1-R-NLstam1 9:14). The perception of the sanctity and preservation of the human body for the afterlife was considered a key deciding factor among these groups (NLstam2-NLstam1 9:12; NLstaw2-NLstam2 9:23).

b) THEME 2: FACTS ON THE DOD PROCESS

Some staff were aware of the Netherlands' status as a Eurotransplant centre, and the shared pooling of donations among the participating countries (NLstam2-NLstam1-NLstaw2-NLstam1-NLstaw3-NLstaw2 9:51). They explained the system to other participants who were unaware of this process and thought that it was based on monetary exchange.

There was some discussion of organ quality and donor eligibility with respect to the ageing population and how specific co-morbidities and lifestyle choices, such as smoking affect certain organs, such as the lungs (NLstam1-NLstaw1-NLstam1-NLstaw2-NLstam1 9:34). These significantly limit the usability of organs and reduce the population of actual donors.

Participants were aware that donors have no choice on the selection of the recipient in DOD cases, in contrast to live donation, where the recipient is often a member of their social circle (NLstam1 9:47). They were also aware of the high percentage of unregistered decisions and family refusal rates, which was estimated as sixty percent (NLstam1 9:24). They also recognised that the family's decision is not legally binding but respected by the healthcare team on a moral basis. They suggested that rare cases in which the team choose to proceed with organ procurement after the family's rejection often result in negative publicity (NLstam1-NLstaw1-NLstam1 9:8).

c) THEME 3: REGISTRATION OPTIONS

Participants discussed how the government issues a form to all citizens at the age of eighteen. Although this was recognised as an important intervention, it was also suggested that most young people disregard the notification and receive no follow up (NLstam1 9:3). In many cases, this is ignored because young people do not want to think about death (NLstam1 9:4).

The form contains three registration options; yes, no or allowing the family to decide. However, the group also agreed that the form is merely a formality to raise awareness, as the ultimate decision is made in hospital by the potential donor's family (NLstam2-NLstam1 9:7).

d) THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS

In most cases, the participants avoided discussion of the topic with their families because it was deemed 'scary' (NLstaw3 9:40). One participant recalled their attempt to discuss the topic with their partner, who was happy to live with the risk of passing away without having registered their decision (NLstaw2 9:16). Nevertheless, the group understood the importance of having these discussions in advance in order to reduce the pressure and decision making burden on their families (NLstaw2 9:38).

Participants discussed the different tone of conversations that take place among family members in their homes and the time-pressured conversations that occur in hospitals. In the former scenario, the conversations were considered 'businesslike', wherein facts and opinions are discussed and evaluated by all participating parties (NLstaw2 9:22). In contrast, hospital discussions are far more pressurised, making it more difficult to make rational decisions at such an emotionally charged time (NLstaw1 9:42). In many cases, this request is unexpected and family members do not want to take responsibility or to be held accountable for making end-of-life decisions for their loved ones (NLstam1 9:37).

The participants that were strongly in favour or strongly against DOD ensured that their families were aware of their wishes (NLstaw2 9:21). However, even then, they were uncertain of the outcome of the discussion and whether or not their family would honour their wishes (NLstaw3 9:39). In some cases, support for DOD came early in their lives and was a product of the family environment (NLstaw1 9:27). There must be greater clarity and transparency on the organ procurement procedure and the processes that follow in-hospital deaths (NLstaw2 9:44). Particular emphasis must be placed on the role of family consent, as participants believed that this is a key area of misunderstanding. This should shift the framing in the donation request question, highlighting, ‘if you don’t register the question will be asked to the relatives’ (NLstam1 9:69). However, the participants believed that donation discussions with relatives may be difficult, as people are averse to hold discussions about death, which is perceived as a morbid topic (NLstam2 9:10).

e)THEME 5: PROMOTIONAL RESOURCES

Participants believed that the topic should be introduced in school Biology lessons. They believed the emphasis should be placed on the hospital protocols and familial consent, rather than on general supporting arguments for DOD (NLstam1-NLstaw2 9:25).

One participant had experience as a speaker in a primary school, promoting the topic at the request of a family member. The remaining participants asked them about the children’s reaction to the topic, which the speaker described as favourable and attributed this to the new generations being more ‘open-minded’ (NLstam1-NLstaw2-NLstam1-NLstaw2-NLstam1-NLstaw2-NLstam1-NLstaw3-NLstam1-NLstaw3-NLstam1 9:29). Classroom based health promotion was considered to reach a smaller audience but with greater impact (NLstam2-NLstam1 9:60).

The participants discussed national awareness initiatives and the concentrated efforts that are made to involve local communities (NLstam2 9:64). These campaigns are not always effective, as some people ignore the messages, becoming desensitised, whilst others are overwhelmed (NLstaw3-NLstam1-NLstaw3 9:75). In addition, participants criticised how this health promotion is typically concentrated in one week and then dissipates (NLstam1 9:59).

The discussion focused on the Dutch transplant society’s efforts to increase awareness and health literacy among minority groups. Some of the staff had contributed to this effort by engaging in door to door health promotion. They took this opportunity to represent the national transplant organisation and to answer any questions that the public may have. They believed that this technique was well received (NLstam1-R-NLstam1 9:45).

This campaign also targeted specific populations by organising talks with transplant recipient patients as speakers (NLstam1-NLstam2 9:32). These speakers were matched with and asked to speak to members of their own religious, cultural or ethnic backgrounds (NLstaw3 9:65). The participants endorsed this culturally sensitive strategy, suggesting that individuals are more likely to pay attention to members of their own community, whose stories and journeys serve as exemplars and encourage word of mouth communication (NLstam2 9:61).

Overall, the group believed the Dutch population are more fact-oriented and that this should be the thrust of promotional campaigns. Emphasis should be placed on hospital procedures and protocols and process regulation (NLstaw3 9:67). This was contrasted to countries that were perceived to be more religious, such as Spain, wherein evocative messages may have a greater impact (NLstaw3 9:67).

The group recalled how previous DOD health promotion campaigns encouraged people to share their decisions with their family through the memorable slogan, ‘make the unpredictable, predictable’ (NLstam2-NLstam1-NLstaw1 9:70).

Table 4. 9 Table of focus group results from Dutch staff discussing each of the five DHQ themes.

PERSONAL VALUES AND DONATION			
NLstaw2	**9:1**	**I think at time is like a story for someone else, but in the back of your mind you know you can have an accident or you can have a disease or whatever and you might need an organ or you die and you have healthy organs left, so you can give these. So, yes, it is quite relevant, but you are not aware of it constantly, because, you know, it is also a scary thought.**	**875-1238**
NLstaw2	**9:18**	**I got the letter when I was 18. And I was, OK if I have an accident, I would like to have a new heart, or liver, whatever I need. Because I don’t know what it’s going to happen.**	**7444-7620**
NLstaw2	**9:17**	**This decision, I think, has to be two-sided. If you are not willing to give something away, then actually you are not in any right to receive something.**	**7825-7977**
NLstaw2	**9:19**	**You cannot say I am not willing to give something away, but then. And that’s why I chose to do it. Because I was like OK, I may come in a situation where I need it, so then I would be very grateful, so if I can help somebody else, and save somebody’s life why not?**	**8106-8369**
NLstam2- NLstaw3- NLstam2	**9:49**	**NLstam2-It could help donation if you knew where your organs were going to go to. Maybe they might feel less reluctant sometimes NLstaw3-Yes, but it’s not in the case you mentioned NLstam2- … you don’t know who is going to get it**	**214117-21628**
NLstam1	**9:11**	**People don’t want their liver to go to an alcoholic or lungs to a smoker or your heart to a murderer.**	**5740-5951**
NLstaw3- NLstam1- NLstaw3	**9:50**	**NLstaw3-But you can’t say ‘OK I am going to be an organ donor, but my heart cannot go to anybody with a criminal record and (giggling) non-smoker, and somebody with blue eyes NLstam1-It doesn’t work like that, it doesn’t work like that**	**21639-21910**

		NLstaw3-Because that makes the matching even smaller	
NLstam1	**9:15**	**Rotterdam of course is one multicultural city, a lot of Muslim Africans… the Turkish, the Romas they don’t give.**	**6779-6969**
NLstam1	**9:14**	**NLstam1- Highly religious Christians they don’t give, Catholics they will give** **R- Catholics will give, but highly religious people will not?** **NLstam1- Christian protestants** **R- So, protestants will not give**	**6971-7211**
NLstam2- **NLstam1**	**9:12**	**NLstam2-Because some religions, I am not religious myself, but I can imagine some religions might think ‘I will be needing my physical body, you cannot take anything out of this, because** **NLstam1-The sanctity of your body**	**6530-6739**
NLstaw2- **NLstam2**	**9:23**	**NLstaw2-That’s maybe why some people will say ‘no, we don’t want it, because we don’t agree or we think the body will look** **NLstam2-Destroyed**	**8983-9109**

FACTS ON THE DOD PROCESS			
NLstam1- **NLstam1-** **NLstaw2-** **NLstam1-** **Nlstaw3-** **NLstaw2**	**9:51**	**NLstam1-Cause actually your organ… who came from abroad** **NLstam1-Yes, it could go abroad** **NLstaw2-Sell your organs or buy your organs?** **NLstam1-No, no, no if you donated an organ, it could go to Belgium** **NLstaw3-Oh, yeah. It doesn’t have to be a Dutch person, OK** **NLstaw2-Because we are all in a database, everybody who needs**	**21916-22279**
NLstam1- **NLstaw1-** **NLstam1-** **NLstaw2-** **NLstam1**	**9:34**	**NLstam1-You see the range of the donors is from 3 months, till my oldest was 86.** **NLstaw1- 86?** **NLstam1-86 yes, …. the register is big but the minority of the donors is between 55 and 70. That’s… women than men ….** **NLstaw2-OK so people in that range die ….** **NLstam1-Die, when you are 60 for example your heart, you can’t donate your heart, you can donate your liver. Over 60 only lungs, but how many packs of cigarette, so kidneys are the only left organ**	**13378-13808**
NLstam1	**9:47**	**It is forbidden by law to select one at this time, at that way. Now, they have living donor programmes. Not that I give my kidney to you, you give it to me** **...that’s not how it works**	**20933-21129**
NLstam1	**9:24**	**Doctors will ask the question to relatives and because there is no registration 60% say no**	**9124-9486**
NLstam1- **NLstaw1-** **NLstam1**	**9:8**	**NLstam1-You don’t have to do this, but we think it’s very bad publicity if you go through with it. The family, the … of the family will say to the media ‘they just stole the organs’. That’s something you don’t want** **NLstaw1-No** **NLstam1-It happens once in a year**	**4554-5481**

REGISTRATION OPTIONS			
NLstam1	**9:3**	**18, when you turn 18 you get, they send you a form to become an organ donor, that's once, you get it once, could throw it back. So, you receive the form once in lifetime, you can throw it away or you could fill it in and that's it.**	**2258-2488**
NLstam1	**9:4**	**The question here in Holland is asked at 18, when you are 18, you are asked if you want to be an organ donor. So, it's something you don't want to think about, yes a problem. I certainly hope that I will live to 90 and healthy, so I hope it won't be**	**1792-2039**
NLstam2-NLstam1	**9:7**	**NLstam2-The person can fill in the form and still later decide otherwise, isn't it?** **NLstam1-More or less. You have 3 options: yes, I am a donor. No, I am not a donor, or let the relatives decide for me, or you don't fill in the form. They also have to ask, the doctor has to ask the relatives. If you say yes, or you are medical suitable, you become donor, but the big problem in Holland is awareness.**	**3840-4229**

COMMUNICATION WITH FAMILY AND FRIENDS			
NLstaw3	**9:40**	**No, they are more like 'don't talk about it', because it's always a little bit scary.**	**16139-16315**
NLstaw2	**9:16**	**But, for example, my husband doesn't have a registration, so we talked about it and I said 'what if you have an accident?', like we cannot help you. He said 'OK, I'll live with that risk. I said OK.**	**7622-7819**
NLstaw2	**9:38**	**Talk about it with each other. Somebody else knows what you want and they don't have to decide at that moment**	**15709-15821**
NLstaw2	**9:22**	**But I can imagine when you talk about it at home or in the office, it's very businesslike. But if you are in the hospital and everything is buzzing and somebody is lying there, ready to die, I think you will react very differently and you will say 'give him the liver now'**	**8659-8981**
NLstaw1	**9:42**	**If anything happens, then there is so much emotion, then you can't think rationally… So, there is nobody to ask. So, the trick is to get the information before somebody dies. Including whether you are an organ donor or how you would like to be treated when you die. But I think most people don't want to talk about it, because then you talk about something that you don't want to happen**	**16821-17466**
NLstam1	**9:37**	**We've talked about it. They just do not want it for themselves … that you called it. You received terrible news that your relative is going to die, that it's over 'I have another question, for an organ donation. Have you ever thought about it?'. 'well, he's going to die, just leave me alone' that is the reaction at this time 'why do you ask me this question at this time?'. That is why campaigns are so important. Just to think about it**	**15131-15699**
NLstaw2	**9:21**	**He registered no, not to give anything away**	**8614-8657**
NLstaw3	**9:39**	**I talked to my family. I said I am an organ donor. So, I hope that they don't say no when**	**15982-16086**
NLstaw1	**9:27**	**I was ten form and we talked about it at home. I knew my parents were organ donors, so it was logical**	**10052-10153**
NLstam2	**9:10**	**I don't think people really want to think about death… and what happens to your physical body after death.**	**5487-5732**

NLstaw2	**9:44**	**Ok somebody dies. What happens? How does somebody get a donor? I think it might help. This is my practical view. .**	**17997-18888**
R- NLstam1	**9:69**	**The family is the one who ultimately decides. Why is this message nowhere in all those campaigns? M1: That's the facts I'm talking about. If you don't register, the question will be asked to the relatives and they can decide.**	**29000-29466**
		PROMOTIONAL RESOURCES	
NLstam1- NLstaw2	**9:25**	**NLstam1-Maybe in biology Many people: yeah, yeah, I guess so NLstaw2-Yeah, but more in the way that is what the hospitals may do, but not in a way, like, why is it important or why do you want it or why don't you want it?**	**9665-9875**
NLstam1- NLstaw2- NLstam1- NLstaw2- NLstam1- NLstaw2- NLstam1- NLstaw3- NLstam1- NLstaw3- NLstam1	**9:29**	**NLstam1-The funny thing is I am doing just that. My sister is a teacher at group 7, primary school, and because I do this job I am asked to give two lessons to school… which is only muslims NLstaw2-Yeah? NLstam1-Yeah NLstaw2-But how do they react the children? How do they react? NLstam1-Good NLstaw2-Yeah? They are not like iii? NLstam1- It's possible to influence them to think about it, just think about it NLstaw3-They are the new generation, maybe a little bit more open minded NLstam1-They are ten year NLstaw3-Ten year? Nine, ten year? NLstam1-Ten**	**10324-10829**
NLstam2- NLstam1	**9:60**	**NLstam2-You go to classrooms and that might be more effective, cause you are reaching, yes, fewer people but what you are doing might be more effective NLstam1-I talk directly to people**	**24533-24705**
NLstam2	**9:64**	**There are national campaigns, it would be an addition to that, the local campaigns. And I think concentrated effort for awareness generally is good, and then if you have your local initiatives to reach the local communities I think it would be, to go to the grassroots.**	**26140-26445**
NLstaw3- NLstam1- NLstaw3	**9:75**	**NLstaw3-And everywhere you go, NLstam1-Donor, donor, donor NLstaw3-And as you mentioned for some people it may be too much. I don't understand why some don't bother.**	**25799-26098**
NLstam1	**9:59**	**But when you only have one week and that's it/ it is an overload of information and the other 51 weeks you don't hear about it**	**24349-24486**
NLstam1- R- NLstam1	**9:45**	**NLstam1-Was it last year? We just went on the streets and talked to people and just gave the information you don't hear on TV or on the campaigns R- What kind of information? NLstam1-…Just asking what their thoughts are about it, so you can talk about it, to take away the anxiety of it. I think that helped**	**18923-19496**
NLstam1- NLstam2	**9.32**	**NLstam1-It's different the Dutch transplant society made a big campaign, that started at Rotterdam, as a platform for a, there's a platform for- Dutch NLstam2-Bring people from their own communities who have received an organ, see what happens, you can help your own people, your own community**	**11188-12200**

NLstaw3	**9.65**	**I can imagine if you talked to somebody who is from your community, people take it more, yeah, they feel familiar with the person, and they think 'OK, if you tell me so, it should be right, and I listen to you'. And if it somebody from the news or the TV people might think 'it is OK,' but it might make people aware but if it is smaller, maybe you reach more people there**	**26455-27034**
NLstam2	**9:61**	**Campaigns in communities might be more effective. Then you create word of mouth from that and that might be a better way to reach more people and get them convinced to sign up**	**24722-24897**
NLstaw3	**9:67**	**It can be difficult because you don't know how it goes in the Netherlands, maybe in Spain, in Sweden and all the different procedures and all the different rules. So, maybe difficult to tell a story that is the same for everyone, because in the Netherlands you are going to tell facts, like OK, we have this, we have this way. Religion is a thing, for a country in which 90% said 'no', then the facts and the numbers are quite different from a country in which … people say no**	**27244-27719**
NLstam2-NLstam1-NLstaw1	**9:70**	**NLstam2- I've seen it in campaigns in the past. Otherwise your family will have to decide, don't make your family decide at that moment, because** **NLstam1-That's not the message they are sending out with this new campaign** **NLstaw1-'Make the unpredictable, predictable'**	**29472-29733**

4.7.3.3 NETHERLANDS: PATIENTS

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.10**.

a) THEME 1: PERSONAL VALUES AND DONATION

Reluctance to donate is often attributed to personal prejudices about potential recipients. This may be discrimination based on cultural characteristics or on deservedness. This mentality was perceived as irreversible (NLpatw2-NLpatw1-NLPatw2 1:97). Following their diagnosis, patients became more aware of the topic. This motivated also members of their family to achieve a greater understanding and become more supportive of DOD (NLpatw3 1:113).

b) THEME 2: FACTS ON THE DOD PROCESS

Some participants were aware that one donor can benefit up to eight patients and suggested that knowledge of the scale of the impact may prompt more positive attitudes (NLpatw2 1:25).In addition, patients believed that the public were aware that transplantation is the ultimate treatment for end organ failure and that for renal patients dialysis is only a temporary solution (NLpatw3 1:133).

A common fear among donor families, especially in paediatric cases, is that they would not have enough time to bid farewell to their loved one. It is assumed that while the medical team are making the donation request, the patient is left unattended. Understanding how death is confirmed and the artificial life-sustaining measures that are used to keep the patient stable help extend the decision-making time frame and give the family sufficient time to say goodbye (NLpatw2 1:34; NLpatw2 1:147). Especially for the Netherlands, it is important for the public to be aware of the programme that pools donors and recipients across Europe (NLpatw2 1:135).

c)THEME 3: REGISTRATION OPTIONS

From the age of 12, a DOD registration form is provided to all young people at their place of education (NLpatw2 1:27). This is the age at which the national government recognise an individual ‘reasonable’ and able to make consent decisions. However, many forms are never returned and are never signed. The patients believed that this was because the children’s parents were not registered as organ donors and they project their opinions and decisions onto their children (NLpatw2 1:29).

To overcome this barrier, the patients suggested that a letter, addressed to the parents, should accompany these forms. Alternatively, schools could hold information evenings for the parents, teaching them about the topic and how to help their child reach a consent decision (NLpatw2 1:30; NLpatw2 1:72). This would also support parents who do not speak the language (NLpatw2 1:119).

d)THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS

The patients recognised that it is difficult to hold discussions about death with one’s family (NLpatw3-NLpatw2 1:75). This is why it is a subject that is generally avoided. Nevertheless, it is important to hold these discussions in advance, as there is very little time to consider all factors and make the correct decision at the critical point (NLpatw2 1:22).

One participant discussed the criticism she received from her friends and extended family after approaching the topic with her young children, aged four and six (NLpatw2 1:75). Children who are introduced to DOD in schools become more sensitised and prepared to participate in these discussions (NLpatw3 1:81).

e)THEME 5: PROMOTIONAL RESOURCES

The majority believed that secondary schools are the best equipped to introduce the topic into curricula. Some participants based this decision on their own experiences (NLpatw1 1:1). Others advocated promoting awareness as early as possible (NLpatw2 1:116). For younger audiences, it was suggested that educational television programmes, involving paediatric patients and their families may be particularly effective (1:116). This creates a culture of awareness, which can also be implemented in home life (NLpatw3 1:81).

Certain participants had taken part in awareness assemblies organised by local secondary schools (NLpatw1 1:89). Their experiences led them to believe that young people are socially conscious and mature enough to understand the complexities of this topic (NLpatw3 1:80). This was demonstrated by their curiosity and interest in learning more (NLpatw1 1:90).

The participants recalled the lasting legacy of a specific televised campaign on DOD and prejudice (NLpatw2 1:98). The focus of this campaign was breaking down barriers related to race and discrimination in donation.

There was also a discussion of a commercial demonstrating the impact of renal dialysis on the quality of life of young patients (NLpatw3-NLpatw1-NLpatw3 1:102). The participants agreed that this commercial was unconvincing as it appeared overly scripted (NLpatw2-NLpatw3-NLpatw2 1:122). Additionally, there was a dislike of narratives focusing on individuals rather than groups, as these are not considered representative enough. In addition, the participants considered the stories of real life patients as superior to scripted role plays. The tone of the commercials was criticised as being overly optimistic and not emphasising the hardships and realities of the DOD issue. Consequently, participants felt that this compromised the credibility of their stories.

There was a general belief that public interest in the topic of DOD wanes as soon as the promotional campaigns end (NLpatw3-NLpatm1-NLpatw3 1:110). This raises the issue of campaign frequency and message memorability. Social media was discussed as one of the main methods of sustaining endemic awareness (NLpatm1 1:11).

Regarding future promotional strategies, the group agreed that greater emphasis must be placed on the consequences of the organ shortage issue on the quality of life of patients and their families, including a more accurate representation of life on dialysis (NLpatw3-NLpatw2-NLPatw3 1:127). The best way to present these facts is through a diverse collection of patient narratives, which also cover the multiple successes and challenges of transplantation, such as organ rejection and lifelong immunosuppression (NLpatw1-NLpatw3-NLpatm1-NLpatw1 1:131; NLpatw1-NLpatw2-NLpatw1-NLpatw3 1:32). In addition, in a multicultural society, there must be a greater effort to diminish the effect of language barriers on access to information. National campaigns must also be sensitive to the needs of non-native speakers, and the information must be accessible on a universal level (NLpatw2 1:120). Campaigns must provide greater awareness of other aspects of transplantation, such as live donation, was seen as a way to generate interest in DOD, which is seen as a more controversial topic (NLpatw3 1:138).

There should be an increased frequency of advertisements and health promotion (NLpatm1 1:114). To accompany this, there must be new material to prevent over-sensitisation, which leads to apathy and indifference (NLpatw3 1:115). New campaigns must be more diverse and representative of the different patient populations, paying particular attention to the extremes, including the youngest and oldest patients (NLpatw3 1:121; NLpatw2 1:156). Finally, trust and transparency must be at the core of health promotion campaigns (NLpatw3 1:154).

Table 4. 10 Table of focus group results from Dutch patients discussing each of the five DHQ themes.

PERSONAL VALUES AND DONATION			
NLpatw2-NLpatw1-NLpatw2	**1:97**	**NLpatw2-One of my brothers-in-law finds, he doesn't like any other religions for example and he's like 'when I can give an organ to someone, I want to choose who gets it or receives it. I don't want anybody that doesn't deserve it** **NLpatw1-Like the story of an alcoholic who gets a liver? (giggles)** **NLpatw2-Or somebody who is a child abuser gets another organ or a refugee. I think we can all think of different examples. You can't really change their minds.**	**14695-15161**
NLpatw2	**1:13**	**When it's happening, you are in the middle of it, so you get a lot more information, you know where to find information. And you have to have someone from your family or friend who has kidney failure or liver failure, then you get more information about the subject.**	**4481-4824**
FACTS ON THE DOD PROCESS			
NLpatw2	**1:25**	**When you say 'you can help, like 8 people maybe'**	**6912-7025**
NLpatw3	**1:333**	**Everybody knows that transplant is the best option. The machine is machine and can do only this much.**	**29938-3010**
NLpatw2	**1:34**	**When your child will be a donor, you only have a short period that you can say goodbye and after the operation, of course your child is back again. But people say 'it's not my child anymore, because he is not complete, the child that I had'. So, then I have to say goodbye within those 5 minutes**	**33193-34036**
NLpatw2	**1:147**	**I only have 1-2 minutes, and then people are pulling my child away. So, maybe when we are open and transparent, like you have, like, an hour or so. Don't think your child on the machine. The machines are doing all the functions**	**34296-34738**
NLpatw2	**1:135**	**I think a lot of people don't realise that we have a connection programme with Europe and we can receive an organ from another country within Europe. I think a lot of people don't realise that**	**30180-30549**

REGISTRATION OPTIONS			
NLpatw2	**1:27**	**When the children are here at school and they are, I think 11 or 12, they get a form and bring it home**	**7204-7306**
NLpatw2	**1:29**	**From 12 years on you get a form and it's allowed to register. But children don't get registered, when their parents have not registered**	**7548-7689**
NLpatw2	**1:30**	**It would be nice, if the parents are also included in that communication. Don't give a form to the children, if the parents don't know what to do with it or they don't really want to do something with it. The child goes 'oh, my parents don't register, why should I do the registration?**	**7691-8084**
NLpatw2	**1:72**	**It would be nice to give a letter with it to the parents or, like, bring in the parents for a few minutes.**	**8287-8437**
NLpatw2	**1:119**	**Also, the refugees are here, not all parents speak our language. Children are much faster speaking our language, maybe they get a letter when they are 12 and what if their parents can't read it?**	**24102-24404**
COMMUNICATION WITH FAMILY AND FRIENDS			
NLpatw3-NLpatw2	**1:75**	**NLpatw3- I think, still, what she said, undiscussable 'oh, it is death. I don't want to talk about my death'. It is a really hard subject** **NLpatw2-Yeah, and especially for me and my children, 4 and 6, when we discuss it, other families, friends, neighbours, whoever, they always say 'I really don't want to think about it if something happens to my children'.**	**9154-9883**
NLpatw2	**1:22**	**Yes, but you have to think about it now, because when the moment is there, do you think that relatives have a lot of time and the emotions are OK to think what you would like?'**	**6527-6905**
NLpatw3	**1:81**	**I think you have to start with children, because if they are open about it they will go to the parents 'look what I've heard at school. Are you a donor?' Or when they are going to talk about it in the family, maybe the awareness comes with the parents.**	**10819-11070**
NLpatw3-NLpatw2	**1:128**	**NLpatw3- they try to make it look bad, but they don't succeed at making it look bad** **NLpatw2- and then you get a wrong perspective of it and people say, 'are you really feeling so miserable?' 'is it really that bad?'**	**27598- 27946**
PROMOTIONAL RESOURCES			
NLpatw1	**1:1**	**I was like 14 years old, so I was not thinking about that kind of things (giggles) at that moment. I never heard, well I guess I had heard like in school**	**2359-2512**
NLpatw2	**1:116**	**I think you should also start at the bottom, teaching children and maybe let children make a commercial. Not only patients, children patients, but maybe also some friends who are really healthy… Make it speakable at school, not only when you are at high school and Biology. No, also earlier.**	**23385-23774**

NLpatw3	**1:81**	**I think you have to start with children, because if they are open about it they will go to the parents 'look what I've heard at school. Are you a donor?' Or when they are going to talk about it in the family, maybe the awareness comes with the parents. And if the awareness starts at schools or with the children, they are brought up with the idea, 'oh, I can help when I am older'. And it will pass on to the next generations**	**10819-11245**
NLpatw3	**1:80**	**I think we forget that children are more aware of the situation than we think.**	**10295-10755**
NLpatw2	**1:98**	**I think once there was a little short movie, I think it was on Facebook or something. I think it was a Pakistanian that gave an organ to a little girl... and saved her life. And then it was a different 'Oh, OK'. So, everybody can be a donor...A lot of people think 'she is different or he is different, don't come close to me'. But he can save someone's life. And I think it should be more in campaigns everybody can help each other.**	**15163- 16255**
NLpatw3- NLpatw1- NLpatw3	**1:102**	**NLpatw3-Oh it's a campaign about collecting money about portable kidney dialysis NLpatw1-Machine (giggles) NLpatw3- He is 31 years old or something like that and he is a father and he's always talking about what the impact has dialysis on his life. But it's just one story, it's not representative of the whole group of kidney patients. Because some people can work and do whatever they want and some people have to be at home and can do nothing. So, it's just not representable**	**17409- 18286**
NLpatw2- NLpatw3- NLpatw2	**1:122**	**NLpatw2-Yeah overacted. You know, when you are behind that commercial you … with that boy, you know he is really sick. But on the other hand, you could also think he played it on the commercial. But you don't really get the emotions from the boy or his parents, or his friends, the real emotions NLpatw3-The impact on the family NLpatw2-The impact is missing from my personal perspective**	**25874-26536**
NLpatw3- NLpatm1- NLpatw3	**1:110**	**NLpatw3-Yeah, it's good that they focus a week on organ donation, but after the week it's just 'OK, let's move on''. NLpatm1-Life goes on NLpatw3-Yeah, there is no talking any more about organ donation after that week. Everyone is focused on that week 'oh, organ donation and we have to donate and we have to put on the register'. And after the week is gone it's 'OK, next subject, refugees'. And that is important. You forget about it very quickly.**	**21091-21549**
NLpatm1	**1:11**	**I think because of social media, it's getting a bit more real than before**	**3838-3907**
NLpatw3- NLpatw2- NLpatw3	**1:127**	**NLpatw3-But dialysis isn't a game. It's hard, you get sick NLpatw2-It's OK to show it ... Not every commercial, but, like, you can show the stories that some people are really sick, and they are getting sicker, feeling REALLY miserable and maybe children are NLpatw3-More susceptible**	**27262-27588**
NLpatw1- NLpatw3- NLpatm1- NLpatw1	**1:131**	**NLpatw1-And a lot of people think when you get a new kidney or other organ you will be healthy again. They forget the check-ups, the medication and NLpatw3-All the side effects of the medications NLpatm1-The injections NLpatw1-Yeah, those kind of things**	**29036- 29268**

NLpatw1- NLpatw2- NLpatw1- NLpatw3	1:132	NLpatw1-Sometimes they are ‘ah, do you really need another one maybe when you are older? Is it not, like, forever?’ NLpatw2-It’s not like you are a machine or something. Change a part of it and it’s functioning like that NLpatw1-They are surprised that the kidney is not going with you forever. Maybe it is possible, but most of the times it doesn’t NLpatw3-Mine didn’t last not even a year	29344- 29714
NLpatw2	1:120	Not all people speak our language. Make it more accessible for all people. And maybe when people learn the Dutch language, they have somebody next to teach, to make that on the speaking level	24406-24693
NLpatw3	1:138	So, make it, if you are campaigning, maybe you should campaign about donating in life. Because it’s not only donating after your death there should be more focus on donating while you are living.	31809- 32004
NLpatm1	1:114	They should make advertisements more often, not for a week, not for two times a month.	22947-23057
NLpatw3	1:115	If it’s on for a long time, people have seen it already, move on	23063-23369
NLpatw3	1:121	The campaign now is only for adults. There are also children, teenagers with kidney disease… So more specific for different groups	23452-23676
NLpatw2	1:156	I think it’s more important to focus on every age group, because there are also kidney patients who are 65 or 70	32815-33141
NLpatw3	1:154	Be open, transparent	11745-11783

4.7.3.4 NETHERLANDS FOCUS GROUP CONCLUSION

This model's attitudinal approach to DOD is rooted in social obligation. This follows an objective perception of the topic as a relevant and pressing contemporary issue, the resolution of which requires collective effort on a national scale.

The severity and scale of the issue have evolved to an extent that they can no longer be rectified by the promise or intention of individuals, which are perceived as not entirely reliable. Effective resolution can only occur through policy-mandated behaviours.

Interventions generated by this mentality have already been implemented. However, their effectiveness is limited. The government-issued correspondence calling for individuals to register donation decisions at the age of eighteen has not induced the desired behaviour change. Whilst this is regarded as a step in the right direction, this process is criticised as operationally faulty.

In a similar manner to past interventional strategies, its basis is rooted in 'nudge theory'. In effect, it is still dependent on individual initiative to reach a decision and return the form. Both of these requirements are a potential source of problems. The former requires a period of contemplation, the length of which may vary depending on the level of exposure and level of previous consideration. The latter behaviour requires a higher level of commitment than young people are accustomed. Furthermore, it requires a value judgement of returning the form versus not.

Behavioural reinforcements may be a potential solution. A harsh punitive strategy would enforce a monetary penalty on those who fail to return, whilst a less austere approach would be issuing frequent reminders. Conversely, the desired behaviour may be achieved by positive reinforcement. Regardless of their choice, individuals could be provided with 'thank you' notes or letters of appreciation, in recognition of the prospective impact of their choice.

This unique initiative of early exposure attests to lifelong collaboration efforts between individuals and the government. However, this intervention is limited in the absence of the necessary infrastructure to guide choice and ensure follow up. Accompanying correspondence to parents and guardians may evoke familial discussion on the topic, creating a collective and collaborative consciousness. Educational resources may be better utilised in this front. Guided debates encourage rational decision making and exposure to arguments and counter-arguments, facilitating objective, informed decision making. Despite agreement on the value of secondary education, the UK and Dutch models foster different mentalities as to the utilisation of this resource. Owing to the advanced social issues underpinned by the topic, participants in the UK sample proposed incorporating the topic into the PSHE curricula. In contrast, the Dutch model prefers DOD education to be part of the Biology curriculum, as young people are already sensitised to the topic as a social issue, requiring instead the technical knowledge necessary to make their decision.

Irreversible attitudes and personal prejudices, especially prominent among older generations provide a rigid barrier to DOD acceptance. Biases about recipient identity and deservingness inhibit adoption of pro-donation behaviours among these individuals and their families.

4.7.4 SPAIN

4.7.4.1 SPANISH MEDICAL STUDENTS

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.11.**

a) THEME 1: PERSONAL VALUES AND DONATION

As medical students, some participants believed their positive attitudes were influenced by their degree (SPmedm1 10:8, SPmedw2 10:20). Experience with patients made them understand the fragile nature of health and how organ donation is an issue that can affect anyone (SPmedw2-SPmedw1-SPmedm1 10:1). The students also experienced cases where people were willing to accept an organ, but were not willing to donate, which they believed was unjust (SPmedm110:7). This was particularly an issue among certain communities (SPmedw1 10:5). Utility was also regarded as an important principle in DOD by the students. They believed that organs should be used where they are most needed, extending the lives of people after the donor has passed (SPmedw3 10:23).

They agreed that a lack of information on the topic contributes to ambiguity in public perception. This is particularly an issue among people who have no personal experience with the issue through a friend or family member to encourage them to think about the issue (SPmedm1 10:41). Even among medical students, there is ambiguity in key issues about organ donation, such as donor selection and donation options, therefore, the students could empathise with the public's uncertainty (SPmedw2 10:54).

b) THEME 2: FACTS ON THE DOD PROCESS

Participants felt that it was important to raise awareness as soon as possible, starting in schools, as there are too many young people in their twenties who are unaware of the topic (SPmedw2 10:52).

Through university societies, some students organised health promotion activities directed at young children, against smoking and alcohol. The participants described how they role playing scenarios, where children acted as the doctors, dispensing health advice to toy patients. This was part of the promotional framework that was provided at a national level for public health clubs (SPmedw2-SPmedw1 10:55). The participants agreed that such role plays could also be useful in DOD health promotion.

Other students took upon the health promotion responsibility for adult learners, hosting an information fair at the town hall. They recalled that there was good engagement, as many attendees took the opportunity to ask questions and register. Common areas of ambiguity were about the donor's say on recipient selection(SPmedw2 10:53).

Experiences with patients were particularly valued by the students (SPmedm1 10:42). They described how they often conveyed their experiences to promote the topic among their social circle and convince them to register as organ donors (SPmedw2 10:21). The students agreed that they had a responsibility, as future doctors, to promote the topic. They suggested a collaboration between medical schools in Europe, which could be funded (SPmedw2 10:66).

c) THEME 3: REGISTRATION OPTIONS

The students believed that most people in their country support DOD and would be willing to grant consent but have not actively registered their decisions or obtained a donor card (SPmedw1 10:16). This reflects a wider belief in the futility of donor cards, given the awareness of familial consent as the deciding factor (SPmedw1 10:15).

One participant described how their mother's role as a first responder in the emergency ambulance team meant that she received specialist training on the identification of potential donors and the circumstances for transplantation. Witnessing grey areas in organ procurement did not change her positive view of DOD (SPmedm1 10:31).

d)THEME 4: COMMUNICATION FOR FAMILY AND FRIENDS

Following their experiences on medical placements in nephrology and ITU departments, many students were inspired to discuss the topic with their families (SPmedm1 10:28).

Most of these conversations revealed support for the participants' decisions and a mutual support for organ donation from family members (SPmedw3 10:19, SPmedw3-SPmedw4 10:26). In some cases, the participant support for DOD was attributed to their family's support (SPmedm1 10:9). This support was also demonstrated by the participants' social circle, which included nursing students (SPmedw4 10:25).

The participants believed that they had to make a greater effort to hold these conversations with members of their social circle who had no association with healthcare (SPmedm1 10:44). They agreed that the first step would be to introduce the topic through anecdotes of their experiences, rather than through facts and statistics. This would immediately make the topic more personable and encourage a positive view on DOD (SPmedw2 10:40).

e) THEME 5: PROMOTIONAL RESOURCES

It was suggested that a good opportunity to promote DOD is in relation to road traffic accidents (SPmedw2 10:35). The shocking images used to promote road safety in the Spanish traffic department commercials embedded the notion of consequence awareness and promoted road safety (SPmedw2-SPmedm1-SPmedw2 10:69). The participants recalled past bone marrow donation appeals, including detail about the specific emotional images that were used. These campaigns were both televised and included on public transport advertising spaces, such as local buses (SPmedw2 10:72).

Some participants recalled health promotion and fundraising marathons for a variety of health-related issues, including cancer and DOD (SPmedw2 10:59). These were seen as effective methods of engaging the public in an activity and encouraging discussion. There was very low awareness among the participants about the ONT national website on DOD (R-all 10:38).

In addition, the Spanish students believed that local religious leaders can be better utilised as DOD advocates and sources of spiritual and factual guidance (SPmedm1 10:6). Several participants implied that this is an underutilised resource in Christian communities. However, one participant endorsed the Church's stoicism, suggesting that this may project certain attitudes on the community, hindering free will and unbiased decision making (SPmedw2 10:48).

The students considered that those with experience in healthcare are more attuned to the DOD issue and therefore more empathetic and receptive to messages. Members of the healthcare team can use their knowledge and experience to act as advocates to the community (SPmedw2 10:45). Health promotion is also considered to benefit from high profile and celebrity endorsement (SPmedw2 10:56).

The students believed that social media is the fastest and most cost-effective method of campaigning for DOD. This has the additional advantage of transforming lay people into advocates for health promotion. Two medical students discussed how they experimented with this means of health promotion by posting a video recorded interview with a transplant patient, after gaining the patient's consent (SPmedw2-SPmedw1-SPmedw2 10:62). This method was successful and they considered developing this further for other health related conditions.

Table 4. 11 Table of focus group results from Spanish medical students discussing each of the five DHQ themes.

PERSONAL VALUES AND DONATION			
SPmedm1	**10:8**	**I have not decided yet, but in the future I would like to become donor. Probably I don't know, the influence of the degree I am studying now, or probably the influence that doctors are**	**3809-3992**
SPmedw2	**10:20**	**I have thought about organ transplantation since I study about this topic, I am studying in the university, this year I am doing practical lessons, intensive care unit, and this is where I learn almost what I know about transplantation**	**5196-5431**
SPmedw2- SPmedw1- SPmedm1	**10:1**	**SPmedw2-I think it will happen, it can happen to anyone, so the more we learn about the thing, the more critical we'll be in that aspect. I think it is important to know, about any topic and particularly that one. SPmedw1- I agree SPmedm1- I agree**	**1539-1767**
SPmedm1	**10:7**	**you know it is not fair, some people 'I do not like to give, but I prefer to accept'**	**3500-3583**
SPmedw3	**10:23**	**I think I wouldn't need my organs, so I prefer that someone, a child for example, or someone who needs it. It is so beautiful**	**5922-6111**
SPmedm1	**10:41**	**since you don't have the personal experience in your family, your own or people who are next to you, you don't really think about that.**	**9531-9666**
SPmedw2	**10:54**	**they have a lot of questions that were not resolved. I, for example, they thought they can choose the recipient. For example, if I am a donor, I can choose who can receive that organ and I said, 'no, you can't be around to'**	**12256-12478**
SPmedw1	**10:5**	**For example gypsy people usually accept organ but they are sceptical about donation, you see this is a problem we have in this community**	**2922-3059**
FACTS ON THE DOD PROCESS			
SPmedw2	**10:52**	**I would get the education by the basics, at school, at the level children are learning but introducing it from the beginning, because I have friends who have never listened about organ donation and the answer is the education. And we are in our twenties, it's quite sad.**	**11784-12054**
SPmedw2- SPmedw1	**10:55**	**SPmedw2-We are in charge of the public health club in our university. And we organised it and we distributed. For example there were about tobacco and alcohol and drugs and an activity which is called 'teddybear hospital' to make children love to become doctors and wear white clothes, so they act as if they are the doctor and they take care of the teddy bear SPmedw1-And this activity, at national level there are many associations**	**12516-13442**
SPmedw2	**10:53**	**I organised last weekend a fair in the town hall about organ donation and organ transplantation and people was quite interested in the topic, maybe because they have a lot of questions that were not resolved. I, for example, they thought they can choose the recipient. For example, if I am a donor, I can choose who can receive that organ and I said, 'no, you can't be around to'**	**12091-12478**
SPmedm1	**10:42**	**We have that positive to go to the hospital and to know all these stories, the stories. I think we have the opportunity to**	**9672-9978**

		hear about this topic, because of those experiences.	
SPmedw2	10:21	One day there was a man who died, and next day there was a man living with a lung donated by this person, so it was really shocking, and it is the experience that I will use to convince anyone to be an organ donor. And I think it's quite helpful	5436-5680
REGISTRATION OPTIONS			
SPmedw1	10:15	I don't have a donor card, but in my family we speak about this and we want to donate our organs, but the donor card in the Spanish is not very useful	4783-4932
SPmedm1	10:31	My mother, she works at the, you know, at the emergency ambulance, and she has to study a lot about the rules about transplant, in case people have an accident or anything so sometimes, she has some negative opinions about some situations that can be a little bit about, about complications but she doesn't really change her opinion about transplants.	7389-7832
COMMUNICATION WITH FAMILY AND FRIENDS			
SPmedm1	10:28	In intensive care unit but also last year I was at the nephrology and you see many, many transplants that and when you go back to your home and you talk with your parents about everyday and the topics, that's why I start with that topic at home	6602-6929
SPmedw3	10:19	I said to my family that I want to be a donor and they know, and they respect my idea, and they also would like to be donors	5694-5817
SPmedw3- SPmedw4	10:26	SPmedw3-Also they want to be donors SPmedw4- I talk about my family	6171-6224
SPmedm1	10:9	The influence of the family, that's probably why I think this way	3995-4059
SPmedw4	10:25	My friends, because they are studying nursing and all agree with the donor organs	6230-6310
SPmedm1	10:44	We have the obligation to communicate to those friends who are not in the medical field or something like that.	9984-10094
SPmedw2	10:40	Her friends are not medical students and I told her the story and she transmitted it or maybe they are not in the medical field and they have to understand the personal story better than the statistics but with numbers. It happens and it can happen to you and with the lung a person will not need anymore another person will. So, that's the story it makes you think about it	9046-9419

SPmedm1	10:6	talk with one of the leaders, the religious leaders, you know in the region there is someone in the (pause) Christians, Catholicism, Baptist	3267-3401
SPmedw2	10:59	I remember that in Catalonia there is some very popular, very special marathon for some health activities, some, one is for cancer	16079-16498
SPmedw1	10:16	most people in Spain don't have donor, for example I haven't,	4571-4631

SPmedw2	**10:66**	**There are many universities in Europe, many medical schools, it's possible to organise a small project similar with your question around the EU, and also with the support of UEMS give money**	**18906-19176**
PROMOTIONAL RESOURCES			
SPmedw2	**10:35**	**I don't mean people will think of transplant due to the traffic accident, but using their methodology to get to the public.**	**20489-20610**
SPmedw2- SPmedm1- SPmedw2	**10:69**	**SPmedw2-For example here, the (Spanish) traffic department made a commercial that really shocking SPmedm1- Shocking, showing traffic accidents SPmedw2- Showing the consequences that your acts can have, if you don't follow the rules**	**19874-20196**
SPmedw2	**10:72**	**For example, a bombardment of bone marrow transplant here in … they made a video with children that were in hospital and they danced and it was very emotional. And they put it on buses and everywhere**	**13492-14399**
R-all	**10:38**	**R-Have you seen the website of ONT? All-No**	**21243-21338**
SPmedw2	**10:48**	**I usually go to church and I have never listened to something like that, no. I don't know what they think about it, but at least they don't transmit it**	**10802-10963**
SPmedw2	**10:45**	**I think the problem is to get the general population consider about the problem, because most of the people are not doctors or nurses, so I think we should focus our effort in giving the general population with the right information, as they cannot experience what we experience in hospital, transmit it in another way, this experience**	**10100-10431**
SPmedw2	**10:56**	**I think we should use a famous person to transmit it.. For example with Angelina Jolie and the breast cancer**	**14406-14913**
SPmedw2- SPmedw1- SPmedw2	**10:62**	**SPmedw2- I think in the social network we can take advantage that everybody is with their smartphone, with a tablet…Everytime in Facebook you share something on the wall, maybe they read it. SPmedw1-We wanted a patient talk about their experience and… I shared it on her wall, and she shared in another wall SPmedw2- You know sometimes you share a message and they share it with 10 friends and the idea is to share an organ, and you share it with another friend**	**17016-1804**

4.7.4.2 SPAIN: STAFF

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.12**.

a)THEME1: PERSONAL VALUES AND DONATION

All participants expressed positive attitudes towards organ donation (R-all 2:26). This was recognised as both a life-improving and life-giving process (SPstaw2 2:1; SPstaw2 2:14).

This reflects shifting attitudes and pragmatic decision making about life after death (SPstam1 2:10, SPstaw1 2:18). Participants described how cremation has been the most common posthumous arrangement in Spain for several years (SPstam1 2:12). This reflects less spiritual and sentimental beliefs (SPstaw1 2:56). Owing to the high population numbers and cemetery overcrowding, cremation is viewed as a more cost-effective, hygienic and practical solution (SPstaw1 2:20; SPstaw1 2:25). The group agreed that there was still some reluctance to think about death, but people would be willing to donate if the situation arose (SPstam2-SPstaw2-SPstaw1 2:35).

Participants agreed that there were some regional variations in attitudes in Spain. Rural areas, inhabited by older populations tend to nurture more traditional attitudes, showing more respect for time-honoured traditions, specifically about death (SPstam1-SPstaw2-SPstaw1 2:52). The group described dynamic as a schism that reflects a ‘cultural illiteracy’ (SPstaw2-SPstaw1-SPstaw2 2:43).

The group were aware and proud of Spain’s leading status in worldwide DOD rates (SPstaw1 2:114). They suggested that this acts as a ‘self-fulfilling prophecy’ and encourages people to act in ways that perpetuate this national status (SPstaw1 2:113).

b) THEME 2: FACTS ON THE DOD PROCESS

The quality of service from the nationalised healthcare system was praised and reported as a protective factor for the treatment of potential donors. This public system was considered superior and more trustworthy compared to private or mixed sector healthcare systems, specifically that of the United States. Participants noted that financial incentives play a greater role in these countries compared to Spain (SPstam3 2:97).

The trustworthiness of the medical system is one of the core factors considered in consent decisions (SPstam3-SPstam1-SPstaw1 2:101). This is also one of the most marketable aspects of the DOD process, which is frequently emphasised in health promotion campaigns (SPstaw1 2:106). However, this factor is not strong enough to overcome reservations about donated the organs of one's children. In these cases, sentimentality, rather than logic, is the deciding factor (SPstaw1 2:100). Regardless of this overwhelming support, there were some participants who believed that the timing of the donation request and the approach of the family by the medical team was inappropriate and insensitive (SPstaw2 2:126).

The standardisation of processes governing the collection and transmission of information between donor families and the healthcare team are part of the successful set of strategies employed by the 'Spanish Model'. Participants believed that effective communication creates an atmosphere that is conducive towards collaboration and donation request pragmitisation (SPstam3 2:94). This simple communication strategy is considered more effective than the more expensive and complex methods employed by more technologically advanced countries with lower DOD rates, such as the US (SPstam3 2:94). This is reflected by the fact that the deceased's family anticipate and expect the donation request (SPstaw1 2:96).

The second successful facet of the 'Spanish Model' rests on the role of transplant coordinators who are responsible for the early identification of potential donors. This extends the time frame available for communication and discussions about health decisions between the healthcare team and the patient's family (SPstam3 2:98). This allows for a more sensitive and less time-pressured discussion.

The transplant coordinator teams allocate individuals who have undergone specialist training in psychology to host the consent discussions with patients' relatives (SPstaw2 2:34). These individuals act separately to the patient's medical team, to prevent conflict of interest (SPstaw1 2:128).

c) THEME 3: REGISTRATION OPTIONS

Participants recognised the importance of familial consent and agreed that in most cases, it would be granted (SPstaw1 2:7). This reflects a respect for the consent decision of the individual, which the participants analogised to a 'will' or 'inheritance', indicating the deceased's wishes (SPstaw2-SPstaw1-SPstaw2-SPstaw1 2:4; SPstaw2-SPstaw1 2:5).

Some participants were particularly supportive of organ donation in paediatric cases. Because of the burial practices, parents are more willing to donate their children's organs as the knowledge that some part of them is alive in another child helps with the palliation process (SPstam2 2:28; SPstaw1 2:29). In addition, a child that has become a donor after their death achieves a great and meaningful act through their death (SPstaw2 2:62).

One participant discussed how her daughter's initial decision to become a blood donor was followed by her decision to register as a deceased organ donor, consenting to whole body donation. The speaker respected her daughter's determination and believed that her own reservations as a parent were secondary (SPstam1 2:36).

d)THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS

Conversations on the topic with one's social circle were seen as a valuable and logical part of the decision-making process (SPstam1 2:81). They also suggested that it is their own responsibility to instigate the discussion if they know that their loved ones are less aware (SPstaw2 2:85).

One of the participants had personal experience with organ donation with a partner that had received a transplant (SPstaw2 2:86). They felt that they had a responsibility to positively promote the topic among their social circle, providing them with information and advice (SPstaw1 2:87).

e)THEME 5: PROMOTIONAL RESOURCES

The participants compared these campaigns to the more recent political campaigns on the refugee crisis, discussing how the raw image of a young boy lying dead on the beach was promoted as an image of martyrdom and made the public reflect on the campaign even more. In addition, the participants discussed the benefit of information days at schools, raising the example of firemen teaching young children about fire safety, ingraining the duty of social responsibility among young people (SPstaw1 2:122). In a similar manner, healthcare professionals and patients could host talks and assemblies on DOD.

The group identified that future promotional strategies would benefit from expert social marketing analyses to attune the campaigns to the public's sensitivities (SPstaw1 2:149). This follows the belief that current strategies make little effort to address different cultural beliefs and attitudes. The group were pragmatic in the consideration of the logistics of future campaigns, suggesting that DOD health promotion is analogous to a 'product' that needs to be advertised and 'sold' to consumers (SPstam1-SPstaw1-SPstaw2-SPstam1 2:146). In addition, repetition of key messages is essential to ensure that awareness is continuous and not intermittent (SPstaw1 2:148). There was some emphasis on the importance of removing the notion of financial incentive and promoting DOD as an ethical act above any other aspect (SPstaw2 2: 147). This highlights the trustworthiness of the donation procedure and provides reassurance on the treatment of potential donors.

Visual and graphic imagery instigate emotional responses and motivate the public in ways that language and text-based materials cannot (SPstam2-SPstaw1 2:79; SPstaw2 2:143). These also help people visualise and comprehend an otherwise abstract process, as well as the impact of the gift of donation

(SPstam2-SPstaw1 2:144). Finally, communication is an overlooked factor in DOD. Participants considered the manner in which a donation request is conducted as more important than the individual's pre-existing attitude (SPstam2 2:132).

Participants believed that pre-existing knowledge removes the shock factor from the donation request and that this is more important than the way in which the team frame the request (SPstaw2 2:127).

This becomes the responsibility of the education system. The group believed that the 13-14 year olds are the best age group to introduce the topic and that informational assemblies by patients and healthcare professionals are the best method (SPstaw2-SPstaw1-SPstaw2-SPstaw1 2:88). However, they also believed that most of the youth are already aware of the topic and a very high percentage would have no objection to donate (SPstam1 2:121).

Table 4. 12 Table of focus group results from Spanish staff discussing each of the five DHQ themes.

PERSONAL VALUES AND DONATIONS			
R-All	**2:26**	**R-Is it important to donate organs after death?** **All-Yes**	**7354-7408**
SPstaw2	**2:1**	**I think it's very important, because you can really save a person's life, or help him to live in better circumstances, at least**	**2868-2995**
SPstaw2	**2:14**	**It will allow another person to live**	**5741-5801**
SPstam1	**2:10**	**Now, it is assumed that the body is not something that has to be preserved**	**4817-4931**
SPstaw1	**2:18**	**So, if you are going to burn the body, use it**	**6964-7009**
SPstam1	**2:12**	**Today the crematorium is already almost general. Today there is no problem, in opposition to some years ago**	**4704-4810**
SPstaw1	**2:56**	**It is science that makes you think that, well, the body is corrupt, which is a series of chemical processes that happen there. They are of no greater importance and good**	**18831-19015**
SPstaw1	**2:20**	**It's a culture. You know, what are they called? Cemeteries, there are in the (inaudible) there are now special places for the ashes. So, it is expensive to put the body in the ground. It's cheaper to put the ashes. So, if you are going to, and it is cleaner, It is cheaper, you know.**	**6680-6962**
SPstaw1	**2:25**	**Population of 7 million people, it is impossible, you know? You have to make. This is practical, so practical, and clean**	**7011-7286**
SPstam1-SPstaw2-SPstaw1	**2:35**	**SPstam1-What happens is that, I do not know if it is only in Spain, but on the subject of donation, there will be few people, and less and less, who are against, after death. What happens is that in Spain little is said about death, talking, then, about donation after death, means talking about death, implicitly.** **SPstaw2- We do not like to talk about death** **SPstaw1- We do not face it until it happens.**	**11613-1207**
SPstam1-SPstaw2-SPstaw1	**2:52**	**SPstam1-I think it's the oldest people.** **It is more by tradition than by religiosity. I know people who are involved in sororities in Seville, who take steps in Easter and are atheists.** **SPstaw2-Well it will be by tradition; But they continue doing it.** **SPstaw1-Because they like to do it. It's a show.**	**16777-17120**
SPstaw2-SPstaw1-	**2:43**	**SPstaw2-It's culture, because really the South, is bad to say, but they are more illiterate than us.**	**14173-14407**

SPstaw2		**SPstaw1- Yes** **SPstaw2-In general. They are more rural. Let's see, it's bad. Culturally illiterate, regarding burials.**	
SPstaw1	**2:114**	**I think Spain is one of the best countries. We have always been good at medicine, always. Just like, for example, in India, they are genius at informatics. Well, I think that, in here, there is a release of very good doctors by percentage of population,**	**33525-33905**
SPstaw1	**2:113**	**If they tell us that we are very good at something or that we have enhanced in something that we excel at something; because that even makes us be more inclined to do it because well. It is also another way of acting: on people' ego.**	**32771-33211**
FACTS ON THE DOD PROCESS			
SPstam3	**2:97**	**On the one hand, it is an advantage to have a Public System, in which there is no economic transfer. I mean when a black man from a suburb of Chicago asks the mother to give him consent to extract the kidneys and liver or whatever, it is clear that in the USA there are very good hospitals… So, people are always a little more mentally reluctant (there) than here, where people do not have that kind of reserve because they know that they're always going to go to a place where that does not exist.**	**27062-27889**
SPstam3- **SPstam1-** **SPstaw1**	**2:101**	**SPstam3- There is a lot of confidence in the System. That is why this works.** **SPstam1- It is evident** **SPstaw1- It is something that helps you logically.**	**30441-30469**
SPstaw1	**2:106**	**In places where there have not been such teams, people have not been able to raise awareness. That culture has been strengthened and people are more prone to it.**	**30740-30995**
SPstaw1	**2:100**	**It helps, of course it helps, but I do not know how decisive it is when you have to assess whether to donate the organs of a child, for example. Knowing there is a good System behind helps.**	**29825-30047**
SPstaw2	**2:126**	**In those moments that you are with the newly deceased, they enter you in a bad way. It's like life insurances, for example**	**36766-36955**
SPstam3	**2:94**	**Because the System is so well organised in that sense, there are very few failures in the collection and transmission of information... compared to the UK or Germany or other countries that are more technically advanced than us (we [Spain], have a higher donation rate because of) such a conducive environment, with the information**	**29049-29518**
SPstaw1	**2:96**	**We have a perfectly coordinated and greased system that allows us to donate the body or the organ of a person we love; we know it will arrive. It is not going to profit somebody economically**	**28455-28746**
SPstam3	**2:98**	**What the ONT did, was creating transplant coordinators in the hospitals so the detection of the donors is made very early. That is the difference.**	**27891-28165**
SPstaw2	**2:34**	**After the coordinators, the psychologists to take this very warm moment**	**9585-9659**
SPstaw1	**2:128**	**Transplant coordination teams are then prepared to deal with people and they already know how to act. Your doctor, your specialist, who is not trained will not come**	**37329-37550**
REGISTRATION OPTIONS			
SPstaw1	**2:7**	**The family would cry but would accept, anyway**	**4556-4600**
SPstaw2- **SPstaw1-** **SPstaw2-**	**2:4**	**SPstaw2-I think, that if your family is against and you decide, the choice is yours, not your family's.** **SPstaw1-You decide. It's your business, not your family**	**3761-4040**

SPstaw1		business. It's your business, if you decide SPstaw2-The opinion of the family… once you consent; they have to admit it. SPstaw1- the last will	
SPstaw2- SPstaw1	2:5	SPstaw2- Indeed, it is an inheritance more SPstaw1- We were making similarities between money. If you need your money, doesn't matter what your family thinks about it, it's your decision. Not your family decision. It's your decision, and they have to respect	4102-4371
SPstam2	2:28	In such cases, it is also very common to think that a part of the child, the child, your child, your daughter, is not only making another child to be alive, but, in a way, your child is, let's say, living there	8010-8471
SPstaw1	2:29	That's the point. It is a part of the body of your relative, loved people who is living, is not burnt … it helps you palliate	8476-8577
SPstaw2	2:62	My children are relatively young. They are teenagers. And I would be very sorry, but from another side, I think: how happy I will feel saving the life of another child and let him live	19735-19992
SPstam1	2:36	Well, the other day my daughter, who has already started donating blood, told me: "I just donated the body" and I said, it seems very good. I know that if something happens to her, I have to respect her will. Among other things, she has decided it freely.	12081-12532
COMMUNICATION FOR FAMILY AND FRIENDS			
SPstam1	2:81	Because ... and of course, giving a favourable opinion to the subject in any conversation of this type or another. Because, it is logical.	24306-24472
SPstaw2	2:85	Of course, indeed. Until *you* raise the issue, you do not know	24882-24942
SPstaw2	2:86	My husband has a transplanted organ, so I know the subject quite deeply. I think, maybe more than other people.	25055-25192
SPstaw1	2:87	I talk to people, people ask me how everything is going. So, it's another way to promote. If it makes you well, you sell it in a positive way, then of course, all the people in your environment and all the people that you, at a given moment, can access. You sell something in a positive way, because of you, your personal situation, your personal experience has been positive. So, well… this is what I can do. I can also advise.	25221-25649

PROMOTIONAL RESOURCES			
SPstaw1	2:122	Fire fighters go to the schools, and give the children a fireman's cap. That is, that love to the firefighter is generated. That respect to the fire fighter figure	35593- 35870
SPstaw1	2:149	People who study the market, who know the sensitivity of the people, can determine in what things or matters that population, as a whole, is more empathic, to act in that sense. Because if they keep repeating the same message to you, it is very effective, because in the unconscious... It makes no distinction between people with more or less culture	20938- 21311

SPstam1- SPstaw1- SPstaw2- SPstam1	**2: 146**	**SPstam1-Anyway, you cannot do the same in different places. SPstaw1-That's what needs to be detected. It can only be done through a marketing study. SPstaw2-We have to base on the fact that it a product that needs to be sold SPstam1-You have to sell it to those you are directing to**	**31772-32266**
SPstaw1	**2:148**	**Perhaps the most effective way is to bombard with publicity. But repeatedly, without a rest. Because the people, we need them to repeat us, to remind us**	**20534-20812**
SPstaw2	**2:147**	**That money doesn't mediate (the process). Trust. Create that trust**	**35055-35208**
SPstam2- SPstaw1	**2:79**	**SPstam2-… a very clear example, with a different subject, for example, the refugee issue. Actually, the civilian population did not realize the tragedy until the dead child appeared on the beach. The image of Aylan. SPstaw1-It was the trigger of a series of reactions, which on the other hand, the Spaniards, we are very sensitive to all of them**	**23563-24132**
SPstaw2	**2:143**	**An image impacts more than any word**	**24138-24210**
SPstam2- SPstaw1	**2:144**	**SPstam2-Faces. Transplanted people's faces. SPstaw1- If they are telling you and putting pictures to you like: "Today this girl has survived thanks to the intervention of these teams and things like that", because all this motivates you to act.**	**23147-23557**
SPstam2	**2:132**	**But a 14-15-year-old-boy who has been transplanted going to a 5-6-year-old-children class... I believe that if they see someone who is very close to them and that can even make jokes that excite the children (like showing the children a scar or something like that).**	**35876-36321**
SPstaw2	**2:127**	**An education in organ donation… it's not as important as how they go asking you**	**37085-37245**
SPstaw2- SPstaw1- SPstaw2- SPstaw1	**2:88**	**SPstaw2-What could be done, through the organs of the schools, is to tell responsible of the schools, to send people, maybe not transplanted but who know the subject and to infuse the children because that, what we said before. Not at young ages, but from 13 - 14 years. SPstaw1-Yes, educational speeches SPstaw2-Yes, exactly. SPstaw1-Informative talks so they know more or less what transplantation is about**	**25692-26150**
SPstam1	**2:121**	**Although good, they already are. I am convinced that youth, 90% of those who being asked this question, they'd say yes**	**35210-35491**

4.7.4.3 SPAIN: PATIENTS

Participant attributions and quote IDs appear in text. These correspond to full quotations for each which can be found in **table 4.13**.

a) THEME 1: PERSONAL VALUES AND DOD

A large portion of the participants were aware and supportive of DOD before they required a transplant (SPpatw3 13:11; SPpatw4 13:34). However, their condition prompted them to research the topic further in order to gain a better understanding of the technical and practical aspects (13:11). The patients believed that, providing there were no contraindications or eligibility issues, all people should be willing to donate (SPpatw4 13:35).

b) THEME 2: FACTS ON DOD PROCESS

During their personal journeys, the patients considered the healthcare team as a helpful and reliable information source and health literacy. This guidance allowed them to navigate through complex information about their treatment, as well as helping them to manage their expectations (SPpatw1 13:3). The patients valued honesty in these communications, as this helped them to prepare for and obtain a realistic understanding of potential hardships and disappointments (SPpatm1 13:15). Some participants believed that healthcare professionals should be involved in wider DOD promotion. Factual information has the greatest impact when it is combined with explanation and guidance from a healthcare professional (SPpatw1 13:22).

c)THEME 3: REGISTRATION OPTIONS

The patients' own experiences prompted discussions of the topic among their social circle (SPpatw1 13:13). These conversations inspired several family members and colleagues to register as organ donors (SPpatw1 13:12; SPpatw4 13:40). Patients demonstrated knowledge of live donation through cases in their social circle. One participant recalled being informed of the potential to find a match in one's family when they first received dialysis (SPpatw1 13:31). Another participant discussed a case of bone marrow transplantation in their extended family (SPpatw1 13:1).

d) THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS

Participants commented that communication about DOD at an early age, is important and raises general awareness about a sensitive topic. Introducing the topic at a younger age, can spark excitement and encourage children to ask questions and become inquisitive about a sensitive topic, to combat any taboos associated with the topic (SPpatw1 13:26). It was affirmed that it is difficult to have everyday conversations about the DOD, but it can be done in a quiet safe environment with people close to you such as friends and family (SPpatw4 13:40). This is especially true if such close members have had personal experiences on the topic e.g. transplant recipients (SPpatw4 13:42).

e) THEME 5: PROMOTIONAL RESOURCES

Communication was regarded as one of the most important and attainable tools for health promotion. These conversations should become part of the national culture and future campaigns should focus on teaching people how to hold these discussions (SPpatw4 13:43). However, there was some disagreement among the participants on how early one can start these conversations with children (SPpatw3-SPpatw1 13:23).

Schools are an important site of health promotion, with the potential to create generations of aware and sensitised individuals. Secondary school was agreed as the best educational stage for this intervention (SPpatw1 13:46). Learning about the topic in school can trigger further conversations with the students' wider social circle, including their friends and relatives, creating a ripple effect and a chain of communication (SPpatw1 13:26).

Television is an effective method of mass information (SPpatm1-SPpatw1 13:19). Both medical dramas and factual documentaries are considered good methods of raising awareness about DOD. This is because several topics can be addressed in a short period of time, such as different types of transplantation and patient narratives (SPpatw1 13:20). One participant recalled the considerable impact of a case that was in the news, where a patient died waiting for a bone marrow transplant, which triggered a national reaction (SPpatw3 13:10).

Beyond sharing their stories, some patients decided to engage in volunteering and fundraising opportunities for organ donation charities. One of the patients discussed how the charity's paraphernalia, were worn by famous figures and sparked media interest. This created a larger platform for sharing the issue (SPpatw1 13:28).

Table 4. 13 Table of focus group results from Spanish patients discussing each of the five DHQ themes.

PERSONAL VALUES AND DONATION			
SPpatw3	**13:11**	**I remember hearing about donations, I remember it was long time ago. When I got involved, I was more interested in knowing how it worked and all that.**	**3824-3973**
SPpatw4	**13:34**	**I always considered it to be very important**	**25486-25553**
SPpatw4	**13:35**	**Precisely, I think when there are people with body and they are well and if they do not have any impediment of some sort ... I think that people should**	**26326-26531**
FACTS ON THE DOD PROCESS			
SPpatw1	**13:3**	**The first consultation I had with the doctor at the UCA was to explain me everything and the first thing he told me was that I was going to be proposed to do the kidney and pancreas transplant, both at the same time.**	**1368-1605**
SPpatm1	**13:15**	**from all this, I conclude that the best thing that has happened to me is the information I was given at the beginning by Dr. Piñeda. Because I've been logged in several times. Things get complicated, you must go in and he explained all that and dialysis first and then we will prepare you to be transplanted, about you don't have to get annoyed if you must enter again two, four or six times, as many as needed. The process is that. Then of course, I had a very great tranquility. I mean, if he came and told me, 'you must enter'. I no longer had panic or anything. It's a normal thing. That has come to me very well.**	**9255-9872**
SPpatw1	**13:22**	**Information through the patients; with a doctor who can explain it**	**19953-20108**
REGISTRATION OPTIONS			
SPpatw1	**13:13**	**Because of that, well, we have always talked about**	**5779-5829**
SPpatw1	**13:12**	**One of my daughters and my brother have become donors**	**5548-5687**
SPpatw4	**13:40**	**No, no, it does not come out. About I do have several colleagues who in fact had signed up to donate**	**28415-28600**
SPpatw1	**13:31**	**He has always been very aware of how I was and he said that his son who had dialysis I do not know how many hours and that was suddenly that and that took a lot in that and in the end the donor was the mother. She was a living donor.**	**24633-24915**
SPpatw1	**13:1**	**It coincided that, unfortunately, a cousin's son needed a bone marrow transplantation.**	**187-345**
COMMUNICATION WITH FAMILY AND FRIENDS			
SPpatw1	**13:26**	**The children just after arriving home say that a doctor came and told us this and this**	**2730-20936**
SPpatw4	**13:40**	**It is not like a topic like Marid-Barcelona- it does not come out. I do have friends, though who in fact make comments about that**	**28415-28600**
SPpatw4	**13:42**	**Many of my friends who had been previously transplanted, only spoke positively to others**	**29980-30251**
PROMOTIONAL RESOURCES			

SPpatw4	**13:43**	**I think that more effective is 'word of mouth' in the conversation. That is, accustom the conversation about it**	**30731-30841**
SPpatw3-SPpatw1	**13:23**	**SPpatw3-The children still do not understand much. The need of transplantation…** **SPpatw1-I think they will understand**	**20113-203711**
SPpatw1	**13:46**	**The schools, the high schools**	**21995-22062**
SPpatw1	**13:26**	**The school, because then the children, that is a novelty, then, just after arriving home, the first thing they are going to do is saying that today a doctor came and told us this and this**	**20730-20936**
SPpatm1-SPpatw1	**13:19**	**SPpatm1-I think the best thing is TV, about a show; Like the ones that are now about hospitals and that. They give real life cases. Well this is the same. Talking about kidney diseases and make it a half hour program or an hour a day. People watch TV a lot.** **SPpatw1-Dedicated exclusively to transplants**	**17116-17405**
SPpatw1-SPpatw1	**13:20**	**SPpatw1-A program would be fine** **X: Where people appear** **SPpatw1-Where people transplanted from ... for example my case of kidney-pancreas, another case of liver ... Yes, each of a different thing; talking about his experience: before and afterwards.**	**17656-17891**
SPpatw3	**13:10**	**I remember, for example, this guy from the South who has recently died asking for marrow donations, come on, that all Spain found out about donations and more cases. I think people are much more informed now**	**4044-4251**
SPpatw1	**13:28**	**If people see that Eva Longoria wears it, it is always going to have more publicity**	**22706-23482**

4.7.4.4 SPAIN FOCUS GROUP CONCLUSION

The Spanish model's success is described as a self-perpetuating phenomenon. Campaigns and schools educate the younger generations on the topic in the context of social studies and encourage them to act in ways that preserve this leading status.

Campaign appeals centre on the role of familial consent. Consequently, the registration of donation decisions and the acquisition of donor cards are perceived futile. As a result, individuals are directed to a simple singular behaviour; speaking to their families. This is in contrast to the majority of European campaigns which present a range of multiple and often complex possible behaviours, requiring formal commitments and involving official bodies and organisations.

Familial discussion is a logical extension of the decision-making process. In most cases, conversation outcomes are homogenous and in favour of DOD and consent granting is reflexive and tacit. This act of interactivity ensures that families anticipate the donation request. Shock, reaction times psycho-cognitive burdens on the families are further alleviated within the clinical setting by hospital protocol standardisation and transparency. Targeted communication strategies facilitate the collaboration, reduce errors, distress and the need for request repetition. As a result, the process becomes more cost-effective.

Furthermore, the protocols of early potential donor identification expand the potential donor pool population and allows for a less time-pressured discussion. The successful organ donation rates occur not because of the presumed consent legislature, but in-spite of this.

Despite the strongly religious Christian character and homogeneity of the sample, religion was surprisingly not an inhibitory variable. Integral to the success of the Spanish model are the increasingly secular attitudes about life after death and burial practices and the dominance of pragmaticism. However, this finding must be analysed in the urban context in which the study was conducted. A geographical, regional schism divides attitudes and practices between rural and urban communities, with a perceived ‘cultural illiteracy’ among the former.

Detailed objective and subjective knowledge about the technicalities of DOD are not integral to the Spanish model’s strength. The strength of factual appeals lies not in their detail but in their simplicity. Core messages are continually recycled and reiterated until they become culturally indoctrinated. The following three examples of conceptual patterning have been identified; (1) DOD is a life-improving and life-giving act, (2) it is impossible without familial consent, (3) Spain is a leader in DOD rates and this exemplar status is a product of collective social effort.

4.7.5 CHAPTER CONCLUSION

This section considered the five themes in the DHQ through focus group discussions. Focus groups were conducted in all three participating countries per individual subgroup. Exploration of the separate themes were used to gain insight into the quantitative results and integrate ideas which could inform future campaigns on DOD explored in the following chapter.

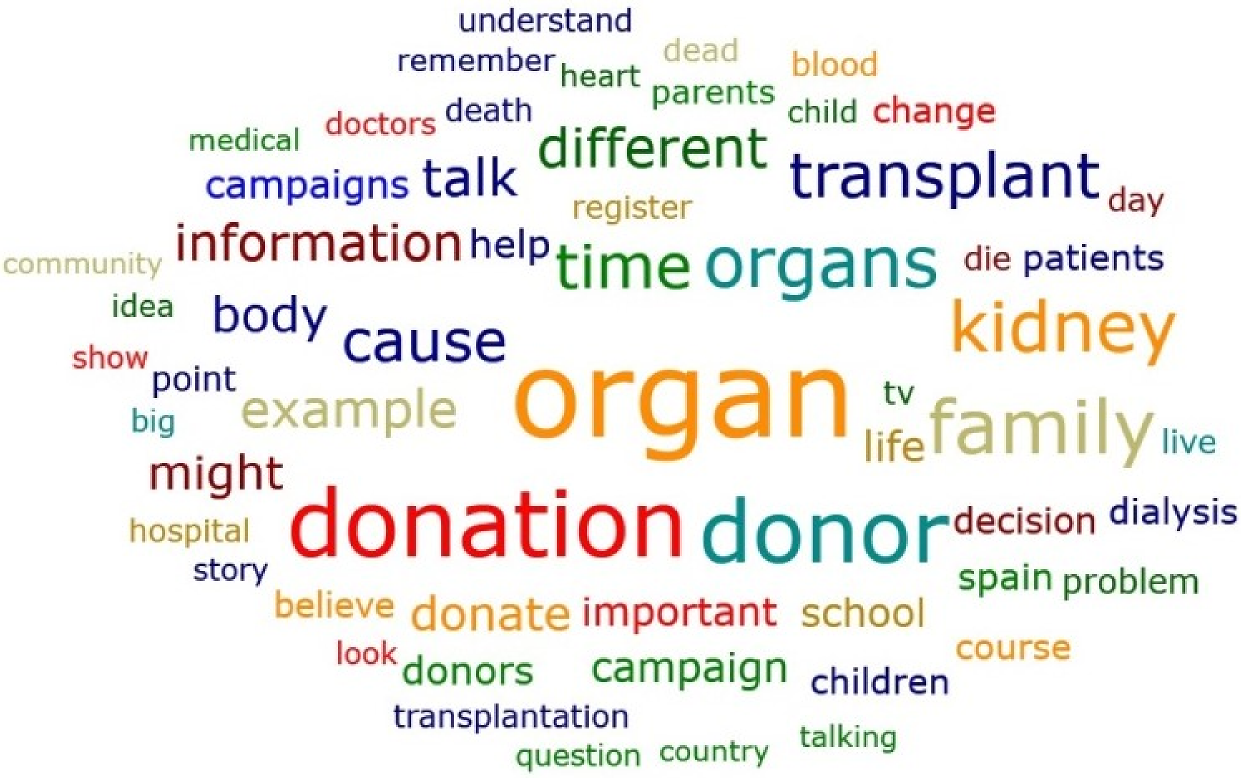


Figure 4. 2 Word Cloud derived from all nine focus groups. Words and topics mentioned in high frequency exploring the five domains examined in each focus group.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

This thesis has developed supporter-registrant profiles on the basis of core health literacy parameters, as identified in the health promotion agenda of three European countries with low, intermediate and high DOD rates. This chapter is a thematic synthesis of these quantitative and qualitative results, examining the implications of these findings firstly in terms of individuals and their attitudes, communication patterns, knowledge about DOD in Section A and finally how this can be effectively utilised integrated into campaign design, in Section B.

5.2 SECTION A: PRE-CAMPAIGN ENVIRONMENT

5.2.1 INDIVIDUALS, CHARACTERISTICS AND THEIR VALUES

a) DEMOGRAPHIC VARIABLES AND SUPPORTER-REGISTRANT STATUS

In all three countries, the mismatch between the 'supporter' and 'registrant' identities confirm the presupposition of independence between the two (Siegel et al, 2010). Supporter status is demographically generalised, as it is compatible with most age groups, ethnicities and religious groups. By comparison, non-supporter and non- registrant profiles are highly specific constructs with niche demographic characteristics, rooted in religiosity, increasing age and ethnic background and educational background.

The findings of the MCA were accurately predicted in the qualitative, focus group analysis. This suggests a high level of critical social awareness among the participants, specifically in identifying inhibitory traits. For the UK, this was correctly perceived as the BAME community and religiosity (Randhawa and Neuberger, 2016). In the Netherlands, the main barrier was identified as low educational background. In Spain, this was a combination of these two factors, which are features of insular or socially isolated communities. In all cases, inhibitory traits are a function of poor interactivity with peers and resources (Ingram, 2013).

This supports the hypothesis that community engagement in public health demands a customised 'fit for purpose' rather than generalised, 'one size fits all' approach (O'Mara-Eves et al, 2013). Failure to adopt this strategy likely results in poor campaign targeting and may not account for individuals with lower rates of HL. This potentially compromises campaign ability to be used where they are needed most (Zwi and Cabral, 1991).

b) VALUE JUDGEMENTS AND SOCIO-COGNITIVE CONSTRUCTS

Cultural influences contribute to preconceptions or schemata. This is because they inform individuals' underlying values and subsequently, their appraisal of information on the topic. These are referred to as socio-cognitive constructs (Akgün et al, 2003).

Several socio-cognitive constructs emerged from the quantitative and qualitative analyses. Some notions are culturally specific, such as notions that DOD disfigures the body, disrupts burial practices, or fear of stigmatisation from communities with traditionalist views. Furthermore, a common theme expressed in focus groups from all three countries is that family consent often contradicts the deceased's personal wishes and undervalues their autonomous decision, made in life. This leads to concerns about the validity of donor cards and a belief in the futility of registration efforts in general. These concerns could be explanatory of low registration rates that were observed.

Other socio-cognitive constructs are more generalised or culturally diverse (Zeiler, 2014). These involve mainly social ethics, such as questions over recipient entitlement and advocacy for DOD as a socially responsible behaviour. This notion of DOD as a shared social obligation follows the rationale of reciprocity; in that meeting somebody else's medical needs suggests that in turn, others must be willing to do the same (Streat, 2004). In the qualitative analyses, participants mainly in the UK and Spain were critical of the fact that this dynamic was not observed by specific groups with higher requirements for organ donation e.g. BAME. Another common belief saw the ageing population as the greatest contributor to the organ shortage issue. This tenet was supported by the statistical analysis, as pro-donation attitudes and behaviours decline with age. This group's perceived 'traditionalist' values, act as barriers to consent, thereby reducing the potential donor population (Miranda et al, 1997). Beyond this, multiple comorbidities lead to poor quality, non-transplantable organs, thereby reducing the actual donor population (Howard, 2002).

Religiosity has often been identified as a significant barrier to DOD (Faltynek, 2013). This was confirmed by the quantitative results of this study. However, an under-reported, inverse scenario emerged through the qualitative analysis, wherein religious groups enable and facilitate positive attitudes towards DOD. This is done by encouraging congregations to behave in ethical, charitable, socially responsible and ultimately, altruistic ways. As a result, the observed inhibitory tendencies of such groups are a function of misunderstanding between the congregation's perception and the official position of their religion (Wakefield et al, 2011).

However, these socio-cognitive inhibitions exhibit poor intergenerational transmission (Dohmen et al, 2011). The focus groups revealed that younger generations do not necessarily convey the mindsets of their elders. As evidenced by the MCA, this finding is best understood when interpreted in the context of educational background. Critical interaction with information and the ability to make individualised, personal decisions are functions of increased literacy and higher education (van der Heide et al, 2013). This indicates a shift in dominance of 'critical health literacy' over 'socially situated health literacy' as the driving force shaping attitudes towards DOD (Mancuso, 2008).

Navigating through these values requires cultural competence (Purnell, 2002). Any proposed behaviour change must be compatible with existing culture. The use of natural or lay helping strategies includes an awareness of local network 'ecology' or dynamics. For instance, as demonstrated by the focus group discussions, ethnic communities are more receptive to the promotional efforts of members of their own community; an observation also made by Towle and Godolphin (2013). Therefore, it is possible that face to face discussions are the most persuasive method for population that are strongly against DOD.

The fact that certain socio-cognitive behaviours are predictive may act as a strength, rather than a weakness. It is possible to utilise individuals' existing networks, such as religious advisors and school educators to facilitate coordinated action (Durlauf, 2002). To achieve this, campaigns must capitalise on two components; firstly, the relational element, residing in the social organisations of which the individual is a member, and secondly the material element; the information conveyed to these groups. This can be crucial in attenuating misunderstanding and bridging cultural divides.

5.2.2 COMMUNICATION

a) CONVERSATION INCIDENCE: TRIGGERS AND AVOIDANCE

The MCA indicates that low levels of communication with one's family are associated with non-registrant status, while the expression of negative views is associated with non-supporter status. Conversely, evidence of good discussion with family members correlates well with both supporter and registrant status.

The behaviours observed in the quantitative results were also described in the focus group discussions. As a result, three communication patterns were identified, relating either to triggers or barriers to discussion. The first scenario considers individuals who have made a formal decision or commitment and choose to share their wishes with their family (Rudge and Buggins, 2012). The second is engaging in discourse with friends and family, with the purpose of clarifying one's own beliefs or learning those of others (Rodrigue et al, 2008). The third pattern is an avoidance behaviour, wherein individuals either feel uncomfortable discussing the topic of death (Tayeb et al, 2010) or anticipate objections from family and wish to avoid conflict (Duronto et al, 2005).

In all three countries, there was a low reported incidence of non-discussion. Whilst this is a positive and promising finding, it must be interpreted in the context of the research sample composition. All three sub-groups operate within the hospital setting and therefore have access to potential environmental triggers that may prompt discussion about DOD. In the focus groups, these were revealed as personal experiences for patients, the hospital working environment for administrative staff and clinical placements in the case of medical students. Subsequently, an area of future study is the communication incidence in lay groups outside of the hospital setting.

Nevertheless, within the focus groups, medical students also described feeling 'unprepared' to host discussions both within their own social circle and with future patients, leading to a critical variant of the 'non-discussion' category. Deficits in non-technical and interpersonal skills may evolve into future barriers in service provision (Stevens et al, 2006) and require enhanced communication training curricula (Wright et al, 2006). By comparison, the patient subgroup were the most proactive in this domain, frequently acting as information sources and advocates within their immediate social group and the extended community. The impact of this prolific campaigning was also reflected by the DHQ results, wherein patient stories where the preferred source in all three countries.

b) CONSENT DECISIONS: AGREEMENT, INTRINSIC AND EXTRINSC INFLUENCE ON CONSENT DECISIONS

In the DHQ, when presented with the hypothetical question of granting consent for family members, there was a strong willingness to do so for close family members such as parents, partners and siblings, compared to more distant family members, such as cousins. In addition, for closer family members, Cohen's kappa indicated that there was a 'fair' agreement between the parties, suggesting that conversations were bidirectional (Biely et al, 2012) and the appraisal of each other's position was accurate (Koerner and Fitzpatrick, 2006). By comparison, the agreement for distant family members was only 'slight'. Furthermore, the participants were moderately equipped to handle uncertainty, with only a few individuals answering that they would grant consent where discussion had not taken place. This testifies to the merit of DOD discussions in overcoming the barrier of familial consent and confirms existing theories on the mechanics of family refusal (Ghorbani et al, 2011).

This is a parameter that merits further exploration, as the results of this study must be interpreted with some consideration of the confounding influence of errors in retrospective recall (Demiray et al, 2018) or hindsight bias on the participants' ability to accurately recall the wishes of their loved ones' views.

c) DESIRABILITY BIAS AND RELATIONAL ADJUSTMENTS

The phenomenon of desirability bias (Grimm, 2010) dictates that when presented with questions that have moral or ethical implications, individuals tend to answer in a way they think society expects them to answer. This would overestimate the proportion of pro-donation responses among the study population. This is mostly a confounding factor in the focus group discussions (Hollander, 2004), which are inherently vulnerable to group dynamics and anonymity is not always possible.

This desirability phenomenon may extend to socially situated or in-hospital conversations. This was most prominent in the descriptive statistics of the Dutch and Spanish samples, where a very small proportion of negative personal were recorded. In Spain, the focus group results indicated that it is common for families to grant consent because they feel a pressure to act in a 'socially responsible' manner, even though this may conflict with their personal values (Etzioni, 2003).

d) HEALTH TEAMS AND FAMILIES: LANGUAGE AND DONATION REQUEST

In the UK focus groups, it was believed that support for DOD gradually diminishes as the context comes closer to the reality of the donation process. In the Spanish focus groups, it was revealed that the healthcare team and transplant coordinators can be instrumental in clarifying uncertainties and explaining technicalities for potential donor families. Marmisa and Escalante (2002) validated this hypothesis, reporting that persistence in communication, attempting further approaches after an initial negative answer and allowing a period of reflection can increase familial consent rates from 59% at first request, to 81% after 'up to five additional requests'. This testifies to the value of bidirectional communication both within and outside the hospital setting.

5.2.3 KNOWLEDGABILITY

Historically, access to information was considered a catalyst in decision making (Woolf et al, 2005). Furthermore, the focus group discussions predicted that campaigns seeking to promote communication about DOD among families must seek to increase knowledge. This is based on the assumption that the quality of discussions is determined by how well individuals address core issues.

For this reason, the DHQ 'confidence' parameter assessed the participants self-perceived knowledge level. The statistical analysis indicated that participants over-estimated their knowledge on DOD, as although positive, there was a weak correlation between the two. Specifically, in the MCA, 'supporter/non-supporter' profiling was most closely related to familiarity with common health topics, such as high blood pressure, diabetes and smoking whilst 'registrant/ non-registrant' profiling was associated with specialised health topic awareness, such as mental illness, HIV/AIDs and Alzheimer's Disease. With regard to the topic of DOD, the quantitative results indicated that overall understanding is limited to the social aspects of topic, such as the organ shortage issue and waiting lists. Conversely, there was limited knowledge on technical and practical aspects, such as registration options and hospital protocols. This was also conveyed in the focus groups, wherein individuals were unaware of the opportunity for selective donation and often cited organ-specific sentimentality with regard to 'eyes' and 'heart' along with perception of DOD as an 'all-or-nothing' commitment for their reluctance to become organ donors. This reiterates the importance of conveying accurate information and emphasising the significance of choice in DOD decisions in order to support individuals' autonomy and accommodating their wishes.

These results suggest that campaigns have thus far been effective in creating a background consciousness and raising awareness of the topic only as a social issue. In the 'trans-theoretical model of change', this is mapped as the 'precontemplation/ contemplation' stage (Prochaska and Velicer, 1997). Public engagement with DOD campaigns remains stagnant as the public underestimate their role and responsibility in this process. A common notion is that the burden of responsibility lies with a second or third party, such as healthcare institutions, governments and other cultural subgroups. Only once individuals regain their sense of control over the social issue they will progress through the transformative stages of behaviour change and overcome this behavioural inertia (Harper et al, 2013).

5.3. SECTION B : CAMPAIGN DESIGN, INTERVENTIONAL SUGGESTIONS FOR MOTIVATING BEHAVIOUR CHANGE

5.3.1 GLM PREDICTIVE MODELLING AND CAMPAIGN DESIGN

Predictive modelling showed that the domains: value judgement, communication and knowledge are prioritised differently in 'supporter' and 'registrant' status profiling. For support, value judgement was the top-ranking domain followed by communication and lastly knowledge. This indicates that campaigns seeking to increase support for DOD should prioritise reconciling individuals' personal attitudes and beliefs with the topic of DOD through *guided interactivity*. In contrast, the predictive model for registrant status prioritised communication, followed by knowledge and lastly value judgements. This suggests that *targeted informativity* and integration of DOD in social culture are integral to promote and uphold the desire of individuals to register for DOD. Guided interactivity and targeted informativity are complementary approaches that can be used to inform campaign design by addressing the HL domains in an ordered manner, to generate either support for the topic of DOD or to facilitate registration behaviours.

5.3.2 OPTIMISING ATTENTIVENESS: ORIENTING RESPONSES AND CULTURAL EMBEDEDNESS

Directing attention to new messages requires an instinctive response to either new or self-benefiting information (Livnat, 2017). Subsequently, systematic repetition establishes the message's presence and persistence in the competitive information landscape (Lewandowsky et al, 2012). The qualitative results indicate that both orientation and maintenance measures are equally important.

Messages that are overutilized may lead to individuals becoming desensitised to them. In the Dutch focus groups, participants believed this to be the cause of the Netherlands' population's perceived indifference to pro-registration campaigns. In contrast, in the UK focus groups, participants criticised the sporadic and intermittent nature of campaigns. This reduces their memorability and provide insufficient time for audience response. An indisputable facet of the success of the health literacy programme in Spain is the cultural integration of the DOD topic.

This reflects a complex balance that must be addressed by HL campaigns for DOD. A respect for the autonomy of individuals requires nuanced health promotion campaigns, facilitating informed consent and decision making (Brennan and Binney, 2010). Therefore, to facilitate transition from precontemplation to contemplation, campaigns must be informative (Di Clemente, 2007). However, to enable the conversion of intention into action, campaigns must be directive (Cho and Salmon, 2006).

5.3.3 GUIDED INTERACTIVITY

The collection of sources that scored highest in usage are also those that are the most easily accessible, through one's social circle and electronic resources (Amante et al, 2014). In contrast, the materials with low usage preference, such as GP consultations and hospital leaflets are more specialist and demand face to face interaction. These tend to be fact-based and demand higher health literacy requirements (Lustria et al, 2011). By comparison, media-oriented content is predominantly audio-visual, thereby minimising difficulties with technical terms and language (Altin and Stock, 2015). The Internet is a preferred source because of its accessibility, and potential for interactive tailoring of information. The qualitative results indicate that people mostly use this resource to access subjective information, such as patient narratives and religious guidance rather than to formally learn about the medical aspects of the topic or to register one's consent decision. However, the literacy requirements of this resource must not be underestimated. Readers must personally appraise the credibility of the source and navigate through large volumes of information (Woolf et al, 2005).

The requirements for guidance increase as registration options multiply and the sphere of information available continues to expand (Woolf et al, 2005). This is because information seekers can obtain a plethora of facts within an instant, however, they struggle to assimilate this information and use it to make judgements (Smith, 2013). Furthermore, elder generations, those of a low socio-economic background or those with limited information technology capabilities become victims of the 'digital divide' (Brodie et al, 2000). The UK focus groups revealed that younger people are socialized differently in the reception and interpretation of media messages. As a result, elder family members often rely on the younger family members to help them navigate this resource. The DHQ results generally conform with expectations about the correlation of source formality and credibility (Diaz et al, 2002). Lower standardised scores were obtained by those who used their place of worship, school, colleagues, TV shows and social media for information. This result is generally expected, considering the subjective nature of these resources (Conesa et al, 2004).

While written information and remote or internet based tools clarify choices and information, these cannot replace the human element in facilitating informed choice. The demanding pace of patient care leaves little time for lengthy and detailed discussions. This is unfeasible in the already time pressured circumstance of the in-hospital donation request. In the community, clinicians also face barriers to the effective implementation of informed consent. This challenge is intensified by low literacy and cultural discrepancies (Rosenberg et al, 2007).

The school setting is responsible for primary introduction and sensitisation (Lister-Sharp et al, 1999). In a wider social context, as mentioned previously, local figures of authority, such as teachers, religious advisors and GPs are influential and underutilised resources. This is the basis of guided interactivity. The information accessed at a local level sets the foundation for the understanding and evaluation of messages in campaigns taking place on a national level.

5.3.4 TARGETED INFORMATIVITY

Targeted informativity is best achieved when messages are direct and singular. In promotion design, memorability is a tradeoff between the content's structure and its complexity. Complex content requires a simple structure (Parvanta et al, 2011). The qualitative results attributed the success of Spanish campaign design lies to its limited use of complex medical topics and endorsing singularity, focusing on three core messages. The first raises awareness of the scale of the organ shortage issue. The second accentuates the leading status of Spain. The third and most important message is that this status may only endure through the actions of its citizens. Consequently, the public are encouraged to discuss the topic with their families and prepare them for the moment of the request. This message triad is sequential and simple and is therefore, easily retained and followed (Matesanz et al, 2017).

However, such an approach must be exercised with caution, otherwise it may become counterproductive. As indicated by the UK and Dutch groups, DOD is already highly sensitive to adverse publicity. Therefore, a lack of transparency on key medical facts and in-hospital protocols may perpetuate notions of distrust in the medical team and organ procurement process (Russell et al, 2012).

Two possible strategies have been identified for incorporating factual information about DOD into campaign design. A severity focused approach emphasises the organ shortage issue, including waiting list length, organ trafficking and the financial burden on national health systems. In contrast, a susceptibility focused approach addresses the lifetime risk of personally requiring a transplant.

A meta-analysis by Carpenter (2010), demonstrated that audiences are more responsive to messages about severity, rather than susceptibility. However, this may not be the case in DOD. Both the quantitative and qualitative analyses identify utilitarian ethics, such as reciprocity and pragmatism as the most influential pro-donation values. Furthermore, the persuasive impact of these arguments was confirmed by studies testing the effectiveness of different messages encouraging registration, on the national UK DOD website. The best-performing message drew on ideas of reciprocity and fairness (Harper et al, 2013). This reiterates that targeted informativity, as aforementioned in Spain is essential to add clarity and confidently convey messages.

It is apparent that rational and emotional appeals are not mutually exclusive, as emotional appeals are not inherently irrational, and vice versa (Parvanta et al, 2011). Patient narratives are an important resource in achieving this balance. These combine subjective experience with objective report. Narratives, exemplars and anecdotes allow audiences to process complex and abstract information. Thus, narratives must be carefully selected to carry the core content of a message; which is encouraging people to make a decision and share this with their families. Otherwise, campaigns run the risk of individuals remembering the narrative but not paying attention to the core content.

5.4 CHAPTER CONCLUSION

This chapter discussed the domains of values, communication and knowledge seen to affect decision-making in DOD. These variables were ranked differently between 'support' and 'registrant' status in predictive modelling and approaches of guided interactivity and targeted informativity were proposed to be useful in designing future campaigns to address each status more effectively. Differences highlighted in each status are essential in personalising messages and building a cultural acceptance of the DOD topic.

7

CHAPTER 6

THESIS CONCLUSIONS

6. 1 INTRODUCTION

The previous chapter discussed the implications and complementary nature of the quantitative and qualitative results in the construction of 'support-registrant' profiling using parameters of HL and the potential use of these findings in providing a guide for campaign design that recognises that two separate approaches are required for achieving supporter status and registrant status.

This final chapter summarises these conclusions, provides an overall review and the researcher's reflection of the thesis and discusses the study limitations. Finally, this chapter considers the position of this work within the wider context and presents opportunities for future studies.

6.2 THESIS SUMMARY

This PhD has combined the three core determinants of HL (Individual: socio-demographics and value judgements, Social: communication patterns and Cognitive: knowledgeability) and deconstructed the HL agenda, as presented by the transplantation public health organisations in each of the three participating countries (each with different national organ donation rates; Netherlands [low], UK [intermediate] and Spain [high]) to construct a DHQ. This was used to assess the relative contribution of each specified parameter in the construction of support-registrant profiling. These results were closely and iteratively considered with the comments of lay individuals with close association to the healthcare setting (patients, administrative staff and medical students) in order to evaluate current campaign design for HL in DOD and make recommendations for future campaigns.

6.3 THESIS CONCLUSIONS

6.3.1 REDEFINING THE ROLE OF HEALTH LITERACY IN DOD

Health literacy is both an individual and societal trait. It is also context dependent and modifiable. Furthermore, health literacy reflects how knowledge is presented by the public health organisations and how those organisations respond to the populations' needs. At its core, health literacy enables access and understanding of the information required to make informed health decisions. At its best, it successfully facilitates health behaviour change. This requires longitudinal and composite campaigning, part of a lifelong socialisation process, instead of sporadic and informationally burdened campaigns.

6.3.2 CONSIDERATIONS FOR DOD AS A UNIQUE CHALLENGE IN HEALTH LITERACY

DOD presents several challenges to the traditional relevance and meaning of conventional health literacy. Where mainstream health literacy has a defined target population of patients, DOD addresses the general population, both as potential donors and as family members of potential donors. This leads to a lack of specificity in targeting and the selection of appeals. Furthermore, traditional health literacy addresses the needs of patients who frequently interact with healthcare services. This allows high frequency, longitudinal, face to face monitoring and guidance. In DOD, the information must reach and be deemed relevant by healthy individuals within their individual social milieu. Therefore, conventional health literacy refers mostly to technical competencies, while HL in DOD requires emphasis on motivation. Views and decisions on DOD depend on the interplay between critical thinking, based on medically accurate information, and the emotional, religious, cultural influences of the individual.

Finally, whilst conventional models focus on individualised outcomes for each patient, DOD programmes must instigate behaviour shifts at the individual level, in order to make a significant difference to collective social outcomes. This requires motivating individuals to consider the impact of their decisions and behaviours within their immediate social sphere, their own families, who will be required to grant consent. Beyond this, they must consider their impact on the wider social sphere, including the anonymous recipients, the recipient’s family and the clinical team.

6.4 STRATEGIES FOR IMPROVING HEALTH LITERACY IN DOD: LESSONS FROM SUPPORTER-REGISTRANT PROFILING

Despite legislative changes, increased public health campaigns and in-hospital protocol revisions, DOD campaigns have been largely unsuccessful in triggering behaviour change on a national scale. Addressing this issue requires re-framing the boundaries of time and space within which behaviour change takes place.

Strategies have been fragmented in their focus, addressing either ‘contemplation’ or ‘action’ phases separately and seldom together. The descriptive and predictive models of this thesis suggest that this non-holistic approach stunts the progression from intention into action. Beyond this, there is little consideration for the infrastructure and foundations required for long-term maintenance and behaviour-normalisation. This thesis endorses a tailored approach, rooted in guided interactivity and targeted informativity for addressing ‘supporter’ and ‘registrant’ behaviours.

6.5 PRE-CAMPAIGN ENVIRONMENT

6.5.1 INDIVIDUAL VALUES

Social patterning is a formative influence on and summative determinant of intention and behaviour. The supporter-registrant profiles indicate that demographic characteristics potentially evolve into socio-cognitive constructs. As evidenced by other studies, and the national DOD information websites, minority, ethnic and religious groups are the least likely to adopt registrant behaviours. Whilst past campaigns viewed these as an inhibitory influences, this thesis recognises that these deterministic tendencies are an opportunity for coordinated action, as evidenced by the self-perpetuating Spanish model.

6.5.2 COMMUNICATION

Family conversations about DOD have the most merit when they are bidirectional. In this way, they prepare individuals for both the role of 'potential donor' and 'family member to potential donors'.

In addition, the setting, frequency and formal outcomes of discussions about donation decisions affect their tone and content. Each of these parameters are modifiable. Agreement and homogeneity are a product of the family environment. Where there is an anticipated absence of homogeneity, the desire to avoid conflict leads to low levels of communication and avoidance behaviours, most commonly observed among non-supporter and non-registrant categories. Subsequently, conflict resolution and preparedness to negotiate outcomes are necessary skills for the creation of conversation-conducive environments.

When presented with the hypothetical scenario, most individuals are willing to grant consent for a loved one. This eagerness is on the basis of agreement, following bidirectional conversations. Participants are less likely to do so in the event of non-discussion. This testifies to the importance of creating a culture in which the donation request is anticipated outside the hospital setting. This facilitates the prospective collaboration between individuals and healthcare teams.

For healthcare teams, the donation request is most successful when mediated by specialist transplant coordination teams. These teams are instrumental for optimising the pool of potential donors in hospitals through early donor identification, thereby expanding the time frame over which the donation request can take place, facilitating communication between the healthcare team and the relatives.

6.5.3 KNOWLEDGE

‘Confidence’ indicates self-perceived knowledgeability and this correlates weakly with calculated knowledge score, suggesting that individuals overestimate their own understanding of DOD. For this reason, knowledge is a complex, dynamic and often inaccurate descriptor of supporter-registrant patterns.

Most individuals have good understanding about the scale of the organ shortage issue and waiting lists. This suggests that campaigns have been successful in promoting DOD as a social issue. In contrast, knowledge about the treatment of potential donors and the organ procurement process is considerably lower. As a result, there must be increased awareness of default consent systems, registration protocols and the possibility of selective donation. This can overcome barriers to donation by supporting the individual’s right to control what happens to their body and diminish the inhibitory influence of sentimentality over specific organs, by emphasising that a partial contribution is preferable to no contribution at all. This dispels the myth that DOD is an ‘all or nothing’ commitment.

6.6 CAMPAIGN DESIGN

Health promotion campaigns are important for population sensitisation. Existing supporters benefit from large scale promotion campaigns, where they are given the opportunity to manifest their wishes and are reminded to actively translate their intention into commitment. Non-supporters benefit from smaller, local campaigns and face to face interaction with familiar, trustworthy figures, to explore their views.

DOD promotional campaigns are infrequent and initiate transient interest and informativity. This means that either the frequency of these campaigns should increase, or the memorability of their content must be enhanced. A high degree of visibility serves to remind the public of the issue so that it becomes ingrained within the collective consciousness.

The internet and social networking sites are the most cost-effective methods of sharing messages rapidly and ensuring ongoing informativity. These tools also have the power to transform lay people into informed health advocates. However, internet use has high critical and technical health literacy requirements in order to navigate through large volume of information which may be inaccurate. Intergenerational support is a solution to this problem, where younger family members with greater technical literacy can assist their elders in obtaining information.

Strong appeals originate from an understanding of the relevant personal values that underlie the topic. Informative, yet motivating, emotional, yet realistic depictions of the issue make information more relatable. Respecting the principles of informed decision making requires nuanced health promotion campaigns that balance informativity and instructivity. To former facilitates the transition from precontemplation to contemplation and contributes to supporter profiling. The latter enables the conversion of intention into action and contributes to registrant profiling and pro-communication behaviours. Patients' stories are engaging and motivating in this regard. These appeal to the humanistic component of the decision making and simplify technical messages.

6.6.1 GUIDED INTERACTIVITY FOR GENERATING SUPPORT FOR DOD AND TARGETED INFORMATIVITIY FOR REGISTRANT BEHAVIOURS

Guided interactivity results from sensitivity towards an individual's local networks. This thesis considers this an essential measure for generating support for DOD. The problem and objectives should be defined from the individuals' viewpoint. Achieving effective cooperation with community figureheads, such as religious and spiritual advisors or school educators is crucial to the success of DOD campaigns.

Schools are an important site of health promotion, with the potential to create generations of aware and sensitised individuals. By comparison, it is more difficult to engage with adults with busy schedules and preconceived beliefs. Debating the topic allows rational analysis, learning the views of others and reaching a personal conclusion. This can trigger further conversations with the students' wider social circle, including their friends and relatives, creating a ripple effect and a chain of communication. The topic may be more effectively incorporated in social studies modules, rather than science curricula, featuring talks from patients rather than professionals.

Younger age groups have greater advantage and familiarity with registration options and health promotion strategies. Driver's licenses and documentation renewal requires an individual to be of a certain age and level of maturity and so are a good time to raise the DOD question and register one's decision. In addition, these bureaucratic processes bring the issue of DOD to the attention of young people, who would otherwise not think about their death.

Targeted informativity endorses singularity in campaign messages. In this thesis, instructive campaigns are considered to be most effective in expediting the progression from DOD support to registration, thereby converting intention into action. Campaigns pertaining to DOD must embrace the topic's moral complexity, simultaneously respecting the autonomy of the individual, whilst continuing to drive social change through actions that benefit the greatest number of individuals. This requires achieving a delicate balance between informativity and instructivity. Therefore, campaigns should emphasise pragmatic singular constructs, such as personal susceptibility, utility and shared social responsibility and instruct individuals to communicate their wishes with their family and register their decision.

6.7 CHALLENGES AND LIMITATIONS

The following section systematically details the limitations identified during each stage of the research process and, where possible, provides suggestions on how these could have been avoided or reduced. This is followed by a discussion of the general limitations that impact this thesis as a whole.

6.7.1 CHAPTER 2: DHQ DESIGN AND VALIDATION

Due to the myriad of definitions on 'Health Literacy' and the complete absence of literature on HL within DOD, there was difficulty in selecting a specific theoretical paradigm on which to base the initial stage of the DHQ development. As a result, the final theoretical framework that was incorporated into the design (emphasising the individual, social and cognitive parameters of HL) was a synthetic amalgamation of several theories that were reviewed and not based on an established, pre-existing model. Identification of such a model would also have enabled the construction of a questionnaire that provided an overall score or quantification of HL, based on validated questions.

Regarding the data collection from the national transplantation websites, the validity of the process could have been enhanced through the use of a second reviewer, to generate an inter-reviewer agreement on the data that was collected and the themes into which this data was categorised. This could have benefited from the use of the coding software available in qualitative data analysis tools, such as ATLAS.ti. The original reasons for avoiding the use of such software was that they only consider textual data, thereby eliminating the element of interactivity and necessitating the removal of audio-visual content. It was felt that this would detract from the content analysis review that also considered how the websites accommodate varying health literacy needs. To this end, it may have been preferable to better utilise the collaborators in each of the three countries. As mentioned in the corresponding chapter, these individuals provided invaluable assistance in enhancing the accuracy of translation for the Dutch and Spanish websites, thereby aiding the eventual hermeneutic analysis. An extension of their role could have been to act as second and third reviewers of the content, to make the data collection and organisation more reliable.

During the DHQ development and validation process, it was advised that questions that were too dependent on participants' recall should be removed. However, such questions were unavoidable in the 'Communication' section, which examined participants' communication patterns, including the ability to recall the incidence of discussions about DOD with their family members and the views that were presented in these discussions, in order to make a decision about willingness to grant consent. These questions were included because they reflect the reality of in-hospital consent decisions, where individuals must recall the wishes of their loved ones.

6.7.2 CHAPTER 3: QUANTITATIVE ANALYSIS OF DHQ

A conscious decision was made to prioritise and emphasise emergent patterns in the overall cohort, rather than focusing on each of the participant subgroups (transplant patients, administrative staff and medical students) and in each of the participating countries separately. As mentioned in the 'Methods' section of the corresponding chapter, this decision was based on both theoretical and practical criteria. The theoretical rationale was that the derived supporter-registrant profiling and its implications on campaign design should have a high degree of universality and generalisability. This is best achieved when considering the sample holistically and providing a cross-sectional overview, powered by countries with different organ donation rates.

As mentioned in the corresponding chapter, the sample size calculation only considered the minimum number of participants required from each country and achieving a roughly equal distribution of participants from all three subcategories (patients, staff and student). At the time, it was felt that no specifications should be made about participant demographic characteristics, so as to allow for randomisation. However, discrepancies in the sample compositions within each of the three countries led to limitations in Part A of the statistical analysis, particularly in the Spanish sample, where there was a high degree of homogeneity in demographic characteristics, limiting the extent to which the sociodemographic hypothesis testing could be conducted.

Furthermore, owing to the overall high proportion of missing values for sociodemographic characteristics in each of the three countries, it was necessary to make practical adjustments, increasing the power of the statistical tests that followed. For instance, in Part D, the demographic results were presented in an independent MCA graph. This made it more challenging to accurately interpret the impact of these variables in relation to the social and cognitive categories which were presented in the main MCA graph.

As mentioned in the limitations for Chapter 2, for Part B: Communication, there was an inclusion of questions that depended on participant recollection. This means that it is possible that hindsight bias may be a confounding influence on the respondents' answers, overestimating agreement. Therefore, a method for overcoming this bias and to more reliably assess attitude congruence and level of agreement would be to issue the questionnaire to both individuals and their loved ones. However, this would require a new and separate study design and participant population.

Finally, with regard to Part E, despite the model's strong predictive performance, the DHQ was mainly designed as an exploratory tool to reveal participant tendencies and on this basis, predict the priority with which HL domains influence these tendencies. Therefore, the mathematical model used in Part E was specifically designed for theoretical purposes. This means that despite considering AIC and potential for generalisability, it must be reiterated that the model is limited by its developmental environment, which may differ from the operational environment.

6.7.3 CHAPTER 4: QUALITATIVE ANALYSIS

The primary limitation in the qualitative stage of the research relates to the need to overcome the language barrier in the Dutch and Spanish groups. This was less of an issue in the Dutch group, wherein most of the participants were able to confidently participate in the discussions in English, being supported by the Dutch research collaborators when necessary. By comparison, as mentioned in the corresponding chapter, there was a significantly greater language barrier encountered in the Spanish group. As a result, the Spanish research collaborator was the primary moderator in this instance. Clarification of the intended research outcomes and interview questions with this collaborator prior to the discussions helped to diminish the influence of potential biases and protocol variations. However, the interpreters used to overcome the language barriers inevitably generate artefacts within the qualitative data through participation in data analysis. A review of the translated transcripts indicated that the topic guide structure was generally well adhered to and there was good cross-comparability of the themes with the data from the UK and the Netherlands FGDs.

In addition, the role of the researcher as the primary moderator of the discussion presents neutrality issues both during the FGDs and in the coding process. During the FGDs, the presence of a second moderator helped to ensure that the discussion was focused on the topic and addressing the research aim and to intervene if they felt that the primary moderator was monopolising the discussion or projecting their own views onto the participants, although there were no such issues. With regard to the transcript coding process, the use of a deductive approach means that it is possible for personal confirmatory bias to influence the allocation of codes to participant quotations, affirming one narrative over another. For this reason, the use of a second coder and the calculation of inter-coder agreement helped to ensure that the quotations were interpreted reliably and categorised under the correct themes. The high level of inter-coder agreement validated that this process was done objectively. Nevertheless, one way of increasing the methodological validity could be during the coding and analytical process, using an emergent-systematic focus group design. This would involve sorting the discussions into two groups. ‘Emergent’ would consider the focus groups that are used for exploratory purposes. ‘Systematic’ refers to the focus groups that are used for verification purposes (Onwuegbuzie et al, 2009).

As mentioned in Chapter 5, within group interviews, there must be some consideration for the ‘desirability phenomenon’ and the underlying group dynamics that have the potential to influence individuals’ answers so that they are skewed towards favourable answers or agreeableness. Efforts were made to minimise this by moderating the FGDs, encouraging contrasting views and advising participants at the beginning of the process that there were no correct answers. A methodological approach to overcome this could have been to conduct one to one interviews. Although this was considered, it was felt that the overall benefit of participant interaction outweighs the possible risk of desirability bias.

6.7.4 OVERALL LIMITATIONS

As mentioned in Chapter 1, the study population is a cross-sectional representation of the key lay figures involved in DOD. Although they represent a random sample of a population, the volunteers who agreed to participate in this study may represent people who hold strong views for or against DOD. This means that further studies are required to assess the generalisability of the defined parameters among the general population and in the non-academic setting.

Finally, as a non- native English speaker, I had to make a considerable effort to improve my language skills and academic writing technique. This was done by attending several skills workshops, seminars and receiving invaluable guidance from my supervisor.

6.8 THE WIDER CONTEXT

In the broadest sense, the implications of these findings will hopefully be used to redefine the use of health literacy principles, agendas and tools and consider expanding its use as a social tool to drive collective behaviour change, beyond its current use within the healthcare setting. For DOD, the implications of this approach could be invaluable in facilitating coordinated actions on a large scale, diminish indecisiveness, passive behaviours and family refusal rates. The purpose of addressing these factors is contributing to the resolution of the organ shortage crisis.

When this PhD first commenced, there were no publications existing on HL within DOD specifically and, as presented in Chapter 1, very few concerning the application of socially situated HL. Now there are several. A small summary of current and ongoing research is summarised below.

a) The UK Donation Ethics committee (2016) published a paper, outlining the role of family in organ donation decision making and offered proposals on how hindering factors could be mitigated and shared decision making could be optimised
b) The Access to Transplant and Transplant Outcome Measures cohort trial (Taylor et al, 2017) outlined how decreased education levels and poor HL were associated with a poor clinical prognosis for CKD patients and significantly affected their ability to participate in shared and informed decision making in terms of their ongoing care.
c) Taylor (2018) investigated the association that low HL in patients with CKD was associated with attenuated understanding of their condition and overall worse clinical outcomes.
d) A study published by Zhou et al, (2018) described higher HL rates in live donor organ recipients compared to deceased donor recipients. A comparative investigation into online websites on live and deceased organ donation indicated that the education level of the commonly used sources surpasses the HL level of the population on average. This indicated that popular sources still need to be amended and tailored to particular populations and ensure informed decisions in terms of their medical care.
e) Chrisholm-Burns et al, (2018) presented the Health Literacy Model in Transplantation which outlined common characteristics of individuals receiving solid-organ transplants who are associated as having low HL. Individual factors and wider variables associated with healthcare systems were described as acting as potential barriers to patient healthcare access.
f) Jones et al (2019), conducted a study investigating the sociodemographic profiles of individuals on the NHS organ donation register. The study reported groups which were over and under-represented on the register and emphasised the importance of designing targeted campaigns to increase registration rates among under-represented groups.

These studies indicate that HL has an emerging and vital role to inform patient understanding and facilitate access to appropriate are which must be further addressed and recognised in relation to organ donation. Factors unique to patients and those in the wider healthcare context associated with low health literacy must be further studied and proposals on how to overcome these inequalities and ultimately improve patient outcomes must be made.

6.9 FUTURE DIRECTIONS

This PhD has demonstrated that principles of health literacy can be used to aid in the design of effective campaigns that can facilitate coordinated social action and make progress in bridging the characteristic intention-behaviour chasm of DOD.

Nevertheless, the use of HL in DOD campaigns is still a developing concept with a vast amount of potential. As such, the research evidence in this study indicates a need for the following research and action steps towards the systematic development of a well-tailored, quantifiable and monitored DOD - health literacy research agenda and action plan:

- Use of an intergenerational approach and health literacy culture which integrates youth, adult and old age DOD health literacy needs and interests into a relational vocabulary and clear way of thinking.
- Broadening the social and ethical scope of health literacy definitions to include the ability to do good and not harm other people's health and well-being (e.g. DOD donation, spread and transmission of infectious diseases, etc.).
- Use of a *grassroots* social marketing education approach which aims to increase the involvement of new people with those already reached in the past; such an approach would ensure a curriculum based *on social learning*
- A carefully prepared DOD Health Literacy *Curriculum that uses blending and balancing* to create a coherent and whole body of knowledge that promotes confidence and prevents confusion and uncertainty; such a curriculum will provide space not only for differentiation but also strategic integration of opposing views about the matter.
- Use of a *case study curriculum* approach, proved to effectively work in a range of multidisciplinary training programs (e.g. police, courts of justice, business apprenticeship training programs, etc.). Based on a scenario and solution oriented clear, positive and strategic use of dialogue such a DOD health literacy practice would encourage both independent and collaborative activities and multidisciplinary research.
- *Field experiences* (e.g. talks, debates and visits to transplant clinics, A&E departments, community centres, etc.) to sensitise and normalise individual and group related D.O.D life experiences and expectations.

- Design of a school-based *primary* DOD health literacy program that supports instruction and training, values clarification, patient empowerment and ‘phronesis’ or practical wisdom.
- Design of a *secondary* local health community DOD health literacy program for ad hoc counselling, advice and guidance of individuals and families who face life threatening and traumatic health crisis situations.
- Design of a *‘Booster’* DOD health literacy training program based at college or work to refresh previous skills, recruit and train peer teaching volunteers at local schools, hospitals, libraries, adult colleges and community centres.
- It would be worth examining the conditions under which registration options are made available to the population and whether the question to register is offered consistently or on an infrequent basis.
- To complement information campaigns, there must be an accompanying implementation strategy for healthcare teams. This requires making amendments to existing clinical protocols and retraining.

6.10 PERSONAL REFLECTION

The process of completing the dissertation served as a learning experience for me both as a researcher and a person. As a researcher, I developed a greater understanding of my own strengths and weaknesses and gained a greater understanding of the different methods of analysing a single data set, in order to obtain the maximum amount of information about current and future trends. On a personal level, studying the topic of DOD and learning the views of others through the focus groups made me appreciate the gift of life and health more than I did at the beginning of my research. In addition, I became more empathetic to people's different reactions to such a sensitive topic and I felt truly privileged by their willingness to share their time and personal experiences in the pursuit of research that they believed would create a brighter future for patients on waiting lists.

Researching the background information of DOD and HL introduced me to the canvas of organ donation, both deceased and living. My excitement led me to pack as many items as I could in the questionnaire to approach the topic as spherically as I could. This strategy was helpful as it allowed me to get a large amount of information on the variables associated with support and registration of lay people as organ donors in three countries. However, in the future I would choose less variables of the topic to focus on them more deeply. Conducting primary research made the topic much more tangible for me. The DHQ showed me that participants were more reluctant to answer certain questions. This could be due to a number of reasons, such as being tired by the length of the questionnaire, difficulty understanding the terms, fear of giving wrong answers or moving on to parts of the questionnaire which were more relatable to them.

Through the focus group discussions, I reflected on my skills as a moderator. I wondered where the line is between directing the discussion strictly to the questions of the focus group and letting participants express their thoughts, arguments, feelings and experiences more freely. I chose to follow the second case, as long as they stayed relevant to the topic, so that through the discussions I could pick more issues than the ones I intended to find. As a result, I gained more insight about my topic. For example, I realised that the word 'donation' was a stronger key word than 'deceased organ donation' for some participants, and they used it as a starting point to talk about and compare different kinds of donation, which were not always directly related to deceased donation specifically (e.g. live-related donation, blood donation etc.). The many sides of donation showed their interests and experiences, but also showed to me that other different kinds of donation are much connected to each other.

I felt conflicted about what I should do in such cases; whether I should immediately interrupt the participants and tell them that the topic was DOD or whether I should let them explain their thinking, so I could more easily follow their train of thought. Interrupting them would mean that the discussion stayed focused on DOD. Letting them talk could give them a sense of freedom and that there were no right or wrong answers. I chose to follow the second path. In some instances, other participants reminded the group that they were focusing on DOD. What I saw was that some participants were more supportive of living donation than DOD. However, I found it interesting that even in the case of living donation, there were some participants had concerns. Some said that they would be willing to give their organs but not accept organs from their family (UKad1).

Ideally, I would have liked to have more study participants who expressed concerns about DOD, but there were few such cases. In the discussions of the UK administrative staff participants shared their concerns and participants in the UK students shared their difficulties for open discussion with families. I think that due to the nature of the groups in the research it was to be anticipated that some participants from the administrative staff, a group closer to the general public, would express concerns. The medical students all said that due to their studies, they were mainly supportive towards DOD, but were aware of some concerns of the general public and talked openly about them. The patients were by nature a group positive to DOD, as most of them were recipients or hoped that one day they would be recipients. At one point, I felt that the passion of some participants to try to better understand the arguments led them to ask too many questions to the participant who expressed concerns and I led the spotlight away from that participant by asking different questions.

I also noticed that the discussion acted as a forum for patients to express their frustrations and questions. At some points the UK patients were not talking about DOD but about transplants and their own experiences before and after transplant. This line of discussion surprised me because I thought that the recipient-patients were satisfied by the fact that they underwent a transplant and that after the operation their life would be instantly improved. However, through their frustrations I realised that the patients cannot be considered a unified group. It also showed me that the transplant was a very important part of their journey, but definitely not the end of their journey. In the future, I would be very interested in learning more about the patients and their families to learn about their anxieties and the gaps of information they have both before and after transplant.

I also saw that the focus groups helped me evolve my moderating skills. During the first focus groups that took place, I was more insecure which made me stay closed to the outline of the questions. Adding to this, the factor of the language barrier in Spain may have made the participants more reticent to speak or the interpreter not translating to me all the things that the participants were saying but rather the central points. In the Netherlands, the discussions were all in English and I felt more experienced as I had more realistic expectations of how the discussions might unfold. Intuitively, I was preparing prompt questions and was trying to continue from where the Spanish discussions were left. In the UK, the discussions flowed more easily. I think that the participants were also more relaxed. Some reasons for this might be the fact that I was also based on the same Institute that they were studying, working or going for treatment.

One of the areas that I need to be more diligent about in the future are my time management skills. Writing the thesis took more time than I anticipated, owing to the high volume of information there was to analyse. In addition, I had to work extremely hard to overcome my personal challenges in writing academically in English. This meant that I kept revising my drafts multiple times, incorporating the comments of my supervisors. It then took several revisions before I was personally satisfied with them. I believe that although lengthy, difficult, and at times, disheartening, this time was a period of personal and professional development, for which I am grateful.

6.11 CHAPTER CONCLUSION

This chapter summarised the significant results obtained from the quantitative and qualitative analysis and the wider context of this thesis. The researcher's personal reflections and the limitations of the thesis were also discussed as proposals for future directions. Through the construction of supporter-registrant profiling, and predictive modelling, this thesis has contributed two novel concepts to HL within DOD, guided interactivity and targeted informativity. This thesis predicts that these concepts will optimise campaigns, for support and registration for DOD respectively.

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APPENDIX A

QUESTIONNAIRE VERSION 1

1. Tick the organs you think can be donated? Yes No
2. Can older people become organ donors? Yes No
3. Until what age can people donate organs?
4. Until what age can patients receive organs?
5. Your knowledge about organ donation is

a) very satisfactory b) satisfactory c) little satisfactory d) not satisfactory

6. Do you know how to register for organ donation? Yes No
7. Even if somebody is registered as an organ donor, the family ultimately decides Yes No
8. Can the waiting list be manipulated? Yes No If yes, by whom?
9. Are waiting lists long? Yes No
10. Are all patients in the waiting lists transplanted? Yes No
11. Are the survival rates a) high b) average c) low
12. Do you believe that the medical stuff treats organ donors effectively, when in critical condition? Yes No
13. Do you know people who are organ donors? Yes No
14. Do you know people who are organ recipients? Yes No
15. Do you know patient who needs transplantation? Yes No
16. How soon after the organ donor is pronounced dead does the retrieval begin?
17. How long does the retrieval of organs last?
18. Is the body of the organ donor disfigured after the retrieval? Yes No
19. Can the funeral be in an open casket? Yes No
20. Can the family of the organ donor meet the recipient? Yes No
21. Should the family of the organ donor meet the recipient? Yes No
22. Do you think that in your country organs could be sold? Yes No
23. Can donated organs be used for research purposes? Yes No
24. Can donated organs be used for cosmetic surgery? Yes No
25. What do you think happens to donated organs that are not transplanted? a) used for research b) used for cosmetic surgery c) wasted d) sold e) other (please name)
26. Do you know the legislation about organ donation? Yes No
27. In your country everyone is presumed to be an organ donor, unless otherwise said Yes No
28. You are informed about organ donation a) very well b) well c) adequately d) not adequately
29. You would like to know more about
    a) brain death b) organ registry c) transplant survival results d) other (please name)

30. Do you support organ donation? Yes No If yes, could you tell the reasons

If no, could you tell the reasons?

31. Do you support living organ donation? Yes No
32. Have you decided to become an organ donor? Yes No
33. Have you registered as an organ donor? Yes No If not, could you tell us the reasons
34. If a member of your family needs transplantation, would you accept cadaveric organ donation? Yes No
35. Would you consent organs of a family member to be donated? Yes No

36. Would you donate your organs after death? Yes No
37. Would you be a living donor for a relative? Yes No
38. I have discussed about organ donation with my family
39. I need my family's opinion before I decide Agree Disagree
40. I need my family's consent about my decision Agree Disagree
41. Talking about death brings bad luck Agree Disagree
42. Registering as a donor brings bad luck Agree Disagree
43. Personality traits of the donor are passed through to the recipient Agree Disagree
44. Should organ donors be written in the driver's licence? Agree Disagree
45. Until what age should people receive organs?
46. The organs should be donated to people of the same religion? Agree Disagree
47. The organs should be donated to people of the same origin?
48. The organs should be donated to people who live in the same country?
49. Are you a blood donor?
50. Would you donate blood only for relatives and friends?
51. Have you read brochures about organ donation? If yes, where? a) GP surgery b) hospital c) other (please name)
52. When was the last time you read it?
53. Have you talked with your GP about organ donation? Yes No
54. Are you aware of a health campaign about organ donation? Yes No
55. Did you talk about organ donation, while at school? If yes, did it happen a) during a course b) by an invited speaker c) accidentally d) other (please name)
56. Have you watched a television advertisement about organ donation? Yes No
57. If yes, when was the last time you watched it?
58. Have you watched a news report about organ donation? Yes No If yes, a) it has answered your questions b) changed your mind c) did not interest you d) other (please name)
59. Have you watched a television documentary about organ donation? Yes No If yes, a) it has answered your questions b) changed your mind c) did not interest you d) other (please name)
60. Do you remember organ donation be mentioned in films? If yes, was it portrayed in a positive manner? Yes No
61. If yes, a) it has answered your questions b) changed your mind c) did not interest you d) other (please name)
62. Do you recall public figures or famous persons talking about organ donation? If yes, please name them
63. Is your faith supportive of organ donation?
64. Have you heard about it during a sermon? If yes, what was the message
65. Have leaders of your faith discussed about it? If yes, what was the message
66. Out of what you have read, heard, watched about organ donation, is there something that has impressed you? (eg. numbers, story, etc.

QUESTIONNAIRE VERSION 2

Sources

1. Are you aware of a health campaign about organ donation?

1 2 3 4 5 6 7 8 9 10
1= not at all 10=very aware

2) Have you read brochures about organ donation? Yes No
If yes, where? a) GP surgery b) hospital c) other (please name)

3) When was the last time you read a brochure?
a) 1-6 months ago b) 6-12 months ago c) more than 1 year

4) What did you think about the brochure?
1 2 3 4 5 6 7 8 9 10
1=did not like it 10=liked it very much

5) Have you talked with your GP about organ donation?
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively

6) Did you talk about organ donation, while at school?
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively

If yes, did it happen a) during a course b) by an invited speaker c) accidentally
d) other (please name)

7) Have you watched a television advertisement about organ donation? Yes No
If yes, when was the last time you watched it?
a) 1-6 months ago b) 6-12 months ago c) more than 1 year

8) Have you watched a news report about organ donation? Yes No
If yes, a) it has answered your questions b) changed your mind c) did not interest you d) other (please name)

9) Have you watched a television documentary about organ donation? Yes No
If yes, it a) has answered your questions b) changed your mind c) did not interest you
d) other (please name)

10) Do you remember organ donation as a theme in films?
If yes, how was it portrayed? a) neutrally b) positively c) negatively d) dangerous e) successful f) unsuccessful e) organ trafficking

11) If yes, a) it has answered your questions b) changed your mind c) did not interest you d) other (please name)

12) Do you recall public figures or famous persons talking about organ donation? If yes, please name them -------------------

13) Is your faith supportive of organ donation?
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively
14) Have you heard about it during a sermon?
If yes, what was the message -----------------------

15) Do leaders of your faith publicly discuss about it?
If yes, what was the message ------------------------

16) Out of what you have read, heard, watched about organ donation, what has impressed you? (eg. numbers, story, etc.)

Knowledge

17) You are informed about organ donation
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively

18) Please list as many organs as you believe that can be donated
Eye lung kidney skin heart liver tissue pancreas bone marrow small intestine

19) Until what age can people donate organs? -----------

20) Until what age can patients receive organs? -----------

21) Your knowledge about organ donation is
1 2 3 4 5 6 7 8 9 10
1=none 10=extensive

22) Do you know how to register as an organ donor?
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively

23) Do you know people who are organ donors? Yes No

24) Do you know people who are organ recipients? Yes No

25) Do you know a patient who needs transplantation? Yes No

26) Even if somebody is registered as an organ donor, the family ultimately decides
1 2 3 4 5 6 7 8 9 10
1=do not agree 10=totally agree

27) Can the waiting list be manipulated?
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively

If yes, by whom? -----------------------

28) Are waiting lists long?
1 2 3 4 5 6 7 8 9 10
1=not at all 10=extensively
29) Are all patients in the waiting lists transplanted? Yes No

30) The survival rates are a) high b) average c) low d) do not know

31) Do you believe that the medical stuff treats organ donors in critical condition as effectively as non donors?
1 2 3 4 5 6 7 8 9 10
1=totally different 10=as effectively

32) How soon after the organ donor is pronounced dead does the retrieval begin?
a) immediately b)1 hour c) 2hours d) do not know

33) How long does the retrieval of organs last?
a) 1 hour b) 2 hours c) more than 3 hours d) do not know

34) Is the body of the organ donor disfigured after the retrieval?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

35) Will the funeral arrangements of the organ donor be different than a non donor's?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=totally different

36) Can the family of the organ donor meet the recipient?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=always

37) Should the family of the organ donor meet the recipient?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=always

38) Do you think that in your country organs can be sold?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=very often

39) Can donated organs be used for research purposes?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=very often

40) Can donated organs be used for cosmetic surgery?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=very often

41) What do you think happens to donated organs that are not transplanted? a) used for research b) used for cosmetic surgery c) wasted d) sold e) other (please name)

42) Do you know the legislation about organ donation?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=very familiar

43) In your country everyone is presumed to be an organ donor, unless otherwise said Yes No

44) You would like to know more about
a) brain death b) organ registry c) transplant survival results d) other (please name)

Attitudes

45) Do you support organ donation?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=without any hesitation

Could you tell the reasons for your decision?

46) Do you support living organ donation?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=without any hesitation

47) Would you be a living donor for a relative?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=without any hesitation

48) Have you decided to become an organ donor?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=confidently yes

49) Have you registered as an organ donor? Yes No
Could you tell the reasons for your decision?

50) If a member of your family needs transplantation, would you accept cadaveric organ donation?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=without any hesitation

51) Would you consent organs of a family member to be donated?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=without any hesitation

52) Would you donate your organs after death?
1 2 3 4 5 6 7 8 9 10

1= not at all 10=without any hesitation

53) Have you discussed about organ donation with your family
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

54) You need your family's opinion before you decide
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

55) You need your family's consent about your decision
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

56) Do you believe that talking about death brings bad luck
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

57) Do you believe that registering as a donor brings bad luck
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

58) Are personality traits of the donor passed through to the recipient
1 2 3 4 5 6 7 8 9 10
1= not at all 10=extensively

59) Should organ donors be written in the driver's licence?
1 2 3 4 5 6 7 8 9 10
1= not at all 10=compulsory

60) Until what age should people receive organs?

61) The organs should be donated to people of any religion
1 2 3 4 5 6 7 8 9 10
1= only 10=irrespectively

62) The organs should be donated to people of any origin
1 2 3 4 5 6 7 8 9 10
1= only 10=irrespectively

63) The organs should be donated to people who live in the same country
1 2 3 4 5 6 7 8 9 10
1= only 10=irrespectively

64) Are you a blood donor?

65) Would you donate blood only for relatives and friends?
1 2 3 4 5 6 7 8 9 10

66) Is registering as an organ donor a decision that is
Strictly individual
Needs to be discussed with family
Needs to have consent by family
Can be made after consulting a religious leader
67. What of these steps would help you make the decision to become organ donors
reading about organ donation consulting specialists watching documentaries
discussing with my family discussing with my religious leader

68. Which of these statements would better reflect your thinking
I support organ donation, but I do not intend to register within the next year
Organ donation is against my religion
I do not want to think about my death
Removal of my organs will disrupt my after death peace
I do not want my body to be disfigured
I am afraid doctors will want to harvest my organs and not pay all the necessary attention
I am too young to register
I am too old to register

Health campaigns

69. Please rank the health issues you consider important
AIDS Alzheimer Cancer Organ Donation Stroke

70. Please mark health campaigns that you consider successful breast cancer AIDS antismoking antidrugs heart conditions

71. What makes a health campaign memorable? a catchphrase a symbol statistics stories of the patients fundraising events

72. If you were to organize a health campaign about organ donation, what would you do brochures documentaries television interviews fundraising events public endorsement by opinion influencing figures education courses to students films legislation interventions

QUESTIONNAIRE VERSION 3: FINAL

Department of Surgery and Cancer

Imperial College
London

DECEASED ORGAN DONATION AND HEALTH LITERACY

PhD Research Project by Dr Maria Theodosopoulou, MSc

You are invited to participate in an Imperial College PhD academic research on a strictly non-paid and anonymous basis. Our study investigates people's views and knowledge about organ donation after death, whether they share their wishes about it, and how they learn about donation of organs and tissue. Organ donation after death means that after the person has died, an organ is given to somebody, who needs a transplant.

Filling in the parts of the survey will take you about 20 minutes. Your collaboration and input are extremely valuable to ensure the design of effective and interactive platforms, campaigns and programs that support lifelong learning about the health issue of deceased organ donation and transplantation – Many thanks in anticipation of your kind consideration and collaboration in our effort.

PART A: Personal views about organ donation after death

The following questions are about your personal views about organ donation after death and the reasons behind them.

1. **Which of the following statements describe your current position with regard to organ donation after death?** Select all that apply

○	**I support deceased organ donation**
○	**I am a registered organ donor**
○	**I have discussed the issue with family /friend(s)**
○	**I have not made a decision about the issue yet**
○	**I need more information about the issue**
○	**I refuse to think about issues related to my death**
○	**I have personally met a person on a transplant waiting list /a donor/a recipient**
○	**I am against deceased organ donation**
○	**I like the idea, but I distrust the medical system**
○	**Other (please explain)**

2. **Reasons you consider to support organ donation after death:** Select all that apply

○ Ultimate act of helping other people
○ Religious beliefs
○ Scientific facts and figures
○ Being remembered as a giving person
○ Relief for the family of the dead donor that one continues to live through
○ Raise awareness and convince others to follow the example
○ None of the above
○ Other (please explain)

3. **Reasons you consider to be against organ donation after death:** Select all that apply

○ Poor medical care of cadaveric donor patients
○ Medical terms are not clear enough
○ Body disfigurement
○ Funeral arrangement complications (eg. delay , open casket service, etc.)
○ Religious objections
○ Cultural traditions
○ There is no argument against it
○ Other (please explain)

4. **In which of the following health issues, do you consider yourself well informed?** Select all that apply

○ Alzheimer
○ Cancer
○ Diabetes
○ Heart Disease
○ High Blood Pressure
○ HIV/AIDS
○ Mental illness
○ Obesity
○ Organ donation
○ Smoking
○ Other (please explain)

PART B: Talking about organ donation after death

The following questions explore whether you share your views about organ donation after death with people close to you and how you view the organ donation of family members.

5. **Have any of the following groups of people communicated a positive, negative or neutral message to you about organ donation after death**?

Please indicate your answer by putting next to each of the following people groups one of the above symbols

	Positive	Negative	Neutral	Never talked about
Parents	○	○	○	○
Siblings	○	○	○	○
Spouse/partner	○	○	○	○
Children	○	○	○	○
Cousin	○	○	○	○
Nephew/niece	○	○	○	○
Friends	○	○	○	○
Colleagues	○	○	○	○

6. **To whom of the following have you expressed your wishes about organ donation after death?** Select all that apply

- ○ Parents
- ○ Siblings (brother/sister/half -brother/half-sister)
- ○ Spouse/partner
- ○ Children
- ○ Cousin
- ○ Nephew/niece
- ○ Friends
- ○ Colleagues
- ○ None of the above
- ○ Other (please explain)

7. **From the list below of people in your life, who has expressed a wish to donate their organs when they die?** Select all that apply

- ○ Parents
- ○ Siblings (brother/ sister/ half -brother/ half-sister)
- ○ Spouse/ partner
- ○ Children
- ○ Cousin
- ○ Nephew/ niece
- ○ Friends
- ○ Colleagues
- ○ None of the above
- ○ Other (please explain)

8. **Would you give your personal consent/ permission in an emergency for the following family members to become an organ donor after death**? Select all that apply

○ Parents
○ Siblings (brother/ sister/ half -brother/ half-sister)
○ Spouse/ partner
○ Children
○ Cousin
○ Nephew/ niece
○ Close friend
○ None of the above
○ Other (please explain)

PART C: How you have learnt about organ donation after death

The following questions explore which sources you use for learning about organ donation after death and how much they have helped you.

9. **Which of the following sources helped you form an opinion about organ donation after death? Select all that apply**

○ Place of worship (e.g. church, mosque, synagogue, etc.)
○ Family and friends
○ School
○ Work colleagues
○ Stories of organ recipients
○ Medical TV shows and films (e.g. ER, Grey's Anatomy, Scrubs, etc.)
○ Family doctor
○ Newspapers & Magazines
○ Medical Documentaries
○ Brochures in a medical clinic or pharmacy
○ Official website of the National Transplant Organisation
○ Other health care websites on the Internet
○ Social media (e.g. Facebook, Twitter, Instagram, etc.)
○ Awareness campaigns
○ Local library
○ Adult learning classes
○ None
○ Other (please explain)

10. **Do you visit the official transplant website of other European countries? Please specify**

○ Yes (please specify which) ……………………………………………….
○ No
○ Other continents (American, Australian, Asian, African)

11. **According to what you know, is there a shortage of organs in this country?**

○ Yes
○ No
○ Not Sure

12. **According to what you know, the legislation in this country about organ donation after death is**

○ Presumed Consent (opting-out)
○ Informed Consent (opting-in)
○ Family consent is always necessary
○ I do not know these terms
○ I do not know the relative legislation

13. **According to what you know, regardless of the legislation in this country about organ donation after death family consent is still necessary**

○ Yes
○ No
○ Not sure

14. **According to what you know, are there financial incentives in this country about organ donation after death (eg. covering funeral costs of the organ donor)?**

○ Yes
○ No
○ Not Sure

15. **In your opinion financial incentives about organ donation after death in this country**

○ would help
○ would NOT help
○ It depends on the kind of incentives

PART D: How clear is your understanding of organ donation after death

The following questions see your understanding around several aspects of organ donation after death.

16. **How confident do you feel explaining the meaning of the following words clear to a family member or friend?** Please select from 1-5 for each statement.

	Very confident 1	2	Somewhat Confident 3	4	Not confident at all 5
Cadaveric organ donation					
Brain stem death					
Circulatory death					
Transplant Coordinator(s)					
Negative Cross match					
Organ Procurement					
Cadaveric organ recipient					
Immunosuppressant medication					
Graft survival					
Tissue donation					
Opt-in/Opt-out system of organ donation					
Higher risk organs					

17. **The statements below discuss different aspects concerning organ donation after death. Please read each statement and circle (T) if it is true, (F) if it is false or (NS) if you are not sure**

People can buy or sell organs in this country T F NS
Organs donated for transplantation include: kidneys, heart, lungs, liver, small bowel and pancreas T F NS
Tissues donated for transplantation include: eyes, heart valves, bone, skin, veins and tendons T F NS
Reproductive organs and tissue are not taken from organ donors after death T F NS
An organ donor registers as a tissue donor as well T F NS

An organ and tissue donor can potentially benefit 8 patients T F NS
A transplanted organ can transmit an infection or cancer to a recipient T F NS
Non transplantable organs and tissues can be offered for scientific research T F NS
If doctors remove organs and tissues, but decide they cannot be transplanted, they dispose them T F NS
Organs and tissue from your country can be offered to patients in another country T F NS
It is statistically more likely for a person to receive rather than donate an organ/tissue T F NS

18. **Statements about waiting lists**

Transplant tourism (patients traveling to a foreign country to obtain an organ) is a serious problem in this country T F NS
Organ donation is not necessary, because stem cell and gene therapy offer safe clinical alternatives to transplantation T F NS
Only people with a healthy medical record can register as organ donors T F NS
Once you register to be a donor, it is not possible to change your mind and withdraw from the register T F NS
Doctors can manipulate the priority criteria and ranking of patients on a transplant waiting list T F NS
Patients on a transplant waiting list who receive media attention increase their chances of receiving an organ/tissue from a deceased donor T F NS
New patients are added to the bottom of a transplant waiting list T F NS
A transplant waiting list is blind to age, sex and race T F NS

19. **Statements about medical care**

You can donate organ(s) only if you die at a hospital T F NS
A brain dead person can never recover T F NS
The medical team follows the same protocol to declare somebody brain dead T F NS
The same medical team that cares for a patient, who is in critical condition, also decides who gets the organ(s) T F NS

20. **Statements about family's role**

Hospitals are required by law to ask for the family's consent/permission even if the patient has signed a donor card T F NS
The deceased patient's family can specify which organs /tissues will be offered for donation T F NS
The donor's family can nominate a specific recipient T F NS
The identity of the recipient(s) is usually revealed to the donor's family T F NS
The recipient and his/her family have the right to describe the characteristics of the organ they would like to accept or decline, eg. non-smoker, young etc. T F NS
The recipient and his/her family have the right to be informed about the condition of the organ and the medical history of the donor, before they accept or decline it T F NS

21. **Statements about funeral and life after death**

An open casket funeral is not possible for a donor as the body is disfigured during surgery T F NS
Organ donation surgery delays a person's funeral T F NS
Organ donation affects a person's after life tranquillity, as the body is injured T F NS

PART E: Organ donation after death in Europe

The following questions explore your views on the issue not only in your country, but seen through a European perspective.

22. Please select from 1-5 for each statement

	Strongly agree 1	**Agree 2**	**Not sure 3**	**Disagree 4**	**Strongly disagree 5**
Shortage of human organs for transplantation is a problem in the European Union					
Trafficking (illegal selling or buying) of human organs is a problem in the European Union					

23. Please answer how is it likely to …?, by selecting from 1-5 for each statement

	Very likely 1	**Likely 2**	**Neutral 3**	**Unlikely 4**	**Very unlikely 5**
Donate your organs/tissues					

after death to a recipient from another European country?					
Register as an organ donor after death of another country-member of the European Union, if you move to it?					

Part F: Demographic information

24. **Have you received an organ transplant? Yes No**
25. **In which year of your medical studies are you at? 1st 2nd 5th 6th**
26. **Your Gender** Please tick the answer

○ **Female**
○ **Male**

27. **Your Age** Please tick the answer

○ **18-29**
○ **30-44**
○ **45-59**
○ **60+**

28. **Your Marital status** Please tick the answer

○ **Single**
○ **Married**
○ **Separated**
○ **Divorced**
○ **Living with a Partner**

29. **Your Education** Please tick the answer

○ **High School or less**
○ **6th form College**
○ **University degree**
○ **Postgraduate studies**

30. **Your Employment** Please tick the answer

○ **Student**
○ **Military personnel**
○ **Self employed**
○ **Part time employee**
○ **Full time employee**
○ **Unemployed**
○ **Retired**
○ **House person**

31. **Your Religion** Please tick the answer

○ **Christian**
○ **Buddhist**
○ **Hindu**
○ **Jewish**
○ **Muslim**
○ **Sikh**
○ **No Religion**
○ **I do not wish to say**

32. **Your Ethnic Background** (categories as seen in the Office for National Statistics). Please tick the answer

○ **White**
○ **Mixed/ multiple ethnic group**
○ **Asian/ Asian British**
○ **Black/ African/ Caribbean/ Black British**
○ **Other (please explain)**
○ **I do not wish to say**

We thank you for your time and cooperation.

QUESTIONNAIRE CODING BOOK

PART A: Personal views about organ donation after death

The following questions are about your personal views about organ donation after death and the reasons behind them.

Which of the following statements describe your current position with regard to organ donation after death? Select all that apply	Q1.position
I support deceased organ donation	Q1.position1
I am a registered organ donor	Q1.position2
I have discussed the issue with family/friend(s)	Q1.position3
I have not made a decision about the issue yet	Q1.position4
I need more information about the issue	Q1.position5
I refuse to think about issues related to my death	Q1.position6
I have personally met a person on a transplant waiting list/a donor/a recipient	Q1.position7
I am against deceased organ donation	Q1.position8
I like the idea, but I distrust the medical system	Q1.position9
Other	Q1.position10

Reasons you consider to support organ donation after death: Select all that apply	Q2.support
Ultimate act of helping other people	Q2.support1
Religious beliefs	Q2.support2
Scientific facts and figures	Q2.support3
Being remembered as a giving person	Q2.support4
Relief for the family of the dead donor that one continues to live through	Q2.support5
Raise awareness and convince others to follow the example	Q2.support6
None of the above	Q2.support7
Other	Q2.support8

Reasons you consider to be against organ donation after death: Select all that apply	Q3.against

Poor medical care of cadaveric donor patients	Q3.against1
Medical terms are not clear enough	Q3.against2
Body disfigurement	Q3.against3
Funeral arrangement complications (eg. delay, open casket service, etc.)	Q3.against4
Religious objections	Q3.against5
Cultural traditions	Q3.against6
There is no argument against it	Q3.against7
Other	Q3.against8

In which of the following health issues, do you consider yourself well informed? Select all that apply	Q4.health
Alzheimer	Q4.health1
Cancer	Q4.health2
Diabetes	Q4.health3
Heart Disease	Q4.health4
High Blood Pressure	Q4.health5
HIV/AIDS	Q4.health6
Mental illness	Q4.health7
Obesity	Q4.health8
Organ donation	Q4.health9
Smoking	Q4.health10
Other	Q4.health11

PART B: Talking about organ donation after death

The following questions explore whether you share your views about organ donation after death with people close to you and how you view the organ donation of family members.

Have any of the following groups of people communicated a positive, negative or neutral message to you about organ donation after death?	Q5.commu
Parents	Q5.commu1
Siblings	Q5.commu2
Spouse/partner	Q5.commu3
Children	Q5.commu4
Cousin	Q5.commu5
Nephew/niece	Q5.commu6
Friends	Q5.commu7
Colleagues	Q5.commu8

To whom of the following have you expressed your wishes about organ donation after death? Select all that apply	Q6.iwish
Parents	Q6.iwish1
Siblings (brother/sister/half-brother/half-sister	Q6.iwish2
Spouse/partner	Q6.iwish3
Children	Q6.iwish4
Cousin	Q6.iwish5
Nephew/niece	Q6.iwish6
Friends	Q6.iwish7
Colleagues	Q6.iwish8
None of the above	Q6.iwish9
Other	Q6.iwish10

From the list below of people in your life, who has expressed a wish to donate their organ when they die? Select all that apply	Q7.theirwish
Parents	Q7.theirwish1
Siblings (brother/sister/half-brother/half-sister)	Q7.theirwish2
Spouse/partner	Q7.theirwish3
Children	Q7.theirwish4
Cousin	Q7.theirwish5
Nephew/niece	Q7.theirwish6
Friends	Q7.theirwish7
Colleagues	Q7.theirwish8
None of the above	Q7.theirwish9
Other	Q7.theirwish10

Would you give your personal consent/permission in an emergency for the following family members to become an organ donor after death? Select all that apply	Q8.consent
Parents	Q8.consent1
Siblings (brother/sister/half-brother/half-sister)	Q8.consent2
Spouse/partner	Q8.consent3
Children	Q8.consent4
Cousin	Q8.consent5
Nephew/niece	Q8.consent6

Close friend	Q8.consent7
None of the above	Q8.consent8
Other	Q8.consent9

PART C: How you have learnt about organ donation after death

The following questions explore which sources you use for learning about organ donation after death and how much they have helped you.

Which of the following sources helped you form an opinion about organ donation after death? Select all that apply	Q9.source
Place of worship (eg. church, mosque, synagogue, etc.)	Q9.source1
Family and friends	Q9.source2
School	Q9.source3
Work colleagues	Q9.source4
Stories of organ recipients	Q9.source5
Medical TV shows and films (eg. ER, Grey's Anatomy, Scrubs, etc.)	Q9.source6
Family doctor	Q9.source7
Newspapers & Magazines	Q9.source8
Medical Documentaries	Q9.source9
Brochures in a medical clinic or pharmacy	Q9.source10
Official website of the National Transplant Organisation	Q9.source11
Other health care websites on the Internet	Q9.source12
Social media (eg. Facebook, Twitter, Instagram, etc.)	Q9.source13
Awareness campaigns	Q9.source14
Local library	Q9.source15
Adult learning classes	Q9.source16
None	Q9.source17
Other	Q9.source18

Do you visit the official transplant website of other European countries? Please specify	Q10.website
Yes	Q10.website1
No	Q10.website2
Other continents	Q10.website3

According to what you know, is there a shortage of organs in this country?	Q11.shortage
Yes	Q11.shortage1
No	Q11.shortage2
Not sure	Q11.shortage3

According to what you know, the legislation in this country about organ donation after death is	Q12.legislation
Presumed Consent (opting-out)	Q12.legislation1
Informed Consent (opting-in)	Q12.legislation2
Family consent is always necessary	Q12.legislation3
I do not know these terms	Q12.legislation4
I do not know the relative legislation	Q12.legislation5

According to what you know, regardless of the legislation in this country about organ donation after death family consent is still necessary	Q13.practice
Yes	Q13.practice1
No	Q13.practice2
Not sure	Q13.practice3

According to what you know, are there financial incentives in this country about organ donation after death (eg. covering funeral costs of the organ donor)?	Q14.financial
Yes	Q14.financial1
No	Q14.financial2
Not sure	Q14.financial3

In your opinion financial incentives about organ donation after death in this country	Q15.incentives
Would help	Q15.incentives1
Would NOT help	Q15.incentives2
It depends on the kind of incentives	Q15.incentives3

PART D: How clear is your understanding of organ donation after death

The following questions see your understanding around several aspects of organ donation after death.

How confident do you feel explaining the meaning of the following words clear to a family member or friend?	Q16.confidence
Cadaveric organ donation	Q16.confidence1
Brain stem death	Q16.confidence2
Circulatory death	Q16.confidence3
Transplant Coordinator(s)	Q16.confidence4
Negative Cross match	Q16.confidence5
Organ Procurement	Q16.confidence6
Cadaveric organ recipient	Q17.confidence7
Immunosuppressant medication	Q17.confidence8
Graft survival	Q17.confidence9
Tissue donation	Q17.confidence10
Opt-in/Opt-out system of organ donation	Q17.confidence11
Higher risk organs	Q17.confidence12

The statements below discuss different aspects concerning organ donation after death.	Q17.aspects
People can buy or sell organs in this country	Q17.aspects1
Organs donated for transplantation include: kidneys, heart, lungs, liver, small bowel and pancreas	Q17.aspects2
Tissues donated for transplantation include: eyes, heart valves, bone, skin, veins and tendons	Q17.aspects3
Reproductive organs and tissue are not taken from organ donors after death	Q17.aspects4
An organ donor registers as a tissue donor as well	Q17.aspects5
An organ and tissue donor can potentially benefit 8 patients	Q17.aspects6
A transplanted organ can transmit an infection or cancer to a recipient	Q17.aspects7
Non transplantable organs and tissues can be offered for scientific research	Q17.aspects8
If doctors remove organs and tissues, but decide they cannot be transplanted, they dispose them	Q17.aspects9
Organs and tissue from your country can be offered to patients in another country	Q17.aspects10

It is statistically more likely for a person to receive rather than donate an organ/tissue	Q17.aspects11

Statements about waiting lists	Q18.list
Transplant tourism (patients traveling to a foreign country to obtain an organ) is a serious problem in this country	Q18.list1
Organ donation is not necessary, because stem cell and gene therapy offer safe clinical alternatives to transplantation	Q18.list2
Only people with a healthy medical record can register as organ donors	Q18.list3
Once you register to be a donor, it is not possible to change your mind and withdraw from the register	Q18.list4
Doctors can manipulate the priority criteria and ranking of patients on a transplant waiting list	Q18.list5
Patients on a transplant waiting list who receive media attention increase their chances or receiving an organ/tissue from a deceased donor	Q18.list6
New patients are added to the bottom of a transplant waiting list	Q18.list7
A transplant waiting list is blind to age, sex and race	Q18.list8

Statements about medical care	Q19.medic
You can donate organ(s) only if you die at a hospital	Q19.medic1
A brain dead person can never recover	Q19.medic2
The medical team follows the same protocol to declare somebody brain dead	Q19.medic3
The same medical team that cares for a patient, who is in critical condition, also decides who gets the organ(s)	Q19.medic4

Statements about family role	Q20.family
Hospitals are required by law to ask for the family's consent/permission even if the patient has signed a donor card	Q20.family1
The deceased patient's family can specify which organs/tissues will be offered for donation	Q20.family2

The donor’s family can nominate a specific recipient	Q20.family3
The identity of the recipient(s) is usually revealed to the donor’s family	Q20.family4
The recipient and his/her family have the right to describe the characteristics of the organ they would like to accept or decline, eg. non-smoker, young etc.	Q20.family5
The recipient and his/her family have the right to be informed about the condition of the organ and the medical history of the donor, before they accept or decline it	Q20.family6

Statements about funeral and life after death	Q21.funeral
An open casket funeral is not possible for a donor as the body is disfigured during surgery	Q21.funeral1
Organ donation surgery delays a person’s funeral	Q21.funeral2
Organ donation affects a person’s after life tranquillity, as the body is injured	Q21.funeral3

PART E: Organ donation after death in Europe

The following questions explore your views on the issue not only in your country, but seen through a European perspective.

The following discussions explore your views on the issue not only in your country, but seen through a European perspective	Q22.europrob
Shortage of organs for transplantation is a problem in the European Union	Q22.europrob1
Trafficking (illegal selling or buying) of human organs is a problem in the European Union	Q22.europrob2

Please answer how is it likely to ….?	Q23.eurodon
Donate your organs/tissues after death to a recipient from another European country?	Q23.eurodon1
Register as an organ donor after death of another country-member of the European Union, if you move to it?	Q23.eurodon2

PART F: Demographic information

Have you received an organ transplant?	Q24.transplant
In which year of your medical studies are you at?	Q25.year

Your Gender	Q26.gender
Female	Q26.genderfemale
Male	Q26.gendermale

Your Age	Q27.age
18-29	Q27.age18-29
30-44	Q27.age30-44
45-59	Q27.age45-59
60+	Q27.age60+

Your Marital status	Q28.marital
Single	Q28.maritalSingle
Married	Q28.maritalMarried
Separated	Q28.maritalSeparated
Divorced	Q28.maritalDivorced
Living with a Partner	Q28.maritalLiving with a Partner

Your Education	Q29.education
High School or less	Q29.educationHigh School
6th form College	Q29.educationCollege
University degree	Q29.educationUniversity
Postgraduate studies	Q29.educationPostgraduate

Your Employment	Q30.employment
Student	Q30.employmentStudent
Military personnel	Q30.employmentMilitary
Self employed	Q30.employmentSelf employed
Part time employee	Q30.employmentPart time
Full time employee	Q30.employmentFull time
Unemployed	Q30.employmentUnemployed
Retired	Q30.employmentRetired
House person	Q30.employmentHouse Person

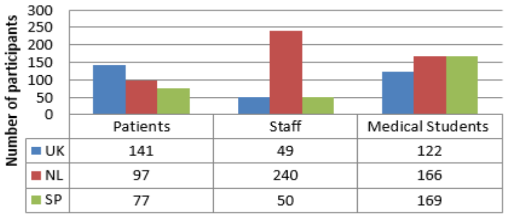
Your Religion	Q31.religion
Christian	Q31.religion_Christian
Buddhist	Q31.religion_Buddhist
Hindu	Q31.religion_Hindu
Jewish	Q31.religion_Jewish
Muslim	Q31.religion_Muslim
Sikh	Q31.religion_Sikh
No Religion	Q31.religion_No Religion
I do not wish to say	Q31.religion_Do not wish to say

Your Ethnic Background	Q32.ethnic
White	Q32.ethnic_White
Mixed/multiple ethnic group	Q32.ethnic_Mixed
Asian	Q32.ethnic_Asian
Black/African/Caribbean	Q32.ethnic_Black
Other	Q32.ethnic_Other
I do not wish to say	Q32.ethnic_Do not wish to say

Table 8. 1 Coding book for quantitative analysis questionnaire.

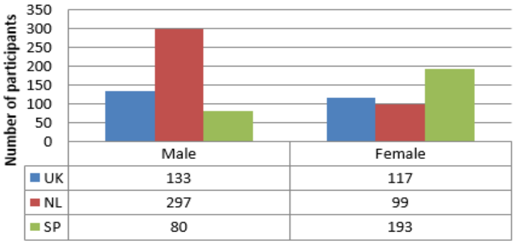
SAMPLE COMPOSITION

A


Subgroup

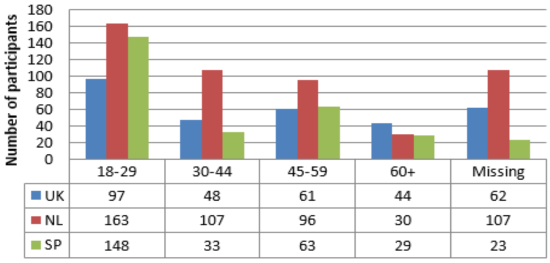
	Patients	Staff	Medical Students
🟦 UK	141	49	122
🟥 NL	97	240	166
🟩 SP	77	50	169

B


Gender

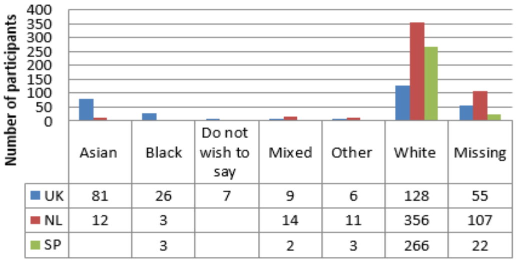
	Male	Female
🟦 UK	133	117
🟥 NL	297	99
🟩 SP	80	193

C


Age

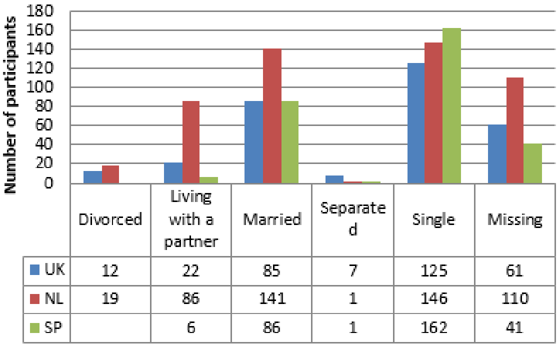
	18-29	30-44	45-59	60+	Missing
🟦 UK	97	48	61	44	62
🟥 NL	163	107	96	30	107
🟩 SP	148	33	63	29	23

D


Ethnic background

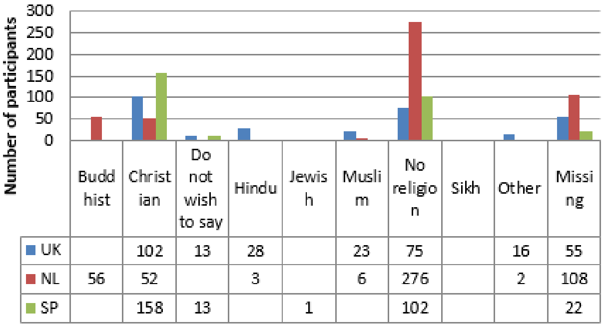
	Asian	Black	Do not wish to say	Mixed	Other	White	Missing
🟦 UK	81	26	7	9	6	128	55
🟥 NL	12	3		14	11	356	107
🟩 SP		3		2	3	266	22

E


Marital Status

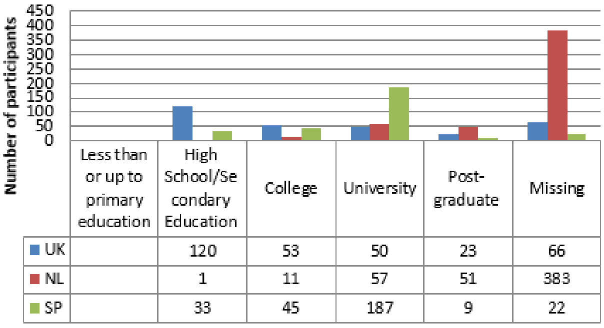
	Divorced	Living with a partner	Married	Separated	Single	Missing
🟦 UK	12	22	85	7	125	61
🟥 NL	19	86	141	1	146	110
🟩 SP		6	86	1	162	41

F


Religious beliefs

	Buddhist	Christian	Do not wish to say	Hindu	Jewish	Muslim	No religion	Sikh	Other	Missing
🟦 UK		102	13	28		23	75		16	55
🟥 NL	56	52		3		6	276		2	108
🟩 SP		158	13		1		102			22

G


Education background

	Less than or up to primary education	High School/Secondary Education	College	University	Post-graduate	Missing
🟦 UK		120	53	50	23	66
🟥 NL		1	11	57	51	383
🟩 SP		33	45	187	9	22

MISSING VALUES

Question code	Variable	Proportion of Missing_values
UK sample		
Q9.source15	Library	0.994428969
Q1.position10	Other	0.988857939
Q9.source16	Adult learning classes	0.988857939
Q1.position8	I am against DOD	0.986072423
Q7.theirwish10	Other	0.986072423
Q1.position6	I refuse to think about issues my death	0.983286908
Q1.position9	I like the idea but i distrust the medical system	0.972144847
Q4.health11	Other	0.972144847
Q2.support7	None of the above	0.969359331
Q6.iwish6	Nephew/ niece	0.969359331
Netherlands Sample		
Q1.position6	I refuse to think about issues my death	0.968102073
Q1.position8	I am against DOD	0.964912281
Q3.against6	Cultural traditions	0.964912281
Q7.theirwish10	Other	0.961722488
Q9.source15	Library	0.958532695
Q9.source16	Adult learning classes	0.956937799
Q1.position5	I need more information about the issue	0.955342903
Q1.position9	I like the idea but i distrust the medical system	0.955342903
Q3.against1	I support DOD	0.95215311

Q7.theirwish5	Their wish niece/nephew	0.950558214
Spain Sample		
Q9.source1	Place of worship	0.495356037
Q9.source15	Local library	0.495356037
Q9.source16	Adult learning classes	0.492260062
Q3.against2	Medical terms are not clear enough	0.486068111
Q3.against3	Body disfigurement	0.486068111
Q3.against4	Funeral arrangement complication	0.486068111
Q3.against5	Religious objections	0.486068111
Q3.against1	Poor medical care of cadaveric donor patients	0.482972136
Q3.against8	Other	0.482972136
Q3.against6	Cultural traditions	0.479876161

MCA, PRINCIPLE DIMENSIONS Chi², Cos²

SOCIO-DEMOGRAPHICS MCA

	Cos 2		Chi 2
Quadrant I	Dim1	Dim2	x
Religion_Hindu	0.0542	0.337	0.0084
Religion_Muslim	0.0367	0.1679	0.0069
Religion_Sikh	0.0656	0.0648	0.0035
Ethnic_background_Asian	0.1652	0.6228	0.0243
60+	0.1532	0.0098	0.0208
High school or less	0.0007	0.1086	0.0425

	Cos2		Chi2
Quadrant II	Dim1	Dim2	x
Female	0.0715	0.1488	0.0839
Single	0.553	0.0712	0.0949
18-29	0.6931	0.0853	0.0851
University	0.167	0.0001	0.0755

Quadrant III	Cos2		Chi2
	Dim1	Dim2	x
Religion_No Religion	0.168	0.02	0.068
Ethnic_background_White	0.215	0.271	0.126

Quadrant IV	Cos2		Chi2
	Dim1	Dim2	x
Religion_Christian	0.0193	0.0845	0.0677
Ethnic_background_Black	0.0421	0.0212	0.0075
30-44	0.083	0.0121	0.0255
45-59	0.2008	0.1162	0.0353
Married	0.4634	0.0041	0.0524
Divorced	0.0371	0.0408	0.0052
Male	0.0715	0.1488	0.0828
College	0.2502	0.0205	0.0258
Postgraduate	0.001	0.0646	0.0229

VALUE JUDGEMENT, COMMUNICATION, KNOWLEDGE MCA

Quadrant I	Cos^2		Chi ^{2}	
	Dim 1	Dim 2	Dim 1	Dim 2
support1_0	0.0194	0.0260	0.280	0.324
support4_0	0.0125	0.0188	0.0384	0.127
support6_0	0.0489	0.055	0.179	0.191
support7_1	0.0159	0.0718	0.528	1.124
Diabetes_0	0.4373	0.00700	0.970	0.123
High_blood_pressure_0	0.368	0.0256	0.900	0.237
HIV/AIDS_0	0.634	0.00142	0.729	0.0345
Obesity_0	0.599	0.00114	0.872	0.0380
My_wish_to_parents_4	0.0433	0.333	0.533	1.478
My_wish_to_siblings_4	0.00917	0.346	0.223	1.367
My_wish_to_partner_2	0.00297	0.0755	0.296	1.491
iwish4_1/ My_wish_to_children_1	0.0389	0.0207	-	-
staff_1	0.101	0.276	0.479	0.7972
student_0	0.365	0.0805	0.505	0.237

Quadrant II	Cos^2		Chi ^{2}
	Dim 1	Dim 2	X
Religious_objections_0	0.000547	0.0539	0.0292
Cultural_traditions_0	6.91E-05	0.0853	0.00148
Alzheimer_1	0.503	0.0249	0.0143
Cancer_1	0.425	0.0369	0.0204
Heart_disease_1	0.5482	0.00484	0.0181
Mental_illness_1	0.447	0.0135	0.0127
My_wish_to_parents_2	0.0197	0.0361	0.00103
My_wish_to_siblings_1	0.0721	0.000465	0.0140
My_wish_to_siblings_2	0.0035	0.0189	0.000454
My_wish_to_siblings_3	0.000367	0.123	0.00224
My_wish_to_partner_3	0.00124	0.121	0.000963
My_wish_to_partner_4	0.0180	0.147	0.00354

Quadrant III	Cos^2		Chi ^{2}
	Dim 1	Dim 2	X
support1_1	0.0194	0.02601	0.0251
support3_1	0.151	0.0252	0.0122
support6_1	0.0489	0.0552	0.0124
Diabetes_1	0.437	0.00700488	0.0215
HIV/AIDS_1	0.634	0.00142	0.0143
Obesity_1	0.599	0.00114	0.0137
My_wish_to_parents_1	0.127	0.0161	0.0168
staff_0	0.101	0.276	0.0217
student_1	0.3648	0.0805	0.0129

Quadrant IV	Cos^2		Chi ^{2}
	Dim 1	Dim 2	X
Poor_medical_care_1	0.00297	0.0297	0.00150
against2_1	0.00465	0.00352	0.00113
Funeral_complications_0	0.00446	0.000891	0.0285
Religious_objections_1	0.000547	0.0539	0.0292
Cultural_traditions_1	0.000691	0.0853	0.00148
Alzheimer_0	0.503	0.0249	0.0169
Cancer_0	0.425	0.0369	0.0108
Heart_disease_0	0.5482	0.00483	0.0132
Mental_illness_0	0.447	0.0135	0.0186
health10_0	0.435	0.000427	0.00980
My_wish_to_parents_0	0.132	0.311	0.00743
My_wish_to_siblings_0	0.0572	0.429	0.00996

APPENDIX B

FOCUS GROUP QUESTION OUTLINE

1) How relevant do you think deceased organ donation is to you?

Can it affect your life or the life of somebody in your family?

2) What is your overall view about deceased organ donation? What has influenced this view positively? What has influenced it negatively?

3) What kind of information/experiences did you have in the process of forming this view/ what information or experience helped you crystalise your view about deceased organ donation? From this what did you find to be the most influential and helpful and produced a strong reaction? What did you find to be the least influential and helpful?

There is a lot of information about deceased organ donation, why do you think there is a shortage of organs?

4) If you were to be part of a group who designed a national campaign about deceased organ donation, what would you like to see in this campaign? What would be your contribution to make the campaign effective? What about if it were a campaign for Europe as a whole?

5) Do you have any other comments?

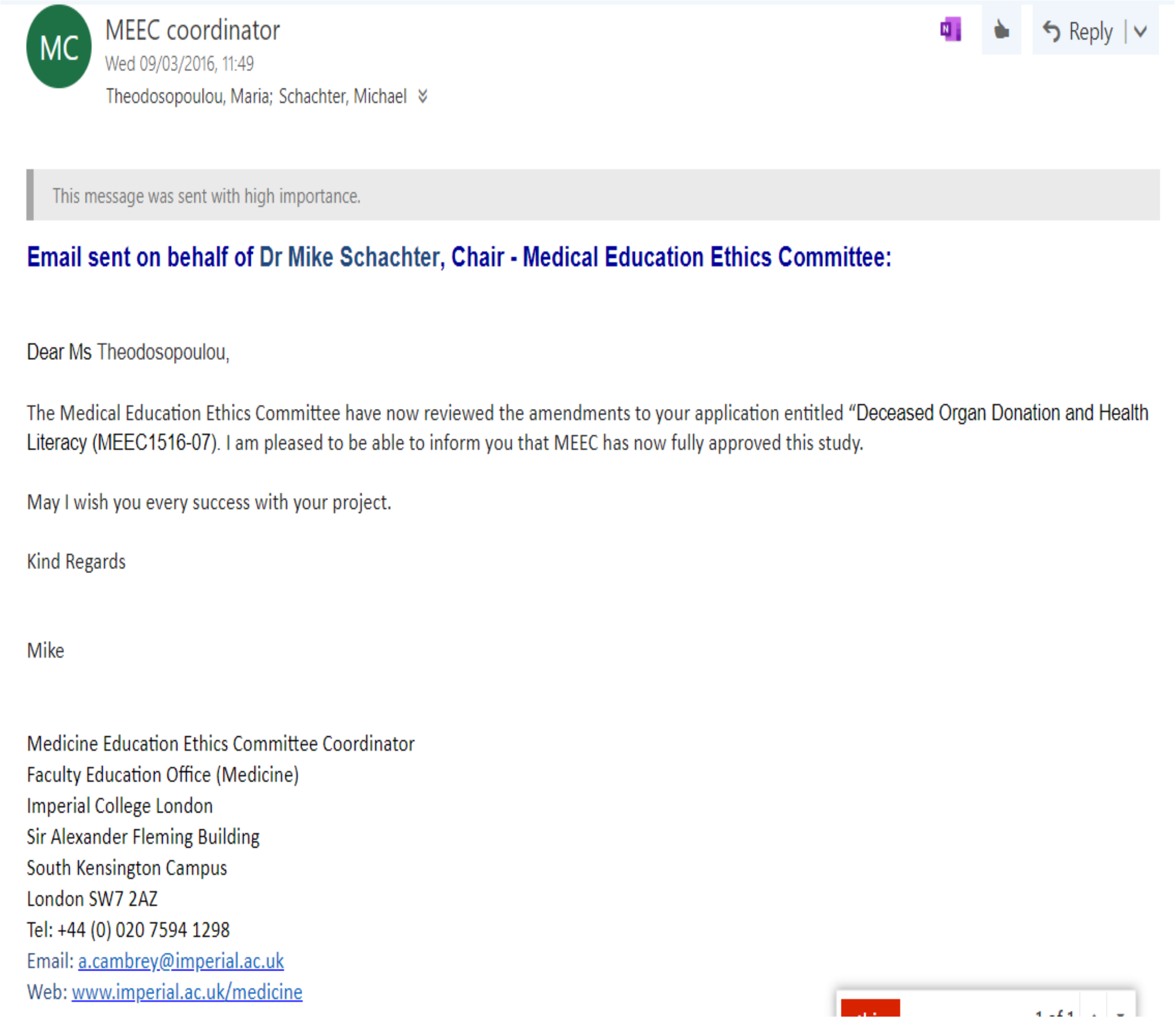
FOCUS GROUP THEMATIC CODEBOOK

THEMES	**DESCRIPTION**	**EXAMPLES**
PERSONAL VALUES AND DONATION	Participants discuss their opinions on the topic of deceased organ donation as well as the opinions of others.	"I don't agree with giving part of my liver to someone who inflicted the illness on themselves"/ "I have been through this process so I understand more than most people"/ "You don't need the organs when you die but someone else does"/ "It interferes with funeral arrangements and I wouldn't want to put the burden on my family"
FACTS ON THE DOD PROCESS	Participants' knowledge of the current system in their country; opinion on the pros and cons of the system Role of healthcare practitioners. Waiting lists Official website	''There are management protocols for patients''/ ''Not every organ will be good''/ ''Maybe some understanding of what happens, when somebody passes''
REGISTRATION OPTIONS	The participants discuss consent in relation to them and their families. Whether they would consent to becoming deceased organ donors - Who else they would grant consent for - Would their family grant consent for them? - Selective or conditional consent - Barriers to consent e.g. donor eligibility Consent processes and criticisms e.g. - Registering as a deceased organ donor	"I have not registered because of laziness"/ "I registered after I saw a really interesting video on it"/ "I registered when I got my driving licence"

COMMUNICATION WITH FAMILY AND FRIENDS	Discussions with family and friends about organ donation. Informing about decision. No discussion with family	‘’Talk through their feelings and what they think’’/ I think the best thing is honesty and transparency’’ ‘’They are more like ‘no, don’t talk about it’
PROMOTIONAL RESOURCES	Participants discuss knowledge of and/or opinions on the way deceased organ donation has been presented in past and present promotional strategies. This can be on a national or local level. This may include comparisons with other social issue or health related campaigns. Participants offer suggestion for future activities.	“It came up on a show, where they took someone off life-support early, which was a bit unsettling”/ “During my school years they brought it up briefly”/ “ The blood drive campaign has been really good, everyone knows about it but you don’t hear anything about organ donation”

APPENDIX C

MEEC APPROVAL



MEEC coordinator
Wed 09/03/2016, 11:49
Theodosopoulou, Maria; Schachter, Michael

This message was sent with high importance.

Email sent on behalf of Dr Mike Schachter, Chair - Medical Education Ethics Committee:

Dear Ms Theodosopoulou,

The Medical Education Ethics Committee have now reviewed the amendments to your application entitled "Deceased Organ Donation and Health Literacy (MEEC1516-07). I am pleased to be able to inform you that MEEC has now fully approved this study.

May I wish you every success with your project.

Kind Regards

Mike

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HAMPSTEAD RESEARCH ETHICS COMMITTEE APPROVAL

NHS
Health Research Authority
London - Hampstead Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
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M1 3DZ

Telephone: 0207 104 8009

25 April 2016

Professor Vassilios Papalois
4th Floor Hammersmith House
Hammersmith Hospital
Du Cane Road London
W12 OHS

Dear Professor Papalois

Study title: **Deceased Organ Donation and Health Literacy**
REC reference: **16/LO/0664**
Protocol number: **16HH3253**
IRAS project ID: **186023**

Thank you for your letter of 15th April 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Miss Amber Ecclestone, nrescommittee.london-hampstead@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

There were no ethical issues raised.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of advertisement materials for research participants	1	22 March 2016
Covering letter on headed paper [Response to Provisonal]		15 April 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		13 July 2014
Interview schedules or topic guides for participants [Focus groups discussion outline]	1	23 March 2016
Interview schedules or topic guides for participants [Focus groups discussion outline]	2	15 April 2016

Letter from sponsor		22 March 2016
Letter from statistician		29 January 2016
Other [PIS for focus groups]	1	23 March 2016
Participant consent form	1	23 March 2016
Participant information sheet (PIS) [PIS for questionnaire]	1	23 March 2016
REC Application Form [REC_Form_23032016]		23 March 2016
Research protocol or project proposal	1	22 March 2016
Research protocol or project proposal	2	15 April 2016
Summary CV for Chief Investigator (CI) [CI and Academic Supervisor]	1	23 March 2016
Summary CV for student		23 March 2016
Summary CV for supervisor (student research) [Prof. Athanasiou-Academic Supervisor]	1	23 March 2016
Validated questionnaire [Date 9/3/2016 Version 1]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

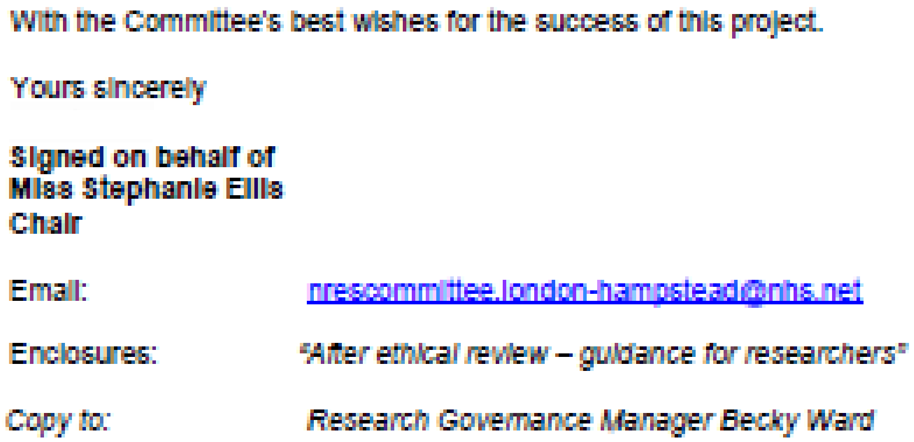
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/



With the Committee's best wishes for the success of this project.

Yours sincerely

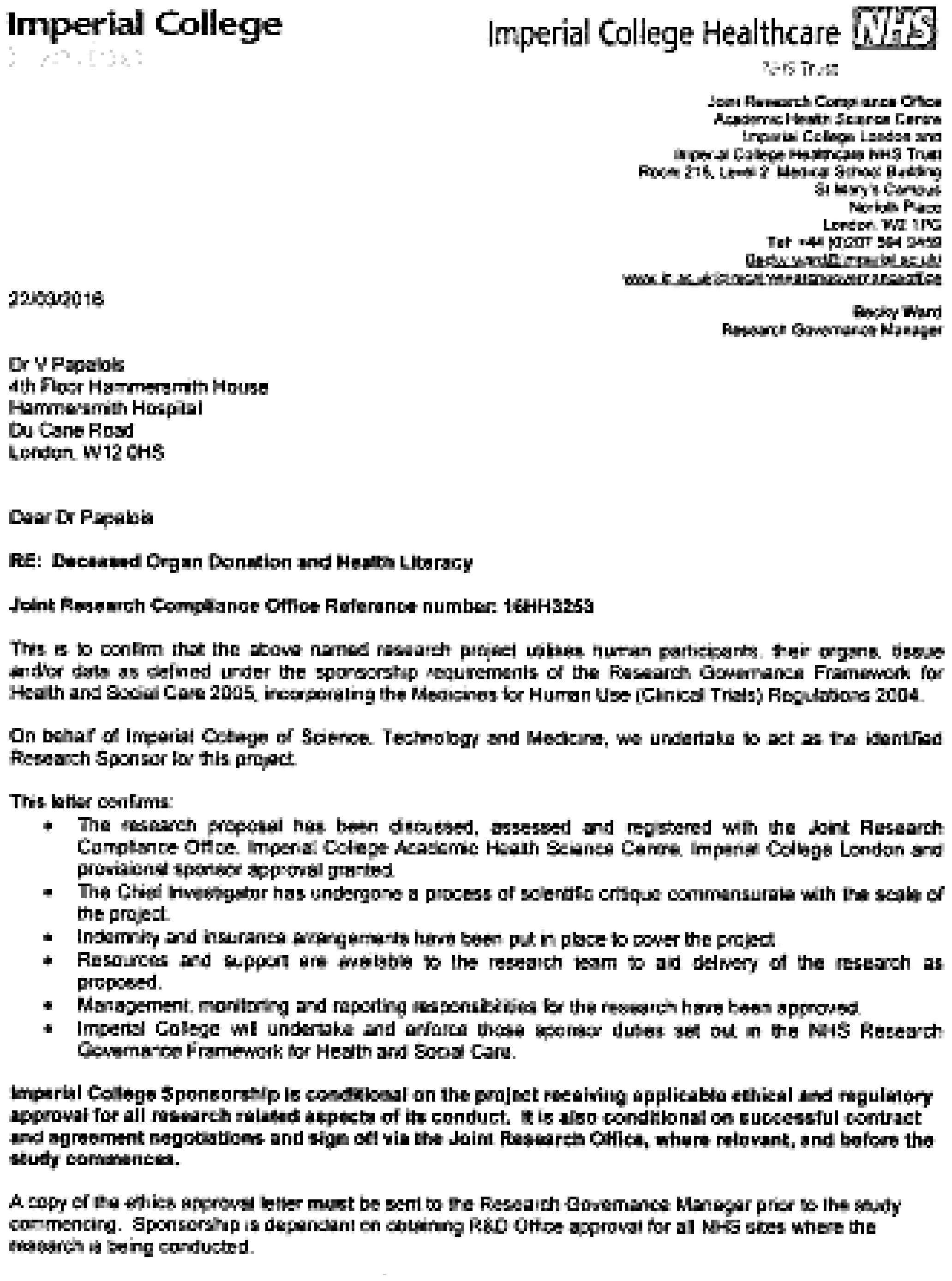
Signed on behalf of
Miss Stephanie Ellis
Chair

Email: nrescommittee.london-hampstead@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Research Governance Manager Becky Ward*

JOINT RESEARCH COMPLIANCE OFFICE APPROVAL



Imperial College

Imperial College Healthcare NHS
NHS Trust

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Becky Ward
Research Governance Manager

22/03/2016

Dr V Papalois
4th Floor Hammersmith House
Hammersmith Hospital
Du Cane Road
London, W12 0HS

Dear Dr Papalois

RE: Deceased Organ Donation and Health Literacy

Joint Research Compliance Office Reference number: 16HH3253

This is to confirm that the above named research project utilises human participants, their organs, tissue and/or data as defined under the sponsorship requirements of the Research Governance Framework for Health and Social Care 2005, incorporating the Medicines for Human Use (Clinical Trials) Regulations 2004.

On behalf of Imperial College of Science, Technology and Medicine, we undertake to act as the identified Research Sponsor for this project.

This letter confirms:

- The research proposal has been discussed, assessed and registered with the Joint Research Compliance Office, Imperial College Academic Health Science Centre, Imperial College London and provisional sponsor approval granted.
- The Chief Investigator has undergone a process of scientific critique commensurate with the scale of the project.
- Indemnity and insurance arrangements have been put in place to cover the project.
- Resources and support are available to the research team to aid delivery of the research as proposed.
- Management, monitoring and reporting responsibilities for the research have been approved.
- Imperial College will undertake and enforce those sponsor duties set out in the NHS Research Governance Framework for Health and Social Care.

Imperial College Sponsorship is conditional on the project receiving applicable ethical and regulatory approval for all research related aspects of its conduct. It is also conditional on successful contract and agreement negotiations and sign off via the Joint Research Office, where relevant, and before the study commences.

A copy of the ethics approval letter must be sent to the Research Governance Manager prior to the study commencing. Sponsorship is dependant on obtaining R&D Office approval for all NHS sites where the research is being conducted.