



Barriers to Registration in the National Donor Registry in Nations Using the Opt-In System: A Review of the Literature

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ABSTRACT

Background. To increase the number of postmortem organ and tissue donors, donor registries (DRs) have been introduced. The aim of this review was to understand why people in nations with an Opt-in system, who are for or against donation after death, do not register in the DR. Knowing these barriers will help in developing policies to increase the registration rate in the DR.

Methods. For this review, 2 authors independently assessed the eligibility of the identified studies from 2000 to 2015 in the Pubmed- Medline database. Included were observational and interventional studies concerned with reported barriers to residents joining the national DR in Denmark, The Netherlands, and the United Kingdom.

Results. We included 15 relevant articles for the review. The main barriers to signing the DR in nations using the Opt-in system were: religion; medical mistrust, anxiety, and affective emotions; lack of information; concern about insufficient time to mourn, and that the funeral may be delayed and the deceased not look presentable; physical integrity; ignorance about how to register in the DR; own benefit; and social status.

Conclusions. The outcome suggests that the main barriers to enrolling in the DR are based on people's doubts about their own ability to perform the registration and cope with the consequences, knowledge, outcome expectations, and concerns about what others will think of them for agreeing to donation. However, not all barriers are easily modifiable, owing to their association with affect or emotions.

IN MANY nations the demand for donor organs for patients on the waiting list for organ transplantation exceeds the supply. To increase the number of postmortem organ and tissue donors, a large number of Western European nations introduced the Opt-out or Opt-in decision-making systems.

According to the Opt-out system, all residents are donors, unless they register objection. Within the Opt-in system, residents have to declare their donor preferences (by free choice). For that latter purpose, the donor registry (DR) records an individual decision to be a donor after death. Examples of European nations that use the Opt-in system with a national DR are Denmark (DK), the Netherlands (NL), and the United Kingdom (UK; except Wales).

The Dutch Organ and Tissue Act has been in force since 1998, including a DR [1,2]. All Dutch citizens, within 1 year

after reaching the age of 18 years, receive an organ donor registration form from the government, on which they can indicate their organ donation preferences. The DR provides 4 options to register: 1) consent, specified per organ and tissue; 2) objection; 3) decision by next of kin; and 4) decision by a specific person. At the time this Act was introduced in 1998, only 36% of the inhabitants administered their choice in the DR [3]. Despite several initiatives, at the time of writing ~41% of the Dutch population ≥18 years of

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age registered their donor preferences. This means that 59% did not take the step to register [2].

When a potential donor is not registered in the DR, the next of kin have to make a decision about donation. In these emotional and often acute situations, most next of kin object to organ (68%) or tissue (84%) donation [4]. Therefore, knowledge of a potential donor's consent or their expressed views and wishes is a key issue.

This high percentage of objection by next of kin seems to be in contrast to surveys suggesting that more than one-half of Dutch citizens advocate organ and tissue donation. When the topic is discussed in a hospital with family members, more than one-half are willing to donate organs from a deceased family member [5,6]. In addition, when the DR is not decisive and next of kin object to donation, approximately one-third regret their decision afterward [7].

Registration in the DR gives people the opportunity to express their donor wishes. This gives clarity and certainty at the time of death to all family members concerned. It is therefore important to understand why people, who are for or against donation after death, do not sign up for the DR. To identify barriers that influence registration in the DR, a review of the literature was made. Knowing these barriers will help to develop policies in order to increase the number of registrations in the DR.

METHODS

Western European nations with Opt-in systems similar that in NL are DK and UK (except Wales) [8]. These nations are the most comparable regarding demography, the legal consent system, and a national DR with similar options (Table 1).

Data Sources and Searches

We performed a literature search from 2000 to 2015 in the Pubmed-Medline database with the use of specific search terms (Table 2).

Study Selection

To understand factors influencing enrollment in the DR, we introduced and developed the concept of a "time line" (Fig 1). In step 1, the person is assumed to be familiar with the existence of the subject of organ and tissue donation, including the DR. In step 2, the person is receptive to the subject of donation. In step 3, which

we call the "preparation phase," the person is orientating and contemplating to make a decision about registration into the national DR. The following step 4, which we call the "action phase," is when the person has to enter his/her preferences regarding organ and tissue donation in the DR.

To categorize the reviewed articles, we applied the time line to sign the DR (Fig 1). Only original research papers were included that showed elements of behavior that apparently influence or are associated with steps 3 and 4.

We included full-text publications written in English, observational or interventional studies, if they complied with reported behavioral factors associated with inhabitants joining the national DR in DK, NL, or UK.

We excluded articles not describing behavioral research concerning enrollment in the DR.

Search Terms

We developed a Boolean search strategy and used the Patient-Intervention-Comparison-Outcome method.

Validity Assessment and Data Abstraction

Two authors (E.V.K. and M.W.) screened the obtained articles and abstracts for eligibility. Results were compared, and in case of any disagreement reconciliation was made through discussion with a 3rd author (N.J.). First, we excluded articles associated with steps 1 and 2 as defined in the time line (Fig 1) on the basis of title, abstract, or full text. Second, when studies seemed to meet eligibility criteria (steps 3 and 4 of the time line or when the information was insufficient to exclude them), we obtained the full-text articles. References that were identified from full-text articles were also collected and screened.

RESULTS

The database search produced a list of 4,853 relevant citations. Of these we excluded 4,234 citations because they concerned other nations than DK, UK, and NL (Fig 2). Potentially relevant citations in the title and abstracts were screened (619), and after exclusion (593) we identified 26 potential articles and 4 articles from the reference lists from these papers (snowball method). After screening full-text articles, we excluded 15 articles that did not meet the inclusion criteria, and we finally included 15 relevant articles for the review.

Table 1. National Donor Registries

Nation	Operation Level	Minimum Age	Additional Details
United Kingdom	National (www.organdonation.nhs.uk)	None	Welsh*: Opt in/deemed consent/opt out. Next of kin are entitled to consent.
The Netherlands	National (www.donorregister.nl)	12	The Donor Registry provides 4 options to register: 1) permission; 2) objection; 3) next of kin decides; and 4) a specific person decides. Next of kin are entitled to consent.
Denmark	National (www.sundhed.dk)	18	Registration includes "yes," "no," and "unsure." Individuals can also add with next of kin approval to their registration. Next of kin are entitled to consent.

*Welsh legislation: The law in Wales has changed to bring in a soft "opt-out" system for consent to organ donation. People living in Wales now have 3 choices: 1) If you want to be a donor, you can either register to be a donor (opt in) on the NHS Organ Donor Registry or do nothing; if you do nothing, you are regarded as having no objection to donating your organs, and this is called "deemed consent"; 2) if you do not want to be a donor, you can register not to be a donor (opt out) on the NHS Organ Donor Registry; and 3) you can also appoint a representative to make the decision for you after your death. By removing your name from the NHS Organ Donor Registry, you put yourself in the "do nothing" or "deemed consent" category.

Table 2. Data Source

Databases and hand search	Pubmed/Medline and snowball
Inclusion criteria	Whether or not observational or interventional studies complied with reported influencing factors associated with residents joining the national donor registry (Fig 1, steps 3 and 4) addressed to nations Denmark, the Netherlands, and United Kingdom.
Type	National or regional donor registry for deceased organ and tissue donation
Search terms	PICO: Population = “donor registry OR tissue and organ procurement” AND Intervention = “behavior OR attitude OR altruism OR motivation OR accept* OR belief* OR attitude* OR willing OR choice OR social responsible* AND Comparison = Netherlands OR Dutch OR Holland OR United Kingdom OR British OR England OR Denmark OR Danish AND Outcome
West European countries with an explicit consent (opt in) system with a national register	Denmark, The Netherlands, and the United Kingdom
Language of articles	English
Date of publication	2000-2015
Ethnicity and age	All lay and informed people
Subject	Factors (behavioral barriers/facilitators) to sign/join the national donor registry
Setting	Observational or interventional study

Study Characteristics

We summarized the included studies (Table 2). All of the studies were conducted in NL (47%) and UK (53%). No relevant articles were found from DK. Most of the research focused on students (NL 47% vs UK 40%), the general public (UK 13%), or ethnic minorities in a geographically defined region or country.

The studies identified were mainly of 2 types; observational (survey) and interventional (education). Some of the studies were based on social cognitive [R6,R9–R14] and noncognitive [R8,R15] theories or studies in which no behavioral theory were described [R1–R5,R7].

Research based on social cognitive theories was mainly performed in NL (NL 33% vs UK 13%) and 13% noncognitive theory in the UK. Research where no behavioral theory was used was mainly performed in the UK (NL 7% vs UK 34%).

Social cognitive theories are based on a person’s self-efficacy beliefs—people’s judgments of their capabilities to organize and execute certain behavior, the importance attached to the behavior, and its impact on how the social environment thinks about that behavior. The social cognitive theories suggest that the intention for a particular behavior is the best predictor of a person’s behavior (eg, register their preference in the DR) [9]. Noncognitive theories are based on beliefs or concerns that are associated with affect or emotions and seem to be stronger predictors of registration than predictors based on cognitive-based theories [10].

We identified 8 broad categories as associated barriers that apparently influenced residents not to sign the DR.

These were: religion; medical mistrust, anxiety, and affective emotions; lack of information about donation; time to mourn/regular funeral; physical integrity; ignorance about how to register in the DR; own benefit; and social status. Many of the articles reported several or multiple factors and therefore appear under several headings. We present the barriers toward considering enrollment in the DR identified with a *P* value of $\leq .01$. We also put forward factors for which no statistical results were reported, but which the authors considered worth presenting. The associated barriers identified are summarized in a scheme and presented in Appendix 1.

Religion

Six studies were retrospectively collected via surveys among residents in UK and NL in an attempt to identify factors associated with religion relevant to enrollment in the DR. Respondents with a Protestant background were less inclined to return their registration form, had less self-efficacy, and experienced more social positive outcome expectations than students with no religion [R11]. Respondents reporting religions other than Roman Catholic or Protestant showed less registration intention than students with no religion (atheist) [R10,R11]. The highest registration rate was among students with no religion, followed by Protestants and Catholics, with Jews and Muslims having the lowest rate. Muslims and Jewish respondents had less knowledge about donation, less self-efficacy, and experienced more negative outcome expectations than participants with no religion [R10]. The majority of Muslim respondents thought that donation was not compatible with their faith and were not aware of the fatwa issued by

Fig 1. Time line to join the donor registry.



the Muslim law Council UK that allows organ donation [R1,R2]. The majority of respondents with an Indo-Asian background were not registered [R2].

Medical Mistrust, Anxiety, and Affective Emotions

Feelings of anxiety and the process of registering as an organ donor were associated with contemplating death [R7,R8]. Registration was shown to be negatively influenced if participants held a higher level of medical distrust, such as misappropriation or misuse of organs [R7]. The more feelings of medical mistrust¹ or affective emotions, eg “Jinx”² or “Ick”³, the less chance there was that participants were registered as an organ donor [R8,R15].

Lack of Information About Donation

We identified 5 papers that included shortage of information about donation as a reason for not registering in the DR. Awareness of organ shortages, knowing someone with a transplant, or a donor in the family are factors positively associated with signing the DR [R1,R5]. Being aware of what eye donation involves, being more knowledgeable of the benefits [R6], and the level of knowledge about organ and tissue donation were positively related to the intention to register as a donor [R13,R14].

Time to Mourn/Regular Funeral

Three papers reported that the most important barriers to registering were that the funeral would be delayed, or that they would not have enough time to say goodbye [R1,R3,R6].

Physical Integrity

Bodily/physical integrity represents the belief in the maintenance of bodily integrity after death. There were 7 papers associated with physical integrity, the idea of mutilation of the body [R1,R2,R4,R6,R8,R15], or the general objection to donating eyes for tissue after death [R6], and when these ideas were present, people were less likely to register.

Ignorance About How to Register in the DR

Two papers indicated that more information was needed on how to register in the DR. Factors associated were not

knowing how to register [R2,R4,R6] or participants thinking it was difficult to complete a registration form [R9].

Own Benefit

Perceived benefit is one of the 6 aspects of the Health Beliefs Model and posits the likelihood that a person will take health-related action depending on rational core beliefs. People imagine perceived benefits, eg, continuing survival of their loved one’s organ after death through the recipient(s); the stronger this perception, the higher the likelihood that they will consent [R8].

Social Status

More strongly endorsing social conformity and less endorsing of hedonism are positively related to intention to register [R14]. People valuing social conformity above hedonism are more likely to register.

DISCUSSION

The main barriers to enrollment in the DR were religion, anxiety and medical mistrust, lack of information about donation, time to mourn/regular funeral, physical integrity, ignorance about how to register in the DR, own benefit, and social status. The studies were based on social cognitive and noncognitive theories, or there was no theory used.

Noncognitive theories are based on beliefs or concerns that are associated with affect or emotions and seemed to be stronger predictors of registration than predictors based on cognitive-based theories.

The more that emotional affective barriers are felt (eg, anxiety, bodily integrity, and medical mistrust) the less chance residents will register as an organ donor. Respondents with a more strict religious background or non-Western beliefs are less willing to register in the DR than atheists.

Based on the research conducted both in UK and NL, the behavioral differences appear to be small when it comes to the barriers to registering in the DR. To meet the goal of the Dutch donation act to obtain more consenting donors for transplantation purposes, much will depend on the response and the decision of the 18-year-olds, who receive a registration form in the year they reach that age. This possibly explains the considerable amount of research conducted among students in NL. In UK, there is no age limit on registering and there is not a yearly campaign such as the one in NL aimed at young adults at the age of 18 years. In UK there are several new campaigns every year, some of them targeting younger people.

Medical Mistrust, Anxiety, and Effective Emotions

Affective attitudes seem to influence whether a person decides to register as a postmortem organ donor [10]. These

¹Medical mistrust is viewed as the common fear that doctors may hasten the death of seriously ill patients to harvest their organs.

²Jinx factor are related to fears and superstitions about the misfortune that would result if a person registered as an organ donor or actually donated his or her organs.

³Ick factor indicates greater feelings of disgust at the idea of organ donation.

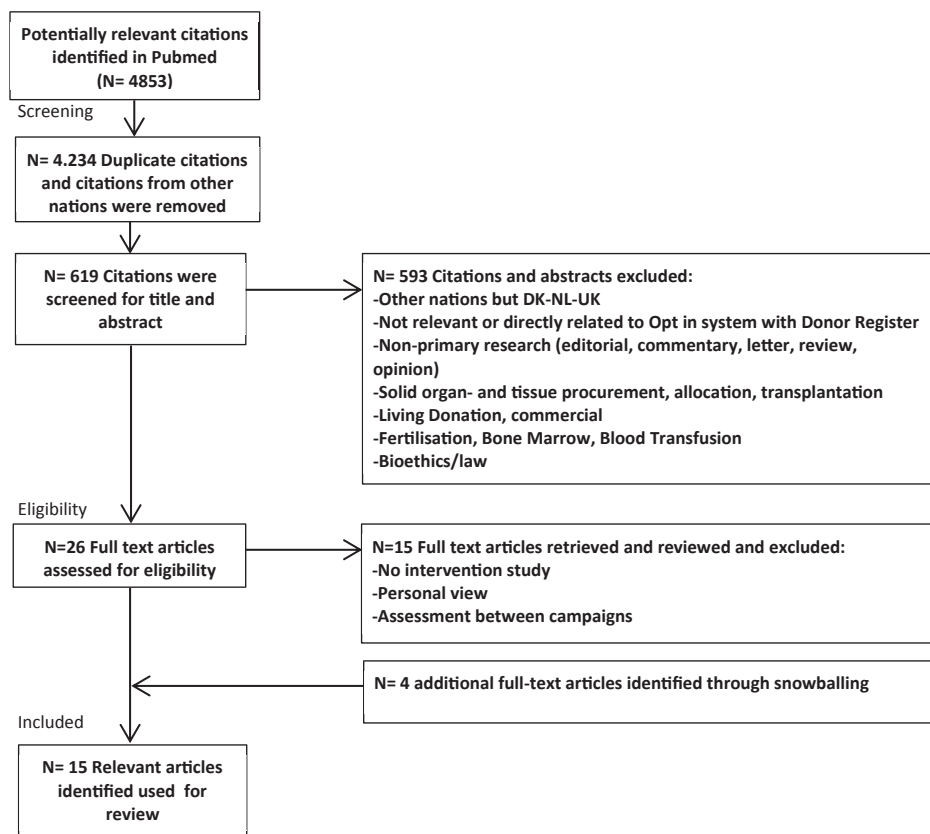


Fig 2. Result of the screening process.

affective attitudes, eg, medical mistrust, “ick” factor, “jinx” factor, and bodily integrity, can be defined as beliefs or concerns that are associated with affect or emotions [11]. People who are not registered as organ donors are more likely to feel negative affective attitudes and are less likely to recognize the benefits of donation. In the context of medical mistrust, people may think that physicians will remove them earlier from mechanical life-sustaining support in a potential donor situation. The common fear is that doctors may hasten death of seriously ill patients to harvest their organs [12–14]. This perception could be reduced with correct information about the process of donation [15,16]. Information should also include the fact that physicians involved in postmortem organ and tissue donation are strictly separated from the transplantation side. The Euro Transplant International Foundation facilitates allocation and cross-border exchange of organs from deceased donors. Allocation of organs and tissue is based on medical and ethical grounds [17]. Anxiety and medical mistrust could be diminished by proper and clear information about the donor procedure.

Some religions advocate (eg, Catholic), allow (eg, Islam), or forbid (eg, Shinto) donation. Of the 15 included articles, 6 (40%) were apparently associated with Western and non-Western religions. Research performed in UK reported influential factors mainly related to Islam or Asian (eg, Hindu, Sikh) religions and research performed in NL was

mainly associated with the Roman Catholic or Protestant religion.

In NL, research shows that church or mosque visitors are less represented in the DR than nonbelievers [18]. Strict religious believers are more reluctant to register in the DR. One of the reasons, for example, is that Muslims struggle with the question whether their faith is compatible with organ donation. Bodily/physical integrity represents the belief in the need to maintain bodily integrity after death or face serious afterlife consequences. The issue of bodily integrity appears to be an important barrier, but in general no religion is against organ donation. On the contrary, all the major religions have issued statements of outright support for organ donation [19]. In general, if the need and the suffering of a patient are high and transplantation with an acceptable risk and chance of success is possible, organ donation may take place. Organ donation is recommended as long as respect for the body is based on force majeure or “emergency breaks law” [19]. This means that the needs of the living outweigh the needs of the dead and must be seriously taken into consideration. To overcome religious barriers for those people who think that their religion does not allow organ donation, religious faith leaders could become more involved. Some research among ethnic minorities shows positive signs [13,20,21]. To Muslims, the holy month of Ramadan seems to be an opportunity to advocate the concept of organ donation and registration in

the DR [22]. To increase registration, the spiritual or faith leaders have an important role in providing honest and reliable information to those who are seeking knowledge about this topic [23]. Spiritual or faith leaders sometimes spread ideas that no longer represent the up-to-date standpoints of their religion regarding donation. It is important that they inform themselves of contemporary guidelines and stimulate the latent awareness of the need for organs and tissues. They could spread targeted information on success and limitations of tissue and organ transplantation, forms regarding donation and its procedure, and information about registration opportunities in the DR [24,25]. To increase donor registration rates, it is better to involve spiritual leaders in discussions from the start.

Perceived benefit involves the aspect of reciprocity, the basis of gift exchange. On the basis of gift exchange, there are dimensions of reciprocity; at one extreme, there is a pure gift, for which nothing is expected in return, and at the other extreme is the maximization of one's own benefit [26]. The Dutch Organ and Tissue Act and its DR assumes that organ donation is a pure gift based on altruism and anonymity. However, organ donation does not differ from the idea of benevolence in blood donation with both the donor and recipient gaining from the transaction. In comparing the individual motivation of blood donors and organ donors, it is clear that in both situations, discussing the matter with family and friends increases the likelihood of the intention to register as donor. Mutual social support seems to be an important factor and to make the decision people also need a positive attitude and have confidence in their ability to carry out the donor registration process, and to cope with the consequences of this decision [27,28]. Research shows that discussing the topic within the family supports registration [29–33]. Besides the appeal to altruism, there are proponents of using incentives to encourage people to enroll in the DR. Despite the natural assumption that personal incentives are likely to appeal to people, research indicates that many do not favor them, especially when it comes to financial incentives [34]. As for blood donation, research studies have shown that financial incentives have a discouraging effect on social behaviors and will reduce the number of blood donors in the long term [34,35]. Ultimately, any incentive intervention must be based on the best evidence and a careful evaluation of long-term consequences [34]. The effect of the incentive depends on people's intention to register or object. Although research has shown that respondents are motivated to donate altruistically, they would also accept reciprocity for organs once consent was given. Payment for organs was viewed as unfavorable; however the respondents found a contribution toward funeral expenses to be acceptable [31] and an indirect incentive, such as a contribution to the burial costs (eg, \$1,500), is therefore likely to be effective [34,36,37].

The result of a nominal group study revealed factors influencing people's decision to register for organ donation. Although that study was performed in Australia, the information presented can give us clues. The top 5 factors from

that study were saving lives, own decision to donate, family opinions, benefit to recipients, and the process of organ donation [25]. In addition, some people are reluctant to register because they thought donation would delay the funeral. Other barriers revealed were also of a practical nature, eg, the barriers of how to register and access the DR. Research on blood donors showed that easy access to the registry could help [28]. Since 2007, the Dutch DR offers the use of an online donor form and thus makes enrollment more accessible. Besides this, the amount of information and knowledge about donation are important factors and are positively related to the intent to register [13,23,30,38,39].

This review, based on articles from UK and NL, revealed the complexity of individuals' behavior toward registration into the DR. Insight into the barriers to registering will help to develop policies and supply general and targeted information in order to increase the number of registrations in the DR.

LIMITATIONS AND STRENGTHS

A limitation of the study is that we measured self-reported intention and willingness to donate instead of actual behavior. Information on actual registration behavior is not available, because the data from the Dutch DR are protected by privacy legislation. Most of the research focused on students, the general public, or ethnic minorities in a geographically defined region or country. There were no results on a country as a whole. The strength of the present review is that it gives insights into barriers to registering in 2 Western nations with similar DRs. Covering a period of 15 years, the included studies were mostly theory based. It is well established that behavioral intentions are a strong and consistent determinant of actual (registration) behavior [9].

CONCLUSION

The DR gives people the opportunity to express their donor wishes. This gives clarity and certainty at time of death to next of kin and physicians involved in the request for donation.

The outcome of this review suggests that the barriers to enrolment in the DR are mainly based on religion, medical mistrust and anxiety/affective attitude, lack of information about donation, physical integrity, own benefit, and social status. Some barriers might be modifiable by giving proper and clear information to potential donors. However, not all barriers are easily modifiable owing to affective attitudes. This review revealed engagement points that could help to develop policies to increase the number of registrations in the DR.

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Appendix 1. Barriers

Study	Study	Method	Not registered in DR, % (total n)	Barriers	Results	
					%	P value
Religion						
Aslam et al, 2008, UK [R1]	Convenience sample	Questionnaire survey among Muslim graduates with nonmedical background	86% (54)	Religious prohibition, participants thought donation was not allowed in Islam	54%	n/a
				Only one-fourth of the graduates were aware of fatwa issued by Muslim Law Council UK that allows organ donation	25%	n/a
Beddi et al, 2015, UK [R2]	Questionnaire	Survey among medical students	61.9% (216)	More students of Indo-Asian ethnicity were not registered than registered.	n/a	<.001
				Pervious experience in transplantation; knowledge, attitudes, and perceptions; atheist not registered vs registered	n/a	<.001
				My religion/belief does not allow organ donation (n = 193)	3.1%	n/a
Hakeem et al, 2015, UK [R4]	Cross-sectional	Survey among junior doctors	30.2% (523)	Junior doctors with atheistic beliefs are likely to be registered as organ donor than not registered.	87.9% vs 12.1%	<.001
				Junior doctors with Muslim belief registered vs not registered.	16.7% vs 83.3%	<.001
				Junior doctors with Hindu belief registered vs not registered.	42.8% vs 57.2%	<.001
Karim et al, 2013, UK [R5]	Voluntary, both online and paper-based approach	Two separate surveys among South Asian Muslims residing in the UK	86.7% (556)	Muslims were less likely than Hindus or Sikhs to be registered donors	5.0% vs 40.3% vs 25.8%	<.001
				Asians living with parents were less likely to agree that organ donation was compatible with their faith: living with vs not living with parents (no statistical difference)	12.0% vs 18.8%	<.086
				Registered organ donor: non-Muslim vs Muslim	n/a	<.001
				Registered organ donor: not very religious vs very religious.	n/a	<.001
Reubsat et al, 2001, NL [R11]	Cross-sectional	Survey among Dutch adolescents	100% (937)	Adolescents with a Protestant background were less inclined to return their registration form	n/a	<.01

Appendix 1. (continued)

Study	Study	Method	Not registered in DR, % (total n)	Barriers	Results	
					%	P value
Reubsæet et al, 2005, NL [R10]	Post-test randomized controlled trial	Intervention and survey among students	n/a (2,868)	Students reporting religions other than Roman Catholic or Protestant showed lower registration intentions measures than students with no religion	n/a	<.001
				Students reporting other religions than Roman Catholic or Protestant were less inclined to register as organ donors, had less knowledge, less self- efficacy, and experienced more negative outcome expectations than students with no religion	n/a	<.001
				Students reporting religions other than Roman Catholic or Protestant had fewer positive social outcome expectations than students with no religion.	n/a	<.05
				Protestant students had less self- efficacy and experienced more social positive outcome than students with no religion	n/a	<.005 <.001
Anxiety, medical mistrust, and affective emotions						
Reubsæet et al, 2001, NL [R11]	Cross-sectional	Survey among Dutch adolescents	100% (937)	Stronger negative outcome beliefs and feelings of anxiety were associated with not returning a completed registration form	n/a	<.01
				The more feelings of anxiety, the less chance there was that they were registered as a organ donor	n/a	<.01
Reubsæet et al, 2001, NL [R12]	Cross-sectional	Survey among Dutch adolescents	100% (1,836)	Anxiety and social outcome expectations	n/a	<.001
McGlade et al, 2014, UK [R7]	Questionnaire	Questionnaire among student nurses	53.2% (667)	Participants associated the process of registering as an organ donor with fear of contemplating death, and participants were 2.9 times more likely to register if they did not fear death	n/a	<.001
				Registration was shown to be negatively affected if participants held a higher level of medical distrust and suspicion of misappropriation of organs ... Or had concerns that their organs might be misused after death	n/a	<.001

O'Caroll et al, 2011, UK [R8]	Experiment	Questionnaire of general public	n/a (151)	A greater feeling of medical mistrust Jinx factor suggests a feeling that it is bad luck to talk about death or becoming an organ donor Ick factor indicates a greater feeling of disgust at the idea of organ donation	n/a n/a n/a	<.0001 <.0001 <.0001
Shepherd et al, 2013, UK [R15]	Randomized control	Questionnaire among undergraduate students	100% (150)	Jinx factor Ick factor Medical mistrust	n/a n/a n/a	<.669 <.843 <.500
Lack of information about donation						
Aslam et al, 2008, UK [R1]	Convenience sample	Questionnaire survey based on convenience sample among Muslim graduates with nonmedical background	86% (54)	Lack of information	46%	n/a
Karim et al, 2013, UK [R5]	Voluntary, both online and paper-based approach	Two separate surveys among South Asian Muslims residing in the UK	86.7% (556)	Awareness versus no awareness of organ shortages Know versus do not know somebody with a transplant South Asians in the UK felt that organ donation promotion was very poorly carried out	n/a n/a 70.5%	<.003 <.022
McGlade et al, 2012, UK [R6]	Questionnaire	Self-explanatory questionnaire among preregistration nurses	n/a (92)	Being more aware of what eye donation involves Being more knowledgeable about the benefits of donation	n/a n/a	<.05 <.05
Ryckman et al, 2010, NL [R14]	Sample	Survey among Dutch adolescents	100% (375)	Level of knowledge about organ donation was related positively to the intention to register as organ donor	n/a	<.001
Reubsat et al, 2004, NL [R13]	Random experimental intervention	Self-administered questionnaire among students	100% (186)	Participants in the video group with discussion were more likely to be willing to register their organ donation preferences and were more likely to intend to register as a posthumous donor	n/a	<.05
Time to mourn/regular funeral						
Aslam et al, 2008, UK [R1]	Convenience sample	Questionnaire survey based on convenience sample among Muslim graduates without a medical background	86% (54)	Participants do not consider organ donation because of delay in funeral	80%	n/a
Figuroa et al, 2013, NL [R3]	Cross-sectional	Survey among medical students	41.0% (506)	Afraid remaining relatives will not have enough time to say goodbye	4%	n/a

Appendix 1. (continued)

Study	Study	Method	Not registered in DR, % (total <i>n</i>)	Barriers	Results	
					%	<i>P</i> value
Physical integrity						
Aslam et al, 2008, UK [R1]	Convenience sample	Questionnaire survey based on convenience sample among Muslim graduates without a medical background	86.0% (54)	Body mutilation	64%	n/a
Beddi et al, 2015, UK [R2]	Questionnaire	Questionnaire survey among medical students	61.9% (215)	I do not like the idea of mutilation of my body after I die	6.7%	n/a
Hakeem et al, 2015, UK [R4]	Cross sectional	Questionnaire survey among junior doctors	30.2% (523)	I don't like the idea of mutilation of my body after I die	4.2%	n/a
McGlade et al, 2014, UK [R7]	Questionnaire	Questionnaire among student nurses	53.2% (667)	Concerns that organs might be misused after death	n/a	<.001
McGlade et al, 2012, UK [R6]	Questionnaire	Self-explanatory questionnaire among preregistration nurses	n/a (92)	A general objection to being left without eyes	n/a	<.05
O'Caroll et al, 2011 UK [R8]	Experiment	Questionnaire of general public	n/a (151)	Belief in the need to maintain bodily integrity	n/a	<.001
Shepherd et al, 2013, UK [R15]	Randomized control	Questionnaire among undergraduate students.	100% (150)	Bodily integrity concerns reduced the likelihood of people registering as an organ donor	n/a	<.001
Unknown how to register in the donor registry						
Beddi et al, 2015, UK [R2]	Questionnaire	Questionnaire survey among medical students	61.9% (216)	I do not know how to register (response rate: <i>n</i> = 193)	10.8%	n/a
Hakeem et al, 2015, UK [R4]	Cross-sectional	Questionnaire survey among junior doctors	30.2% (523)	I do not know how to register	3.0%	n/a
McGlade et al, 2012, UK [R6]	Questionnaire	Self-explanatory questionnaire among preregistration nurses.	n/a (92)	Need more information how to register	n/a	<.05
Reubsamet et al, 2003, NL [R9]	Pre-post test control design	Intervention experience and questionnaire among 4th- and 5th-grade students.	n/a (242)	Being able to register at more convenient places	n/a	<.05
				Participants thought it was difficult to complete a registration form	41.0%	
				After the registration training session the participants thought that completion was difficult	12.0%	
				Intention to register at baseline "Do you intend to fill in and return the registration form when you reach the age of 18 years?"	n/a	<.001
				Self-efficacy at baseline: "How difficult or easy do you think it is to complete a donor registration form?"	n/a	<.05

Own benefit

O'Caroll et al, 2011, UK [R8]	Experiment	Questionnaire of general public	n/a (151)	Nondonors perceived less benefit of being an organ donor	n/a	<.007
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Social status

McGlade et al, 2012, UK [R6]	Questionnaire	Self-explanatory questionnaire among preregistration nurses	n/a (92)	Beliefs that underpin the nurses' attitude: cause other people to think I am a better person	n/a	<.005
Reubsaet et al, 2001, NL [R12]	Cross-sectional	Survey among Dutch adolescents	100% (1,836)	Anxiety and social outcome	n/a	.01
Ryckman et al, 2010, NL [R14]	Sample	Survey among Dutch adolescents	100% (375)	Participants who more strongly endorsed social conformity and less strongly endorsed hedonism reported that they intended to register as posthumous organ donors	68.12%	<.001
