

## **Current Perception and Willingness towards Organ Donation and Transplantation: A Survey of Undergraduate Students at University of Malaya**

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### **ABSTRACT**

The poor number of organ donation is becoming a very worrying phenomenon especially to those patients with chronic diseases, as well as those who require an immediate transplant. Although a variety of programmes and promotional campaigns have been organised and promoted by the agencies responsible for handling the organ donation, the number of donors is still at a discouraging level. Therefore, the objective of this study is to analyse the perceptions of young generation in regard to organ donation. Random samplings of 387 respondents consisting of undergraduate students at University of Malaya were selected for this study. The study found that young people's perceptions were very much influenced by their family members and friends, as well as family history. There is a significant difference between mean of gender and willingness towards organ donation and transplantation ( $t = -2.60$ ,  $df = 385$ ,  $p < .05$ ). The Spearman correlation shows a positive but weak correlation between the intention of the surveyed students towards registering as donors and their perceptions about organ donation and transplantation ( $r = .354$ ,  $p < 0.05$ ). In sum, discussions on the issue of organ donation and transplantation should be held regularly in Higher Learning Institutions in order to change the misperceptions and misconceptions of the younger generation about organ donation and transplantation.

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## INTRODUCTION

In recent years, organ donation has been a widely discussed topic among the public. We often hear and read news from mass media channels, either traditional media or social media like Facebook, about the sufferings of patients who are in need of organ transplants in order to continue their lives. Although organ donation is gradually being accepted by more and more people recently, Malaysia has one of the worst records for organ donation (below 5 per million population [pmp]) in Southeast Asia, as well as in the world; this is followed by Philippines, Guatemala, India, Bulgaria, Kazakhstan, UAE, Tunisia, Morocco, Ukraine, Algeria and Myanmar (Global Observatory on Donation and Transplantation, 2012; "15,420 Malaysians", 2012; Goh, 2013; Makmor et al., 2014).

Organ donors in Malaysia are palpably low compared to other countries. The number of patients who need organs falls far short of needs and demands. As of October 2014, there were 18,444 patients still waiting for organ transplants, of which 18,418 were waiting for new kidneys, 13 were waiting for livers, five were waiting for hearts, six were waiting for lungs and three were waiting for lungs and hearts (*Unit Perkhidmatan Transplan dan Pusat Sumber Transplan Nasional* [Transplantation Service Unit and National Transplant Resource Centre], 2014). Comparing these figures against the registered organ donors, there were only 270,000 people who pledged to donate their organs; that is

0.9% of Malaysia's strong population ( $\pm 30$  million as of 2014). When compared to some European countries, we are still far behind from getting 30% to 40% of registered organ donors of the country's population (Ahmad, Ibrahim, Mustafa, & Chang, 2011; Hillson, 2012).

*Since its inception in 1997, the National Transplant Resource Centre (NTRC), through the Ministry of Health and the Transplantation Service Unit, has worked closely with the media to promote and educate the public about organ donation. Various media campaigns, news write-ups and social media promos have been used. It has also worked closely with various non-governmental organisations, public groups, universities, schools, teachers, students and many others in order to reach the public and create an informed public. These include mass media, social media campaigns and education interventions strategy approaches for a more effective increase in the organ donation registration rates and simultaneously change the public attitude towards organ donations. This strategy is said to be effective in decreasing the gap between the need for organ donation and supply, as well as to increase the consent and conversion rates for transplantable organs (Feeley & Moon, 2016). A positive approach was made by the NTRC, Ministry of Health, Department of Islamic Development (JAKIM) and the Institute of Islamic Understanding of Malaysia (IKIM) to openly discuss the *Dos* and *Don'ts* in Islamic teaching and ruling regarding organ donation. It was a much-*

needed guideline for those of the Muslim faith to understand the right and wrong with regard to organ donation. A national level forum entitled, "Organ Donation for the Islamic Perspective", held in Putrajaya, in conjunction with Organ Donation's Week Campaign, was broadcasted in 2014 by TV Al-Hijrah, presenting panellists from the health professionals, the Islamic leaders and the media practitioners discussing the topic. A huge media coverage entailed the forum, which was a positive campaign towards educating the public about and encouraging them to sign up for organ donations.

Nonetheless, recent figures showed that more than 15,000 patients are still awaiting organs for a second shot at a healthy life, and this number is rather alarming (Hillson, 2012). Due to the shortage of organ donors, especially for kidneys, it was reported that Malaysian patients take risks in purchasing cadaveric kidneys from overseas, especially from the People Republic of China (Medical Development Division, Ministry of Health Malaysia, 2007; Hillson, 2012). The reason is simple; the longer kidney patients wait for renal transplants, the worse their health conditions will be. Dialysis treatment only helps the kidneys to function at 10%. As a consequence, the longer the time taken for the patients to undergo dialysis, the less fit they will be for kidney transplant surgery (Ng, 2014).

Many researches have denoted that the factors responsible for organ shortfall across the world are insufficient

information, lack of awareness, lack of trust and traditional cultural beliefs (Badrolhisam & Zakaria, 2012; Noordin et al., 2012; Perenc, 2012; Makmor et al., 2014). Findings of some previous studies show that majority of the Malays believe that Islam does not allow them to donate their organs (Noordin et al., 2012). This finding contradicts with Badrolhisam and Zakaria's (2012) research, in which they found that most Muslims agreed to donate their organs to someone who is in need even though the *fatwa* (i.e., statement issued by the Islamic Scholar Council) denies it. This apparently shows that the former result projects lack transparent disclosure or discussion about organ donation among the Muslim respondents, although Islam is a religion which inculcates love and caring among its followers in order to benefit other people who are in need of help, let alone saving a life of an individual through organ donation (Badrolhisam & Zakaria, 2012; Tham & Zanuddin, 2015).

In many cases, the early steps of informing and advocating an individual about health issues, prevention and cure are always through awareness, and this are what many health care practitioners and institutions usually do in this era of health communication (Nelkin, 1991; Caburnay et al., 2003; Mallika & Katare, 2004; Tong, 2006; Ibrahim, Mustaffa, & Chang, 2010). Health communication is essentially an indispensable component of an integrated public health response plan and an important element to achieving greater empowerment of individuals and

communities through dissemination of information and public engagement in disease prevention and cure (World Health Organisation [WHO], 1998; Santibañez, Siegel, O'Sullivan, Lacson, & Jorstad, 2015). It is the key to the dissemination of information and public engagement with disease prevention and cure, as well as to ensure quality health care (WHO, 1998; Schiavo, 2014).

Communication is of paramount importance in health communication. Without it, doctors and nurses are unable to inform patients of the severity of various diseases and the need for prevention and cure. Rimal and Lapinski (2009) revealed that communication lies at the heart of public health and plays an important role in exchanging information. In the field of communication, when the public is exposed to an issue through the media, it allows the issue to become salient among a group of people. Based on what the mass media have reported in the communicating text, these people who are much interested in a reported issue, talk to others and may even mobilise their own groups and organisations in response.

Therefore, it is essential to provide clear information and knowledge about organ donation at the youngest age. Youths bring a new perspective to organ donation. Therefore, educating the public and improving transparency of the organ donation, transplantation process and performance are critical to narrowing the donor-organ gap, especially among the youths who are the hope of a

nation. This study generally sought to examine the willingness and perception of undergraduate students at University of Malaya about organ donation. More specifically, this study serves the purpose to: (1) find out the types of media used by students in seeking information about organ donation and transplantation; (2) find out if there is statistically significant difference between gender and willingness of undergraduate students towards organ donation and transplantation; and (3) find out the barriers for students to sign up for organ donation and transplant.

## **THEORETICAL FRAMEWORK**

This study adopts the theory of reasoned action (TRA) to study youths' intention and attitudes towards organ donation and transplant. The Theory of Reasoned Action has been employed in a variety of research on examining behavioural intentions. These works include blood donation (Burnkrant & Page, 1982), bone marrow donation (Bagozzi, Lee, & Van Loo, 1996), religious donation (Chuchinprakarn, Greer, & Wagner, 1998), behaviour on internet banking (Albarq & Alsughayir, 2013) and organ donation (Weber, Martin, & Corrigan, 2007; Jeffres, Carroll, Rubenking, & Amschllinger, 2008). Nonetheless, very little research on organ donation and transplant has used the theory to further explore the public's intention on this health issue. The theory (presented in Figure 1) essentially attempts to explain that someone is ready to take an action or respond to a certain behaviour if he/

she has the intention and is ready to do so (Fishbein, 1967; Ajzen & Fishbein, 1980). According to this theory, the most accurate determinant of behaviour is behavioural intention. As defined by Ajzen and Fishbein (1980), intention is the “probability, as stated by the respondent, that he/she will perform the stated action” (p. 180).

In other words, intention is the extent to which someone is ready to engage in a certain behaviour or likelihood that someone will perform a given behaviour. Based on the theory, two components are expected to influence one’s behavioural intention, which are attitudes and subjective norms.

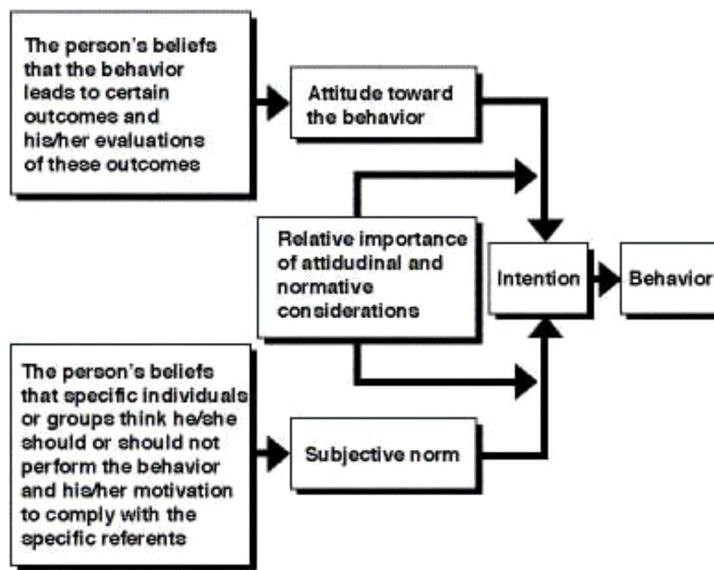


Figure 1. Reasoned action model (Adopted from Ajzen & Fishbein, 1977).

**Attitudes towards Behaviour**

Attitude is a stands for a person’s general feeling of favourableness or unfavourableness towards a behaviour (Albarq & Alsughayir, 2013). At times, a person will endorse either a positive or negative reaction or emotion towards another person, a concept, or an idea, based on his self-evaluation. The person will evaluate a behaviour whether it gives a positive, valuable, beneficial, desirable and advantageous outcome to him if he

performs a given behaviour (Hayden, 2009). On that count, this is associated with one’s behavioural beliefs. Thus, in organ donation context, when a person has a positive salient belief about his behaviour towards organ donation and transplant, he will the have a positive attitude vis-à-vis that behaviour. In contrast, when he has a negative salient belief regarding the outcome of performing organ donation and transplant, which is then considered to be a negative attitude, in return, he will not perform the behaviour.

### **Subjective Norm towards Behaviour**

According to Azjen and Fishbein (1980), subjective norms are “a person’s own estimate of the social pressure to perform or not to perform the intended behaviour” (p. 6). It refers to whether important referents, who are important to the person, approve or disapprove of the performance of a behaviour—which is called normative beliefs, weighted by the person’s motivation to comply with those referents (Ajzen & Fishbein, 1980). In short, a subjective norm is the perceived social pressure to engage or not to engage in a certain behaviour (Hayden, 2009). Putting this into the context of organ donation and transplant, their behaviour and decisions depend on how and what their family and friends think about the outcome of performing organ donation and transplant (normative belief), and the degree to which this influences the behaviour or action of the person responsible (motivation to comply). It is not about the “individual’s opinion”, but most importantly are the “people around him/her and their opinions” that matter in determining the behavioural outcome. These people are those we hold high esteem like parents, friends or peers, religious figures, health care providers, etc. Due to a person wishes to “please” and comply with these people’s expectations, subjective norm then plays a role in influencing one’s intention to engage in a particular behaviour.

### **HYPOTHESES**

Guided by the theory of reasoned action, this study aims to study how male and female students differ in their willingness to donate organs to those in need and register as organ donors. Is intention of registering as an organ donor associated with their beliefs in organ donation and transplantation? Based on the central propositions of the theory of reasoned action, that intention is influenced by someone’s attitudes and subjective norms. Thus, the following (two) hypotheses were proposed in the present study:

*H1: There is a statistically significant difference between male and female students on their willingness towards organ donation and transplant.*

*H2: Intention of students to registering as organ donors is positively associated with their behavioural belief about organ donation and transplant.*

### **METHODOLOGY**

#### **Sample and Sampling Methods**

This study used cross-sectional data that were collected by using structured questionnaires. Survey questionnaires were distributed to 387 undergraduate students who were from different faculties and years of studies at the university. The researchers employed Yamane’s formula to systematically ascertain the sample size (Yamane, 1967). Respondents in this study were selected based on their willingness to participate in the study. The



researchers obtained the consent from the respondents prior to collecting the data. All the respondents were informed that their responses to the questionnaire of this study would be strictly treated as private and confidential.

### Questionnaire

The questionnaire used in this study consists of closed-ended questions. Scoring was based on a 5-point Likert Scale, in which a value of one (1) to five (5) was assigned to each respondents' response options, ranging from strongly disagree to strongly agree. The instrument was developed and modified to suit the Malaysian setting based on previous research (Sanner, 2002; Albright et al., 2005; Ozer, Ekerbicer, Celik, & Nacar, 2010; Milaniak, Przbylowski, Wierbicki, & Sadowski, 2010; Noordin et al., 2012). Some words in the questionnaire were added or amended after pre-test to ensure its validity and also its compatibility to the culture in Malaysia. The questionnaires comprised questions in Section A, which represent factor of perceptions of the younger generation about organ donation with Cronbach Alpha  $\alpha = .67$  and factor B focused on their willingness and barriers to registering as organ donors that was gained Cronbach Alpha  $\alpha = .64$ . Factor C, which focused on Media Role Effectiveness initially gained a rather weak Cronbach Alpha  $\alpha = .52$ . Item 5C (I got more information from organ donation awareness campaigns) was eliminated in order to improve the Cronbach Alpha value to  $\alpha =$

.66. Fundamentally, the alpha value should be positive and usually greater than 0.70 in order to provide a good support for internal consistency reliability. Nevertheless, Kline (1999) noted that Cronbach's alpha value below .70 could be accepted when dealing with psychological constructs. This is due to the diversity of constructs being measured in the questionnaire (cited in Field, 2009).

Table 1  
*Validity and reliability test*

No Item	Factors	Alpa Value ( $\alpha$ )
A1-A6	Perceptions to Organ Donations	.670
B1-B7	Barriers to Organ Donations	.639
C1-C6	Media Role Effectiveness*	.660*

*Note:* Asterisk indicates that item C5 was deleted as suggested in order to improve  $\alpha$  value = .52 to  $\alpha = .66$

### Data Analysis

The data collected were analysed using descriptive analysis and Spearman correlation to find out the relationship between the variables (namely, intention to register as organ donors and belief about organ transplant), while *t*-test was employed to find out the difference between them. Predictive Analysis SoftWare (PASW) was used as to produce descriptive statistics and conduct statistical tests.

## RESULTS

### Demographics

Table 1 presents the socio-demographic characteristics of the sample. The overall

response rate for this survey was 100%. Out of 387 respondents, more than 50% of the respondents are female (62%) and 38% are male. In terms of religion, majority of the participants are Muslims (79.8%), followed by Buddhists (12.1%), Hindus (2.8%) and other religions (5.2%). Out of all the studied participants, 37.7% were third year students, 31.3% second year's students, 25.1% first year students, 4.4% fourth year students, 0.8% fifth year students, 0.5% sixth year students and 0.3% seventh year students. As far as pledging as an organ donor is concerned, only 6.2% of the total respondents have pledged to donate their organs to people who are in need.

Table 2  
*Socio-demographic characteristics*

Variable		#	%
Gender	Male	147	38.0
	Female	240	62.0
Religion	Islam	309	79.8
	Buddhist	47	12.1
	Hindu	11	2.8
	Others	20	5.2
	Year of Studies	First Year	97
	Second Year	121	31.3
	Third Year	146	37.7
	Fourth Year	17	4.4
	Fifth Year	3	0.8
	Sixth Year	2	0.5
	Seventh Year	1	0.3
Pledged as an Organ Donor	Yes	24	6.2
	No	363	93.8

N=387

### Source of Information about Organ Donation and Transplantation

As shown in Table 3, the survey results showed that majority of the respondents obtained organ donation-related information from the social media (72.4%), followed by television (63.3%), media campaigns (62.5%) and newspapers (59.4%).

Table 3  
*Source of information about organ donation*

Source	#	%
Social media (Facebook, YouTube, the Internet, etc.)	280	72.4
Television	245	63.3
Media campaigns	242	62.5
Newspapers	230	59.4
Posters	189	48.8
Radio	146	37.7
Health care practitioners	138	35.7
Friends	132	34.1
Family members (parents and siblings)	85	22.0

### Perceptions and Willingness towards Organ Donation and Transplantation among Respondents Who Use Social Media

Among those who used social media like Facebook, YouTube, the Internet, etc. to obtain information vis-à-vis organ donation and transplantation, they have a strong perception towards health issues. The survey results showed that 45.4% of the respondents were ready to donate their organs to those who are in need after their death. Although more than 50% of the respondents had the intention to register



as organ donors (55.7%), 80% of them said that they had to get prior permission from their family members before registering as organ donors. In terms of their behavioural belief about organ donation and transplant, the results showed that the surveyed undergraduate students have strong belief that organ transplant is an effective treatment to save someone's life (84.6 %).

### Willingness towards Organ Donation and Transplantation

In this study, 46.5% indicated their willingness to donate their organs after their death. The finding was indeed encouraging. More than 50% of the students stated that they had the intention to register as organ donors (54.2%). Independent *t*-test was conducted to compare the difference between the mean of gender and willingness towards organ donation and transplant. The hypothesis postulated that there is a significant difference in the respondents' willingness towards organ donation and transplantation between males ( $M = 3.64, SD = .66$ ) and females ( $M = 3.81, SD = .63$ ) respectively,  $t = -2.60, df = 385, p < .05$ . The mean difference ( $M = -.17$ ) showed that the female students were more willing to donate their organs to people who are in need compared to the male students. Interestingly, a high proportion of the surveyed students (77%) stated that they would have to obtain an agreement or consent from their family members before registering themselves as organ donors.

Table 3 shows a positive correlation between the surveyed students' intention to registering as organ donors and their perceptions about organ donation and transplant ( $r = .354, p < .05$ ). Although the results showed a weak correlation between the variables (Chua, 2013), it indicated that the higher the intention of a student to register as a donor, the higher the positive perception about organ donation of that particular student would be.

Table 4  
*Relationship between respondents' intention to registering as organ donors and their perception about organ donation and transplant*

	<b>I have the intention to register as an organ donor.</b>	<b>I believe that organ transplant is an effective treatment to save someone's life.</b>
<b>Spearman's rho</b>	1	.354**
<b>Sig. (2-tailed)</b>		.000
<b>N</b>	387	387

\*\* Correlation is significant at the 0.01 level (2-tailed).

### Barriers towards Organ Donation and Transplantation

The participants who expressed their concerns about the barriers to organ donation and transplant gave a variety of reasons: "I lack exposure to the concept of brain death" (236; 60.9%); "I have negative perception about organ donation and transplantation because the influence of my family members and friends" (52; 13.4%); "I am afraid of and worried about post-mortem when I am dead" (150; 38.3%); "I

am influenced by the video in YouTube on organ transplant surgery, which it scares me to death” (114; 29.5%); None of my family members or close friends has chronic diseases which they need to undergo organ transplant surgery” (242; 62.5%); Religion is a hindrance for me to donate my organs” (35; 9%).

## DISCUSSION

This cross-sectional study revealed the current perception and willingness towards organ donation and transplantation among undergraduate students at University of Malaya. Several important findings merit further consideration. The proposed theoretical framework indicates that students' intention in registering as organ donors is associated with their behavioural beliefs about organ donation and transplant. This finding supports the theoretical assumption. The researchers found that out of 387 surveyed students, only 6.2% or 24 students had pledged as organ donors. This portrays that our students are not ready for organ donation and transplant. Makmor et al. (2014) revealed that the lack of information and trust were the factors contributing to apathetic to organ donation among the respondents. Therefore, they need more motivation and certainty about the perceived costs and also benefits of registering as donors.

Many times, much of the public's understanding about health issues is not from their direct experiences, but from mediated sources (Brännström, & Lindblad, 1994; Miller, Kitzinger,

Williams, & Beharrell, 1998; Tong, 2006; Chanda, Mchombu, & Nengomasha, 2008; Ibrahim et al., 2010; Tham & Zanuddin, 2012; Ahmed & Bates, 2013; Tham, 2014). Although health care practitioners have historically been the primary sources of health and medical information, with the advancement of communication and media technologies, everyone now has easy access to a varied arrays of alternative sources of health information, much of it is available at our fingertips (World Health Organisation [WHO], 1998; Brodie, Kjellson, Hoff, & Parker, 1999; Kremer & Ironson, 2007; Slooten, Friedman, & Tanner, 2013). In terms of sources of information about organ donation and transplantation, social media such as Facebook, YouTube and the Internet are the most preferred sources for the surveyed students to obtain organ donation and transplant-related information. Nevertheless, some respondents revealed that these social media could also be one of the obstacles for them to attain a better understanding of organ donation. About a quarter of surveyed students responded that they were influenced by the videos in YouTube, portraying scary pictures of organ transplant surgery. This provides an important insight into ethical issues concerning organ donation and transplant in social media. This aspect must be developed into school curriculum in order to improve both students' and online users' awareness, knowledge, attitudes and commitments.

The willingness towards organ donation and transplant varied to a statistically significant degree according

to the surveyed students' gender. Females were more willing to become organ donors. This might be due to females having greater affection for suffering compared to the males. Nonetheless, the result is different from the research conducted by Perence, Radochonski, and Radochonski (2012), in which they found out that the male respondents were more willing to become donors in the case of sudden death.

As far as the traditional culture is concerned, a high proportion of the surveyed students stated that a decision about organ donation should be made after consulting their family members about it. This subjective norm factor can be seen in other research as well. Among other, Perence et al. (2012) also revealed that 6.7% (compared with 77% of the surveyed students in this study) of the participants would have to consult with their family members about organ donation; without their family's support, they would not agree to donate their organs after death. This gives some insight to us that family influence could be one of the factors in motivating younger generation to pledge as a donor. In fact, the survey shows that the students had a negative perception about organ donation and transplant because of the influence by their family members and friends.

As such, public health campaigns organised by non-governmental organisations or the Ministry of Health should not be limited only to the younger generation, but also their parents and relatives. Therefore, the public can have

a better understanding and knowledge of the importance of organ donation, and thereafter influence their children to help more people's lives by donating their organs.

When examining the association between the surveyed students' intention towards registering as organ donors and their perceptions about organ donation and transplant, there was a weak and yet positive correlation between the two variables. This indicates that the higher the intention of a student to registering as a donor, the higher his / her positive perception would be about organ donation.

Although some studies have shown religion as the main constraint to organ donation in Malaysia (see for instance, Loch, Himi, Mazam, Pillay, & Choon, 2010; Muda, 2012; Badrolhisam & Zakaria, 2012; Noordin et al., 2012), this research revealed that religion was not an outstanding hindrance to organ donation and transplant among the surveyed students. In this study, when the researchers asked the students on "*what are the barriers to organ donation and transplantation?*", more than 50% of them answered that they would only perform organ donation if their immediate family members or best friends were suffering from chronic diseases such as kidneys failure, liver cancer, etc. This, again, suggests that reaching out to the niche group (family members of chronic patients) may enable them to better relate to problems of organ failure, thereafter triggering one's affection for patients' suffering.

## LIMITATIONS

As far as the methodological perspective is concerned, this research used only the quantitative approach to study the students' perception of organ donation and transplant. From the post-positivism point of view, the researchers cannot observe the world in a purely objective way as people's perceptions are rather subjective. Due to the limitations mentioned above, it is recommended that a mixed method approach would be applied in future studies in order to provide discourse of knowledge to organ donation and transplant. Other than this, the study is also limited to only undergraduate students at University of Malaya. Hence, a future comprehensive study could be conducted by examining members of public about their perceptions, intentions and behavioural beliefs about organ donation and transplant. As Malaysia is a multi-ethnic country, the religious element could also be further explored so as to grasp a better understanding of the role of religion in exploring the issue.

## CONCLUSION

These results highlight both a disturbing issue and a great potential for public health communication regarding organ donation and transplant. Lack of knowledge and exposure to organ donation and transplant contributes to the low responses to organ donor registration in Malaysia. This study suggests that while networked media and social media become ever-increasing popular among youths, public health

campaigns and social marketing campaigns can be targeted at youths via these channels. More open discussions about organ donation and transplant should be conducted using these platforms, as well as face-to-face interpersonal communication among parents and youths. While many people have misinterpretations about the role of religion in prohibiting its followers to donate organs, religion leaders can be invited to schools and public health campaigns to discuss about and highlight the relationship between religion and organ donation. Research related to organ donation and religious beliefs from each ethnic group should be delved further so as to improve and re-evaluate the current national policies, educational policies, public health policies and public health campaigns.

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