

# Doctors' Attitudes Towards Opting-Out and the Implication of This Legislation for a Small Island State

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## 1. Introduction

The debate on whether to introduce the opting-out system is complex and involves various ethical, philosophical, psychological and legal issues. Different answers are given to questions such as "Who owns the body of the dead person? Does the State own the body of the deceased person or does the body belong to the next of kin? Should the decision whether or not to donate the organs of a dead relative be taken by the State? How informed are people about opting-out? If persons are not aware of the system, would the organs still be taken even when relatives are against opting-out?" Because there is no consensus regarding these and other questions, some sections of society and groups may present resistance to introducing the system. On the other hand, doctors' associations as well as other lobby groups argue that organs should not go to waste and agree with State intervention to retrieve more organs through the introduction of opting-out. The question asked by those in favour of opting-out is "How fair is it for thousands of people to keep on waiting for an organ transplant, when it is possible to reduce these numbers drastically by legislation?" This is the problem facing policy makers. Should the state try to encourage and facilitate a gradual change in public opinion towards opting-out or should legislation on presumed consent be introduced?

## 2. Legislation on organ retrieval

Different countries have different legislation on the retrieval of organs. The main two legislative frameworks are "informed consent" also known as the "opting-in system" and the other is "presumed consent", also referred to as the "opting-out system". There are variations in practice in both the opting-in as well as the opting-out system.

Opting-in, sometimes known as explicit consent requires that the individual authorises organ removal after death by for example carrying a donor card or joining a national registry (Organ Donation Taskforce, 2008). In many countries organs can be retrieved from the dead body only if permission from the family of the deceased is given. Even the presence of a donor card signed by the deceased does not give the doctors a right to remove organs from the body unless there is consent from the nearest relative. 'Nearest relative', according to the guidelines issued by the Medical Ethics Department of the British Medical Association in 2009 is defined, in order of priority, as an adult who is the deceased person's spouse or civil partner, partner living with the adult in a meaningful relationship for at least

six months, child, parent, brother or sister, grandparent, grandchild, uncle or aunt, cousin, niece or nephew or friend of long-standing (British Medical Association Ethics, 2009).

In some states in the USA there is a system similar to the opting-in system with the provision that it is mandatory for medics to ask the family of the injured person whether they are willing to donate the organs before a life-support machine is switched off (Hamilton, 2003). This is known as the “required request” policy. It states that it is irresponsible as well as illegal to disconnect a ventilator from an individual who is declared dead following brain stem testing without first making proper enquiry as to the possibility of that individual’s tissues and organs being used for the purposes of transplantation (Uniform Anatomical Gift Act, 1987).

The opting-out system on the other hand allows, indeed requires, doctors to take organs from the dead body if they can be used for transplantation purposes without necessarily having the permission of the family. The only restriction is that in cases where the deceased had indicated when alive his or her wish not to donate organs, doctors must respect these wishes. Countries which have introduced the opting-out system of organ retrieval include France, Italy, Belgium, Finland and Portugal. Some, like Austria have a strong/hard approach whilst others, such as Spain have a weak/soft approach. The difference between these two approaches and practices of opting-out is that the latter is more sensitive to the needs of the victim and his or her family (Organ Donation Taskforce, 2008).

Both the opting-in and the opting-out systems have their advantages and shortcomings. There is no unanimous agreement about the best legislation and code of practice. Table 1 summarises the main advantages and disadvantages of both systems.

	Opting-out system	Opting-in system
Advantages	<p>Reduces waiting list for cadaveric organs</p> <p>Relieves relatives of making the difficult decision themselves</p> <p>Organs do not go to waste</p>	<p>Altruism is encouraged</p> <p>Relatives are not coerced into donating if they are unwilling to do so</p> <p>Relatives feel that they are doing a good deed voluntarily</p>
Disadvantages	<p>Could be traumatic for family members of the cadaver when they are in disagreement</p> <p>The sense of altruism of voluntary donation is lost</p> <p>Doctors and other medical professionals could be perceived as insensitive fostering a lack of trust in them</p> <p>Not everyone might know when alive that there is presumed consent and might not make it known to the relevant authorities if they are against giving their organs</p>	<p>Difficult for doctors to approach family when their loved one is dying or has just died</p> <p>Traumatized families might refuse to donate</p> <p>Many organs go to waste and transplant opportunities are missed</p> <p>The family may not know the views on organ donation of their dead relative and so might find it difficult to say yes for fear of being disrespectful</p>

Table 1. Advantages and Disadvantages of the opting-in and the opting-out

### 3. Is opting-out the solution?

There are various studies which indicate that introducing the opting-out system increases the number of donations (Gnant et al., 1991; Low, 2006; Rithalia et al., 2009; Roels et al., 1991; Soh & Lim, 1992). Table 2 gives the top ten countries in Europe with the highest donations and transplants per 1 million population and indicates whether they practice opting-in or opting-out in their country. Ireland is the only country out of the top ten who have the opting-in system (Europe for Patients, 2010). When this data was collected, Malta was not included in the study. The number of organs retrieved in Malta varies depending on the year and the number of accidents that take place during that year. Being a small country, the number of organs donated fluctuates between 47 pmp to 137 pmp. This is clearly above the EU average of 17.8 per million population.

Country	Donation rates per million population (1 pmp)	Opting-in or opting-out policies
Spain	33.8	Opting-out
Belgium	27.1	Opting-out
France	23.2	Opting-out
<b>Ireland</b>	<b>22.7</b>	<b>Opting-in</b>
Italy	21.3	Opting-out
Finland	21.0	Opting-out
Portugal	20.1	Opting-out
Austria	18.8	Opting-out
Czech Republic	18.8	Opting-out
Latvia	18.7	Opting-out

Source: Council of Europe (2007). Deceased organ donors in the European Union.

Table 2. Donation rates in the top ten countries in Europe per million population (pmp)

Several factors besides legislation may influence the number of donors per capita. Some of these factors include mortality from road traffic accidents (Coppens et al., 2005), advancement in medical technology, neurosurgical practice and paramedical care (The Parliamentary Office of Science and Technology, 2004), lack of 'transplant culture' (The Parliamentary Office of Science and Technology, 2004), family involvement (Transplant Committee of the Council of Europe, 2007), the legislative framework (English, 2007; Wright, 2007), religion and religious beliefs (Gimbel et al., 2003; Rumsey et al., 2003), the efficiency of a country's transplant co-ordination (Johnson & Goldstein, 2004); GDP and health expenditure per capita (Healy, 2005), awareness of organ donation (Oz et al., 2003), blood donation rate (Abadie & Gay, 2006), knowledge of someone who had donated an organ after death and awareness of any one who received a donated organ (Rumsey et al., 2003), education (Gimbel et al., 2003), and attitudes towards organ donation and presumed consent (Roels et al., 1997).

The impact of presumed consent legislation on cadaveric donation was studied for a 10 year period in 22 countries by Abadie and Gay (2006). The researchers found that while differences in other determinants of organ donation explain much of the variation in

donation rates, after controlling for those determinants, presumed consent legislation has a positive and sizeable effect on organ donation rates. Similar conclusions were obtained by other studies. Rithalia et al. (2009) surveyed results of various studies carried out on the impact of presumed consent on donation rates in various countries with and without presumed consent and concluded that presumed consent alone is unlikely to explain the variation in organ donation rates between countries and that there must be other factors which may play a part even though their relative importance is unclear. There were a few studies which did not find a statistically significant relationship between presumed consent legislation and increase in the number of donors pmp in countries who had introduced presumed consent (eg. Coppen et al., 2005; Healy, 2005).

#### **4. Attitudes towards opting-out**

There are many studies investigating attitudes of people towards organ donation and towards opting-out. Surveys carried out in the UK before 2000 report low levels of support ranging from 28% to 57%. However a more recent survey carried out by YouGov in 2007 reported 64% of respondents supported opting-out. Another survey carried out in Scotland in 2004 showed that 53% of the participants did not agree with opting-out and 74% of the respondents agreed that the wishes of relatives should be considered before doctors are automatically allowed to take organs for transplantation (Haddow, 2006). In Malta the level of support for opting-out is even lower and only 22% agreed with this way of procuring organs in 2006. A further 20% said that they were unsure but tended towards being in favour (Lauri, 2006). In another study carried out in Spain in the 2003, only 24% of the participants agreed with the law of presumed consent. Indeed 53% considered that taking the organs without the family's permission was an abuse of authority (Conesa et al., 2003). This study was carried out after the law of opting-out had been introduced. Similarly in Belgium, a survey was carried out ten years after the introduction of presumed consent. In this country, the majority of the respondents were in favour of presumed consent however 44 % of the respondents still believed that the decision about the removal of their own organs after death should be taken by themselves only (Roels et al., 1997). In America, yet another study showed that 72% were opposed to the opting-out system (Klenow & Youngs, 1995) while in another study among actual donors, only 24% favoured a presumed consent law with an opting-out provision (Rodrigue et al., 2006). These and other studies carried out in various countries show that the level of agreement with opting-out varies. Variations in attitudes between surveys may reflect differences in methods and phrasing of questions and this has to be taken into consideration when taking policy decisions (Organ Donation Taskforce, 2008, p. 10.) However a pattern can be observed. It seems that many people are in favour of organ donation but have reservations about opting-out.

There are fewer studies which investigate the attitudes of doctors towards opting-out. Prottas and Batten (1988) found that physicians showed serious hesitation about dealing with donor families. However, in a more recent study by Schaeffner et al. (2004), researchers found that health professionals with a higher level of medical education are more likely to hold an organ donor card and also feel more comfortable in approaching relatives of potential organ donors. A study carried out by Persson et al. (1998) found that the majority of physicians in their study said that they would be willing to donate their own organs after their death but disagreed with the idea of using organs from a dead person who had a

negative opinion towards organ donation. The British Medical Association which represents the majority of doctors in the UK, supports a system of soft presumed consent, with safeguards, for organ donation by deceased people over the age of 16. The association claims that in this system, relatives' views would always be taken into account (British Medical Association, 2008). They argued that having organ donation as the default position would relieve relatives from the burden of decision-making. They also point out that legislation would encourage a more positive view of the process (Organ Donation Taskforce, 2008, p. 16). This was not borne out by the studies carried out by Conesa et al. (2003) in Spain and by Roels et al. (1997) in Belgium years after the introduction of the presumed consent legislation.

The Royal College of Surgeons, the British Transplant Society and the Royal College of Pathologists have also declared their support for a system of presumed consent (British Medical Association, 2008). A survey carried out by the International Society for Heart and Lung Transplantation (ISHLT) in 2002 showed that 74% of the healthcare professionals who participated in the study and who came from 15 countries, agreed with the introduction of presumed consent however only 39% agreed that presumed consent was the single most effective way to increase organ donation. More than half of the respondents believed that donation rates could also be improved by other interventions. These included indirect compensation, better awareness and more education on organ donation among the general public, having more medical staff to talk with families and building a rapport with them and legally binding donor cards (Oz et al., 2003).

## 5. Reservations about opting-out

One reservation related to the introduction of opting-out is the argument of whether persons have a right over their body. Those who believe that they own their bodies and that this right is transferred to the next of kin upon one's death, argue that the State has no right to remove organs from a dead person without having the family's consent or a living will stating that the person wants to donate his or her organs (Wintor, 2008). People may have different social representations of organ donation and ownership of the body. Those who believe in an afterlife may fear that donating organs could interfere with this process (Lauri, 2009). There are others however who believe that ownership of organs rests with the State. These believe that it right and just for the State to delegate its authority to the hospital and transplant team so that these can authorize the removal of organs from dead persons and give them to patients in need of a transplant (Farrugia, 2000). Patients, they argue, should not depend on the generosity of others. Other arguments put forward by those against opting-out is the definition of brain death (Hill et al., 1999) the potential loss of choice and autonomy (Lawson, 2008) and ethical implications involved (Bell, 2006).

The difference in opinion on whether or not to introduce the opting-out system exists among the general public as well as the professionals and authorities. A quick look at the on-line comments posted on January 14 by readers of the English newspaper *The Times*, in answer to the article written by the then Prime Minister Gordon Brown, shows that some readers did believe that in the context of long waiting lists for organ transplants, legislation should intervene in order to save the lives of people waiting for a transplant. However, many of the readers' letters showed how talk about the opting-out system can revive the fears surrounding organ donation. Readers wrote about 'mutilated', 'violated', and

'incomplete' bodies. One reader exclaimed 'Over my dead body!', describing the system as 'corpse robbing' and used the terms 'evil', 'ungodly', and 'repugnant'. But perhaps of more concern are the objections raised by those who, in principle, are in favour of organ donation. One such person wrote that 'If people want to give the gift of life, that is their right, but it must be something that is voluntary'. Another insisted that organ donation should be an 'active choice' and another wrote that, instead of forcing the issue through legislation, the Prime Minister should be 'educating people and using a campaign to donate organs' (Webster, 2008).

This paper will contribute to the debate on opting-out by investigating the attitudes of a sample of 151 Maltese doctors towards opting-out obtained by using an on-line survey. In the second part of the paper the data collected through interviews with five doctors who are directly involved in organ donation are reported.

## 6. The Maltese context

Malta is a small island in the Mediterranean with a population of about 400,000 people. The National Health System is free in Malta. However many families opt to have a family doctor whom they pay for every visit. It is not rare that the family doctor often lives in the town or village of his patients and knows the families well. Neither is it uncommon for the same doctor to look after two and sometimes three generations of the same family. The family doctor is possibly the most trusted person by the family, with the parish priest being a close second. For this reason, knowing the attitudes of doctors towards the introduction of opting-out is important. Doctors are opinion leaders.

In Malta, there is one hospital which carries out organ transplants. Organs are retrieved mainly from cadaveric donors through the opting-in system. Doctors working in Intensive Care report that the rate of refusal is low. Organs transplanted in Malta are kidneys, hearts and corneas. On average, eight kidney transplants and one heart transplant are performed every year. Currently, the number of people on the waiting list for a kidney or heart transplant is 81 (P. Calleja, personal communication, August 9, 2011).

Since doctors are not requested to record the number of refusals, there is no way of knowing how many families refuse to donate. In an earlier study carried out in Malta, doctors and medical professionals concur that the number of families who refuse to donate is low (Lauri, 2008). In spite of the fact that the number of transplants has steadily increased over the years, the problem of organ shortage is still present. The question whether we should be considering the introduction of opting-out is therefore pertinent.

## 7. The survey

This paper investigates the attitudes of Maltese doctors towards opting-out through a questionnaire administered in June 2011. Doctors' Associations were approached and asked to send the link to an anonymous on-line questionnaire to their members. There are 1707 registered doctors in Malta (Malta Medical Council, 2010). One hundred and fifty-eight respondents answered the questionnaire six questionnaires had incomplete information. Table 3 gives the ages and gender of the respondents. The questionnaire was made up of seven questions. Question 1 asked doctors whether they agree or disagree with the

introduction of opting-out in Malta. Questions 2 and 3 asked for reasons why they agreed or disagreed with the introduction of this legislation. Question 4 asked for their opinion why people sometimes refuse to give the organs of their dead relatives while question 5 was an open-ended question asking the respondents for adjectives they would use to describe 'opting-out'. Questions 6 and 7 asked for the gender and age of participants.

Age	Male	Female	Total
21-30	28	31	59
31-40	16	16	32
41-50	21	15	36
51-60	9	4	13
Over 60	11	0	11
			152

Table 3. Gender and age of respondents

## 8. Results

Results show that two-thirds of the respondents are in favour of opting-out. Younger doctors in the 21-31 age bracket were more in favour of introducing opting out than older doctors and female doctors were more in favour than male doctors. The association between age and being in favour or against introducing opting-out in Malta was significant (Chi-square=12.3, df=4, p=0.02). Respondents between the ages of 21 and 40 were more in favour of opting out while those over 50 were more against it.

Age	Percentage of respondents who were in favour		Percentage of respondents who were against		Total	
	Male	Female	Male	Female	Male	Female
21-30	15.9	12.6	2.6	7.9	18.5	20.5
31-40	9.3	7.3	1.3	3.3	10.6	10.6
41-50	7.9	6.6	6.0	3.3	13.9	9.9
51-60	2.0	1.3	4.0	1.3	6.0	2.6
Over 60	2.6	0.0	4.6	0.0	7.3	0.0

Table 4. Attitudes of male and female doctors on opting-out

Table 5 gives the three most common reasons given by respondents for being in favour or against opting out. Other reasons given for being in favour were that many people, even if in favour of organ donation, because of laziness or apathy never get around to applying for the card or expressing their wishes. Another reason given is that people who are actually in favour of donating their organs do not carry a donor card or register their names because they are superstitious and believe that they would be tempting faith if they do so (Lauri, 2009).

Other reasons given for being against opting-out are that such a system will hurt the family of the dead person, that Maltese culture does not favour such as system and that no one has the right to dissect a person's body without his or her explicit consent or those of the family.

	Reasons	Percentage of respondents
In Favour	1. Organs do not go to waste	42.4 %
	2. Family will not have to take difficult decision	39.7 %
	3. Reduces waiting list for transplants	32.5 %
Against	1. Cadaver does not belong to the state	19.9 %
	2. Should encourage altruism not coercion	19.9 %
	3. Patients may come to distrust doctors	11.9 %

Table 5. Reasons for being in favour or against opting-out

There were no significant associations between age or gender and those who gave reason 1-3 in favour of introducing opting-out. In the case of those against, there were no significant association for reason 1 however there were significant associations between age and reason 2 ( $\chi^2=16.9$ ,  $df=4$ ,  $p=0.002$ ) and age and reason 3 ( $\chi^2=12.2$ ,  $df=4$ ,  $p=0.02$ ), with older doctors mentioning these two reasons more frequently than the younger ones. There were no significant associations between gender and the three reasons given against opting-out.

These results support those given in the next question. Respondents were asked to describe opting-out using adjectives. A Multiple Correspondence Analysis (MCA) of the four variables (i) agreement or disagreement with opting-out, (ii) gender, (iii) age, and (iv) adjectives used to describe opting-out was carried out.

Some of the adjectives were synonyms and conveyed the same meaning. These were grouped together as shown below. Besides synonyms, some adjectives were placed in a particular group because they conveyed the same concept. For example the group of adjectives 'sensible, logical, rational, makes sense, proactive, practical, convenient' are describing opting-out from a rational, logical perspective as opposed to for example the group 'altruistic, act of generosity, benevolent, benefit for others, unselfish' which describe it from an altruistic point of view. Following are the groups of adjectives used to describe opting-out. The eleven adjectives in bold were the categories of the variable 'adjectives' which was used in the MCA.

The first five groups of adjectives used to describe opting-out in a positive light are:

- **Good**, pro-socoal, positive, fairly good idea, very good , important
- **Fair**, beneficial
- **Necessary**, essential
- **Sensible**, logical, rational, makes sense, proactive, practical, convenient
- **Altruistic**, act of generosity, benevolent, benefit for others, unselfish

Adjectives used to describe opting-out in a negative light included

- **Unethical**, immoral
- **Insensitive**, disrespectful
- **Coercive**, dictatorial, forced
- **Bad**, not the right approach
- **Arrogant**, egoistic, take advantage
- **Unnecessary**, not reasonable

In order to obtain a multivariate picture of the four variables YES/NO (agreement and disagreement with opting-out), GENDER, AGE, ADJECTIVES and their possible interactions, the MCA carried out, using SPSS Version 19, was used to extract two dimensions which between them accounted for 88% of the sample's variability on these four variables. Figure 1 shows a plot of the categories defined by the four variables against the two dimensions.

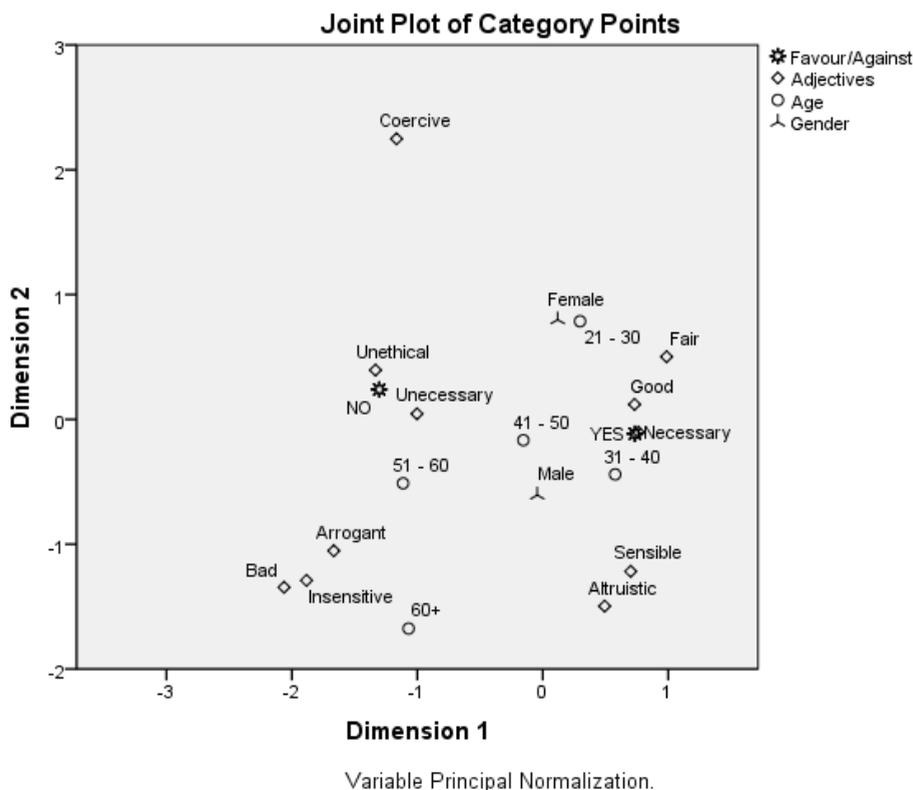


Fig. 1. Multiple Correspondence Analysis joint category plot showing adjectives used to describe opting-out, gender, and favours/not favours opting-out.

It is clear that the Dimension 1 discriminates between those in favour and those against opting-out and the corresponding adjectives describing opting-out favourably and unfavourably. Dimension 2 seems to vary along two characteristics. One of these is the age of the respondents. This dimension corresponds to moving from the highest age bracket (60+yrs) to the lowest one (21-30yrs). At the same time, this variation corresponds to a second characteristic, which reflects the nuance of the adjectives used to describe opting-out. The adjectives used by the younger age group seem to reflect the legal and ethical aspect of the issue and therefore they describe opting-out as being 'coercive', 'unethical' and 'fair'. The older age group use adjectives such as 'insensitive', 'bad', 'arrogant', 'sensible', 'altruistic' which bring out more the emotive aspect rather than the legalistic.

## **9. Interviews with doctors in contact with donors and recipients**

The second part of the study involves the interviewing of five medical professionals who are directly involved in organ donation. These doctors meet organ donors, recipients and potential recipients waiting for an organ transplant every day and therefore are very much aware of the issues involved. Malta being such a small community, giving any information about the five participants would result in their identification and for this reason their roles will be kept anonymous.

### **9.1 Method**

Interviews were recorded with the permission of the interviewees. Interviews were transcribed and thematic analysis was carried out. Theoretical thematic analysis involves searching across a data set to identify themes and patterns that relate to a theoretical area of interest (Braun & Clarke, 2006). In the first phase of the analysis the primary text was broken up into discrete segments which described or referred to an independent idea or concept. Each segment was labelled with a keyword or phrase. A complete list of keywords together with the quotations to which they referred was generated. This restructured version of the primary texts was the basis for the second phase of the analysis. In this phase, the basic units of analysis were the keywords together with their lists of quotations. The keywords were classified into themes which brought together related keywords. The themes in turn were grouped into categories. The classification of keywords into themes and categories is given in Table 6. The next section is an analysis of the interviews and a discussion of some of the salient issues that emerged.

### **9.2 Doctors' attitudes toward opting-out**

In this study the five doctors interviewed were, in principal, in favour of the opting-out system but felt that the decision to introduce it could create problems and affect the respect people have towards the medical profession. They all agreed that it should be postponed to a later date when people were in a better position to understand the necessity of opting out if the need becomes acute. The reasons given for their position were various and the six main ones are discussed below.

CATEGORIES	THEMES	KEYWORDS
Refusals	Few refusals	Low refusal rate
	Lack of knowledge	Children
Families	Sensitive organs	Identifying problem areas
	Consulting family	Lack of official records
	Permission	Doctor-patient relationship
	Awareness	Must still involve relatives
Wish of the deceased	ID card	Family doctor
	Family discussion	Priest
	Public campaigns	Imposition
Altruism	Encouraging altruism	Difficult for doctors to ask
	Individualism	Anonymity
Anonymity	News	Difficult decision made easier
	Small country	Knowing the wish of the deceased
Trust in doctors	Lack of trust	Disrespect
	Family doctor	Voluntary donation
	Official document	Informed consent
		Health system
		Values
		Religion
		Personality traits
		prosocial
		Maltese context
		ITU personnel
		Newspapers
		News
		Television
		Right timing
		Discussion
		ID card
		Trust
		Respect
		Tarnish relationship
		Consult family

Table 6. Factors influencing the decision on whether to introduce opting-out

### 9.2.1 Low rate of refusals

Interviewees pointed out that although no statistics are kept regarding the number of refusals, they know that it is low.

*We have to see if there is a need for it to become law. Over the past ten years, how many refusals were there? If there were refusals in England, then they need it. If we don't have that many refusals, then I don't think we need to. At the end of the day, nobody likes to have it imposed on him. It is much better to ask. (Doctor 1)*

*So many people are in favour of it [donating organs], that there isn't a need in Malta. By nature, if we can help, we do so... (Doctor 5).*

*Here, most people do give permission for their relative's organs to be used. We rarely find people who object to it (Doctor 4)*

Doctors observed some trends in families who refuse to donate. Refusals often come when the potential donor is a child. Parents find it very difficult to give permission to doctors to take organs from children. Another difficult decision is to give the eyes of the dead relative. Relatives may also refuse to donate because they are not cognizant of the procedures involved. The professionals might explain but at such a difficult moment the cognitive functions are overwhelmed and the affective element takes over.

*For example, in one case, a nun who was the dead man's niece entered the room and said, "But he is still alive, look at him, feel him, he's still warm." I explained what it is. But these problems can and do arise. (Doctor 2)*

### **9.2.2 Role of the family of the deceased**

Interviewees argued that if opting-out is in place, it would be very difficult for most of the doctors to remove organs without informing the relatives and getting their cooperation. If legislation on opting-out is introduced, when relatives object to the organs being taken from the deceased, a very uncomfortable situation would arise. Although legally correct to remove the organs, going against the wishes of the relatives would increase the anguish and suffering of the family. Since family consent is still commendable, the opting-out system still presents problems similar to opting-in.

*When I attended meetings with Spanish and Italian colleagues, who have the opting-out system, they claim that it is still socially necessary to inform relatives and ask for consent. (Doctor 2)*

### **9.2.3 Altruism**

Interviewees pointed out that introducing the opting-out system would remove the element of altruism from the act of donating organs. Doctors interviewed were of the opinion that altruism should be encouraged and donation should not be imposed by legislation.

*If we wish to keep having high standards, then we need to accept altruism as part of our health care. We can't ignore it.... We can't reach that level. (Doctor 4)*

*"You have to give people the option to be altruistic." (Doctor 3)*

### **9.2.4 Knowing the wish of the deceased**

According to the research carried out by the European Commission (Europeans and Organ Donation, 2007, Special Eurobarometer 272D/Wave 66.2 – TNS Opinion and Social), more than four out of ten Europeans have already discussed with their family the question of organ donation and transplantation (p. 20). Malta stands out as the only new Member State to record a score above the European average (44% versus the average of 42% for the countries in the EU). One of the interviewees confirmed that the fact that persons would have already discussed this subject with their family has a strong influence on the willingness to donate organs of a relative.

*Doctors find that a number of potential donors had, during their life-time, signed a consent form for donation and whilst doing this they had informed their family of their strong views in favour of donation. A signed donor card helps families reach a favourable decision. (Doctor 2)*

*It is one of our good traits. Many times, they [the family] approach you first, before you even feel comfortable to approach them yourself... (Doctor 5).*

One of the interviewees was of the opinion that rather than introducing opting-out, Government should ask persons to decide whether they want to donate their organs or not and this is registered in their ID card. Knowing the wishes of the deceased would help both the doctor to ask and the family to decide. He also pointed out that regular campaigns should inform the public about the implications of signing this document so that there is informed consent. He pointed out that it is important to find out why people refuse and then address that particular problem.

*Is it because people refuse on moral, religious grounds, is it they don't really care? Is it a certain apathy? Because if it is one of these, then it should be addressed rather than going to something completely different and drastic.....(Doctor 3)*

This participant claimed that in Malta this system would work out better than introducing opting-out. People would be against any form of imposition or coercion and their attitudes would ultimately undermine the aim of increasing the number of donated organs.

### **9.2.5 Anonymity**

Another issue related to opting-out according to the participants is that in a small country, it is very difficult for donors and recipients to remain anonymous. This could create problems when all or some members of the family of the deceased person from whom the organs are taken are against the idea of donating the organs. In many countries anonymity is observed, however Malta presents a different context where, because of its size, it is very easy for persons to contact each other.

*It depends on the local culture. Regarding cadaveric donations, in England, everything is done to make sure that the identity of the donor is not known. Now in Malta, it is useless trying to do that. Even if the entire staff is on board not to divulge information, newspapers report that there has been a fatal traffic accident and those waiting for an organ would know that there are organs available. (Doctor 1)*

If due to opting-out, people are forced to donate the organs of their relative when they do not want to, members of the family can vent their anger on the recipient and the family.

### **9.2.6 Trust in the medical profession**

One other important argument which the participants discussed was that if opting-out is introduced, it could tarnish the trust that exists between the patient and the doctor. The medical profession has always been respected and trusted. Introducing opting-out, the respondents claimed, could tarnish this relationship.

*If there is no trust I don't do anything....If there is lack of trust once, he will tell someone else, and it keeps happening. And once you lose it [a patient's trust], there is no way coming up. So we'd rather err on the safe side. (Doctor 5)*

Before the relatives take the decision to donate the organs of the deceased, they consult their family doctor who is always very close to the family as well as relatives. Often they also need the comfort of a priest they trust. These discussions are important. Forcing the relatives to donate when they are not in agreement is not conducive to creating a culture of trust in the medical profession.

*Many times, you know what they are going to say before, because you build a rapport with them. It is important...If they respect you, they say 'this is the doctor who looked after my daughter, my son, parents. I trust him. I know that he did all he could to save him, now he is trying to do all he can to save someone else. (Doctor 5)*

Possibly this could be the strongest argument put forward and must be evaluated in depth. Having the citizens of a country commit themselves on an ID card about whether or not they are willing to donate, will make the relatives much more at peace with themselves when taking decisions to donate. Having one's view on the ID card implies that (i) it is easier for doctors to ask relatives (ii) knowing the views of the deceased, relatives find it easier to decide to donate (iii) more organs become available. All this would be achieved without coercion and without drastically changing the existing system.

## 10. Discussion

The data collected from the interviews and the survey indicate that the respondents are not in agreement as to whether opting-out should be introduced in Malta. The survey shows that 65.8% of those who answered, said that they are in favour and described donation in very positive terms. However the other 34.2% had negative attitudes towards the introduction of opting-out. Moreover the doctors who work with potential donors and recipients think that Malta, as opposed to other countries, does not need to introduce the system yet. They argue that in a small country, the relationship between the families and the family doctor, who is almost a member of the family, is still very warm and that people's respect and trust in the medical profession is also strong. This facilitates the dynamics when doctors ask for the organs of their deceased relative. When asked, the potential donor family consults with the family doctor and very often the parish priest and depending on their advice, they decide. This works well most of the time because doctors and the public are in favour of organ donation and could be one of the reasons why there are few refusals (Lauri & Zarb Adami, 2010). Introducing opting-out could create a debate which could undermine the donation process. Since in the sample we found that more than 34% of doctors are against presumed consent and since a survey carried out in 2006 showed that more than 52% of Maltese people are against presumed consent, there is a probability that the debate will backfire creating doubts in people's minds and in so doing diminishing the trust they have in hospital doctors. This may result in people becoming less positive about organ donation and less people carrying the donor card. As things are, with the opting-in system, the decision is based on trust, goodwill and altruism. If the system changes, these values may be jeopardised.

This may be a different scenario from other countries where the economies of scale are different. Maybe in other countries, because of different health schemes, the bond between the family doctor and the family is less strong and maybe the families do not consult the family doctor when they are asked to donate, resulting in many refusals. It could also be

that family members and extended family are not as close-knit as Maltese families who often include two or three generations living in houses in the same square mile. Maltese families are very possessive and present a united front against anything or anybody that in any way threatens them.

Many researchers point out that most people would wish to act in an altruistic manner and help others by donating their organs after death. However what actually happens is that while the majority of people would be willing to donate organs, only a small number register their names on the Organ Donor Register or carry a donor card. This is also true for Malta. However whereas in other bigger countries, people may not have close family members who can be contacted easily, in Malta it actually takes minutes to do so, and therefore doctors can check quickly the wishes of the relatives.

The British Medical Association argue that a shift to presumed consent would prompt more discussion within families about organ donation (Organ Donation in the 21<sup>st</sup> Century, 2000). This is true, but in the case of this island, the debate will probably be a very emotional one rather than a rational one since research has already shown that the social representations which Maltese people have regarding the body and organ donation are very complex (Lauri, 2009). The majority still believe that this is a decision to be taken by the family members and nobody else. Even some doctors believe that this should be the case.

Another point made by the British Medical Association is that with a shift to presumed consent, organ donation becomes the default position and that this represents a more positive view of organ donation which is to be encouraged. This will not necessarily be the case in Malta. In fact it will probably create more negative attitudes than positive ones and would influence the metaphors people use to grapple with the issue of organ donation (Lauri, 2009). Presumed consent has not resulted in more positive views towards opting-out as can be borne out by studies carried out in other countries with presumed consent such as Spain, Brazil and Belgium.

## 11. Conclusion

In the case of Malta, because of its size and culture, it seems that the best way forward is to have an intensive campaign every three to five years encouraging the discussion of organ donation within the family and introducing a system whereby every citizen who applies for a formal document, in the case of our country, the ID card, are asked to register whether they want to donate their organs after their death. This document will help the family decide in the event that they are asked to donate the organs of the deceased. In a survey carried with a random sample of 400 Maltese citizens, respondents were asked whether they would donate the organs of their loved one if they knew that he or she would have wanted them to do so or would have carried a donor card. Only 9% of the respondents said they that they would not (Lauri, 2000). Having the wishes of the deceased registered on the ID card would make the family's decision very much easier.

The belief is that a shift to presumed consent is not likely to have a positive effect on donation rates in Malta at this point in time. Maybe this can be considered again in a few years' time but from the results obtained in this study, it seems that according to some doctors and the professionals working with potential donors and recipients, it is neither necessary nor judicious to introduce opting-out in Malta.

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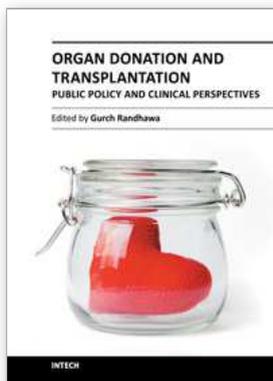
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