

# The need for increasing the retrieval of organs: doctors' attitudes towards opting-out

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## Abstract

Some countries have introduced the opting-out system of organ donation as a way of increasing the number of available organs for transplants. Public opinion is divided on this issue and so are medical recommendations. While some claim that opting-out is the only way forward to increase the harvesting of organs and transplants, others claim that the decision whether or not to donate the organs of a dead relative should be a voluntary decision taken by the next of kin. In this paper, five doctors who are directly involved in organ donation or transplantation in Malta were interviewed on the issue of the harvesting of organs. The interviews were recorded, transcribed and analysed. The interviewees concur that since the rate of refusals is still low in Malta, the opt-in system which is currently in practice should be retained.

## Introduction

The report commissioned by the European Commission, Europeans and Organ Donation<sup>1</sup> describes organ transplantation as one of the great medical success stories of the 20th century. As early as 1902, Dr Alexis Carel, who attempted to transplant organs on animals declared that "Although organ transplantation is today merely a clinical curiosity, it may one day have a certain practical interest." That day is now and the success rate of organ transplantation is creating a need for a greater supply of organs.

There are two main practices or legislations on organ retrieval. The opting-in system is practised in countries like England, Germany and Canada.<sup>2</sup> 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. The opting-in policy has its challenges. When approached about organ donation, the family of the deceased are still under shock from the news of the unanticipated, often traumatic death of a loved one.<sup>3</sup> It is for this reason that doctors very often find it difficult to approach the family and ask for permission to take organs. Moreover, in many countries, approximately half the families of those approached to donate the organs of a family member refuse consent.<sup>4</sup> Often, the family feels that by giving permission to doctors they might be showing disrespect towards the dead person. This happens mostly when they would not know the wishes of the deceased regarding organ donation.<sup>5</sup> Moreover, the family sometimes would not know what is involved in organ donation and rather than asking what this entails, the family decides to withhold permission.<sup>6</sup> One of the fears which the family experiences when taking the decision whether or not to donate the organs of a relative who has just died is that of disfiguring the body of their loved one.<sup>7</sup> Another fear is the possibility that their loved one is not really dead. This fear is sustained when they see on the monitor that the heart is still beating.<sup>8</sup> The reluctance to sign a donor card very often is the result of perceived risks and unarticulated fears about death and donation.<sup>9,10</sup>

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.<sup>11</sup> This is known as the "required request" policy. It states that it is irresponsible as well as illegal to disconnect a ventilator from

## Keywords

Opting-out, organ donation, transplantation, attitudes

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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.<sup>12</sup> As a result of this policy, less opportunities of organ donations are lost.

On the other hand, under the opting-out system which is practised in countries like Spain, Austria and Belgium, the law 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. There are various studies which indicate that introducing the opt-out system increases the number of donations.<sup>13</sup> Donation rates range from 33.8 deceased donors per million population (pmp) in Spain to 1 deceased donor per million population in Romania. Table 1 gives the top ten countries in Europe with the highest donations and transplants per 1 million population and indicates whether they practise opting-in or opting-out in their country. Ireland is the only country out of the top ten who have the opting-in system. When these data were 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.<sup>14</sup>

**Table 1: Donation rates in the top ten countries in Europe per million population**

Country	Donation rates per million population (pmp)	Opt-in or opt-out policies
Spain	33.8	Opting-out
Belgium	27.1	Opting-out
France	23.2	Opting-out
Ireland	22.7	Opting-in
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: Advantages of the opting-in and the opting-out system**

Opting-out system	Opting-in system
Reduces waiting list for cadaveric organs	Ultruism is encouraged
Relieves relatives of taking a difficult decision	Relatives are not coerced into donating if they are unwilling to do so
Organs do not go to waste	May be less traumatic for family members
Family who refuse may later regret not giving the organs	Families may feel they are being disrespectful towards their loved one

### Deciding which policy to implement

The introduction of the opting-out system is never without controversies. One relatively recent example occurred in England in January 2008, triggered by an article in the Telegraph by Gordon Brown.<sup>15</sup> The then English prime minister, Brown wrote in favour of the opting-out system of organ donation and said that parliament was considering legislation to enable doctors to remove organs from dead patients without permission of their next of kin.

There was a strong reaction to his statement. On one side, the lobby groups for patients' rights claimed that the State does not own the body of a dead person and the decision whether or not to donate one's organs after death should be a private decision. On the other hand, England's chief medical officer, Sir Liam Donaldson as well as The British Medical Association supported the opting-out system.<sup>16</sup>

Both opting-in and the opting out systems have their advantages and their disadvantages and this is the reason why there is no unanimous agreement about the best legislation and code of practice. Table 2 summarises the advantages and shortcomings of both systems.

### Ownership of the cadaver

One fundamental ethical issue related to the introduction of opting-out is the argument of whether or not persons have a right over their body and whether it is their property. Those who believe that we own our 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. There are others however, who believe that ownership of organs rests with the State, and that it right and just for the State to delegate its authority to the hospital and transplant team so that these can authorise the removal of organs from dead persons and give them to patients in need of a transplant.<sup>17</sup> Patients, they argue, should not depend on the generosity of others. "If people's needs play a crucial role in a

theory of justice, one may find it hard to draw the line between justice and generosity."<sup>18</sup>

A related ethical issue is that of whether there should be financial remuneration for the donation of organs. Ethicists, professionals in the medical field as well as public opinion are generally against the idea of buying and selling organs.<sup>19</sup> However, not everyone is in agreement. Some researchers argue that giving monetary incentives would increase the supply of organs for transplant sufficiently to eliminate the very large queues of patients.<sup>20</sup> Since it is generally accepted that buying and selling of organs is unethical, patients have to wait for someone to donate the organs at the cost that a patient may die whilst still on the waiting list. It is argued that financial incentives for the donation of organs would give a greater chance to such patients.<sup>21</sup>

### Organ donation in Malta

In Malta, organs are retrieved mainly from cadaveric donors through the opting-in system. Doctors in Intensive Care report that the rate of refusal is low. The organs transplanted in Malta are the kidneys, the heart and the cornea. The number of hearts transplanted is less than the number of kidneys. On average the number of kidney transplants carried out in Malta is between five and eight. Kidneys which are harvested but do not match the tissues of any of the Maltese potential recipients are sent abroad as indicated in Table 3. 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.<sup>22</sup> In spite of the fact that the number of transplants has steadily increased over the years, the problem of organ shortage is still present as seen in Table 3. The question whether we should be considering the introduction of opting-out is therefore pertinent.

### Methods

This brief study is of a qualitative nature and involves the interviewing of five doctors involved in organ donation and transplantation whose identity will be kept anonymous. The

Maltese public's attitudes towards the opting-out system was discussed in another paper.<sup>10</sup> This qualitative study on doctors' attitudes is the first phase of the research. The second phase will involve a survey with the members of the medical profession. The interviews reported in this preliminary study will inform the questionnaire which will be used in the second phase.

Interviews were recorded with the permission of the interviewees and transcribed. What follows is an analysis of the interviews and a discussion of some of the salient issues involved in the retrieval of organs.

### Analysis of data

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.<sup>23</sup> 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. 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 4. The two relevant categories which emerged will be discussed in the next section.

### Opting-out and some of its implications

Opting-out is practiced in many European countries. It is adopted in those countries where the demand is much higher than the supply and where the rate of refusal for the donation of organs is high.

*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*

**Table 3: Harvesting of kidneys**

Year	Patients waiting for kidney transplants	Kidney transplants from cadaveric donors	Kidney transplants from live donors	Total number of kidney transplants in Malta	Number of kidneys sent abroad for transplantation
2005	68	6	2	8	0
2006	70	8	4	12	4
2007	71	5	2	7	1
2008	75	8	3	11	2
2009	75	4	4	8	*

**Source:** Mr A. Bugeja, Transplant Co-ordinator (personal communication)

\*Data not available

**Table 4: Attitudes of doctors towards organ retrieval**

Categories	Themes	Keywords
Opting-out	Rate of refusals Ideal policy Altruism	<ul style="list-style-type: none"> <li>• Must still involve relatives</li> <li>• Refusing to donate</li> <li>• Imposition and coercion</li> <li>• Removing element of Altruism</li> <li>• Individualism</li> <li>• Low refusal rate in Malta</li> <li>• Children</li> <li>• Eyes</li> <li>• Organ harvesting</li> <li>• High demand</li> </ul>
Cadaveric Donation	Withdrawing and withholding care Anonymity Family discussions	<ul style="list-style-type: none"> <li>• Brain death</li> <li>• Legislation</li> <li>• Accidents</li> <li>• Counselling</li> <li>• Donor card</li> <li>• Difficult for doctors to ask</li> <li>• Anguish and suffering of relatives</li> <li>• Lack of cooperation</li> <li>• ITU personnel</li> <li>• Legal framework</li> <li>• Right timing</li> <li>• Discussion</li> <li>• Maltese context</li> </ul>

*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)*

The doctors interviewed 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 to some extent getting their cooperation. If the relatives object, a very uncomfortable situation would arise. Although legally correct to remove the organs, this would increase the anguish and suffering of the family. Hence, 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 opt-out system, they claim that it is still socially necessary to inform relatives and ask for consent. (Doctor 2)*

Interviewees pointed out that introducing the opt-out system would remove the element of altruism from the act of donating organs. Doctors interviewed were of the opinion that we should encourage altruism and not impose by legislating on opting-out.

*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 as they are doing in America. We can't reach that level. We need to be ready to help others. And donating kidneys is one such way. (Doctor 4)*

Not many families refuse to donate organs when asked. 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.

*Yes, because if you do not explain it is just the cornea, they say that they don't want to be walking somewhere and they see the eyes of their relative..... But, that is just their impression. (Doctor 5)*

### Issues related to cadaveric donation

In a previous study carried out in 2001,<sup>24</sup> doctors talked about the context in which organ donation takes place including the lack of cooperation from other doctors in the wards who fail to alert the ITU personnel of possible organ donors. They also discussed policy issues such as the lack of a legal framework for organ donation, hospital policies and budgeting. They mentioned medical and ethical issues such as problems involved in live donations and withdrawing and withholding care once brain death has been declared.

In this study, the issue of legislating in favour of the opting out system was discussed by all participants. All doctors interviewed were in favour of the opting-out system but felt that the decision to introduce it could create problems and hence should be postponed to a later date when people were in a better position to understand the necessity of opting out.

The participants explained the difficult context in which family are asked to donate organs. When brain death is confirmed, the family of the person is approached and told their family member is dead. Some families do not understand

the notion of brain death and that a family member, who is apparently still alive and with his or her heart beating, is in fact dead. This could lead some relatives to refuse to donate.

*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)*

According to the research carried out by the European Commission,<sup>1</sup> more than four out of ten Europeans have already discussed with their family the question of organ donation and transplantation. 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 pointed out that the fact that respondents 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)*

The doctors interviewed are not in agreement about whether the donors and the recipients should remain anonymous. In many countries anonymity is observed, however Malta presents a different context where, because of its size, it is very easy to find out who the donor was. Some doctors believe that it can be therapeutic for both the donor family and the recipient to get to know each other. Others think that anonymity is better.

*If a transplant goes wrong, there is a tendency for the family of the recipient or the recipient himself or herself, to blame the donor for possibly leading a risky life. I think anonymity is important. (Doctor 3)*

*I personally still discourage them because things change. One day you think one way, the next, you think another way. It is best that no one knows anything. (Doctor 5)*

*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, the newspapers report there has been a fatal traffic accident, so there are organs available. (Doctor 1)*

## Conclusion

The attitudes of the five participants cannot be generalised to those of all medical doctors. That is not the scope of a qualitative study. However, it is of interest to note that all the five participants who work closely with both organ donors as well as potential recipients, argue that introducing an opting-out system may in fact have negative repercussions and will not help the cause of organ donation in Malta. A quantitative study

with a larger number of participants is proposed to ascertain to what extent the views of the five participants are consonant with the attitudes of Maltese doctors.

The debate on whether to introduce the opting-out system depends on many issues. Questions such as "Who owns the body of the dead person?", "Does the State own the body of the 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?" are very pertinent questions. Because of these and other complex questions, sections of societies are against the opting-out system and hence may present resistance to introducing the system. On the other hand, doctors' associations, such as the British Medical Association as well as other 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 or should legislation on opting-out be introduced. It seems that, according to the doctors interviewed in this preliminary study, opting-out is as yet neither judicious nor necessary in Malta.

## Acknowledgements

The authors would like to thank Ms Maria Ali who helped the authors with transcriptions as well as the preparation of this paper.

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