

# The Lay Person and Transplantation

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## ***Introduction***

The work I will be presenting in this paper is part of a project carried out by a group of people coming from different disciplines. The aims of the project were four. These were:

1. To create greater awareness of organ donation among the public;
2. To provide information about organ donation;
3. To foster positive attitudes towards organ donation and decrease negative ones,
4. To increase the number of donor card holders.

To reach these objectives we decided to launch a nation campaign on organ donation. The campaign was based on the Social Marketing Model proposed by Kotler (Kotler & Roberto, 1989). The formative research carried out before the campaign consisted of a national survey with a quota sample of 400 people, 12 interviews with doctors, donor families and recipients and five focus groups. In this paper I shall only present the results of the survey. I shall also discuss briefly the results of two other surveys carried out after the campaign.

The project started in 1995 and came to an end this year in 1999, covering a span of five years. In 1995, twelve years after the first kidney transplant in Malta, organ donation was still a relatively new concept for the majority of the Maltese people. Many had heard about it but very few knew what it meant or what it involved. Many people had never heard about the donor card. It was therefore decided that one of the first investigations should be a survey of attitudes of the Maltese public about organ donation.

## ***The Survey***

In order to be able to compare the results with research carried out in Britain, the questions asked were a translation of those used in a survey commissioned by the British Kidney Patient Association and carried out by Gallup Ltd. (Social Surveys (Gallup Poll) Ltd., 1994). The survey consisted of eight questions which were asked in Maltese. The responses to these questions are compared with the British data. Some questions are analysed in more detail using chi-square tests of independence, and hierarchical log-linear analysis.

## ***Methodology***

The survey was carried out with a sample of four hundred persons aged eighteen years and over living in Malta and Gozo. The only exclusion was of persons living in an institution at the time of the survey. MISCO International was commissioned to administer the questionnaire. They were given the set of questions and they provided the collected data on diskette. The questions were pre-tested with a sample of 20 people to ensure that the questions were clear and understandable. As a result of the pre-testing, minor adjustments were made to the wording of some questions prior to submitting them to MISCO.

The Maltese survey was carried out in twenty areas randomly selected within the six regions as given in the “Demographic Review of the Maltese Islands” (Central Office of Statistics, Malta 1994). Sixteen trained interviewers carried out face to face interviews in the respondents’ homes according to a quota representative of the age and sex of the Maltese population.

Fieldwork was carried out between 27 April and 10 May 1995. All the responses to the questionnaire were classified by gender, age and socio-economic status of the respondent. Age was coded into one of three categories (18-34 years, 35-54 years and 55 years or more) and socio-economic class was recorded in one of four categories (A-B, C1, C2 and D-E categories).

## **Results**

Each response is analysed first by comparing the results obtained in the Maltese survey with the corresponding response obtained in the British survey held by Gallup in 1994. This analysis is somewhat brief and limited in scope because only basic tabulations from the Gallup survey are available and not the actual data. But following this comparative study, the data for the response of the Maltese survey is then, where appropriate, subjected to more detailed statistical analysis. Details how this is done are given below when the relevant question is being analysed.

### **(i) Awareness of Organ Donation**

The first question respondents were asked was the following:

*Question 1. Are you aware that you can leave your organs to be used by somebody else after your death?*

Table 1 compares the responses obtained to this question in the Maltese survey and the Gallup survey carried out in Britain in 1994. In the Maltese survey, 93.5% of the respondents had heard about organ donation. This figure was surprisingly high since it was even higher than that registered in the British survey where the corresponding percentage was 73%. This could be due to two factors. One is the social desirability bias where respondents want to appear in good light with the interviewer. The other was a TV programme on organ donation which had been screened during prime time some weeks before the campaign.

**Table 1: Responses to Question 1 - Maltese and British figures**

	Malta 95	United Kingdom 94
Yes	93.5%	73%
No	6.5%	16%
		10% (Do not know)

(Base for percentages: All respondents)

Analysis of the Maltese data in more detail was carried out by performing the chi-square test of independence on each of the following contingency tables: (i) response (awareness

of organ donation) by socio-economic class, (ii) response by gender and (iii) response by age.

A strong association was found between awareness of organ donation and socio-economic status ( $\chi^2=9.8$ ,  $df=3$ ,  $p=0.02$ ). As can be seen from Table 2, the percentage of those in the D-E categories who were unaware of organ donation was 10.4%. This proportion varied considerably with socio-economic class, with everybody in the A-B categories saying that they had heard about organ donation.

The association between awareness and gender or age was not found to be significant.

**Table 2: Responses to Question 1 - Analysis of Maltese sample by socio-economic class**

Ever heard about organ donation	Soc-economic classification				Total
	A-B	C1	C2	D-E	
Yes					
Count	71	79	103	121	374
Column percentage	100.0%	96.3%	92.0%	89.6%	93.5%
No					
Count	0	3	9	14	26
Column percentage	0.0%	3.7%	8.0%	10.4%	6.5%
Total					
Count	71	82	112	135	400
Row percentage	17.8%	20.5%	28.0%	33.8%	100.0%

$\chi^2=9.8$ ,  $df=3$ ,  $p=0.02$

(Sample base: All respondents)

***(ii) Willingness to Donate Organs After Death***

Respondents were then asked the following question:

*Question 2: Would you agree to donate your organs after your death?*

The responses indicated that the majority of the Maltese sample approved of donation. When asked whether they would agree to donate their organs after their death, 55% of the respondents answered “Yes definitely” and 26% answered “Probably yes”. This compared well with the 72% reported to be in favour of donating their organs after their

death in the Gallup survey carried out in Britain. Only 14% of the Maltese respondents said that were against organ donation and would not give their organs after their death. The percentage of British respondents who were against organ donation in the Gallup survey was 18%. (See Table 3.)

**Table 3: Responses to Question 2 - Maltese and British figures**

	Malta 95	United Kingdom 94
Yes definitely	55%	72% (In favour)
Possibly yes	26%	
No	14%	18%
Do not know	5%	10% (Neutrals+Do not know)

(Base for percentages: All respondents)

To analyse the Maltese responses to this question in terms of socio-demographic characteristics, it was decided to filter out the responses of those who, in answer to the first question, had said that they had never heard about organ donation (26 respondents out of 400). Therefore only responses of those who had heard about organ donation are considered in the following more detailed statistical analysis (374 respondents).

Again separate chi-square tests of independence were carried out for the contingency tables classifying the response to this question (willingness to donate organs after death) and each of the three socio-demographic characteristics. Yet again, the strongest association found was that between the responses to the question and socio-economic class (chisq=16.6, df=9, p=0.06). Although this association is not as significant as the one noted above for the awareness question, one can still discern from Table 4 that positive attitudes towards organ donation are strongest amongst the A-B classes and become weaker amongst the D-E classes.

**Table 4: Responses to Question 2 - Analysis of Maltese Sample by Socio-economic Class**

Willing to donate after death	Soc-economic Classification				Total
	A-B	C1	C2	D-E	
Surely yes					
Count	49	52	60	59	220
Column percentage	69.0%	65.8%	58.3%	48.8%	58.8%
Possibly yes					
Count	12	21	27	36	96
Column percentage	16.9%	26.6%	26.2%	29.8%	25.7%
No					
Count	7	5	9	21	42
Column percentage	9.9%	6.3%	8.7%	17.4%	11.2%
Do not know					
Count	3	1	7	5	16
Column percentage	4.2%	1.3%	6.8%	4.1%	4.3%
Total					
Count	71	79	103	121	374
Row percentage	19.0%	21.1%	27.5%	32.4%	100.0%

*chisq=16.6, df=9, p=0.06*

(Sample base: All respondents aware of organ donation)

The associations measured between willingness to donate and gender and between willingness to donate and age were both not significant. However, this question, dealing with respondents' willingness to donate organs, is very crucial especially from the point of view of designing a campaign in order to promote donation. It was therefore felt that this data warranted a multivariate statistical analysis in order to probe more deeply into the relationship between the response and the socio-demographic characteristics and to discover any significant higher order associations.

It was therefore decided to carry out a hierarchical log-linear analysis (running the *HILOGLINEAR* procedure from the *SPSS* package) on the variables in question, that is, the response to the question (willingness to donate organs after death), gender, age, and socio-economic class. Hierarchical log-linear analysis constructs multiway crosstabulations involving all the variables and provides many procedures to help unravel complex relationships which might exist between the variables. The backward elimination variable-selection method was employed. With this method *HILOGLINEAR* removes interaction terms which are not significant until it reaches a model containing interactions of the variables which best fit the data.

The result of running this procedure indicated that, apart from the association between the response and socio-economic class which was noted and considered above, an interaction between gender and age could have an important contribution in explaining the associations amongst the data. This question was explored further by analysing contingency tables of response by age for male and female respondents separately. It was found that although for males the association between their willingness to donate and age was not significant, it became highly significant for females ( $\chi^2=14.0$ ,  $df=6$ ,  $p=0.03$ ). Table 5 indicates that the younger females tend to be more willing to donate their organs after their death than older ones.

**Table 5: Responses to Question 2 - Analysis of Maltese Sample by Age for Females**

Willing to donate after death	Age			Total
	18-34 years	35-54 years	55+ years	
Surely yes				
Count	48	47	25	120
Column percentage	76.2%	67.1%	45.5%	63.8%
Possibly yes				
Count	11	14	17	42
Column percentage	17.5%	20.0%	30.9%	22.3%
No				
Count	3	6	10	19

Column percentage	4.8%	8.6%	18.2%	10.1%
Do not know				
Count	1	3	3	7
Column percentage	1.6%	4.3%	5.5%	3.7%
Total				
Count	63	70	55	188
Row percentage	33.5%	37.2%	29.3%	100.0%

$\chi^2=14.0, df=6, p=0.03$

(Sample base: All female respondents aware of organ donation)

The findings were similar to those found by other researchers, for example, Perkins (1987) and Manninen and Evans (1985).

### **(iii) Donor Cards**

Respondents were then asked the following question:

*Question 3: You may know that people carry a donor card which they can fill in to say which organs they would like to donate after their death. Will you look at this card and tell me which answer applies to you?*

The responses to this question are summarised in Table 6 below which also compares them with the Gallup survey. The percentage of Maltese respondents who said that they have donor cards was only 7% when compared to the 35% reported in the Gallup survey carried out in Britain in 1994. Those who had not heard about the donor card in the Maltese sample was 23%. No corresponding figure was given in the British sample.

**Table 6: Responses to Question 3 - Maltese and British figures**

	Malta 95	United Kingdom 94
Have donor card, carry it	5%	26%
Have donor card, do not carry it	2%	9%
Do not have but consider getting one	38%	26%
Do not think I could carry a donor card	8%	8%
Don't think it's worth carrying one	4%	9%
Do not want to carry card	5%	17%



Not sure	15%	5%
Never heard about it	23%	

(Base for percentages: All respondents)

In order to analyse the responses of the Maltese sample to Question 3 in terms of socio-demographic characteristics, a filtering out of some respondents was again effected. Only the responses given by those who had heard about organ donation (Question 1) and those who had expressed willingness to donate their organs after death (Question 2) were considered. This gave a total of 316 respondents. This was done because it was assumed that people who were against organ donation would necessarily be against carrying a donor card. For the purpose of this analysis the responses to this question were classified under the following categories:

1. *Have a card.* Those who said that they have a card and they carry it and those who have a card but do not carry it (8.9%).
2. *Consider getting a card.* Those who do not have a card but have often thought about getting one (46.8%).
3. *Would not carry a card.* Those who do not think they would carry a card, those who see no sense in their carrying a card, and those who do not want to carry a card (14.2%).
4. *Uncertain.* Those who were not sure which options best described their opinion (12.7%).
5. *Never heard.* Those who had never heard about the donor card (17.4%).

Again separate chi-square tests of independence were carried out for the contingency tables classifying the response to this question (opinion about donor card) and each of the three socio-demographic characteristics. The strongest associations found were that between response to the question and socio-economic class (chisq=26.4, df=12, p=0.01) and that between response and age (chisq=16.5, df=8, p=0.04). As usual, those from the A-B and C1 classes and the younger respondents had a more favourable attitude towards the donor card.

This question asking respondents their opinion about the donor card is another very crucial one, especially with regard to the planning of a campaign promoting donor cards. Therefore multivariate techniques were also used here. A hierarchical log-linear analysis was again carried out in a way similar to that used above for Question 2. This analysis indicated that an interaction between age and socio-economic class was important in explaining associations between the response and socio-demographic characteristics of the sample. In fact, on further analysis it was found that for the youngest (18-34 years) and the oldest (55 years and over) age groups the association between attitudes on the donor card and class was not significant whereas it was very significant for the middle age group (chisq=26.2, df=12, p=0.01), that between 35 and 45 years.

**Table 7: Responses to Question 3 - Analysis of Maltese Sample by Socio-economic Class (35-54 years)**

Opinion about donor card	Soc-economic Classification				Total
	A-B	C1	C2	D-E	
Have card					
Count	5	6	2	3	16
Column percentage	23.8%	18.2%	5.0%	10.7%	13.1%
Consider getting card					
Count	9	16	21	9	55
Column percentage	42.9%	48.5%	52.5%	32.1%	45.1%
Will not carry card					
Count	2	6	3	5	16
Column percentage	9.5%	18.2%	7.5%	17.9%	13.1%
Uncertain					
Count	5	4	2	3	14
Column percentage	23.8%	12.1%	5.0%	10.7%	11.5%
Never heard about card					
Count	0	1	12	8	21
Column percentage	0.0%	3.0%	30.0%	28.6%	17.2%
Total					
Count	21	33	40	28	122
Row percentage	17.2%	27.0%	32.8%	23.0%	100.0%

*chisq=26.2, df=12, p=0.01*

(Sample base: Respondents aware and willing to donate, 35-54 years)

This could imply that the youngest respondents are more generally in favour of getting the donor card and the older ones are generally against, irrespective of class. However, for the middle age bracket, the general tendency to have a card or to be considering to get one is more significantly felt amongst the A-B and C1 classes than amongst the C2 and D-E classes (see Table 7). The same applies for those who had never heard about the card.

Those who were in favour of organ donation but were against carrying a donor card (45 respondents) were asked to give their reasons. (This question was not asked in the Gallup survey.) Many of the respondents (40%) could not explain why they would refuse to carry a donor card. Other respondents voiced the fear that if they carry a donor card and are involved in an accident, doctors would not try to save their lives but would prefer to let them die in order to give their organs to somebody else. Others were afraid that doctors would take their organs before they are actually dead. Other reasons for not carrying a donor card were the fear of being mutilated, not knowing who would take the organs and forgetting to carry the card. These responses are summarised in Table 8.

**Table 8: Responses to Question 4 - Reasons for Not Wanting to Carry a Donor Card**

	<b>In favour of organ donation but against carrying a card</b>
Afraid not really dead	18%
Will not try to save my life	16%
Will not know who takes organs	2.2%
Do not like being cut up	4.4%
Because I forget	24%
Other (unspecified)	40%

(Base: 45 respondents; each could give more than one answer)

#### ***(iv) Discussion with Family***

In an effort to find out what helps respondents come to a decision in donating the organs of a family member, the respondents were asked whether or not they would want to donate the organs of a relative who had just died. They were presented with three different situations. These were the following.

*Suppose you had a relative who died and the doctors asked you your permission to take the organs. Would you give permission in the following situations?*

*Question 5 (Situation 1).*

*Your relative was not carrying a donor card and had never made his or her views clear.*

*Question 6 (Situation 2).*

*If this time your relative was not carrying a donor card, but had made it clear that he or she was willing to donate their organs.*

*Question 7 (Situation 3).*

*If this time your relative was carrying a donor card but had not made it clear that he or she was willing to donate their organs.*

In the first scenario 35% said they would definitely agree to give the permission while 32% thought that they would probably say yes. The data collected in the Gallup survey showed that a higher percentage (58%) answered “yes definitely”.

In the second scenario the percentage of Maltese respondents who answered that they would agree to give permission to doctors to remove organs (56%) was higher than in the

previous scenario. An additional 34% answered that they would probably agree. These figures are similar to those found by Gallup in Britain.

The results for the third scenario were very similar to those in the second. This indicates that for most respondents, knowing a person's view about organ donation carries the same weight as knowing that the person is a donor card holder.

The percentage of respondents who would not give permission to doctors in the first situation is 29%. This is much higher than the percentage of those who are against organ donation (14%). This means that there are many people who though willing to donate their own organs would not donate those of a member of their family unless they know specifically that it was their wish.

**Table 9: Responses to Questions 5,6,7 - Maltese and British Figures**

<i>Question 5 (Situation 1)</i>		
	Malta 95	United Kingdom 94
Yes definitely	35%	58%
Probably yes	32%	
No	29%	31%
Do not know	4%	11%
<i>Question 6 (Situation 2)</i>		
Yes definitely	56%	89%
Probably yes	34%	
No	7%	6%
Do not know	4%	5%
<i>Question 7 (Situation 3)</i>		
Yes definitely	53%	82%
Probably yes	36%	
No	9%	9%
Do not know	2%	9%

(Base for percentages: All respondents)

### **(v) The “Opting-out” System**

There are two major systems of organ procurement. The one which is practised in Malta is that of “opting-in”, where the persons who wish to donate organs after their death fill in a donor card and have their names registered in a National Organ Donor Register. On the other hand, some countries like Spain, France and Belgium, follow the “opting-out” system. In these countries the doctors do not need to ask the permission of the relatives of the person who has just died before they remove the organs unless the person had made it known during his or her life that they are against it.

To find out respondents' reactions to the two systems they were asked the following question:

*Question 8. In some countries one way which is used to increase the number of donor organs is to say that organs could always be taken from adults who had just died, unless they had specifically forbidden it. Do you agree that this procedure be adopted in Malta?*

In the Maltese sample 52% said that they would not be in favour of the opting-out system. This percentage was slightly higher than the percentage of British respondents (48%) who were against this system (see Table 10).

**Table 10: Responses to Question 8 - Maltese and British Figures**

	Malta 95	United Kingdom 94
Yes definitely	18%	43%
Possibly yes	25%	
No	52%	48%
Do not know	4%	9%

(Base for percentages: All respondents)

This general disagreement with the opting-out system was quite uniform across the socio-demographic spectrum of the sample, and no significant association between the response and age, gender or class was found.

### ***Discussion***

This survey gave a first picture of the attitudes of the Maltese people towards organ donation. The major points which emerged were that:

1. Most respondents (81%) had positive attitudes towards organ donation and were willing to donate their organs after their death even though some of these people had many unanswered questions and fears.
2. While many were in favour of organ donation, few of the respondents (7%) had a donor card. Moreover a high proportion (23%) did not know about the existence of the card.

3. While many of the respondents were willing to donate their own organs after their death, they found it more difficult to donate the organs of their relatives. Only 67% said that they would give permission if they did not know the relative's wishes about the matter. This difficulty seems to be greatly resolved if the dead person had talked about his or her wishes before dying. 90% said that they would allow donation of organs if they knew that the dead relative had wanted to be a donor.
4. More than half of the respondents (52%) were against the opting out system and felt that organ donation should be voluntary and should not be taken for granted by the state.
5. There was no significant difference between males and females in their willingness to donate their organs after their death.
6. Respondents from the A-B and C1 classes tended to have more positive attitudes towards organ donation.
7. The respondents who were most favourable towards carrying a donor card were those in the 18-34 age bracket and those in the A-B and C1 classes.

### ***Post-campaign Surveys***

Between April and May 1996, about three months after the end of the campaign, the second national survey was carried out. With the exception of two, the questions asked in this survey were the same as those asked the year before, in May 1995. The questions investigated awareness of organ donation campaign, attitudes about organ donation, donor cards and the "opting-out" system.

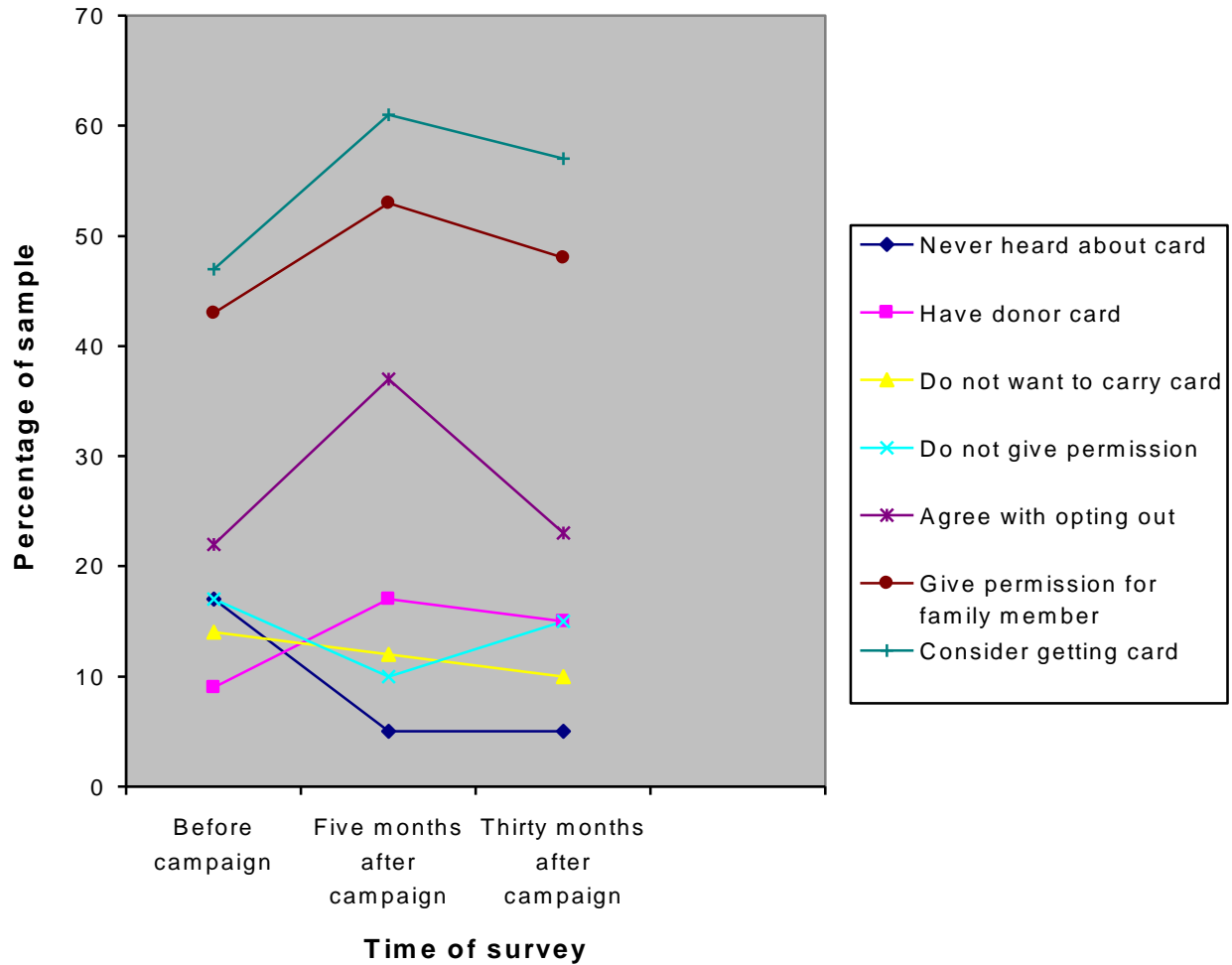
The survey was again conducted with a sample of 400 persons aged 18 and over and living in Malta and Gozo.

The following points briefly summarise the main differences between the two surveys.



1. In the first survey 46.8% said that they are considering getting card. This figure went up to 60.8% in the post-campaign survey.
2. The proportion of respondents who had never heard about the donor card went down from 17.4% to 4.5%.
3. In the pre-campaign survey, 18% of those who were willing to donate their organs but were against carrying donor card gave as a reason the fear that they would not really be dead when the organs are removed. This proportion went down to 8% in the post-campaign survey.
4. In the pre-campaign survey, 43.4% of participants said that they would donate the organs of dead relative without knowing his/her intention about organ donation. This proportion went up to 53.2% in the post-campaign survey.
5. The proportion of those who said that they were definitely in favour of the opting out system went up from 22% to 36%.

A third survey with the same sample size was held 30 months after the campaign to assess the longer term effects of the campaign. The same questions were asked and this survey showed that, although the improved perceptions were largely maintained, there was a downward trend in some aspects (see Figure 1).



**Figure 1: Changes in Public Perception Regarding Organ Donation**

The greatest change occurred in the percentage of people who had never heard about the donor card. Before the campaign 17% of those in favour of organ donation had never heard about the card (95% confidence interval: 17% ± 4%). This percentage went down to 5% (± 2%) in the second survey and when surveyed again 30 months later this percentage remained 5% (± 2%). (All these and subsequent intervals are 95% confidence intervals.)

This change was accompanied by a considerable increase in the number of people who said that they were considering getting a donor card. The percentage went up from 47% (± 6%) to 61% (± 5%) after the campaign. In the third survey this figure declined to 57%

(± 5%). The difference in proportions between the first and third surveys was still significant ( $z=2.76$ , one-tailed  $p<0.005$ ). In the long run therefore, the effects of the campaign were maintained but declined from the peak achieved immediately after the campaign. The number of people who were definitely in favour of the “opting out system” increased significantly from 22% (± 5%) to 37% (± 5%) in the first survey carried after the campaign. This percentage went down to 23% (± 5%) in the third survey. Again, this could indicate that unless the issue is kept in the public sphere, the salience and therefore the support for the issue tends to diminish.

Other changes registered by the surveys were a change in the number of respondents who said that they would certainly give permission to doctors to take organs from a family member after death even when not knowing the deceased’s views on organ donation. This figure went up from 43% (± 5%) to 53% (± 6%) in the second survey and then went down again to 48% (± 5%) in the third survey. Whereas the difference between the first and second survey was statistically significant ( $z=2.58$ , one tailed  $p=0.005$ ), the difference between the first and third survey was not statistically significant ( $z=1.30$ , one-tailed  $p=0.10$ ).

The percentage of those who replied that they would not give permission to donate organs of their relatives in this situation went down significantly from 17% (± 4%) to 10% (± 3%), but in the third survey this went up again to 15% (± 4%).

A significant increase from 9% (± 3%) to 17% (± 4%) ( $z=3.08$ , one tailed  $p=0.001$ ) took place in the number of respondents who had a donor card. This increase was largely maintained in the third survey with 15% (± 4%), the difference between the first and the third survey remaining statistically significant ( $z=2.38$ , one-tailed  $p=0.01$ ). These figures are summarised in Table 11.

**Table 11: Changes in Public Perception of Organ Donation**

	1 <sup>st</sup> survey	2 <sup>nd</sup> survey	3 <sup>rd</sup> survey	Difference between 1 <sup>st</sup> /2 <sup>nd</sup> surveys: <i>p</i> values	Difference between 1 <sup>st</sup> /3 <sup>rd</sup> surveys: <i>p</i> values
Never heard about card	17%	5%	5%	<0.0001	<0.0001
Have card	9%	17%	15%	0.001	0.01
Do not want to carry card	14%	12%	10%	n.s.	n.s.
Consider getting card	47%	61%	57%	0.0001	<0.005
Would give permission to remove relative's organs	43%	53%	48%	0.005	n.s.
Would not give permission	17%	10%	15%	<0.05	n.s.
Agree with opting out system	22%	37%	23%	<0.0001	n.s.
Sample base for percentages: All who had heard about organ donation and were in favour	316 respondents	314 respondents	328 respondents		

**Conclusion**

The survey carried out in May 1995 was part of the formative research for the Organ Donation Campaign held between October 1995 and January 1996. The two post-campaign surveys served to measure the success of the campaign in terms of changes in people's attitudes towards organ donation.

Apart from these surveys a number of other investigations were carried out in order to delve more deeply into the Maltese public's view of organ donation, of particular importance being ten focus groups (five held before and five after the campaign). These investigations gave a more detailed picture of how organ donation is represented amongst the Maltese lay person and will be presented in another paper.

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