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# Determinants for Communicating Willingness to Donate Organs

#### Abstract:

Although almost eight out of ten Swedes are in favor of organ donation, only about 1,5 million have officially registered as organ donors, causing a discrepancy between the supply and demand of cadaveric organs. The purpose of this study is to empirically examine factors that may affect people's likelihood to declare their willingness to donate their organs after death. Based on results from an online survey among students at the Stockholm School of Economics and at the Stockholm School of Social Work, we have – using a linear regression model – tested eight hypotheses on what affects communication of donor will. Our regression analysis gives overall mixed support for the variables tested. Three variables were proved significant – social responsibility, bodily integrity and subject sensitivity. We conclude that these aspects should be addressed in future campaigns aimed at increasing the amount of organ donors.

#### Tutor: Magnus Johannesson

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Keywords: Organ donation, donor behavior, communicating donor will

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## 1 Introduction

The first successful organ transplant took place in Boston 1954, when a kidney was transplanted from one twin to another. Since then the number of transplanted kidneys, hearts, livers and other organs has increased rapidly, and transplantations are nowadays common surgery. As a result of improvements in transplantation technology more people than ever can receive a new organ. However the supply of organs donated has not followed the increase in demand. The result is a growing number of people waiting for new organs.

The first successful kidney transplant in Sweden was performed in April 1964. Since then, organ transplantation in Sweden has had a similar development as in the U.S. and other Western countries. In the beginning of 2011 more than 750 people were on the waiting list for organs in Sweden (Donationsrådet). Most of them have to wait several years before receiving a new organ, and some do not get transplantation in time. The long waiting time means large socioeconomic costs due to absenteeism and medical costs (Njurförbundet), but it also results in a great deal of suffering and reduced quality of life for many people.

According to statistics from the Swedish Council for Organ and Tissue Donation (Donationsrådet, December 2010), the need for organs and tissues is vastly greater than the number available for transplantation. In Sweden three out four persons are willing to donate organs, but only around 50 percent have clearly declared such a will.

Transplant operations are unique in that they are dependent on people's positive attitude toward donation of organs and tissues. That is why the subject "determinants of communication of willingness to organ donation in Sweden" makes for such an interesting subject. Economic incentives are not permitted and there are no legal buyers or sellers of organs. In the light of the imbalance between demand and supply on the "organ and tissue market" it becomes important to identify what factors influence people to communicate their willingness to donate.<sup>1</sup>

#### 1.1 Statement of purpose and delimitation

Our initial investigation showed that while there is considerable research on the subject "organ donation", there is a lack of understanding about which factors affect both donor

<sup>&</sup>lt;sup>1</sup> When the term organ donor is used, we refer to a person who has actively communicated her/his willingness to donate.

will and above all the clear communication of will. Therefore the purpose of our study is to empirically examine possible factors that may affect people's likelihood to declare their willingness to donate their organs after death. On the basis of that research, we aim to discuss what should be addressed in future initiatives aimed at increasing the number of organ donors.

Looking at previous research in the area of organ donation as well as the literature on product knowledge, sociological and psychological behavior, we to try to determine what factors make people take an active position toward organ donation. On the basis of this research we have formulated eight hypotheses about what influences a person's likelihood to communicate his or her willingness to donate. We attempt to test these hypotheses based on data gathered from an online survey.

The efficiency of the organ donation and transplantation system is of course influenced by external factors. These are for example technological, organizational and logistical issues of the institutions involved in the organ procurement and transplantation process. Furthermore there are demographic factors such as income and ethnic background that may affect donor behavior. Due to time constraints and we will unfortunately not be able to research all these factors and we have decided that these are outside the scope of our study. We also only focus on postmortem organ donation and not donations from living donors.

## 2 Organ donation in Sweden – context and background

## 2.1 Regulations

In 1988 Sweden enforced a new *Law on death.*<sup>2</sup> The law is important because it makes it possible to declare a person dead whose brain has completely ceased to function, but whose other bodily functions can be maintained with the help of a respirator. The oxygenation of the body through a respirator is a requirement for the organs to be acceptable for possible transplantation.

In 1996 the Law on Transplantation<sup>3</sup> came into force. At the same time, the computerized National Donor Registry was launched, a service managed by the National Board of Health and Welfare (Socialstyrelsen). The law says in brief that the transplantation of organs and tissues from a deceased person is possible if her/his declaration of consent is registered. If the deceased's wishes are unknown, it is presumed that she/he wanted to donate the organs. This policy is called "presumed consent". However, the law adds that in these cases, next-of-kin of the deceased must be informed and also agree to the donation of the deceased's organs. Therefore the family's attitude is decisive if the dead person's will is unknown.

#### 2.2 The Council for Organ and Tissue Donation (Donationsrådet)

In 2005 the donation rate (the number of transplants performed per million inhabitants) in Sweden was only 14,2 donors per million people (Donationsrådet). The donation rate was then among the lowest in Europe. This was a major reason for the Swedish government to found a national organization with an overall responsibility for donation – *The Council for Organ and Tissue Donation*.

The Council is linked to the National Board of Health and Welfare (Socialstyrelsen), but works as an independent national advisory council. The main objective is "to increase the rate of donation by making it possible for deceased persons to donate organs and tissues according to their wishes". An important part of the Council's work is to present statistics and other information about donation and transplantation to the public, media and medical personnel. The overarching goal of the Council is that Sweden shall have reached 200 organ donors per year by 2014. (The number was 128 in 2010). An area of focus in reaching this objective is to increase the knowledge and awareness of organ donation and

<sup>&</sup>lt;sup>2</sup> SFS 1987:269 with amendments in SFS 1995:833

<sup>&</sup>lt;sup>3</sup> SFS 1995:831

create an active and positive attitude towards donation among the general public. (Donationsrådet)

#### 2.3 Facts about organ and tissue donation in Sweden

Organs that can be transplanted include the kidneys, liver, heart, lungs, pancreas and intestines. Tissues that are being transplanted today are mostly corneas and heart valves, but also skin and bone. Almost 700 organ transplantations are performed in Sweden each year. Over 400 of these are kidney transplantations. About 1 000 tissue transplantations are also carried out in Sweden every year. (Donationsrådet)

Statistics from The Council for Organ and Tissue Donation shows that on the 1<sup>st</sup> of January 2010, 628 people were waiting for organs. On the 1<sup>st</sup> of January 2011 the number had risen to 765 peoples, of whom 593 were waiting for kidneys. In April 2011 there were 1 499 337 people registered on the Donation registry, out of 9.2 million inhabitants.

Almost everyone is able to register a donor, especially as there is no age limit. There are three ways to communicate the intent of donation. One can either register on the National donor register, fill in and sign a donor card and/or make your wishes known to your family.

## 2.4 Outcome of conducted surveys in Sweden on organ donation

On behalf of the National Board of Health and Welfare, an opinion poll was conducted in November 2008 and a second one in December 2010 (Socialstyrelsen). The opinion polls show in short the following results.

In the most recent poll, almost all respondents (97%) were aware of the possibility of posthumously donating organs and tissues, which is the same figure as in the year 2008. Only 77 percent were willing to donate organs and tissues, which is a slight decrease compared to the poll in 2008 (79%).

Almost one third of the respondents (29%) answered No when asked if they knew how to make their will known. The figure has grown from 23 percent since the last measurement. Slightly more than half (52%) of those who knew how to go about making their will known had actively taken a position. That was a decrease from 58 percent since the last measurement. About 45 percent of those who had not made their will known, "just had

not thought about it". Six out of ten of those who had actively taken a position had done so by filling out a donor card. In 2008 only 48 percent had signed a donor card. Most people are also unaware of their relatives' will for organ donation, indicating a lack of communication about organ donation amongst family members.

To summarize, it seems that things are moving in the wrong direction at present. The donation rate that was considered low when the Council was founded has decreased in recent years. There is probably no single explanation for the low donation rate, and there is no single measure that will solve the problem, but researching the important determinants of donor behavior may help achieve the set goal of 200 organ donors per year by 2014.

## 3 Previous literature and hypotheses

## 3.1 This study

Looking at attitudes to donation can give an idea of what people might associate with organ donation, what they feel is most important about the subject and what might be a barrier to making the decision to become an organ donor. This is important information to have when planning a campaign to increase the amount of donors.

This study was designed to clarify the relationship of product knowledge of organ donation together with several factors influencing attitude toward organ donation with communication rates of donor will.

Based on previous research and on what seems most relevant for our sample population we have chosen a number of factors to focus on. The following subjects were considered important to include in the survey: knowledge of organ donation, subjective norms, altruism, bodily integrity, reciprocity, social image, subject sensitivity, and social responsibility.

In previous research, similar data was used to model people's willingness to become potential organ donors. Factors such as product knowledge and personal values are correlated firstly with attitude to organ donation, and secondly to willingness to donate (Horton & Horton 1991, Lwin *et al.* 2002). We have chosen to leave out the middle link of attitude to organ donation, and to look at the relationships between values and knowledge, and whether or not one has communicated one's will to donate. The reason for this is that studies have shown that Sweden has a very high percentage of the population that is positive toward organ donation (Donationsrådet). Therefore this is not an interesting aspect to explore. The issue is the fact that very few, compared to the amount of people that are positive to the subject, actually communicate their will. This is why we consider it more interesting to test whether there are factors on an individual level that are related to whether a person is prone to communicate her/his will or not.

Enhancing positive associations with organ donation in campaign has greater affect than trying to decrease the negative associations (Skumanich & Horton 1990, as cited in Horton 1991). Consequently, it is important to not only look at what causes people to have a negative stance toward organ donation, as Krekula *et al.* (2008) have done, but to also

research why they do want to be donors. This explains why most, but not all, of the factors we have looked at in our survey are factors we predict to be positively correlated with having communicated one's will to donate.

#### 3.2 Knowledge

Knowledge of organ donation was considered relevant to investigate in this study as in previous studies, product knowledge has been proven to have a positive effect on attitude toward organ donation (Horton & Horton 1990, Radecki & Jaccard 1997). A positive correlation between product knowledge and the willingness to donate and communicate one's will would imply that information about organ donation should be increased in order to obtain more registered donors.

Two information campaigns were held in Sweden by the Swedish organization "The Gift of Life" and the Ministry of Health and Social Affairs in 2001 and 2003-2005 respectively. These were aimed to increase awareness among the general public about organ donation, create a positive attitude concerning organ donation as well as increase awareness about how one can communicate one's will. An evaluation of these campaigns showed that although awareness about how to register increased, only 14 percent of the Swedish population had actually registered (Krekula *et al.* 2008). Shanteau *et al.* state, "the shortage of organs does not appear to be due to a lack of knowledge or an absence of empathy" (1992, p. 211), as surveys show high and consistent awareness of organ donation. Nevertheless, it is still worthwhile to test the level of knowledge that the students in our sample have about organ donation and transplantation. We also want to test whether or not this is related to having communicated willingness to donate. We predict and test the following hypothesis:

H1: The higher level of knowledge the respondent has, the higher probability that the respondent has communicated her/his willingness to donate.

#### 3.3 Subjective norms

Subjective norms are in this case the desire to subordinate oneself to the wishes of others, more specifically to close relatives or friends. In the study of Dutch adolescents' primary values, performed by Reubsaet *et al.* in 2001, social conformity had the highest level of influence on intent to donate, compared to the nine other values. The predictions in the study are based on the level of individualism versus collectivism in Dutch society. This

result concerning social conformity is fitting with the idea that Dutch culture encourages adolescents to respect their elders. Due to the geographical and cultural similarity between Holland and Sweden, it is reasonable to assume that subjective norms would have a significant effect on willingness to donate in Sweden as well. We find this worth testing. We predict and test the following hypothesis:

H2: The stronger belief the respondent has that the most important person to them is positive towards organ donation, the higher probability that the respondent has communicated her/his willingness to donate.

#### 3.4 Altruism

Altruism is a frequently reoccurring value that comes up when researching about attitudes toward organ donation. For example Parisi (1986) states that the "positive dimension [of people's attitudes] involves belief in the humanitarian benefits of organ donation" (p. 565). From an evolutionary perspective, altruism is a behavioral act which increases the fitness of others by decreasing one's own fitness (Sober & Wilson 1998, p. 17). Altruism in the case of posthumous organ donation does not follow the regular patterns of altruism, as the donor will be dead when the act is carried out. Therefore donating does not, in a practical sense, decrease the fitness of the donor.

However from a social-psychological perspective altruism is a disposition or identity. It's an intentional, non-rewarded and voluntary action oriented toward the welfare of others (Simmons 1991, as cited in Healy 2004). This perspective often looks at the issue of the purity of motive to determine whether or not an act is altruistic or not (Healy 2004). With this definition one can argue that registering as an organ donor does qualify as an altruistic act. Healy (2004) argues that this type of act does not however stem from the person's individual-level character or value orientation. The author goes on to explain that this is because rates of altruism vary with the variations in organizational institutions that manage these acts, such as organ procurement centers. Registering as an organ donor is highly institutionalized and it has been proven that the logistical efforts of organizations do have a positive relation to the rates of donation (Healy 2004).

For the sake of this study's scope however, we will focus on the individual level of altruism, and not concern ourselves with how the organizational logistics affect the registration rate. Something to bear in mind is that in many cases it is close relatives who make the decision of whether or not to donate the deceased family member's organs. They get no reward for this, and often do not know the recipient. This, like signing a donor card, qualifies the decision to donate as an act that is intentional, non-rewarded and voluntary. We predict and test the following hypothesis:

H3: The more of an altruistic act the respondent views organ donation, the higher chance that she/he has communicated her/his will to donate.

## 3.5 Social image

Horton (1991) utilizes Rothschild's framework (1979) to determine how one possibly can sell a concept, as opposed to a product or service. One of the examples used from Rothschild's work is how one defines and sells the product military service. Horton draws a parallel between military service and organ donation. He argues that one way of defining the concept of donation is that it is "an enhanced ego through an act that is perceived by the recipient as selfless" (1991, p. 40). As we are looking only at posthumous donation, this concept is still worth exploring as a registered donor may also experience an enhanced ego as her/his friends and family may perceive her/him as selfless.

We would like to investigate if being a registered organ donor is potentially caused by the fact that people view it as something that can benefit their social image. This information can be useful when creating a campaign to increase the amount of registered donors. We have seen that other non-profit organizations and charities make use of people's desire to enhance their social image through the use of symbols that are visible to others, such as the Pink Ribbon, aimed to display breast cancer awareness<sup>4</sup>. In Bénabou and Tirole's study (2006), results show that publicity and praise generally "encourages prosocial behaviour". Ellingsen and Johannesson (2008) also argue that if a person has a desire for social esteem, then this desire can act as a source of prosocial behavior. We therefore find it important to test if there is a significant relationship between being a registered organ donor and social image. We predict and test the following hypothesis:

H4: The more the respondent feels that being an organ donor benefits her/his social image, the more likely it is that this respondent has communicated her/his willingness to donate.

<sup>&</sup>lt;sup>4</sup> www.pinkribbon.org

#### 3.6 Reciprocity

Bénabou and Tirole (2006) explain that people often act according to the honor or the shame attached to their actions by social norms and pressures. A definition of a social norm is for example "the specification of desirable behavior together with sanction rules in a community" (Kandori 1989, p. 1) or as Elster explains, " For norms to be social, they must be shared by other people and partly sustained by their approval and disapproval" (1989, p. 99-100).

As Fehr and Gächter (2000) stress, reciprocity is not the same as altruism; rather it refers to when people respond to friendly actions with kindness and cooperation. Altruism is a kind act performed unconditionally, whereas "reciprocity is an in-kind response to beneficial or harmful acts" (Fehr & Gächter, 2000, p. 2). When applied to the context of organ donation, when someone registers as an organ donor to – after death – potentially help someone unknown in society, then the rest of society should be prepared to do the same.

In Sanner's study (1998), the correlation between readiness to give and to receive is examined through the use of a survey about organ donation. The results show large discrepancies between readiness to give and to receive suggesting that "the rather wellestablished ethical norm of reciprocity is not valid here". Sanner discusses the possibility of that the unease, that can be felt regarding donation, is only surmountable when it comes to saving the life of a next-of-kin, and not a stranger. This is why we consider it relevant to investigate how the respondents' attitude to registering as an organ donor is affected by their stance on the social norm of reciprocity. Even though Sanner's study shows that this norm is not valid in this case, our hypothesis is still that if a person supports the notion of reciprocal behavior in society, then the probability is higher that the person is an organ donor. We predict and test the following hypothesis:

H5: The higher the respondent values the norm of reciprocity within organ donation the higher chance it is that she/he has communicated her/his will to donate.

#### 3.7 Social responsibility

Simply speaking, when we look at social responsibility, we refer to organ donation being viewed as something that a "good" citizen does.

Alden & Cheung (2000) study differences in culture and how they relate to different rates of willingness to donate organs after death. The authors explain that people in Western countries tend to be individualistic rather than collectivistic, and that this implies citizens placing "relatively greater value on more abstract relationships to larger social entities, such as the community and "mankind" (p. 297), rather than on closer entities such as family. This falls in line with Ryckman *et al.* (2009) in their study on values of Dutch adolescents. Although the latter describe these tendencies to be in line with a collectivistic culture, Ryckman *et al.* state that citizens are to be "independent and act in ways that help facilitate the social good" (p. 216). Furthermore, Hofstede and Hofstede (2005) mention that Sweden is indeed a individualistic society.

We thought it would be relevant to test whether people perceive organ donation to be a social responsibility, but not to further define the reasons for this feeling of responsibility, as it often stems from the pressure of social and personal norms.<sup>5</sup> This is too extensive for the limited scope of our investigation. We predict and test the following hypothesis:

H6: The more the respondent believes organ donation is one's social responsibility, the higher probability that she/he has communicated her/his will to donate.

#### **3.8 Bodily integrity**

The definition used for bodily integrity in this study is the value placed in having a body remain whole postmortem. Bodily integrity is closely related to religiosity as the desire to keep the body whole often stems from religious beliefs concerning life after death (Stephenson *et al.* 2008).

The survey used in Krekula *et al.*'s evaluation (2008) of two information campaigns on knowledge and formal decision-making surrounding organ donation in Sweden, shows that the main reason for not wanting to donate organs was that the respondents felt they were "too old". This attitude has not been examined in this study as the sample population consisted only of university students. Lengthening the survey with a question about this felt

<sup>&</sup>lt;sup>5</sup> In Piliavin and Charng's review of previous literature on altruism (1990), a well-summarized definition of personal norms is found: "personal norms are situated, self-based standards for specific behavior generated from internalized values during the process of behavioral decision making" (Schwartz & Howard 1984, p. 234 in Piliavin & Charng, 1990, p. 32). Personal norms, meaning the feeling or moral obligation to act or not act in a certain way, can also lie behind the reasons behind altruistic behavior, or behind abiding to social norms (Schwartz 1984, Karylowski 1982 in Piliavin & Charng 1990).

unnecessary. However, the next three top reasons for not wanting to donate organs postmortem was "dislike of being cut into", "lack of respect to not leave the body in peace" and "do not want a part of me to live in another person" (Krekula *et al.* 2008, p.346). The relatively high number of respondents that named these as a reason for not wanting to donate made it relevant to see how bodily integrity associates with the rates of donor registration in our study. Parisi (1986) also states that "the negative [dimension of one's attitude to organ donation are] fears of body mutilation and of receiving inadequate medical treatment when one's life is at risk" (p. 566).

An important factor that can affect bodily integrity, and that also is closely tied to this subject is religiosity. Religions and their varying doctrines of life after death can influence the desire to keep one's body intact or not. In Ryckman *et al.*'s study (2004), there is a distinction made between intrinsic and extrinsic religiosity, the former being where individuals use doctrines as guidelines in their way of life. The latter is where individuals use religion to their own personal benefit. The results of the survey responses showed that intrinsic religiosity was unrelated to the willingness to donate, and only extrinsic individuals with "strong social orientation" (Ryckman *et al.* 2004, p. 196) were more probable to want to donate postmortem. Lwin *et al.* (2002), in their study on Singaporean attitudes toward organ donation, take Horton & Horton's (1991) model of willingness to donate and add a third variable; *spiritual beliefs*, as a value whose effect is to be tested on a person's attitude toward organ donation. The results they come up with are that that the greater a person's spiritualism and superstitious beliefs, the more negative is her/his attitude toward organ donation, and therefore the less likely they are to donate.

Sweden, however, is one of the least religious countries in the world, with less than 20 percent of the population being religious (Eurobarometer Poll 2005). Therefore it did not feel necessary to provide the survey respondents with more than one statement about religion, or to test religiosity separately, but to include it in the test for bodily integrity. We predict and test the following hypothesis:

H7: The higher bodily integrity is valued, the less chance of the respondent being a registered organ donor.

## 3.9 Subject sensitivity

Thinking or talking about organ donation, especially within the family, can be a sensitive subject, primarily because it brings up the subject of death, which, as Sanner states (1994), "is a highly charged subject, and people's opinions on what might be done with a dead body are influenced by their ideas of death"(p. 284). Shanteau *et al.* (1992) state that "discomfort in thinking about death and facing one's own mortality can be a tremendous psychological barrier to signing a donor card" (p. 212).

In a survey performed in England about donating parts of brain after death for research purposes, two of the main fears of death were to feel pain and to not really be dead when organs are removed. Those with these fears were less likely to agree to organ donation (Stevens 1998). We predict that the more a respondent finds organ donation to be a sensitive subject, the less likely it will be that the respondent has communicated her/his willingness to donate. Because of the sensitive nature of organ donation, we predict and test the following hypothesis:

H8: The more unease the respondent associates with organ donation, the less likely it is that she/he has communicated her/his willingness to donate.

## 4 Method

We decided to carry out an online survey among students at the Stockholm School of Economics (SSE) and students at Stockholm School of Social Work (SSSW). The main purpose of the survey was to identify the students' knowledge of organ donation, their views on organ donation and what attitudes they have to factors we believe are related to organ donation. The data was gathered to create eight hypotheses with respective independent variables, which were then used in a linear regression on the dependent dummy variable, which was whether or not the respondent had communicated her/his willingness to donate.

#### 4.1 Survey participants

Participants in our survey were recruited throughout the whole student body of the SSE and the SSSW. A link to the online-survey was sent out to more than 5 400 students by email. As an incentive to complete the survey a gift card worth 400 crowns was offered. The survey contained 30 questions and was typically completed in 3-5 minutes. A week after the initial mailing, a reminder was sent. We received a total of 397 responses, where 294 were complete. The survey's response rate was 5,4 percent.

The survey started with the question: "If you were struck by a life-threatening disease, would you want to receive a new organ?" with three single-choice answers: Yes, No and I don't know. This was done in order to put the subject of organ donation into context, as many think only about themselves having their own organs removed and transplanted, but not so much the other way around. Then there was a set of knowledge-based questions concerning organ donation, followed by a set of statements used to measure the respondent's attitudes toward the subject. The last section of the survey asked if the respondents had, or intended to communicate their will to donate; followed by open-field questions asking why had they had or had not done so.

#### 4.2 Items of measurement

Some factors were measured by using the average value of responses to more than one question. This was done in order to have only one variable per factor in the model, as this facilitates the analysis of the regression model. Furthermore, this also avoids, to some extent, the problem of multicollinearity, as the questions grouped together were often highly correlated when measured separately.

The questions in the survey had different response options. The questions on knowledge were answered using *true* or *false*. The response option for the question on subjective norms was a 7-point scale ranging from *definitely not* to *definitely yes*. The response options for the remaining questions on attitude were on a 7-point scale ranging from *strongly disagree* to *strongly agree*.

Below we present our eight independent variables and their related questions, as well as our dependent variable *Communication*:

## Knowledge

The students' knowledge of organ donation was measured using the percentage of correct answers on seven questions about the procedure and regulations surrounding organ donation. Examples of items included are: "The doctor responsible for the organ donor is someone other than the doctor responsible for the transplantation" and "The demand for organs is greater than the supply".

#### Subjective norms

The variable subjective norms was measured the same way Stephenson *et al.* do in their 2008 study (p. 443), using only one question: "Think of the most important person in your life (an adult). Do you think this person is in favor of organ donation?"

## Altruism

To test the significance of altruistic feelings concerning organ donation we used the average value of two items: "Organ donation is an act of compassion" and "I view organ donation as a benefit to humanity". These two items are the same as those used to measure "attitude to organ donation" in Stephenson *et al.*'s study (2008, p. 443)

## Subject sensitivity

When looking at subject sensitivity we used the average value of two items: "I don't like the thought of organ donation as it reminds me of my own mortality" and "Organ donation is a sensitive subject to discuss within the family."

### Bodily integrity

Bodily integrity was measured using the average value four items: "I am against organ donation because I don't like the thought of someone removing organs from my body", "I am against the idea of my organs living on in someone else's body", "The body should be kept whole for burial" and "People who donate their organs risk displeasing God or nature". The last two are the same as the items used in Stephenson *et al.*'s study when measuring bodily integrity (2008, p. 442).

## Reciprocity

The variable *reciprocity* is based on the following item: "If I sign up as an organ donor, I encourage other to do the same, thereby increasing my chances of receiving an organ should I need one in the future."

## Social responsibility

We used the item "Becoming an organ donor is one's social responsibility" to measure if people felt a responsibility toward society concerning organ donation.

## Social image

As the final item for looking at the respondent's attitude to donation, we used "Being an organ donor benefits one's social image" to measure the significance of social image.

## Communication

To find out whether the respondent had communicated her/his willingness to donate, we used the following item: "I have registered my will to donate through" and four possible choices: 1) registering on-line on the Organ Donor Register 2) carrying a donor card, 3) telling my family and 4) I have NOT communicated my will to donate through any of these means.

This question excludes the possibility of people who have communicated their desire to NOT be a donor to show through what means they have communicated their position. We did not consider this to be an issue as it is only a very small amount of the population that does this (Donationsrådet).

The last section of the survey asked if the respondents had, or intended to communicate their will to donate; followed by open-field questions asking why they had or had not done so, as well as why they want or do not want to be an organ donor.

The respondents also had to fill in their age, gender and university, before choosing whether or not to enter the lottery for the gift card by filling in an open field with their email address.

We tested our hypotheses using a linear regression model. The method used was OLS<sup>6</sup> regression and the statistical program used was Intercooled Stata v. 9.2. By construct, we could predict that there would be heteroskedasticity present in our model. After a positive Breusch-Pagan test for heteroskedasticity we decided to run the regression with robust standard errors.

The dependent variable in our model is the dummy variable *communicated*, which takes the value of 1 if the person has communicated her/his positive will to donate and 0 otherwise.

The model has eleven independent variables whereof eight  $(\beta_1 - \beta_8)$  are connected to one hypothesis each, and three are control variables. We decided to include these control variables because we presume that they contribute to a better classification of the relationship between the dependent and independent variables.

The regression model looks as follows:

 $\begin{aligned} Communicated &= \beta_0 + \beta_1 * knowledge + \beta_2 * subjective \ norms + \beta_3 * altruism + \beta_4 * unease + \beta_5 * bodily \\ integrity + \beta_6 * reciprocity + \beta_7 * social \ responsibility + \beta_8 * social \ image + \beta_9 * age + \beta_{10} * male + \beta_{11} * SSE \\ &+ u \end{aligned}$ 

To decide statistical significance we accept p-values of at most ten percent.

Our survey included a question about financial compensation. This question is related to incentives for organ donation and do not fit in with the other questions which are related to attitudes. Therefore we chose to exclude the variable *payment* from our hypotheses and regression model. The result of the question is presented in table 6.2 as it is used in the discussion part of the paper.

<sup>&</sup>lt;sup>6</sup> Ordinary Least Squares

## 5 Results

In this section we first present descriptive data from our survey. We present the general facts and response results of the survey, mainly in tables. After the presentation of descriptive data, we report the outcome of our regression. We also comment on the coefficient and significance of each variable and how the results relate to the predictions of our hypotheses.

## 5.1 Descriptive data

A sample of 294 students completed the online survey. The sample consisted of 37 percent male students and 63 percent female students. Of the respondents, 63 percent were students at SSE and 37 percent were students at SSSW.

The gender ratios of the respondents from the both universities differed; at SSE men were in slight majority (53%), while at SSSW the sample consisted of 85 percent women. The average age of the respondent was 25,8 years.

## Knowledge about organ donation

When testing the general knowledge about organ donation, the students on average answered about 80 percent of the questions correctly. There was only a negligible difference in knowledge between SSE (80%) and SSSW (79%) students. The same can be said about the results for men (79%) and women (81%).

Below we compile the proportion of correct answers to the knowledge questions, used to measure the variable *knowledge*. The correct answer of each question is reported in brackets.

Table 1       H1- Knowledge on organ donation				
Question	Percentage of correct answers			
It takes more time before a funeral or cremation can occur, if a person is an organ donor. <b>(No)</b>	78%			
People older than 65 are not suitable as organ donors. (No)	65%			
When you are registered as an organ donor, your relatives can not stop your donation of organs. <b>(Yes)</b>	75%			
Relatives can get financial compensation if a family member is an organ donor. <b>(No)</b>	87%			
Only people that are completely healthy can register as organ donors. (No)	77%			
The doctor responsible for the organ donor is someone other than the doctor responsible for the transplantation. <b>(Yes)</b>	72%			
The demand for organs is greater than the supply. (Yes)	95%			

The answers show that more than one out of three students incorrectly thought that "People older than 65 are not suitable as organ donors". On the other hand, almost all respondents (96%) knew that "The demand for organs is greater than the supply", indicating a strong awareness of the problem. Almost 90% of the students knew that relatives cannot receive financial compensation if a family member is an organ donor. The four remaining questions have a qualified majority of correct answers.

## Attitude to organ donation

The questions about the student's attitude to organ donation had a 7-point scale ranging from *Strongly disagree* (1) to *Strongly agree* (7) and for the question about subjective norms, from *Definitely not* (1) to *Definitely yes* (7). Below we present the average score of the answers in Table 2. We also relate the questions to the variable they were used to measure. When two or more questions are used for one variable, we also present their average score.

Table 2 Attitude to organ donation	
Question	Average score
H2 - Subjective norms	
1. Think of the most important person in your life (an adult). Do you think this person is in favor of organ donation?	5.78
H3 - <i>Altruism</i> (average score: 5.76)	
2. Organ donation is an act of compassion	5.54
3. Organ donation is a benefit to humanity	5.98
H4 – <i>Social image</i> (average score: 2.65)	
4. I don't like the thought of organ donation as it reminds me of my of my own mortality	2.62
5. Organ donation is a sensitive subject to discuss within the family	2.67
H5 - <i>Bodily integrity</i> (average score: 1.88)	
<ol> <li>I am against organ donation because I don't like the thought of someone removing organs from my body</li> </ol>	2.12
7. The body should be kept whole for burial	2.31
8. People who donate their organs risk displeasing God or nature	1.41
9. I am against the idea of my organs living on in someone else's body	1.67
H6 - Reciprocity	
10. If I sign up as an organ donor, I encourage others to do the same, thereby increasing my chances of receiving an organ should I need one in the future	5.06
H7 - Social responsibility	
11. Becoming an organ donor is one's social responsibility	4.39
No hypothesis - Payment	
12. It is ethically wrong to accept payment to become an organ donor.	4.12
H8 – Subject sensitivity	
13. Being an organ donor benefits one's social image.	4.14

The answers related to *subjective norms* show that the students have a strong belief that their relatives are in favor of organ donation. The responses also indicate that a high proportion of students have an *altruistic* connection to organ donation. The answers related to *subject sensitivity* show that most students do not think that organ donation reminds them of their own mortality, neither is it a sensitive subject to discuss within the family. Most students reject the thought of *bodily integrity* as an argument against organ donation. According to the answers, most students see organ donation as an act of *reciprocity*. The questions concerning *social responsibility* and *social image* have more answers in the middle position, indicating a

greater ambiguity. The answers to the question regarding financial compensation were spread evenly across the seven options, with the average score being close to the middle.

## Communication of will to donate

More than half of the students (54%) have actively communicated their willingness to donate. Some students have declared their will in more than one way. Of those who had communicated their willingness to donate, 65 percent had done so through the online donor registry, 36 percent through signing a donor card, and 81 percent through communication with their family. In total, 46 percent have <u>not</u> declared their will to donate, however a clear majority (79%) of them respond that they are not against organ donation.

The statement below was answered by the respondents who either already had or intended to communicate their will to donate. We have classified the open-field answers into the eight categories in Table 3.

Table 3 I am/want to be an organ donor because:	Percentage of answers
1. Altruism - help others, good cause	58%
2. Obligation, responsibility, duty	4%
3. Morally/ethically correct - the right thing to do	7%
5. Optimal/rational choice	3%
6. Reciprocity - I should donate so that others will do the same for me	12%
7. I don't have any use for my organs after I'm dead	9%
8. Other reasons	8%

As shown in the table, altruism is the dominating category. Typical answers are: "It is good thing to do for others in need" and "I'd like to help others".

The statement below was given to the respondents who had <u>not</u> communicated their will to donate. We have classified the open-field answers into the seven categories in Table 4.

Table 4 I have not communicated my will to donate because:	Percentage of answers
1. I have not thought about it	42%
2. Young / I don't like to think about death	16%
3. I don't know how to do it	4%
4. Lazy	5%
5. Undecided about my will	14%
6. Other reasons	19%
7. I don't want to be an organ donor	1%

As shown in the table, the main reason for not having communicated willingness to donate is that the student "had not thought about it" or "It has not been a priority as to this date". Only one percent of the students had not communicated their willingness because they do not want to be an organ donor.

## 5.2 Regression

We started our regression analysis by creating a correlation matrix for all variables. The results are presented in Tables 7a and 7b in Appendix 2. This was done in order to identify any abnormal inter-variable relationships. No such relationship was found.

Table 5 Results of the	regression				
Dependent variable:	Communicated				
	Coefficient	Robust Standard Error	t	P>t	
knowledge	.0023644	.0015014	1.57	0.116	
subjective norms	.00499	.0159946	0.31	0.755	
altruism	.0396948	.024704	1.61	0.109	
subject sensitivity	-0.0882768	.0224461	-3.93	0.000	
bodily integrity	0975615	.0335367	-2.91	0.004	
reciprocity	.0298562	.018275	1.63	0.103	
social responsibility	.0642508	.0162079	3.96	0.000	
social image	004979	.0188218	-0.26	0.792	
age	.001257	.0036785	0.34	0.733	
male	0462601	.0535442	-0.86	0.388	
SSE	1685447	.0550444	-3.06	0.002	
constant	.1881324	.27909	0.67	0.501	
Number of observations	294				
F(11, 282)	27.57				
Prob > F	0.0000				
R-squared	0.3755				

To increase the significance of the variables with p-values just outside the 10 percent significance range, we tried removing insignificant variables by stepwise regression. This did not produce any apparent change in the significance of the other variables. The three variables *knowledge*, *altruism* and *reciprocity* were still slightly above the 10 percent limit. A table of the limited regression is presented in Appendix 1, Table 6.

## Knowledge

The variable knowledge had a p-value just over our chosen significance level, but with a positive sign as expected in the hypothesis. The coefficient can be interpreted as a 0,2 percent increase in likelihood that the respondent has communicated their willingness to donate for each point increase in the score. Because of the low significance, the coefficient should be interpreted with caution.

#### Subjective norms

The variable *subjective norms* was highly insignificant. Therefore we cannot make any inference about the sign of the variable. We cannot find any support for our hypotheses.

#### Altruism

The variable altruism was just insignificant, but with a positive sign as expected in the hypothesis. As the altruism value increases, so does the probability that the respondent is an organ donor. The coefficient can be interpreted as a 4,0 percent increase in likelihood that the respondent has communicated their willingness to donate, for every unit increase in altruism. Because of the low significance, the coefficient should be interpreted with caution.

#### Subject sensitivity

The variable subject sensitivity was highly significant, with a negative sign as expected in the hypothesis. The more a respondent considers organ donation as a "sensitive subject", the less likely he or she has communicated his or her willingness to donate. The coefficient can be interpreted as a 8,8 percent decrease in likelihood that the person has communicated their willingness to donate, for every unit increase in the variable sensitive subject.

## **Bodily integrity**

The variable bodily integrity was highly significant, with a negative sign as predicted in the hypothesis. The more the respondent considered post-mortem bodily integrity important, the less likely it was that she/he had communicated his or her willingness to donate. The coefficient can be interpreted as a 9,8 percent decrease in likelihood the person is an organ donor, for every unit increase in the variable bodily integrity.

## Reciprocity

The variable reciprocity was barely insignificant, but with a positive sign as expected in the hypothesis. As the reciprocity value increases, so does the probability that the respondent is an organ donor. The coefficient can be interpreted as a 3,0 percent increase in likelihood the person is an organ donor, for every unit increase in the variable reciprocity. Because of the low significance, the coefficient should be interpreted with caution.

## Social responsibility

The variable social responsibility was highly significant, with a positive sign as expected in the hypothesis. As the social responsibility value increases, so does the probability that the respondent is an organ donor. The coefficient can be interpreted as a 6,4 percent increase in likelihood the person is an organ donor, for every unit increase in the variable social responsibility.

## Social image

The variable social image was highly insignificant. Therefore we can't make any inference about the sign of the variable. We can't find any support for our hypotheses.

Of the three control variables *age*, *male* and *SSE*, only the last is significant. The model itself is highly significant.

## 6 Discussion

We first discuss the results obtained with respect to the hypotheses and then proceed with a more general discussion of possible limitations in the study and what future research would be appropriate.

The purpose of our study was to empirically examine possible factors that may affect people's likelihood to declare their willingness to donate their organs after death. On the basis of our first research we formulated eight hypotheses factors that can influence a person's willingness to donate:

- 1. The higher level of *knowledge* the respondent has, the higher probability that the respondent has communicated her/his willingness to donate.
- 2. The stronger belief the respondent has that the most important person to them is positive towards organ donation, the higher probability that the respondent has communicated her/his willingness to donate. (*subjective norms*)
- 3. The more of an *altruistic* act the respondent views organ donation, the higher chance that she/he has communicated her/his will to donate.
- 4. The more the respondent feels that being an organ donor benefits her/his *social image*, the more likely it is that this respondent has communicated her/his willingness to donate.
- 5. The higher *bodily integrity* is valued, the less chance of the respondent being a registered organ donor.
- 6. The higher the respondent values the norm of *reciprocity* within organ donation the higher chance it is that she/he has communicated her/his will to donate.
- 7. The more the respondent believes organ donation is one's *social responsibility*, the higher probability that she/he has communicated her/his will to donate.
- 8. The more unease the respondent associates with organ donation (*subject sensitivity*) the less likely it is that she/he has communicated her/his willingness to donate.

We tested our eight hypotheses using a linear regression model. In summary the regression shows that three of our independent variables were highly significant, both statistically and economically. The highly significant variables are *responsibility* (H7), *bodily integrity* (H5), and *subject sensitivity* (H8). Another three variables were located just outside of the accepted significance range. These variables are *knowledge* (H1), *altruism* (H3) and *reciprocity* (H6). The variables *subjective norms* (H2) and *social image* (H4) were not close to being significant.

The answers indicate a rather good knowledge about organ donation. Like previous work by Shanteau *et al.* (1992), the amount of knowledge does not seem to have any significant effect on whether or not someone is more prone to be an organ donor (H1). This also falls in line with the evaluation of the two information campaigns held in Sweden in 2001 and in 2003-2005 by Krekula et al (2008), where the results showed that although there was an increase in knowledge and awareness about organ donation, only a few percent (14%) actually signed up officially as donors. This shows that when planning a new campaign, which has university students as the main target, there are more effective factors to focus on. It is also worth noting that the sample used for our survey was students with or undergoing a higher education. Had the sample included people with no higher education, then knowledge may have played a more significant role in the regression.

The answers show that the students have a strong belief that their relatives are in favor of organ donation, but that this did not have an effect on whether or not someone had communicated their willingness to donate, which was slightly unexpected (H2). We assumed that there would be a similarity here in our study compared with Stephenson *et al.* (2008) and Reubsaet *et al.*'s (2001) studies. The difference between these two and the present study however may be explained by our sample. The survey of Reubsaet *et al.* was answered by adolescents between the ages of 16 to 18. At this age subjective norms probably play a much larger role than when a person is reaching their mid-twenties. At 16 a person is most likely still living at home and parents and other family members consequently have more influence on one's decision. The results found in this study imply that that Swedish people, with an average age of 26 years, may not place a lot of value into the thoughts and wishes of important people to them when it comes to making own decisions. The implications that this could have for an organ donation campaign is that the communication of peoples' wishes should be urged, but consulting friends and family need not be stressed.

The responses indicate that a high proportion of students have an altruistic connection to organ donation, as expected (H3). However, even when performing the stepwise regression, the p-value was just over the chosen significance level, and therefore we found no information to support our predicted hypothesis. This can imply that viewing organ donation as an altruistic act has a negligible effect on someone's likelihood to actually communicate the desire to donate. Most respondents felt that it is an altruistic act. With this as a given, we argue that in a campaign, it would not be worth pushing the idea that

people should donate as an act out of kindness toward others. Instead, it could be more effective to advocate the view that organ donation is a moral-social obligation, which will be discussed further in the section about social responsibility.

Social image is apparently not something that has any significant effect on whether or not a person is an organ donor (H4). Therefore we have not found any information to support the idea that creating social image incentives, such as a pin to be worn displaying a positive position toward organ donation, would help increase the amount of organ donors.

No information was found to support the expectation that the more a respondent felt that organ donation is a part of the social norm of reciprocity, the more likely it would be that she/he was an organ donor (H5).

Although most students seemed indifferent to the statement of organ donation being one's social responsibility, the variable did have a significant and positive effect on having communicated the willingness to donate (H6), as predicted. This positive effect may be due to by Sweden's individualistic culture, as explained by Hofstede and Hofstede (2005). As Alden and Cheung (2000) argue, individualistic citizens care more for the greater good of society than for closer entities such as the family.

The answers show that most students do not think that organ donation reminds them of their own mortality and neither is it a sensitive subject to discuss within the family (H8). However, those that do find it an uncomfortable subject, have a much lower chance of having communicated their willingness to donate. These results show that death is not an easy subject to discuss or to think about. Changing attitudes toward death could potentially have a large effect on donor's decisions, but practically it is a very deep and complicated issue. De-dramatizing the subject of death is perhaps beyond the capabilities of an organ donation campaign. However, encouraging communication within the family could be more feasible. This is also very important as relatives have a decisive authority when the deceased wishes are unknown. Communicating wishes to relatives is also probably the easiest form of actively declaring a position and stressing this could result in a significant increase in organ donors. The goal would be to de-dramatize the subject of organ donation, as done in the two previous information campaigns in Sweden (Krekula *et al.* 2008).

Most students reject the thought of bodily integrity as an argument against organ donation, but it was a very significant variable, implying that those who do value bodily integrity are less prone to have declared their willingness to donate (H7). This means that bodily integrity should most definitely be addressed in a campaign. As Stephenson *et al.* (2008) suggest, using the biomechanical model of the body can be a way of decreasing the sentiments of bodily integrity importance after death. This model views the human body as "a machine composed of individual body parts, which can be fixed or even replaced with new ones when broken or lost" (Marcum 2004, p. 311). Marcum explains how the use of the model has had positive effects on modern healthcare from a medical perspective, but that patients have been unsatisfied with their personal treatment by medical personnel who do not appear to respect the patient's body's integrity (2004). However, a sensitive and careful inception of this mechanical model could make a number of people more positively inclined to donate their organs.

In general the data collected through the survey supports our hypotheses about organ donation. This is not surprising since the hypotheses are based on previous literature. However most of the variables cannot be properly interpreted due to their lack of significance.

## 6.1 Limitations

We are aware of the inherent limitations of our model and that the model can be further developed. One limitation is that we cannot exclude the possibility that there are other factors that influence willingness to donate and communication of donor will. This could for example be demographic or other personality variables that we have not accounted for, such as self-esteem or cultural background of the respondent.

However, the main limitation of this study is that the sample is not representative of the population as a whole. Our sample is not randomly selected, and is composed solely of young and highly educated people. We have only focused on two different universities and our sample size is relatively small; less than 300 people. Therefore it is not possible to generalize and apply our results to the whole student body of Sweden and even less to the general public. It can be assumed that a random, larger and more representative sample would have provided a somewhat different result.

We also need to carefully consider what actually is measured with the questions asked in the survey, and we must account for the possibility that the questions could perhaps have been formulated differently. Considering the abstract nature of these factors, using only one item to measure some of the variables could be considered insufficient.

## 7 Concluding remarks

The purpose of our study was to empirically examine possible factors that may affect people's likelihood to declare their willingness to donate their organs after death.

On the basis of earlier research we formulated eight hypotheses about what influences a person's willingness to donate. Three of our eight hypotheses turned out as the important determinants – *social responsibility, bodily integrity* and *subject sensitivity*. Three other determinants received ambiguous support – *knowledge, altruism* and *reciprocity*. These three variables were located just outside of the accepted significance range. The variables *subjective norms* and *social image,* however, were not close to be significant.

We can conclude that, although most students seemed indifferent to the statement of organ donation being one's social responsibility, the impact of social responsibility is strong, which should be addressed in a campaign aiming to increase the willingness to donate. We can conclude that the goal to de-dramatize the subject of organ donation, as done in the two previous information campaigns in Sweden, could be effective as well as addressing the issue of bodily integrity using the biomechanical model of the body.

We did not receive information to support all our predicted hypotheses, and this could be due to a number of different reasons discussed in the study's limitations. We have however fulfilled the purposed of this study by reporting significant determinants of the communication of donor will.

With this thesis we have taken a further step in understanding the complex nature of organ donation and the determinants of donor will.

## 7.1 Further research

Due to the growing number of people waiting for new organs it is important that research in this field continues, in order to help the supply of organs to meet the demand. Through our model, we have tested a number of possible variables that may affect donor behavior. It would be interesting to test more variables not accounted for in our study. We therefore believe that it would be worthwhile to repeat the study, but with some adjustments. First we recommend a larger and more representative composite sample. Second, as mentioned above, there may exist other influencing variables that we have not paid attention to in our survey. Third, to get a more nuanced understanding of the subject, supplementing research methods could be used, for example deep interviews and focus group studies.

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## Appendix 1

Table 6	Regression after stepwise elimination			
Dependent variable:	Communicated will			
	Coefficient	Robust Standard Error	t	P>t
knowledge	.0023984	.0014899	1.61	0.109 M
altruism	.0395864	.0244761	1.62	0.107 M
subject sensitivity	0899502	.0216837	-4.15	0.000 S
bodily integrity	1016603	.0327363	-3.11	0.002S
reciprocity	.0287098	.0177812	1.61	0.107 M
social responsibility	.0637595	.0148899	4.28	0.000 S
SSE	16815	.055174	-3.05	0.003 S
constant	.234962	.254676	0.92	0.357 N
Number of observations	294			
F(11, 282)	44.00			
Prob > F	0.0000			
R-squared	0.3733			

Table 7 A						
	knowledge	subjective norms	altruism	subject sensitivity	bodily integrity	reciprocity
knowledge	1					
subjective norms	0.0857	1				
altruism.	0.0708	0.1993	1			
subject sensitivity	-0.0047	-0.138	-0.0605	1		
bodily integrity	-0.1595	-0.3417	-0.3965	0.4329	1	
reciprocity	-0.0365	0.0874	0.2408	-0.0358	-0.1988	1
social responsibility	0.1425	0.1733	0.3674	-0.1361	-0.3724	0.3427
social image	0.0609	0.2057	0.2568	0.071	-0.1571	0.276
age	0.1246	0.0074	-0.0416	0.0321	-0.1193	-0.0787
male	-0.0439	0.006	-0.0151	0.1447	0.1824	-0.0281
SSE	-0.0898	0.0166	0.101	0.0638	0.1851	0.0181

# Appendix 2 Pearson correlation coefficient

Table 7 B					
	social responsibility	social image	age	male	SSE
social responsibility	1				
social image	0.3566	1			
age	0.0861	-0.0451	1		
male	-0.0706	0.1302	-0.106	1	
SSE	-0.0505	0.1663	-0.3839	0.3945	1