

# Improving the organ donor card system in Switzerland

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## Summary

This paper analyses the current organ donor card system in Switzerland and identifies five problems that may be partially responsible for the country's low deceased organ donation rates. There are two minor issues concerning the process of obtaining a donor card: the Swisstransplant website understates the prospective benefits of donation, and the ease with which donor cards can be obtained raises questions regarding whether any consent to donation provided is truly informed. Furthermore, there are two major practical problems that might affect those who carry an organ donor card: the lack of a central donor registry increases the likelihood that donors' wishes will be "lost", and there is a high probability that family members will veto organ donation. The fact that these two practical problems are not mentioned to potential donors by Swisstransplant constitutes the fifth problem. Donation rates would probably improve if more accurate information about the benefits of donation were provided to potential donors, a central donor registry were created, and families were not permitted to veto donation from those on the registry.

**Key words:** *Organ donation; ethics; Swisstransplant; public health*

## Introduction

Despite relatively high living donation rates, Switzerland has surprisingly low deceased organ donation rates, particularly in the Swiss-German part of the country, with around 13 donations per million people in 2011 [1]. The precise reasons for this are unclear. The country used to have a presumed consent system and is now widely regarded as having an elective opt-in system. However, this is not quite correct; Switzerland actually has a hybrid system where a donor card can indicate that someone wants their organs to be taken when they die, that they do *not* want their organs to be taken, or that they wants someone else to make the decision for them. Effectively, this operates as an opt-in system, but Switzerland is quite unusual in that one can have an organ donor card which states that one does not want to donate one's organs. In most countries with an opt-in system, anyone with a donor card is regarded as a poten-

tial donor; only Australia, Canada and New Zealand enable both those who want to donate and those who do not to register their preference [2].

Another very unusual feature of the Swiss system is that there is no electronic record of donors; the only database containing any information on the identities of donors is composed of the cards themselves. This means that it is impossible to check whether someone has or had a card if it is misplaced, which raises several important issues.

## Swisstransplant and the Swiss organ donor card

Swisstransplant is the organisation responsible for governing and promoting organ donation in Switzerland. It is remarkably easy to obtain an organ donor card: you simply go to the website, fill in some information, and print out your card. The application form offers would-be donors various options regarding donation, which are as follows:

- "I authorise, in the case of death, removal of any organs, tissues and cells, and any preliminary medical measures.
- I authorise, in case of death, removal of the organs indicated hereafter: heart, lung, liver, kidneys, intestine, pancreas, eyes, skin, other tissue and cells (a box can be ticked for each option).
- I do not authorise the removal of organs, tissues, or cells from my body.
- If I die, the trusted person indicated hereafter will make the decision regarding removal of organs." [3]

Thus there are four main options: donate all organs, donate specified organs, refuse to donate and nominate someone to make the decision. This offers admirable freedom of choice, and means that not only donors, but also those who do not wish to donate and those who are not yet sure can carry a donor card expressing their wishes. However, this variability poses some practical problems, as shall become clear, and means that it is something of a misnomer to call it a "donor card". (Interestingly, only those aged over 16 can obtain donor cards, which may increase the likelihood that children in need of organs will die. In the United Kingdom, children can join the register if competent and their parents can put them on it if they are not.)

Although the Swisstransplant website makes it very easy to obtain a donor card, the information it supplies is slightly misleading in some regards. First, the application form uses the slogan: “it’ll take 3 minutes and could offer an entire life to someone”. This undersells the potential benefits of donation: several lives could be saved, and as many as seven people could benefit in one way or another from each donor, if all organs are donated. In this sense, Swisstransplant is missing an opportunity and underselling the immense benefits of organ donation. A more accurate phrase would be “it’ll take a few minutes and could save several people’s lives”. (This point and the next are minor, but worth mentioning nonetheless.)

Second, another potential problem is raised by the sheer ease with which potential donors can fill in the form and print their cards. Three minutes is not a very long time to consider such an important decision. In terms of increasing donation rates by making things easy for the donor, this is excellent, but it also means that it would be very easy to create a card for someone who does not want to donate (although this is an unlikely scenario). Furthermore, many people believe that the standard of consent required for posthumous donation should be just as high as that for living donation [4, 5], and the Swisstransplant website does not meet this standard. The same criticism can be levelled at the system in the United Kingdom, where the application form for a driving licence allows people to tick a box indicating that they want their organs to be taken [6]. (Others would argue that this concern is misplaced, and a much lower standard of consent is appropriate for posthumous donation, as no harm can come to the donor. Nonetheless, people should be encouraged to learn about donation and provided with accurate information before making a decision, regardless of whether fully informing them improves donation rates.)

In addition, the information brochure that is provided to the would-be donor by Swisstransplant is 12 pages long, and would therefore take a lot longer than 3 minutes to read properly [7]. Therefore, any truly informed donor would take longer than the advertised 3 minutes to consent and fill in the form, and only those who do not bother to read the form can complete the process in 3 minutes. Many people will already have thought about donation before reaching this stage, but the information provided about the length of time to read the material thoroughly should be accurate. (It could also be argued that the form should only be useable after the brochure has at least been accessed, in order to provide a minimum safeguard of consent.)

Another minor point is that it is technically misleading to state that “organs, tissue or cells can be removed from a deceased person only if we have his consent and death has been certified”. “Only if” implies no exceptions, but families are asked to provide consent when the dead person’s wishes were unknown; in such cases, the deceased did not consent, but organs are taken anyway. (Indeed, the brochure immediately goes on to state, on page 3, that those close to the deceased will be asked to make a decision if the potential donor’s wishes were unknown.) Furthermore, it has been suggested that some non-beating heart donors are certified as dead despite not fully meeting all the criteria for whole brain death [8]. However, this is likely to be-

come less of a problem with the increasing number of this type of donor and the introduction of new tests to confirm brain death [9].

## Practical problems with the donor card system

In addition to these problems concerning the process of obtaining a donor card, there are several practical problems that could affect would-be donors even if they carry an organ donor card. The first is that the organ donor card is the only place where the donor’s wish is recorded, and there is no central database or registry on which to check someone’s organ donor status. Given that many potential donors die in car crashes, where it might be very difficult to locate their card, this is a major oversight. Even if a card were found, of course, it might indicate only that the person did not want to donate his organs; this is potentially problematic because even if a card is found after a crash, it might be illegible, and doctors might assume that it is an opt-in card rather than an opt-out. (In the United Kingdom, donor cards are almost never referred to, with the central donor registry being used in almost all cases [10].) Given that the statement on a donor card is equivalent in law to a last testament or will [11], it is very unfortunate that there is no central registry as a “back-up” for lost cards.

A related issue is the option on the application form to specify a trusted person to make the decision after the donor’s death. While this is a commendable option to have on the donor card, the lack of a centralised database in Switzerland means it is unlikely to be very useful. What if this person cannot be reached, or disagrees with the family? What if the card is not found, and the family make a decision instead? The application form also misleads donors in this sense, as it does not warn about these potential problems. The same applies to those who refuse to donate, as the card offers a false assurance that their organs will not be taken; if the card is not found, their organs might well be taken if the family is willing. Of course, if there were a central donor registry, it could easily be checked whether someone wanted to donate, and this information could also be used to help persuade families who object to donation (see below). Swisstransplant does urge those who obtain a card to tell their relatives, but many people fail to do so, and even if they do express their wishes, relatives often make poor decisions regarding donation because they are distressed [12].

The second and more important practical problem concerns families vetoing organ donation. Swiss law states that families are only asked for their opinion if there was not a previously expressed wish, suggesting that vetoing of donation never take place; similarly, the Swisstransplant brochure for potential donors states that relatives/friends can make a decision only in the absence of a declaration of donation. However, research has also shown that families frequently veto organ donation in Switzerland, with 43.5% of all donations being stopped by the family [13] although it is not clear how many of these potential donors had expressed a wish to donate. United Kingdom law states the same thing [14] but vetoing frequently takes place there. The SwissPOD project [15], which is intended to capture

a wide variety of data on organ donation, will hopefully provide more up-to-date information on this issue, but it appears likely that many families are vetoing donation even when they knew their loved one wanted to donate their organs, in contravention of the law and the wishes of the deceased. Indeed, the Swiss Federal Health office has suggested that this is the case, with refusal rates “basically high”, but varying substantially between hospitals [16]. Swisstransplant state in their information to donors that “the transplant law determines these conditions”, but if the law is not being obeyed then this unfortunately means that Swisstransplant is providing erroneous information. If vetoing of donation or refusal does take place, then donors and refusers should be informed about this (by swisstransplant.org, among others) so they can take steps to persuade their families not to veto. (Interestingly, Franz Immer, chief executive officer of Swisstransplant, has stated that even if Switzerland returned to the presumed consent system, doctors would insist on asking families for their permission [17].)

Another issue connected to the veto is the fact that people can only indicate a “trusted person” on their donor cards if they are not also registering their intention to donate. The application form states that only one option should be chosen, so those who wish to donate organs are not allowed to nominate a trusted person. This is unfortunate, because it could increase donation rates if would-be donors could also nominate a trusted person. Given that families appear to be consulted even if the deceased person wanted to donate, it would avoid disagreement if one family member (or friend) had already been nominated to make the decision. (This would be similar to the system of advance commitment suggested elsewhere [18].) Of course, if the person wanted to donate as proven by his or her donor card, the family should not really have a say in the matter, in accordance with Swiss law.

Furthermore, if vetoing does take place, a family could also potentially veto the refusal of donation recorded on a loved one’s donor card. The Swiss transplant law states that families are approached only in the absence of any documented consent or refusal [12], yet vetoing of donation occurs; therefore, vetoing of refusal is also theoretically possible. Although this might seem unlikely, a family could truthfully claim that a relative had changed his mind since recording a refusal on a donor card. Many members of the public would probably find a family’s approval of donation despite a statement to the contrary by the deceased more troubling than a family’s denial of donation despite the deceased’s wish to donate; this is somewhat ironic, given that the family’s veto of refusal saves lives, while veto of donation leads to deaths.

## Recommendations

This paper has identified five problems that may be partially responsible for low deceased organ donation rates in Switzerland: the benefits of donation are undersold by Swisstransplant, the consent process is questionable, donors’ wishes may be lost, families may veto donation even where the donor’s intentions were clear (and possibly veto refusal), and Swisstransplant is not completely honest

about these last two facts with would-be donors. The first and last problems are the most easily solved: Swisstransplant should provide more accurate information regarding the benefits of donation and the risks of lost wishes and vetoing on its website. The minor flaws in the consent process might be viewed as problematic, although some would argue that the normal standards of informed consent need not be met in the case of posthumous donation. Nonetheless, it might be helpful to avoid claiming that a card can be produced in 3 minutes, given that anyone who reads the information leaflet would take much longer. The only way to solve the third problem would be to create a central donor registry, which could easily be done, despite the possibility of some concerns about privacy. It is unfortunate that Switzerland does not have a central donor registry, when creating one would be relatively cheap and could save or improve hundreds of lives each year. And finally, the law does not permit a family veto, and distressed families should not be allowed to overrule the wishes of their dead relatives, no matter how difficult the situation might be for them and for medical staff [12].

## Conclusion

This paper has pointed out two key practical problems and several minor ones related to the organ donor card system in Switzerland. Swisstransplant is making admirable efforts, but could provide much more accurate information to potential donors, particularly with regard to the immense benefits of donation and the importance of getting a card and telling family members to respect one’s wishes. More importantly, the creation of a central donor registry would avoid many of the practical problems with the donation process and would also provide useful evidence to convince families not to veto donation. Creating such a registry could boost donation rates substantially. And finally, families should not be allowed to veto donation when the wishes of the deceased are clear.

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