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## Attitudes towards organ donation and relation to wish to donate posthumously

Julius Weiss<sup>a</sup>, David Shaw<sup>b</sup>, Roger Schober<sup>a</sup>, Viviana Abati<sup>a</sup>, Franz F. Immer<sup>a</sup> and the Comité National du Don d'Organes (CNDO)\*<sup>a</sup> Swisstransplant, the Swiss National Foundation for Organ Donation and Transplantation, Bern, Switzerland<sup>b</sup> Institute for Biomedical Ethics, University of Basel, Switzerland

\* See appendix for list of members of the CNDO

### Summary

**BACKGROUND:** Organs donated for transplantation remain a scarce resource in Switzerland. One of the reasons for this situation is the high percentage of patients or families who refuse to consent to donation. This study aimed to provide an overview of attitudes towards organ donation among Swiss residents, including any intention to donate organs after death, and whether they had already declared their wish and/or communicated it to anyone.

**METHODS:** A representative poll investigating the attitude of the Swiss population towards deceased organ donation was conducted between 16 and 28 March 2015. Survey data were collected in 1000 structured telephone interviews. Participants consisted of residents aged 15 years and over from all Swiss regions, and covering the German, French and Italian language areas.

**RESULTS:** Of the 1000 survey participants, 92% stated that they have a very positive (58%) or quite positive (33%) attitude towards organ donation, while 6% have a very negative (2%) or quite negative (4%) view. Some 81% of respondents said that they would be willing to donate their organs after death, and 9% expressed a wish not to become a donor. A total of 53% of participants said that they had already communicated or documented whether they wish to donate.

**CONCLUSION:** Our study highlights the importance of continuing to raise awareness about the importance of communicating wishes, both in written form and to family members, and suggests that more work is needed to reap the benefits of the substantial support for organ donation among the Swiss population.

**Key words:** organ donation; transplantation; poll; donor card; family communication; Switzerland

### Introduction

Organs donated for transplantation remain a scarce resource in Switzerland, and the post mortem donation rate is low compared with other countries at 14.1 donations per million population over the last 5 years (mean; range 12–17.4 pmp) [1]. One of the main reasons for this situation is the high percentage (54%) of patients or their family members who refuse to consent to organ donation (mean; range 53–56%) [2]. Previous studies have tried to identify variables that affect organ donation activity in Switzerland, such as factors associated with the consent rate, the role of discussion within families about donation, the general attitude towards organ donation, cultural differences between language regions, and the donor card system [2–7]. Aside from that, action has been taken to increase the awareness of organ donation in the hospitals, and to improve the detection and referral of potential donors [8]. Switzerland has an explicit consent (opt-in) organ donation policy, and no donor register. Therefore, post mortem organ donation can only take place if the deceased person's wish to donate is documented in a donor card or an advance healthcare directive, or if the family or a designated person of trust consents to organ donation (where no documented wish is present). In the latter case, the family or person of trust will be asked to decide according to the patient's known or supposed wish. This means that, in cases where the patient's wishes are unknown the burden of the decision is left with the family. Therefore, public campaigns by the Federal Office of Public Health have focused on raising public awareness about organ donation, and the importance of making a decision and communicating it to the family. In this context, knowledge of the reasons that motivate people to make a decision and communicate it to their family is pivotal.

In this paper, we present the results of a representative population survey among residents of Switzerland. It was conducted with the aim of providing an overview of their attitude towards organ donation, any intention to donate organs after death, and whether they already had declared their wish and/or communicated it to anyone. In order to gain insight into the decision-making process, participants were specifically asked to provide reasons for having made a decision con-

cerning organ donation and the communication of their wish, or for postponing it.

## Materials and methods

A representative poll about the Swiss population's attitude towards deceased organ donation was commissioned by Swisstransplant, the Swiss National Foundation for organ donation and transplantation, and conducted by DemoSCOPE AG (Adligenswil, Switzerland). The survey was conceived by Swisstransplant in association with DemoSCOPE, based on a questionnaire that consisted of basic demographic data, 28 questions related to organ donation, and supplementary information, such as household data, highest completed level of education and whether respondents consider themselves as religious or not. The survey questionnaire took respondents approximately 15 minutes to answer.

Survey data were collected in structured telephone interviews with computer-assisted telephone interviewing technology, conducted between 16 and 28 March 2015. In total, 1000 interviews were conducted, giving a margin of error of  $\pm 3.1\%$  with a 95% confidence interval. Based on telephone directory data, a random sample of households was generated for each language area. Within the individual households, a combined quota of age and sex was used. Survey participants were cold called, and consisted of residents aged 15 years and over from all Swiss regions, covering the German, French and Italian language areas. The recruitment rate of the telephone survey was 24.8% (number of interviews conducted [n=1000] divided by the total number of successful interviews [n=1000] plus the number of individuals called who were not able to participate [n=397] or declined participation for various reasons [n=2636]). Within the individual households, a combined quota of age and sex was used. The results presented in this study have been weighted moderately for appropriately representing sex, age and living areas, in order to match the actual population structure. Owing to rounding of weighted data, the number of participants in the subgroups as presented in the tables may not always add up to the grand total.

## Results

Of the 1000 survey participants, 92% stated that they had a very positive (58%) or quite positive (33%) attitude towards organ donation, whereas 6% had a very negative (2%) or quite negative (4%) view. A total of 81% of respondents said that, in principle, they would be willing to donate their organs after death. Only 9% expressed a wish not to become an organ donor. Slightly more than half of the participants (53%) said that they had already communicated or documented whether they wished to donate or not, whereas 46% had not yet done so.

Baseline demographic data for the survey participants are shown in table 1. It also provides information about their attitude towards organ donation in general, whether participants wished to donate their organs after death, and whether they had communicated or documented their wish in some way or another.

The general attitude towards organ donation was slightly more favourable among women than men (93% vs 90%), and also more positive in the two younger age groups compared with participants aged 55 years or above (94% vs 87%). With regard to the language areas, the attitude was most positive in

respondents from the French-speaking part of Switzerland (99%), and similar in participants from the Italian- (91%) and German- (89%) speaking areas. With regard to educational levels, there was very little difference in the pro attitude among the subgroups (range 90–94%). Subjects who considered themselves as very religious also had a less positive attitude towards organ donation (87%) than participants who declared that they were fairly religious (92%), not very religious (94%), or not religious at all (90%).

In the comprehensive study population, the proportion of respondents who wished to donate their organs post mortem (81%) was lower than the 92% of subjects who declared that they had a generally positive attitude towards organ donation. A similar reduction of roughly 10 percentage points in the wish to donate was observed in nearly all categories and subgroups, with the distribution remaining mostly constant. The only remarkable drop in the “translation” from “pro” attitude to wish to donate was in the household income category, where 92% of subjects in the lowest group had a positive attitude, but only 75% wished to donate their organs. Consistent with a negative attitude, the wish not to donate was most pronounced in very religious subjects (17%), and those with the second lowest household income (15%).

Among all participants, only 53% answered that they had already declared their wish by either recording the decision (e.g., with a donor card) or by communicating it to somebody. Again, the distribution among the subgroups was very similar with regard to attitude and wish to donate. Subjects who had a positive attitude and who wished to donate were also more likely to have communicated or documented their wish. The proportion of participants who had communicated or documented their wish was highest among subjects who were not religious (65%), those with a university degree (64%) and those living in a single household (63%), as well as in female participants in general (63%). In contrast, the smallest proportion of subjects who had communicated or documented their wish was found among participants with the lowest education level (36%), men in general (43%) and subjects with the lowest household income (also 43%).

## Positive and negative aspects of organ donation

To inquire further into the motives that may play a role in decision making, survey participants were asked to identify positive and negative aspects of donation (table 2). Allowing for multiple answers, the most frequently mentioned positive aspects of organ donation were “saving lives” or “helping others” (84%), and “organs can be used after death” (14%). Only 21 participants (2%) said that “they were against organ donation” or that “nothing speaks for it” (data not shown in table). This answer was chosen by the second largest relative amount (n = 17) of all participants with a negative attitude towards organ donation (n = 60), as well as the second largest proportion (n = 18) of those did not wish to donate (n = 94).

When asked about negative aspects, 34% of respondents stated that “nothing speaks against it” or “I am pro organ donation”; in addition, 8% chose “I don't know”. Religious reasons, as well as less specific ethical, moral or cultural concerns were mentioned by 14% in total, and 11% of subjects cited the risk of misuse as a negative aspect. The other responses regarding negative aspects of donation were given by fewer than 5% of participants.

**Table 1:** Survey demographics, attitude towards organ donation, and wish to donate.

		Total	Attitude towards organ donation			Wish to donate			Wish already communicated or documented		
			Positive	Negative	n/a <sup>a</sup>	Yes	No	n/a <sup>a</sup>	Yes	No	n/a <sup>a</sup>
<b>Total participants</b>		1000	917	60	24	812	94	93	534	458	7
		100%	92%	6%	2%	81%	9%	9%	53%	46%	1%
<b>Sex</b>	Male	490	442	32	16	389	54	47	211	276	3
		49%	90%	6%	3%	79%	11%	10%	43%	56%	1%
	Female	510	474	28	8	423	40	46	323	182	5
		51%	93%	5%	2%	83%	8%	9%	63%	36%	1%
<b>Age group (years)</b>	15–34	302	284	12	5	251	21	30	152	147	3
		30%	94%	4%	2%	83%	7%	10%	50%	49%	1%
	35–54	361	338	16	7	301	29	30	205	155	2
		36%	94%	4%	2%	84%	8%	8%	57%	43%	*%
	≥55	337	294	31	12	260	45	32	178	157	3
		34%	87%	9%	3%	77%	13%	10%	53%	46%	1%
<b>Language area</b>	German	714	638	54	22	554	83	77	366	343	5
		71%	89%	8%	3%	78%	12%	11%	51%	48%	1%
	French	239	236	3	–	216	8	14	141	95	3
		24%	99%	1%	–	91%	3%	6%	59%	40%	1%
	Italian	47	43	3	1	42	3	2	27	20	–
		5%	91%	6%	3%	90%	7%	3%	57%	43%	–
<b>Domestic situation</b>	Single	72	68	3	1	63	5	4	45	25	2
		7%	94%	4%	1%	87%	7%	6%	63%	35%	3%
	Partnership without children	205	183	18	4	159	27	19	111	93	1
		20%	89%	9%	2%	77%	13%	9%	54%	45%	*%
	Partnership with children	549	505	30	15	445	51	53	297	249	3
		55%	92%	5%	3%	81%	9%	10%	54%	45%	1%
	Single parent	28	24	3	–	22	3	2	16	11	–
		3%	88%	12%	–	81%	12%	7%	58%	42%	–
	Alternative ways of living <sup>b</sup>	145	136	5	4	122	8	15	65	79	1
		15%	94%	4%	3%	84%	5%	11%	45%	54%	1%
n/a <sup>a</sup>	2	2	–	–	2	–	–	1	1	–	
	*	100%	–	–	100%	–	–	35%	65%	–	
<b>Education</b>	Compulsory education	147	138	6	4	120	11	16	53	90	3
		15%	94%	4%	2%	82%	7%	11%	36%	62%	2%
	Vocational college	391	352	24	14	315	38	37	207	183	1
		39%	90%	6%	4%	81%	10%	9%	53%	47%	*%
	High school	122	113	6	2	99	9	14	62	57	2
		12%	93%	5%	2%	81%	7%	12%	51%	47%	2%
	University of applied sciences	213	194	18	1	174	22	16	133	80	–
		21%	91%	8%	*%	82%	10%	8%	62%	38%	–
	University / Federal Institute of Technology	123	115	5	3	99	14	10	78	44	1
		12%	93%	4%	2%	81%	12%	8%	64%	35%	1%
n/a <sup>a</sup>	5	5	–	–	5	–	–	1	4	–	
	1%	100%	–	–	100%	–	–	18%	82%	–	
<b>Household income (Swiss Francs)</b>	<4000	62	57	5	–	47	8	7	27	33	3
		6%	92%	8%	–	75%	13%	12%	43%	53%	5%
	4000–5999	153	135	16	2	118	23	12	90	62	1
		15%	88%	10%	1%	77%	15%	8%	59%	41%	1%
	6000–7999	192	181	6	5	161	12	19	99	92	1
		19%	94%	3%	3%	83%	6%	10%	52%	48%	*%
	8000–9999	171	161	7	2	142	12	16	98	71	1
		17%	95%	4%	1%	84%	7%	9%	58%	42%	1%
	>10000	248	226	16	6	204	25	19	145	103	–
		25%	91%	7%	2%	82%	10%	8%	58%	42%	–
	n/a <sup>a</sup>	174	156	10	8	141	14	20	76	97	1
		17%	90%	6%	5%	81%	8%	11%	43%	56%	1%

**Table 1** (continued)

Religiosity	Very religious	132	116	13	4	98	23	12	68	64	1
		13%	87%	10%	3%	74%	17%	9%	51%	48%	1%
	Rather religious	459	422	26	10	370	42	46	237	216	5
		46%	92%	6%	2%	81%	9%	10%	52%	47%	1%
	Rather not religious	229	215	8	6	197	15	17	117	111	1
		23%	94%	4%	2%	86%	7%	7%	51%	49%	*%
	Not religious	163	147	12	4	135	14	15	107	56	–
		16%	90%	7%	2%	82%	8%	9%	65%	35%	–
n/a <sup>a</sup>		17	17	–	–	13	–	3	6	11	–
		2%	100%	–	–	81%	–	19%	36%	64%	–

Answers were grouped; "positive" consists of "very positive" and "rather positive" (likewise for "negative").  
<sup>a</sup> n/a includes no answer given, and answer "I don't know".  
<sup>b</sup> includes e.g., living community, living with parents.  
<sup>\*</sup> indicates a percentage <0 and <0.5.

**Table 2:** Main positive and negative aspects of organ donation.

	Total	Attitude towards organ donation			Wish to donate			Wish already communicated or documented		
		Positive	Negative	n/a <sup>a</sup>	Yes	No	n/a <sup>a</sup>	Yes	No	n/a <sup>a</sup>
<b>Total participants</b>	1000	917	60	24	812	94	93	534	458	7
	100%	92%	6%	2%	81%	9%	9%	53%	46%	1%
<b>Positive aspects</b>										
Saving lives / helping others	838	792	25	21	699	57	82	452	382	5
	84%	94%	3%	2%	83%	7%	10%	54%	46%	1%
Organs can be used after death	135	132	–	3	124	1	10	81	53	1
	14%	98%	–	2%	92%	1%	7%	60%	39%	1%
It is a good thing to do	65	65	–	*	60	2	3	37	26	2
	7%	99%	–	1%	92%	4%	5%	57%	39%	3%
<b>Negative aspects</b>										
Nothing / I am pro organ donation	342	336	1	5	320	11	10	213	129	–
	34%	98%	*%	1%	94%	3%	3%	62%	38%	–
Risk of misuse (e.g., organ trafficking)	114	104	8	2	89	11	14	56	57	1
	11%	91%	7%	2%	78%	9%	12%	49%	50%	1%
Religious reasons	86	81	4	1	71	8	8	50	36	–
	9%	93%	5%	2%	82%	9%	9%	58%	42%	–
Distrust in brain death diagnosis	64	54	8	2	39	11	14	35	29	–
	6%	84%	13%	3%	60%	17%	23%	55%	45%	–
Health-related reasons	57	54	1	1	47	5	5	31	25	1
	6%	95%	3%	2%	83%	9%	8%	54%	43%	2%
Ethics, morals, culture	56	49	6	1	37	8	11	24	32	–
	6%	88%	10%	2%	66%	15%	19%	43%	57%	–
Bodily integrity should be maintained	49	42	4	3	31	10	7	20	28	1
	5%	85%	9%	6%	63%	21%	15%	41%	57%	2%

Answers were grouped; "positive" consists of "very positive" and "rather positive" (likewise for "negative").  
<sup>a</sup> n/a includes no answer given, and answer "I don't know".  
<sup>\*</sup> indicates a percentage <0 and <0.5.  
Multiple answers were allowed. Only aspects mentioned by at least 5% of participants are included in the table.

## Declaration of wishes regarding donation

After answering general questions about their attitude towards organ donation, participants were asked if they had already decided whether they wished to donate their organs post mortem or not, and if they had declared their wish. The declaration of one's wish was defined as having communicated the decision to somebody (typically, to a family member or a close friend), or recording it in a donor card, for example. Of the 1000 participants, 53% said that they had already declared their wish, and 46% answered that they had not yet done so. Among the 534 participants who had declared their wish, the wish to donate was more prominent (91%), compared with the general survey population (81%), whereas the proportions of

participants who did not wish to donate was almost equivalent in both groups (8% and 9%, respectively).

Table 3 shows that, among the 534 subjects who had declared their wish, family communication was by far the most common method chosen (94%; multiple methods were allowed). A total of 49% said that they had filled in a donor card and 13% stated their wish in an advance healthcare directive. Only 3% used the digital donor card provided by the "Echo 12" smartphone application introduced in late 2014 and 2% documented their wish in a last will (data not shown in the table). These results indicate that among all survey participants, 50% had communicated or documented their wish and 26% had filled in a donor card.

In any method chosen to express one's wish, the proportion of participants who wish to donate was higher than in the gen-

eral survey population. Accordingly, the proportion of participants who did not wish to donate was lower among subjects who had declared their wish than among the general study population for all methods chosen, except for those who had documented their wish in an advance healthcare directive.

**Table 3:** Methods chosen for the declaration of one's wish.

	Total	Wish to donate		
		Yes	No	n/a <sup>a</sup>
Total number of participants who have declared their wish	534	486	42	6
	100%	91%	8%	1%
<b>Communicated their wish to the next of kin</b>				
Yes	503	459	37	6
	94%	91%	7%	1%
No	29	24	5	–
	5%	83%	17%	–
n/a <sup>a</sup>	3	3	–	–
	1%	100%	–	–
<b>Documented their wish in the donor card</b>				
Yes	262	258	4	–
	49%	98%	2%	–
No	271	226	38	6
	51%	84%	14%	2%
n/a <sup>a</sup>	2	2	–	–
	–	100%	–	–
<b>Documented their wish in an advance healthcare directive</b>				
Yes	70	61	10	–
	13%	86%	14%	–
No	460	421	33	6
	86%	92%	7%	1%
n/a <sup>a</sup>	4	4	–	–
	1%	100%	–	–

<sup>a</sup> n/a includes no answer given, and answer "I don't know". Multiple answers were allowed. Percentages in the "Total" column are relative to the question whether the method was chosen or not. Percentages in the "Wish to donate" column are relative to the total number of participants in the respective group.

Survey participants were also asked to specify one or more reason(s) why they had or had not stated their wish (table 4). Of the 534 subjects who had declared their wish, 26% mentioned "clarity about what happens after own death" as a reason for having communicated or documented their wish; 17% answered that they were motivated by the wish to save lives or the opportunity to help others. The conviction that organ donation is good, important or sensible was a reason mentioned by 16% in total. Among the subset of participants who had declared their wish, the wish not to donate was highest (18%) in the group who said they had declared their wish following discussions about organ donation.

Among the 458 participants who had not yet declared their wish, 48% said that they had no time or reason to think about organ donation yet, 20% believed that they are either too young or too old to donate organs (age distribution: 15–34 years, n = 56; 35–54 years, n = 11; ≥55 years, n = 23), and 17% were uncertain about how to decide. A lack of knowledge was the reason cited by 7% for not having stated their wish. Interestingly, the fear of misuse or of receiving inferior treatment as a potential organ donor was cited by less than 2% in total in this subset of participants. Overall, the wish to donate in the 458 participants who had not yet declared their wish was lower (71%) than in the general study population (81%). However, it was similar (78%) in the relatively large group (n = 218) of those who stated that they had not yet had time or a reason to think about organ donation.

**Table 4:** Main reasons for the declaration or non-declaration of one's wish.

	Total	Wish to donate		
		Yes	No	n/a <sup>a</sup>
<b>Participants who have declared their wish</b>	534	486	42	6
	100%	91%	8%	1%
Clarity about what happens after own death	139	117	18	3
	26%	85%	13%	2%
Wish to save lives / opportunity to help others	92	91	1	–
	17%	99%	1%	–
It is good/important/reasonable	85	82	3	–
	16%	96%	4%	–
It makes me proud to be a potential organ donor	71	71	–	–
	13%	100%	–	–
I don't want to burden my next of kin with taking the decision	58	50	8	–
	11%	87%	13%	–
I don't want anybody else to take the decision for me	47	40	7	–
	9%	86%	14%	–
Previous discussions of the topic	45	36	8	1
	8%	79%	18%	3%
Personal experience of family or friends	33	31	1	1
	6%	93%	4%	3%
<b>Participants who have not yet declared their wish</b>	458	324	51	83
	100%	71%	11%	18%
I haven't got round to doing it yet	218	170	16	33
	48%	78%	7%	15%
Because I am too young / old	90	67	11	13
	20%	74%	12%	15%
I am still undecided	76	35	12	28
	17%	45%	16%	37%
I have pushed this subject to the back of my mind	52	34	6	12
	11%	66%	12%	23%
Lack of knowledge	32	26	2	5
	7%	80%	6%	14%
For health-related reasons	23	16	5	2
	5%	70%	20%	10%

<sup>a</sup> n/a includes no answer given, and answer "I don't know". Multiple answers were allowed. Only reasons mentioned by at least 5% of participants are included in the table. Percentages in the "Total" column are relative to the total number of participants per category (wish declared, wish not declared). Percentages in the "Wish to donate" column are relative to the number of participants who mentioned the respective reasons.

## Discussion

A very large majority of participants (92%) in this representative survey had a positive attitude towards organ donation, and roughly 80% stated that they would be willing to donate their organs after death. However, only slightly more than half of the respondents (53%) said that they had already stated their wish. In this group, 94% had communicated their decision to someone but only 63% had recorded their wishes on an organ donor card (49%) or an advance directive (13%).

### Positive and negative aspects of organ donation

Participants' positive attitudes towards donation tended to relate to the beneficial effects of donation. A total of 86% of respondents with a positive attitude (n = 917) stated that organ donation saves lives and/or helps others. A lower proportion chose the reasons "organs can be used after death" (14%) and "it is a good thing to do" (7%). Among those who wished to donate their organs (n = 812), the figure for each of these reasons was almost identical: 86% for saves lives/helps others, and 15% for use after death, and 7% for donation being good.

In contrast, those without a positive overall attitude to donation ( $n = 60$ ) did not tend to choose these aspects. Somewhat surprisingly, only 42% (25/60) of those with a negative attitude to donation recognised the fact that donation saves lives and helps others, and only 61% (57/94) of those who did not wish to donate mentioned these aspects. These results are surprising in that they reveal that many of those opposed on some level to donation do not recognise the good that donation can do. However, this may be explained by respondents' reluctance to endorse as good and helpful behaviour that they are unwilling to endorse for other reasons (see below). Among participants who did not wish to donate, 19% said that there were no positive aspects to donation or that they were against it, which may also explain the lack of recognition of the good that donation can do by some respondents.

The negative aspects of donation identified by those who did not wish to donate their organs are also revealing (here we focus on aspects chosen by at least 5% of respondents). Distrust of brain death was one of the frequently identified aspects, with 11 of 94 respondents choosing this reason. Eleven respondents also chose the "risk of misuse" such as organ trafficking as a reason. Similarly, 10 respondents who were not willing to donate identified concerns about bodily integrity as a reason; 8 gave religious reasons, and 8 also gave ethical/moral/cultural reasons (see below). Most strikingly, however, 11 respondents who were not willing to donate claimed that donation had no negative aspects, or that they were pro-organ donation. This discrepancy could be explained by participants being in favour of donation in general, but also being either unwilling to donate or regarding themselves as unable to do so for some other reason (see next section).

Generally, our findings reflect the literature in terms of demographics, with some minor variations. Respondents from the French-speaking part of Switzerland tended to have very positive attitudes towards donation, which is in line with the literature [2, 5, 6]. People tended to be more supportive of donation the younger, more educated, of higher socioeconomic class and less religious they were [9–19]. However, we found that very religious people were less likely to support donation than fairly religious or non-religious people. This suggests that strong religious belief results in less altruistic behaviour in the context of organ donation. Notably, other researchers have suggested that religion is sometimes used as an excuse for not donating, and that religious misunderstandings may also be at play [15, 19]. Interestingly, many of our respondents who supported donation and were willing to donate also had religious reservations about donation. Among the 86 respondents who mentioned religious reasons as a negative aspect of donation, only 9% did not wish to donate, whereas 82% were willing to do so. This suggests that the perceived good of donation trumped any religious concerns regarding the practice for most religious respondents. In contrast, only 56 respondents mentioned "ethics/morals/culture" as a negative aspect of donation, and only 66% of this group were willing to donate their organs. Given that 88% of this group had a positive attitude to donation, it seems likely that cultural factors rather than ethical ones are responsible for the lower number willing to donate. Those with ethical or moral objections to donation would be unlikely to have a positive attitude towards it, but people might think of donation as ethical but be unwilling to donate for cultural reasons.

## Reasons for communication of wishes

The most common reason given by the 534 respondents in this category (whether it was a positive or negative wish) was to ensure clarity about what happens after death (table 4).

Among the 486 respondents who had communicated a positive wish to donate, 117 mentioned clarity, and three other reasons were frequently mentioned: wanting to save lives / help others (91 respondents), "it is good / important / reasonable" (82) and being proud about being an organ donor (71). The wish to ensure clarity is in a sense complementary to these other reasons, as it makes sense to be clear in order to ensure that the important aim of helping others and saving lives is achieved. Among the 42 respondents who had communicated a wish to not donate, 18 mentioned clarity, 8 mentioned avoiding burdening their family with the decision and 8 mentioned previous discussion. These results parallel those from an Australian study, where the second most commonly cited reasons for communicating a wish was "to control the decision without family interference" – a similar motivation to "clarity" in our study [20]. Notably, the proportion of participants who have communicated or documented their wish was as low as 41% among those who said that "bodily integrity should be maintained after death" when asked about negative aspects of organ donation. This is somewhat surprising, since one would assume that people who believe in the importance of bodily integrity after death would have a strong motivation for documenting their wish. However, this finding is in line with the general observation that people who wish not to donate were less likely to communicate or document their wish than those who wish to donate. One possible reason why people who do not wish to donate communicate or document their wish less frequently is that, with an explicit consent policy, they assume that there is no need to take any action to ensure that donation does not take place. However, in cases where they have not told their family, donation could go ahead if the family provides consent, so this assumption will often be incorrect (see below).

Participants were not asked why they chose a particular method of communication. Although 94% had communicated their decision to someone, only 63% had recorded their wishes on an organ donor card or an advance directive (table 3). (In the entire study sample, we found an increased proportion of participants who stated that they had a donor card [26%], compared with two previous Swiss studies where approximately 15% of participants had a donor card [3, 6].) The discrepancy between oral and written communication of a wish might be seen as surprising given that recording a wish in written form would seem to offer greater assurance that one's wishes will be followed. However, one explanation is that participants in this study trust their family and friends to make the right decision, even if the evidence shows that family members tend to be upset at the loss of a relative and might fail to respect the wishes of the deceased. The reliance on informing family members may be related to a recent campaign by the Swiss Federal Office for Public Health, which aimed to communicate the importance of talking to family members about donation. This trust in family members might also explain why 47% of respondents had not communicated a wish in any way; if they feel no need to have a written record of their wishes because they trust their family members to make the right decision, they might also feel no need to even discuss the matter with family members. Indeed, results from previous research in Switzerland also suggested that most Swiss people trust their families to make the right decision [4, 6]. However, there is some evidence that trusting families to make the right decision is inadvisable for those who wish to

donate: results from a Spanish study indicate that families only permit donation in 50% of cases when there was no indication of the patient's wishes, compared with an 87% donation rate where the patient had communicated a wish [11].

It is also worth noting that other research has identified other benefits of communicating one's donation intentions to family members: Murray and colleagues found that "participants who had discussed organ donation with a family member were more likely to be registered as a donor and more inclined to donate organs for themselves or a family member." [21] Similarly, Afifi et al. found that family interaction improved attitudes towards and increased the likelihood of donation for both those initiating the discussion and their family members [22]. Consequently, the same authors produced a brochure designed to help people discuss donation with their families: "If your family says this, here is how to respond" [22]. If family communication about donation intentions in Switzerland follows a similar pattern, then encouraging the high proportion of Swiss residents who have not communicated a wish could yield substantial benefits in terms of increased donation rates.

### Tensions between attitudes, willingness to donate and communication

The results also indicate several tensions between respondents' attitudes to donation and willingness to donate on one hand, and between willingness to donate and communicating their wishes on the other. The most obvious tension is the one between recognising the good that donation can do and being willing to donate one's organs, yet failing to take the necessary steps to ensure that donation could take place. In fact, 40% of those who wished to donate had not communicated their wishes. This tension is made even clearer when we consider the reasons given by those who wished to donate but had not yet communicated a decision (324 respondents). One of the reasons given was "I haven't got round to doing it yet" (52%), which is somewhat in tension with the results from many of the same respondents regarding positive aspects of donation. If organs save lives, then failure to communicate donation intentions could cost lives by increasing the chance that organs will not be donated because wishes were unknown. Similarly, 10% of respondents in this group admitted that they had pushed the subject to the backs of their minds. The explanation for these results may lie in ambiguity regarding the timing of donation. Respondents might be willing to donate their organs *at some point* but not be willing to consider the possibility that they might die at any time. This would explain why 20% thought they were too young (or old) to donate organs; of those who chose this reason, almost two-thirds were under 35. Combating misperceptions about age might be one way to increase donation rates in Switzerland. For younger potential donors, the message would have to focus on the fact that death could occur at any point; for older potential donors, it could be pointed out that over a third of all organ donors are over 60 [9]. Another explanation for failure to communicate wishes could be that some respondents in this category suffer from *akrasia*, the Greek term for knowing the right thing to do but being too weak-willed (or lazy) to actually do it. Other reasons given by the 324 respondents who intended to donate but had not yet communicated their wishes are more understandable: 26 (8%) felt they did not know enough about the subject, and 35 (11%) said that they were still undecided (despite saying that they wanted to donate their organs).

Second, there is a clear tension between having a positive attitude to donation, yet refusing to donate one's organs after death: 92% of respondents reported having a positive attitude towards organ donation, but only 81% were willing to donate their organs. This means that 11% of respondents supported donation in general but did not want to donate themselves. The most likely explanation here is that respondents were willing to benefit from donation if they needed an organ (hence their approval), but were (somewhat selfishly) unwilling to donate to help others in need. Others might have supported donation but thought they were too old to donate for medical reasons.

### Study strengths and limitations

The main strengths of this study are its large sample size, adequate representation of the demographic structure of the Swiss population, inclusion of participants across the main three linguistic areas of Switzerland, and minimisation of sample bias via random selection of participants. One limitation is that organ donation is a subject that some people may consider as delicate or very personal. One might assume that people with a general negative attitude towards organ donation could have been less likely to be willing to participate in the survey. Further limitations are typical for this type of survey. Participants tend to give answers that they regard as socially acceptable, which could lead to overestimation of positive attitudes towards donation. With regard to the survey using telephone interviews, one should keep in mind that residents whose phone numbers are not included in the telephone registry used for the random selection of households (approximately 25%) were excluded from the study population *a priori*. However, general non-response bias was offset by moderately weighting the results according to the current demographic structure figures provided by the Swiss Federal Statistical Office.

One further limitation consists in the fact that the questions about donation intentions might seem rather hypothetical to some participants. Finally, some questions were open-ended, so some granularity of responses may have been lost when results were placed into categories.

### Conclusions

The results of our representative survey of Swiss residents show that a large majority of participants have a positive attitude towards organ donation, and intend to donate their organs after death. However, we also found that only half of respondents have stated whether they wish to donate their organs or not; even more strikingly, only around one quarter of respondents had filled out an organ donor card. This highlights the importance of continuing to raise the awareness in the general population about the importance of communicating their wishes both in written form and to their family, and suggests that more work is needed to reap the benefits of the substantial support for organ donation among the Swiss population.

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## Correspondence

Franz F. Immer, MD  
 Consultant cardiovascular surgeon FMH  
 Swisstransplant  
 Effingerstrasse 1  
 Postfach  
 CH-3011 Bern  
 franz.immer[at]swisstransplant.org

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## Appendix: Members of the Comité National du Don d'Organes

The members of the CNDO are (in alphabetical order): PD Dr. med. Markus Béchir (President CNDO, regional network head Luzern), Schweizer Paraplegikerzentrum Nottwil; PD Dr. med. Yvan Gasche (Vice President CNDO), Hôpitaux Universitaires de Genève; Dr. med. Philippe Eckert (regional network head Programme Latin de Don d'Organes), Centre Hospitalier Universitaire Vaudois; Dr. med. Susann Endermann (regional network head St. Gallen), Kantonsspital St. Gallen; med. pract. Renato Lenherr (regional network head Donor Care Association), Universitätsspital Zürich; Dr. med. Mathias Nebiker (regional network head Bern-Solothurn), Inselspital Bern; Dr. med. Kai Tisljar (regional network head Basel), Universitätsspital Basel; Petra Bischoff, Inselspital Bern; Corinne Delalay, Hôpital de Sion; Dr. med. Adam-Scott Feiner, Centre Hospitalier Universitaire Vaudois; Eva Ghanfili, Ospedale Regionale di Lugano; Dr. med. Sven Mädler, Pallas Klinik Olten; Diane Moretti, Centre Hospitalier Universitaire Vaudois / Hôpitaux Universitaires de Genève; Stefan Regenscheit, Universitätsspital Zürich; PD Dr. med. Thomas Riedel, Inselspital Bern, Dr. med. Thomas Sauter, Inselspital Bern.