

Opinion no. 72 of 8 May 2017 on the public solicitation of organs from a living donor

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Addendum: Guidelines for directed altruistic donation (solicited specified donation) from the Dutch Transplant Foundation

1. Request for an opinion

On 17 February 2015, Dr. D Matthys, chairperson of the medical ethics committee of the University Hospital Gent/University Gent (UZ Gent/UGent), posed the following question:

“The Medical Ethics Committee of the University Hospital Gent recently discussed a question relating to the issue of a case of living kidney donation. In the context of this case, an appeal was made via the internet (on a website and on facebook) to solicit kidney donor candidates. According to the initiators of this appeal, a number of people were found via the website who were willing to donate a kidney. This was an exceptional situation as there was neither a familial nor a friendship tie between donor and recipient; this is unusual in Belgium. In the past, our Committee has dealt with other cases in which family members and/or friends, with a proven long-term friendship, were candidate donors.

The members of the Medical Ethics Committee are not opposed to the involvement of the hospital in a donation from a living donor, insofar it is an altruistic, anonymous donation whereby the organ is offered via Eurotransplant.

Given that we are not the only institution to be confronted with this issue, we wish to present this question to the Advisory Committee on Bioethics, with a view to obtaining an unambiguous national position on this issue.”

2. Medical aspects

2.1. People die every year in our country due to a lack of organs. The demand for organs for transplantations is constantly increasing, as can be seen by the number of candidate recipients on the waiting list (Figure 1).



Figure 1: Evolution of the number of candidate recipients on the waiting list in Belgium (source: Luc Colenbie, expert at the federal government Ministry of Public Health [FOD Volksgezondheid] and transplant coordinator at the University Hospital Gent)

2.2. There is however a relatively large pool of organs from deceased donors (see Figure 2), thanks to the *opting-out* system set in place by the Law on transplantation of 13 June 1986.

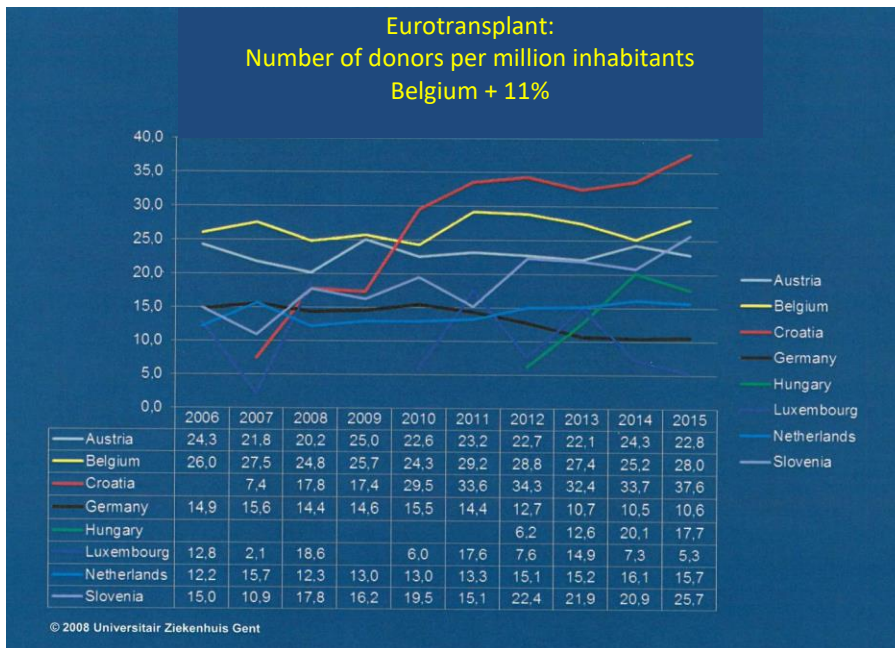


Figure 2: Evolution of the number of donors per million inhabitants in the European transplant countries (source: Luc Colombie, expert at the federal government Ministry of Public Health [FOD Volksgezondheid] and transplant coordinator at the University Hospital Gent)

In the future, the number of available organs in our country might increase even more thanks to “Donation after Circulatory Death” (DCD) donors (cf. Opinion no. 63 of 12 October 2015 from the Advisory Committee on Bioethics regarding the draft protocol “Donation after Circulatory Death (DCD) of the Belgian Transplantation Council and the Belgian Transplantation Society”, which can be consulted at www.health.belgium.be/bioeth).

In addition to these two sources, there is also living donation. In living donation, an organ is donated by a donor while he/she is still alive in order to make the recipient with a chronic illness, better. Living donation of kidneys and parts of the liver is occurring at this moment in Belgium.

In this context, it should be emphasised that the survival and success rate with living donation is just as good or even better than with a donation in which the donor is deceased ((35)¹ (kidney); (39) (liver)). Given the shortage of organs (cf. Figure 1 above), this method of donation certainly deserves to be examined with the necessary attention.

1 The number between brackets refers to the list with literature references at the end of this document.

LIVING DONOR TRANSPLANTS 2015

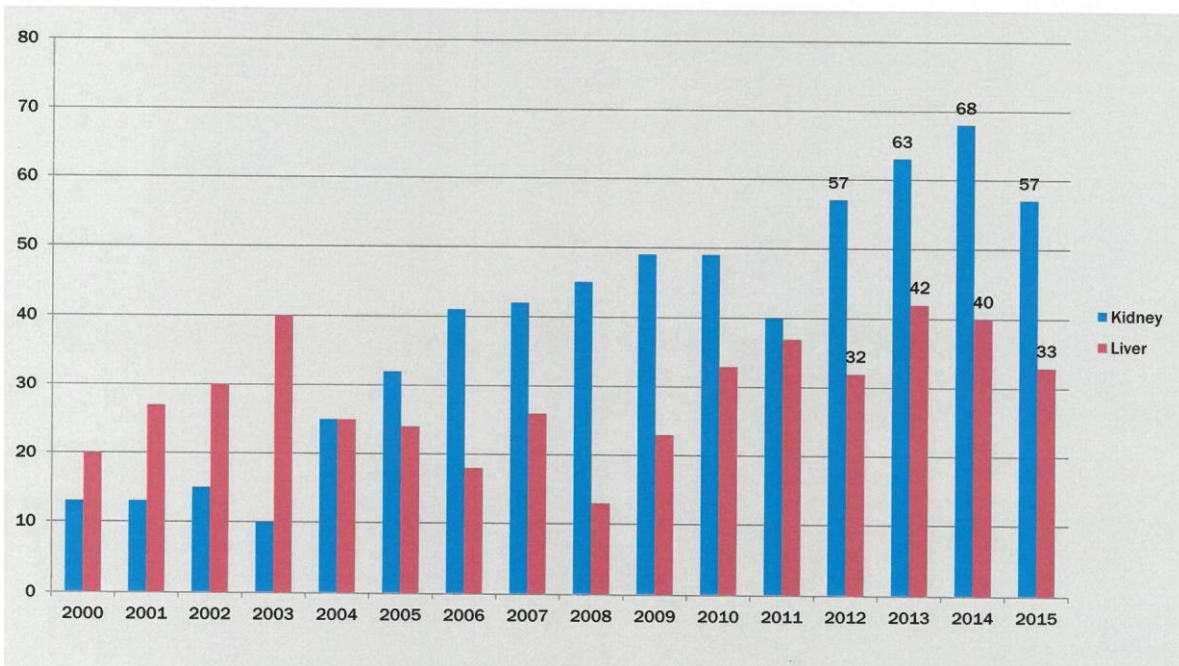


Figure 3: Evolution of the number of kidney and liver transplants coming from living donors in Belgium (source: Luc Colenbie, expert at the federal government Ministry of Public Health [FOD Volksgezondheid] and transplant coordinator at the University Hospital Gent).

2.3. Medical risks for living donors²

With respect to organ donation by living donors, three types of organs are mentioned in the literature: kidney, part of the liver, and part of the pancreas.

- The kidney is the most frequently donated organ. Studies on the consequences for a kidney donor involved in living donation report that this has no harmful effects on a healthy donor (22) (11). These positive results were recently confirmed by a recent literature review which makes a clear positive assessment.
- Regarding living donation of a liver fragment, the reports on the follow-up of the health of the donor are also positive, with a relatively limited mortality rate after the intervention (27) (9). The risk for the donor of a liver fragment is nonetheless much more pronounced than for a kidney donor.
- Finally, donation of a pancreas fragment by living donors is carried out in countries such as China, but, for obvious medical and ethical reasons, not in Belgium. After all, the postoperative consequences for the living donor, such as the development of *diabetes mellitus* (DM), are too serious (6).

² In this respect, see also chapter 2 of Opinion no. 50 of the Committee from 9 May 2011 on certain ethical aspects of the changes made by the Law of 25 February 2007 to the Law of 13 June 1986 on the removal and transplantation of organs, which can be consulted at www.health.belgium.be/bioeth.

2.4. Types of living donation

Three types of living donation are possible, each of which asks for a different approach (50).

The *first possibility* is the gift of an organ to a family member, partner or close friend. In this case, the doctor needs to take into account the risk for the donor and also be alert to any invisible pressure based on “compulsory” heroism. The fact of undergoing the intervention and any possible (long term) consequences are only acceptable if the donor will not be harmed. He/she must therefore be in a good state of health, and the *post hoc* risks must be weighed up against the increased chances of the recipient.

The *second possibility* is a donor who randomly makes his/her organ available in order to help people on the waiting list, without expressing a preference. This is a purely voluntary act of extreme altruism with respect to someone unknown to the donor (so-called undirected or Samaritan donation). In cases where the risk for the donor is minimal, it is difficult to be ethically opposed to this.

The *third possibility* is the donation of an organ by a donor to a specific recipient. This possibility is usually used by candidate recipients in extreme need. In such cases, social media and the press are increasingly being turned to. It is this third hypothesis which is discussed further under point 6. It goes without saying that the risk for the donor should also be minimal in this case.

2.5. In spite of all efforts, there remains a lack of organs. Every measure which leads to an expansion of the pool of organs and which respects the law and ethics deserves to be thoroughly researched.

3. Legal framework

In Belgium, the Law of 13 June 1986 on the removal and transplantation of organs stipulates that anyone who is registered in the population register or who has been registered in the foreigners register for more than 6 months, automatically becomes a donor after death (an *opting-out* system), except if it is stated that this person has expressed opposition to such donation (Art. 10).

If someone wishes to donate while he/she is still alive, the same Law stipulates the following:

1/ The donor must be at least 18 years old and must have given his/her informed consent (Art. 5).

2/ “If removal [of the organ] from a living person can have serious consequences for the donor, of if it concerns an organ which does not regenerate, it can only be carried out if the recipient is in mortal danger and an organ transplant (...) from a deceased person would not produce an equally satisfactory result.” (Art. 6; own translation)

3/ “If removal [of the organ] from a living person under normal circumstances has no serious consequences, and if it concerns organs which can regenerate and if it is intended for a transplantation for a sibling, it can be carried out with persons who have not yet reached the age of 18 years.” (Art. 7, §1; own translation) Such a removal “is only possible from someone who has

reached the age of 12 years, is able to express his/her own will and who has consented to the removal in advance.” (Art. 7, §2; own translation)

4/ “Consent to the removal of an organ from a living person must be given freely and knowingly. It can be revoked at any time.” (Art. 8, §1; own translation) “Consent must be given in writing in the presence of an adult witness. It must be dated and signed by the donor and the adult witness.” (Art. 8, §2; own translation)

5/ “Every removal [of an organ] from a living person must be the subject of a prior multidisciplinary consultation³ between physicians and other carers, with the exclusion of the physicians and carers who are treating the recipient or who will conduct the removal or the transplantation. The participants of the multidisciplinary consultation shall independently judge the potential donor, including his/her capacity to consent to a removal of organs (...).” (Art. 8bis; own translation)

6/ “The physician who intends to conduct the removal of an organ must ensure that the conditions of Articles 5 to 8 are met. He/she must inform the donor clearly and fully about the physical, psychological, familial and social consequences of the removal. He/she must ascertain that the donor has made his/her decision judiciously and with an undeniably altruistic goal.” (Art. 9; own translation)

7/ “All organs removed, assigned and transplanted in Belgium, should be able to be traced from donor to recipient and vice versa, in order to safeguard the health of donors and recipients. This traceability implies the development of a donor and recipient identification system, so that all donations and all associated organs and recipients can be identified (...).” (Art. 3quinquies; own translation)

8/ Finally, Article 4 of the same Law stipulates that:

“§1. Donations of organs by living or deceased donors are voluntary and unpaid. Neither the donor nor his/her next of kin can assert any right with respect to the recipient.

§ 2. The principle of unpaid donation does not prevent living donors from receiving compensation, as long as this is limited to covering the direct and indirect costs and the loss of income related to the donation.

The King defines the conditions under which this compensation may be granted, in order to avoid financial incentives or benefits for potential donors.

§ 3. Any measure highlighting the need for or availability of organs which aims at offering or obtaining financial or similar gains, is forbidden.

§ 4. The removal of organs must take place without profit.” (own translation)

4. Redefinition of the request for an opinion

³ In this context, see also the Committee's opinion per letter on the “Donor Advocate” from 19 March 2013, which can be consulted at www.health.belgium.be/bioeth, under “List of opinions”.

1/ Are attempts to solicit donors via social media justified if there is a lack of spontaneous donation?

2/ Can this donation be directed towards (meaning: intended for) someone who specifically addresses social media for this purpose?

3/ Are transplant centres obliged to receive all potential donors, to screen them and subsequently to choose the 'best' donor from the population presented?

4/ When answering the previous question: who will be responsible for the increased staff and resource costs related to the preliminary screening and supervision of a large number of candidate donors?

The members of the Committee note that the Dutch Transplant Foundation has taken several initiatives in this area, in cooperation with the various transplant centres. It is therefore appropriate to first present their experiences with and approach to this possibility of donation.⁴

5. The situation in the Netherlands

Faced with a similar question, the Dutch transplant centres decided to form a joint venture, whereby the Erasmus Medical Centre, Rotterdam, was designated as coordination centre.

After consulting the centres, there appeared to be no definitive objection to solicitation via social media in the Netherlands. The appeals for living organ donation via social media followed an upward trend: from 1 appeal in 2010 to 18 in 2015 (shared figures for Belgium and the Netherlands, cited by Mrs. Van de Wetering).

An observational study from the Erasmus Medical Centre, Rotterdam, found that solicitation via social media between January 2013 and July 2015 resulted in 30 potential donors for 6 recipients. After a first contact, 19 candidate donors proceeded to screening. After screening, a conversation with a psychologist and immunological testing, two candidate donors were left. One of these donated to the recipient who had solicited via the internet. The other donor choose, after consultation, for "undirected" donation, i.e. via a transplant list.

This study shows that solicitation via social media results in a very limited yield, as compared to the 129 living donations which happened in the same period, and certainly in view of the significant time investment, in order to end up with two candidate donors. The solicitation yield via social media can, on the basis of this study, be estimated at an increase in donation of maximum 2%.

In conclusion, it can be argued that if all potential donors register from the beginning, the workload for transplant centres will be too heavy. In order to deal with this, the involvement of the

⁴ The select committee who prepared this opinion heard in this regard Dr. Jacqueline van de Wetering, internist-nephrologist and medical coordinator of the department preparation for kidney transplant and donation, Department of Internal Medicine, section Nephrology and Transplantation of the Erasmus Medical Centre in Rotterdam.

general practitioner (GP) might be considered, as trusted doctor of the donor. The GP could carry out preliminary screening and provide potential donors with the necessary information.

It is important that candidate donors contact the transplant centre themselves. The centre itself will never be the first to contact a candidate donor who is brought forward by someone on the waiting list.

In summary, transplant doctors in the Netherlands accept solicitation via social media, but emphasise the importance of preliminary screening of candidate donors, if possible by the GP, and the importance of establishing nationwide criteria for living organ donation.⁵

6. Ethical considerations⁶

6.1. Public solicitation of organs from a living donor via social media

The transplant community is clearly much more reserved on this issue and therefore has a number of pertinent questions:

a/ The absence of a financial motive. There is a well-known ethical consensus in Europe that organs may not be traded (1) (cf. also Article 21 of the European Convention on Human Rights and Biomedicine, Council of Europe, 1997; for the situation in the United States, see (37)). However, this is a very difficult criterion to check when organ donation solicitation for the benefit of one specific person occurs via social media.

b/ Directed donation disregards the laboriously established rules of priority whereby organs are made available via internationally (Eurotransplant) or nationally (UNOS in the United States) recognised bodies. Conversely, it can be argued that whenever someone receives an organ, a place becomes free on the common waiting list.

c/ Directed donation can also be accompanied by ethically problematic selection criteria. What if the donor expresses a preference regarding race, skin colour, sexual preference or philosophical or political conviction? For example, can a labourer determine that a major capitalist not receive his organ, or a Muslim that his organ not go to a Christian or Jew, or vice versa?

Taking into account the above caveats, it is possible that the story of a patient in distress spread via social media encourages potential donors to make a 'good Samaritan' gift.

Finally, it is up to the regulatory authority to foresee a procedure to screen possible candidate donors in a meaningful way. The GP can play an important role here, as primary care doctor. In the final selection, not only the technical-medical side of the organ donation should be examined, the psychological history of the candidate donor should also be tested. Attention should be paid to the

⁵ See the "Guidelines for directed altruistic donation" from the Dutch Transplant Foundation, included as an addendum to this opinion.

⁶ See in this respect chapter C of opinion no. 11 from 20 December 1999 from the Committee on the removal of organs and tissue from living, healthy subjects with a view to transplant their organ or tissue, which can be consulted at www.health.belgium.be/bioeth.

impact of the living donation on the relationship between the donor and his/her family. For example, someone who donates an organ to a stranger or an acquaintance on social media, will no longer be able to do this for a family member who might need it later.

6.2. Literature study

Based on the following extensive analysis of the literature carried out by one of the Committee members, it can be deduced that the ethical discussion on this topic is conducted in a wide variety of ways. Various ethical models and approaches are used by different authors in order to ethically clarify the issue.

The members of the Committee are of the opinion that reviewing the arguments listed for and against the public solicitation of organ donation from living donors is important in order to arrive at an informed and balanced opinion.

6.2.1. Pragmatic arguments

6.2.1.1. Pro

Given the current extreme shortage of organs and the average waiting time for an organ, it is inevitable that ways will be sought to find an organ donor. Outright prohibition is thus not a feasible option (49) (50) (2) (16) (17) (41) (56) (10) (55) (18).

The internet simply cannot be regulated. We cannot control how the internet is used or how relations between donors and recipients are built up online (12) (33).

This method is (currently) not illegal, so long as no payment is involved. This means that we lack the juridical means to intervene (44) (16) (13) (40).

It is possible for transplant centres to conduct a psychological screening in each case of both the donor and the recipient, in order to minimise or eliminate possible ethical problems such as payment, exploitation, coercion and uninformed consent (44) (28) (17) (12) (10) (18).

The possibility of helping concrete people is more attractive than the option of donating to someone anonymously. Public solicitation has the potential, therefore, to attract more organ donors than general campaigns; this is relevant given the existing organ shortage (44) (16) (2) (5) (57).

6.2.1.2. Contra

Since the internet is unregulated, it lends itself very well to abuse and exploitation of donors and recipients. Websites such as "matchingdonors.com" are only 'regulated' by the members themselves (33) (5) (10) (57) (58) (4).

It is impossible to check whether payment occurs, above or under the table. Even good screenings do not exclude this possibility. Given the grave risk of payment, many authors find that organ donation between strangers should not be allowed or should only rarely be allowed (33) (56) (20) (51) (5).

Other authors argue that public solicitation cannot be the solution to the shortage of kidney donations (13). There already exist non-commercial channels for those who wish to make a truly generous and altruistic living donation (54).

6.2.2. Utilitarian arguments

6.2.2.1. Pro

Allowing organ donors to solicit online or via advertising can increase the number of available organs, including for the classical circuit, because specific campaigns also publicly emphasise the general importance of donation with, as a result, more people registered as donors (2) (57) (15) (18).

Expecting 'pure' altruism from living donors would impose such a strict requirement that only a very limited number of people would be able to become a living donor. This means that organs that would have been available, will be 'wasted' (34) (26).

A policy that forbids altruistic donation between strangers will cause discontent in the general public, many of whom find that it should be possible (47).

If someone on a waiting list manages to solicit an organ online or via advertising, this can be considered to be to the advantage of everyone on the waiting list after that patient, given that they will all move up one place (55) (40).

6.2.2.2. Contra

Allowing people to solicit living donors online or via advertising can hurt the general trust in the normal allocation system (3) (43) (10) (18).

Public solicitation can result in organs becoming a 'commodity' (or that this view of organs is strengthened) (50) (10) (57) (34) (52) (18).

There is a risk that allowing public solicitation will lower the standards for donation in the long-term (e.g. regarding efficiency, autonomy, safety etc.) (49) (3).

Some patients may be reluctant to speak to their family and prefer public solicitation. This could lead to a decrease in the number of available organs (20).

It is characteristic of social media that a faulty use of the privacy settings can lead to the spread and disclosure of delicate medical information (5).

6.2.3. Arguments based on consistency

6.2.3.1. Pro

Directed living organ donation is already allowed between certain people, such as life partners, family, close friends, sometimes even acquaintances, etc. There is no obvious and consistent line that can be drawn for why donation to strangers would not be allowed (28) (25)(46) (29) (52).

'Pure' altruism is expected in the case of living donation between strangers. But even with donation between acquaintances there is no 'perfect' or 'pure' altruism. This means that it is inconsistent to request this of living organ donation between strangers (28).

Many authors argue that internet solicitation can facilitate discrimination. In reality, these authors are specifically opposed to favouring *some* people, e.g. rich or white (Caucasian) people. We do not

mind if children or minorities are favoured. Criticism based on discrimination is thus not consistently applied (48).

6.2.3.2. Contra

People who solicit online or via advertising have a sad tale, but so do all patients in need of an organ. Therefore, if we attach importance to people's stories, we should also do this for people on the waiting list whose stories are unknown (20) (58).

6.2.4. Autonomy arguments

6.2.4.1. Pro

Living donors should be free to choose to whom they will donate an organ (20) (15) (40) (50) (53). It gives patients the opportunity to actively and autonomously undertake something against a 'failing' system. The only alternative is passively waiting for an organ that will arrive too late or not at all (41).

In the absence of an emotional bond between donor and recipient, the donor can decide even more autonomously and voluntarily. If there is a strong emotional bond, emotional or social pressure may play more of a role (29).

6.2.4.2. Contra

Even if, for a living donor, choosing to whom he/she will give an organ is an exercise in autonomy, the ethical principles of justice and efficiency weigh more strongly (20) (50).

Advertisements or profiles on websites are often very personal and are written only for the purpose of persuading people. It often comes close to emotional blackmail. We should therefore take direct or subtle coercion into account, by which people are unable to make a sufficiently informed or autonomous choice (28) (16) (56) (38) (31) (52).

Allowing donors to choose their recipients, or allowing recipients to choose their donors, allows them the possibility of choosing on the basis of discriminatory grounds (e.g. someone who only wishes to donate to a white person or someone of the same religion) (50) (20) (18).

Contrary to what is sometimes claimed, the donation of an organ is not a purely autonomous or individual decision. Donation demands a social structure and institutions (e.g. a transplant community, hospitals, doctors, nurses, etc.). Therefore, as a society we have an interest in the fair and just distribution of organs (50) (28) (16) (10) (50) (18).

6.2.5. Beneficence arguments

6.2.5.1. Pro

Donors 'shopping' between different recipients on a website such as "Matchingdonors.com" can be an expression of altruism, e.g. by choosing a recipient who him/herself also supports many good causes. In this way, good is done for people who in turn can do good for others (28).

The donation of an organ to a stranger can be a very meaningful act for the donor. The importance of this should not be minimalised but, on the contrary, applauded (31).

By refusing some living organ transplants, transplant centres or the UNOS (US) fail in their 'duty to care' or their aim not to 'waste' organs. After all, people could have been helped with those organs (57) (47).

If people can be helped with an organ, it does not necessarily matter whether the organ is given due to a bad motive (e.g. someone who only wants to donate to white people) (52).

6.2.5.2. Contra

People who are not suitable for organ donation could also solicit and receive an organ in this way (e.g. people with certain diseases – although in the Belgian regulated medical setting this seems less probable). The organ which could have been used to help someone, is thus 'wasted' (20).

The intention behind allowing the solicitation of organs, was to give people the chance to do good for someone else, not to facilitate exploitation and discrimination. However, stories and anecdotes suggest that this is (or has become) the case (58).

6.2.6. Non-maleficence arguments

6.2.6.1. Pro

No one is harmed by online solicitation. The donor who is found online or via advertising, would not otherwise donate his/her organ. The standard allocation system is thus not deprived of an organ (28) (25) (2) (40) (56) (10) (55) (41) (3).

If there is no payment (monetary or in kind), there is no great danger of exploitation of donor or recipient (2).

6.2.6.2. Contra

Public solicitation can harm donors and recipients if they fall victim to exploitation (49) (41) (31) (57) (55) (59).

Doctors and transplant centres also have a duty towards donors. Living donation may well result in physical or psychological injury for the donor (41) (10) (4) (23).

There are indications that some living donors solicited would also have anonymously donated to the normal circuit. This means that the system is indeed deprived of an organ, harming those on the waiting list (56) (10) (58).

Donation is 'big business' for transplant centres, who have an interest in conducting many transplants. In that light, it is not certain whether the interests of the living donor will always be sufficiently protected (52).

6.2.7. Justice arguments

6.2.7.1. Pro

The existing allocation system, such as for example the one organised by the UNOS (US), contrary to what is sometimes claimed, is not a completely fair or just system. It is therefore not the case that public solicitation does injustice or forms a threat to a perfect system (3) (7) (30) (47).

Allowing living organ donation within a family or between acquaintances, but not between strangers, favours those who have the good fortune to have a family member, friend or acquaintance who wishes to donate. This is unfair towards those who have the misfortune to have no one close to them who wishes to donate. They cannot do anything about this inequality, and advertisements and websites reduce such inequalities (2) (56) (5) (57) (18).

6.2.7.2. Contra

Organs must be distributed in an independent, efficient, fair and just manner. Solicitation of living donors via the internet or advertisements would distribute organs according to unfair, unjust and morally irrelevant criteria such as: wealth, access to the internet, the extent to which someone's story is appealing, emotional criteria etc. (49) (44) (50) (33) (16) (3) (41) (56) (20) (21) (43) (31) (10) (57) (58) (7) (59) (4) (54) (52) (18) (28).

Some authors claim that the UNOS system is not fair. In contrast to the internet, it is a controlled system that cannot be reviewed and improved. The fact that it is not perfect, is no argument to circumvent it (20).

6.3. Ethical discussion

As has been extensively documented in the above review of the literature, many arguments can be cited both for and against solicitation of organ donors via social media. The use of social media may, at first glance, increase the pool of organ donors. Besides the pragmatic, utilitarian and beneficence arguments, the autonomy of the recipient should also be taken into account. The primary motivation of the person waiting for an organ is to acquire this organ through all ethical and legal methods possible. However, this does not mean that one may go so far as to acquire an organ through trade, as unfortunately happens in certain countries. This would be a step too far as it violates one of the general principles of deontological ethics, namely that a person may not be used simply as a means to an end, but is always an end in themselves. This condition is also mentioned in the extensive literature study above, cf. the pragmatic arguments contra and the utilitarian arguments contra.

Conversely, ethical objections can also be raised against the possibility of solicitation via social media. These have been comprehensively cited in the "contra" arguments in the review of the literature. The justice criterion is here the most striking set of arguments. It is not possible for some people to make use of social media, given that internet literacy in our society is still not yet 100% as has been widely shown. Another important factor is the possibility that the 'sales argument' will hereby creep into our world. After all, the unbridled use of social media could mean that, once the discussion is over, the population no longer agrees with the opting out principle as embedded in our national legislation, resulting in ultimately a decrease, not an increase, in the number of available organs.

In spite of all efforts, there is still a shortage of organs to meet medical needs. Every year patients die whilst on the transplant waiting list. Every measure which leads to an expansion of the organ pool and which respects the law and ethics deserves therefore to be supported.

Living donation as a sign of empathy for one's fellow human beings in need is certainly very valuable when it takes place with due observance of a number of conditions (e.g. minimum risk for the donor, revocable informed consent, prior multidisciplinary consultation). Such a living donation, usually of a kidney or a part of the liver (marrow and blood donation and tissue donation in general have not been considered in this opinion), is usually done for a family member, partner or friend.

In the classical situation of living donation for a family member or close friend, basically no one objects to this directed donation. The question raised in this opinion is whether for example a facebook relationship is sufficiently close to justify directed donation. Much will depend on what is understood by such a social media relationship: is this comparable to a personal relationship? Are the donor and the recipient encouraged to meet each other? Do they get to know each other, etc... or is it sufficient just to declare oneself a candidate donor?

Some members point to the fact that a undirected donation to the pool (the so-called Samaritan donation) is not a problem, unless there is an underlying psychopathology. The wish to donate an organ to a stranger whilst alive is according to these members so extreme that it in some cases can be reason to doubt the psychological health of the candidate donor. This is the reason that a psychological evaluation of the candidate donor is necessary. It should also be checked in cases of directed donation whether there is any misunderstood 'compulsory heroism' in the mind of the donor.

POSITION 1

These members believe that public solicitation of living organ donors, including via social media, should be prohibited and that transplant centres should not accept proposals of directed organ donation to recipients with no close relationship to the donor (family members, partner, close friend), especially considering that the risk of payment is too high in this instance.

They believe that it is not because social media has such a large scope and range, that everything spread via social media should be accepted unthinkingly. This would otherwise mean that organ trafficking should also not be prohibited simply because it now occurs. In their view, certain activities can indeed be banned. Even if it is impossible to enforce the prohibition in practice, it can be appropriate to keep the prohibition as a signal to society.

These members draw attention to the increased risk of payment/commercialisation. The internet lends itself perfectly to the emotional blackmail, abuse and exploitation of donors and recipients. Websites which specialise in this area are only 'regulated' by the operators or the members themselves. It is impossible to verify whether payment occurs, directly or indirectly. Even good screenings cannot exclude this possibility.

The question is what motivates people who wish to donate an organ while they are still alive? They are probably moved by the personal story of the one looking for an organ. However, a candidate donor does not have to follow that path. He/she can easily make contact with a transplant centre and make a donation to the organ pool of Eurotransplant.

POSITION 2

These members believe that transplant centres should refuse an organ offered to a recipient with whom the donor has no close relationship (family member, partner, close friend) but has met online or via social media (i.e. so-called directed altruistic living donation). In other words, they believe that the only acceptable altruistic donation is undirected (for the pool of Eurotransplant),

especially considering that this is the only way to allocate organs in a medically responsible, independent and just way.

They believe that directed donation goes against the principle of justice, given that the donor donates to someone of his/her choice, while there are for example other people on the waiting list who need an organ more urgently. If on the other hand a donation is made to the pool, one can be certain that medical criteria will be respected when the organ is assigned to a recipient.

To accept directed donation would be according to these members unfair towards the altruistic donor who donates to the pool, meaning to an anonymous recipient on the waiting list.

POSITION 3

These members believe that it is pointless to legally prohibit something if it is impossible to enforce this prohibition in practice. They observe a fact, a reality, that now exists, and society has to decide how it is going to deal with it.

Candidate *recipients* make use of social media to support their search for an organ. Why should they be prohibited from making known via social media that they need an organ? Not everyone has a large family or an extended social network...

At the present time (2017), the Belgian legal and regulatory arsenal does not dispose of the means to restrict someone's constitutional freedom to publicly communicate their search for an organ, and the chance that the (constitutional) legislator will restrict this freedom is, according to these members, a utopian dream.

It is legitimate that a candidate recipient in need attempts to create an emotional bond with candidate donors. It is not the case that there are no problems if there is a sufficient personal bond and that if the relationship is relatively more distant that there would automatically be abuse such as hidden payment: it is perfectly possible that a donor found via the internet is altruistic, and family and friendship ties can be instrumentalised. One must always be aware of the risk of trading (the law speaks of 'payment') and instrumentalisation, regardless of the relationship between candidate donor and recipient. In itself, directed donation as a result of public solicitation is therefore not an argument to refuse an organ.

The members who believe that it is impossible to prohibit a search for candidate donors via the internet, emphasise that it is up to the professionals of the transplant centres to proceed with the procedure in an ethical way. The recommendations of the Committee are also addressed to them. Needless to say, the candidate donor must meet all the conditions in order to be accepted by a transplant centre.

These members draw attention to the persistent glaring shortage of organs and the average waiting time for an organ. They believe that allowing the solicitation of organ donors online or via advertising would increase the number of available organs, also for the organ pool, because specific campaigns also publicly emphasise the general importance of donation, and can thereby encourage more people to register themselves as donors.

7. Conclusions and recommendations

All members agree that all efforts should be made to increase the number of available organs.

The Committee wishes to recall before everything else the disinterested character of organ donation. We must continue to combat any payment for obtaining an organ (except as compensation for the costs incurred), both to protect the people involved and out of respect for international ethical rules and to comply with the Belgian legislation in this matter.

Some members believe that the public solicitation of living organ donors, including via social media, should be prohibited and that transplant centres should not accept proposals of directed organ donation to recipients with no close relationship to the donor (family members, partner, close friend), especially considering that the risk of payment is too high in this instance.

Other members believe that the only acceptable altruistic donation is undirected (for the pool of Eurotransplant), especially considering that this is the only way to allocate organs in a medically responsible, independent and just way.

Still other members believe that, although reservations may be expressed surrounding the solicitation of living donors via social media, it cannot be prevented given the wide spread of social media in the 21st century. They are in favour of accepting public solicitation of living organ donation, including via social media, provided the necessary support and framework is given. They refer in this respect to the Dutch transplant centres who allow this type of solicitation, and emphasise the importance of an initial filtering of candidate donors and of the establishment of nationwide criteria for living organ donation.

Taking all of this into account, these members came to the “weighted” conclusion that a directed donation must not be refused, so long as no discrimination criteria such as skin colour, sexual orientation etc are at stake.

These members make the following *recommendations*:

1. Not only the medical suitability but also the psychological history of the candidate donor should be tested. Attention should be given, in this respect, to the impact of living donation on familial relationships.
2. Transplant centres should not actively recruit altruistic donors, either for undirected or directed donation. Those who wish to make an altruistic donation have to go to a transplant centre themselves, without the intervention of external intermediaries.
3. It is advisable that the competent authorities develop criteria in order to organise the preselection (if possible via the general practitioner) of donors, found online, on a larger scale than separate transplant centres. Otherwise, a great deal of energy and time will have to be invested in very costly and unproductive procedures, which could result in less time and resources for effective selection in the traditional pool.

4. Online solicitation should be conducted as far as possible using a standard application form (identity of the candidate recipient, the motivation of the candidate donor, the opinion of his/her doctor, confirmation that he/she has received all the necessary information regarding the risks, ...)

5. After potential donors have been found, the transplant doctor should always first advise undirected donation. However, if the donor then explicitly chooses for personal (directed) donation, this should not be refused. In any case, the choice for recipients on the basis of discriminatory criteria (no organs for immigrants, homosexuals, people of a different skin colour, etc) is unacceptable.

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The working documents of the select committee 2015-2bis – request for opinion, personal contributions of the members, minutes of the meetings, documents consulted – are stored as annexes 2012-5bis at the Committee's Documentation Centre, where they may be consulted and copied.

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This opinion is available on the website www.health.belgium.be/bioeth, under the “Opinions” section.

ADDENDUM



NEDERLANDSE **TRANSPLANTATIE** VERENIGING

Guidelines for directed altruistic donation (solicited specified donation)

(Translation from the Dutch original)

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Source document:

Guidelines for directed altruistic donation (June 2014) from The British Transplant Society.

Directed altruistic donation is a relatively new (and so far rare) form of living donation. Due to the increased attention for this form of donation, it is important for the Dutch transplant centres to reach an agreement on how to handle this. This guideline is in part based on the “Guidelines for directed altruistic donation” (June 2014) of The British Transplant Society.

Definition

Directed altruistic donation

One can speak of directed altruistic donation if no relationship between the donor and the recipient existed before the need for a donor organ arose for the recipient. The potential donor and the recipient only came into contact with each other after attention was drawn to the need of the patient for a donor organ through social networks, reports on local or national media or websites specifically designed for this purpose.

Basic assumptions and points of departure

The transplant centres take a neutral position towards altruistic donation and do not take part in the active recruitment of donors. The purpose of these guidelines is to develop a standard approach for this form of individual matching between donor and recipient. This method aims at an efficient use of the abilities of the Dutch centres and the prevention of possible coercion or commercial activities in organ transplantations.

To ensure equal access for all potential recipients to the available donor organs, and to achieve an optimal result for each donation, undirected altruistic donation is to be preferred. Directed altruistic donors should be informed of the possibility of undirected altruistic donation and participation in crossover programmes if donation for the intended recipient turns out not to be possible.

Directed altruistic donation is only intended for donation for a specific person. It is not possible to donate to a certain group on the waiting list (e.g. on the basis of age, gender or ethnicity). This is in line with the allocation of organs on the post-mortem waiting list.

Recommendations

The following recommendations form an initial impulse for guidelines that will create workable principles for handling initiatives that bring together potential living donors and recipients in an alternative way, e.g. via social media. These guidelines complement the policy used by transplantation centres for donation by living donors.

1. All potential donors considering directed altruistic donation and their intended recipients should be informed over all aspects of living donation (the different forms of living donation, the procedure, the risks associated with living donation, etc.) so that they can make a well-informed choice. Generic information is available at www.donatiebijleven.nl and in the generic brochure of the Kidney Foundation and the Dutch Kidney Patients Association about living donation.

2. The potential directed altruistic donor should turn to a transplant centre in accordance with the “altruistic donation approach”. No external intermediary should play a role in this process.

3. Potential donors for directed altruistic donation or matches between donors and recipients arising from paid intervention will not be considered. This can come to light at the start of or during the donation process and can result in the exclusion of the potential donor, regardless of the phase of the donation process at that point.

4. The transplant centre screens all potential directed altruistic donors who have made contact with the recipient. The transplant centres play no role in bringing potential donors and recipients into contact with each other.

5. For patients for whom a transplant is difficult, the screening of multiple potential donors can increase the chance of a match. The registration of multiple potential donors for a single recipient forms a logistic and emotional challenge for the associated recipients, donors and healthcare providers with respect to the workload, costs and the high dropout rate of this group. This in turn raises ethical questions. If multiple potential donors register themselves to donate to a single recipient, the transplant centre will only be able to fully screen one or a limited number of potential donors. However, it is possible, in the case of recipients with a high immune response, to carry out a short pre-screening of multiple potential donors simultaneously, with subsequent cross testing.

6. In order to increase the efficiency of the screening procedure, the transplant centre can ask potential donors to have their own general practitioner conduct a part of the medical screening. We advise each centre to introduce a procedure for the screening of multiple donors on the basis of appendix 1 and to publish this on their website.

7. If the recipient has a high level of immune response, it can occur that the chance that the tissue typing of potential donors and the recipient match is so small, that transplant centres refuse to screen potential donors. For these donors, the Acceptable Mismatch Programme of Eurotransplant or possibly a desensibilisation treatment provide alternative options to make a transplant possible. These recipients should also be discouraged from resorting to a social media campaign, with a clear explanation of the reasons why.

8. If possible, potential donors who are refused for reasons other than medical and/or psychological, should be made aware of the possibility of undirected altruistic donation.

9. Donors who indicate that they wish to opt for undirected altruistic donation in the case of incompatibility with the intended recipient, can already be included in a complete information and assessment route at an early phase.

10. The transplant centres decide on which donors will be screened and which donor is best suited to the recipient. This occurs on the basis of medical and social-psychological grounds.
