

USING SOCIAL MEDIA TO FIND A LIVING KIDNEY DONOR: ETHICAL CONSIDERATIONS

Who we are and what our research was about.

We are Professor Heather Draper and Dr Greg Moorlock, from Warwick Medical School, University of Warwick. We were part of a team of researchers looking at how trust and empathy operate online when people's lives or well-being are at risk (see <http://www.space4sharingstudy.org>). We looked at the ethical aspects of using social media (such as Facebook, Twitter, or dedicated websites) to advertise for living kidney donors. This means that we are interested in the 'rights and wrongs' of this way of finding kidney donors.

Not everyone thinks that living kidney donation is a good thing because of the potential medical risks to the donor. It is, however, a relatively common procedure and transplants from living donors are generally considered the best treatment for renal failure. NHS Blood and Transplant would like to increase the number of people who receive kidneys from living donors. In this information sheet, we will not address the rights and wrong of living donation in general but will outline some of the ethical issues specifically associated with the use of social media to find living donors.

What are the benefits of turning to social media?

Social media can help people to feel that they are taking control and doing all they can to improve their situation.

Some people face a long wait for a kidney transplant. During this time, they undergo regular dialysis with all the restrictions on daily living that this entails. Other people are not yet on dialysis, but will soon need it. A transplant can prevent the need for dialysis.

Outcomes for recipients of kidneys from living donors are generally better than outcomes using deceased donor kidneys. Some people have a family member or friend who is willing and able to donate either directly to them, or as part of paired-donation. Other people do not have this option. Rather than waiting on dialysis, or to avoid dialysis altogether, some people use social media to try to find a living donor more quickly. Social media campaigns have the potential to generate a lot of interest, and are one way for patients or their families to try to actively improve their situation. Since their health, well-being and sometimes life is at risk whilst they are waiting for a transplant, it could be argued that people have the right to do all they can (within the law) to improve their situation.

Social media may attract people who would not otherwise have considered being a living donor.

Sometimes people who are not friends or family of someone with renal failure decide that they would like to be a living donor for an anonymous stranger. This is called non-directed altruistic donation. These donors donate directly into the 'pool' of patients waiting for a kidney. The kidney they donate is allocated in the same way as deceased donor kidneys. More people might be willing to be non-directed kidney donors if they realised this was a possibility. Equally, people who have been thinking about being a donor but haven't yet

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acted on this might be prompted to action by a social media campaign. There may also be people who have never previously considered donating, but are so affected by a specific person's social media campaign that they want to help that person by donating to them. In this respect, social media and its ability to help tell the stories of patients needing transplants, may be increasing empathy for those in need of a kidney transplant. It may be argued that all legal means of increasing the number of living donors are a good thing because this reduces the number of people on the waiting list and thereby reduces the waiting time.

Some potential living donors may prefer to choose who will benefit from their gift

Non-directed kidney donors usually donate anonymously – their identity is not revealed to the recipient. But some people who are thinking about being a living donor may prefer to know who the recipient is going to be. Giving a kidney is a big decision. Some people argue that potential donors should, if they wish, be allowed to choose to whom they make their donation. This is after all the case when family and friends offer to be a donor. Organ donation is often described as 'the gift of life', which strongly suggests that what is given is a gift. People often decide when and how to gift things. For example, people have favourite charities or prefer to give goods or services directly to people who they know are need of them. If potential recipients share their need for a kidney using social media, potential donors can then decide based on the information provided, and perhaps after getting to know the potential recipient a little better, whether or not they are willing to be their donor. In this respect, social media may be likened to increasing a recipient's friendship circle. The donor stops being a stranger. Sharing information, and getting to know someone online may be a way of building up trust between the donor and the recipient.

What are the risks of potential recipients using social media to find a living donor?

Using social media may expose a recipient to exploitation.

When family and friends give a kidney they can be seen as getting some direct benefit from doing so. It is distressing to experience the suffering of a loved one, or know that their life is threatened. Removing this suffering or threat can remove this distress. This possibility for mutual benefit is sometimes thought to outweigh the immediate medical risks to the donor. The possibility for mutual benefit is unclear in non-directed living donation. Sometimes people wonder 'what's in it for the donor?' and this makes them suspicious of a donor's motives and even psychological health. This suspicion may itself be uncharitable, however, as some people just do want to help others without receiving anything in return.

Anonymity also offers some protection to the recipients of charity. Gratitude for spontaneous kindness is often appropriate. It would, though, seem wrong for donors to insist that this gratitude is exhibited in particular ways. For example, some people are concerned that donors attracted by social media advertising will expect money or other goods for their kidney. Commercial trade in organs is illegal in most countries, including the UK, but not all trade is commercial. If something is given, the gift should not have strings attached to it. Some people are concerned that donors who respond to adverts may expect something else in return for their donation: perhaps friendship, love or other reciprocated

giving. This may not be clear from the start. Without the protection of anonymity, recipients may become oppressed by the future demands or expectations of donors. This is, of course, a possibility in the case of living donation from family and friends. It is thought less likely to happen, however, because those involved are better known to each other, and also because the donor already gains from the gift as described above.

A potential recipient may also be encouraged to over-share personal information with a potential donor. The sharing of information may be mutually beneficial, but the potential recipient has no way of determining in advance whether the potential donor is sincere, or just playing a game. Likewise, if the potential donor is sincere but trying to decide between potential recipients, the person who is not chosen may feel both rejected and drained of personal information that they would not otherwise have been willing to share with a stranger.

Using social media may expose potential donors to exploitation.

Anonymity can protect living donors. First, the potential donor may feel that it is easier to change his or her mind. It is often harder to withdraw when the person potentially in receipt of the gift is known to you. This is a known risk of donation from family and friends. Second, potential donors drawn to social media campaigns have no way of knowing whether the recipient is being completely honest about themselves. As we have already said, some donors may be attracted by the idea of being able to choose the person to whom they are donating. But this assumes that the characteristics they prefer – whatever these are – are truthfully represented by the recipient. These may well have to be accepted at face value. Medical confidentiality may prohibit those counselling a potential donor for consent from rectifying misinformation about the recipient.

Patient initiatives to seek their own donor may result in an unfair allocation of organs and transplant-related resources.

Kidneys obtained by non-directed living donation are allocated according to policies that have been designed to be both effective and fair. This system of allocation is bypassed when a recipient introduces a potential donor – whether this is someone previously known to them or a new acquaintance. Some people will be better at organising social media campaigns than others, and/or may be more attractive to potential donors than others, and therefore be more likely to find a willing donor. Although it arises as a result of their own efforts, those in less urgent need may get transplants ahead of those in greater need.

There is also a danger that the patients most likely to resort to social media to find a donor are those whose medical circumstances will make it difficult for them to find a match. Tissue-typing and donor assessment is expensive. A successful social media campaign may result in many willing potential donors agreeing to be tested, but without a possible donor being identified. Some of these individuals may be willing to consider donating to the general waiting list (as non-directed living donors do). Experience to date, however, suggests that this is unlikely to be the case. From the point of view of transplant services, this means that patients' social media campaigns may prove very costly, without these costs being off-set by patient benefit or savings to services elsewhere. So, whilst it is

understandable that patients may want to do all they can to maximise the chances of finding a donor, in doing so they may be using resources that may be better spent on other patients. This may undermine trust in the fairness of NHS services. Since the NHS has an obligation to spend its resources effectively and fairly it may be reasonable to refuse to fund multiple tissue-typing tests when it is unlikely that those being tested will go on to become living donors.

Should I use social media to help find a donor?

It is legal to use social media to find a living donor in the United Kingdom, but we would advise you to carefully weigh up the potential risks and benefits to yourselves, potential donors and the transplantation system more generally, before making a decision on whether to do so.

Key messages

- Given the risks to life and well-being of waiting for a transplant, it may be unreasonable to take measures to prevent patients from using social media to attract a living donor.
- The potential risks include:
 - queue jumping: disruption of the allocation system, which may erode trust;
 - greater but less effective demands on limited resources for tissue typing;
 - loss of anonymity for donor and recipient
 - turning down offers of organs from deceased donors, in favour of a living donation that does not materialise
 - may invest a lot of time and emotional labour, yet still not find a willing donor
- The potential benefits include:
 - shorter waiting time (or pre-emptive transplant) for the person who is able to find a donor;
 - less competition for kidneys for those remaining on the waiting list;
 - raising awareness.

All of these points apply whenever and however patients actively seek a living donor. They are not unique to the use of social media. Social media is, however, easier to harness and has a greater potential to reach a wider audience than conventional media.