HARNESSING OF SOCIAL MEDIA IN PURSUIT OF LIVE KIDNEY DONORS: KEY MESSAGES FOR TRANSPLANT PROFESSIONALS

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'A Shared Space and a Space for Sharing' explored how trust and empathy operate in online spaces when people's lives or well-being are at risk from suicide, serious physical health risks (cancer, renal disease), disasters and recreational drug use (see http://www.space4sharingstudy.org/)

Here we outline the key messages for transplant practitioners/organisations, incorporating the common threads that emerged from the project as a whole. We have also produced information, aimed at patients, which summarises the key ethical considerations, to be read alongside this sheet.

Public Solicitation is a Peer-to-peer Solution to a Societal Problem

- Online spaces are a venue where peer-to-peer solutions can be found for a range of problems that users do not think are wholly or satisfactorily addressed by governments, institutions, or other authorities. In some instances, the usual authorities may be completely failing to meet need. In others, users may have needs that go beyond those the authorities could reasonably be expected to address. Using social media to attract a kidney donor may be regarded by patients (or their family / friends) as a completely ordinary response – not so dissimilar to e.g. crowd funding for a good cause. One of the perceived advantages of seeking peer-to-peer solutions online is that it is a mechanism for individuals to (re)gain control of their situation.

- Patients (re)gaining some sense of control may result in a corresponding loss of control for authorities/institutions: using social media to find a donor disrupts the normal system for allocating kidneys that are not donated by family and friends. It may, therefore, be perceived as queue jumping. This perception itself may be inconsistent with encouraging a patients' family/friends to be living donors, since in both cases kidneys may be donated *only* because they are destined to help a specific recipient.
- The ultimate aim of a transplantation system should be to meet the needs of those requiring transplants. Patients working for themselves to find donors may allow for needs to be met more fully.

- Potential problems created for transplant services could be addressed by working *with* patients who wish to use social media sites such as Facebook, as opposed to discouraging or resisting their use. This would itself need careful management, but

could permit for maximisation of benefits while mitigating risks.

- Bearing in mind NHSBT's targets for living donation (26 living donors per million population by 2020), we recommend that NHS Blood and Transplant should work with willing patients near to the top of the transplant list to harness social media to attract a donor. This could take advantage of the potential reach and impact of social media, while ensuring that wait-listed patients still receive transplants in roughly the order they would have done if living donor kidneys were donated 'unconditionally'.

Supporting Public Solicitation by Shaping Online Spaces and Interactions

- By working with potential recipients, the information shared through social media to solicit donations may be tempered to maximise the chances of potentially compatible donors volunteering. Potential recipients may also be encouraged to simultaneously raise money for tissue testing multiple donors, or to present the case for donation to the general pool or to start a paired/pooled donation if not a 'match' for the advertising recipient.

- Whilst many users seek to preserve the internet as an unregulated space – which includes its own risks and benefits - it is also the case that many online spaces are moderated. Moderation may be formal - a webmaster - or informal, achieved using norms that are negotiated and maintained by users of a given space. For example, some formally moderated sites insist on the use of pseudonyms, and anything that may enable others to contact a person outside of a specific online space may be removed from posts. Users of informally moderated sites may ignore or respond sharply to posts in breach of site norms.

- Transplantation in the UK often proceeds on the basis of anonymous donation and online spaces readily accommodate the use of anonymity, pseudonymity and relationships that only exist online. However, the reason that potential recipients take to social media is to obtain a transplant in the off-line world. Anonymity/pseudonymity can therefore only be maintained for a limited period. Concerns have been raised that peer-to-peer organised kidney donation arrangements therefore have the potential to be exploitative or even to involve illegal trade.

- By embracing social media and working with potential recipients and donors it may be possible for NHSBT / local transplant communities to mitigate risks by running sites on which recipients and donors can 'meet', but which are moderated to prevent e.g. commercial activities. If such sites are being considered, the combined findings of our project suggest:

    - Moderated sites may be acceptable to at least some users provided that they still enable needs to be met.

- People who do not wish for their communications to be moderated/monitored tend to stop using sites but may also find:
  - Other ways to communicate with selected members of the site;
  - Other spaces which are less or differently moderated.
- Practitioners could influence the norms of the online space to minimise the sharing of dishonest or misleading personal information.
- Making the recipient a 'known' rather than 'faceless' victim may promote greater empathy for his/her situation.
- The potential donor and recipient will need to establish and consolidate a trusting relationship for the transplantation to proceed (see patient information sheet)
- People may 'lurk' on the fringes of sites for periods of time, perhaps testing the water before fully engaging – this could be regarded as initial trust-building. Thus, the 'tone' of a site and how interactions on it, may encourage or deter 'lurkers' from engaging. This tone is something that practitioners might also influence using moderation.
- Building trust between potential recipient and donor may mean sharing increasingly personal information. This could, however, lead to over-sharing and non-commercial forms of exploitation for both donor and recipient.
- It may be easier for the recipient to be inclined to be trusting because they are already in a position of risk, and they would carry the personal cost of not receiving the potential benefits that are contingent on a level of trust. The NHS as an organisation and those who work in it are habituated to working with scarce resources and patients at risk. This may lead to the normalisation of extremis (an idea that has been seen elsewhere in the project, where the 'extreme' becomes 'every-day'). This normalisation may compound the current tendency to regard non-family/friend donors with suspicion.
- Patients need to have realistic expectations about the likelihood of living donation going ahead from a given donor, particularly if there is also a likelihood of them being offered organs from deceased donors.
- Working with patients who wish to harness social media to find a living donor would enable evidence to be collected that supports or contradicts this default position of mistrust and suspicion. If current assessment processes for non-directed and living-related donors are considered to offer appropriate safeguards, then in the absence of evidence to the contrary these processes could be considered trustworthy to provide appropriate safeguards for cases with social media involvement.