

Position Statement Social Media Donor

2025

Introduction

- I. Social media has proven to be a powerful tool for increasing awareness about organ donation and transplantation, reaching millions of people rapidly and effectively. Campaigns and personal stories shared on platforms like Facebook, Twitter, and Instagram can dispel myths, provide accurate information, and encourage individuals to register as organ donors.
- II. The use of social media in organ donation raises significant ethical issues, including concerns about privacy, coercion, and the potential for misinformation or exploitation. Without clear policies, individuals may inadvertently share sensitive personal information or feel pressured to donate due to public solicitation.
- III. Not all patients have equal access to social media or the skills to use it effectively, which can create disparities in who benefits from online organ donation campaigns. A policy can help ensure that guidance is provided to minimize these disparities and promote fair access to organ donation opportunities.
- IV. Transplant centres and hospitals face challenges in guiding patients on how to use social media safely and effectively to find living donors. Policies can offer step-by-step guidance on what information is appropriate to share, how to protect privacy, and how to avoid legal or ethical pitfalls such as coercion or undue influence.
- V. Social media communities are arranged in many ways and without standardization, raising concerns about transplant candidates and potential donors' quality of care. Currently, no national ethical guidelines have been developed regarding the use of social media to foster organ transplantation. We need an ethical framework to guide transplant stakeholders in using social media for public and patient communication about transplantation and living donation, and to offer recommendations for transplant clinical practice.
- VI. Professional societies (SATS, SATCS) can play an important and influential role in recommending that transplant hospitals raise awareness, informing their patients, and staff about risk and benefits of using social media when seeking a living donor organ for transplantation.
- VII. Transplant hospitals that do not use or encourage transplant candidates' use of social media, may inadvertently create more disparities for transplant access. Transplant hospitals can reduce potential disparities in access to transplantation by encouraging the ethical use of social media.

Purpose

- I. The primary purpose of a social media transplant policy is to provide clear guidance for members of the transplant community-including professionals, patients, and organisations-on how to engage responsibly and effectively with persons seeking transplant that have met on social media platforms. This ensures that interactions support the mission of increasing organ donation and transplantation while safeguarding against potential risks such as misinformation, privacy breaches, and ethical concerns.
- II. The policy establishes boundaries to protect patient confidentiality and donor privacy. It addresses ethical issues such as coercion, undue influence, and the risk of exploitation or commercialisation of organ donation.
- III. By setting standards for content and conduct, the policy helps maintain public trust and ensures that social media activities align with professional and legal standards.
- IV. To ensure that there is standardisation, compliance and clear guidelines related to the transplantation of patients and or individuals who have secured a potential living donor on social media.
- V. To ensure that there is standardisation, compliance and clear guidelines related to the transplantation of patients and or individuals who have identified a potential living recipient on social media. (Advertised by the person seeking assistance for a transplant).
- VI. Outline clear guidelines and procedures for using social media platforms to ethically and effectively promote and Facilitate Altruistic organ donation.
- VII. Ensures standardised approach to awareness and education – accurate respect and inspiring content is shared to raise public awareness. And importance of altruistic organ donation.
- VIII. Directs engagement with Donor’s recipients and Transplant teams.
- IX. To ensure that the processes comply with National Laws, Medical Ethics, organisational policies and The Declaration of Istanbul - related to organ donation social media communication.
- X. Potential risks like misinformation, breach of confidentiality, or incentivised donation are managed through clear processes and protocols.
- XI. To ensure that processes policies and procedures are in place to identify coercion and financial incentivisation and to prevent this in all possible instances.

Defining social media

- I. Social media is a collection of web-based technologies that share a user-focused approach to design and function, where users actively participate in content creation. Social media (e.g. blogs, tweets, wikis, crowdfunding and social networks) can accelerate and foster communication and action among large communities across wide geographical locations. Facebook, used by 80% of all internet users, is currently the most popular social media site. Social media also expresses individual and cultural identity. Additionally, deeply felt connections between strangers can form on social media too thereby creating donor-recipient intimacy before face-to-face meetings. Social media has changed our definition of “friend”. As a result, transplant candidates may feel more comfortable asking online friends for an organ.
- II. Currently the transplant community uses social media to promote deceased donor registration and the benefits of deceased donation.
- III. Transplant programs are increasingly using Facebook to promote and advertise their programs and to provide resources to the public about living donation. Transplant candidates creating personal Facebook pages to identify potential donors was first documented in 2011.

Privacy and confidentiality

- I. Maintaining recipient and donor privacy/confidentiality is becoming increasingly challenging with the explosion of social media and news media coverage about organ donation.
- II. Anecdotal evidence from online transplant lists suggests that recipients commonly seek information about their donors from news sources like online platforms, local TV news and newspaper obituaries.
- III. Privacy and confidentiality are further challenged by viral social media posts, which are especially persuasive and involve widespread dissemination of the user-intended message through peer-to-peer communication.
- IV. For donors and recipients whose only relationship is “virtual”, social media may create a potential power imbalance between the parties, and some capabilities, such as private and direct messaging, may inadvertently create tension. For example, a potential donor may wish to meet a transplant candidate before the transplant, but the feeling may not be mutual.
- V. The transplant candidate could feel pressured to meet with the donor before the transplant in order to ensure the donation. Social media can therefore create the possibility of a non-directed donation becoming a directed donation.
- VI. Ensure that the Transplant teams working with these candidates protect the identities and medical information of both parties and their families unless they have explicitly consented without coercion to share.
- VII. Individuals must be free to make informed voluntary decisions (Autonomy) about organ donation

- VIII. Social media content must never pressure, guilt or manipulate users to become donors.
- IX. Organ donation should be viewed by both parties as a gift not a transaction
- X. Under all circumstance the transplant teams should ensure that harm is avoided, by preventing exploitation of venerable populations or promotion of unsafe practices
- XI. Potential donors should understand that posting about interest in donation or one's donor evaluation can lead to uninvited public feedback.

Truthfulness

- I. Truthfulness is a significant ethical consideration given that what transplant candidates reveal about themselves personally or medically on social media may potentially influence who is interested in donating. Transplant candidates may feel compelled to compose their social media profiles in the most positive sounding way to draw more potential donors to their cause.
- II. Transplant personnel should provide guidelines to transplant candidates stressing the importance of truthfulness in representing oneself in social media profiles, and the potential harm to potential donors of transplant candidates' misrepresentation and embellishment.

Informed consent, education, undue influence and coercion

- I. Social media has the capacity to affect the informed consent process and present added risks to potential donors or transplant candidates.
- II. The scarcity of organs and transplant candidates' desperate medical needs make stories shared through social media compelling to potential donors and friends or family.
- III. Facebook posts may present a spectrum of personal and identifying information, from positive to negative, from truthful to embellished.
- IV. Individuals may deliberately enhance their mediagenic profiles to boost interest among followers.
- V. Therefore, the informed consent process for potential donor or transplant candidates should include discussion of the potential influence of social media on decision making treatment.
- VI. Social media provides a public forum where undue influence, external pressure to donate and coercion may arise to a larger degree, raising greater concerns than for traditional communication.
- VII. Social media posts can reach large audiences, frequently far beyond immediate social circles.
- VIII. Feigned interest can contribute to individuals initiating donor evaluation, only to later drop out as the process intensifies which could create false hope for the transplant candidates and undermine the ethics of care.

- IX. Barriers to identifying potential donors include discomfort with initiating discussions, concerns about inducing guilt, or burdening family members and friends and these barriers may also extend to social media.

Equity and fairness

- I. No group or individual should be unfairly targeted in donation campaigns, equal action for donation and transplant services is bound by law.
- II. Transplant hospitals that do not use or encourage transplant candidates' use of social media, may inadvertently create more disparities for transplant access. Transplant hospitals can reduce potential disparities in access to transplantation by encouraging the ethical use of social media.

Definitions

- I. **Altruism** -The selfless concern for the well-being of others, often demonstrated through actions intended to help others without expecting any personal gain, reward, or benefit.
- II. **Living recipient** - person who receives an organ or a portion of an organ from a living donor through a surgical transplant procedure. This typically occurs when someone with end-stage organ failure-such as kidney or liver failure-receives an organ from a healthy living person, rather than waiting for an organ from a deceased donor
- III. **Social media**- is a collection of web-based technologies that share a user-focused approach to design and function, where users actively participate in content creation. Social media (e.g. blogs, tweets, wikis, crowdfunding and social networks) can accelerate and foster communication and action among large communities across wide geographical locations.

Press and Social Media

- I. Transplant candidates and potential living donors should be informed to NOT post the following items to social media: personal phone numbers, personal email addresses, residential addresses, family information and any other sensitive information and inappropriate photographs.

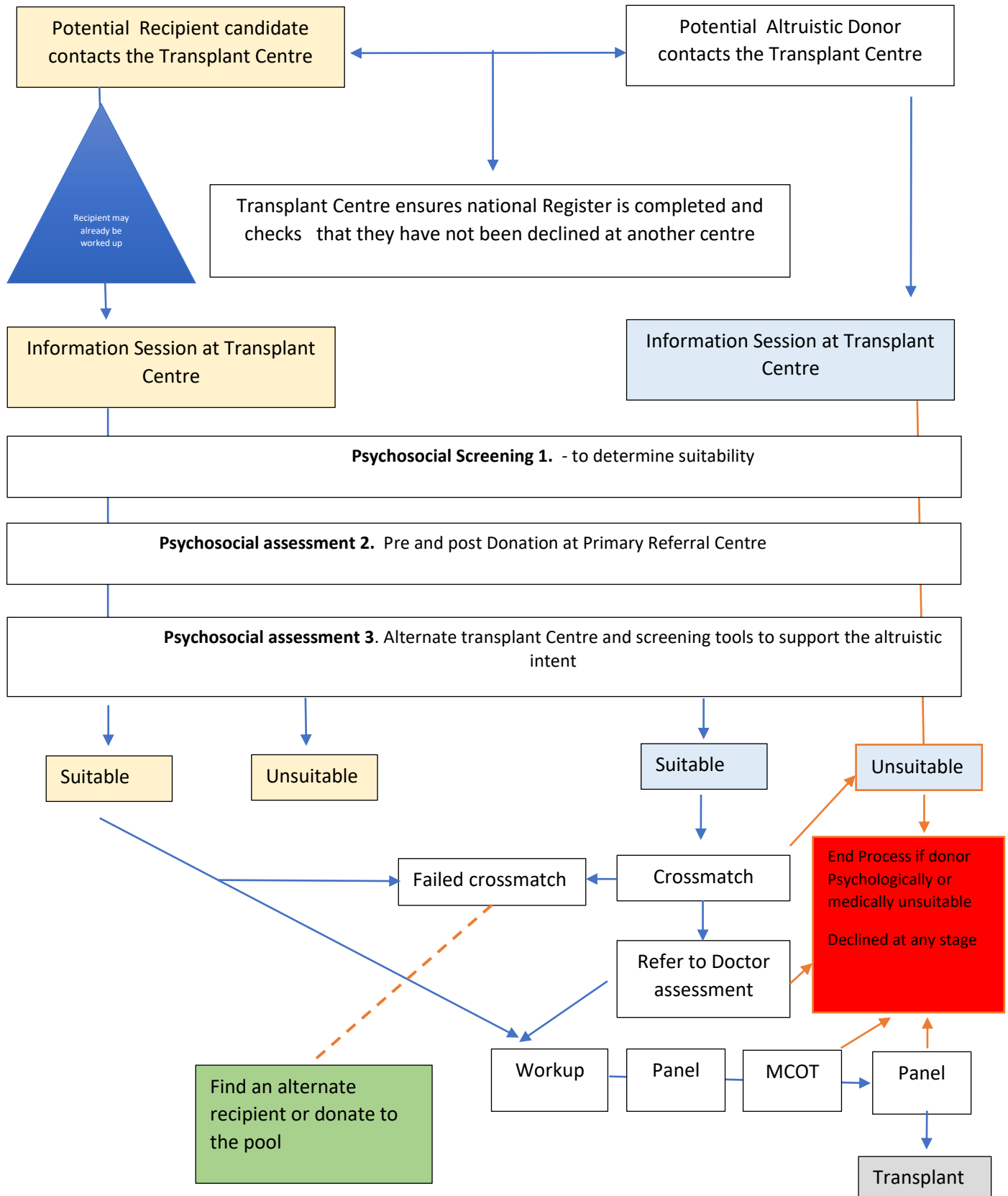
Roadmap of the Social Media Donor and Recipient

At any stage of the assessment if candidates are found to be unsuitable the process will be halted and candidates informed.

- I. South African Transplant centres will need to collaborate on a central register of Social media donors and recipients to ensure that if candidates are declined they do not centre hop.
- II. Potential Altruistic candidates contact the Transplant Centre or Transplant staff
 - a. Transplant candidate and donor evaluation should address social media risk and uncertainties, and their potential influence on decisions concerning donation.
 - b. Potential donors should understand that posting about interest in donation or one's donor evaluation can lead to uninvited public feedback.
- III. An appointment for an information session is made for the donor or recipient to ensure a standardised approach to awareness and education – accurate respect and inspiring content is shared to raise public awareness and importance of altruistic organ donation ,if candidate is found to be unsuitable, they will be informed and the process halted.
- IV. Basic Physical exam (Assessment) and if suitable will be further referred for MDT assessment
- V. Candidates seen by the transplant MDT team will need to undergo:
 - a. **Psychosocial Screening 1.** - to determine suitability
 - i. Although the current psychosocial evaluation process already investigates the potential financial motivation to donate, a new assessment question should be tailored to donors identified via social media, such as “Was there anything mentioned in the post you saw that would indicate you would get some type of reward or incentive for donating to this person?”
 - b. **Psychosocial assessment 2.** Pre and post Donation at Primary Referral Centre
 - i. Although the current psychosocial evaluation process already investigates the potential financial motivation to donate, a new assessment question should be tailored to donors identified via social media, such as “Was there anything mentioned in the post you saw that would indicate you would get some type of reward or incentive for donating to this person?”

- c. **Psychosocial assessment 3.** Alternate transplant Centre and screening tools to support the altruistic intent
- i. Although the current psychosocial evaluation process already investigates the potential financial motivation to donate, a new assessment question should be tailored to donors identified via social media, such as “Was there anything mentioned in the post you saw that would indicate you would get some type of reward or incentive for donating to this person?”

Social Media Donor and Recipient Pathway



If at any stage of the process the donor and recipient are found to be an unsuitable match – the donor can be requested to donate to another recipient on the waiting list.

Approval to proceed or not to proceed

- I. Patient will be presented at a local Transplant Panel meeting for unanimous decision to proceed or not to proceed.
- II. Referred to a Nephrologist and other MDT members as per work up process if approved.

Panel Approval

- I. The case needs presentation at Panel to strengthen the application at MCOT or strengthen and document the decision not to proceed.
- II. Any decision taken will be updated in the National patient registry.

Work up

All Candidates will, if approved, follow the standard ULD workup process and approvals framework

It is very important to note that policing transplant candidates online/social media profiles is outside the scope of professional responsibility for transplant personnel.



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