

Transparency in Program Selection

OPTN Ethics Committee

Rationale for White Paper

- The Final Rule requires the OPTN to develop equitable allocation policies, and to promote patient access when developing such policies
- The ethical principles that are the foundation of an ethical allocation system support transparency in listing criteria and patient-centered information
- To ensure patient autonomy and shared decision-making through the transplant process

Purpose of White Paper

- Apply the ethical principles of organ allocation to the concept of transparency
 - Autonomy, equity, procedural justice, and utility
- Consider how transparency improves the transplant program selection process and eases access for patients
- Develops the foundation for further review of OPTN data and policies to enhance patient autonomy

Ethical Principles

- **Autonomy**
 - One's ability to be self-directing, have a decisive impact on what happens to oneself in the future, and, in terms of transplant, the ability to participate in decisions that lead to medical treatment.
- **Procedural Justice**
 - Upholds a commitment to treating like cases similarly, transparently, and predictably.
- **Equity**
 - Removing structural barriers to accessing transplant and mitigating undue disadvantage experienced by those who come from structurally marginalized communities or have fewer resources.
- **Utility**
 - Maximization of net benefit (including promoting graft survival, reducing waste, and improving efficiency)

Complicating Questions

- Unintended Side-effects of publishing data
 - The distinction between information and data that would aid in patient decision making not metrics
- Disclosure and Paternalism
 - Patients should have a role in determining which information they are interested in
- Potential Misinterpretations in Disclosure
 - Education resources can be provided to ensure that patients understand the information provided

Key Findings

- The ethical principles of organ allocation support increased transparency in transplant center-specific and patient-centered information in order to inform transplant center selection
- Challenges that may arise when increasing transparency can be mitigated and should not deter centers from increasing transparency
- Information ought to be provided in a way that is accessible and patient-centered

What do you think?

- What are other factors that would be important to patients when selecting a transplant program?
- Do patients and transplant professionals think that it is important to share program specific listing criteria prior to transplant evaluation?
- What best practices have transplant programs developed for increasing transparency?
- Do clinicians/transplant professionals think this information, shared with patients, would strengthen the doctor-patient relationship, and/or provide better care for patients?