OPTN

White Paper

Transparency in Program Selection

OPTN Ethics Committee

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OPTN

Transparency in Program Selection

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Executive Summary

Patient access to transplant continues to be a topic of concern in the transplant community. The Ethics Committee developed this white paper to better understand and address how equity in organ allocation can be improved by considering the beginning of the transplant process: patients who are pursuing evaluation and registration on the waitlist. The Committee applied the ethical principles of organ allocation to the concept of transparency and focused their analysis on how transparency can be improved for patients selecting a transplant program.

The ethical principles of autonomy, equity, procedural justice, and utility are the impetus for more transparent and patient-centered information to enable patients to make better-informed decisions on where they want to pursue transplant evaluation and listing. In order to address the existing lack of information that is available to patients prior to transplant, the Committee uses four examples to illuminate the ways that increased information is rooted in the ethical principles of organ allocation and can be beneficial to patients selecting a transplant center. The white paper identifies and addresses potential complicating questions that could arise when considering increased transparency, without dictating medical practice or requiring transplant centers to disclose any specific information.

The goal of this white paper is to provide an ethical framework for the OPTN Board of Directors to consider ways in which it can assist the transplant community to improve the transparency of information for patients pursuing transplant evaluation. It also establishes the ethical underpinnings essential for any future improvements to OPTN policy or data collection.

Background

In May 2021, the OPTN Policy Oversight Committee (POC) identified an opportunity to improve the types of transplant program-specific information and the manner in which it is provided to patients at the pre-waitlist stage of transplant. To better understand the issue, the OPTN Ethics Committee (hereafter 'the Committee') undertook an ethical analysis considering the ethical principles in support of transparency to inform patient selection of a transplant center. The Final Rule requires the OPTN to develop equitable allocation policies, and to promote patient access to transplantation when developing such policies.[1] The transplant community has expressed overwhelming interest in patient access to organ transplant.[2] Such interest is highlighted in the recent report by the National Academies of Sciences, Engineering, and Medicine (NASEM) that identifies areas for improvement in the U.S. transplant system.[3] Some organizations, such as the Scientific Registry of Transplant Recipients (SRTR), are addressing this interest through patient focus groups aimed at identifying what information is the most pertinent to patients when pursuing transplantation.[4] Others are analyzing and evaluating the impact of Social Determinants of Health and how they can be connected to health disparities, access, and outcomes.[5,6] The Committee opted to address the lack of transplant program-specific information provided to patients who are pursuing evaluation and registration on the waitlist in order to improve shared decision-making.

The POC first approved the Committee's work on this topic in May 2021. At this time, the Committee developed a memo to the OPTN Data Advisory (DAC), Minority Affairs (MAC), and Patients Affairs (PAC) Committees highlighting the ethical principles that support transparency of information at the pre-waitlist stage.[7] The purpose of this memo was to provide a timely ethical analysis that could be used to inform the work of these Committees. To better understand how patient-centered information and access to transplant could be improved, the Committee undertook a formal literature review. The literature noted some areas of interest for patients and highlighted opportunities for improvement that have been identified by both patients and transplant professionals. Currently, transplant centers' patient acceptance criteria vary drastically, and often times exclusionary criteria are not provided to patients prior to their transplant evaluation.[8] For many patients, insurance only covers one transplant evaluation, heightening the consequences of center selection.[9] To preserve patient autonomy and support shared decision-making, there is a need to provide additional information to patients at the pre-

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[1] 42 CFR §121.8(a)(5)

[2] Christine Park et al., "A scoping review of inequities in access to organ transplant in the United States, *International Journal for Equity in Health* 21, 22 (Feb 2022). https://doi.org/10.1186/s12939-021-01616-x.

[3] National Research Council, "Realizing the Promise of Equity in the Organ Transplantation System," 2022, Washington, DC: The National Academies Press. https://doi.org/10.17226/26364.

[4] Scientific Registry of Transplant Recipients, "The Task 5 Initiative," https://www.srtr.org/about-srtr/the-task-5-initiative/.

[5] Norine W. Chan et al., "Social Determinants of Health Data in Solid Organ Transplantation: National Data Sources and Future Directions," *American Journal of Transplantation* (May 2022). https://doi.org/10.1111/ajt.17096.

[6] Organ Procurement and Transplantation Network, "OPTN to study data collection to related social determinants of health," February 7, 2021, https://optn.transplant.hrsa.gov/news/optn-to-study-data-collection-to-related-social-determinants-of-health/.

[7] *Transparency in Program Selection Memo*, OPTN Ethics Committee, February 2022.

[8] Cory R. Schaffhausen et al., "How patients choose kidney transplant centers: A qualitative study of patient experiences," *Clinical Transplantation* 33, 5 (Mar 2019). https://doi.org/10.1111/ctr.13523.

[9] Rachel E. Patzer, et al., "A Population Health Approach to Transplant Access: Challenging the Status Quo," *American Journal of Kidney Disease* (Feb 2022). https://doi.org/10.1053/j.ajkd.2022.01.422.

transplant stage.[10,11,12] The memo was well received by each group and their feedback was included in the development of the white paper. The DAC, MAC, and PAC were identified as early stakeholders because of their interest and efforts to support work associated with the pre-transplant stage. These groups were also identified to ensure that patient and minority experiences were appropriately captured in the memo and subsequent white papers. Representatives from DAC, MAC, and PAC were invited to join the workgroup and contributed to the completion of the white paper.

This white paper considers the ethical principles of autonomy, procedural justice, equity, and utility:

- "The concept of respect for **autonomy** holds that actions or practices tend to be right insofar as they respect or reflect the exercise of self-determination."[13]
- "**Procedural justice** refers to appraisal of the fairness of how decisions are made."[14]
- **Equity** "refers to fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program."[15]
- "The principle of **utility**, applied to the allocation of organs, thus specifies that allocation should maximize the expected net amount of overall good (that is, good adjusted for accompanying harms), thereby incorporating the principle of beneficence (do good) and the principle of non-maleficence (do no harm)."[16]

To further underscore the role the above-mentioned principles play, the Committee considered experiential examples where more transparent information would aid a patient in deciding where to pursue transplant evaluation. These examples include alcohol use, obesity, potentially frail patients, and highly sensitized patients. These examples are not meant to be inclusive of all patient conditions or information that would be valuable to them, nor do they serve to dictate medical practices to transplant programs. Instead, these examples illuminate how transparent program-specific information could increase shared decision-making and the ethical principles that require such disclosure.

The Committee also explores complicating questions that may arise from an increase in patient-centered transparency during the pre-waitlisting phase. These questions dissect potential concerns and opposition to transparency and emphasize that these concerns can be mitigated and ought not to be a barrier to pursuing increased transparency. These complicating questions provide a balanced perspective by acknowledging and addressing potential challenges from the outset.

The Committee also distinguishes that simply providing information on the internet is insufficient in meeting the needs of all patients by assuming digital access, digital literacy, and accessibility of

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[10] Melania Calestani et al., "Patient attitudes towards kidney transplant listing: Qualitative findings from the ATTOM study," *Nephrology Dialysis Transplantation* 29, 11 (Nov 2014): 2144-2150. https://doi.org/10.1093/ndt/gfu188.

[11] Allison Tong et al., "'Suspended in a paradox' – Patient attitudes to wait-listing for kidney transplantation: Systematic review and thematic synthesis of qualitative studies," *Transplant International* 28, 7 (Jul 2015): 771-787. https://doi.org/10.1111/tri.12575.

[12] Cory R. Schaffhausen et al., "Comparing Pretransplant and Posttransplant Outcomes When Choosing a Transplant Center: Focus Groups and a Randomized Survey," *Transplantation* 104, 1 (Jan 2020).https://doi.org/10.1097/TP.0000000000002809.

[13] *Ethical Principles in the Allocation of Human Organs*, OPTN Ethics Committee, June 2015, https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/.

[14] Mark Fondacaro, Bianca Frogner, and Rudolf Moos, "Justice in Health Care Decision-Making: Patients' Appraisals of Health Care Providers and Health Plan Representatives," *Social Justice Research* 18, 1 (March 2005): 63-81. https://doi.org/10.1007/s11211-005-3393-3.

[15] *Ethical Principles*, OPTN Ethics Committee.

[16] Ibid.

resources. In order to be patient-centered, the information provided prior to transplant evaluation needs to reach the patient and meet their needs.

Purpose

This white paper conducts an analysis considering the ethical principles that necessitate the availability of transparent, patient-centered information for patients pursuing transplant evaluation. This analysis uses the ethical principles of autonomy, equity, procedural justice, and utility, which have been cemented as the ethical foundation in organ allocation.[17]

The white paper may be used to help the OPTN Board develop recommendations that could lead to transplant programs providing more information about clinical criteria for transplant. For example, the white paper could serve as a reference point for transplant programs that want to increase transparency for patients. The white paper highlights the challenge of relying on the internet for patients to access transplant information and illustrates the detriment of assuming digital literacy to achieve health literacy. It also provides an ethical justification for providing certain types of information that patients and their families need access to, and the potential tradeoffs that may need consideration as part of a decision to seek a listing at a particular program. Ultimately, the goal of this paper is to provide the OPTN Board with an ethical framework when developing solutions aimed to improve patients' decision-making process when faced with selecting a transplant center to pursue evaluation, waitlist registration, and transplant.

NOTA and Final Rule Analysis

This white paper is proposed under the authority of the OPTN Final Rule, which tasks the OPTN with developing policies that promote equitable allocation of organs,[18] and "reduce inequities resulting from socioeconomic status."[19] Furthermore, the Final Rule requires that "Transplant hospitals shall assure that individuals are placed on the waiting list as soon as they are determined to be candidates for transplantation. The OPTN shall advise transplant hospitals of the information needed for such listing."[20] The Ethics Committee offers the proposed white paper to advise the OPTN Board and committees on the ethical considerations to undertake if they develop policies to address these topics. The Committee theorizes that allocation could be more equitable for all patients, including those of different socioeconomic statuses, if patients are able to make an informed decision about where they are listed, based on the transparency of the listing practices employed by each individual transplant program.

Conclusion

The Committee concludes that principles of autonomy, equity, utility, and procedural justice strongly support increased patient access to information about the transplant evaluation process and waitlisting decisions. These principles are fundamental to the organ transplant system and imperative to maintaining an ethical system of allocation.[21] Transparent information that contributes to and improves patients' ability to be waitlisted is necessary for ensuring equitable access to care while supporting patient autonomy and utility, while noting that this information needs to be accessible to all patients.

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[17] Ibid.

[18] 42 CFR §121.4(a)(1)

[19] 42 CFR §121.4(b)

[20] 42 CFR §121.5(b)

[21] *Ethical Principles*, OPTN Ethics Committee.

Greater transparency about pre-listing information can help patients find programs that are the best fit for their health needs, values, and preferences. This white paper supports transparency and accountability within the transplant system through an ethical analysis that lays the foundation for further review of the OPTN data and policies to enhance patient autonomy. The Committee maintains that patient-centered and program-specific transparency is essential to uphold the OPTN's foundation that "equitable access to the transplant waiting list is the cornerstone of equitable organ allocation."[22]

Considerations for the Community

The Committee encourages all interested individuals to comment on this proposal in its entirety, but specifically asks for feedback on the following:

- Do community members think that it is important to know what criteria transplant programs use to evaluate patients for listing?
- What are other factors that would be important to you in selecting a program?
- 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?

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[22] Ibid.

Transparency in Program Selection

Introduction

Choosing a transplant program[23] (transplant program selection) is a decision with important implications for patients' chances to successfully complete the evaluation process, be waitlisted for an organ, and ultimately receive a transplant. In the United States, research shows that many patients consider multiple programs, and may choose programs far from their home, or pursue listing at multiple programs.[24,25,26,27,28] Patient acceptance criteria, waiting time, and mortality vary significantly by program, underscoring the importance of transparency about factors which may influence program selection.[29,30]

Disparities in access to transplant remain, including disparities by age, clinical presentation, body mass index (BMI), and race.[31] Disparities in access to care may be exacerbated by a lack of public information about transplant programs' listing practices. For example, patients may be unaware of differing BMI thresholds, abstinence requirements for substance use, social support requirements, and financial requirements between programs.[32] This can be particularly problematic for patients for whom insurance will only cover one evaluation and who find out during the evaluation process that they will not be listed at a given program because of one of these factors. Even patients who are ultimately listed may benefit from knowing this information earlier. Patients are often unaware of the impact that differences in program-specific acceptance criteria, waiting times, and mortality rates can have on their likelihood of being waitlisted and receiving a transplant.[33] Challenges persist in understanding how quickly patients will be placed on the waitlist, and the likelihood that they would be deemed an acceptable candidate for a particular program based on their physical, medical, or social characteristics. Lack of access to data about patient evaluation and listing practices limits the ability to make informed choices about where to seek care.

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[23] OPTN Policy 1.2 Definitions defines transplant program as "A component within a transplant hospital that provides transplantation of a particular type of organ."

[24] Cory R. Schaffhausen et al., "The importance of transplantprogram measures: Surveys of three national patient advocacy groups," *Clinical Transplantation* 32, 12 (Oct 2018): e13426. https://doi.org/10.1111/ctr.13426.

[25] Bertram L. Kasiske et al., "The geography of kidney transplantation in the UnitedStates," *American Journal of Transplantation* 8, 3 (Feb 2008): 647–657. https://doi.org/10.1111/j.1600-6143.2007.02130.x.

[26] Kendra E. Brett et al., "Perspective on Quality of Care in Kidney Transplantation: A Semistructured Interview Study," *Transplant Direct* 4, 9 (Sep 2018): e383. https://doi.org/10.1097/TXD.0000000000000820.

[27] Mohammad Sanaei Ardekani and Janis M. Orlowski, "Multiple listing in kidney transplantation," *American Journal of Kidney Diseases* 55, 4 (Apr 2010): 717–725. https://doi.org/10.1053/j.ajkd.2009.11.022.

[28] Cory R. Schaffhausen et al., "Comparing Pretransplant and Posttransplant Outcomes When Choosing a Transplant Center: Focus Groups and a Randomized Survey," *Transplantation* 104, 1 (Jan 2020).https://doi.org/10.1097/TP.0000000000002809.

[29] Jesse D. Schold et al., "The pivotal impact of centercharacteristics on survival of candidates listed for deceased donor kidney transplantation," *Medical Care* 47, 2 (Feb 2009): 146–153. https://doi.org/10.1097/MLR.0b013e31818475c9.

[30] Andrew Wey et al., "Association of pretransplant and posttransplant program ratings with candidate mortality after listing," *American Journal of Transplantation* 19, 2 (Feb 2019): 399-406. https://doi.org/10.1111/ajt.15032.

[31] Christine Park et al., "A scoping review of inequities in access to organ transplant in the United States," *International Journal for Equity in Health* 22 (Feb 2022). https://doi.org/10.1186/s12939-021-01616-x.

[32] Cory R. Schaffhausen et al., "Tool to Aid Patients in Selecting a Liver Transplant Center," *Liver Transplantation* 26, 3 (Mar 2020): 337-348. https://doi.org/10.1002/lt.25715.

[33] Cory R. Schaffhausen et al., "How patients choose kidney transplant centers: A qualitative study of patient experiences," *Clinical Transplantation* 33, 5 (Mar 2019). https://doi.org/10.1111/ctr.13523.

In light of these challenges and persistent disparities, there is an urgent need to increase patient access to pre-transplant referral and evaluation information.[34] To this end, the OPTN Ethics Committee, hereafter the Committee, examines the principles of disclosure in transplantation and considers examples where transparency of pre-listing information supports equitable and patient-centered access to transplantation.

Review of Relevant Literature

The Committee conducted a systematic literature review to identify information that patients (transplant candidates, transplant recipients, transplant support persons, or living donors) believe is relevant to the selection of a transplant program. During this literature review, the Committee also identified some types of information that transplant professionals thought would be useful for patients.

Table 1-1 provides further details about the literature review screening process and the identified sources.[35] Supplemental information on the literature review and article selection process can be found in Tables 1-2 and 1-3 of Appendix 1.

Through the analysis, 17 articles were identified that report data about content desired by patients or suggested by professionals. [36,37,38] While most of the articles focus on the kidney transplant population, a few include patients or transplant professionals of other organ types. However, the Committee was unable to find data on patients awaiting intestine, lung, or pancreas transplant. [39,40,41] To summarize the findings, the desired information fell into six main categories: general information about the transplant program or staff, referral and evaluation, waitlisting, transplant and perioperative outcomes, long-term follow up and outcomes, and living donation. [42,43,44] Table 1-1 provides details about the subtopics of information desired within each of the six major categories. Patients wanted more information about the experiences that patients who had similar demographic or disease characteristics as themselves had at a transplant program, in addition to more general data about volume and outcomes. [45,46,47,] Of note, many topics that patients wanted to learn more about are areas where data is not currently included in

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[34] Anil Chandraker et al., "Time for reform in transplant program-specific reporting: AST/ASTS transplantmetrics taskforce," *American Journal of Transplantation* 19, 7 (July 2019): 1888-1895. https://doi.org/10.1111/ajt.15394.

[35] See Appendix 1.

[36] Brett, "Perspective."

[37] Natalia Crenesse-Coizen et al., "Kidney Transplant Evaluation: Inferences from Qualitative Interviews with African American Patients and their Providers," *Journal of Racial and Ethnic Health Disparities* 6, 5 (Oct 2019). https://doi.org/10.1007/s40615-019-00592-x.

[38] Elisa J. Gordon et al., "Opportunities for Shared Decision Making in Kidney Transplantation," *American Journal of Transplantation* 13, 5 (May 2013): 1149-1158. https://doi.org/10.1111/ajt.12195.

[39] David H. Howard and Bruce Kaplan, "Do report cards include hospital choice? The case of kidney transplantation," *Inquiry* 43, 2 (2006): 150-159. https://doi.org/10.5034/inquiryjrnl_43.2.150.

[40] Syed Ali Husain et al., "Patients prioritize waitlist over posttransplant outcomes when evaluating kidney transplant centers," *American Journal of Transplantation* 18, 11 (Nov 2018): 2781-2790. https://doi.org/10.1111/ajt.14985.

[41] Syed Ali Husain et al., "Association Between Declined Offers of Deceased Donor Allograft and Outcomes in Kidney Transplant Candidates," *JAMA Network Open* 2, 8 (Aug 2019). https://doi.org/10.1001/jamanetworkopen.2019.10312.

[42] Warren T. McKinney et al., "Designing a patient-specific search of transplant program performance and outcomes: Feedback from heart transplant candidates and recipients," *Clinical Transplantation* 35, 2 (Feb 2021). https://doi.org/10.1111/ctr.14183.

[43] Warren T. McKinney et al., "Development of a Patient-specific Search of Transplant Program Outcomes and Characteristics: Feedback from Kidney Transplant Patients," *Transplant Direct* 6, 8 (Aug 2020). https://doi.org/10.1097/TXD.0000000000001036

[44] Sudeshna Paul et al., "Kidney transplant program waitlisting rate as a metric to assess transplant access," *American Journal of Transplantation* 21, 1 (Jan 2021): 314-321. https://doi.org/10.1111/ajt.16277.

[45] Schaffhausen, "How patients."

[46] Schaffhausen, "Comparing."

[47] Schaffhausen, "Tool."

the Scientific Registry of Transplant Recipients (SRTR) program reports (e.g. patient-reported outcomes including quality of life and patient satisfaction).[48] Furthermore, some professionals assert that not all of the desired topics are easily assessed or compared (e.g. continuity of providers throughout the transplant process). [49,50,51,52] While this literature has provided a better understanding of what information is important to patients and transplant professionals, it also expounded on the need for more transparent, consistent, and patient-friendly information to improve shared decision-making.

Ethical Principles

The Committee considers autonomy, procedural justice, equity, and utility as the critical principles to guide the recommendations as to what types of information patients should be aware of when making decisions about where and how to seek transplant care.[53]

Autonomy

The principle of **autonomy** refers to one's ability to be self-directing, have a decisive impact on what happens to oneself in the future, and, in terms of transplantation, the ability to participate in decisions that lead to medical treatment, including program selection. The principle of autonomy is also associated with respect for persons, i.e., the notion that patients should be treated in a way that facilitates choice and that preserves dignity. Finally, autonomy holds that actions or practices tend to be right insofar as they support individuals' independent choices, as long as the choices do not impose harm to others.[54,55] The accessibility and clear presentation of information relevant to medical decision-making are critical to support patients' ability to exercise their autonomy. Therefore, autonomy justifies the disclosure of program-specific information relevant to transplant program selection and shared decision-making.[56]

Procedural Justice

Procedural justice upholds a commitment to treating like cases similarly, transparently, and predictably. Procedural justice pertains to transparency in program selection in two primary respects: 1) public accessibility of allocation decisions and the rationale for making these decisions, and 2) all justifications

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[48] Scientific Registry of Transplant Recipients, "Program-Specific Reports," accessed June 4, 2022, https://srtr.org/reports/program-specific-reports/.

[49] Jesse D. Schold et al., "Quality Metrics in Kidney Transplantation: Current Landscape, Trials and Tribulations, Lessons Learned, and a Call for Reform," *American Journal of Kidney Disease* 74, 3 (Sep 2019): https://doi.org/10.1053/j.ajkd.2019.02.020.

[50] Sarah E. Van Pilsum Rasmussen et al., "Transplant community perceptions of the benefits and drawbacks of alternative quality metrics for regulation," *Clinical Transplantation* 33, 4 (Apr 2019). https://doi.org/10.1111/ctr.13500.

[51] Deirdre Sawinski and Jayme E. Locke, "Can you hear me now? Patient preferences for evaluating kidney transplant centers," *American Journal of Transplant* 18, 11 (Nov 2018): 2624. https://doi.org/10.1111/ajt.15066.

[52] Cory R. Schaffhausen et al., "What patients and members of their support networks ask about transplant program data," *Clinical Transplantation* 31, 12 (Dec 2017). https://doi.org/10.1111/ctr.13125.

[53] *Ethical Principles in the Allocation of Human Organs*, OPTN Ethics Committee, June 2015, https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs/.

[54] Ibid.

[55] Tom. L Beauchamp and James F. Childress, *Principles of Biomedical Ethics 4th edition* (Oxford: Oxford University Press, 1994).

[56] For an example of how shared decision-making can successfully be incorporated into the transplantation process, see: William F. Parker and Marshall H. Chin, "Epistemic Authority and Trust in Shared Decision Making About Organ Transplantation *AMA Journal of Ethics* 22, 5 (May 2020). https://10.1001/amajethics.2020.408.

of decisions should rely on rationales that are reasonable and appeal "to evidence, reasons, and principles that are accepted as relevant by fair-minded people."[57,58]

While the exact content of what information procedural justice requires remains somewhat open, in the context of organ transplantation, the Committee concludes that it is important for there to be greater symmetry of information between patients and clinicians about features of transplant program evaluation, waitlisting, and transplant that could affect a patient's decision to pursue transplant at a given program. The OPTN maintains, "procedural justice is critical to preserving public trust and participation in the transplant system, as it ensures that all patients in need will receive similar treatment."[59]

Procedural justice also requires that patients have access to the reasons underlying each decision that affects access to transplant, such as the decision to register a patient for the waitlist (or not), and to make a patient inactive (or not). Procedural justice does not require every program to provide the same services or approach, but instead, to provide consistent information on what is available, factors impacting patient success, and the program's approach for patient decision-making. Transparency of information relevant to transplant program selection allows for the transplant listing process to be evaluated for fairness and consistency, facilitates a patient's ability to hold a program accountable, and enhances trust in the system.

Equity

The principle of **equity** refers to removing structural barriers to accessing transplantation and mitigating undue disadvantage experienced by those who come from structurally marginalized communities or have fewer resources. The principle of equity invokes a commitment to health equity by focusing on reducing health disparities commonly defined as the "systematic, plausibly avoidable health differences adversely affecting social disadvantaged group" such as "race or ethnic group, skin color, religion, language, or nationality; socioeconomic resources or position; gender, sexual orientation, or gender identity; age, physical, mental or emotional disability or illness, geography, political or other affiliation; or other characteristics."[60] Asymmetry of information may worsen outcomes for structurally marginalized patients, further exacerbating disparities, such as the lack of awareness and differential use of race as a coefficient in the glomerular filtration rate (GFR) for Black patients with kidney disease.[61,62] The lack of accessible information about transplant program listing practices may disproportionately affect these populations, including those who may be disqualified due to nonmedical criteria.[63,64] Transparency of program information facilitates equity in patient access – such as when

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[57] Sofia Gruskin and Norman Daniels, "Process Is The Point," *American Journal of Public Health* 98, 9 (Sep 2008): 1573-1577. https://doi.org/10.2105/AJPH.2007.123182.

[58] Govind Persad, "What Is the Relevance of Procedural Fairness to Making Determinations about Medical Evidence?," *AMA Journal of Ethics* 19, 2 (Feb 2017): 183-191. https://doi.org/10.1001/journalofethics.2017.19.2.pfor1-1702.

[59] *Manipulation of the Organ Allocation System Waitlist Priority through the Escalation of Medical Therapies,* OPTN Ethics Committee, June 2018, accessed March 1, 2022, https://optn.transplant.hrsa.gov/media/2500/ethics_whitepaper_201806.pdf.

[60] Paula A. Braveman et al., "Health disparities and health equity: The issue is justice," *American Journal of Public Health* 101, 1 (Dec 2011): S149-S155. https://doi.org/10.2105/AJPH.2010.300062.

[61] Lesley Inker et al., "New Creatinine and Cystatin C-Based Equations to Estimate GFR without Race," *New England Journal of Medicine* 385 (Nov 2021). https://doi.org/10.1056/NEJMoa2102953.

[62] During the June 2022 OPTN Board of Directors meeting, the Board approved changes to OPTN policy to disallow the use of race-inclusive eGFR calculators for OPTN purposes.

[63] *Revise General Considerations in Assessment for Transplant Candidacy*, OPTN Ethics Committee, July 2021, https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/general-considerations-in-assessment-for-transplant-candidacy/.

[64] Rachel E. Patzer, et al., "A Population Health Approach to Transplant Access: Challenging the Status Quo," *American Journal*

insurance policies pay for only one transplant evaluation, a common logistical and financial constraint.[65] Even when insurance may cover multiple evaluations, patients and families incur costs and burdens, including those associated with co-pays, transportation, missed work, and dependent care, among others. When relevant information is available in a clear and timely manner, it lessens the burden on patients to self-educate. Self-education is more challenging when patients have fewer resources and lack access to resources.

Utility

Finally, the principle of **utility**, which in the context of organ allocation refers to the maximization of net benefit (including promoting graft survival, reducing waste, and improving efficiency), may also justify greater transparency in listing practice, although this remains an open empirical question.[66,67] For example, increasing disclosure of relevant information could lead patients pursuing transplantation to more rapidly identify a program that fits their needs, thus reducing health care expenditures arising from multiple waitlist evaluations. Without this, patients may engage in duplicate testing and evaluations after being predictably turned away from a given program owing to failure to disclose and explain relevant data. Conversely, transparency of information, clarity of communication, and shared decision-making are conducive to efficient treatment and increased attention to the patient perspective.[68] However, it is possible that transparency in transplant listing criteria may negatively impact utility, for example, if greater requirements for transparency and disclosure were to negatively influence transplant programs to be more defensive or conservative. We will address this exception below. Traditionally, the organ transplant field considers utility related to organ allocation, but utility also applies to patient optimization of transplant options. Although this paper demonstrates how utility may be positively impacted, further research here is needed.

Complicating Questions

Having addressed ethical principles that underlie the need to enhance the accessibility of data to inform decisions about where to pursue transplant, there are three examples of potential negative consequences that may arise from increased access to information, specifically data, which require further exploration.

Unintended Side-effects of Publishing Data

First, should data be published if doing so might have the unintended consequence of decreasing programs' willingness to transplant patients whose outcomes they fear may affect other patients or referring physicians' perceptions of the program? The "cherry-picking" concern here is that an increase in publicized data might negatively influence transplant programs to engage in defensive patient selection practices, thus diminishing patients' ability to choose a transplant program. Similar concerns

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of Kidney Disease (Feb 2022). https://doi.org/10.1053/j.ajkd.2022.01.422.

[65] Ibid.

[66] Norman Daniels and James E. Sabin. Setting Limits Fairly (Oxford: Oxford University Press, 2002): 45-46.

[67] *Ethical Principles in the Allocation of Human Organs* defines "the principle of utility, applied to the allocation of organs, thus specifies that allocation should maximize the expected net amount of overall good (that is, good adjusted for accompanying harms), thereby incorporating the principle of beneficence (do good) and the principle of non-maleficence (do no harm)." https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/.

[68] L. E. Boulware et al, "Perceived transparency and fairness of the organ allocation system and willingness to donate organs: A national study," *American Journal of Transplant* 7, 7 (July 2007). https://doi.org/ 10.1111/j.1600-6143.2007.01848.x.

were previously raised about the implementation of "report cards," a concern which ultimately proved unfounded, in part due to limited patient use of the data.[69,70]

If public reporting contributes adversely to the cherry-picking of patients, prioritizing those most likely to be predicted to have good outcomes, it may undermine equity and utility.[71] This underscores the critical task of determining not only what data are relevant to disclose, but also how these may be appropriately risk-adjusted and presented predictably and consistently across various transplant programs. Nonetheless, empirical challenges to appropriately risk adjust should not impede efforts to promote autonomy and equity.

Perhaps much of the concern about the unintended consequences of publishing data can be allayed by considering the distinction between the terms "data" and "metrics." Data are quantitative information, not value judgments. Metrics, by contrast, are "measures that have been developed to support self-assessment and quality improvement at the provider, hospital and/or health care system level."[72] In light of the distinction between these two terms, it is critical to emphasize that the recommendations rooted in this principles-based analysis concern the disclosure of data, not metrics. It is also important to acknowledge that making a distinction between "data" and "metrics" is not to suggest that data are in all cases neutral. The selection of which data to scrutinize and publicize, and how to frame these strategic decisions, are values-based decisions, ultimately affecting the overall interpretation of data. In this case, access to data that could be understood and used by patients to decide where and how to seek care that aligns with their values is at the core of autonomy and shared decision-making. To support this, there is a need for transplant programs to provide information, including data, to patients during the pre-listing stage, the period of transplantation at which data sharing and transparency is most conspicuously lacking.

Disclosure and Paternalism

Second, what should be done in cases where patients are not necessarily interested in data, but the referring clinician or transplant professional thinks the data may help the patient in their transplant program decision? For example, transplant professionals might view the organ acceptance rate ratio as relevant data even if patients have not yet requested this information.[73] Considerations like this, in turn, lead to a more fundamental question: is the appropriate data collected to benefit the patient? The Committee maintains that the information and data that is disclosed be done so in a manner that is consistent with promoting patients' interests.

Regarding potential concerns about paternalism, rather than immediately deciding that particular information should not be provided, transplant professionals should engage in a discussion with patients to determine what information would be meaningful to them, how to interpret the information and its

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[69] E. C. Schneider and A. M. Epstein, "Use of public performance reports: A survey of patients undergoing cardiac surgery," *Journal of the American Medical Association* 279, 20 (May 1998): 1638-1642. https://doi.org/10.1001/jama.279.20.1638.

[70] Xuan Li et al., "Comparing the Impact of Online Ratings and Report Cards on Patient Choice of Cardiac Surgeon: Large Observational Study," *Journal of Medical Internet Research* 23, 10 (Oct 2021). https://doi.org/10.2196/28098.

[71] Jesse D. Schold, Charlotte J. Arrington, and Greg Levine, "Significant alterations in reported clinical practice associated with increased oversight of organ transplant center performance," *Progress in Transplantation* 20, 3 (Sep 2010): 279-287. https://doi.org/10.7182/prtr.20.3.bj6mh237p6912251.

[72] Robert O. Bonow et al., "ACC/AHA classification of care metrics: performance measures and quality metrics: a report of the American College of Cardiology/American Heart Association Task Force on Performance Measures," *Circulation* 118, 24 (Dec 2008): 2662-2666. https://doi.org/10.1161/CIRCULATIONAHA.108.191107.

[73] *Enhance Transplant Program Performance Monitoring System,* OPTN Membership and Professional Standards Committee, August 2021, https://optn.transplant.hrsa.gov/media/4777/transplant_program_performance_monitoring_public_comment_aug2021.pdf.

potential impact. It may turn out that this is a case in which paternalism stands in tension with autonomy, where providing patients too much information, or information that is not relevant or useful, may hinder their decision-making process and impede shared decision-making. Just as a patient can feel paralyzed in confronting an illness when presented with too many options, so could the act of over-informing render an already onerous process even more overwhelming.[74] Thus, it is important to acknowledge that there are reasonable limits to disclosure and transparency. In keeping with the principle of autonomy described above, this type of extraneous information should be determined in advance and should remain unshared in a manner which is consistent and non-discriminatory (despite that it also may not be completely uniform). This is a question of balance, calling attention to the importance of engaging patient stakeholders in the process of identifying the information that they find the most useful to select a program and to increase transparency, which may also elucidate barriers and facilitators of early access to transplant, or delineate the impact of varied experiences at the referral and evaluation stages of transplantation.

Potential Misinterpretations in Disclosure

Third, conversely related to the issue of paternalism, are there circumstances where it is ethical to withhold information when there is evidence (or merely concern) that patients may misinterpret the data, potentially adding to their anxiety or inducing them to make decisions that do not optimize their chance to receive a transplant?

When disclosing any information, it is always important to consider the possibility that data can be misinterpreted. If there is a concern that patients are misinterpreting data, the first step should be an assessment of the reason(s) for the misunderstanding. Does the confusion arise from how the data are presented? Is the patient receiving conflicting information from other sources? Does the patient lack comprehension of how the data apply to them? Widespread, persistent misinterpretations of data could have a negative effect on patients and should lead to a systematic effort to consider how the data are defined, collected, publicly presented, described, and portrayed.

In other words, rather than withholding information because of concerns about how it might be interpreted, it is better to offer educational resources which aid interpretation. There still may be valid exceptions to disclosure, but these could be addressed on a case-by-case basis, with specific reasons proffered when information is withheld. In keeping with a patient-centered approach to transparency, it is imperative that the public understands both what is shared and, in exceptional cases, the process by which certain data are determined to remain exclusive.

Experiential Examples of Transparency

The ethical principles described above support the disclosure of additional information that may be helpful to patients when selecting a transplant program. The Committee presents four examples in which patients might seek greater clarity and transparency during the pre-evaluation phase. Collectively, these examples demonstrate how information that comprehensively addresses a variety of medical characteristics can inform transplant evaluations,[75] thereby impacting imminent decision-making. The Committee justifies transparency within each example by appealing to **autonomy, procedural justice, equity, and utility** as detailed above.

Although the Committee chose to focus on these representative conditions, which reflect many patients seeking transplantation, this is not an exhaustive list. A discussion of concrete examples illustrating the

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[74] Brett, "Perspectives."

[75] Schaffhausen, "Comparing."

ethical justifications supports ease of understanding for a diverse readership. The patient-facing data suggested in each example are meant to be illustrative, not exhaustively inclusive. They are not meant to be comprehensive of all patient experiences, nor do they dictate medical practice to transplant programs.

Example 1: Alcohol Use

Liver transplant patients may struggle to identify programs available to them before initiating evaluation and may need information about how selection criteria impact access to transplant, as well as information specific to their medical characteristics, both of which inform decision-making.[76] Patients with end-stage liver disease with a recent history of alcohol use could be concerned about their perceived fitness for referral.[77] This subset of patients may ask the question: "If I were to be evaluated for transplant, how likely is it that I would be waitlisted at that program? What are the requirements, if any, about abstinence periods?" Information regarding the steps for physician referral and self-referral promotes autonomy by allowing the patient to search for programs that would accept them for pre-transplant evaluation despite recent alcohol use while excluding programs that disqualify patients before evaluation due to recent alcohol use.[78] If a patient were informed of a required abstinence period prior to evaluation, they would be able to more adequately consider their options prior to utilizing their insurance and other out-of-pocket expenses.[79,80] This underscores the importance of bi-directional communication prior to the evaluation process, where a patient becomes aware of clear expectations for what might be required to move a process forward and possibly given resources with which to do so.

Example 2: Obesity

Obese patients may face challenges in trying to understand a particular program's listing practices for patients based on high BMI if data are not publicly available, an issue that is exacerbated because obese patients often face longer time on the waitlist because of their weight. [81]

Data show that 21% of kidney transplant programs do not list any patients with BMI greater than 40 kg/m^2, and 15% do not list patients with BMI greater than 35 kg/m^2.[82] The median time to transplant for patients with kidney disease and a BMI greater than or equal to 35 kg/m^2 is 10 months longer than for patients with a BMI below 30.[83] Improved transparency about BMI criteria and time to transplant for patients with high BMI presents substantial opportunities for improving equity in access. Sharing information about why BMI matters more at a particular transplant program and why the program sets a BMI threshold will include obese patients in the process of selecting an appropriate transplant

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[76] Ibid.

[77] Philippe Mathurin and Michael R. Lucey, "Liver transplantation in patients with alcoholic-related liver disease: current status and future directions," *The Lancet Gastroenterology & Hepatology* 5, 5 (May 2020): 507-514. https://doi.org/10.1016/S2468-1253(19)30451-0.

[78] Ibid.

[79] Sumitha Ganji et al., "Concerns regarding the financial aspects of kidney transplantation: perspectives of pre-transplant patients and their family members," *Clinical Transplantation* 28, 10 (Oct 2014): 1121-1130. https://doi.org/10.1111/ctr.12428.

[80] Leigh Anne Dageforde et al., "Understanding Patient Barriers to Kidney Transplant Evaluation," *Transplantation* 99, 7 (July 2015): 1463-1469. https://doi.org/10.1097/TP.0000000000000543.

[81] Amy G. Fiedler et al., "Survival in orthotopic heart transplantation in patients with BMI >=35 with and without diabetes," *Clinical Transplant* 35, 10 (Oct 2021): e14400. https://doi.org/10/1111/car.14400.

[82] Dorry L. Segev et al., "Obesity Impacts Access to Kidney Transplantation," *Journal of the American Society of Nephrology* 19, 2 (Feb 2008): 349-355. https://doi.org/10.1681/ASN.2007050610.

[83] Ivo G. Tzvetanov et al., "Robotic kidney transplantation in the obese patient: 10-year experience from a single center. *American Journal of Transplantation* 20, 2 (Sep 2019): 430-440. https://doi.org/10.1111/ajt.15626.

program, leading to an increase in access for these patients (upholding equity). A patient's likelihood to have a successful transplant may depend on having some knowledge of the program's record of getting people transplanted who entered the evaluation with a high BMI.

Patients with higher BMIs might benefit from understanding which approaches a program takes to waitlisting status while they attempt to lose weight to achieve a target BMI. They may also wonder what resources are available at programs to help them achieve weight loss and meet the program's stated target. Patients may seek to know which programs offer sleeve gastrectomy in combination with transplant or robotic-assisted kidney transplant, which show good outcomes for obese patients. [84] Providing the program's BMI cut-off would be more patient-friendly and informative than requiring patients to search through outcome data to inform their decision.

To summarize, the principle of autonomy supports publicizing criteria that programs use in deciding whether to list patients who are obese, how obesity affects time on the waitlist, and what the outcomes are for obese patients compared to non-obese patients. Autonomy and equity would be served by a uniform approach to presenting this information accessibly and in a way that does not reduce access for people because of their weight, but provides information on the rationale for placing limits on BMI.[85]

Example 3: Potentially Frail Patients

Organ transplants are rigorous procedures under the best of circumstances, with lung transplants reporting 1-and 5-year survival of 85% and 59%, respectively, since 2010.[86] Patients that have increased vulnerability to adverse outcomes or decreased capacity to tolerate stressors may be considered higher risk.[87] Patients may want to know what additional considerations programs take when deciding who has the physical capacity to undergo surgery and who is too frail. Frailty is a clinical syndrome, and currently, there is no consensus about standards for defining it.[88,89] Patient awareness of their characteristics that might lead transplant programs to consider them frail, and knowledge of how a program might evaluate them for suitability, would allow patients to make wiser choices about evaluation. For example, a patient with diabetes and below the knee amputation may be limited in their ability to perform a timed walk test, which is a common test in a transplant evaluation, but may meet other criteria for robustness.[90] Patients may also learn whether transplant programs have services to help them increase endurance.[91]

Frail individuals may experience decreased pain tolerance and additional physical trauma from surgical complications. They may ask: "What resources are available for patients like me at this transplant

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[84] Mario Spaggiari et al., "Simultaneous robotic kidney transplantation and bariatric surgery for morbidly obese patients with end-stage renal failure," *American Journal of Transplant* 21, 4 (Apr 2021): 1525-1534. https://doi.org/10.1111/ajt.16322.

[85] Christopher J. Hill et al., "Recipient obesity and outcomes after kidney transplantation: a systematic review and meta-analysis," *Nephrology Dialysis Transplantation* 30, 8 (Aug 2015):1403-1411. https://doi.org/10.1093/ndt/gfv214

[86] Saskia Bos et al., "Survival in adult lung transplantation: where are we in 2020?" *Current Opinion in Organ Transplantation* 25, 3 (June 2020):268-273. https://doi.org/10.1097/MOT.0000000000000753.

[87] Gotaro Kojima, Ann Liljas, and Steve Iliffe, "Frailty syndrome: Implications and challenges for health care policy," *Clinical Journal of the American Society of Nephrology* 11, 4 (Feb 2019):684-693. https://doi.org/10.2147/RMHP.S168750.

[88] Linda P. Fried et al., "Frailty in older adults: Evidence for a phenotype," *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences* 56, 3 (Mar 2001): M146-156. https://doi.org/10.1093/gerona/56.3.m146.

[89] George Bayliss, "Frailty and Kidney Transplantation," *Rhode Island Medical Journal* 104 (Feb 2021): 15-19.

[90] Mara A. McAdams-DeMarco et al., "Perceptions and Practices Regarding Frailty in Kidney Transplantation: Results of a National Survey," *Transplantation* 104, 2 (Feb 2020): 349-356. https://doi.org/10.1097/TP.0000000000002779.

[91] Ram Jagannathan et al., "Physical activity promotion for patients transitioning to dialysis using the "Exercise is Medicine" framework: A multi-center randomized pragmatic trial (EIM-CKD trial) protocol," *BMC Nephrology* 19, 230 (Sep 2018). https://doi.org/10.1186/s12882-018-1032-0.

program?" Pain management and special attention to this patient population (such as providing access to pre-habilitation services and anticipating potential complications) will lead to more frail patients being eligible for transplant, in turn, leading to greater utility.[92]

Patients who may meet one or more of a programs' criteria for frailty would have an interest in knowing if a transplant program offers pre-habilitation services to enhance functional capacity prior to surgery.[93] As an alternative to being declined for transplant completely, these patients might benefit from being made aware of plans for improving their strength and nutrition and what risk factors that might cause a program to move a patient to inactive status or off the waitlist entirely.

Finally, frail patients may have a tougher time rehabilitating or tolerating prescribed post-transplant drug regimens and therefore derive greater utility from the transparency of information regarding program standards for management and communication after a surgical procedure. Beyond 1-year and 3-year patient and graft survival, these patients may seek information on other factors that significantly influence their experienced quality of life, such as oxygen dependence, chronic lung allograft dysfunction, and the chance of returning home (as opposed to a rehabilitation or skilled nursing facility) post-transplant.[94,95]

Example 4: Highly Sensitized

Approximately 35% of patients waitlisted for a kidney transplant are sensitized to human leukocyte antigens (HLA), which increases their chances of acute rejection after transplant and decreases the number of individuals who can donate to them.[96] Highly sensitized patients can expect longer times on the waitlist and may require multiple evaluations with potential living donors due to cross-match incompatibility.[97]

Highly sensitized patients would arguably benefit from additional data about transplant program structure that may not be as relevant to less sensitized patients. Transplant programs that incorporate paired exchange programs or provide intravenous immune globulin (IVIG) therapy may be preferable to the highly sensitized patient who otherwise may rely solely on the deceased donor allocation system. Since highly sensitized patients often require more potential living donor evaluations to find a good match, they may want to know a program's policy about evaluating multiple potential donors simultaneously or benefit from additional data about living donation. They may wonder: "does the program have donor recruitment coaching or assistance in starting a living donor chain?" These patients may also benefit from understanding the roles of program staff who are dedicated to living donor services.[98] Because immunosuppressive and desensitization therapies increase the risk of complications like infection, highly sensitized patients may have a greater need for access to longer-term program outcomes beyond the 1-year and 3-year benchmarks.[99]

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[92] McAdams-DeMarco, "Perceptions."

[93] Fei-Pi Lin et al., "Prehabilitation-Driven Changes in Frailty Metrics Predict Mortality in Patients with Advanced Liver Disease," *American Journal of Gastroenterology* 11, 10 (Oct 2021): 2105-2117. https://doi.org/10.14309/ajg.0000000000001376.

[94] Bos, "Survival."

[95] Kendra E. Brett et al., "Quality metrics in solid organ transplantation: A systematic review," *Transplantation* 120, 7 (July 2018): e308-330. https://doi.org/10.1097/TP.0000000000002149.

[96] Enver Akalin, "A New Treatment Option for Highly Sensitized Patients Awaiting Kidney Transplantation," *American Journal of Kidney Diseases* 71, 4 (Apr 2018): 458-460. https://doi.org/10.1053/j.ajkd.2017.10.024.

[97] Ibid.

[98] Jayme E. Locke et al., "Enhanced Advocacy and Health Systems Training Through Patient Navigation Increases Access to Living-donor Kidney Transplantation," *Transplantation* 104, 1 (Jan 2020). https://doi.org/10.1097/TP.0000000000002732.

[99] Douglas S. Keith and Gayle M. Vranic, "Approach to the Highly Sensitized Kidney Transplant Candidate," *Clinical Journal of the American Society of Nephrology* 11, 4 (Apr 2016):684-693. https://doi.org/10.2215/CJN.05930615.

Information about donor selection criteria and outcomes may be relevant for a patient who already has a potential donor in mind. The autonomy of both the donor and the patient must be respected without marginalizing the desires of either. The donor, who is a healthy altruistic individual voluntarily submitting to an extensive battery of tests prior to a substantial surgical procedure, is understandably warranted in wanting to seek a clear understanding of the workup, para-surgical, and follow up processes required by the program. Transparency in information regarding these two related, yet distinct, protocols enhance procedural justice for the donor-recipient pair. Autonomy is restricted when patients are relegated to choosing a transplant program based on limited information.

Accessing versus Understanding Information

Equitable access to information is essential to ensuring transparency in program selection. However, merely making information available, and not ensuring that information is usable, understandable, and accessible to patients will fall short of the goals of protecting patient autonomy and improving equity. Even if relevant information is available, some patients may have barriers to accessing it or may find the information challenging to navigate. Patients who can access the information may face difficulties understanding it or may be overwhelmed by the scope of information.[100] The process is further complicated by the fact that pre-transplant concerns will vary depending on whether the person seeking information is the patient, a potential living donor, or a member of a patient's social support network.[101]

While optimal health communication poses an important and persistent challenge for public health agencies and clinicians (and one where guidance is beyond the scope of this paper), the Committee briefly notes a few issues that must be addressed to achieve the goal of increased transparency in line with the ethical principles outlined above.

Reliance on Internet for Information Availability

Three overwhelming issues arise when relying on the internet (Worldwide Web) for information: infrequent internet access, inadequate digital literacy necessary to inform their decisions, [102] and insufficient health literacy. The digital information available may not sufficiently inform a patient about how best to pursue a transplant. The U.S. Department of Education estimates that 16% of American adults are not digitally literate.[103,104] Digital illiteracy is higher in Black (22%), Hispanic (35%), and advanced age population (28% in 55-65 years old), which are all groups disproportionately represented on the waitlist.[105,106] When a patient is required to rely on technology, which assumes access and digital literacy to find information on which to make decisions, inadequate internet access and computer ability impede upon one's autonomy and ability to make well-informed decisions for their health. Health literacy poses a second concern. Health literacy is defined by the National Institutes of Health (NIH) as

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[100] Schaffhausen, "The importance."

[101] Heather F. Hunt et al., "Strategies for Increasing Knowledge, Communication, and Access to Living Donor Transplantation: an Evidence Review to Inform Patient Education," *Current Transplantation Reports* 5, 27 (Feb 2018): 27-44. https://doi.org/10.1007/s40472-018-0181-1.

[102] John B. Horrigan, "Digital Readiness Gaps," *Pew Research Center* (Sep 2016), accessed May 2, 2022, https://www.pewresearch.org/internet/2016/09/20/digital-readiness-gaps/.

[103] U.S. Department of Education, *A Description of U.S. Adults Who Are Not Digitally Literate,* Saida Mamedova and Emily Pawlowski. NCES 2018-161, Washington, D.C.: 2018, https://nces.ed.gov/pubs2018/2018161.pdf (accessed March 28, 2022).

[104] The above report defines "not digitally literate" through the PIAAC requirements for determining basic computer competence: "(1) prior computer use, (2) willingness to take the assessment on the computer, and (3) passing a basic computer test (by successfully completing four of the six simple tasks, such as using a mouse and highlighting text on the screen."

[105] U.S Department of Education, "A Description."

[106] Park, "A scoping."

"the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others."[107] The current system relies on digital literacy to facilitate health literacy but falls short in meeting the needs of the patient. Low health literacy has been associated with lower rates of referral to transplant evaluation.[108] Steps can be taken to mitigate these inequities to access. For example, a national service that telephonically provides selection support independent of professional relationships and standard referral patterns[109] could enhance autonomy and provide utility to patients regardless of structural barriers and health literacy.

Accessibility of Information:

Equity is furthered by increasing opportunity to access information, not just for people with equipment, skills, and ability to understand it. Further, resources should be accessible for patients with visual or hearing impairments, non-native English speakers, and those with limited health or digital literacy. Information should support autonomy for all, including persons who do not have access to a smartphone or computer or lack access or functional skills adequate to explore online databases and materials.

Information written for a clinical audience that is not appropriately adapted for patients limits the proportion of patients that can incorporate the data into their decision-making process. Further, there is often a disconnect between patient preferences for information and what providers think patients want.[110] Patient-centered design techniques, including patient co-ownership of the development process at each stage and iterative refinement with the patient, can avoid user-related design errors that impede access and dissemination of transplant program information.[111]

Conclusion

The Committee concludes that principles of autonomy, equity, utility, and a procedural justice strongly support increasing patient access to pre-waitlist data and information about the transplant evaluation process and waitlisting decisions. These principles are core to the organ transplant system and imperative to maintain an ethical system of allocation.[112] Transparent data that contribute to patients' ability to be waitlisted is necessary for ensuring equitable access to care while supporting patient autonomy and utility. Greater transparency about pre-listing information can help patients find programs that are the best fit for their health needs, values, and preferences. This white paper supports transparency and accountability within the transplant system through an ethical analysis that lays the foundation for future improvements.

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[107] National Institutes of Health, "Health Literacy," accessed May 20, 2022, https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/health-literacy#:~:text=%22Personal%20health%20literacy%20is%20the,actions%20for%20themselves%20and%20others.

[108] Vanessa Grubbs et al., "Health Literacy and Access to Kidney Transplantation," *Clinical Journal of the American Society of Nephrology* 4, 9 (Jan 2009): 197-198. https://doi.org/10.2215/CJN.03290708.

[109] Rachel C. Forbes et al., "Implementation of telehealth is associated with improved timeliness to kidney transplant waitlist evaluation," *Journal of Telemedicine and Telecare* 24, 7 (Aug 2018): 485-491. https://doi.org/10.1177/1357633X17715526.

[110] Christine Bechtel and Debra L. Ness, "If You Build It, Will They Come? Designing Truly Patient-Centered Health Care," *Health Affairs* 25, 9 (May 2010). https://doi.org/10.1377/hlthaff.2010.0305.

[111] Victor P. Cornet et al., "Patient-centered Design Grounded in User and Clinical Realities: Towards Valid Digital Health," *Proceedings of the International Symposium on Human Factors and Ergonomics in Health Care* 8, 1 (Sep 2019): 100-104. https://doi.org/10.1177/2327857919081023.

[112] *Ethical Principles*, OPTN Ethics Committee.

366 **Table 1-1: Types of information desired by patients and professionals, by phase of transplant process)**

Types of Information desired by phase of transplant process	Who the information is desired by and what literature it was found in
General center data	
Center years performing transplant	Patients (Husain 2018)
Clinical practice differences from other centers	Professionals (Gordon 2013)
Continuity of providers throughout transplant process	Patients (Husain 2018)
Distance from home	Patients (Husain 2018)
Outreach or support program	Patients (Husain 2018, Schaffhausen 2019)
Participation in research or innovation	Patients (Schaffhausen, 2019)
Patient satisfaction	Professionals (Brett 2018, Husain 2018, van Pilsum Rasmussen 2019)
Reputation	Patients (Husain 2018)
Risk tolerance of the center	Professionals (Gordon 2013)
Staff & surgeon training	Patients (Husain 2018, Schaffhausen 2019)
Teaching institution	Patients (Husain 2018, Schaffhausen 2019)
Referral	
Citizenship status of candidate donor or recipient	Patients (Schaffhausen 2017)
Cost of pre-transplant evaluation	Patients (Husain 2018)
Insurance accepted	Patients (Husain 2018)
Multiple/alternative center listing for transplant	Patients (Schaffhausen 2017, Crenesse-Covien 2019, Schaffhausen 2019, Schaffhausen 2020)
Patient qualifications for transplant	Patients (Schaffhausen 2017, Schaffhausen 2019)
Quality of life among referred patients	Professionals (van Pilsum Rasmussen 2019)
Second opinion evaluations	Patients (Schaffhausen 2017)
Waitlisting rate (ratio of patients who are waitlisted relative to the person-years referred for evaluation) / ease of getting waitlisted	Patients (Schaffhausen 2017, Husain 2018) Professionals (Paul 2021)
Waitlisting	
Health status changes for waitlisted patients	Professionals (Brett 2018)
Organ acceptance & refusal trends	Professionals (Husain 2017, 2019, Schold 2019, van Pilsum Rasmussen 2019)
Organ acceptance, high-risk organs	Patients (Schaffhausen 2017, Schaffhausen 2019)
Quality of life among waitlisted patients	Professionals (van Pilsum Rasmussen 2019)

Types of Information desired by phase of transplant process	Who the information is desired by and what literature it was found in
Time on waiting list / time to transplant	Patients (Schaffhausen 2017, Husain 2018, Schaffhausen 2019) Professionals (Gordon 2013, van Pilsum Rasmussen 2019)
Transplant rate	Professionals (Sawinski 2018, Schold 2019, Schaffhausen 2020) Patients (Husain 2018)
Variations in illness severity at time of transplant	Patients (Schaffhausen 2017, Schaffhausen 2020)
Variations in organ availability	Professionals (Husain 2018)
Waitlist mortality	Patients (Schaffhausen 2019) Professionals (Brett 2018, Schold 2019, van Pilsum Rasmussen 2019)
Transplant	
Cost of procedure	Patients (Schaffhausen 2017, Husain 2018)
Volume of transplants, overall	Professionals (Gordon 2013, van Pilsum Rasmussen 2019) Patients (Schaffhausen 2017, Husain 2018)
Volume of transplants, based on donor-specific health characteristics (e.g. increased risk, HCV)	Professionals (McKinney 2020) Patients (Schaffhausen 2020)
Volume of transplants, based on patient-specific health characteristics (e.g. age, BMI)	Patients (Husain 2018, McKinney 2020, Schaffhausen 2017, Schaffhausen 2020)
Volume of transplants, complex cases	Patients (Husain 2018)
Post-transplant	
Complications & readmissions	Patients (Husain 2018) Professionals (Brett 2018, van Pilsum Rasmussen 2019)
Functional status of recipients	Professionals (van Pilsum Rasmussen 2019)
Immunosuppression regimen variations	Professionals (Gordon 2013)
Infectious disease transmission	Professionals (Brett 2018)
Patient-reported outcomes	Professionals (Schold 2019)
Patient or graft survival	Patients (Husain 2018, Schaffhausen 2017, Schaffhausen 2019, Schaffhausen 2020) Professionals (Gordon 2013, Howard 2006, Schold 2019)
Post-transplant care expectations and ease	Patients (Husain 2018) Professionals (Gordon 2013)
Post-transplant length of stay	Professionals (Brett 2018, van Pilsum Rasmussen 2019)

Types of Information desired by phase of transplant process	Who the information is desired by and what literature it was found in
Quality of life among transplanted patients	Professionals (van Pilsum Rasmussen 2019)
Living donor	
Living donor outcomes	Patients (Schaffhausen 2017)

Table 1-2: Database search terms

	Question 1: Patient selection of transplant programs	Question 2: Patient selection of transplant programs in Hispanic and African American patients
Medline (EBSCO)	**356 Results | English Language** ((TI transplant* OR AB transplant*) N5 (TI center* OR AB center* OR TI program OR AB program OR TI programs OR AB programs)) AND (MM "Patient Preference" OR MM "Patient Education as Topic" OR MM "Choice Behavior" OR (TI patient-centered OR TI patient-specific OR AB patient-centered OR AB patient-specific OR ((TI patient* OR AB patient* OR TI candidate* OR AB candidate* OR TI recipient* OR AB recipient) AND (MH “Decision Making”)) OR ((TI patient* OR AB patient* OR TI candidate* OR AB candidate* OR TI recipient* OR AB recipient*) N7 (TI decision-making OR AB decision-making OR TI decision-support OR AB decision-support OR TI preference* OR AB preference* OR TI perception* OR AB perception*)))) AND (LA English) NOT (TI clinical-decision-making OR AB clinical-decision-making)	**178 Results | English Language** (MH “Organ Transplantation+” OR MH “Transplant Recipients” OR ((TI transplant* OR AB transplant*) N5 (TI organ OR AB organ OR TI organs OR AB organs OR TI liver* OR AB liver* OR TI kidney* OR AB kidney* OR TI heart* OR AB heart* OR TI lung* OR AB lung* OR TI pancreas OR AB pancreas OR TI center* OR AB center* OR TI program OR AB program OR TI programs OR AB programs OR recipient*))) AND (MM "Patient Preference" OR MM "Patient Education as Topic" OR MM "Choice Behavior" OR (TI patient-centered OR TI patient-specific OR AB patient-centered OR AB patient-specific OR ((TI patient* OR AB patient* OR TI candidate* OR AB candidate* OR TI recipient* OR AB recipient*) AND (MH “Decision Making”)) OR ((TI patient* OR AB patient* OR TI candidate* OR AB candidate* OR TI recipient* OR AB recipient*) N7 (TI decision-making OR AB decision-making OR TI decision-support OR AB decision-support OR TI preference* OR AB preference* OR TI perception* OR AB perception*)))) AND (MH "Ethnic Groups+” OR MH "Minority Groups+” OR MH "Minority Health+" OR TI african-american* OR AB african-american* OR TI afro-american* OR AB afro-american* OR TI black* OR AB black* OR TI Hispanic* OR AB Hispanic* OR TI Mexican* OR AB Mexican* OR TI latino* OR AB latino* OR TI Latina* OR AB latina* OR TI latinx OR AB latinx OR TI minorit* OR AB minorit* OR TI race OR AB race OR TI racial OR AB racial OR TI ethnic-group* OR AB ethnic-group* OR TI ethnicit* OR AB ethnicit*) AND (LA English)

	Question 1: Patient selection of transplant programs	Question 2: Patient selection of transplant programs in Hispanic and African American patients
PubMed narrow	**Exact phrases for transplant centers/programs** **368 Results | English Language** ((transplant-center*[tiab] OR transplant-program[tiab] OR transplant-programs[tiab] OR transplantation-center*[tiab] OR transplantation-program[tiab] OR transplantation-programs[tiab]) AND ("Patient Preference"[majr] OR "Choice Behavior"[majr:noexp] OR "Patient Education as Topic"[majr] OR patient-centered[tiab] OR patient-specific[tiab] OR ((patient*[tiab] OR candidate*[tiab] OR recipient*[tiab]) AND ("Decision-Making"[mesh:noexp] OR decision-making[tiab] OR decision-support[tiab] OR preference*[tiab] OR perception*[tiab]))) AND english[filter]) NOT (clinical-decision-making[tiab])	**Exact phrases for transplant centers/programs/organs)** **277 Results | English Language** ("Organ Transplantation"[mesh] OR "Transplant Recipients"[mesh] OR organ-transplant*[tiab] OR liver-transplant*[tiab] OR heart-transplant*[tiab] OR kidney-transplant*[tiab] OR lung-transplant*[tiab] OR pancreas-transplant*[tiab] OR transplant-center*[tiab] OR transplant-program[tiab] OR transplant-programs[tiab] OR transplantation-center*[tiab] OR transplantation-program[tiab] OR transplantation-programs[tiab] OR transplant-recipient*[tiab]) AND ("Patient Preference"[majr] OR "Choice Behavior"[majr:noexp] OR "Patient Education as Topic"[majr] OR patient-centered[tiab] OR patient-specific[tiab] OR ((patient*[tiab] OR candidate*[tiab] OR recipient*[tiab]) AND ("Decision-Making"[mesh:noexp] OR decision-making[tiab] OR decision-support[tiab] OR preference*[tiab] OR perception*[tiab]))) AND ("Ethnic Groups"[mesh] OR "Minority Groups"[mesh] OR "Minority Health"[mesh] OR african-american*[tiab] OR afro-american*[tiab] OR black*[tiab] OR Hispanic*[tiab] OR Mexican*[tiab] OR latino*[tiab] OR Latina*[tiab] OR latinx[tiab] OR minorit*[tiab] OR race[tiab] OR racial[tiab] OR ethnic-group*[tiab] OR ethnicit*[tiab]) AND english[filter]
PubMed broad *These search terms were used.*	**Transplant with center or program in title/abstract** **1132 Results | English Language, remove clinical decision-making from title/abstract** ((transplant*[tiab]) AND (center[tiab] OR centers[tiab] OR program[tiab] OR programs[tiab]) AND ("Patient Preference"[majr] OR "Choice Behavior"[majr:noexp] OR “Patient Education as Topic”[majr] OR patient-centered[tiab] OR patient-specific[tiab] OR ((patient*[tiab] OR candidate*[tiab] OR recipient*[tiab]) AND ("Decision-Making"[mesh:noexp] OR decision-making[tiab] OR decision-support[tiab] OR preference*[tiab] OR perception*[tiab]))) AND english[filter]) NOT (clinical-decision-making[tiab])	**Transplant within title/abstract of organs/programs/centers** **314 Results | English Language** ("Organ Transplantation"[mesh] OR “Transplant Recipients”[mesh] OR ((transplant*[tiab]) AND (organ[tiab] OR kidney*[tiab] OR liver[tiab] OR heart[tiab] OR lung*[tiab] OR pancreas[tiab] OR center*[tiab] OR program[tiab] OR programs[tiab] OR recipient*[tiab]))) AND ("Patient Preference"[majr] OR "Choice Behavior"[majr:noexp] OR "Patient Education as Topic"[majr] OR patient-centered[tiab] OR patient-specific[tiab] OR ((patient*[tiab] OR candidate*[tiab] OR recipient*[tiab]) AND ("Decision-Making"[mesh:noexp] OR decision-making[tiab] OR decision-support[tiab] OR preference*[tiab] OR perception*[tiab]))) AND ("Ethnic Groups"[mesh] OR "Minority Groups"[mesh] OR "Minority Health"[mesh] OR african-american*[tiab] OR afro-american*[tiab] OR black*[tiab] OR Hispanic*[tiab] OR Mexican*[tiab] OR latino*[tiab] OR Latina*[tiab] OR latinx[tiab] OR minorit*[tiab] OR race[tiab] OR racial[tiab] OR ethnic-group*[tiab] OR ethnicit*[tiab]) AND english[filter]

Table 1-3: Article selection flowsheet