

# *Briefing to the OPTN Board of Directors on*

# **Ethical Evaluation of Multiple Listing**

*OPTN Ethics Committee*

*Prepared by: Stryker-Ann Vosteen, MPA and Cole Fox, MPA  
UNOS Policy and Community Relations Department*

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# Ethical Evaluation of Multiple Listing

*Sponsoring Committee:* Ethics  
*Public Comment Period:* January 19, 2023 – March 18, 2023  
*Board of Directors Meeting:* June 26, 2023

## Executive Summary

Multiple listing as a policy permits patients to be listed at multiple transplant programs and accept organ offers from more than one transplant program simultaneously. The purpose of the *Ethical Evaluation of Multiple Listing* white paper is to provide an analysis of multiple listing in relation to equity (including distributive justice and procedural justice), autonomy, and utility, which are the foundation of an ethical transplant system. In addition to the ethical analysis, the OPTN Ethics Committee (hereafter, the Committee) examined data regarding the prevalence of multiple listing, whether it confers an advantage in likelihood of transplant, and the sociodemographic patterns of utilization of multiple listing.

Since multiple listing tends to be used by patients with higher socioeconomic status and is associated with higher transplant rates compared to single listed candidates, it may exacerbate existing disparities with equitable access to transplant.<sup>1</sup> The Committee affirms in its ethical analysis that:

- There is a need for optimizing access to multiple listing for pediatric patients, candidates who list at Veterans Affairs (VA) hospitals and highly sensitized candidates
- Providing better financial support and more consistent information about multiple listing and multiple evaluations for patients may reduce inequities
- Not allowing transplant programs to deny listing a patient because they want to be multiply listed would ensure more consistent treatment for all patients

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<sup>1</sup> Katrina Gauntt, Keighly Bradbrook, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Kidney and Liver Candidates by Geography,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, September 14, 2022.

## Purpose

The purpose of this white paper is to conduct an ethical analysis of multiple listing and the implications of how the practice impacts the transplant system. The Committee conducted two data requests to examine the prevalence of multiple listing, whether it confers an advantage in likelihood of transplant, and examined the sociodemographic patterns of utilization of multiple listing. The purpose of reviewing these data was to complement the ethical analysis and provide feedback to the Board that is most relevant and grounded in current evidence. Ultimately, this white paper answers the question “What are the ethical implications of permitting patients to be listed at multiple transplant programs?”

## Background

### Policy

This ethical analysis was conducted in consideration of the existing multiple listing policies. Multiple listing is established by *OPTN Policy 3.4.F: Multiple Transplant Program Registrations*, which permits transplant candidates to register for an organ at multiple transplant programs.<sup>2</sup> Additionally, *OPTN Policy 3.2: Notifying Patients of Their Options* requires transplant programs to inform the patient that they have the option to register at multiple transplant programs, and whether that transplant program accepts patients with multiple registrations.<sup>3</sup> Although current policy requires that patients be informed of this option, compliance with the requirement is not actively monitored, so it is difficult to ascertain the degree to which transplant programs comply with this policy. It is also difficult to assess the degree to which patients understand and can act on the knowledge of multiple listing.

Since the OPTN Board of Directors last considered modifying multiple listing policy in 2003, the practice has continued to generate controversy regarding its potential impact, equity, and benefit.<sup>4,5,6,7,8</sup> While changes to the multiple listing policy have been considered by the Board previously, the ethical implications of the policy have not.<sup>9,10,11</sup> The history of OPTN consideration of changing multiple listing policy is extensively reviewed in the January 2023 multiple listing public comment proposal.<sup>12</sup> The white paper uses the following definitions in reference to the ethical principles of transplant:

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<sup>2</sup> *OPTN Policy 3.4.F Multiple Transplant Program Registrations*, 2022.

<sup>3</sup> *OPTN Policy 3.2 Notifying Patients of Their Options*, 2022.

<sup>4</sup> OPTN/UNOS Board of Directors Meeting Minutes, November 20-21, 2003, Richmond, Virginia

<sup>5</sup> Nino Dzebisashvili et al., “Following the Organ Supply: Assessing the Benefit of Inter-DSA Travel in Liver Transplantation,” *Transplantation* 95, 2 (Jan 2013). <https://doi.org/10.1097/TP.0b013e3182737cfb>.

<sup>6</sup> Eitan Neidich et al., “Consumerist Response to Scarcity of Organs for Transplant,” *AMA Journal of Ethics* 15, 11 (Nov 2013): 966-972. <https://doi.org/10.1001/virtualmentor.2013.15.11.pfor2-1311>.

<sup>7</sup> Konrad Hoetzenecker, “Commentary: The Ethical Dilemma of Multiple Listing,” *Seminars in Thoracic and Cardiovascular Surgery* 34, 1 (March 2022): 336. <https://doi.org/10.1053/j.semctvs.2021.04.045>.

<sup>8</sup> Gebhard Waegener, “Multiple Listings: Good for a Few, but No Solution for the Organ Shortage,” *Transplantation* 104, 4 (Apr 2020). <https://doi.org/10.1097/TP.0000000000002966>.

<sup>9</sup> United Network for Organ Sharing Board of Directors Meeting, March 21, 1988, Washington D. C.

<sup>10</sup> United Network for Organ Sharing Board of Directors Meeting Transcript, March 1-2, 1995, New Orleans, Louisiana.

<sup>11</sup> OPTN/UNOS Board of Directors Meeting Minutes, November 20-21, 2003, Richmond, Virginia

<sup>12</sup> OPTN Ethics Committee, *Ethical Evaluation of Multiple Listing Public Comment Proposal*, pg 3-5. January 2023, [https://optn.transplant.hrsa.gov/media/150dohtm/ethical-evaluation\\_multiple-listing\\_white-paper\\_ethics\\_pc-winter-2023.pdf](https://optn.transplant.hrsa.gov/media/150dohtm/ethical-evaluation_multiple-listing_white-paper_ethics_pc-winter-2023.pdf)

## Ethical Principles

- **Equity** “refers to fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program.”<sup>13</sup>
  - **Distributive justice** in organ allocation is defined as dictating “fairness in the distribution of scarce resources so that similarly needy patients have an equal opportunity to benefit from transplantation.”<sup>14</sup>
  - **Procedural justice** refers to appraisal of the fairness of how decisions are made.”<sup>15</sup>
- “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.”<sup>16</sup> Notably, autonomy of one individual cannot impair the autonomy of another individual.
- “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).”<sup>17</sup>

These ethical principles are the foundation of an ethical transplant system and require thoughtful deliberation to ensure the system continues to operate as intended. Each of the above-mentioned principles is detailed in the analysis and its connection to multiple listing is emphasized. In this revised draft, the role of autonomy is clarified and explained in further detail, as it was a focus of public comment feedback.

## Review of Data

To review current evidence relevant to the ethical implications of multiple listing, the Committee submitted two data requests which depict patient access and geographic variability in multiple listing.<sup>18,19</sup> The intent of these data requests was to better understand the accessibility of multiple listing and did not review the outcomes of patients who were single versus multiple listed. The data supplements the ethical analysis by depicting the connection between the theoretical and the practical. The Committee examined data regarding multiple listing to consider whether patients can equally utilize the practice and whether it confers an advantage in the likelihood of obtaining a transplant.

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

<sup>14</sup> OPTN Ethics Committee, *Manipulation of the Organ Allocation System Waitlist Priority through the Escalation of Medical Therapies*, June 2018, [https://optn.transplant.hrsa.gov/media/2500/ethics\\_whitepaper\\_201806.pdf](https://optn.transplant.hrsa.gov/media/2500/ethics_whitepaper_201806.pdf).

<sup>15</sup> 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 (Mar 2005): 63-81. <https://doi.org/10.1007/s11211-005-3393-3>.

<sup>16</sup> OPTN Ethics Committee, *Ethical Principles*, June 2015.

<sup>17</sup> *Ibid.*

<sup>18</sup> Keighly Bradbrook, Katrina Gauntt, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Candidates By Organ Type,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, May 11, 2022.

<sup>19</sup> Katrina Gauntt, Keighly Bradbrook, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Kidney and Liver Candidates by Geography,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, September 14, 2022.

## Findings

The data analysis and ensuing discussions by the Ethics Committee indicate that multiple listing may conflict with improving equity in access to transplant. Multiple listed kidney and liver candidates have higher transplant rates compared to single listed candidates, while these multiple listed liver and kidney candidates are less likely to be on Medicaid, more likely to have private insurance, and less likely to report lower education levels.<sup>20</sup> This implies that while the current multiple listing policy complies with formal equality of opportunity by being available to all patients, it does not demonstrate fair equality of opportunity, which requires that all have a genuine and similar opportunity to achieve a particular end.<sup>21</sup> In the case of multiple listing, this would mean that all patients can similarly demonstrate and meet criteria necessary for multiple listing, as opposed to just being informed that multiple listing is permissible. Thus, the data suggest that multiple listing provides an advantage that not all patients can equally exercise.

## Overall Sentiment from Public Comment

The proposal was released for public comment from January 19, 2023 to March 18, 2023. It received 274 comments out of a total of 2,735 comments received on all projects out for public comment this cycle. Respondents were able to participate through in-person/virtual regional meetings, committee meetings, and a form on the OPTN website. Demographic information was collected from all respondents, including state of origin and stakeholder association.<sup>22</sup> The comments received represented at least 35 states across the country and all member types, with the greatest participation coming from organ procurement organizations and transplant hospitals.<sup>23</sup> It is important to consider the demographics participating in the public comment relevant to this proposal thereby ensuring that the ultimate recommendation to the Board represents all stakeholders, even those whose volume of participation may be lower.

The sentiments collected reflected a mixture of support and opposition, as indicated by a Likert score of 3.1.<sup>24</sup> There were concerns about restricting patient autonomy related to the recommendation to limit multiple listing policy to difficult to match patients. Another area of feedback was potential unintended consequences of restricting access to multiple listing to difficult to match patients, and questions about how a limited multiple listing policy would work. Continuous distribution was noted as potentially mitigating the impact of inequity in multiple listing, as well as negating the potential need to use multiple listing (and the need to address its inequity by limiting its access). However, strong support was

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<sup>20</sup> Multiple listed kidney patients were one-third as likely to be on Medicaid compared to single listed kidney patients (4.8% versus 13.2%), and multiple listed liver patients were a quarter as likely to be on Medicaid compared to singly listed liver patients. Multiple listed kidney and liver transplant patients were disproportionately more likely to have private insurance or private pay compared to single listed kidney transplant patients (53.5% versus 43.3%) and liver patients (68.8% versus 50.8%), respectively. Multiple listed kidney and liver candidates were less likely to have reported an education level of grade school or less compared to single listed kidney (3.5% versus 8%) and liver (3.4% versus 7.5%) candidates, respectively. Multiple listed kidney and liver candidates were also less likely to have reported an education level High School or GED to single listed kidney (30.1% versus 37.2%) and liver (27.3% versus 35.8%) candidates, respectively.

<sup>21</sup> Barry Goldman and Russell Cropanzano, "Justice" and "fairness" are not the same thing," *Journal of Organizational Behavior* 31, 2 (Feb 2015): 313-318. <https://doi.org/10.1002/job.1956>.

<sup>22</sup> Respondents at regional meetings represent the perspective of an institution, therefore their demographic information represents that of the institution and not the individual submitting the comment.

<sup>23</sup> Most attendees at regional meetings are transplant programs which accounts for the large volume of sentiment scores from transplant programs.

<sup>24</sup> Sentiment was collected on a 5-point Likert scale from strongly oppose to strongly support (1-5).



also expressed for the Committee's effort to address inequities resulting from multiple listing and to strengthen trust in the transplant system, even when members did not support all of the recommendations in the original public comment draft.

The white paper was not supported by most of the stakeholders who provided feedback (the exception being the International Society for Heart and Lung Transplantation (ISHLT), which considered the white paper a good resource even if continuous distribution solved most of the issues with multiple listing). Stakeholders expressing concerns included the American Society of Nephrology (ASN), Transplant Families, American Society of Transplant Surgeons (ASTS), North American Transplant Coordinators Organization (NATCO), American Society of Transplantation (AST), American Nephrology Nurses Association (ANNA), and the Society of Pediatric Liver Transplantation (SPLIT). Most concerns from these stakeholders centered around discomfort with imposing limitations on multiple listing as an option that patients may pursue. Some stakeholders (ANNA, ASN, and NATCO in particular) noted support for the efforts of the white paper to enhance equity but still expressed concern about the potential impact of trying to limit the application of multiple listing. SPLIT identified living donor transplants as an important option for pediatric candidates, a vulnerable population, and stressed the importance of leaving multiple listing as an option for candidates such as these that seek living donation but should still have the option to list elsewhere for a deceased donor organ.

Several OPTN Committees considered the white paper – Kidney, Liver, Patient Affairs, Minority Affairs, Transplant Coordinators (TCC), Transplant Administrators (TAC), Lung, Pediatric, and Histocompatibility. Many of these groups had mixed feedback – applauding the Ethics Committee for addressing inequities in the system, while expressing concerns about how the proposed changes, if adopted by the Board, would actually be applied. The comments mirrored those in the community: concern about unintended consequences, support for addressing barriers in access to transplant for those with low socioeconomic status, and questions about overlap with continuous distribution.

**Figure 1** shows sentiment by member type. All member types were represented, with the highest number of comments from transplant hospitals. Support was stronger among patients and the general public compared to stakeholder organizations and transplant hospitals, which had the lowest support for the white paper.

**Figure 1: Sentiment by Member Type**

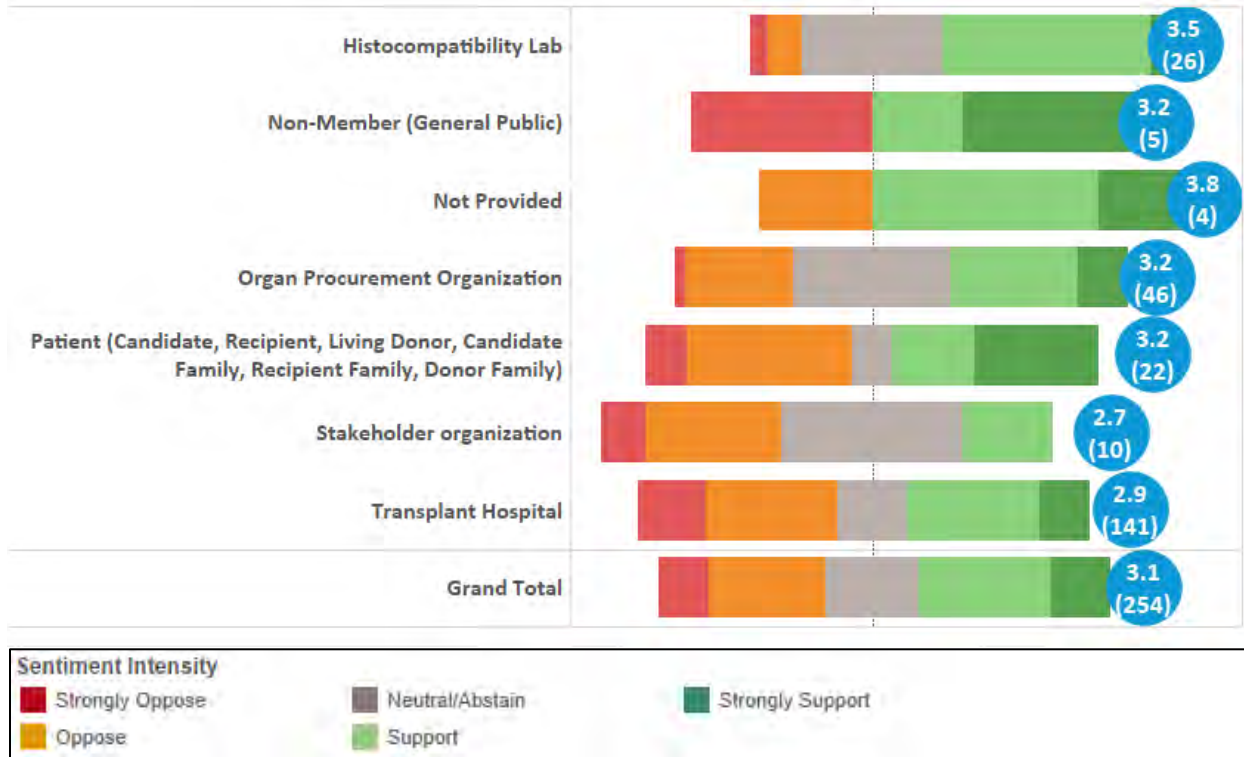
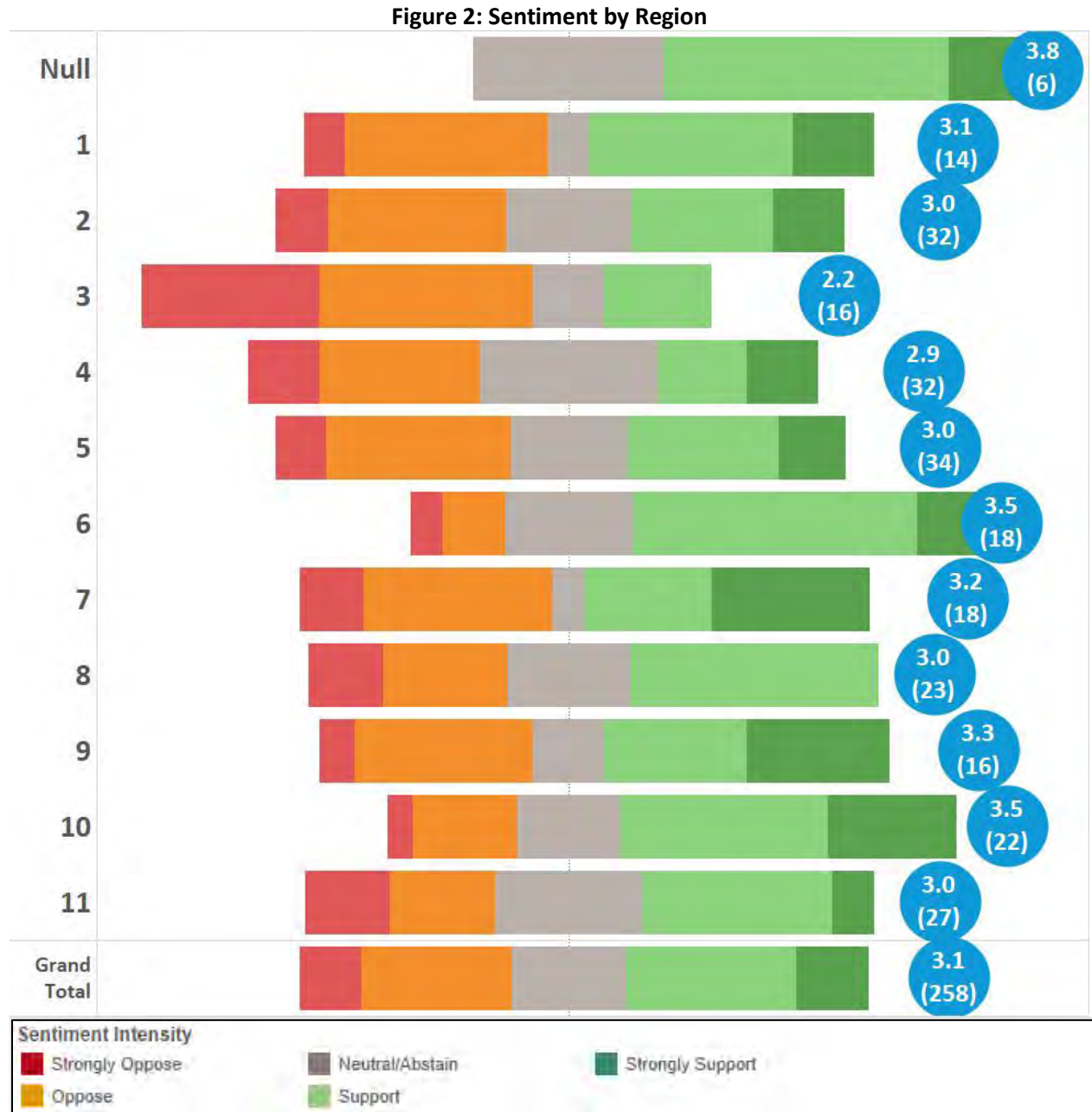


Figure 2 shows sentiment by region. The white paper was supported most strongly in regions 6 and 10. Regions 7 and 9 were also overall supportive, and regions 1, 2, 5, 8, and 11 were mixed in their sentiment. Regions 3 and 4 were opposed.







## Public Comment Themes

Feedback from the community varied by region and by stakeholder type, and perspectives differed greatly within these categories as well. However, three themes were present consistently in public comment discussions of the multiple listing white paper: 1) concerns about the impact on patient autonomy, 2) the potential for unintended consequences of removing multiple listing as an option from policy for all patients except those difficult to match, and 3) support for the importance of tackling equity issues in the transplant system. These themes and the Committee's responses are reviewed below.

### *Patient Autonomy*

The white paper issued for public comment recommended that the Board remove policy allowing multiple listing as an option except for difficult to match patients. There was a considerable amount of feedback during public comment concerned about this recommendation and its potential impact on patient autonomy. Commenters identified that challenges with insurance are imbedded in discussions of socioeconomic disparities and the recommendations limiting access would not address those challenges and suggested that acting on the recommendations in the white paper would restrict patient autonomy without addressing or solving the inequity identified. Concerns about patient autonomy were raised by almost all the stakeholder organizations, most of the regions, Board members, and some of the committees that reviewed the proposal as well.<sup>25</sup>

These comments were discussed at length during the Ethics Committee's in person meeting in deciding what changes would be appropriate to make post-public comment. The Committee noted that autonomy is defined in the paper and the particular issue of restricting access was addressed in the white paper as well. Specifically, the white paper identified that limitations on autonomy may be warranted if doing so acts as redress to perpetuating inequities in access to transplant. The Committee identified that greater clarity regarding what exactly is meant by 'autonomy' – and what is **not** meant – could be potentially helpful in addressing public comment feedback.

The Committee considered that simply not being able to address all inequities (insurance, socioeconomic barriers, etc.) is not a reason to not address potential inequity in access to multiple listing. The Committee also discussed at their in-person meeting that multiple listing is often brought up as a perceived inequity, as well as an actual one, and may impact public trust in the transplant system. Therefore, much of the substance of the ethical analysis within the white paper was retained as reflecting relevant implications about equity and public trust that the transplant community should consider.

The Committee acknowledged that there are various ways the Board could optimize multiple listing and consider impacts on autonomy. Therefore, the Committee removed its recommendations, while still highlighting the most important findings from the analysis for any next steps that the Board considers appropriate to pursue. The Committee also added an addendum to the paper for further clarity regarding questions raised during public comment, including those focused on patient autonomy.

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<sup>25</sup> Importantly, these concerns were shared by the Patient Affairs and Minority Affairs Committees, two important stakeholders to consider in terms of equity in access for patients and implications of socioeconomic disparities.

## Unintended Consequences

Another theme heard during public comment was concern about unintended consequences if the recommendations in the white paper were adopted. Commenters questioned restricting multiple listing to difficult to match patients when other patient groups may benefit from it, and highlighted that implementation efforts of continuous distribution allocation frameworks may address some of the inequities associated with multiple listing. These concerns about unintended consequences are detailed below, along with Committee responses.

### Restricting Access to Multiple Listing to Difficult to Match Patients

Some commenters discussed the potential unintended consequences of limiting patient access to multiple listing. Public comment feedback provided a variety of instances in which multiple listing may be beneficial to many different types of candidates:

- Veterans<sup>26</sup> who list at VA centers not near them as well as local center
- Pediatrics while they seek living donors
- Patients that may age out of center waitlisting practices
- Patients who may have socioeconomic access barriers but have family in another place who could take care of them
- Patients who may be more comfortable with the team at one center but encouraged by the center to list elsewhere if other centers are more aggressive or have different criteria; in these cases, they may be reluctant to sever ties with the center with which they've worked most closely
- Those living in medically underserved or rural areas may have better access through multiple listing
- Those seeking living donation may still seek access to a deceased donor organ and should not be restricted for doing so


The Committee acknowledged that the impact on vulnerable populations such as pediatrics and candidates who list at VA hospitals should be incorporated in any effort to optimize multiple listing as a practice, and the relevant conclusion about improving access to multiple listing for certain vulnerable populations was modified accordingly.

### How Limiting Multiple Listing Would Work

Community members expressed concerns with limiting multiple listing to difficult to match patients without identifying who these patients would be. Similarly, feedback included questions regarding how the logistics of implementing limitations to multiple listing would work; some comments noted the challenges of limiting access to multiple listing when patient behavior may reflect changing

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<sup>26</sup> It was noted post-public comment that veterans may not be the only people who list at Veterans Affairs hospitals, and the final white paper was updated to refer to “candidates who list at Veterans Affairs hospitals.” Details about the types of people eligible to receive care at VA hospitals can be found at the VA website (see: <https://www.va.gov/health-care/eligibility/>) and is also described in Code of Federal Regulations in the *Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) - Medical Care for Survivors and Dependents of Certain Veterans* (Code of Federal Regulations, *Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) - Medical Care for Survivors and Dependents of Certain Veterans*, 87 FR 41600, July 13, 2022)



knowledge/comfort level of the transplant system and the patient’s own understanding of what would be in their best interest.

Although the white paper gave examples of difficult to match patients (such as highly sensitized candidates), the Committee declined to define the term in the white paper because it was beyond scope. The Committee similarly identified in the white paper that how implementation of changes to policy would occur is beyond scope and would be identified by other OPTN committees. The Committee affirmed these stances as reflecting appropriate limitations of Ethics Committee purview in post-public comment review.

### Continuous Distribution

Another logistical concern was the overlap with efforts to implement continuous distribution. Some members suggested delaying the recommendations of the Committee while continuous distribution was being developed, since the continuous distribution effort specifically aims to improve equity in the system, thus potentially negating the need for multiple listing. Another member suggested incorporating attributes into upcoming continuous distribution efforts to prioritize access instead of limiting multiple listing.

The white paper submitted for public comment in January acknowledged the potential impact of continuous distribution and noted that the ongoing effort to move all allocation policy frameworks to continuous distribution does not negate the importance of considering the ethical implications of multiple listing in the current policy landscape. The Committee confirmed post-public comment that the language was appropriate in expressing the current importance of evaluating the implications of multiple listing while acknowledging it may be appropriate to re-evaluate in the future.

### *Support for Addressing Equity in Access*

While there were concerns about the impact on patients if certain recommendations within the white paper were enacted, others expressed strong support for the Ethics Committee directly addressing an inequity in the transplant system. One member specifically noted the enhanced trust that the white paper generates for donor families skeptical of the transplant system by acknowledging and providing ideas for addressing inequities. In another example, a TAC member shared anecdotal feedback how support for multiple listing can erode the longer that an individual works in transplant, because of seeing firsthand who gets access to this option (namely that multiply listed candidates tend to be wealthier and more educated). One comment shared that prioritizing highly sensitized candidates would also positively impact access for non-White women, who face greater barriers in access to transplant compared to other groups.<sup>27</sup>

This feedback affirmed the Committee’s approach in exploring potential inequities implied by multiple listing and highlighted the importance of the ethical analysis provided within the white paper.

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<sup>27</sup> Am J Transplantation. 2006;6:2556-2562. 2. Tambur AR, Campbell P, Claas FH, et al. Sensitization in transplantation: assessment of risk (STAR) 2017 working group meeting report. Am J Transplant. 2018;18:1604-1614. 3. Tambur AR, Campbell P, Chong AS, et al. Sensitization in transplantation: assessment of risk (STAR) 2019 working group meeting report. Am J Transplant. 2020;20:2652-2668.

## White Paper for Consideration

The Committee modified the white paper in several key respects: to provide additional clarity regarding the discussion of patient autonomy; to include additional vulnerable populations for consideration in optimizing access to multiple listing (specifically, pediatrics and candidates who list at VA hospitals); and to remove specific recommendations regarding policy. The Committee kept the ethical analysis intact, in affirmation of its importance in exploring implications of equity within the transplant system, and highlighting relevant findings identified from the analysis:

- There is a need for optimizing access to multiple listing for pediatric patients, candidates who list at VA hospitals and highly sensitized candidates
- Providing better financial support and more consistent information about multiple listing and multiple evaluations for patients may reduce inequities
- Not allowing transplant programs to deny listing a patient because they want to be multiply listed to ensure more consistent treatment for all patients

The Committee also provided to the white paper an addendum highlighting common questions and pertinent answers for enhanced readability.

## Compliance Analysis

### NOTA and OPTN Final Rule

This white paper is proposed under the authority of NOTA, which requires the OPTN to establish "a national list of individuals who need organs"<sup>28</sup> and the Final Rule, which requires every transplant program to "assure that individuals are placed on the waiting list as soon as they are determined to be candidates for transplantation."<sup>29</sup> The Ethics Committee offers the proposed white paper to provide the OPTN Board and committees with the ethical implications of multiple listing practices.

### OPTN Strategic Plan

This white paper is in alignment with the following aspect of the OPTN Strategic Plan:

#### *Improve equity in access to transplants:*

This white paper analyzes the practice of multiple listing and its impact on equity in access to transplant. Multiple listed candidates have higher transplant rates than single listed candidates, indicating a potential advantage in access to transplant. At the same time, multiple listed candidates are more likely to reflect socioeconomic advantages in insurance and education.<sup>30</sup> Together, these trends suggest multiple listing may be perpetuating an inequity. Analyzing potential inequities and exploring the implications serve the ultimate goal of improving equity in access to transplant.

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<sup>28</sup> 42 U.S.C. §274(b)(2)(A)(i)

<sup>29</sup> 42 C.F.R. §121.5(b)

<sup>30</sup> Katrina Gauntt, Keighly Bradbrook, and Jesse Howell, "Data Request – Characteristics of Multiple Listed Kidney and Liver Candidates by Geography," OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, September 14, 2022.



## Conclusion

The *Ethical Evaluation of Multiple Listing* white paper identifies that multiple listing may perpetuate inequities and that there are opportunities for optimizing access to the practice, providing better support for those who may most need access to it, and considering the impact of transplant programs being able to deny listing to patients who wish to be multiply listed. This white paper was modified in response to public comment to expand relevant populations who should be considered in optimizing access to multiple listing, to clarify the extent of patient autonomy and its implications within the paper, to remove recommendations in acknowledgement of the OPTN Board's purview over next steps to address potential inequities in the transplant system, and to add an addendum answering common questions about the analysis.

# Ethical Evaluation of Multiple Listing

## 1 Introduction

2 Multiple listing is an opportunity for transplant candidates to be registered at and receive offers from  
3 more than one transplant hospital simultaneously, which has raised ethical questions throughout the  
4 last three decades but has not undergone a formal analysis by the Ethics Committee (hereafter ‘the  
5 Committee’). Policy permitting multiple listings was initially passed by the OPTN Board of Directors in  
6 1987, but faced repeal attempts in 1988, 1994, and 2001 associated with the concern that permitting  
7 multiple listings favored wealthy patients who had the means to travel while disadvantaging those who  
8 did not.<sup>31,32,33,34</sup> In response to these repeal attempts, multiple listing was prohibited from January to  
9 March 1988, but has been a permanent component of OPTN policy since that time.<sup>35</sup> Currently, *OPTN*  
10 *Policy 3.4 Multiple Transplant Program Registrations* allows patients to be registered for an organ at  
11 multiple transplant programs and allows transplant programs to determine whether or not to accept a  
12 candidate who is listed at multiple transplant programs for an organ.<sup>36</sup> Additionally, *OPTN Policy 3.2*  
13 *Notifying Patients on their Options* requires transplant programs to inform patients that they are able to  
14 pursue listing at multiple programs.<sup>37</sup> While this practice is formally referred to as multiple registrations  
15 in policy, the practice is more colloquially known as multiple listing, which is how it will be referred to  
16 throughout this white paper.

17 The concerns evident in literature today echo arguments made in past debates. Historically, those  
18 opposed to multiple listing believed the practice would be utilized by individuals with the financial  
19 resources to fly across the country to obtain a transplant, thereby disadvantaging other patients and  
20 exacerbating inequities.<sup>38,39</sup> Alternatively, those in support of multiple listing championed the use of the  
21 policy for highly sensitized or medically urgent patients and recommended educating patients about the  
22 option and informing patients if a program does not multiple list.<sup>40,41,42</sup> Ultimately, policy repeals have  
23 failed in the past due to the agreement that patient access should not be limited, despite the disparities  
24 that may persist.<sup>43,44</sup> An Addendum (page 26) covers the concerns received during the most recent  
25 public discussions of multiple listing and Ethics Committee responses to these objections. This  
26 endeavors to address, one by one, each of the issues members raised during public comment, hopefully  
27 allaying any misgivings they might initially have had about the paper.

28 Justice in a system of organ donation and allocation is upheld by ensuring that allocation rules are  
29 applied equitably and consistently. Although system-level allocation priorities and practices promote a  
30 just and balanced distribution of benefits and burdens across all stakeholders, individual stakeholders

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<sup>31</sup> United Network for Organ Sharing Board of Directors Meeting, August 10, 1987, Atlanta, Georgia.

<sup>32</sup> United Network for Organ Sharing Board of Directors Meeting, March 21, 1988, Washington D. C.

<sup>33</sup> United Network for Organ Sharing Board of Directors Meeting, November 2-3, 1994, Atlanta, Georgia.

<sup>34</sup> Report of the OPTN Patient Affairs Committee to the Board of Directors, November 15-16, 2001, Alexandria, Virginia.

<sup>35</sup> UNOS Board of Directors Meeting, March 1988.

<sup>36</sup> OPTN Policy 3.4.F Multiple Transplant Program Registrations, 2022.

<sup>37</sup> OPTN Policy 3.2 Notifying Patients of Their Options, 2022.

<sup>38</sup> United Network for Organ Sharing Board of Directors Meeting Transcript, March 1-2, 1995, New Orleans, Louisiana.

<sup>39</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 15-16, 2001, Alexandria, Virginia.

<sup>40</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 20-21, 2003, Alexandria, Virginia.

<sup>41</sup> Richard J. Glasscock, “National Kidney Foundation Response to UNOS Policy Proposal Statement Regarding the Listing of Patients on Multiple Transplant Waiting Lists,” March 14, 1988.

<sup>42</sup> Jack W. Owen, “American Hospital Association Comments on the Multiple Listing of Transplant Candidates,” March 17, 1988.

<sup>43</sup> United Network for Organ Sharing Board of Directors Meeting, March 21, 1988, Washington D. C.

<sup>44</sup> OPTN/UNOS Board of Directors Meeting Minutes, November 20-21, 2003, Richmond, Virginia.



31 may pursue non-standard and less accessible approaches of moving from one center to another or  
 32 listing at multiple centers to increase chances of transplantation. Although it may be understandable  
 33 why individuals may take actions to pursue lifesaving treatment, policies governing organ allocation at a  
 34 national level must consider potential for systemic inefficiencies and inequalities introduced when a  
 35 small set of individuals self-select to list at multiple centers, increasing their chances of transplantation  
 36 relative to others who do not, or cannot, multiple lists. For that reason, it is imperative to examine how  
 37 multiple listing impacts all patients, not just individually. This white paper considers the ethical  
 38 implication of permitting patients to receive organ offers, simultaneously, from more than one  
 39 transplant program, thus, potentially receiving more organ offers. This white paper aims to answer the  
 40 question, ‘What are the ethical implications of permitting patients to be listed at multiple programs?’

41 The Committee conducts this ethical analysis within the scope, purview, and mission to “to guide the  
 42 policies and practices of the OPTN related to organ donation, procurement, distribution, allocation, and  
 43 transplantation so they are consistent with ethical principles.”<sup>45</sup> The Committee must consider the  
 44 ethical principles described below as they pertain to the transplant community broadly: equity  
 45 (including distributive and procedural justice), utility, and autonomy.

46

<b>Patient Autonomy and Access to Transplant</b>
<b>Autonomy</b> entails that “actions or practices tend to be right insofar as they respect or reflect the exercise of self-determination”, while not impairing the autonomy of another individual. <sup>46</sup>
<b>Equity</b> “refers to fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program.” <sup>47</sup> <b>Distributive justice</b> in organ allocation is defined as dictating “fairness in the distribution of scarce resources so that similarly needy patients have an equal opportunity to benefit from transplantation.” <sup>48</sup> <b>Procedural justice</b> refers to appraisal of the fairness of how decisions are made.” <sup>49</sup>
Efforts to protect autonomy may <b>come into conflict with equity and distributive justice</b> . The OPTN supports a <i>balance</i> of ethical principles within the transplant system, which implies that <b>limits to patient autonomy exist</b> . Similarly, efforts to address equity or justice cannot be considered in a vacuum but are considered <b>within the overall balance of ethical principles that support a robust and transparent transplant system</b> .
In the context of multiple listing, <b>it is important to fully account for all the ethical principles that support trust in the transplant system, and not just autonomy</b> .

47

<sup>45</sup> Ethics Committee, OPTN, accessed December 3, 2022. <https://optn.transplant.hrsa.gov/about/committees/ethics-committee/>.

<sup>46</sup> OPTN Ethics Committee, *Ethical Principles in the Allocation of Human Organs*, June 2015, <https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/>

<sup>47</sup> Ibid.

<sup>48</sup> OPTN Ethics Committee, *Manipulation of the Organ Allocation System Waitlist Priority through the Escalation of Medical Therapies*, June 2018, [https://optn.transplant.hrsa.gov/media/2500/ethics\\_whitepaper\\_201806.pdf](https://optn.transplant.hrsa.gov/media/2500/ethics_whitepaper_201806.pdf).

<sup>49</sup> 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 (Mar 2005): 63-81. <https://doi.org/10.1007/s11211-005-3393-3>.

48 The core ethical concern associated with multiple listing involves ensuring equitable access to  
49 transplantation and examining the level of advantage multiple listing provides over single listing. Recent  
50 national reports and requests for information by Centers for Medicare & Medicaid Services (CMS) have  
51 emphasized the importance of ensuring equitable access to transplant and removing or modifying  
52 policies that perpetuate disparities experienced by structurally minoritized persons.<sup>50,51</sup> Although  
53 formally available to all, in practice, multiple listing is viewed as only being accessible for those with the  
54 means and influence to seek an advantage in obtaining access to transplantation.<sup>52</sup> In order to pursue  
55 multiple listing, the patient and their caregiver may need to travel to additional transplant programs for  
56 transplant evaluation, attain lodging, receive time off work, and potentially pay for the additional  
57 transplant evaluation if not covered by insurance. Media coverage of high-profile cases has raised  
58 concerns over the use of multiple listing by exceptionally wealthy individuals that may be harmful to  
59 public perception and imply that wealth and private transportation provide a disproportionate  
60 advantage to accessing transplant.<sup>53,54</sup> Public trust is the basis for a successful transplant system, and  
61 deterioration of trust may impact individual and donor family willingness to donate. A commitment to  
62 balancing ethical principles and upholding public trust requires an ethical analysis of the multiple listing  
63 policy.

64 The Committee supports greater transparency in transplant evaluation criteria and strongly supports  
65 patients in their ability to pursue evaluation and listing at the transplant program that best aligns with  
66 their needs, preferences, and clinical characteristics. **Approaching multiple centers and completing  
67 multiple evaluations in an attempt to find one that best supports patients' needs is not considered  
68 multiple listing as defined and discussed in this white paper.**<sup>55</sup> As described in the *Transparency in  
69 Program Selection* white paper, programs may vary significantly in their evaluation practices, donor  
70 acceptance practices, and utilization of marginal organs, among other factors.<sup>56</sup> Some of these factors  
71 may be known and understood by patients at the point of evaluation and listing, while other factors may  
72 become apparent only after listing at a given program. Access to multiple evaluations and ensuring that  
73 waiting time follows patients to any program upholds patient autonomy and efficiency. This encourages  
74 patients to find transplant program that best meet their goals and preferences and supports transplant  
75 programs in efforts to improve transparency about their evaluation and listing process.

76 The overarching question, 'What are the ethical implications of permitting patients to be listed at  
77 multiple centers?,' will be answered by analyzing the ethical principles of equity (including distributive  
78 and procedural justice), autonomy, and utility as they pertain to multiple listing. Each ethical principle  
79 was analyzed, practically applied to multiple listing, and the relevant data considered OPTN data

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<sup>50</sup> National Research Council. 2022. *Realizing the Promise of Equity in the Organ Transplantation System*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26364>.

<sup>51</sup> "Request for Information: Health and Safety Requirements for Transplant Programs, Organ Procurement Organizations, and End-Stage Renal Disease Facilities." *Centers for Medicare & Medicaid Services (CMS)*. Dec. 03, 2021. Available at: <https://www.federalregister.gov/documents/2021/12/03/2021-26146/request-for-information-health-and-safety-requirements-for-transplant-programs-organ-procurement>

<sup>52</sup> Eitan Neidich et al., "Consumerist Response to Scarcity of Organs for Transplant," *AMA Journal of Ethics* 15, 11 (Nov 2013): 966-972. <https://doi.org/10.1001/virtualmentor.2013.15.11.pfor2-1311>.

<sup>53</sup> Denise Grady and Barry Meier, "A Transplant That Is Raising Many Questions," *The New York Times*, June 22, 2009.

<sup>54</sup> Marilynn Marchione, "Organ transplant lists in the US favor the rich, according to new study," *Associated Press*, Nov 9, 2015.

<sup>55</sup> The OPTN Ethics Committee is a proponent of patients exercising their autonomy through the transplant evaluation process by identifying the transplant program that best aligns with their needs, preferences, and values to assist their decisions-making in the transplant program selection process. See: OPTN Ethics Committee, *Transparency in Program Selection*, August 2022, [https://optn.transplant.hrsa.gov/media/05elwuzv/bp\\_transparency-in-program-selection\\_ethics.pdf](https://optn.transplant.hrsa.gov/media/05elwuzv/bp_transparency-in-program-selection_ethics.pdf).

<sup>56</sup> Ibid.



80 pertaining to each principle. The white paper will show that inequities perpetuated by multiple listing  
81 may conflict with the guiding principles of equity and utility.<sup>57</sup> The Committee recognizes the following:

- 82 • There is a need for optimizing access to multiple listing for pediatric patients, candidates who  
83 list at Veterans Affairs (VA) hospitals<sup>58</sup> and difficult to match candidates through multiple listing
- 84 • Providing better financial support and more consistent information about multiple listing and  
85 multiple evaluation for patients may reduce inequities
- 86 • Not allowing transplant programs to deny listing a patient because they want to be multiply  
87 listed would ensure more consistent treatment for all patients

## 88 Review of Relevant Data

### 89 *Utilization of Multiple Listing, February 4, 2020 – March 31, 2022*

90 In congruence with the ethical analysis, OPTN data were reviewed to better understand patient access  
91 and the implications of multiple listing for improving the likelihood of transplantation.<sup>59,60</sup> As previously  
92 mentioned, the Committee defined multiple listing as “being on the transplant wait-list for a particular  
93 organ type at more than one transplant program simultaneously,” as opposed to identifying patients  
94 who had ever been listed at more than one program.<sup>61</sup> During this two-year period, the sample size of  
95 patients who are multiple listed is relatively small, with only 6.4% of registered candidates listed at two  
96 or more transplant hospitals for the same organ on December 31, 2021.<sup>62</sup> Kidney had the largest  
97 percentage of candidates multiple listed at 7.2%, liver at 1.5%, and thoracic organs were less than 1%  
98 each.<sup>63</sup>

99 First, the Committee reviewed the demographics and geography of patients who were single and  
100 multiple listed. This analysis used patients waitlisted on December 31, 2021, as a representative sample  
101 of what the waitlist could look like on a given day.<sup>64</sup> The Committee examined the utilization of multiple  
102 listing across all organ types, individual-level demographics (age, sex, race/ethnicity, insurance status,  
103 education, blood type) and geocoded zip code level demographics (median household income, poverty  
104 percent). Registration-level data, depicting region, time to transplant, medical urgency status, time  
105 between primary and secondary listing hospital, distance between primary and secondary listing  
106 hospital, and location of most common primary, secondary, and tertiary listings, were also assessed.<sup>65</sup>

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<sup>57</sup> OPTN Ethics Committee, Ethical Principles in the Allocation of Human Organs, June 2015,  
<https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs/>.

<sup>58</sup> Details about the types of people eligible to receive care at VA hospitals can be found at the VA website (see:  
<https://www.va.gov/health-care/eligibility/>) and is also described in Code of Federal Regulations in the *Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) - Medical Care for Survivors and Dependents of Certain Veterans* (Code of Federal Regulations, *Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) - Medical Care for Survivors and Dependents of Certain Veterans*, 87 FR 41600, July 13, 2022)

<sup>59</sup> Keighly Bradbrook, Katrina Gauntt, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Candidates By Organ Type,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, May 11, 2022.

<sup>60</sup> Katrina Gauntt, Keighly Bradbrook, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Kidney and Liver Candidates by Geography,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, September 14, 2022.

<sup>61</sup> Decoteau et al., “The Advantage.”

<sup>62</sup> Bradbrook, “Data Request,” May 11, 2022.

<sup>63</sup> Ibid.

<sup>64</sup> Bradbrook, “Data Request,” May 11, 2022.

<sup>65</sup> Heart and lung were combined into one group, thoracic, due to small sample size. Primary listings are defined as the initial transplant center a patient listed at, while secondary listings are as the second transplant hospital that a given patient was listed for transplant at.

107 Further analysis included a review of multiple listing practices between February 4, 2020, and December  
108 31, 2021 for liver patients and March 15, 2021 to December 31, 2021 for kidney patients.<sup>66</sup> In particular,  
109 transplant rates, calculated as the number of transplants per 100 inactive and active years waiting, were  
110 analyzed for cohorts post-acuity circles and stratified by whether the multiple listing occurred in the  
111 same donor service area (DSA), outside the DSA but in the first priority circle, or outside of the first  
112 priority circle. Transplant rates were used to further illuminate any shifts in allocation from DSA to acuity  
113 circles in order to consider the role that changing allocation systems has had on multiple listing  
114 practices. Additionally, transplant rates were calculated based on an ever-waiting cohort from  
115 implementation of acuity circles to March 31, 2022. For liver this was candidates ever waiting between  
116 February 4th, 2020, to March 31, 2022 and for kidney this was candidates ever waiting between March  
117 15, 2021 to March 31st, 2022.<sup>67</sup> Candidates were indicated as ever multiple listed if at any point in the  
118 cohort time frame the candidate had two or more listings at multiple programs simultaneously.  
119 Candidate waiting time was considered by taking the time in days from the first listing date to either the  
120 date of transplant or the date of candidate removal from all listings from the waitlist, including both  
121 active and inactive waiting time for the candidate.<sup>68</sup>

122 It is important to note that as allocation changes, the role and impact of multiple listing evolves in  
123 tandem.<sup>69</sup> OPTN data reflects changes in listing behavior and the subsequent impact of multiple listing  
124 as allocation shifted from DSA to acuity circles. It is fair to hypothesize that the development of  
125 continuous distribution, an allocation framework that deemphasizes geography, will continue to affect  
126 the role, benefit, and prevalence of multiple listing. The relevant themes from the data will be analyzed  
127 in juxtaposition to the ethical principles of equity (including distributive and procedural justice), utility,  
128 and autonomy.

129 Limitations to the analysis: It is important to note that zip code data, which were utilized to depict the  
130 median household income and poverty levels for single and multiple listed kidney, liver, and thoracic  
131 patients, have limitations. Aggregated environmental factors are not always good descriptors of an  
132 individual's access, situation, barriers, and personal situation, as these individual-level situations often  
133 attenuate any disadvantage that may be conferred by one's environment. While zip code data offers  
134 comparisons of multiple and single listed patients on aggregate, it falls short in providing the level of  
135 granularity that would be provided by candidate-level socio-economic measures, which are not available  
136 in OPTN data as patient addresses are not collected. Future analyses would benefit from incorporating  
137 third-party data with OPTN data to look at the effect of multiple listing on equity and access to  
138 transplant, adjusting for individual level socio-economic factors. Thoracic sample sizes are small and  
139 future analyses would benefit from using a larger cohort when more data are available. Further  
140 limitations include data quality for self-reported information, such as zip code, and the occurrence of  
141 patients being listed at two programs on the same day, which were excluded from the analysis.<sup>70,71</sup>

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<sup>66</sup> Gauntt, "Data Request," September 14, 2022.

<sup>67</sup> "Ever waiting" is inclusive of candidates who spent any time waiting during the time period described - whether the candidate was on the waiting list the entire time period or a shorter subset

<sup>68</sup> Additional details about the methods can be found in Appendix A.

<sup>69</sup> Decoteau et al., "The Advantage."

<sup>70</sup> Arline T. Geronimus, John Bound & Lisa J. Neidert, "On the Validity of Using Census Geocode Characteristics to Proxy Individual Socioeconomic Characteristics," *Journal of the American Statistical Association*, 91 (1996): 529-537. <https://doi.org/10.1080/01621459.1996.10476918>.

<sup>71</sup> Bradbrook, "Data Request," May 11, 2022.

142 *Data Analysis Pertaining to Equity in Multiple Listing*

143 To examine whether utilization is socially patterned in ways consistent with structural discrimination,  
 144 three variables (race/ethnicity, insurance status, and education) were explored. Table 1-1 depicts the  
 145 percentages of single and multiple listed kidney and liver patients by race/ethnicity, insurance status,  
 146 and education.<sup>72,73,74</sup>

147 **Table 1-1 (Race/Ethnicity, Insurance Status, and Education for Single and Multiple Listed Kidney and**  
 148 **Liver Patients)**

		Kidney – Single listed patient	Kidney – Multiple listed patient	Liver – Single listed patient	Liver – Multiple listed patient
Race/ Ethnicity	White, Non- Hispanic	35.8%	36.3%	66.5%	72.2%
	Black, Non-Hispanic	30.9%	36.1%	7%	5.7%
	Hispanic/Latino	21.5%	16.3%	19.5%	15.9%
	Asian, Non-Hispanic	9.2%	9.5%	5.1%	5.1%
Insurance Status	Private or self pay	43.3%	53.5%	50.8%	68.8%
	Medicaid	13.2%	4.8%	20.1%	5.7%
	Medicare <sup>75</sup>	40.3%	35.9%	23.6%	17.1%
	Department of VA	1.6%	4.1%	2.1%	7.4%
	Public or charity, other <sup>76</sup>	1.2%	1.4%	3.1%	1.1%
Education	Grade school or less	8%	3.5%	7.5%	3.4%
	High school or GED	37.2%	30.1%	35.8%	27.3%
	Attended College/ Technical School	25%	26.1%	24.3%	26.7%
	Associate/Bachelor Degree	19.1%	25.1%	19.9%	22.7%
	Post-College Graduate Degree	7.1%	12.0%	7.4%	11.9%
	Unknown	3.3%	3.1%	3.5%	6.2%

149 Although there were fewer candidates reporting a Hispanic/Latino ethnicity in the multiple listed kidney  
 150 group there were more candidates reporting Black, Non-Hispanic ethnicity in the multiple listed kidney  
 151 group but fewer for liver, and very little difference among candidates reporting White, Non-Hispanic.<sup>77</sup>  
 152

153 It is important to note that data reflect the patients who are successfully listed for transplant and  
 154 successfully multiple listed. It does not include those who have yet to be registered on the waitlist or  
 155 have been unsuccessful in their attempts to multiple lists, which could account for racial breakdown  
 156 highlighted above, or those who have successfully multiple listed and received a transplant.

<sup>72</sup> Additional options for race/ethnicity are available for patients to self-identify and select, however, this Table 1-1 only reflects patient responses with more than 5%.

<sup>73</sup> Bradbrook, “Data Request,” May 11, 2022.

<sup>74</sup> The full demographic comparison can be found in Appendix A, Table 1.

<sup>75</sup> This includes both “Medicare FFS (Fee for Service)” and “Medicare & Choice” insurance options.

<sup>76</sup> This includes all other public insurance or charity options, including: “CHIP (Children’s Health Insurance Program,” “Other government,” “Donation,” “Free care,” and “Foreign Government, specify.”

<sup>77</sup> Bradbrook, “Data Request,” May 11, 2022.

157 **Multiple listed kidney patients were one-third as likely to be on Medicaid compared to single**  
158 **listed kidney patients (4.8% versus 13.2%), and multiple listed liver patients were a quarter as likely to**  
159 **be on Medicaid compared to singly listed liver patients. Multiple listed kidney and liver transplant**  
160 **patients were disproportionately more likely to have private insurance or private pay compared to**  
161 **single listed kidney transplant patients (53.5% versus 43.3%) and liver patients (68.8% versus 50.8%),**  
162 **respectively.<sup>78</sup>**

163 **Multiple listed kidney and liver candidates were less likely to have reported an education level of**  
164 **grade school or less compared to single listed kidney (3.5% versus 8%) and liver (3.4% versus 7.5%)**  
165 **candidates, respectively. Multiple listed kidney and liver candidates were also less likely to have**  
166 **reported an education level High School or GED to single listed kidney (30.1% versus 37.2%) and liver**  
167 **(27.3% versus 35.8%) candidates, respectively.<sup>79</sup>**

168 Some studies have shown that health literacy and higher socioeconomic status, sometimes proxied  
169 through higher educational attainment or private insurance, have been associated with higher likelihood  
170 of being referred to transplant, completing the transplant evaluation successfully, being waitlisted, and  
171 obtaining a transplant.<sup>80,81,82,83</sup> When considering the benefits of private insurance, for example,  
172 research shows that individuals with private insurance are more likely to be referred for liver transplant  
173 when compared to publicly insured patients.<sup>84</sup> OPTN data clearly depict patients with private insurance  
174 as comprising a larger proportion of multiple listed patients. This trend aligns with structural disparities  
175 and questions of potentially unequal access between patients with private versus public insurance.

176 Navigating the transplant system is challenging and those with higher level of education are often more  
177 successful in maneuvering these complexities to be successfully listed, and multiple listed, for  
178 transplant. OPTN data confirm this by showing that those with advanced education are more likely to be  
179 multiple listed when compared to single listed patients across all organ types.<sup>85,86</sup> Higher levels of  
180 education often correspond with greater health literacy, while lower levels of health literacy are  
181 negatively correlated with access to transplant.<sup>87,88</sup> Transplant candidates are a particularly vulnerable  
182 population as the stress, anxiety, and general experience of not feeling well while living with an end  
183 stage disease may contribute to a decreased ability to understand important information. The  
184 complexity of the transplant evaluation and listing process and the high levels of digital health literacy  
185 required to navigate multiple listing may further disadvantage marginalized and vulnerable groups.<sup>89</sup>

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<sup>78</sup> Ibid.

<sup>79</sup> Ibid.

<sup>80</sup> Marie A. Chisholm-Burns, Christina A. Spivey, and Logan R. Pickett, "Health literacy in solid-organ transplantation: A model to improve understanding," *Patient Preference and Adherence* 12 (Nov 2018): 2325-2338. <https://doi.org/10.2147/PPA.S183092>.

<sup>81</sup> 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>.

<sup>82</sup> K. Bartolomeo et al., "Factors Considered by Nephrologists in Excluding Patients from Kidney Transplant Referral," *International Journal of Organ Transplantation Medicine* 10, 3 (2019): 101-107.

<sup>83</sup> Jerry McCauley et al., "Factors determining the rate of referral, transplantation, and survival on dialysis in women with ESRD." *American Journal of Kidney Diseases* 30, 6 (Dec 1997): 739-48. [https://doi.org/10.1016/s0272-6386\(97\)90077-9](https://doi.org/10.1016/s0272-6386(97)90077-9).

<sup>84</sup> Julius M. Wilder et al., "Role of patient factors, preferences and distrust in health care and access to liver transplantation and organ donation," *Liver Transplantation* 22, 7 (Mar 2016): 895-905. <https://doi.org/10.1002/lt.24452>.

<sup>85</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>86</sup> Decoteau, "The Advantage," 2021.

<sup>87</sup> Marie A. Chisholm-Burns, Christina A. Spivey, and Logan R. Pickett, "Health literacy in solid-organ transplantation: A model to improve understanding," *Patient Preference and Adherence* 12 (Nov 2018): 2325-2338. <https://doi.org/10.2147/PPA.S183092>.

<sup>88</sup> 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>.

<sup>89</sup> Dominic M. Taylor et al., "Limited health literacy in advanced kidney disease," *Clinical Investigation* 90, 3 (Sept 2016): 685-695. <https://doi.org/10.1016/j.kint.2016.05.033>

186 Patients with high levels of digital literacy are more successful at navigating the complexities of the  
187 healthcare system than those with limited internet access and health literacy.<sup>90</sup> To obtain the maximum  
188 benefit from the vast amounts of information publicly available regarding the performance of organ  
189 procurement organizations (OPO) and transplant programs, patients must have the tools and skills to  
190 locate available information, understand and make use of the complex information available to them in  
191 a way that impacts their health, and network with transplant professionals and other recipients who can  
192 provide additional insight.<sup>91</sup> Beyond making an informed decision to seek out multiple listing, and at  
193 which program(s), patients may need to self-advocate with their health care provider team and third-  
194 party payer.

195 For example, digital literacy rates are three times lower for Hispanic adults when compared to white  
196 adults,<sup>92</sup> which may influence the finding that Hispanic patients are less likely to be multiple listed  
197 compared to single listed Hispanic patients seeking a kidney or liver transplant.<sup>93</sup> In contrast, Black  
198 adults are twice as likely to be digitally illiterate than white adults, and yet black patients accounted for  
199 nearly an equal percentage of kidney multiple listings as white patients.<sup>94,95</sup> While the findings for  
200 Hispanic patients are consistent with the continued disparities in access to transplant for Hispanic  
201 patients across the U.S., the findings for Black patients depict an increase in the proportion of Black  
202 patients pursuing multiple listing for kidney compared to single listed Black kidney patients.<sup>96</sup> Health  
203 literacy is essential for accessing transplant and without the relevant information, or the ability to  
204 understand it, patients with a lower health literacy will continue to face barriers to equitable access.

205 Ultimately, the current policy allowing multiple listing complies with formal equality of opportunity by  
206 being available to all patients, but as it currently is formulated it cannot alone promote fair equality of  
207 opportunity. The data reviewed indicate that not all patients can equally exercise the option to multiple  
208 lists, despite having equal access to multiple lists.

## 209 Ethical Analysis

### 210 Background

211 The Committee adopts Decoteau et al.'s definition of multiple listing, "being on the transplant wait-list  
212 for a particular organ type at more than one transplant program simultaneously."<sup>97</sup> The Committee  
213 assessed whether multiple listing confers an advantage in terms of likelihood of transplantation;  
214 whether this is equitably distributed; and whether any ethical principles would support widespread use  
215 of multiple listing for any candidate who wishes to pursue it.

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<sup>90</sup> Kathy Harris, Gloria Jacobs, and Julie Reeder, "Health Systems and Adult Basic Education: A Critical Partnership in Supporting Digital Health Literacy," *Health Literacy Research and Practice* 3, 3 (Jul 2019): S33-S36. <https://doi.org/10.3928/24748307-20190325-02>.

<sup>91</sup> Chisholm-Burns, "Health," 2018.

<sup>92</sup> 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 Nov 4, 2022).

<sup>93</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>94</sup> U.S. Department of Education, A Description, 2018.

<sup>95</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>96</sup> Cristina M. Arce et al., "Differences in Access to Kidney Transplantation between Hispanic and Non-Hispanic Whites by Geographic Location in the United States," *Clinical Journal of the American Society of Nephrology* 8 (Dec 2013): 2149-2157. <https://doi.org/10.2215/CJN.01560213>.

<sup>97</sup> Mary A. Decoteau et al., "The Advantage of Multiple Listing Continues in the Kidney Allocation System Era," *Transplantation Proceedings* 53, 2 (Mar 2021): 569-580. <https://doi.org/10.1016/j.transproceed.2020.10.036>.

## 216 *Equity*

217 Concerns about multiple listing relate largely to promoting equitable access to transplantation, as  
218 required by the Final Rule.<sup>98</sup> The concept of equity as it pertains to multiple listing may be understood as  
219 one of fair versus formal equality of opportunity. Although frequently described in the context of  
220 competitive advantage for the purposes of obtaining jobs and offices, the concept of fair versus formal  
221 equity underscores the difference between a policy merely allowing a benefit to be available to all  
222 (formal), versus one that requires that all are equally able to be considered for and have access to the  
223 benefit (fair).<sup>99</sup> Corresponding to the idea of reducing the competitive advantages that favorable social  
224 circumstances confer on some individuals in the context of job seeking, Rawls suggests “fair equality of  
225 opportunity.”<sup>100</sup> Fair equality of opportunity requires that any individuals who have the same native  
226 talent and the same ambition (or in the case of transplant, the same need and willingness to pursue  
227 multiple listing) will have the same prospects of success in circumstances where success determines  
228 future long term benefit (in this case access to life-saving treatment).<sup>101,102</sup>

229 Formal equality of opportunity follows the notion that official rules should not exclude or disadvantage  
230 individuals from achieving certain goals by making reference to personal characteristics, such as race,  
231 socioeconomic status, gender, religion, gender identity, and sexuality, among other criteria. While  
232 formal equality of opportunity speaks to equal consideration of all people, the challenge is that it is  
233 merely formal, and formal equity is insufficient in achieving equality of opportunity because it is  
234 conditional on people being able to fairly access the option and be considered. Instead, **fair equality of  
235 opportunity requires that all have a genuine and similar opportunity to achieve a particular end.** In the  
236 case of multiple listing, this would mean that all patients can similarly demonstrate and meet criteria  
237 necessary for multiple listing, as opposed to just being informed that multiple listing is permissible.

238 Here too, the distinction between “equality” and “equity” or “formal” and “fair” becomes important. To  
239 promote equitable access to transplantation, patients that face disproportionate challenges to being  
240 matched for transplant may need to be listed at multiple programs to ensure that their likelihood of  
241 transplantation is comparable to other patients on the waitlist. Although much public attention has  
242 been focused on concerns of affluent patients receiving an unfair advantage by being waitlisted at  
243 multiple locations, less attention has been paid to the equally important issue: the benefits of multiple  
244 listing to patients who are disproportionately difficult to match, due to pre-sensitization, extreme size  
245 matching, or relative contraindications.

246 If the goal is to ensure equitable access to transplantation, patients who are hardest to match with a  
247 deceased-donor organ may require multiple listing to “level the playing field,” or have a similar  
248 likelihood of receiving a transplant as other patients. This would reduce disparities in transplantation by  
249 equalizing the likelihood of obtaining a transplant, particularly for populations that have reduced access  
250 to transplant such as non-white women who are highly sensitized.<sup>103</sup> Similarly, optimizing access to  
251 multiple listing for pediatric candidates and candidates who list at VA hospitals may be supported by

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<sup>98</sup> 42 U.S.C. §274.

<sup>99</sup> Barry Goldman and Russell Cropanzano, “Justice” and “fairness” are not the same thing,” *Journal of Organizational Behavior* 31, 2 (Feb 2015): 313-318. <https://doi.org/10.1002/job.1956>.

<sup>100</sup> John Rawls, *A Theory of Justice: Revised Edition* (Cambridge, Massachusetts: Harvard University Press, 1999), 57-64.

<sup>101</sup> *Ibid.*

<sup>102</sup> John Rawls, *Justice as Fairness: A Restatement* (Cambridge, Massachusetts: Harvard University Press, 2001), 42-50.

<sup>103</sup> Am J Transplantation. 2006;6:2556-2562. 2. Tambur AR, Campbell P, Claas FH, et al. Sensitization in transplantation: assessment of risk (STAR) 2017 working group meeting report. *Am J Transplant*. 2018;18:1604-1614. 3. Tambur AR, Campbell P, Chong AS, et al. Sensitization in transplantation: assessment of risk (STAR) 2019 working group meeting report. *Am J Transplant*. 2020;20:2652-2668.

252 these groups being particularly vulnerable populations that require additional ethical considerations in  
253 their access to transplant. Pediatric candidates often use multiple listing when pursuing the potential of  
254 a living donor transplant, which may be offered at fewer centers, farther from their home when  
255 compared to adult transplant centers. Veterans and sometimes their family members may list at  
256 Veterans Affairs (VA) hospitals in addition to local centers, indicating there are structural issues in access  
257 to transplant that imply multiple listing may be a necessary process for these candidates to pursue.

## 258 Distributive Justice

259 Numerous theories of distributive justice require us to consider the concerns of the worst-off, those  
260 whom the existing allocation system and organ supply may not serve as well.<sup>104,105,106</sup> Patients who are  
261 exceptionally difficult to match for reasons outside of their control may be unlikely to benefit from  
262 organ transplantation without multiple listing and could be harmed if this policy were to constrain their  
263 ability to access transplantation. Patients pursuing transplant, including patients on dialysis in need of a  
264 kidney transplant, are doing their best to obtain the in dire need of life-saving treatment they are in dire  
265 need of. Their individual reasons for pursuing multiple listing do not reflect these systemic moral  
266 considerations about distributive justice. **However, while transplantation cannot resolve or rectify all**  
267 **existing social disparities, this fact does not absolve the transplant community from remediating the**  
268 **policies that exacerbate disparities within transplantation.** Optimizing multiple listing to support access  
269 for difficult to match patients may help to mitigate a barrier impeding equitable access to  
270 transplantation. Differences in program practices, selection practices, organ acceptance rates, and risk  
271 aversion are reasons to justify multiple evaluations, but not necessarily multiple listing (the ability to  
272 receive multiple offers simultaneously from different programs).

## 273 Procedural Justice

274 Procedural justice approaches are concerned with treating like with like, in other words, treating  
275 persons of similar needs consistently, transparently, and predictably.<sup>107</sup> To uphold procedural justice,  
276 transplant programs must notify patients of their ability to multiple list, which is a current requirement  
277 when registering a patient on the waitlist.<sup>108</sup> Despite it being a requirement, how, when, and the  
278 consistency with which transplant programs convey this information may vary.<sup>109</sup> Moreover, it remains  
279 unclear how well patients understand this information. Finally, the degree to which programs are willing  
280 to evaluate and list patients who are already listed at other programs varies, which can lead to  
281 inconsistent practices for patients to navigate.<sup>110</sup>

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<sup>104</sup> Distributive justice in organ allocation is defined as dictating “fairness in the distribution of scarce resources so that similarly needy patients have an equal opportunity to benefit from transplantation.” See: OPTN Ethics Committee, *Manipulation of the Organ Allocation System Waitlist Priority through the Escalation of Medical Therapies*, June 2018, [https://optn.transplant.hrsa.gov/media/2500/ethics\\_whitepaper\\_201806.pdf](https://optn.transplant.hrsa.gov/media/2500/ethics_whitepaper_201806.pdf).

<sup>105</sup> Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, (Berkeley, California: University of California Press, 2003).

<sup>106</sup> 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>.

<sup>107</sup> OPTN Ethics Committee, *Transparency*.

<sup>108</sup> OPTN Policy 3.2 Notifying Patients of Their Options, 2022.

<sup>109</sup> While OPTN policy requires transplant hospitals to inform patients about multiple listing, policy does not dictate how this must be done which introduces variability in presenting this information to patients. The subcommittee shared anecdotes of how their respective centers inform patients of multiple listing, which confirmed the variability that policy allows.

<sup>110</sup> OPTN Policy 3.4.F Multiple Transplant Program Registrations, 2022.

## 282 Application of Equity to Multiple Listing

283 In the case of multiple listing, formal equity exists through the requirement to inform patients about the  
284 opportunity to multiple lists despite the possibility that this may not occur consistently.<sup>111</sup> Formally  
285 providing notification that patients are able to be multiple listed does not equally result in patients  
286 successfully multiple listing. Fair equality of opportunity would require additional assistance be provided  
287 to those less able to act on this information, either those with less ability to multiple lists, or those less  
288 able to understand the information about multiple listing and use that information to navigate multiple  
289 listing. **Fair equality of opportunity might include: the ability to understand and follow the steps  
290 required to meet criteria for multiple programs; the resources (financial, time, transportation, support  
291 person) to meet residency requirements at more than one location; complete evaluations; the ability  
292 to arrive in time for a transplant; and the insurance coverage to allow for multiple evaluations.**

293 There may be a variety of steps needed to ensure such fair equality of opportunity to those patients at a  
294 disadvantage. Patient navigation or more accessible education materials can be made available for  
295 patients with limited health literacy. Some possible solutions to help those with limited means to meet  
296 criteria for multiple listing include greater education, providing scholarships to cover housing or other  
297 expenses, redistributing resources to promote with health literacy, waiving residency criteria, and  
298 lobbying insurers to cover additional transplant evaluations, and ensuring that multiple listing is  
299 encouraged especially for patients who face greater difficulty in being matched with an organ. As more  
300 is done to provide opportunities that enable persons from any social group to meet multiple listing  
301 criteria, the objection that none but the financially, educationally, or socially better off may benefit from  
302 multiple listing is overcome. At some point, depending on the availability of such resources, sufficient  
303 opportunities to achieve multiple listing may be achieved, and fair equality of opportunity would prevail.  
304 However, the transplant community should consider whether merely ensuring formal equality of  
305 opportunity is sufficient, or whether it is necessary but insufficient to achieve the goals of promoting  
306 equitable access to transplantation for all persons of similar need.

307 **Although many of these factors are structural concerns embedded in the fabric of society and beyond  
308 the scope of the transplant community to fix entirely, the transplant community should not be  
309 dissuaded from making improvements towards improving distributive justice, even if greater,  
310 harmonized efforts are needed to achieve the systemic improvements desired at the public health  
311 level.**

## 312 *Autonomy*

313 The concept of respect for autonomy holds that actions or practices tend to be ethical insofar as they  
314 respect or reflect the exercise of self-determination as long as the decisions do not impose harm to  
315 others.<sup>112 113</sup> We consider implications of autonomy for multiple listing.<sup>114</sup>

316 Ensuring that patients can select the transplant program that best meets their needs is paramount to  
317 preserving patient autonomy and may help negate the need for multiple listing. Importantly, this ability  
318 is preserved when patients are able to select a transplant program that aligns with their preferences,

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<sup>111</sup> This sentiment has been shared anecdotally during subcommittee discussions. While there is not literature to substantiate this comment, it highlights a variation in how patients are informed.

<sup>112</sup> OPTN Ethics Committee, Ethical Principles in the Allocation of Human Organs, June 2015, accessed November 18, 2022, <https://optn.transplant.hrsa.gov/professionals/by-topic/ethical-considerations/ethical-principles-in-the-allocation-of-human-organs/>.

<sup>113</sup> Ibid.

<sup>114</sup> Sanjay Kulkarni and Keren Ladin, "Leveling-up versus leveling-down to address health disparities in transplantation," *American Journal of Transplantation* 21, 3 (Mar 2021): 917-918. <https://doi.org/10.1111/ajt.16458>.



319 and meets their needs in terms of approach, location, cost, support programs, et cetera. For patients to  
320 truly realize this opportunity, there must be transparent and accessible information about transplant  
321 programs that would allow patients to seek care at the program that is most appropriate for them.<sup>115</sup>

322 As the definition of autonomy holds that an action is right insofar as it does not impose undue burden to  
323 others, the principle of autonomy raises some concerns with the practice of multiple listing, especially if  
324 it is not equally available to all. Optimizing multiple listing for patients who disproportionately need this  
325 option owing to their difficulty to benefit from the existing system, would uphold autonomy.

### 326 Application of Autonomy to Multiple Listing

327 When analyzing multiple listing, autonomy is exhibited in a challenging dichotomy wherein patients,  
328 transplant programs, and insurance providers can exercise autonomy in a way that infringes on the  
329 autonomy of others. At the center of these considerations are the patients who are informed at  
330 evaluation that they are eligible to pursue multiple listing.<sup>116</sup> In theory, this should allow patients the  
331 independence to determine what is in their best interest and consider whether to pursue multiple  
332 listing. Realistically, patients face a litany of barriers to accessing transplant that can explicitly impact  
333 their ability to pursue listing at a secondary or tertiary transplant program.<sup>117</sup> In an effort to overcome  
334 barriers to access, shared decision-making between transplant programs and patients could be better  
335 utilized to inform and empower patients to exercise their autonomy and determine if they would like to  
336 pursue multiple listing.<sup>118</sup>

337 However, patients who have decided to pursue multiple listing face additional obstacles in their quest.  
338 Policy allows transplant programs to determine if they will accept candidates with multiple registrations  
339 or allow candidates to transfer wait time to their transplant program.<sup>119</sup> Thus, a patient may determine  
340 they want to pursue multiple listing, but both their current program and their intended program may  
341 limit their ability to do so. If the patient's primary listing program permits them to pursue multiple  
342 listings, the patient is still eligible to consider alternative programs. However, their time and other  
343 resources may be depleted if they were used at a program that ends up not accepting the patient as a  
344 secondary listing. If the patient's primary listing program does not permit them to pursue multiple  
345 listings, then the patient's autonomy is overruled in favor of the transplant program. In both instances,  
346 patient autonomy is infringed upon, yet the latter can place total limitations on the patient's choice to  
347 be multiple listed.

348 Lastly, patients are beholden to the decision of their insurance provider to enable them to pursue  
349 multiple listing. In some instances, insurance providers will only cover care when performed by certain  
350 institutions, such as Centers of Excellence, which limit patient choice and restrict patient autonomy.<sup>120</sup>  
351 In other instances, payers will only cover one transplant evaluation per year thus inhibiting a patient's

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<sup>115</sup> OPTN Ethics Committee, *Transparency in Program Selection*, August 2022, [https://optn.transplant.hrsa.gov/media/05elwuzv/bp\\_transparency-in-program-selection\\_ethics.pdf](https://optn.transplant.hrsa.gov/media/05elwuzv/bp_transparency-in-program-selection_ethics.pdf).

<sup>116</sup> OPTN Policy 3.2.

<sup>117</sup> Teri Browne et al., "Everybody needs a cheerleader to get a kidney transplant: a qualitative study of the patient barriers and facilitators to kidney transplantation in the Southeastern United States," *BMC Nephrology* 17, 208 (July 2016). <https://doi.org/10.1186/s12882-016-0326-3>; George Cholankeril et al., "Trends in Liver Transplantation Multiple Listing Practices Associated With Disparities in Donor Availability: An Endless Pursuit to Implement the Final Rule," *Gastroenterology* 151, 3 (Sept 2016): 382-386. <https://doi.org/10.1053/j.gastro.2016.07.026>.

<sup>118</sup> 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>; OPTN Ethics, *Transparency*.

<sup>119</sup> OPTN Policy 3.2 and 3.4.F.

<sup>120</sup> Roger W. Evans, "Public and Private Insurer Designation of Transplantation Programs," *Transplantation* 53, 5 (May 1992): 1041-1046.

352 ability to make decisions that align with their preferences and priorities.<sup>121</sup> Worst case, patients in need  
353 of organ transplantation may never have the opportunity to exercise their autonomy if they are  
354 uninsured and unable to access transplantation.<sup>122</sup>

355 In considering the overlapping complexities associated with a patient's successful secondary waitlist  
356 registration, transplant programs and insurance providers should not be the limiting factor for patients  
357 to pursue life-saving organ transplantation. While autonomy exists individually between the three actors  
358 described above, patient autonomy ought not to be overshadowed by program or payer preferences.

### 359 *Utility*

360 Utility could be positively impacted if patients are able to be transplanted expediently or if an increased  
361 number of transplants occur (e.g. if multiple listed patients accept more marginal organ offers), but  
362 there are currently insufficient data to establish this. There are important tradeoffs to consider. Clinical  
363 continuity was originally developed as a concept to include a patient's primary care team in all relevant  
364 medical decisions impacting care delivery.<sup>123,124</sup> Pre-transplant care is a complex, multilevel process that  
365 requires coordinated communication to optimize patient care. For example, a patient listed for kidney  
366 transplantation accesses care through their dialysis units, primary care provider, specialty referrals such  
367 as cardiology, and the transplant program. It is evident that care coordination between these  
368 stakeholders is not optimal at baseline and there are several proposed care and reimbursement models  
369 to improve care coordination of the pre-transplant kidney patient.<sup>125</sup> The challenge of clinical continuity  
370 and care coordination is clearly increased by multiple listing, where several of the key elements  
371 providing pre-transplant care are susceptible to fracture by geography, differing care pathways, and  
372 suboptimal communication. If a waitlisted patient experiences an ER visit for chest pain, it is unclear if  
373 this will effectively be communicated to all transplant programs at which they are listed. By negatively  
374 impacting clinical continuity, the ability for patients to receive optimum care can decrease as their care  
375 is managed in a disjointed way.

376 Multiple listing can provide challenges for transplant programs as their list management strategies focus  
377 on patient preparedness to accept an organ for transplantation. In circumstances where a listed patient  
378 may choose to list at multiple transplant programs, the patient may be subject to different testing  
379 requirements, waitlist clinical pathways, and potential duplicate testing. These factors have the  
380 potential to increase costs prior to transplant, causing the patient, transplant program, and payer to all  
381 incur a cost thus increasing the overall healthcare cost.

382 Because organ transplantation is a zero-sum situation, increasing the chances of any given patient by  
383 allowing them multiple chances in different regions by definition decreases the relative chances of  
384 another patient in the regions in which they list, yet it improves the chances of a patient in the region  
385 they left.

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<sup>121</sup> Rachel E. Patzer et al., "A population Health Approach to Transplant Access: Challenging the Status Quo," *American Journal of Kidney Disease* 80, 3 (Feb 2022): 406-415. <https://doi.org/10.1053/j.ajkd.2022.01.422>.

<sup>122</sup> Andrew A. Herring, Steffie Woolhandler, and David U. Himmelstein, "Insurance Status of U.S. Organ Donors and Transplant Recipients: The Uninsured Give, but Rarely Receive," *International Journal of Health Services* 38, 4 (Oct 2008): 641-652. <https://doi.org/10.2190/HS.38.4.d>.

<sup>123</sup> Michael D. Cabana and Sandra H. Jee, "Does continuity of care improve patient outcomes?" *Journal of Family Practice* 53, 12 (Dec 2004): 974-980.

<sup>124</sup> Martin Gulliford, Smriti Naithani, and Myfanwy Morgan, "What is 'continuity of care'?" *Journal of Health Services Research & Policy* 11, 4 (Oct 2006). <https://doi.org/10.1258/135581906778476490>.

<sup>125</sup> Marie Dirix et al., "Timing of the pre-transplant workup for renal transplantation: is there room for improvement?" *Clinical Kidney Journal* 15, 6 (Jan 2022): 1100-1108. <https://doi.org/10.1093/ckj/sfac006>.

386 On par, the principle of utility is inconclusive and highlights a number of considerations related to  
387 multiple listing, including systemic concerns related to efficiency. Although sometimes in tension, in this  
388 case, the principles of equity and utility both suggest that multiple listing, if broadly used, would violate  
389 the basic premises of justice and efficiency. However, using multiple listing to address the  
390 disproportionate needs of potentially underserved groups would allow both equity and utility to occur.

### 391 Data Analysis Pertaining to Utility in Multiple Listing

392 While multiple listing may appeal to patients with the possibility of decreased time to transplant, OPTN  
393 data found that multiple listed kidney and liver recipients had a higher median waiting time when  
394 compared to single listed kidney and liver recipients.<sup>126</sup> Despite the benefits of early transplant  
395 described above, it is not clearly shown that multiple listing leads to a decreased time on the waitlist. It  
396 is possible that the increased wait time accounts for patients who are hard to match or pre-sensitized;  
397 however, additional research is needed to establish those conclusions.

398 **OPTN data found that most often patients are multiple listed at locations that are within driving**  
399 **distance of their home. However, kidney candidates who listed closer to home (under 250 nautical**  
400 **miles) were less likely to benefit from multiple listing compared to those listing outside of the 250**  
401 **NM range.**<sup>127</sup> This finding expands upon prior literature, and differs by analyzing the role of multiple  
402 listing within the same acuity circle as the primary listing program.<sup>128,129,130,131</sup> For kidney transplant  
403 candidates, 77% of the secondary listing programs were located within 250 nautical miles, the initial  
404 acuity circle used to allocate kidneys, of the primary transplant program, compared to 52% of multiple  
405 listed liver candidates who pursued their secondary listing at a program that was within 150 nautical  
406 miles, the initial acuity circle used to allocate livers, from the primary transplant program.<sup>132</sup>

407 While the close proximity of the secondary listing program makes the case for increased access to  
408 multiple listing, the close proximity calls into question what the added benefit of multiple listing may be.  
409 The current allocation framework prioritizes patients within a given nautical mile radius and by only  
410 minimally expanding the radius one is eligible to receive offers from, the benefit of multiple listing is  
411 likely reduced. The practice of multiple listing inside the initial circle suggests that some of the benefits  
412 may be more attributable to program practices such as offer acceptance patterns rather than  
413 geographic differences in donor availability.

414 Since acuity circles are a relatively newer allocation model, multiple listing within acuity circles has not  
415 been reviewed, thus this analysis differs from contemporary literature, which considers instances of a  
416 patient pursuing secondary listing outside of their primary transplant program's acuity circle.<sup>133</sup> The  
417 Committee hypothesized that the prevalence of patients multiple listed close to their primary listing  
418 program is likely a lingering result of the transition from allocating within donor service areas (DSAs) to  
419 acuity circles.

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<sup>126</sup> Gauntt, "Data Request," September 14, 2022.

<sup>127</sup> Gauntt, "Data Request," September 9, 2022.

<sup>128</sup> Sara Brown et al., "Multiple Regional Listing Increases Liver Transplant Rates for Those With Model for End-stage Liver Disease Score <15," *Transplantation* 104, 4 (Apr 2020):762-769. <https://doi.org/10.1097/TP.0000000000002965>.

<sup>129</sup> Decoteau, "The Advantage," 2021.

<sup>130</sup> Zahara Gharibi and Michael Hahsler, "A Simulation-Based Optimization Model to Study the Impact of Multiple-Region Listing and Information Sharing on Kidney Transplant Outcomes," *International Journal of Environmental Research and Public Health* 18, 873 (Jan 2021). <https://doi.org/10.3390/ijerph18030873>.

<sup>131</sup> Appendix A, Figures 1-3 Distances Between Primary and Secondary Listing Transplant Hospitals for Multiple Listed Kidney, Liver, and Thoracic Candidates on December 31, 2021.

<sup>132</sup> Bradbrook, "Data Request," May 11, 2022

<sup>133</sup> Decoteau et al., "The Advantage."

420 Additionally, recent allocation changes impact transplant wait times with differences noted between  
421 organs. Kidney allocation changed from DSA to acuity circles and has seen a decrease in kidney multiple  
422 listings, while liver patients experienced the inverse.<sup>134</sup> However, it is important to note that the sample  
423 size for multiple listed liver patients was much smaller than kidney patients and covered a shorter length  
424 of time since the transition from DSA to acuity circles. Additionally, due to the difference in wait time  
425 between kidney and liver patients, it may be fair to assume that the proportion of liver patients seeking  
426 multiple listing has not increased, but the liver patients who had multiple listed prior to the change in  
427 allocation were transplanted. The overall trend after allocation change from DSAs to acuity circles was a  
428 net decline in organ multiple listings.<sup>135</sup>

429 Lastly, the myriad of regional variation in transplant rates for patients who are multiple listed cannot be  
430 clearly captured in the data analysis but requires consideration. Potential contributors to regional  
431 variation include density and practices of organ procurement organizations (OPOs) and transplant  
432 programs, regional practice differences (regional practice of splitting livers), population density,  
433 population health, and attitudes towards transplant.<sup>136,137</sup> These factors, some of which are not clearly  
434 known by patients seeking transplant, can lead to longer wait times based on transplant center  
435 selection. As such, multiple listing could help to correct disparities caused by differences in program  
436 practices that may inadvertently lengthen a patient's time to transplant. Examples of program practices  
437 that affect wait time include offer acceptance patterns, such as DCD organ utilization, HCV positive  
438 organ utilization, and pulsatile preservation utilization to maximize transplantable organs.

## 439 Conclusions

440 Multiple listing has an extensive history in transplant policy, but not without controversy both within the  
441 transplant community and in the public at large. Any future project to revise this longstanding policy  
442 would require significant empirical analysis to review utilization patterns, as well as ethical analysis to  
443 inform whether the policy is justified, given the patient access and usage. It is with humility,  
444 compassion, and a commitment to uphold the goals of the OPTN that the Committee approaches the  
445 ethical analysis of multiple listing. Because transplant is a zero-sum system, our analysis provides  
446 concerning evidence about the legitimacy of being able to simultaneously receive multiple organ offers  
447 for some people, while others in the same system are unable to exercise that benefit.

448 Data analyzed for this paper demonstrates a nuanced picture, one of existing disparities by payer,  
449 education, and race/ethnicity, mirroring existing disparities in health access and a less clear picture by  
450 geocoded level income and poverty level. Moreover, removing the practice of multiple listing overall  
451 may resolve some disparities, but could exacerbate others, particularly for patients with medical  
452 complexity, those who are already sensitized to potential donors, or otherwise difficult to match; also,  
453 for pediatric candidates and candidates who list at VA hospitals. Although multiple listing is narrowly  
454 utilized, in the context of the transplant community's commitment to equity, policies governing access  
455 to transplantation should ensure and promote the transplant community's commitment to equitable

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<sup>134</sup> Gauntt, "Data Request," September 14, 2022.


<sup>135</sup> Ibid.

<sup>136</sup> Kristen L. King et al., "Major Variation across Local Transplant Centers in Probability of Kidney Transplant for Wait-Listed Patients," *Journal of the American Society of Nephrology* 31, 20 (Dec 2020): 2900-2911.

<https://doi.org/10.1681/ASN.2020030335>.

<sup>137</sup> George Cholankeril et al., "Disparities in Liver Transplantation Resulting From Variations in Regional Donor Supply and Multiple Listing Practices," *Clinical Gastroenterology and Hepatology* 15, 2 (Feb 2017): 313-315.

<https://doi.org/10.1016/j.cgh.2016.08.036>.



456 access to care. Although the transplant community cannot resolve all public health disparities, it must  
457 strongly consider revising policies that entrench them and continue efforts to rectify these.

458 Ethical principles, including equity and utility, validate concerns over the widespread use of multiple  
459 listing, however, they uphold the import of multiple listing in certain cases, including patients who are  
460 difficult to match. As such, multiple listing should be retained and used to increase equitable access to  
461 transplantation for patients that are difficult to match.

462 The Committee notes that multiple listing is different from multiple evaluation, wherein a patient can be  
463 evaluated at multiple programs if they are dissatisfied with their treatment at a given program at any  
464 time. Increased transparency at the outset would help minimize patients selecting programs that do not  
465 align with their goals.

466 The transplant community cannot by itself resolve the socioeconomic factors that contribute to inequity  
467 in healthcare. While true, this fact does not absolve the community from remediating the policies that  
468 exacerbate disparities within transplantation that are consistent with social patterning of privilege.

469 The ethical analysis of multiple listing strongly supports the use of this policy for patients that are  
470 difficult to match, pediatric candidates and candidates who list at VA hospitals. The Committee also  
471 recognizes that the multiple listing policy is valued by many, and many centers and patients are  
472 accustomed to having this option. **Although recommendations are beyond the scope of this analysis,**  
473 **greater efforts ensuring that all patients are informed of this option and have the ability to exercise**  
474 **are crucial to ensuring that it promotes the goals of the OPTN.** These may include improving patient-  
475 centered education about multiple listing; financial support such as scholarships or other resources to  
476 support multiple listing for patients in need where possible; prohibiting programs from refusing multiple  
477 listed patients; and increasing transparency in evaluation, listing, and organ acceptance practices to help  
478 patients choose a primary program that best fits their needs.

## Appendix A: Data Requests

479 Appendix A details the methods of the two data requests performed at request of the Ethics  
480 Committee.<sup>138, 139</sup>

### 481 Methods – 1<sup>st</sup> Data Request

482 The first data request borrowed the definition of multiple listing used in the Decoteau et al. article.<sup>140</sup>  
483 Multiple listing was defined as any candidate who is on the transplant waitlist for a particular organ at  
484 more than one program simultaneously. A candidate was be considered multiple listed regardless of the  
485 time between first listing and subsequent listing. In this way, the multiple listing definition captured all  
486 candidates who both intended to multiple lists from the outset and those who for whatever reason  
487 made the decision further into their waitlist tenure (potentially due to frustration or inability to secure a  
488 quality offer). All of the following metrics were be calculated based on a recent snapshot of candidates  
489 waiting on the heart, liver, lung and kidney waitlist as of December 31, 2021. All metrics were presented  
490 by organ type (kidney, liver, and thoracic – heart and lung were combined due to small sample size) and  
491 compare multiple listed and single listed candidates, unless otherwise stated. Note that candidates  
492 could have been listed for multiple organs. Candidates, for example, who were listed for a heart and  
493 kidney appeared in both the heart and kidney counts but are only counted once in overall totals.

494 Candidate Demographics: The following candidate demographics are summarized by organ type for  
495 multiple and single listed candidates:

- 496 • Age at snapshot date (years)
- 497 • Race/Ethnicity (American Indian or Alaska Native, Black or African American, Native Hawaiian or  
498 other Pacific Islander, Asian, Hispanic or Latino, White)
- 499 • Insurance Status (private/public) at registration
- 500 • Education level (None, Grade School or less, High School or GED, College or Technical, Associate  
501 or Bachelor Degree, Post-College Graduate Degree)
- 502 • Blood Type (AB, A, B, O)
- 503 • MELD/PELD (Liver Only)
- 504 • Heart Status (Heart Only)
- 505 • LAS (Lung Only)
- 506 • Medically Urgent (Kidney Only)
- 507 • Annual Household Income\* (based on candidate zip code and using census data)
- 508 • Annual Household Income\* by Insurance level
- 509 • Poverty Percent (based on candidate zip code and using census data)
- 510 • Region (11 OPTN regions)

511 Note: The committee expressed interest in looking at indicators of socioeconomic status and correlates  
512 of social determinants of health, such as annual household income. In order to do this OPTN data was  
513 linked to Census data via candidate’s primary zip code at listing, which was found on the transplant  
514 candidate registration (TCR) form. It is important to note that there are several limitations in the use of

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<sup>138</sup> Keighly Bradbrook, Katrina Gauntt, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Candidates By Organ Type,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, May 11, 2022.

<sup>139</sup> Katrina Gauntt, Keighly Bradbrook, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Kidney and Liver Candidates by Geography,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, September 14, 2022.

<sup>140</sup> Mary A. Decoteau et al., “The Advantage of Multiple Listing Continues in the Kidney Allocation System Era,” *Transplantation Proceedings* 53, 2 (Mar 2021): 569-580. <https://doi.org/10.1016/j.transproceed.2020.10.036>.

515 candidate zip codes from OPTN data and the usage of environment level factors like annual household  
516 income in describing patient level determinants of health. Candidate zip codes are not validated in OPTN  
517 data and so data entry problems are likely to exist, and the linkage is not perfect and can often result in  
518 zip codes that do not link to census data. Further, research shows that family income or annual  
519 household income at the aggregated geography level (county, state) are not always good descriptors of  
520 an individual's access, situation, or barriers. Often, for individuals who may be better off than what the  
521 aggregated data would suggest, their own personal situation attenuates any disadvantage that might be  
522 conferred by their environment.

523 Poverty percent is the percent of people living in poverty within a ZCTA within a year (zip code  
524 tabulation areas) and is based on the Census data.

525 Demographics were summarized as count and percent for categorical variables and mean and standard  
526 deviation for continuous covariates, in tabular form. Distributions of candidate characteristics were  
527 plotted by organ type.

528 **Metrics for Multiple listed candidates only:** The subcommittee was also interested in describing  
529 characteristics of multiple listed candidates at the time of first multiple listing. The following metrics  
530 describe the distribution of time between primary listing and secondary listing where primary listing is  
531 defined as the first registration to occur in time and secondary listings those occurring after the primary  
532 (i.e. the second, third, fourth or fifth listing locations). Only first and secondary listings were considered.  
533 The following metrics were calculated using a subset of multiple listed candidates from December 31,  
534 2021, snapshot data by organ type:

- 535 • Distribution of age, medical urgency status and hospitalization at secondary listing
- 536 • Distribution of time between initial listing and secondary listing for multiple listed candidates
- 537 • Distance from primary transplant program to secondary (or additional transplant programs)

538 These metrics will be presented in tabular form as min, max, median, mean and IQR and graphed.

539 **Geography:** The subcommittee was also interested in looking at the geography of multiple listings. All  
540 secondary listings were included in these analyses. Results were de-identified with regard to transplant  
541 program. The following metrics were calculated using a subset of multiple listed candidates from the  
542 December 31, 2021, snapshot data by organ type:

- 543 • The percent of multiple listed candidates at each program – do a majority of multiple listings  
544 occur at a handful of programs?
- 545 • Percent of multiple listings by state and OPTN region (based on transplant program location, not  
546 candidate location)

## 547 **Methods – 2<sup>nd</sup> Data Request**

### 548 *Methods*

549 Similar to the first data request, this follow-up request borrowed the definition of multiple listing used in  
550 the Decoteau et al. article. Multiple listing was defined as any candidate who is on the transplant waitlist  
551 for a particular organ at more than one program simultaneously. A candidate was considered multiple  
552 listed regardless of the time between first listing and subsequent listing. In this way, the multiple listing  
553 definition captured all candidates who both intended to multiple lists from the outset and those who for  
554 whatever reason made the decision further into their waitlist tenure (potentially due to frustration or  
555 inability to secure a quality offer). All of the following metrics were calculated based on waitlist data. A  
556 recent snapshot of candidates waiting on December 31, 2021, was used for all metrics with the

557 exception of transplant rates. The metrics focused on liver and kidney candidates unless otherwise  
558 stated. Thoracic was excluded at the request of the subcommittee.

559 The committee requested the median time to transplant by listing status, due to limitations in data the  
560 median time to transplant could only be provided for those that had received a transplant. In order to  
561 provide more insight to the question of equity in access the workgroup sought to evaluate, the  
562 transplant rate was provided calculated as transplant per 100 inactive and active patient-years. The  
563 transplant rates were calculated based on an ever-waiting cohort from implementation of acuity circles  
564 to March 31, 2022. For liver this was candidates ever waiting<sup>141</sup> between February 4th, 2020, to March  
565 31, 2022, and for kidney this was candidates ever waiting between March 15, 2021 to March 31st, 2022.  
566 Candidates were indicated as ever multiple listed if at any point in the cohort time frame the candidate  
567 had two or more listings at multiple programs that overlapped. Candidate waiting time was considered  
568 by taking the time in days from the first listing date to either the date of transplant or the date of  
569 candidate removal from all listings from the waitlist, including both active and inactive waiting time for  
570 the candidate.

571 *Additional Metrics*

- 572 • Number/percent of candidates listed (primary listing) before the removal of DSA policy on  
573 March 15, 2021, by organ type
- 574 • Number/percent of Kidney and Liver multiple listed candidates whose (first) secondary listing  
575 was outside of the DSA from primary listing
- 576 • Number/percent of Kidney and Liver multiple listed candidates whose (first) secondary listing  
577 was outside of the priority circle (250NM for Kidney and 150 NM for Liver)
- 578 • Number/percent of Kidney and Liver multiple listed candidates who had any secondary listing  
579 outside of the DSA from primary listing
- 580 • Number/percent of Kidney and Liver multiple listed candidates who had any secondary listing  
581 outside of the priority circle (250NM for Kidney and 150 NM for Liver)
- 582 • Transplant rate per 100 patient-years by multiple listing status, geography (pending sample  
583 size), and multiple listing and geography for Kidney and Liver candidates, separately

584

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<sup>141</sup> “Ever waiting” is inclusive of candidates who spent any time waiting during the time period described - whether the candidate was on the waiting list the entire time period or a shorter subset



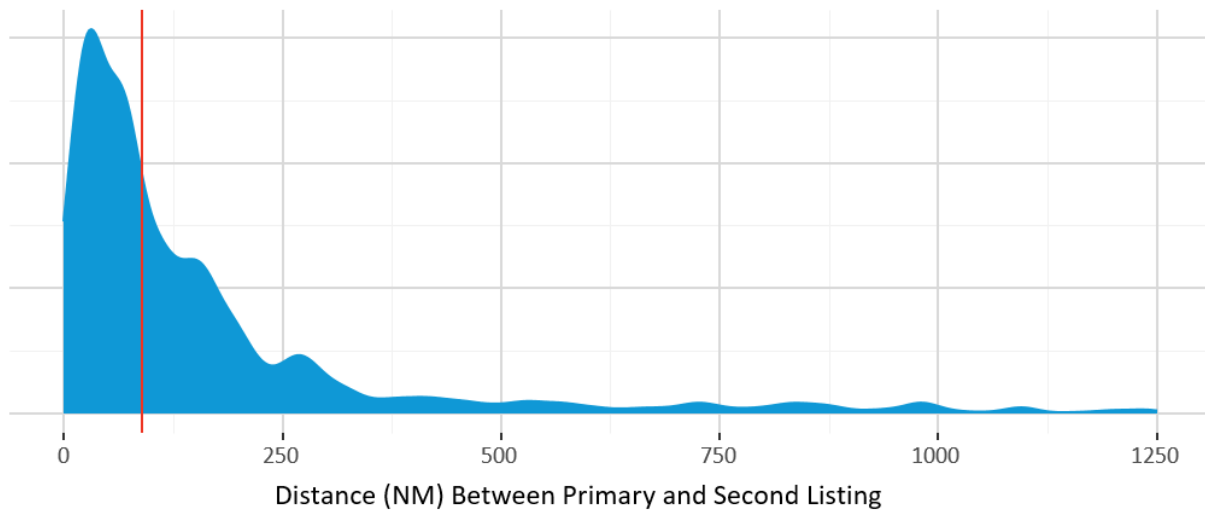
Table 1

	Overall	Single Listed Kidney	Multiple Listed Kidney	Single Listed Liver	Multiple Listed Liver	Single Listed Thoracic	Multiple Listed Thoracic
n	106647	83958	6525	11435	176	4516	37
Age at Snapshot (%)							
<18	1889 (1.8)	1056 (1.3)	14 (0.2)	340 (3.0)	2 (1.1)	456 (10.1)	1 (2.7)
18-34	8414 (7.9)	6799 (8.1)	536 (8.2)	506 (5.2)	16 (9.1)	461 (10.2)	6 (16.2)
35-49	22934 (21.5)	18623 (22.2)	1615 (24.8)	1862 (16.3)	26 (14.8)	801 (17.7)	7 (18.9)
50-64	46125 (43.3)	35167 (42.6)	2883 (44.2)	5441 (47.6)	95 (54.0)	1926 (42.6)	13 (35.1)
65+	27305 (25.6)	21713 (25.9)	1477 (22.6)	3196 (27.9)	37 (21.0)	872 (19.3)	10 (27.0)
Sex = Male (%)	65933 (61.8)	51709 (61.6)	4192 (64.2)	6917 (60.5)	99 (56.2)	2991 (66.2)	27 (73.0)
Race/Ethnicity (%)							
White, Non-Hispanic	42759 (40.1)	30023 (35.8)	2366 (36.3)	7609 (66.5)	127 (72.2)	2609 (57.8)	25 (67.6)
Black, Non-Hispanic	30290 (28.3)	25935 (30.9)	2355 (36.1)	795 (7.0)	10 (5.7)	1105 (24.5)	9 (24.3)
Hispanic/Latino	21983 (20.6)	18072 (21.5)	1061 (16.3)	2235 (19.5)	28 (15.9)	584 (12.9)	3 (8.1)
Asian, Non-Hispanic	9097 (8.5)	7730 (9.2)	622 (9.5)	587 (5.1)	9 (5.1)	149 (3.3)	0 (0.0)
Amer Ind/Alaska Native, Non-Hispanic	889 (0.8)	751 (0.9)	29 (0.4)	92 (0.8)	1 (0.6)	16 (0.4)	0 (0.0)
Native Hawaiian/other Pacific Islander, Non-Hispanic	571 (0.5)	522 (0.6)	20 (0.3)	20 (0.2)	1 (0.6)	8 (0.2)	0 (0.0)
Multiracial, Non-Hispanic	1139 (1.1)	925 (1.1)	72 (1.1)	97 (0.8)	0 (0.0)	45 (1.0)	0 (0.0)
Insurance Status (%)							
Not Reported	403 (0.4)	315 (0.4)	23 (0.4)	44 (0.4)	0 (0.0)	21 (0.5)	0 (0.0)
Private or Self	47892 (44.9)	36370 (43.3)	3493 (53.5)	5808 (50.8)	121 (68.8)	2076 (46.0)	24 (64.9)
Public or Charity	58352 (54.7)	47273 (56.3)	3009 (46.1)	5583 (48.8)	55 (31.2)	2419 (53.6)	13 (35.1)
Education (%)							
<5 Yrs Old	698 (0.7)	269 (0.3)	4 (0.1)	187 (1.6)	3 (1.7)	235 (5.2)	0 (0.0)
Associate/Bachelor Degree	20793 (19.5)	16045 (19.1)	1640 (25.1)	2279 (19.9)	40 (22.7)	778 (17.2)	11 (29.7)
Attended College/Technical School	26600 (24.9)	20095 (25.0)	1705 (26.1)	2773 (24.3)	47 (26.7)	1068 (23.6)	12 (32.4)
Grade School or Less	8116 (7.6)	6711 (8.0)	230 (3.5)	856 (7.5)	6 (3.4)	311 (6.9)	2 (5.4)
High School or GED	38907 (36.5)	31215 (37.2)	1961 (30.1)	4095 (35.8)	48 (27.3)	1580 (35.0)	8 (21.6)
Post-College Graduate Degree	7892 (7.4)	5927 (7.1)	783 (12.0)	846 (7.4)	21 (11.9)	313 (6.9)	2 (5.4)
Unknown	3641 (3.4)	2796 (3.3)	202 (3.1)	399 (3.5)	11 (6.2)	231 (5.1)	2 (5.4)
Blood Type (%)							
A	30593 (28.6)	23303 (27.8)	1434 (22.0)	4377 (38.3)	81 (46.0)	1299 (28.8)	9 (24.3)
AB	2626 (2.5)	2202 (2.6)	113 (1.7)	236 (2.1)	3 (1.7)	72 (1.6)	0 (0.0)
B	16592 (15.5)	13644 (16.3)	1182 (18.1)	1201 (10.5)	11 (6.2)	463 (10.3)	1 (2.7)
O	57016 (53.5)	44809 (53.4)	3796 (58.2)	5621 (49.2)	81 (46.0)	2682 (59.4)	27 (73.0)
OPTN Region (%)							
1	6532 (6.1)	4836 (5.8)	206 (3.2)	1146 (10.0)	9 (5.1)	335 (7.4)	0 (0.0)
2	13389 (12.6)	10409 (12.4)	935 (14.3)	1553 (13.6)	32 (18.2)	455 (10.1)	5 (13.5)
3	12455 (11.7)	9783 (11.7)	1059 (16.2)	1045 (9.1)	10 (5.7)	554 (12.3)	4 (10.8)
4	10600 (9.9)	7256 (8.6)	1387 (21.3)	1411 (12.3)	51 (29.0)	495 (11.0)	0 (0.0)
5	23592 (22.0)	19405 (23.1)	990 (15.2)	2559 (22.4)	24 (13.6)	518 (11.5)	6 (16.2)
6	2920 (2.7)	2437 (2.9)	60 (0.9)	294 (2.6)	5 (2.8)	124 (2.7)	0 (0.0)
7	8098 (7.6)	6476 (7.7)	426 (6.5)	700 (6.1)	14 (8.0)	480 (10.6)	2 (5.4)
8	4399 (4.0)	3419 (4.1)	142 (2.2)	520 (4.5)	7 (4.0)	218 (4.8)	3 (8.1)
9	8311 (7.8)	6823 (8.1)	368 (5.6)	692 (6.1)	11 (6.2)	409 (9.1)	8 (21.6)
10	6434 (6.0)	4933 (5.9)	201 (3.1)	749 (6.6)	4 (2.3)	541 (12.0)	6 (16.2)
11	10097 (9.5)	8181 (9.7)	751 (11.5)	766 (6.7)	9 (5.1)	387 (8.6)	3 (8.1)
Poverty Percent (mean (SD))	14.66 (9.14)	15.00 (9.26)	14.28 (9.24)	12.83 (8.14)	11.42 (6.79)	13.62 (8.58)	12.11 (8.60)
Median Household Income (mean (SD))	66619.13 (27568.90)	65913.33 (27401.04)	67680.45 (29314.09)	70712.11 (27728.19)	74816.94 (29624.40)	67490.22 (27271.61)	73285.00 (28741.55)

586 **Figure 1**

587 Figure 1, below, shows the distribution in nautical miles (NM) between first listing hospital and second  
 588 listing hospital for multiple listed kidney candidates. The media distance between listing hospitals for  
 589 kidney candidates that multiple listed was 89 NM.

590  
 591 **Figure 1. Distance Between Primary and Secondary Listing Transplant Hospitals for Multiple Listed**  
 592 **Kidney Candidates on December 31, 2021**  
 593



594  
 595  
 596 \*There were 193 Multiple Listed candidates that had secondary registrations at a transplant hospital that  
 597 exceeded 1,250 NM in distance from the hospital they were primarily listed at.

The red line shows the median distance from primary to secondary listing.

600

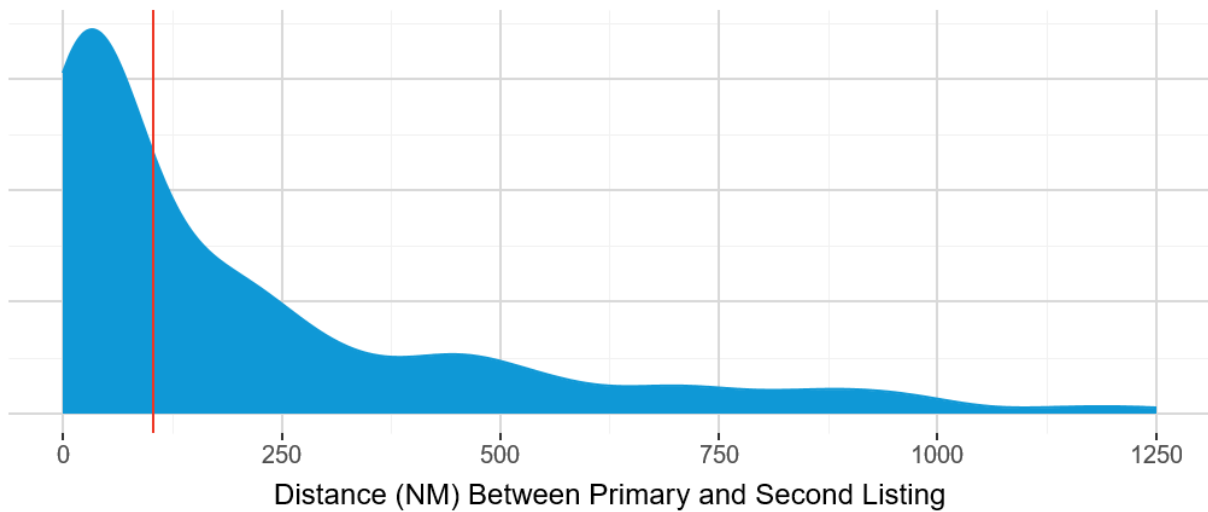
Candidates	Minimum	25 <sup>th</sup> -Quantile	Mean	Median	75 <sup>th</sup> -Quantile	Maximum
6525	0	32	213.65	89	199	4186

601

602 **Figure 2**

603 Figure 2, below, shows the distribution in nautical miles (NM) between first listing hospital and second  
 604 listing hospital for multiple listed liver candidates. The media distance between listing hospitals for liver  
 605 candidates that multiple listed was 103.5 NM.

606  
 607 **Figure 2. Distance Between Primary and Secondary Listing Transplant Hospitals for Multiple Listed**  
 608 **Liver Candidates on December 31, 2021**



609  
 610 \*There were 10 Multiple Listed candidates that had secondary registrations at a transplant hospital that  
 611 exceeded 1,250 NM in distance from the hospital they were primarily listed at.  
 612  
 613 The red line shows the median distance from primary to secondary listing.  
 614

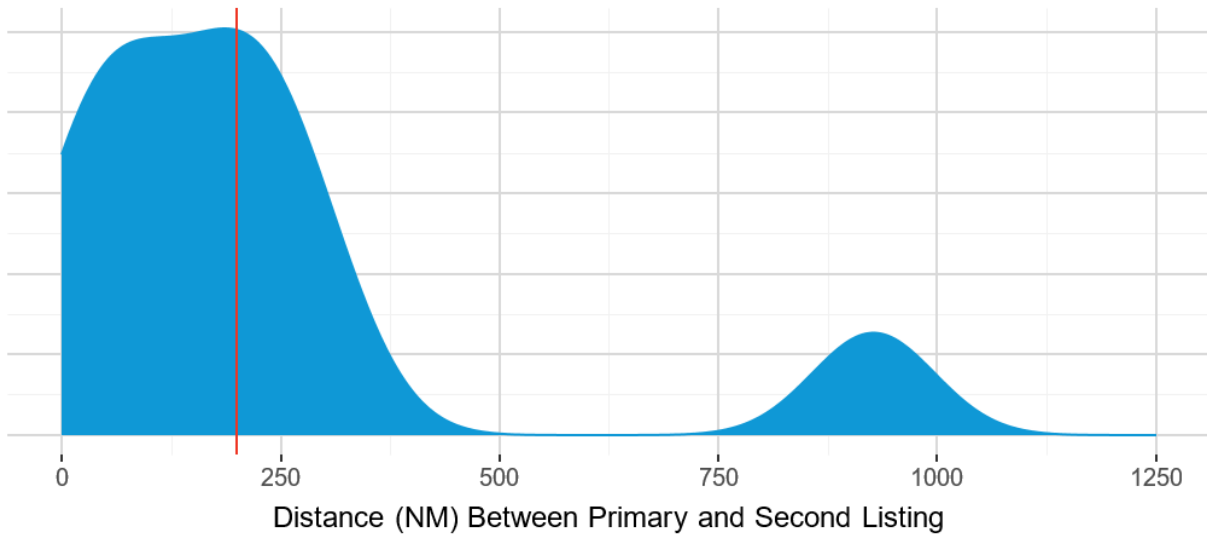
Candidates	Minimum	25 <sup>th</sup> -Quantile	Mean	Median	75 <sup>th</sup> -Quantile	Maximum
176	0	29	300.77	103.5	362.5	3378

615

616 **Figure 3**

617 Figure 2, below, shows the distribution in nautical miles (NM) between first listing hospital and second  
 618 listing hospital for multiple listed thoracic candidates. The media distance between listing hospitals for  
 619 liver candidates that multiple listed was 161 NM.

620  
 621 **Figure 3. Distance Between Primary and Secondary Listing Transplant Hospitals for Multiple Listed**  
 622 **Thoracic Candidates on December 31, 2021**



623  
 624 \*A single Multiple Listed candidate that had a secondary registrations at a transplant hospital that  
 625 exceeded 1,250 NM in distance from the hospital they were primarily listed at.

626  
 627 The red line shows the median distance from primary to secondary listing.

628

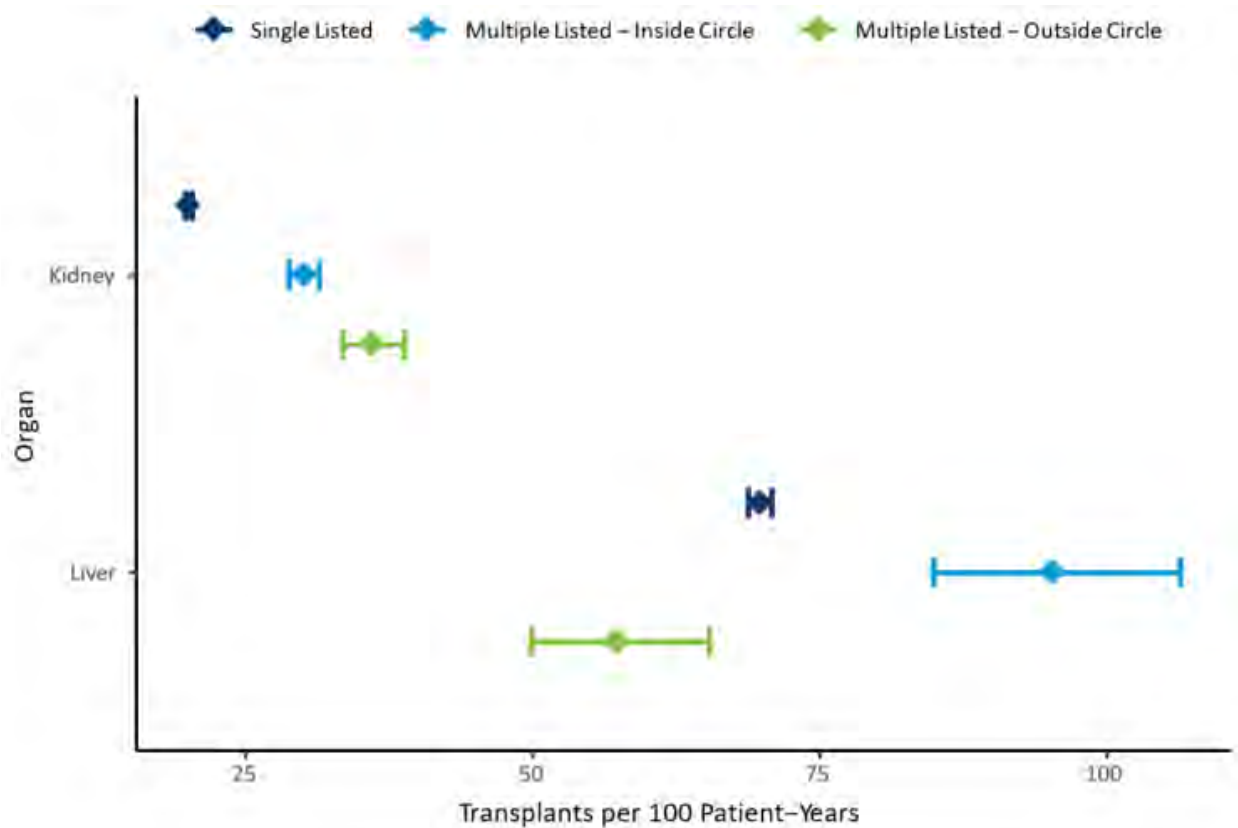
Candidates	Minimum	25 <sup>th</sup> -Quantile	Mean	Median	75 <sup>th</sup> -Quantile	Maximum
37	11	75	300.86	161	273	2129

629

630 **Figure 4**

631 Figure 4 shows the transplant rate by listing status and secondary listing location for both kidney and  
632 liver candidates every waiting from circle allocation implementation to March 31, 2022 broken out by  
633 organ. For kidney, singly listed candidates had a lower transplant rate than both of the multiple listing  
634 categories, with multiple listed outside of the circle having the highest transplant rate. Single listed  
635 kidney candidates had a transplant rate of 20.01 per 100 patient-years vs. 30.07 per 100-patient years  
636 for multiple listed kidney candidates inside of the circle and 36.01 per 100 patient-years for multiple  
637 listed kidney candidates outside of the circle. For liver, multiple listed liver candidates outside of the  
638 circle had the lowest transplant rate at 57.27 transplants per 100 patient-years, and multiple listed liver  
639 candidates inside of the circle had the highest transplant rate at 95.24 transplants per 100 patient-years.

640  
641 **Figure 4. Transplant Rate by Listing Status and Secondary Listing Location for Kidney and Liver**  
642 **Candidates Ever Waiting from Circle Allocation Implementation by Organ to March 31, 2022**  
643



644

645 **Table 2**

646 **Table 2. Transplant Rate by Listing Status for Kidney and Liver Candidates Ever Waiting from Circle**  
 647 **Allocation Implementation by Organ to March 31, 2022**

Organ	Listing Status	Candidates	Transplants	Total Years Ever Waiting	Transplants Per 100 Patient-Years (Active and Inactive)	95% CI
Kidney	Single Listed	118180	17074	85346	20.01	(19.71, 20.31)
	Multiple Listed - Inside Circle	8287	1996	6637	30.07	(28.77, 31.42)
	Multiple Listed - Outside Circle	2481	716	1989	36.01	(33.42, 38.74)
Liver	Single Listed	38955	17606	25196	69.88	(68.85, 70.92)
	Multiple Listed - Inside Circle	524	310	325	95.24	(84.93, 106.46)
	Multiple Listed - Outside Circle	409	218	381	57.27	(49.92, 65.4)

## Addendum to “Ethical Evaluation of Multiple Listing: A Comprehensive Response to Public Comment”

### 648 Public Comment Overview

649 The Ethics Committee deeply values feedback shared during the public comment period, which exists in  
650 service of giving stakeholders in the transplantation community the opportunity to share their  
651 perspectives. In response, the committee offers this addendum to “Ethical Evaluation of Multiple  
652 Listing” in hopes of responding thoughtfully and thoroughly to the well-taken objections that have been  
653 shared with us.

654  
655 The Ethics Committee would first like to note that the public comment period revealed that overall,  
656 there was **considerable support** for the white paper, and in particular for its attempt to uphold an  
657 equitable and efficient system of organ allocation. This support was displayed even by members who  
658 raised concerns. Indeed, many in public comment acknowledged that candidates who multiply list tend  
659 to be individuals of more means, education, and resources with which to travel, having family, friends,  
660 and other forms of support in more than one geographic region that make them more likely to receive a  
661 transplantation than others on the waiting list who lack these resources.

662  
663 This noted, there were seven general categories of criticism the Ethics Committee felt merited focused  
664 responses. These include: (1) The white paper singles out organ transplantation as inequitable, but our  
665 whole healthcare system suffers from inequity, something we will not solve simply by calling attention  
666 to organ allocation policy. Why, then, single out inequity in organ allocation in this particular instance?  
667 (2) Despite equity concerns, doesn't the principle of autonomy provide a larger justification for the  
668 practice of multiple listing? (3) An ethic of care not only permits, but also requires, us to do every and  
669 anything in our power to help our loved ones who are desperate for a bodily organ. Should not anybody  
670 similarly circumstanced do whatever they could to help find their loved ones the organ they needed? (4)  
671 Does the effort to undo the practice of multiple listing sufficiently take into account the logistical  
672 realities of transplantation in different regions of the country? (5) The Ethics Committee supports the  
673 practice of multiple listing in the case of difficult to match patients, but how does it propose to establish  
674 thresholds which separate difficult to match patients? And (6) is the Ethics Committee acting within its  
675 scope?

676  
677 The Ethics Committee is grateful for the opportunity to respond to each of these thoughtful objections.

678  
679 **(1) We are not likely to fix disparities in the whole healthcare system. Why should we focus**  
680 **exclusively on one practice, multiple listing, within one facet of healthcare, organ**  
681 **transplantation? And why problematize multiple listing while still allowing for multiple**  
682 **evaluations?**

683  
684 The Ethics Committee acknowledges that there is no shortage of examples of inequitable treatment in  
685 the United States, where those with means experience disproportionate benefit and access to care.  
686 However, that a large system is problematic doesn't alleviate the burden of trying to fix some part of it.  
687 In focusing on the practice of multiple listing, the Ethics Committee examined what was proposed to be  
688 the legitimate rationale for this policy, and to question, if that rationale could not be clearly identified,

689 whether it could continue to be supported. Thus, the Ethics Committee did not seek to “single out” the  
690 practice of multiple listing for attention. The Committee reviews all policies to assess their ethical  
691 implications and how they balance ethical principles underpinning the organ transplant system. The  
692 multiple listing policy has been scrutinized for many years and has never undergone ethical analysis. As  
693 such, this was a priority for the OPTN and the Committee.

694  
695 Under the assumption that organ transplantation is zero-sum, when it comes to those on the waiting  
696 list, if one person receives an organ, then that is one organ another does not receive. Ensuring fairness  
697 as a value in itself, and also promoting the utility end of preserving the perception of fairness of the  
698 transplant system is imperative. For these reasons, the Ethics Committee felt that our attention to  
699 decreasing disparities in multiple listing was worth our attention and effort, particularly in light of the  
700 recently issued National Academies of Sciences, Engineering and Medicine (NASEM) report which  
701 instructs all stakeholders in the transplantation community to try to make organ allocation more  
702 equitable.<sup>142</sup>

703  
704 Some members additionally raised the issue that by calling attention to the practice of multiple listing,  
705 but not multiple evaluation, we were essentially deferring the problem of inequity within  
706 transplantation, not solving it. In response, the Ethics Committee notes, as described in the  
707 “Transparency” white paper, seeking evaluations at multiple centers supports patient-centered care and  
708 autonomy, without negatively impacting others. In contrast, when one multiply lists, at that moment in  
709 time one becomes the beneficiary of having more than one avenue towards transplantation, accruing an  
710 advantage well beyond determining what transplant center represents the right fit.

711  
712 **(2) Why would the Ethics Committee try to curtail patient autonomy, which would seem to**  
713 **permit multiple listing?**

714  
715 Autonomy is a critical principle in medical ethics, and in transplantation ethics specifically, but autonomy  
716 is not an absolute right, absolved from the burden of being placed in balance with other ethical  
717 principles. In addition, a tacit but indispensable constraint on the autonomy of one person is that it can’t  
718 lead to the curtailment of the autonomy (and flourishing) of another. But retaining a policy of multiple  
719 listing across the board would do just this. In specific, it would curtail the autonomy of marginalized and  
720 structurally disadvantaged individuals among us. Lower levels of insurance, education, and at times  
721 race/ethnicity (particularly in the case of liver) limit access to transplant. Since it is also true that  
722 multiple listing is associated with higher likelihood of transplant, in the status quo the privileged would  
723 be gaining an advantage at the expense of the underprivileged.

724  
725 Currently, multiple listing is not a practice that all patients are able to exercise or utilize. The use of  
726 multiple listing is patterned in a way that exacerbates existing disparities in access to transplant and  
727 healthcare. For example, patients with less than a high school education are 50% less likely to be  
728 multiple listed for a kidney or liver transplant, while those with a post-college graduate degree are 60%  
729 more likely to be multiple listed for liver and kidney transplant. Patients with Medicaid are at least three  
730 times less likely to be multiple listed than those with private insurance for kidney and liver transplant.<sup>143</sup>

731

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<sup>142</sup> National Research Council. 2022. *Realizing the Promise of Equity in the Organ Transplantation System*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26364>.

<sup>143</sup> Katrina Gauntt, Keighly Bradbrook, and Jesse Howell, “Data Request – Characteristics of Multiple Listed Kidney and Liver Candidates by Geography,” OPTN, Descriptive Data Request for the Ethics Committee Multiple Listing Subcommittee, September 14, 2022.





732 Limiting multiple listing would reduce an advantage that aligns with socioeconomic disparities in access  
733 to transplant, thereby creating more of a level playing field with regard to ensuring everyone’s ability to  
734 exercise their autonomy. This calls attention to one of the ways in which organ transplantation is  
735 perhaps distinctive, for unlike other areas of healthcare, as mentioned above, transplant is a zero-sum  
736 game. When one patient is able to accept an organ offer from multiple centers simultaneously, another  
737 patient’s likelihood to receive an organ decreases. In this respect, the Ethics Committee sees itself in the  
738 end as upholding the principle of autonomy, despite that an analysis undertaken without taking into  
739 account social disparities might lead one to draw the opposite conclusion.

740

741 **(3) Why would the Ethics Committee get in the way of individuals doing whatever they can to**  
742 **help the ones they love? Shouldn’t we support policies that defend the loving impulses of the**  
743 **families of those in desperate situations?**

744

745 The Ethics Committee acknowledges and has a great deal of sympathy for this objection, which is  
746 compelling because we can all imagine how we would feel if we were in the shoes of one, or those of a  
747 family member of one, who needed an organ. In responding, it is critical to make a distinction between  
748 the perspective from the ethics of care, which operates at the level of the individual, and the ethics of  
749 systems of allocation, which must always consider justice at the population-level. The Ethics Committee  
750 acknowledges explicitly in our white paper that on an individual level the current policy on multiple  
751 listing can open up a precious extra option for those facing desperate circumstances. However, this  
752 individual level of analysis does not easily translate into a policy meant to determine the fair allocation  
753 of scarce resources, which by definition is a public enterprise. There are many actions (e.g. paying for  
754 organs) that, although they may promote the benefit of an individual in pursuing an organ transplant,  
755 are not permissible at the population/societal-level.

756

757 **(4) Does the Ethics Committee’s attention to the practice of multiple listing fully capture the**  
758 **logistical realities of transplantation in different regions of the country, and does it cohere**  
759 **with concurrent initiatives underway of Continuous Distribution?**

760

761 Some present a compelling objection by stating that multiple listing solves a larger disparity in organ  
762 transplantation by shifting patients from areas with long waitlists to areas with shorter waitlists. They  
763 acknowledge that, while this may lengthen the waitlist in areas where patients are secondarily listed, it  
764 relieves the burden from regions disproportionately experiencing long waits. Moreover, they note that  
765 allowing patients to retain their primary listing, which is most commonly near their primary residence,  
766 allows patients to keep relationships with transplant teams, which patients and centers value highly.

767

768 The Committee acknowledges that use of multiple listing as a workaround to smooth differences in  
769 waiting times is appealing and understandable at the individual level. However, the Committee notes  
770 that organ allocation policies are created to ensure a balance of ethical principles of utility, justice, and  
771 respect for persons for all stakeholders and operate at the health-system level. Geographic differences  
772 in waiting times should be resolved by policies governing the system as a whole, including new  
773 initiatives to continuous distribution, and not through individual workarounds which are likely to benefit  
774 some but not all. Similar to arguments made in the white paper on manipulating waitlist priority,  
775 individual-level manipulation of waitlist priority through interventions or multiple listing increases a  
776 transplant candidate’s priority on the waitlist relative to others, undermines the legitimacy and balance  
777 of ethical principles of the organ allocation system as a whole.

778

779 **(5) The Ethics Committee supports the ethical justification for multiple listing in the case of**  
780 **difficult to match patients, but how can we distinguish these patients?**

781  
782 The Ethics Committee is aware that in response to our white paper members seek more specific  
783 guidance regarding medically complex or difficult to match patients. What is the definition, some asked,  
784 of “medically complex?”

785  
786 Our response is that simply in acknowledging that there is a category of prospective organ recipients  
787 who are biologically uncommonly difficult to match, we do not at the same time fail to recognize that  
788 physicians and other clinical staff at specific transplant centers are the ones best positioned to make the  
789 determinations about who falls into this category on a case-by-case basis. By identifying the category of  
790 patients who are difficult to match, the Ethics Committee is merely staking out a weaker position than  
791 might be suggested in other analyses which recommend the abolishment of the practice of multiple  
792 listing altogether. The Ethics Committee leaves it to organ-specific committees and other committees to  
793 arrive at standards for what constitutes “difficult to match,” and hopes only that these might be applied  
794 consistently and transparently across the board. Significantly, the Ethics Committee acknowledges a  
795 qualitative difference between non-medical criteria like privilege and material advantage, which should  
796 not bear on one’s place on the waiting list, and sensitization, which arguably should. That the Ethics  
797 Committee acknowledges this category as exceptional does not imply that the Ethics Committee sees  
798 itself as the adjudicator of eligibility for it.

799  
800 **(6) Is the Ethics Committee out of scope?**

801  
802 The concern that the Ethics Committee has somehow veered out of its proverbial lane is one we are  
803 pressed to address in different contexts from time to time. We want to emphasize that we serve only in  
804 a guidance capacity to transplantation policy. The mission and scope of the Ethics Committee is:

805  
806 *“The Ethics Committee aims to guide the policies and practices of the OPTN related to organ donation,*  
807 *procurement, distribution, allocation, and transplantation so they are consistent with ethical principles.*  
808 *The Committee makes recommendations to Board of Directors for changing, creating, or eliminating*  
809 *policies if warranted by ethical concerns. The Committee also provides written guidance pertaining to*  
810 *ethical considerations to OPTN members, after approval by the Board of Directors. The Committee does*  
811 *not address individual patient issues or disputes.”<sup>144</sup>*

812  
813 The Ethics Committee leaves it to others to make actionable recommendation that might be inferred  
814 from our analysis. The Ethics Committee hopes that stakeholders bear in mind the mandate issued in  
815 the NASEM report to improve equity in transplantation policy, which implies improving access for  
816 patients to match who have the least means at their disposal. This noted, this white paper does not  
817 change the existing policies allowing multiple listing. It reviews the ethical considerations and  
818 preliminary data of the practice of multiple listing and undertakes an ethical analysis based on these  
819 findings.

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<sup>144</sup> “Ethics Committee.” OPTN: Organ Procurement and Transplantation Network - OPTN. Accessed April 7, 2023.  
<https://optn.transplant.hrsa.gov/about/committees/ethics-committee/>. Charter is listed at the top of this webpage.