

## *White Paper*

# Ethical Evaluation of Multiple Listing

*OPTN Ethics Committee*

*Prepared by: Laura Schmitt, MS and Houlder Hudgins  
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 15, 2023

## Executive Summary

The purpose of this white paper is to conduct an ethical analysis of multiple listing, and understand how the practice fares against the ethical principles of transplant. This white paper will serve to concretely conclude the decades-old debate surrounding multiple listing, which is a process that permits patients to be listed at multiple transplant programs and accept organ offers from more than one transplant program simultaneously. Ultimately, this white paper answers the question “What are the ethical implications of permitting patients to be listed at multiple transplant programs?” The Committee considers this question with a focus on access to multiple listing and how it impacts the transplant system as a whole, as opposed to the individual.

To address this question, the Ethics Committee considers the ethical principles of 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 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 this data was to compliment the ethical analysis and provide recommendations that are an outgrowth of the current practice.

The Committee recommends that multiple listing be retained as an option only for patients who are exceptionally difficult to match, and that transplant programs should underscore the value of multiple listing to patients who meet the agreed-upon criteria. This would apply to sensitized patients or patients exhibiting other agreed-upon characteristics that represent medical complexity. To ensure equity, patients who meet new criteria for multiple listing should be supported in pursuing this option, including financial support such as scholarships or other resources, where possible. Furthermore, the Committee recommends prohibiting transplant programs from refusing multiple listed patients, in support of patient autonomy over transplant program autonomy. Lastly, to increase patient autonomy, transplant hospitals are encouraged to increase transparency in evaluation, listing, and organ acceptance practices to help patients choose a primary transplant program that is an optimal fit for their needs. The Committee acknowledges the challenges defining this medically complex group and defers the identification of these individuals and modification of the relevant policies to other OPTN committees.

Although the transplant community cannot resolve all public health disparities, it must strongly consider revising policies that entrench them and continue efforts to rectify these. Any future project to revise this longstanding policy would require significant empirical analysis to review utilization patterns, as well as ethical analysis to inform whether the policy is justified, given the patient access and usage.

## Background

The Ethics Committee, hereafter the “Committee,” began the ethical analysis of multiple listing in early 2022. While the OPTN Board of Directors has considered this topic in the past, the Ethics Committee has never completed a formal ethical analysis of the practice. As such, the Committee felt the transplant

system would benefit from an ethical analysis of the practice as it continues to be a topic of discussion and controversy. The act of having multiple transplant registrations is colloquially known as ‘multiple listing,’ and will be referred to as such throughout the duration of this document. The purpose of this project is to conduct an ethical analysis of the multiple listing practice, to address the question: what are the ethical implications of permitting patients to be listed at multiple transplant programs? This question was analyzed with specific regard to access to multiple listing and the implications for transplant candidates to receive multiple organ offers simultaneously from different transplant programs. The Committee examined data about multiple listing to examine whether patients are able to equally utilize the practice and whether it confers an advantage in the likelihood of obtaining a transplant, and conditional on it being advantageous examined potential ethical justifications. The Committee examined corresponding data to determine if there are discrepancies in access and the implications on the transplant system, however, this analysis was cursory. Future analysis should more comprehensively examine the distribution of benefits from multiple listing.

This ethical analysis is positioned in consideration of the existing multiple listing policies. Multiple listing is established in policy through *OPTN Policy 3.4.F Multiple Transplant Program Registrations*, which permits transplant candidates to register for an organ at multiple transplant programs.<sup>1</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 or not that transplant program accepts patients with multiple registrations.<sup>2</sup> Although current policy requires that patients be notified of this option, the degree to which this policy is carried out and the degree to which patients understand and can act on this varies.

The Committee distinguishes between pursuing multiple evaluations and multiple listing. Multiple evaluations allow patients to exercise their autonomy to identify the transplant program that best meets their needs, preferences, and values prior to registering on the waitlist. The Committee recognizes that limitations exist in allowing all patients to pursue multiple evaluation, but support providing as much information as possible to patients to maximize their ability to select the program best meets their needs.<sup>3</sup> Multiple listing, on the other hand, permits patients to receive organ offers from more than one transplant program simultaneously. While patients may be exercising autonomy through multiple listing, their autonomy must not negatively impact another patient.

Multiple listing has an extensive history in the OPTN. On August 10, 1987, the OPTN Board of Directors passed a resolution to allow patients to be added to the waitlist of more than one local transplant program, the first iteration of the multiple listing policy to be implemented by the OPTN.<sup>4</sup> The new policy faced immediate criticism for several reasons, the most common being that permitting multiple listings favored wealthy patients who had the means to travel while disadvantaging those who did not.<sup>5</sup> Differences in health literacy, education, and insurance type, among other social determinants of health, may also play a significant role in contributing to differential utilization of multiple listing. Subsequently, the OPTN proposed prohibiting multiple listings pending a public comment period which would occur in 1988. The proposal received a plethora of responses, with stakeholder organizations acknowledging the potential inequities created by allowing multiple registrations, but encouraging the OPTN Board of Directors not to ban the practice until organ allocation better accounted for the needs of highly

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<sup>1</sup> *OPTN Policy 3.4.F Multiple Transplant Program Registrations*, 2022.

<sup>2</sup> *OPTN Policy 3.2 Notifying Patients of Their Options*, 2022.

<sup>3</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>4</sup> United Network for Organ Sharing Board of Directors Meeting, August 10, 1987, Atlanta, Georgia.

<sup>5</sup> United Network for Organ Sharing Board of Directors Meeting, January 15, 1988, New Orleans, Louisiana.

sensitized and medically urgent patients.<sup>6,7</sup> The OPTN Ethics Committee recommended specific revisions including the designation of a primary transplant program, adjusting points within allocation priority to eliminate advantage, and regional agreements regarding inter-regionally listed patients.<sup>8</sup> Following the public comment period, the former OPTN Organ Procurement and Distribution Committee reversed its position on the multiple listing policy in favor of keeping it, and in March of 1988, the Board decided not to proceed with the prohibition on multiple listings, allowing the 1987 resolution to persist.<sup>9</sup>

The multiple listing policy was brought to the forefront again in November of 1994 with a proposal from the former OPTN Kidney and Pancreas Transplantation Committee to prohibit multiple listing except for patients who were listed for a kidney-pancreas combined transplant at one program, and an isolated kidney transplant at another.<sup>10</sup> During public comment, the Ethics Committee submitted comment in unanimous support of a ban on multiple listing; the Committee felt that the practice gave an advantage to individuals with the access and means to utilize the practice thereby disadvantaging other patients.<sup>11</sup> However, following public comment feedback, the Kidney and Pancreas Transplantation Committee reversed their positions on the multiple listing ban. This reversal led to a tied vote at the board meeting and the Board decided to table the proposed resolution, thereby leaving the policy permitting multiple listing in effect.<sup>12,13</sup>

By the end of 2001, the multiple listing policy was reevaluated for a third time, this time in an effort led by the OPTN Patient Affairs Committee (PAC). The PAC's initial evaluation was aligned with those in the past who opposed the policy: due to inequities created by the advantage given to patients with greater means, the multiple listing policy should be eliminated.<sup>14</sup> However, by November of 2002 after discussion and public comment, the PAC ultimately proposed to allow multiple registrations, but restricting it to critical populations: patients that met high sensitization and medical urgency criteria would still be allowed to multiple list.<sup>15</sup> In 2003, the PAC proposed a modification to the multiple listing policy based on equity and access concerns.<sup>16</sup> The proposal suggested eligibility criteria and patient education requirements, including informing patients of their right to transfer care without loss of wait time and informing patients if a transplant program does not multiple list.<sup>17</sup> At the November 2003 meeting, the Board of Directors voted not to restrict the multiple listing policy, but did approve the amendments regarding patient education.<sup>18</sup>

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<sup>6</sup> Richard J. Glasscock, March 14, 1988, "National Kidney Foundation Response to UNOS Policy Proposal Statement Regarding the Listing of Patients on Multiple Transplant Waiting Lists," March 1988.

<sup>7</sup> Jack W. Owen, "American Hospital Association Comments on the Multiple Listing of Transplant Candidates," March 17, 1988.

<sup>8</sup> United Network for Organ Sharing Board of Directors Meeting, March 21, 1988, Washington D. C.

<sup>9</sup> Ibid.

<sup>10</sup> Report of the Kidney and Pancreas Transplantation Committee to the Board of Directors, November 2-3, 1994, Atlanta, Georgia.

<sup>11</sup> United Network for Organ Sharing Board of Directors Meeting Transcript, March 1-2, 1995, New Orleans, Louisiana.

<sup>12</sup> Ibid.

<sup>13</sup> Report of the Kidney and Pancreas Transplantation Committee to the Board of Directors, March 1-2, 1995, New Orleans, Louisiana.

<sup>14</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 15-16, 2001, Alexandria, Virginia.

<sup>15</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 14-15, 2002, Alexandria, Virginia.

<sup>16</sup> OPTN/UNOS Board of Directors Meeting Minutes, November 20-21, 2003, Richmond, Virginia.

<sup>17</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 20-21, 2003, Richmond, Virginia.

<sup>18</sup> OPTN/UNOS Board of Directors Meeting Minutes, November 20-21, 2003, Richmond, Virginia.

Despite the decision in 2003, controversy continues over the impact, equity, and benefit of multiple listing.<sup>19,20,21,22</sup> For this reason, the Committee agreed that a timely review of the ethical implications of multiple listing is warranted, especially given the changes in allocation since the last review. The Committee poses the question “What are the ethical implications of permitting patients to be listed at multiple transplant programs?” In answering this question, the white paper considered the ethical principles of equity (including distributive justice and procedural justice), autonomy, and utility:

- **Equity** “refers to fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program.”<sup>23</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>24</sup>
  - **Procedural justice** refers to appraisal of the fairness of how decisions are made.”<sup>25</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>26</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>27</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. Additionally, to holistically understand the role the ethical principles play with regard to multiple listing, the Committee submitted two data requests which depict patient access and geographic variability in multiple listing.<sup>28,29</sup> The intent of these data requests was to better understand the accessibility of multiple listing

<sup>19</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>20</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>21</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.semtcvs.2021.04.045>.

<sup>22</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>23</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>24</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>25</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>26</sup> OPTN Ethics Committee, *Ethical Principles*, June 2015.

<sup>27</sup> Ibid.

<sup>28</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>29</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.

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.

## Purpose

The purpose of this white paper is to conduct an ethical analysis of multiple listing, and understand how the practice fares against the ethical principles of transplant.<sup>30</sup> 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 this data was to compliment the ethical analysis and provide recommendations that are an outgrowth of the current practice. Ultimately, this white paper answers the question “What are the ethical implications of permitting patients to be listed at multiple transplant programs?”

## NOTA and Final Rule Analysis

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>31</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>32</sup> The Ethics Committee offers the proposed white paper to advise the OPTN Board and committees on the ethical considerations regarding multiple listing practices.

## Conclusion

As part of a forward-looking, responsive, patient-centered organization, policies (both current and existing) must be reviewed to ensure that they are ethically justifiable and serving the goals of the OPTN to promote equitable access to transplantation and efficiency of the transplantation system. With these considerations in mind, the ethical analysis reveals that retaining the existing multiple listing policy does promote equitable access to transplantation. Widespread availability of multiple listing may undermine equity and utility, by allowing some patients to accept organ offers from more than one program simultaneously but not all patients are able to participate in the process. However, encouraging multiple listing for patients who are disproportionately difficult to match is ethically justifiable to promote their equal access to transplant.

Although the transplant community cannot resolve all public health disparities, it must strongly consider revising policies that entrench them and continue efforts to rectify these. Moreover, removing the practice of multiple listing overall may resolve some disparities, but could exacerbate others, particularly for patients with medical complexity, those who are already sensitized to potential donors, or otherwise difficult to match. The Committee acknowledges the challenges defining this medically complex group and defers the identification of these individuals and modification of the relevant policies to other OPTN committees.

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<sup>30</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>31</sup> 42 U.S.C. §274(b)(2)(A)(i)

<sup>32</sup> 43 C.F.R. §121.5(b)

## Considerations for the Community

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

- Do community members have recommendations about how access to multiple listing can be encouraged for patients who are exceptionally difficult to match?
- Do community members have recommendations about how to better direct patients who are seeking multiple evaluations?
- Do community members agree with the recommendations?
- How do patients feel about the recommendations?

# 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.<sup>33,34,35,36</sup> In response to these repeal attempts,  
7 multiple listing was prohibited from January to March 1988, but has been a permanent component of  
8 OPTN policy since that time.<sup>37</sup> Currently, *OPTN Policy 3.4 Multiple Transplant Program Registrations*  
9 allows patients to be registered for an organ at multiple transplant programs and allows transplant  
10 programs to determine whether or not to accept a candidate who is listed at multiple transplant  
11 programs for an organ.<sup>38</sup> Additionally, *OPTN Policy 3.2 Notifying Patients on their Options* requires  
12 transplant programs to inform patients that they are able to pursue listing at multiple programs.<sup>39</sup> While  
13 this practice is formally referred to as multiple registrations in policy, the practice is more colloquially  
14 known as multiple listing, which is how it will be referred to throughout proceeding white paper.

15 The concerns evident in literature today echo arguments made in past debates. Historically, those  
16 opposed to multiple listing believed the practice would be utilized by individuals with the financial  
17 resources to fly across the country to obtain a transplant, thereby disadvantaging other patients and  
18 exacerbating inequities.<sup>40,41</sup> Alternatively, those in support of multiple listing championed the use of the  
19 policy for highly sensitized or medically urgent patients and recommended educating patients about the  
20 option and informing patients if a program does not multiple list.<sup>42,43,44</sup> Ultimately, policy repeals have  
21 failed in the past due to the agreement that patient access should not be limited, despite the disparities  
22 that may persist.<sup>45,46</sup>

23 While multiple listing is ethically justified at the individual level, as one strives to receive the opportunity  
24 to obtain a life-saving transplant, it is essential to consider how a patient’s decision to multiple list  
25 impacts those patients who are unable to access multiple listing. For that reason, it is imperative to  
26 examine whether keeping multiple listing as policy is warranted given its impact on all patients. This  
27 white paper considers the ethical implication of permitting patients to receive organ offers,  
28 simultaneously, from more than one transplant program, thus, potentially receiving more organ offers.

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<sup>33</sup> United Network for Organ Sharing Board of Directors Meeting, August 10, 1987, Atlanta, Georgia.

<sup>34</sup> United Network for Organ Sharing Board of Directors Meeting, March 21, 1988, Washington D. C.

<sup>35</sup> United Network for Organ Sharing Board of Directors Meeting, November 2-3, 1994, Atlanta, Georgia.

<sup>36</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 15-16, 2001, Alexandria, Virginia.

<sup>37</sup> UNOS Board of Directors Meeting, March 1988.

<sup>38</sup> OPTN Policy 3.4.F Multiple Transplant Program Registrations, 2022.

<sup>39</sup> OPTN Policy 3.2 Notifying Patients of Their Options, 2022.

<sup>40</sup> United Network for Organ Sharing Board of Directors Meeting Transcript, March 1-2, 1995, New Orleans, Louisiana.

<sup>41</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 15-16, 2001, Alexandria, Virginia.

<sup>42</sup> Report of the OPTN/Patient Affairs Committee to the Board of Directors, November 20-21, 2003, Alexandria, Virginia.

<sup>43</sup> Richard J. Glascock, “National Kidney Foundation Response to UNOS Policy Proposal Statement Regarding the Listing of Patients on Multiple Transplant Waiting Lists,” March 14, 1988.

<sup>44</sup> Jack W. Owen, “American Hospital Association Comments on the Multiple Listing of Transplant Candidates,” March 17, 1988.

<sup>45</sup> United Network for Organ Sharing Board of Directors Meeting, March 21, 1988, Washington D. C.

<sup>46</sup> OPTN/UNOS Board of Directors Meeting Minutes, November 20-21, 2003, Richmond, Virginia.



29 This white paper aims to answer the question, ‘What are the ethical implications of permitting patients  
30 to be listed at multiple programs?’

31 The Committee conducts this ethical analysis within the scope, purview, and mission to “to guide the  
32 policies and practices of the OPTN related to organ donation, procurement, distribution, allocation, and  
33 transplantation so they are consistent with ethical principles.”<sup>47</sup> The Committee must take into account  
34 the ethical principles described below as they pertain to the transplant community broadly: equity  
35 (including distributive and procedural justice), utility, and autonomy.

36 The core ethical concern associated with multiple listing involves ensuring equitable access to  
37 transplantation and examining the level of advantage multiple listing provides over single listing.  
38 Oftentimes multiple listing is viewed as only being accessible for those with the means and influence to  
39 seek an advantage in obtaining access to transplantation.<sup>48</sup> In order to pursue multiple listings, the  
40 patient and their caregiver may need to travel to additional transplant programs for transplant  
41 evaluation, attain lodging, receive time off work, and potentially pay for the additional transplant  
42 evaluation if not covered by insurance. Some exceptional cases, like Steve Jobs traveling from California  
43 to Tennessee for a liver transplant in 2009, can be harmful to public perception and may institute  
44 concerns that wealth and private transportation provide a concerning advantage to accessing  
45 transplant.<sup>49,50</sup>

46 The process by which patients pursue multiple transplant *evaluations* in order to find the transplant  
47 program that best aligns with their needs, preferences, and clinical characteristics is not considered  
48 multiple listing as defined and discussed in this white paper.<sup>51</sup> The Committee affirms the ethical  
49 justification for multiple evaluations, meaning that all patients may seek multiple evaluations  
50 simultaneously at any program that they deem may be a good fit for their values and preferences. As  
51 described in the *Transparency in Program Selection* white paper, programs may vary significantly in their  
52 evaluation practices, donor acceptance practices, and utilization of marginal organs, among other  
53 factors.<sup>52</sup> Some of these factors may be known and understood by patients at the point of evaluation  
54 and listing, while other factors may become apparent only after listing at a given program. Supporting  
55 multiple evaluations and ensuring that waiting time follows patients to any program upholds patient  
56 autonomy and efficiency. This encourages patients to find transplant program that best meet their goals  
57 and preferences, and supports transplant programs in efforts to improve transparency about their  
58 evaluation and listing process.

59 The overarching question, ‘What are the ethical implications of permitting patients to be listed at  
60 multiple centers?,’ will be answered by analyzing the ethical principles of equity (including distributive  
61 and procedural justice), autonomy, and utility as they pertain to multiple listing. Each ethical principle  
62 was analyzed, practically applied to multiple listing, and the relevant data considered OPTN data  
63 pertaining to each principle. The white paper will outline recommendations to ensure the ethical

<sup>47</sup> Ethics Committee, OPTN, accessed December 3, 2022. <https://optn.transplant.hrsa.gov/about/committees/ethics-committee/>.

<sup>48</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>49</sup> Denise Grady and Barry Meier, “A Transplant That Is Raising Many Questions,” *The New York Times*, June 22, 2009.

<sup>50</sup> Marilynn Marchione, “Organ transplant lists in the US favor the rich, according to new study,” *Associated Press*, Nov 9, 2015.

<sup>51</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>52</sup> *Ibid.*

64 foundation of the organ transplant system is upheld,<sup>53</sup> concluding that the ethical principles do not offer  
 65 justification for policies that allow people to accept offers from more than one center at a time if they  
 66 are not exceptionally difficult to match.

### 67 *Ethical Analysis Background*

68 The Committee adopts Decoteau et al.'s definition of multiple listing, "being on the transplant wait-list  
 69 for a particular organ type at more than one transplant program simultaneously."<sup>54</sup> The Committee felt  
 70 this definition reflects the intentionality of pursuing listing at more than one programsimultaneously.  
 71 The Committee assessed whether multiple listing confers an advantage in terms of likelihood of  
 72 transplantation; whether this is equitably distributed; and whether any ethical principles would support  
 73 widespread use of multiple listing for any candidate who wishes to pursue it.

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

75 In congruence with the ethical analysis, OPTN data were reviewed to better understand patient access  
 76 and the implications of multiple listing for improving the likelihood of transplantation.<sup>55,56</sup> As previously  
 77 mentioned, the Committee defined multiple listing as "being on the transplant wait-list for a particular  
 78 organ type at more than one transplant program simultaneously," as opposed to identifying patients  
 79 who had ever been listed at more than one program.<sup>57</sup> The sample size of patients who are multiple  
 80 listed is relatively small, with only 6.4% of registered candidates listed at two or more transplant  
 81 hospitals for the same organ on December 31, 2021.<sup>58</sup> Kidney had the largest percentage of candidates  
 82 multiple listed at 7.2%, liver at 1.5%, and thoracic organs were less than 1% each.<sup>59</sup>

83 First, the Committee reviewed the demographics and geography of patients who were single and  
 84 multiple listed. This analysis used patients waitlisted on December 31, 2021, as a representative sample  
 85 of what the waitlist could look like on a given day.<sup>60</sup> The Committee examined the utilization of multiple  
 86 listing across all organ types, individual-level demographics (age, sex, race/ethnicity, insurance status,  
 87 education, blood type) and geocoded zip-code level demographics (median household income, poverty  
 88 percent). Registration-level data, depicting region, time to transplant, medical urgency status, time  
 89 between primary and secondary listing hospital, distance between primary and secondary listing  
 90 hospital, and location of most common primary, secondary, and tertiary listings, were also assessed.<sup>61</sup>

91 Further analysis included a review of multiple listing practices between February 4, 2020, and December  
 92 31, 2021 for liver patients and March 15, 2021 to December 31, 2021 for kidney patients.<sup>62</sup> In particular,

<sup>53</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>54</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>.

<sup>55</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>56</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>57</sup> Decoteau et al., "The Advantage."

<sup>58</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>59</sup> Ibid.

<sup>60</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>61</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.

<sup>62</sup> Gauntt, "Data Request," September 14, 2022.

93 transplant rates, calculated as the number of transplants per 100 inactive and active years waiting, were  
 94 analyzed for cohorts post-acuity circles and stratified by whether the multiple listing occurred in the  
 95 same donor service area (DSA), outside the DSA but in the first priority circle, or outside of the first  
 96 priority circle. Transplant rates were used to further illuminate any shifts in allocation from DSA to acuity  
 97 circles in order to consider the role that changing allocation systems has had on multiple listing  
 98 practices. Additionally, transplant rates were calculated based on an ever-waiting cohort from  
 99 implementation of acuity circles to March 31, 2022. For liver this was candidates ever waiting between  
 100 February 4th, 2020 to March 31, 2022 and for kidney this was candidates ever waiting between March  
 101 15, 2021 to March 31st, 2022. Candidates were indicated as ever multiple listed if at any point in the  
 102 cohort time frame the candidate had two or more listings at multiple programs simultaneously.  
 103 Candidate waiting time was considered by taking the time in days from the first listing date to either the  
 104 date of transplant or the date of candidate removal from all listings from the waitlist, including both  
 105 active and inactive waiting time for the candidate.<sup>63</sup>

106 It is important to note that as allocation changes, the role and impact of multiple listing evolves in  
 107 tandem.<sup>64</sup> OPTN data reflects changes in listing behavior and the subsequent impact of multiple listing  
 108 as allocation shifted from DSA to acuity circles. It is fair to hypothesize that the development of  
 109 continuous distribution, an allocation framework that deemphasizes geography, will continue to affect  
 110 the role, benefit, and prevalence of multiple listing. The relevant themes from the data will be analyzed  
 111 in juxtaposition to the ethical principles of equity (including distributive and procedural justice), utility,  
 112 and autonomy.

113 Limitations to the analysis: It is important to note that zip code data, which were utilized to depict the  
 114 median household income and poverty levels for single and multiple listed kidney, liver, and thoracic  
 115 patients, have limitations. Aggregated environmental factors are not always good descriptors of an  
 116 individual's access, situation, barriers, and personal situation, as these individual-level situations often  
 117 attenuate any disadvantage that may be conferred by one's environment. While zip code data offers  
 118 comparisons of multiple and single listed patients on aggregate, it falls short in providing the level of  
 119 granularity that would be provided by candidate-level socio-economic measures, which are not available  
 120 in OPTN data as patient addresses are not collected. Future analyses would benefit from incorporating  
 121 third-party data with OPTN data to look at the effect of multiple listing on equity and access to  
 122 transplant, adjusting for individual level socio-economic factors. Further limitations include data quality  
 123 for self-reported information, such as zip code, and the occurrence of patients being listed at two  
 124 programs on the same day, which were excluded from the analysis.<sup>65,66</sup>

## 125 Equity

126 Concerns about multiple listing relate largely to promoting equitable access to transplantation, as  
 127 required by the Final Rule.<sup>67</sup> The concept of equity as it pertains to multiple listing may be understood as  
 128 one of fair versus formal equality of opportunity. Although frequently described in the context of  
 129 competitive advantage for the purposes of obtaining jobs and offices, the concept of fair versus formal  
 130 equity underscores the difference between a policy merely allowing a benefit to be available to all

<sup>63</sup> Additional details about the methods can be found in Appendix A.

<sup>64</sup> Decoteau et al., "The Advantage."

<sup>65</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>66</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>67</sup> 42 U.S.C. §274.

131 (formal), versus one that requires that all are equally able to be considered for and have access to the  
 132 benefit (fair).<sup>68</sup> Corresponding to the idea of reducing the competitive advantages that favorable social  
 133 circumstances confer on some individuals in the context of job seeking, Rawls suggests “fair equality of  
 134 opportunity.”<sup>69</sup> Fair equality of opportunity requires that any individuals who have the same native  
 135 talent and the same ambition (or in the case of transplant, the same need and willingness to pursue  
 136 multiple listing) will have the same prospects of success in circumstances where success determines  
 137 future long term benefit (in this case access to life-saving treatment).<sup>70,71</sup>

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

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

156 If the goal is to ensure equitable access to transplantation, patients who are hardest to match with a  
 157 deceased-donor organ may require multiple listing to “level the playing field”, or have a similar  
 158 likelihood of receiving a transplant as other patients. This would reduce disparities in transplantation by  
 159 equalizing the likelihood of obtaining a transplant. Conversely, patients who are better-off and better  
 160 able to be listed at multiple programs may exacerbate existing disparities by receiving a  
 161 disproportionate share of organs as a group.

## 162 *Distributive Justice*

163 Numerous theories of distributive justice require us to consider the concerns of the worst-off, those  
 164 whom the existing allocation system and organ supply may not serve as well.<sup>72,73,74</sup> Patients who are

<sup>68</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>69</sup> John Rawls, *A Theory of Justice: Revised Edition* (Cambridge, Massachusetts: Harvard University Press, 1999), 57-64.

<sup>70</sup> Ibid.

<sup>71</sup> John Rawls, *Justice as Fairness: A Restatement* (Cambridge, Massachusetts: Harvard University Press, 2001), 42-50.

<sup>72</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>73</sup> Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, (Berkeley, California: University of California Press, 2003).

<sup>74</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>.

165 exceptionally difficult to match for reasons outside of their control may be unlikely to benefit from  
 166 organ transplantation without multiple listing, and would be harmed if this policy were to constrain their  
 167 ability to access transplantation. Patients pursuing transplant, including patients on dialysis in need of a  
 168 kidney transplant, are doing their best to obtain the in dire need of life-saving treatment they are in dire  
 169 need of. Their individual reasons for pursuing multiple listing do not reflect these systemic moral  
 170 considerations about distributive justice. Moreover, transplantation cannot resolve or rectify all existing  
 171 social disparities. Yet, this fact does not absolve the transplant community from remediating the policies  
 172 that exacerbate disparities within transplantation. Distributive justice affords the rationale for allowing  
 173 people to list at multiple programs when they are exceptionally hard to match at their primary program  
 174 (the Ethics Committee defers to other OPTN Committees to define those specific criteria). Allowing them  
 175 this benefit helps to mitigate a barrier impeding equitable access to transplantation. However,  
 176 distributive justice does not offer justification for policies that allow people to accept offers from more  
 177 than one transplant program at a time if they are not exceptionally difficult to match. Differences in  
 178 program practices, selection practices, organ acceptance rates, and risk aversion are reasons to justify  
 179 multiple evaluations, but not necessarily multiple listing (the ability to receive multiple offers  
 180 simultaneously from different programs).

### 181 *Procedural Justice*

182 Procedural justice approaches are concerned with treating like with like, in other words, treating  
 183 persons of similar needs consistently, transparently, and predictably.<sup>75</sup> To uphold procedural justice,  
 184 transplant programs must notify patients of their ability to multiple list, which is a current requirement  
 185 when registering a patient on the waitlist.<sup>76</sup> Despite it being a requirement, how, when, and the  
 186 precision with which transplant programs convey this information may vary.<sup>77</sup> Moreover, it remains  
 187 unclear how well patients understand this information. Finally, the degree to which programs are willing  
 188 to evaluate and list patients who are already listed at other programs varies, which can lead to  
 189 inconsistent practices for patients to navigate.<sup>78</sup>

### 190 *Application of Equity to Multiple Listing*

191 In the case of multiple listing, formal equity exists through the requirement to inform patients about the  
 192 opportunity to multiple list despite the possibility that this may not occur consistently.<sup>79</sup> With all other  
 193 factors different, the official notification that patients are able to be multiple listed does not equally  
 194 result in patients successfully multiple listing. Fair equality of opportunity would require additional  
 195 assistance be provided to those with less access, for example, to be able to successfully multiple list. Fair  
 196 equality of opportunity might include: the ability to understand and follow the steps required to meet  
 197 criteria for multiple programs; the resources (financial, time, transportation, support person) to meet  
 198 residency requirements at more than one location; complete evaluations; the ability to arrive in time for  
 199 a transplant; and the insurance coverage to allow for multiple evaluations.

200 There may be a variety of steps needed to ensure such fair equality of opportunity to those patients at a  
 201 disadvantage. Patient navigation or more accessible education materials can be made available for  
 202 patients with limited health literacy. Some possible solutions to help those with limited means to meet

<sup>75</sup> OPTN Ethics Committee, *Transparency*.

<sup>76</sup> OPTN Policy 3.2 Notifying Patients of Their Options, 2022.

<sup>77</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>78</sup> OPTN Policy 3.4.F Multiple Transplant Program Registrations, 2022.

<sup>79</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.

203 criteria for multiple listing include: providing scholarships to cover housing or other expenses,  
204 redistributing resources to promote with health literacy, waiving residency criteria, and lobbying  
205 insurers to cover additional transplant evaluations. As more is done to provide opportunities that enable  
206 persons from any social group to meet multiple listing criteria, the objection that none but the  
207 financially, educationally, or socially better off may benefit from multiple listing is overcome. At some  
208 point, depending on the availability of such resources, sufficient opportunities to achieve multiple listing  
209 may be achieved, and fair equality of opportunity would prevail. However, the transplant community  
210 should consider whether merely ensuring formal equality of opportunity is sufficient, or whether it is  
211 necessary but insufficient to achieve the goals of promoting equitable access to transplantation for all  
212 persons of similar need.

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

### 217 *Data Analysis Pertaining to Equity in Multiple Listing*

218 To examine whether utilization is socially patterned in ways consistent with structural discrimination,  
219 three variables (race/ethnicity, insurance status, and education) were explored. Table 1-1 depicts the  
220 percentages of single and multiple listed kidney and liver patients by race/ethnicity, insurance status,  
221 and education.<sup>80,81,82</sup>

222

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<sup>80</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>81</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>82</sup> The full demographic comparison can be found in Appendix A, Table 1.

223 **Table 1-1 (Race/Ethnicity, Insurance Status, and Education for Single and Multiple Listed Kidney and**  
 224 **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>83</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>84</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%

225  
 226 Although there were fewer candidates reporting a Hispanic/Latino ethnicity in the multiple listed kidney  
 227 group there were more candidates reporting Black, Non-Hispanic ethnicity in the multiple listed kidney  
 228 group but fewer for liver, and very little difference among candidates reporting White, Non-Hispanic.<sup>85</sup>

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

233 Patients with Medicaid were one-third as likely to be multiple listed compared to single listed for kidney  
 234 transplant (4.8% versus 13.2%), and were a quarter as likely to be multiple listed for liver compared to  
 235 single listed candidates (5.7% versus 20.1%). Patients with private insurance or private pay were  
 236 disproportionately more likely to be multiple listed than single listed for kidney transplant (53.5% versus  
 237 43.3%) and liver transplant (68.8% versus 50.8%), respectively.<sup>86</sup>

238 Candidates with less than a high school degree or equivalent were less than half as likely to be multiple  
 239 listed compared to single listed for kidney (3.5% versus 8%) and liver (3.4% versus 7.5%) transplantation.

<sup>83</sup> This includes both “Medicare FFS (Fee for Service)” and “Medicare & Choice” insurance options.

<sup>84</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>85</sup> Bradbrook, “Data Request,” May 11, 2022.

<sup>86</sup> Ibid.

240 Candidates with high school education were also less likely to be multiple listed for kidney (30.1%  
241 multiple listed versus 37.2% single listed) and liver (27.3% multiple listed versus 35.8% single listed).<sup>87</sup>

242 Some studies have shown that health literacy and higher socioeconomic status, sometimes proxied  
243 through higher educational attainment or private insurance, have been associated with higher likelihood  
244 of being referred to transplant, completing the transplant evaluation successfully, being waitlisted, and  
245 obtaining a transplant.<sup>88,89,90,91</sup> When considering the benefits of private insurance, for example,  
246 research shows that individuals with private insurance are more likely to be referred for liver transplant  
247 when compared to publicly insured patients.<sup>92</sup> OPTN data clearly depict patients with private insurance  
248 as comprising a larger proportion of multiple listed patients. This trend aligns with structural disparities  
249 and questions of potentially unequal access between patients with private versus public insurance.

250 Navigating the transplant system is challenging and those with higher level of education are often more  
251 successful in maneuvering these complexities to be successfully listed, and multiple listed, for  
252 transplant. OPTN data confirm this by showing that those with advanced education are more likely to be  
253 multiple listed when compared to single listed patients across all organ types.<sup>93,94</sup> Higher levels of  
254 education often correspond with greater health literacy, while lower levels of health literacy are  
255 negatively correlated with access to transplant.<sup>95,96</sup> Transplant candidates are a particularly vulnerable  
256 population as the stress, anxiety, and general experience of not feeling well while living with an end  
257 stage disease may contribute to a decreased ability to understand important information. The  
258 complexity of the transplant evaluation and listing process and the high levels of digital health literacy  
259 required to navigate multiple listing may further disadvantage marginalized and vulnerable groups.<sup>97</sup>

260 Patients with high levels of digital literacy are more successful at navigating the complexities of the  
261 healthcare system than those with limited internet access and health literacy.<sup>98</sup> To obtain the maximum  
262 benefit from the vast amounts of information publicly available regarding the performance of organ  
263 procurement organizations (OPO) and transplant programs, patients must have the tools and skills to  
264 locate available information, understand and make use of the complex information available to them in  
265 a way that impacts their health, and network with transplant professionals and other recipients who can

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<sup>87</sup> Ibid.

<sup>88</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>89</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>90</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>91</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>92</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>93</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>94</sup> Decoteau, "The Advantage," 2021.

<sup>95</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>96</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>97</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>

<sup>98</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>.



266 provide additional insight.<sup>99</sup> Beyond making an informed decision to seek out multiple listing, and at  
 267 which program(s), patients may need to self-advocate with their health care provider team and third-  
 268 party payer.

269 For example, digital literacy rates are three times lower for Hispanic adults when compared to white  
 270 adults,<sup>100</sup> which may influence the finding that Hispanic patients are less likely to be multiple listed  
 271 compared to single listed Hispanic patients seeking a kidney or liver transplant.<sup>101</sup> In contrast, Black  
 272 adults are twice as likely to be digitally illiterate than white adults, and yet black patients accounted for  
 273 nearly an equal percentage of kidney multiple listings as white patients.<sup>102,103</sup> While the findings for  
 274 Hispanic patients are consistent with the continued disparities in access to transplant for Hispanic  
 275 patients across the U.S., the findings for Black patients depict an increase in the proportion of Black  
 276 patients pursuing multiple listing for kidney compared to single listed Black kidney patients.<sup>104</sup> Health  
 277 literacy is essential for accessing transplant and without the relevant information, or the ability to  
 278 understand it, patients with a lower health literacy will continue to face barriers to equitable access.

279 Ultimately, the policy allowing multiple listing complies with formal equality of opportunity by being  
 280 available to all patients, but the policy alone cannot promote fair equality of opportunity. The data  
 281 reviewed indicate that not all patients can equally exercise the option to multiple list, despite having  
 282 equal access to multiple list.

## 283 Autonomy

284 The concept of respect for autonomy holds that actions or practices tend to be ethical insofar as they  
 285 respect or reflect the exercise of self-determination.<sup>105</sup> Persons and their actions are never "fully"  
 286 autonomous (as their role of decision maker in pursuing multiple listing is finite); nevertheless, it is  
 287 possible to recognize individuals and their decisions as more or less substantially autonomous, meaning  
 288 they have the right to make decisions free from coercion and interference as long as the decisions do  
 289 not impose harm to others.<sup>106</sup> If there is no way to equalize opportunity between underserved  
 290 populations and those with the greatest access, and provide the benefits needed to ensure equitable  
 291 access to multiple listing for patients who may be unable to exercise this option, it is important to  
 292 consider how autonomy may be affected.<sup>107</sup>

293 Ensuring that patients can select the transplant program that best meets their needs is paramount to  
 294 preserving patient autonomy and may help negate the need for multiple listing. Importantly, this ability  
 295 is preserved when patients are able to select a transplant program that aligns with their preferences,  
 296 and meets their needs in terms of approach, location, cost, support programs, et cetera. For patients to

<sup>99</sup> Chisholm-Burns, "Health," 2018.

<sup>100</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>101</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>102</sup> U.S. Department of Education, A Description, 2018.

<sup>103</sup> Bradbrook, "Data Request," May 11, 2022.

<sup>104</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>105</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>106</sup> Ibid.

<sup>107</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>.

297 truly realize this opportunity, there must be transparent and accessible information about transplant  
 298 programs that would allow patients to seek care at the program that is most appropriate for them.<sup>108</sup> As  
 299 previously mentioned, multiple evaluations is distinct from multiple listing, whereby multiple  
 300 evaluations upholds patient autonomy and allow patients to explore multiple programs and select the  
 301 center of preference, with no detriment to other patients.

302 As the definition of autonomy holds that an action is right insofar as it does not impose undue burden to  
 303 others, the principle of autonomy raises some concerns with the practice of multiple listing, especially if  
 304 it is not equally available to all and restricts the autonomy of those who are unable to access multiple  
 305 listing. Restricting multiple listing appears to limit autonomy for some who currently enjoy the  
 306 opportunity to pursue this practice, but directing multiple listing towards patients who  
 307 disproportionately need this option owing to their difficulty to benefit from the existing system, would  
 308 uphold autonomy as these patients are unlikely to adversely influence the likelihood of others in their  
 309 program awaiting organ offers.

### 310 *Application of Autonomy to Multiple Listing*

311 When analyzing multiple listing, autonomy is exhibited in a challenging dichotomy wherein patients,  
 312 transplant programs, and insurance providers can exercise autonomy in a way that infringes on the  
 313 autonomy of others. At the center of these considerations are the patients who are informed at  
 314 evaluation that they are eligible to pursue multiple listing.<sup>109</sup> In theory, this should allow patients the  
 315 independence to determine what is in their best interest and consider whether or not to pursue  
 316 multiple listing. Realistically, patients face a litany of barriers to accessing transplant that can explicitly  
 317 impact their ability to pursue listing at a secondary or tertiary transplant program.<sup>110</sup> In an effort to  
 318 overcome barriers to access, shared decision-making between transplant programs and patients could  
 319 be better utilized to inform and empower patients to exercise their autonomy and determine if they  
 320 would like to pursue multiple listing.<sup>111</sup>

321 However, patients who have decided to pursue multiple listing face additional obstacles in their quest.  
 322 Policy allows transplant programs to determine if they will accept candidates with multiple registrations  
 323 or allow candidates to transfer wait time to their transplant program.<sup>112</sup> Thus, a patient may determine  
 324 they want to pursue multiple listing but both their current program and their intended program may  
 325 limit their ability to do so. If the patient's primary listing program permits them to pursue multiple  
 326 listings, the patient is still eligible to consider alternative programs. However, their time and other  
 327 resources may be depleted if they were used at a program that ends up not accepting the patient as a  
 328 secondary listing. If the patient's primary listing program does not permit them to pursue multiple  
 329 listings, then the patient's autonomy is overruled in favor of the transplant program. In both instances,

<sup>108</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>109</sup> OPTN Policy 3.2.

<sup>110</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>111</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>112</sup> OPTN Policy 3.2 and 3.4.F.

330 patient autonomy is infringed upon, yet the latter can place total limitations on the patient's choice to  
331 be multiple listed.

332 Lastly, patients are beholden to the decision of their insurance provider to enable them to pursue  
333 multiple listing. In some instances, insurance providers will only cover care when performed by certain  
334 institutions, such as Centers of Excellence, which limit patient choice and restrict patient autonomy.<sup>113</sup>  
335 In other instances, payers will only cover one transplant evaluation per year thus inhibiting a patient's  
336 ability to make decisions that align with their preferences and priorities.<sup>114</sup> Worst case, patients in need  
337 of organ transplantation may never have the opportunity to exercise their autonomy if they are  
338 uninsured and unable to access transplantation.<sup>115</sup>

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

### 343 Utility

344 Utility could be positively impacted if patients are able to be transplanted expediently or an increased  
345 number of transplants were occurring (multiple listed patients accepting more marginal organ offers),  
346 but there are currently insufficient data to establish this. There are important tradeoffs to consider.  
347 Clinical continuity was originally developed as a concept to include a patient's primary care team in all  
348 relevant medical decisions impacting care delivery.<sup>116,117</sup> Pre-transplant care is a complex, multilevel  
349 process that requires coordinated communication to optimize patient care. For example, a patient listed  
350 for kidney transplantation accesses care through their dialysis units, primary care provider, specialty  
351 referrals such as cardiology, and the transplant program. It is evident that care coordination between  
352 these stakeholders is not optimal at baseline and there are several proposed care and reimbursement  
353 models to improve care coordination of the pre-transplant kidney patient.<sup>118</sup> The challenge of clinical  
354 continuity and care coordination is clearly increased by multiple listing, where several of the key  
355 elements providing pre-transplant care are susceptible to fracture by geography, differing care  
356 pathways, and suboptimal communication. If a waitlisted patient experiences an ER visit for chest pain,  
357 it is unclear if this will effectively be communicated to all of the transplant programs at which they are  
358 listed. By negatively impacting clinical continuity, the ability for patients to receive optimum care can  
359 decrease as their care is managed in a disjointed way.

360 Multiple listing can provide challenges for transplant programs as their list management strategies focus  
361 on patient preparedness to accept an organ for transplantation. In circumstances where a listed patient  
362 may choose to list at multiple transplant programs, the patient may be subject to different testing

<sup>113</sup> Roger W. Evans, "Public and Private Insurer Designation of Transplantation Programs," *Transplantation* 53, 5 (May 1992): 1041-1046.

<sup>114</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>115</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>116</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>117</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>118</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>.

363 requirements, waitlist clinical pathways, and potential duplicate testing. These factors have the  
 364 potential to increase costs prior to transplant, causing the patient, transplant program, and payer to all  
 365 incur a cost thus increasing the overall healthcare cost.

366 Because organ transplantation is a zero-sum situation, increasing the chances of any given patient by  
 367 allowing them multiple chances in different regions by definition decreases the relative chances of  
 368 another patient in the regions in which they list, yet it improves the chances of a patient in the region  
 369 they left. In alignment with distributive justice, the principle of utility may support the use of multiple  
 370 listing for patients that are difficult to match due to being allosensitized to potential donors or  
 371 possessing other complex medical factors. For these patients, expanding the pool of available organs  
 372 may increase utility by reducing waitlist deaths.

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

### 378 *Data Analysis Pertaining to Utility in Multiple Listing*

379 While multiple listing may appeal to patients with the possibility of decreased time to transplant, OPTN  
 380 data found that multiple listed kidney and liver recipients had a higher median waiting time when  
 381 compared to single listed kidney and liver recipients.<sup>119</sup> Despite the benefits of early transplant  
 382 described above, it is not clearly shown that multiple listing leads to a decreased time on the waitlist. It  
 383 is possible that the increased wait time accounts for patients who are hard to match or presensitized;  
 384 however, additional research is needed to reach those conclusions.

385 OPTN data found that most often patients are multiple listing at locations that are within driving  
 386 distance of their home. However, kidney candidates who listed closer to home (under 250 nautical  
 387 miles) were less likely to benefit from multiple listing compared to those listing outside of the 250  
 388 NM range.<sup>120</sup> This finding expands upon prior literature, and differs by analyzing the role of multiple  
 389 listing within the same acuity circle as the primary listing program.<sup>121,122,123,124</sup> For kidney transplant  
 390 candidates, 77% of the secondary listing programs were located within 250 nautical miles, the initial  
 391 acuity circle used to allocate kidneys, of the primary transplant program, compared to 52% of multiple  
 392 listed liver candidates who pursued their secondary listing at a program that was within 150 nautical  
 393 miles, the initial acuity circle used to allocate livers, from the primary transplant program.<sup>125</sup>

394 While the close proximity of the secondary listing program makes the case for increased access to  
 395 multiple listing, the close proximity calls into question what the added benefit of multiple listing may be.  
 396 The current allocation framework prioritizes patients within a given nautical mile radius and by only

<sup>119</sup> Gauntt, "Data Request," September 14, 2022.

<sup>120</sup> Gauntt, "Data Request," September 9, 2022.

<sup>121</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>122</sup> Decoteau, "The Advantage," 2021.

<sup>123</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>124</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>125</sup> Bradbrook, "Data Request," May 11, 2022

397 minimally expanding the radius one is eligible to receive offers from, the benefit of multiple listing is  
398 likely reduced. The practice of multiple listing inside the initial circle suggests that some of the benefits  
399 may be more attributable to program practices such as offer acceptance patterns rather than  
400 geographic differences in donor availability.

401 Since acuity circles are a relatively newer allocation model, multiple listing within acuity circles has not  
402 been reviewed much, thus this analysis differs from contemporary literature, which considers instances  
403 of a patient pursuing secondary listing outside of their primary transplant program's acuity circle.<sup>126</sup> The  
404 Committee hypothesized that the prevalence of patients multiple listed so close to their primary listing  
405 program is likely a lingering result of the transition from allocating within donor service areas (DSAs) to  
406 acuity circles. Consequentially, it does appear that multiple listing may be more accessible to patients if  
407 the costs associated with travel and lodging to pursue multiple listing are minimal. Anecdotally, multiple  
408 listing has been believed to be accessible only by those with access to private transportation, yet the  
409 practical utilization of multiple listing indicated that the median distance between patients' primary and  
410 secondary transplant programs are within driving distance from each other, making the practice more  
411 attainable and accessible than previously believed to be.<sup>127</sup>

412 Additionally, recent allocation changes impact transplant wait times with differences noted between  
413 organs. Kidney allocation changed from DSA to acuity circles and has seen a decrease in kidney multiple  
414 listings, while liver patients experienced the inverse.<sup>128</sup> However, it is important to note that the sample  
415 size for multiple listed liver patients was much smaller than kidney patients and covered a shorter length  
416 of time since the transition from DSA to acuity circles. Additionally, due to the difference in wait time  
417 between kidney and liver patients, it may be fair to assume that the proportion of liver patients seeking  
418 multiple listing has not increased, but the liver patients who had multiple listed prior to the change in  
419 allocation were transplanted. Despite these opposing effects, the overall trend after allocation change  
420 from DSAs to acuity circles was a net decline in organ multiple listings.<sup>129</sup>

421 Lastly, the myriad of regional variation in transplant rates for patients who are multiple listed cannot be  
422 clearly captured in the data analysis but requires consideration nonetheless. Potential contributors to  
423 regional variation include density and practices of organ procurement organizations (OPOs) and  
424 transplant programs, regional practice differences (regional practice of splitting livers), population  
425 density, population health, and attitudes towards transplant.<sup>130,131</sup> These factors, some of which are not  
426 clearly known by patients seeking transplant, can lead to longer wait times based on transplant center  
427 selection. As such, multiple listing could help to correct disparities caused by differences in program  
428 practices that may inadvertently lengthen a patient's time to transplant. Examples of program practices  
429 that affect wait time include offer acceptance patterns, such as DCD organ utilization, HCV positive  
430 organ utilization, and pulsatile preservation utilization to maximize transplantable organs.

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<sup>126</sup> Decoteau et al., "The Advantage."

<sup>127</sup> Bradbrook, "Data Request," May 11, 2022

<sup>128</sup> Gauntt, "Data Request," September 14, 2022.

<sup>129</sup> Ibid.

<sup>130</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>131</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>.

## 431 Recommendations and Conclusions

432 Multiple listing has an extensive history in transplant policy, but not without controversy both within the  
433 transplant community and in the public at large. Any future project to revise this longstanding policy  
434 would require significant empirical analysis to review utilization patterns, as well as ethical analysis to  
435 inform whether the policy is justified, given the patient access and usage. It is with humility,  
436 compassion, and a commitment to uphold the goals of the OPTN that the Committee approaches the  
437 ethical analysis of multiple listing and issues the following conclusions and recommendations. Multiple  
438 listing does not raise issue of valuing some people's autonomy over others, nor an issue of not  
439 supporting people who are trying to seek lifesaving care for loved ones. Because transplant is a zero-  
440 sum system, our analysis provides a statement about the legitimacy of being able to simultaneously  
441 receive multiple organ offers for some people, while others in the same system are unable to exercise  
442 that benefit. Even with the removal of multiple listing, patients who wish can still seek alternatives by  
443 pursuing evaluations at multiple programs and exercising the autonomy to identify the transplant  
444 program whose behaviors, values, and care is compatible with their preferences.

445 Data analyzed for this paper demonstrates a nuanced picture, one of existing disparities by payer,  
446 education, and race/ethnicity, mirroring existing disparities in health access and a less clear picture by  
447 geocoded level income and poverty level. Moreover, removing the practice of multiple listing overall  
448 may resolve some disparities, but could exacerbate others, particularly for patients with medical  
449 complexity, those who are already sensitized to potential donors, or otherwise difficult to match.  
450 Although multiple listing is narrowly utilized, in the context of the transplant community's commitment  
451 to equity, policies governing access to transplantation should ensure and promote the transplant  
452 community's commitment to equitable access to care. Although the transplant community cannot  
453 resolve all public health disparities, it must strongly consider revising policies that entrench them and  
454 continue efforts to rectify these.

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

459 The Committee notes that multiple listing is different from multiple evaluation, wherein a patient can be  
460 evaluated at multiple programs if they are dissatisfied with their treatment at a given program at any  
461 time. Increased transparency at the outset would help minimize patients selecting programs that do not  
462 align with their goals, but multiple evaluation should be retained as to not limit autonomy. The need for  
463 preserving autonomy through multiple evaluation does not justify the need for multiple listing.

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

467 Following the ethical analysis, the Committee recommends that multiple listing be retained as an option  
468 only for patients who are exceptionally difficult to match, and that transplant programs should  
469 underscore the value of the opportunity to multiple list patients who meet the agreed-upon criteria.  
470 This applies to sensitized patients or patients exhibiting other agreed-upon characteristics that  
471 represent medical complexity. The Committee acknowledges the challenges defining this medically  
472 complex group and defers the identification of these candidates and modification of the relevant  
473 policies to other OPTN committees. To ensure equity, patients who meet new criteria for multiple listed  
474 should be supported in pursuing this option, including with financial support such as scholarships or

475 other resources, where possible. Furthermore, the Committee recommends prohibiting programs from  
476 refusing multiple listed patients, in support of patient autonomy over transplant program autonomy.  
477 Lastly, to increase patient autonomy, transplant programs are encouraged to increase transparency in  
478 evaluation, listing, and organ acceptance practices to help patients choose a primary program that is an  
479 optimal fit for their needs.

480

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## Appendix A

Appendix A details the methods of the two data requests performed at request of the Ethics Committee.<sup>132, 133</sup>

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

The first data request borrowed the definition of multiple listing used in the Decoteau et al. article.<sup>134</sup> Multiple listing was defined as any candidate who is on the transplant waitlist for a particular organ at more than one program simultaneously. A candidate was be considered multiple listed regardless of the time between first listing and subsequent listing. In this way, the multiple listing definition captured all candidates who both intended to multiple list from the outset and those who for whatever reason made the decision further into their waitlist tenure (potentially due to frustration or inability to secure a quality offer). All of the following metrics were be calculated based on a recent snapshot of candidates waiting on the heart, liver, lung and kidney waitlist as of December 31, 2021. All metrics were presented by organ type (kidney, liver, and thoracic – heart and lung were combine due to small sample size) and compare multiple listed and single listed candidates, unless otherwise stated. Note that candidates could have been listed for multiple organs. Candidates, for example, who were listed for a heart and kidney appeared in both the heart and kidney counts but are only counted once in overall totals.

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

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

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

<sup>132</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>133</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>134</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>.



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

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

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

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

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

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

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

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

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

### *Methods*

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

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

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

### *Additional Metrics*

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

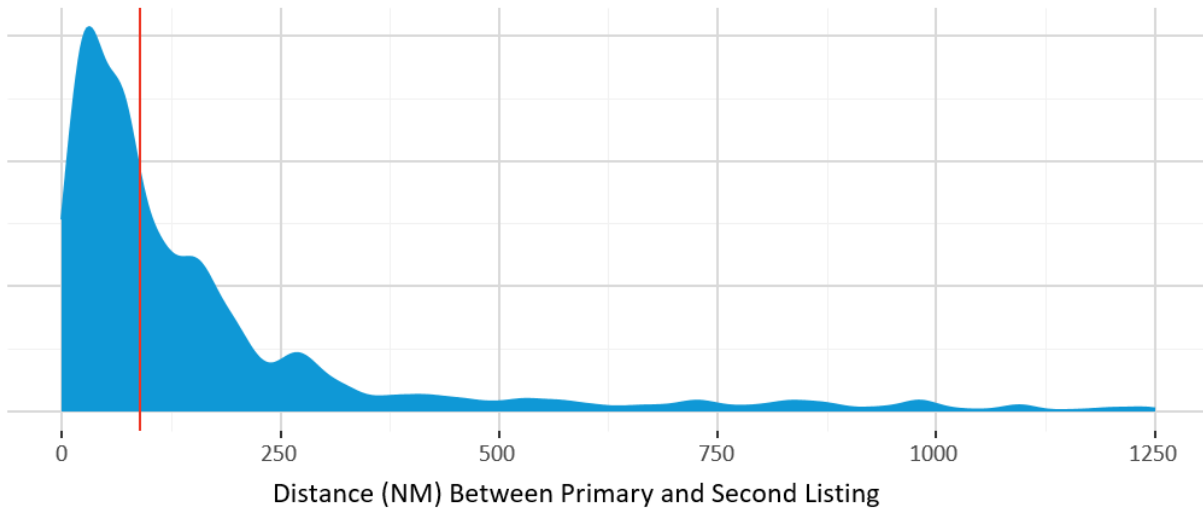
Table 1

	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 (%)	65935 (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)

Figure 1

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

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



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

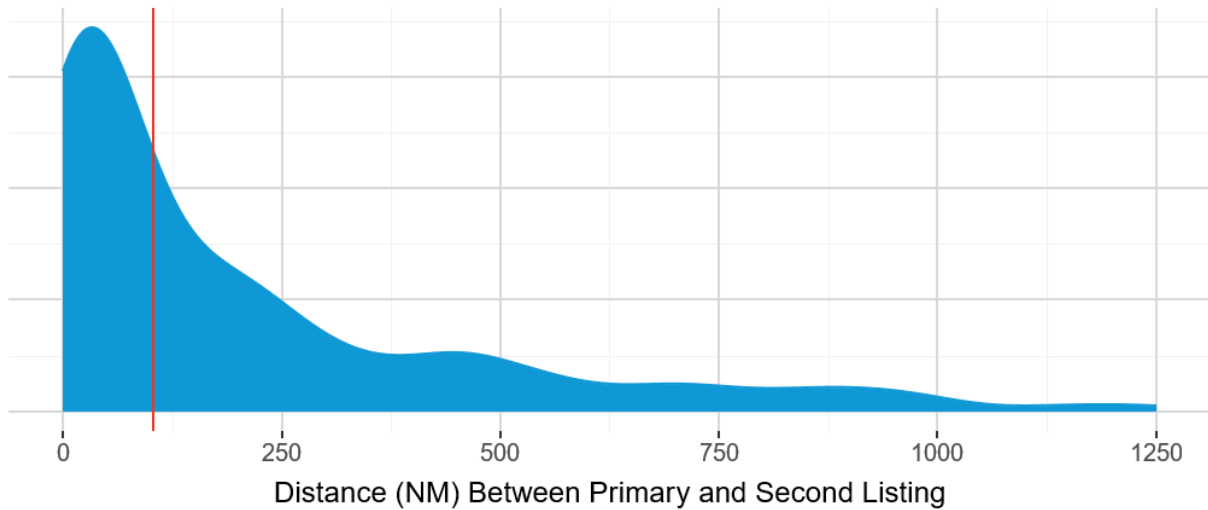
The red line shows the median distance from primary to secondary listing.

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

Figure 2

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

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



\*There were 10 Multiple Listed candidates that had secondary registrations at a transplant hospital that exceeded 1,250 NM in distance from the hospital they were primarily listed at.

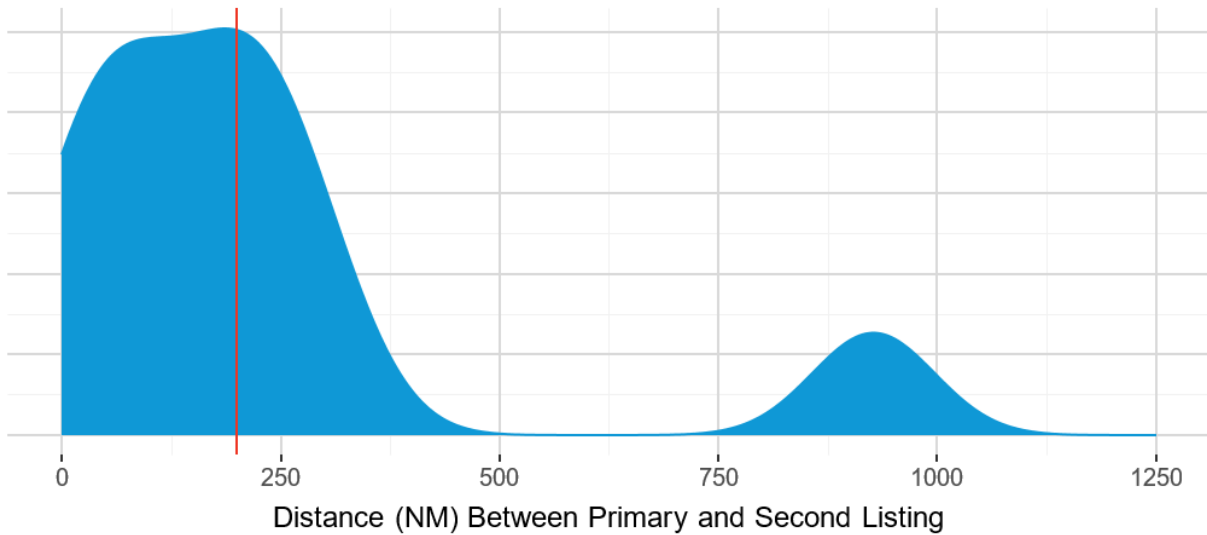
The red line shows the median distance from primary to secondary listing.

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

Figure 3

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

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



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

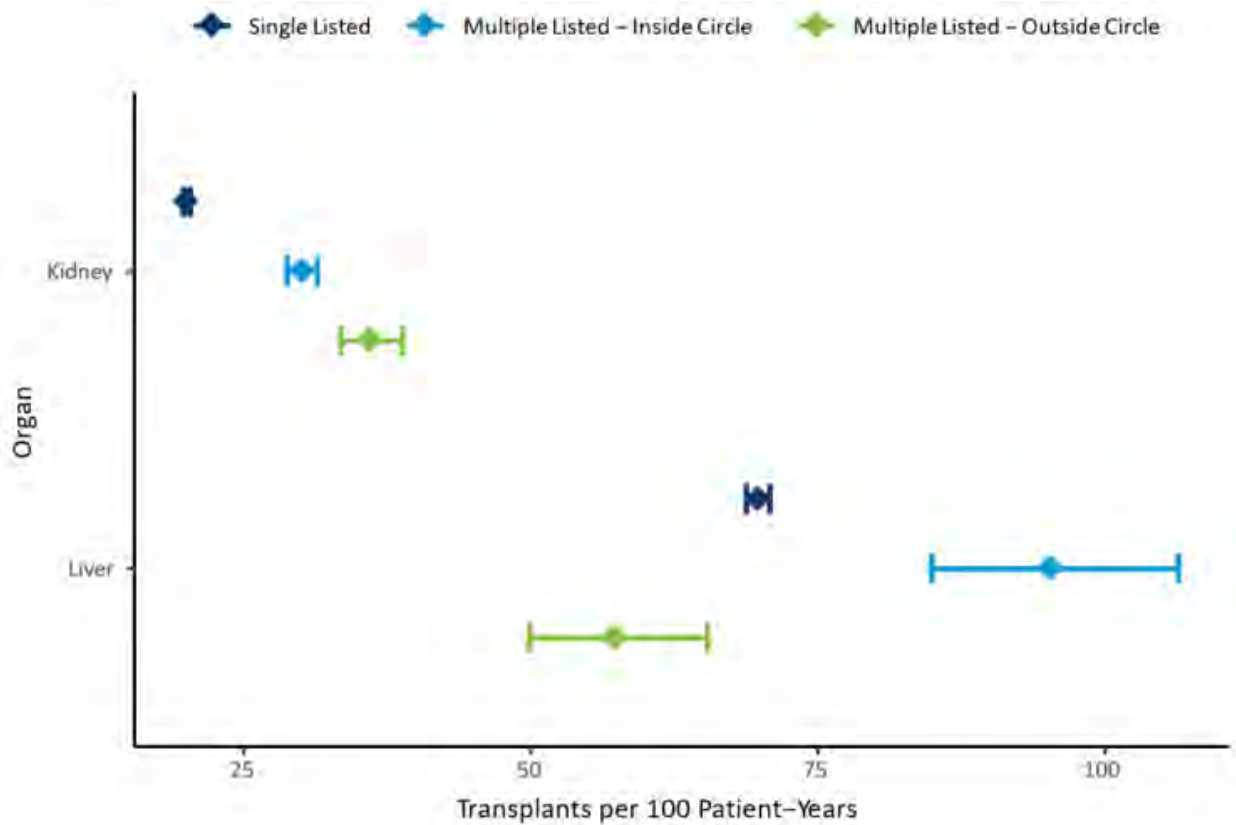
The red line shows the median distance from primary to secondary listing.

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

Figure 4

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

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



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Table 2

**Table 2. Transplant Rate by Listing Status for Kidney and Liver Candidates Ever Waiting from Circle 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)