



March 15, 2023

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Keren Ladin, PhD
Chair
Organ Procurement and Transplantation Network
Ethics Committee
Tufts University School of Arts and Sciences
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574 Boston Ave, Medford, MA 02155

RE: White Paper: Ethical Evaluation of Multiple Listing

Dear Dr. McCauley and Dr. Ladin:

On behalf of the more than 37,000,000 Americans living with kidney diseases and the 21,000 nephrologists, scientists, and other kidney health care professionals who comprise the American Society of Nephrology (ASN), thank you for the opportunity to respond to provide comment regarding the Organ Procurement and Transplantation Network (OPTN) white paper “Ethical Evaluation of Multiple Listing.”

Maximizing patients’ access to kidney transplant—and ensuring that access is equitably available to all patients—is of utmost priority for ASN. The society stands ready to work with OPTN, and the OPTN Ethics Committee, to achieve this goal. As ample research demonstrates, many aspects of our nation’s kidney health ecosystem, including those related to kidney transplantation, are not equitably available to all patients. Significant disparities in transplant access and outcomes exist along racial/ethnic, socioeconomic, geographic, and other lines, and ASN is dedicated to addressing these gaps and increasing health equity.

ASN is concerned, however, that the recommendation advanced in the white paper “Ethical Evaluation of Multiple Listing,” to eliminate patients’ ability to list at multiple centers may have unintended consequences that will make it *more* difficult for patients to access kidney transplants than under the current system without meaningfully advancing equity. The society wholeheartedly supports OPTN and the Ethics Committee’s emphasis on “revising policies that entrench [health disparities]” and respectfully urges OPTN and the committee to focus its efforts to achieve this goal by reforming other aspects of the system to reduce inequities, particularly inequities in accessing multiple listing, discussed in more detail throughout this response and listed in Appendix 1.

Rather than limiting many patients to the lowest common denominator of access (at a maximum of just one transplant center), at this moment in time, our efforts should be focused on helping more patients overcome individual, institutional, and systemic barriers that impede their ability to maximize their likelihood of getting a kidney transplant at the transplant center(s) most likely to help them succeed, in accordance with their individual care goals.

Many of ASN's recommendations for other avenues to ensure equity in the system are also surfaced in the white paper, and the society appreciates OPTN's inclusion of these opportunities to improve the system and advance health equity. ASN is eager to work collaboratively with OPTN, HHS, the United States Congress, and other policymakers to identify opportunities to implement these concepts.

The World Health Organization's definition of health equity states that "health equity is achieved when everyone can attain their full potential for health and well-being." The society believes that helping every kidney patient achieve their full potential for health means we must work in partnership with every patient who would benefit from a kidney transplant to obtain one, according to their individual care goals, maximizing the odds that that goal is attained. This vision requires that our system focus on expanding the pathways to kidney transplantation and ensuring those pathways **are** equitably accessible to every patient, not limiting the pathways to full health potential because we realize they are not equitably accessed today.

Variation in transplant center practices

Different transplant centers have different types of expertise in treating unique populations of patients. Different transplant centers have substantially different criteria for patient acceptance and organ acceptance, and different levels of risk tolerance—each of which can evolve over time, even from month-to-month. This variation is a key strength of our nation's transplant system, enabling different centers to play to their own strengths and develop niche capabilities.

Despite the overall positive effect of this variation, at present, it can be very difficult—and in some cases impossible—from the patient's or the general nephrologist's point of view to ascertain which programs have attributes that would make that particular program a good fit based on that patient's unique needs. Indeed, at many transplant centers, it is not possible to ascertain what a program can or will do on behalf of a given patient until that patient has been accepted into the program. These challenges, and some potential policy solutions, were explored in the recent OPTN white paper "*Transparency in Program Selection.*"ⁱ

Pioneering work funded by the Agency for Healthcare Research and Quality (AHRQ) aims to help empower patients with more of this type of information, but this laudable effort is in its infancy.ⁱⁱ Increasing transparency regarding center practices and attributes in patient-centered formats is an essential step in leveling the playing field in terms of access. ASN believes that, eventually, this proof-of-concept platform should be expanded into a nationwide matching clearinghouse to help patients identify the transplant center(s) that are the optimal fit, including integration with electronic health records (EHRs) at dialysis facilities, nephrology clinics, and transplant centers nationwide. Not only would this clearinghouse increase transparency for patients and referring nephrologists, but it would also decrease redundancy (such as eliminating one-off interfaces sharing the same information with multiple transplant centers) and reduce transplant coordinator effort, allowing the care team to focus on higher-value ways to help patients.

While certain aspects of center practices are periodically made available via the Scientific Registry of Transplant Recipients (SRTR) website, the reality is that different centers use different criteria to say yes or no to the same donor kidney, and those criteria frequently shift. A patient listed at two centers in the same metropolitan area (and within the same Donor Service Area) that appear similar on paper may have a donor kidney declined on their behalf at one center, while the second center may accept the same kidney on their behalf. Therefore, having the ability to be considered at the same time by multiple transplant centers can be an important option in our current system. It is an option we should be helping more patients avail themselves of, in accordance with their individual care goals, not fewer. If we succeed in having most patients list at just one center, but those centers are not the best centers to transplant them because the right information was not available at the time of their selection, we have not advanced the cause of equity and in fact, run the risk of deepening it.

- *Goal: Increase transparency regarding transplant centers' organ offer acceptance practices, including the use of bypass filters, and ensure the accessibility of this information in a patient-centered format*
- *Goal: Strengthen and expand the AHRQ-funded <https://transplantcentersearch.org/> study, leveraging this proof-of-concept to create a national matching clearinghouse, including integration with EHRs at dialysis facilities, nephrology clinics, and transplant centers nationwide*
- *Goal: Informed by shared decision-making regarding patient preferences and goals for their health, support all patients in pursuing multiple listing when that approach aligns with their desires*

Transplant center efficiency and choice

ASN recognizes that it is inefficient for a transplant center to coordinate many patients that it won't end up transplanting. However, the society believes the best approach is not so much to regulate the programs as to what they can or can't do with respect to multi-listing, but to let them operate as they feel they operate best—provided centers are transparent about their practices. There is certainly more room for OPTN and/or other HHS regulation and oversight to ensure that patients (and other health professionals who are part of their care team outside of the transplant center) are aware of what programs are a good fit for their individual needs and care goals.

- *Goal: Permit transplant centers to operate according to their own expert assessment of their capability and capacity with respect to multi-listing—but require those practices to be made transparent and easily understandable to patients and their care teams—rather than mandating a uniform approach to multi-listing.*

Education, health literacy, and digital literacy

Navigating the transplant system is, as the white paper rightly observes, very challenging. “As noted, “those with advanced education are more likely to be multiple listed when compared to single listed patients [and]...the complexity of the transplant evaluation and listing process and the high levels of digital health literacy required to navigate multi-listing may further disadvantage marginalized and vulnerable groups.” It is a massive problem that patients with lower levels of education, health literacy, and digital literacy all face bigger barriers to accessing the optimal therapy for kidney failure as compared to patients with higher levels. As a society, we must commit to addressing the root causes of social determinants of health, including

education. At the same time, we must also leverage every tool at our disposal to support patients in overcoming the obstacles created by educational, health literacy, and digital literacy gaps, including, in the context of the kidney health ecosystem through the following goals:

- *Goal: Increase utilization of the Medicare Kidney Disease Education benefit*
- *Goal: Develop and disseminate educational resources regarding kidney transplantation options for all levels of health literacy, ensuring these resources are available in numerous culturally competent forms and in a diverse array of languages*
- *Goal: Dedicate more resources to support patient education and awareness efforts, including those available to patients in analog formats*
- *Goal: Consider the development of a patient navigator program, as called for by the National Kidney Foundation*
- *Goal: Explore, particularly with input from patients and patient organizations, the utility of a requirement that transplant centers notify patients that different centers have different approaches to transplant decision-making, and that the patient may wish to seek multiple evaluations and/or multiple listings in order to ensure the best fit(s) for them*

The white paper states “the policy allowing multiple listing complies with formal equality of opportunity by being available to all patients, but the policy alone cannot promote fair equality of opportunity;” however, ASN maintains that no policy should exist alone in a vacuum: policies exist in an ecosystem of other policies that, together, should work to maximize patients’ equitable access to transplantation. In this instance, we should focus on strengthening and funding other policies that help overcome educational and literacy gaps to further enable every patient to pursue the optimal path to kidney transplant, according to their own individual care goals.

Insurance status

“OPTN data clearly depict patients with private insurance as comprising a larger proportion of multiple listed patients. This trend aligns with structural disparities and questions of potentially unequal access between patients with private versus public insurance,” states the white paper ASN concurs: throughout American healthcare, it is a tragic yet well-recognized fact that patients with private insurance are often considered “preferable” to patients with various forms of public insurance.ⁱⁱⁱ The federal government itself has acknowledged that “inadequate health insurance coverage is one of the largest barriers to health care access, and the unequal distribution of coverage contributes to disparities in health.”^{iv}

- *Goal: Address structural barriers to adequate insurance coverage for people with kidney diseases*

ASN concurs with the white paper that “insurance providers should not be the limiting factor for patients to pursue life-saving organ transplantation.” In the case of kidney transplantation, if the evidence suggests that insufficient Medicare and/or Medicaid reimbursement is creating a barrier to patients’ access to the optimal therapy, ASN believes the ethical response is to advocate for increased, sufficient reimbursement, tackling the root cause of the problem so that all forms of insurance (public and private) cover patients’ access to necessary transplant care at an equally appropriate level. Indeed, the Medicare ESRD program guarantees coverage for kidney transplant care for all Americans with kidney failure, which should include appropriate reimbursement for necessary evaluation and transplantation.

- *Goal: Assess the degree to which Medicare and Medicaid provide appropriate reimbursement for transplant evaluation and transplant care and advocate for changes as appropriate to ensure beneficiaries have access to the optimal therapy.*

While recommending eliminating the option of multi-listing for all but “exceptionally difficult to match” patients, the white paper also proposes allowing patients to pursue multiple evaluations “in order to find the transplant program that best aligns with their needs, preferences, and clinical characteristics.” ASN concurs that it is often necessary to undergo an evaluation to determine if a patient will actually be a good fit for a given center—particularly because of the current lack of patient-accessible information about center practices (a topic also addressed in the recent OPTN white paper “*Transparency in Program Selection*”).^v

As is noted in this white paper, limitations exist in allowing all patients to pursue multiple evaluation—including that some insurers do not cover more than one transplant evaluation annually: “In order to pursue multiple listings, the patient and their caregiver may need to travel to additional transplant programs for transplant evaluation, attain lodging, receive time off work, and potentially pay for the additional transplant evaluation if not covered by insurance.” It appears that many of the same barriers exist to receiving multiple evaluations as exist to being multi-listed. Accordingly, ASN questions how likely the proposal to allow multiple evaluations (but disallow multiple evaluations for all but a few patients) is to succeed in the goal of creating equitable access. From an equity of access perspective, how significant is the difference in permitting multiple evaluations but not allowing multiple listings for all patients?

A national, federally-funded program, the National Living Donor Assistance Center (NLDAC), exists to support living donors cover the costs of travel, lodging, lost wages during time off of work, and dependent care expenses. This program exists in recognition of the fact that “many people would like to donate an organ to a family member or friend, but would have trouble paying for related expenses that...might make living organ donation impossible.”^{vi} Recognizing that many of these same barriers exist for patients who would benefit from evaluation at more than one transplant center, we should explore the creation of a similar program to support kidney transplant candidates to foster more equitable access to evaluation.

The Department of Veterans Affairs (VA) also provides a potential model to support multi-listing. The VA encourages patients to list at more than one centers, and more VA patients are multiple listed (4.1% of all multi-listed patients) than single-listed patients (1.7% of all single-listed patients). The VA covers the cost of travel and lodging at a VA facility located somewhere where the patient does not reside for both the patient and a designated caregiver.^{vii} The VA presents a compelling example that policy changes can support patients in overcoming socioeconomic, educational, or other drivers of disparities in lack of access to multi-listing and enable patients to be considered at more than one center.^{viii} Rural patients who must travel long distances to list at any transplant center and are socioeconomically disadvantaged could also benefit from such a program. Patients have voiced support for programs to help patients, particularly those in rural areas, defray travel and lodging costs.^{ix}

- *Goal: Using NLDAC and the VA as models, explore the creation and federal funding of a program to support kidney transplant patients access transplant evaluation at program(s) that might be a good fit for them*

ASN wonders if it would be possible for OPTN to shed some light on how much of the gap between patients who are multi-listed with Medicare or Medicaid versus those multi-listed with private insurance might be due to restrictions in the public programs on multiple evaluations. Research shows that “patients with Medicare, Medicaid, other insurance, and no insurance [are] at a substantial disadvantage compared with privately insured individuals” with respect to being assessed for transplantation—the first step to listing.^x ASN believes it would also be valuable to understand the extent to which private payers are also placing restrictions on multiple evaluations. These findings could point to new opportunities for advocacy to increase appropriate coverage in both public and private insurance markets.

Excerpt from White Paper *Ethical Evaluation of Multiple Listing*
Table 1-1

Insurance status	Single-listed kidney patient	Multi-listed kidney patient
Private or self-pay	43.3%	53.5%
Medicaid	13.2%	4.8%
Medicare	40.3%	35.9%
Dept. of VA	1.6%	4.1%

- *Goal: Understand the extent to which patients may be inappropriately limited to just one transplant evaluation under various forms of insurance coverage, and advocate for changes as appropriate to ensure beneficiaries have access to the optimal therapy*

One reason that some insurers may be reluctant to cover more than one kidney transplant evaluation is the litany of identical tests that each transplant center performs in the course of patient evaluation. These redundant tests also come with associated patient co-payments, which can add up over the course of multiple evaluations in the quest to find a program(s) willing to accept a patient and constitute a financial barrier for some patients. Similarly, the time it takes to receive this battery of tests can pose a challenge, particularly for patients who may have competing dialysis regimens, jobs, or dependent care duties. Thus, reducing the amount of redundant tests would help level the playing field for access to transplant in general, and to multi-listing in particular.

By integrating with patients’ EMRs, the national matching clearinghouse described earlier would obviate the need for much of this costly, time consuming, and often duplicative testing. Each patient would have a core set of agreed-upon basic tests for transplant evaluation completed once, which would then be automatically integrated into the clearinghouse database and be accessible by each stakeholder in the kidney transplant journey—including all participating transplant centers—nationwide. Centers that wish to perform additional testing not part of the core set would be able to ask patients to obtain these tests on a one-off basis—and the test results would then be available via the clearinghouse to any other programs or health professionals.

- *Goal: Reduce redundant testing and associated costs by developing a core set of tests shared by every transplant center and make patients test results available to all programs via the national matching clearinghouse*

Geography

Patients' chances of being added to the waitlist and receiving a kidney transplant vary by many factors, including by geography.^{xi} There is significant geographic variation in the number of kidneys recovered per wait-listed candidate both within and between regions, and this variation affects patients' access to transplant.^{xii, xiii, xiv} Although the new Kidney Allocation System aims to eliminate kidney transplant candidates' location as a determining factor influencing their likelihood of transplantation, geographic inequities in access to transplantation continue to exist.^{xv} Eventually, a shift to a system of continuous distribution may fully eliminate geographic variation, but numerous advancements in infrastructure, technology, and policy must first be achieved to realize the promise of continuous distribution.

- *Goal: Design and implement structural and policy changes, and invest in innovative technologies, that will pave the way for eventual adoption of a system of continuous distribution*

In the meantime, patients who reside in areas of the country with longer wait times remain at a disadvantage as compared with patients who live in areas with shorter wait times. Until we have a system that better addresses the foundational challenge of geographic disparity in wait times for kidneys—which inherently advantage some patients and disadvantage others—it seems unfair to more fully entrench many patients' access to just one transplant center. At the same time, NLDAC and the Department of VA provide compelling examples of programs to help patients who are socioeconomically disadvantaged cover the cost of travel to a program within the VA healthcare system is best-suited to meet their needs, to ensure that access to optimal care via multi-listing is equitable across socioeconomic lines.

ASN also believes that sustaining and expanding upon the use of telemedicine for kidney transplant candidate care—including aspects of the initial evaluation, ongoing evaluation, and post-operative care—would help bridge the physical distance between many patients and the transplant center(s) best positioned to accept and transplant them, as well as alleviate many of the cost-related barriers posed by travel. Telemedicine is a powerful tool to help level the playing field in terms of access to transplant care, including making multi-listing more feasible for patients who would have previously struggled to engage with distant but appropriate programs due to geographic and socioeconomic challenges.

- *Goal: Sustain and expand the use of telemedicine to bridge geographic as well as socioeconomic barriers related to transplant care*

Interestingly, the data presented in the white paper show the median distance patients who are multi-listed travel between their primary and secondary center is 89 miles. This suggests that most patients who are multi-listing are not be engaging in extreme long-distance traveling (such as Steve Jobs, cited in the white paper as an example of behavior that is “harmful to public perception). Also based on the data presented in the white paper, a small number of patients do travel vast distances—an expense that may indicate high socioeconomic status among this population: 193 multi-listed kidney patients received care at two centers with a median distance of more than 1,250 miles apart. 193 patients represent approximately .002% of all the patients on the kidney waitlist, so extreme long-distance travel is not the norm.

Nonetheless, the fact remains that patients with greater resources have greater ability to leave their home geography to seek a kidney transplant at a program likely to help them succeed in that goal if the program closest to their place of residence cannot or will not. Rather than accept

most patients' fate as inextricably tied with their place of residence and limit multi-listing more than the system already does, ASN recommends exploring the development of a program to support the transportation and other expenses of socioeconomically disadvantaged patients whose care needs require evaluation or transplantation outside their immediate geography.

- *Goal: Using NLDAC and the VA as models, explore the creation and federal funding of a program to support kidney transplant patients access transplant evaluation at program(s) that might be a good fit for them*

Patient perspective

ASN appreciates that OPTN has specifically called for input from patients with respect to this white paper and urges that their voices be taken strongly into account.

The onus to achieve equity is the responsibility of the system that serves the patients—not the responsibility of the individual patients themselves. Aiming to increase equity by placing the onus on the individual patient to choose just one program, particularly in the absence of readily accessible program information and in the context of documented geographic disparities in organ wait times—could have the unintended consequence of shifting some of this responsibility onto patients.

In sum, ASN appreciates OPTN's and the committee's dedication to ensuring equity in kidney transplantation and is grateful for the opportunity to provide input on this white paper. ASN also acknowledges that many other simultaneous changes to the current kidney health ecosystem must occur urgently to achieve the goal of maximizing access to transplant and ensuring that access is equitable. The society stands ready to work with OPTN and the committee on the many recommendations included in this letter as well as towards other shared goals. Please contact ASN Strategic Policy Advisor Rachel Meyer at rmeyer@asn-online.org with any questions or to discuss this letter in more detail.

Sincerely,



Michelle A. Josephson, MD, FASN
President

Appendix 1. Select ASN recommendations to increase access and ensure equity in kidney transplant, particularly related to multi-listing:

1. Increase transparency regarding transplant centers' organ offer acceptance practices, including the use of bypass filters, and ensure the accessibility of this information in a patient-centered format
2. Strengthen and expand the AHRQ-funded <https://transplantcentersearch.org/> study, leveraging this proof-of-concept to create a national matching clearinghouse, including integration with EHRs at dialysis facilities, nephrology clinics, and transplant centers nationwide
3. Informed by shared decision-making regarding patient preferences and goals for their health, support all patients in pursuing multiple listing when that approach aligns with their desires
4. Permit transplant centers to operate according to their own expert assessment of their capability and capacity with respect to multi-listing—but require those practices to be made transparent and easily understandable to patients and their care teams—rather than mandating a uniform approach to multi-listing.
5. Increase utilization of the Medicare Kidney Disease Education benefit
6. Develop and disseminate educational resources regarding kidney transplantation options for all levels of health literacy, ensuring these resources are available in numerous culturally competent forms and in a diverse array of languages
7. Dedicate more resources to support patient education and awareness efforts, including those available to patients in analog formats
8. Consider the development of a patient navigator program, as called for by the National Kidney Foundation
9. Explore, particularly with input from patients and patient organizations, the utility of a requirement that transplant centers notify patients that different centers have different approaches to transplant decision-making, and that the patient may wish to seek multiple evaluations and/or multiple listings in order to ensure the best fit(s) for them
10. Address structural barriers to adequate insurance coverage for people with kidney diseases
11. Assess the degree to which Medicare and Medicaid provide appropriate reimbursement for transplant evaluation and transplant care and advocate for changes as appropriate to ensure beneficiaries have access to the optimal therapy.
12. Using NLDAC and the VA as models, explore the creation and federal funding of a program to support kidney transplant patients access transplant evaluation at program(s) that might be a good fit for them
13. Understand the extent to which patients may be inappropriately limited to just one transplant evaluation under various forms of insurance coverage, and advocate for changes as appropriate to ensure beneficiaries have access to the optimal therapy.
14. Reduce redundant testing and associated costs by developing a core set of tests shared by every transplant center and make patients test results available to all programs via the national matching clearinghouse
15. Design and implement structural and policy changes, and invest in innovative technologies, that will pave the way for eventual adoption of a system of continuous distribution
16. Sustain and expand the use of telemedicine to bridge geographic as well as socioeconomic barriers related to transplant care

ⁱ <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/transparency-in-program-selection/>

ⁱⁱ <https://transplantcentersearch.org/>

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- iii <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6452575/>
- iv <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01466>
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- vi <https://www.livingdonorassistance.org/About-Us/Mission-Background>
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- viii Transplantation. 2017 Jun;101(6):1191-1199. doi: 10.1097/TP.0000000000001377.PMID: 27482965
Additional reference showing that VA transplant demographics are different and highlight impact on racial and SE barriers in transplantation.
- ix Garner, L *CJASN* [15\(4\):p 439-440, April 2020.](#) | DOI: 10.2215/CJN.02130220
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- xi National Research Council. 2022. *Realizing the Promise of Equity in the Organ Transplantation System*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26364>.
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- xv Zhou S., Massie A.B., Luo X. Geographic disparity in kidney transplantation under KAS. *Am J Transplant.* 2018;18:1415–1423