Organ Procurement and Transplant Equity Among US Residents: The 5% Guideline

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Policy Forum highlights aspects of nephrology relating to payment and social policy, legislation, regulation,
demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members
of the kidney community, including providers, payers, and patients.
There are an estimated 11 million undocumented or non-US citizens/US residents (i.e. undocumented immigrants) living in the United States (U.S.) and the number of non-US citizens/US residents who need an organ transplant is unknown. The National Organ Transplantation Act (NOTA) of 1984 requires that only medical criteria be used in organ allocation decisions. Despite this law, the Organ Procurement Transplant Network (OPTN) however does require transplant programs and Organ Procurement Organizations (OPOs) to collect citizenship and residency status data for all transplant candidates and donors. Though this policy has changed over time (Figure 1), there is concern that citizenship and residency status data collection, and its impact on listing and transplantation contributes to inequities in transplantation of non-US citizens/US residents in need of organ donation.

The initial 1986 OPTN policy recommended that non-US citizens (including US residents and non-US residents) should comprise less than 10% of all kidney transplant recipients per transplant center. In 1994, this number was lowered to 5% for all organs-above this threshold, an audit of the transplant center could be triggered. Though no formal review or detailed audit was ever performed, the consequences of this policy resulted in many transplant centers becoming fearful of transplanting residents with unknown or unclear immigration status. Due to concerns of transplant inequity, the World Health Organization requested member states review their transplant policies “to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs.” A summit meeting with 150 stakeholders convened in 2008 to address these concerns led to the creation of the Declaration of Istanbul. Under this declaration, transplant tourism is defined as “organ trafficking and/or transplant commercialism, or if resources (organs, professionals and transplant centers) devoted to providing transplant to patients from outside a country undermine the country’s ability to provide transplant services for its own population.”
Given concern for equity in transplantation, the OPTN Ad Hoc International Relations Committee (IRC) began reviewing OPTN policies related to the transplantation of all non-US citizens (including US residents and non-US residents) in 2010. Prior to 2010, the citizenship categories included U.S. citizen, resident alien (i.e. non-citizen /US resident), and non-Resident alien (i.e. non-citizen /non-US resident). In 2011, the OPTN board of directors changed the citizenship data collection field for non-US citizen categories to distinguish US residency: non-US citizen/US resident and non-US citizen/non-US residents. Non-US citizen/US resident is a US resident who does not have citizenship. A non-US citizen/non-US resident is a non-citizen who does not reside in the U.S., and is further divided to distinguish those who traveled to the US for transplant and those who traveled to the US for reason other than transplant. These categories ask two questions: “1) are you a citizen of the United States? and 2) Are you a US resident (‘is the US your permanent abode?’)”. There is no ascertainment further into type of immigration status as defined by the United States Immigration and Naturalization service. In 2015, country of origin was also collected for non-residents. Table 1 outlines the correlation between OPTN citizenship status definitions and those used by the US government, as well as highlights transplant healthcare coverage.

In further effort for accountability and transparency, in 2012 OPTN and UNOS introduced a revised policy which replaced the 5% audit trigger with a review of all US residency and US citizenship data for listings and transplants made available in an annual publicly available report. While these data aimed to improve equity in access to transplantation for non-US citizen/U.S. residents – and should not impact transplantation decisions or metrics- the citizenship status question remains largely misunderstood.

First, there is still a lack of understanding regarding the meaning of these terms and how to collect and report them. There is variation in how citizenship and US residency data are collected by
transplant center for recipients, and by the OPO for donors. These terms do not reflect immigration status definitions used by the United States Immigration and Naturalization service and no visa status is recorded. In 2020, the OPTN requested program information from any program who had more than 5% or 5 non-US citizen/non-US resident transplants in order to better understand transplant centers’ policies and practices regarding accepting non-US citizens/non US residents as transplant candidates. Forty-eight percent of those responding did not have a formal process for accepting non-US citizen/non-US resident, and 20 programs reported US citizenship information was self-reported (with the remainder using passports, family, or government documents). In response to these discrepancies, the OPTN released a guidance document in 2021 addressing accurate definitions of citizenship terms and how to record and follow up these patients. Despite this guidance, how to obtain citizenship information remains challenging, and the definition of “US resident” remains vague. Further, there are challenges to using immigration status language in the health care setting, and it is unclear how certain immigration statuses (such as temporary protected status, green card holders, refugees, etc) may fit into this framework.

Secondly, recording citizenship terms may have a negative effect on non-US citizens/US-residents – both families of donors and recipients who may be afraid to report their status. This in itself may create a barrier that reduces donation and access to transplantation. Further, patients and families may not be truthful due to fear of deportation or denial of services. Non-US citizen/non-US residents are asked to report whether they were travelling for the sake of transplant – these data are difficult to verify as there is no way to track how long these patients have been in the country. Overall, clinical benefits from the citizenship data are unclear.

Lastly, the 5% guideline itself remains misunderstood. There are too often stories about non-US citizens/US-residents who are denied a transplant due to ambiguity of the 5% guideline. In 2019, 5.9% of all adults added to the organ waitlist were non-US citizen/US resident and 1.2% added were non-US
citizen/non-US residents. A study reviewing heart and lung transplants from 2013-2018 showed transplantation of non-US citizens (including US residents and non-US residents) is increasing by about 0.3% a year. Notably, 69% of the non-US citizen group were US residents. This group was more likely to be Latinx ethnicity and use Medicaid insurance—indicating that the majority of those classified as non-US citizens/US residents are likely underserved populations who overall receive disproportionately fewer organ transplants. Despite the rise in transplantation and waitlist registration among non-US citizens (both US residents and non-US residents), the total number of non-US citizen/non-US resident organ transplants remains small, less than 1% of total transplants performed between 2013-2016. The lack of understanding regarding definitions of citizenship and residency status and changes to the 5% guideline are likely contributing, in part, to these disparities in transplanting non-US citizens/US residents.

It is unclear if non-US citizen/US residents are denied a transplant due to lack of benefits given that non-US citizens/US residents are excluded from Medicare, the provisions of the Affordable Care Act, and most state Medicaid programs (Table 1). Other reasons they are denied a transplant may include—concern that non-US citizens/US residents are a financial drain, concern that they may lose their graft, and concern about the distribution of scarce organs. Counterarguments for the provision of transplant for non-US citizens/US residents are that they gift their organs in the US, they tend to be young, working-age, taxpayers who contribute to the Medicare Trust Fund and they have graft outcomes similar to US citizens. Concerns for poorer transplant outcomes in non-US citizens has not been shown in kidney, liver, lung and heart transplant. The reason for providing US residency status is to identify those candidates traveling for transplant tourism who may potentially worsen organ scarcity in the US. In comparison, non-US citizen/US residents, regardless of immigration status,
contribute to the organ donor pool and are thus not contributing to organ scarcity. In 2019, non-US citizens/US-residents contributed 3.2% of organs, though of note an additional 9.8% of donors have an unknown US citizenship status. In some areas, non-US citizens contribute up to 10% of the total organ pool.

As we move towards more equitable organ procurement and transplantation, it must be clear to transplant programs across the country that the former ‘5% guideline’ set forth by the OPTN Ad Hoc IRC committee should not be a barrier to transplantation for non-US citizens/US residents. There are many ‘transplant decision’ and for some, the use of non-medical criteria is acceptable—we urge transplant centers and OPOs to review OPTN guidelines which are intended to improve transplant equity for non-US citizens/US residents.

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References


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<tr>
<th>Immigration status</th>
<th>Description</th>
<th>OPTN Citizenship Category</th>
<th>Transplant Healthcare Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>US citizen</td>
<td>Born in the US or a parent is a US citizen.</td>
<td>US Citizen/US Resident</td>
<td>Medicare, Medicaid, and/or Health Insurance Marketplace</td>
</tr>
<tr>
<td>Undocumented immigrant</td>
<td>Does not have permission to live or work in the US and is at risk of deportation.</td>
<td>Non-US Citizen/US Resident*</td>
<td>Some states allow transplant under Medicaid or other state-funded health coverage Off Marketplace or private insurance</td>
</tr>
<tr>
<td>Lawful permanent resident or &quot;green card’</td>
<td>Received permission to live and work in the U.S. Can be obtained by family petitions, employer petitions, and violence against women act self-petitions.</td>
<td>Non-US Citizen/US Resident*</td>
<td>In most states, there is a 5-year waiting period before qualifying for Medicaid and Medicare Health Insurance Marketplace</td>
</tr>
<tr>
<td>Refugee</td>
<td>Received permission prior to entering the US based upon persecution or fear of persecution in one’s home country because of race, religion, nationality, membership in a particular social group, or political opinion.</td>
<td>Non-US Citizen/US Resident*</td>
<td>Medicare and Medicaid Health Insurance Marketplace</td>
</tr>
<tr>
<td>Asylee</td>
<td>Meets the definition of refugee as above, but seeks or obtains protection from persecution from inside the US or at the border.</td>
<td>Non-US Citizen/US Resident*</td>
<td>Medicare and Medicaid Health Insurance Marketplace</td>
</tr>
<tr>
<td>Asylum seeker</td>
<td>A person seeking asylum under the criteria above but has not been granted asylum status by USCIS or immigration courts.</td>
<td>Non-US Citizen/US Resident*</td>
<td>Same as undocumented immigrant</td>
</tr>
<tr>
<td>Non-Immigrant</td>
<td>Received permission from the government (usually in the form of a ‘visa’) to live in the US for a limited</td>
<td>Non-US Citizen/US Resident*</td>
<td>Health Insurance Marketplace</td>
</tr>
</tbody>
</table>
period of time and for a specific purpose (e.g. study, work, visit family, or tourism).
Examples of some visas:
- U visa (victim of criminal activity)
- T visa (victim of human trafficking)
- Student visa
- Visitor visa
- Temporary worker visa

<table>
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<tr>
<th>Conditional Permanent resident</th>
<th>Received permission from the government because the individual is married to a US citizen or they have an employment-based green card as an entrepreneur. Valid for 2 years and then must apply for removal of conditional status 90 days before green card expires.</th>
<th>Non-US Citizen/US Resident*</th>
<th>Same benefits as lawful permanent resident; however, they receive conditional status.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temporary Protected status</td>
<td>Permission from the government granted to nationals of countries whose conditions prevent people from returning home safely (e.g. due to national disasters or other extraordinary conditions).</td>
<td>Non-US Citizen/US Resident*</td>
<td>Health Insurance Marketplace</td>
</tr>
<tr>
<td>Tourist</td>
<td>Visiting the US and does not reside in the US</td>
<td>Non-US Citizen/non-US Resident* Traveling for transplant or travelling for reasons other than transplant**</td>
<td>None</td>
</tr>
</tbody>
</table>

*Residency is self-reported, there are no guidelines on the length of time required to be residing in the country.

**Reasons for traveling are self-reported
Figure 1. Timeline of transplant policies related to non-US citizens/US residents

*Transplant tourism is ‘organ trafficking and/or transplant commercialism, or if resources (organs, professionals, and transplant centers) devoted to providing transplant to patients from outside a country undermine the country’s ability to provide transplant services for its own population.
1986
OPTN policy: Non–US citizens should be <10% of all KTRs

1994
OPTN policy: Non–US citizens should be <5% of all KTRs

2004
Declaration of Istanbul: Defines transplant tourism*

2008
WHO: Urges member states to take measures against transplant tourism and organ trafficking

2010
OPTN policy: 5% guideline replaced with a review of all US citizenship and US residency data

2012
OPTN: Released guidance addressing accurate definitions of citizenship terms and how to record and follow up these patients

2015
OPTN: Records country of origin for noncitizens

2021
OPTN policy: Non–US citizens should be <5% of all KTRs