

# Guidance for Data Collection Regarding Classification of Citizenship Status

*OPTN Ad Hoc International Relations Committee*

# Purpose of Guidance Document

- To provide guidance to the transplant community on how to accurately enter citizenship status data on OPTN data collection forms for transplant candidates, living donors, and deceased donors
- To provide guidance to the transplant community on how to improve rates of follow-up data submission given a patient's citizenship status

# Guidance Document

- Registration Data Collection
  - Addresses factors that contribute to inaccurate citizenship status data collection & provides guidance on ways to improve accurate citizenship status data collection
    - Clarity on citizenship status definitions
    - Challenges to language barriers and legal status
    - Processes for ensuring accurate citizenship status data collection

# Guidance Document

- **Follow-up Data Collection**

- Addresses factors which contribute to low rates of follow-up data submission & ways to improve follow-up data submission rates given a patient's citizenship status
  - Lack of support and resources for non-U.S. citizen/non-U.S. resident and non-U.S. citizen/U.S. resident donors and recipients as well as concern regarding financial burden, health insurance, job security, and immigration status
  - Relationship building by utilizing dedicated living donor coordinators or social workers
  - Develop strong staff commitment to ensure adherence to follow-up
  - Relationship development between recipient/donor and primary care physician
  - Develop a systematic approach to follow-up with quality assurance

# Rationale

- Quality data is essential to monitor patient safety and analyze trends in order to inform the development of evidence-based policy
- Feedback from the transplant community showed lack of clarity on how to enter citizenship status data accurately
- Data and research showed low rates of follow-up data submission for non-U.S. citizen/non-U.S resident & non-U.S. citizen/U.S resident recipients and donors

# Member Actions

- Transplant community members may use the guidance document for reference and training materials