

Action Item from the Ad Hoc International Relations Committee and the Ethics Committee

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(Ethics Committee)

Meeting of the Board of Directors

June 28-29, 2011

Richmond, Virginia

Background

- In November, 2010, the Executive Committee approved the AHIRC's request to revise Policy 6.0 (Transplantation of Non-Resident Aliens)
- **First step:** Update and simplify data collection on organ donors and candidates who are not residents of the United States

Policy 6.2.5: Community Participation

- Policy Language:
 - Each member center which lists non-resident aliens on its Waiting List should establish a mechanism for community participation and review of its candidate acceptance criteria.

Current goal: to promote transparency and public trust in the OPTN

Core Problems with Current Non-Resident Alien Data Collection

- Minimal public “transparency” of practice with current data collection policy
- Programs find themselves in the “immigration business”
- Programs may be unnecessarily hesitant to transplant non-resident aliens for fear audit
- “Under the radar” transplantation may endanger public trust
- Data collection does not permit adequate delineation of individuals who travel to the US for transplant from those who travel to the US for reasons other than transplant

Current Category Definitions in Policy 6.0

■ 6.1.1 Non-Resident Alien

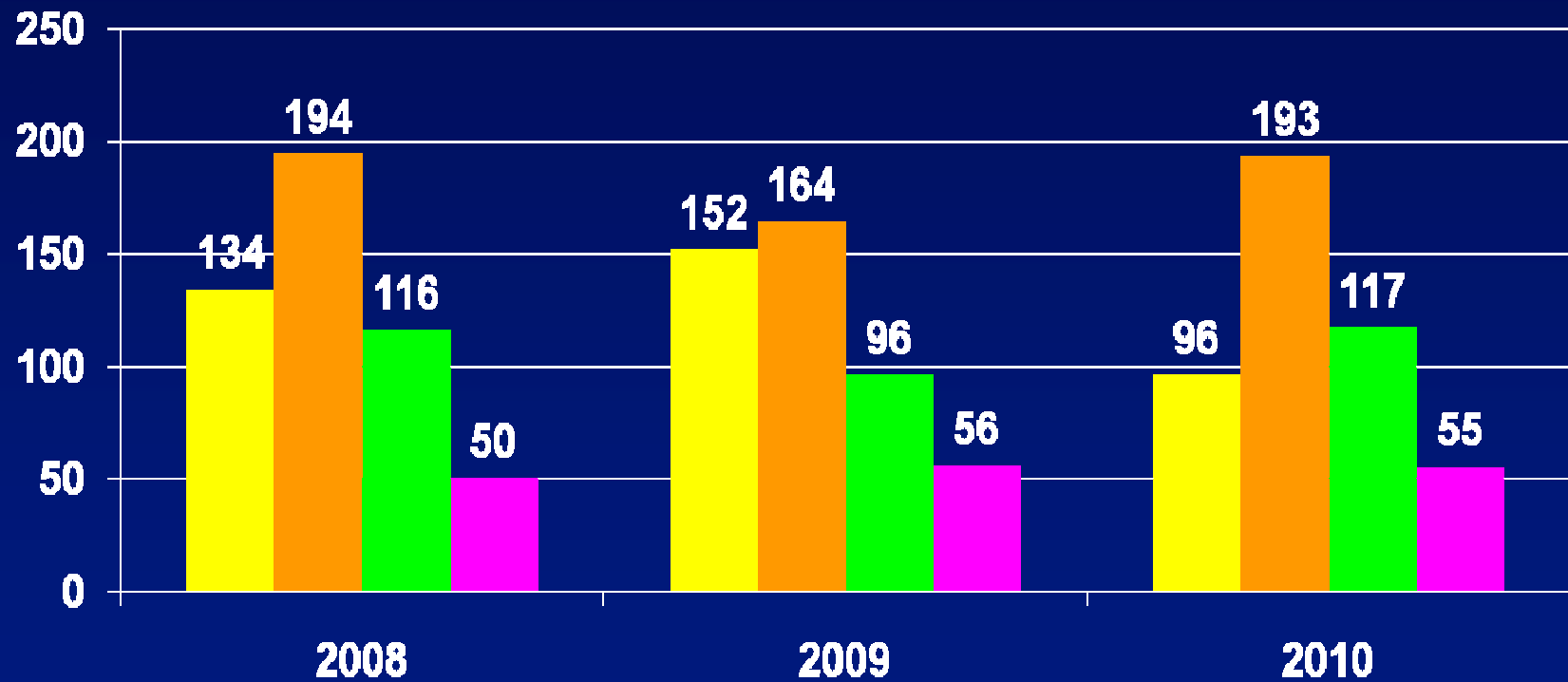
- A non-resident alien is an individual granted permission by the United States Government to enter the United States on a temporary basis as a non-immigrant alien for purposes which include tourism, business, education, medical care, or temporary employment.

■ 6.1.2 Domestic, American Candidate or Resident Alien

- A domestic, American candidate or resident alien is an individual who is either an American citizen or is an immigrant alien granted permanent resident status by the United States Government **or any individual, regardless of immigrant status, qualified for health care entitlement funds from state or federal government sources.**

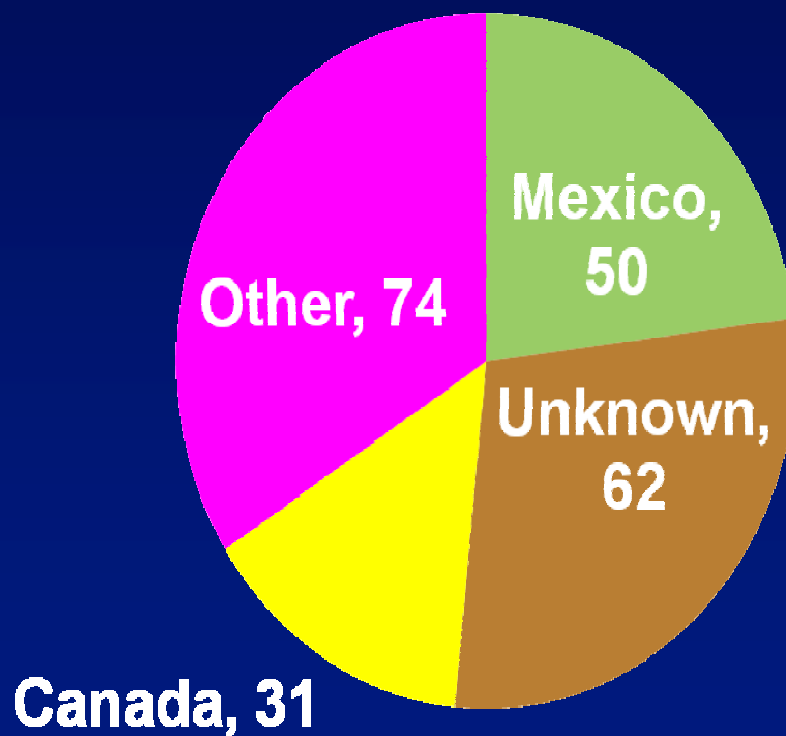
Non-Resident Alien Transplantation 2008-2010

2008: Total of 7,990 deceased donors, 21,748 deceased donor transplants, 6,218 living donors
 2009: Total of 8,022 deceased donors, 21,855 deceased donor transplants, 6,610 living donors
 2010: Total of 7,944 deceased donors, 22,104 deceased donor transplants, 6,564 living donors

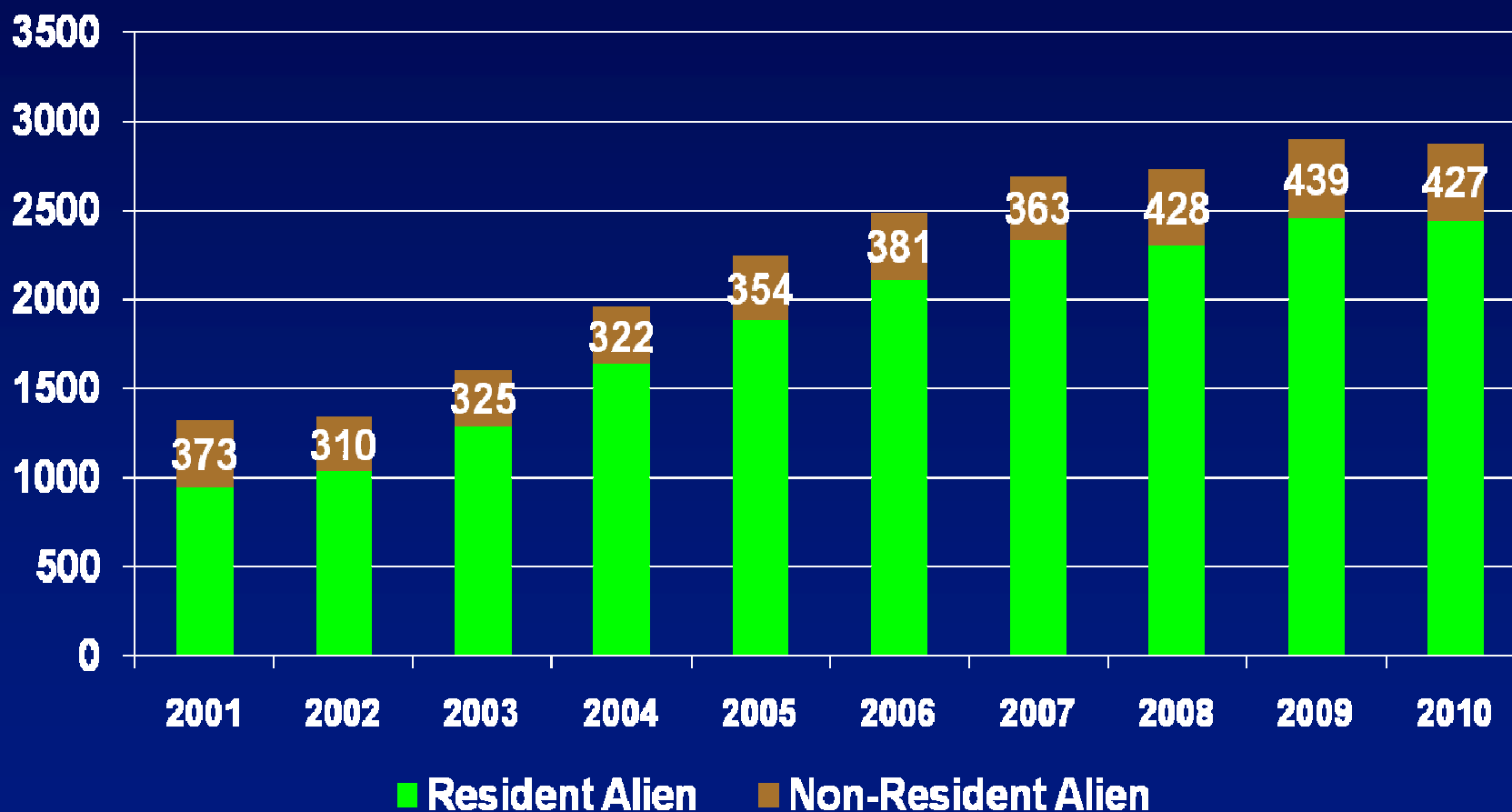


■ Transplants with NR Deceased Donors
 ■ Transplants NR DD Recipients
■ Transplants with NR Living Donors
 ■ Transplants NR LD Recipients

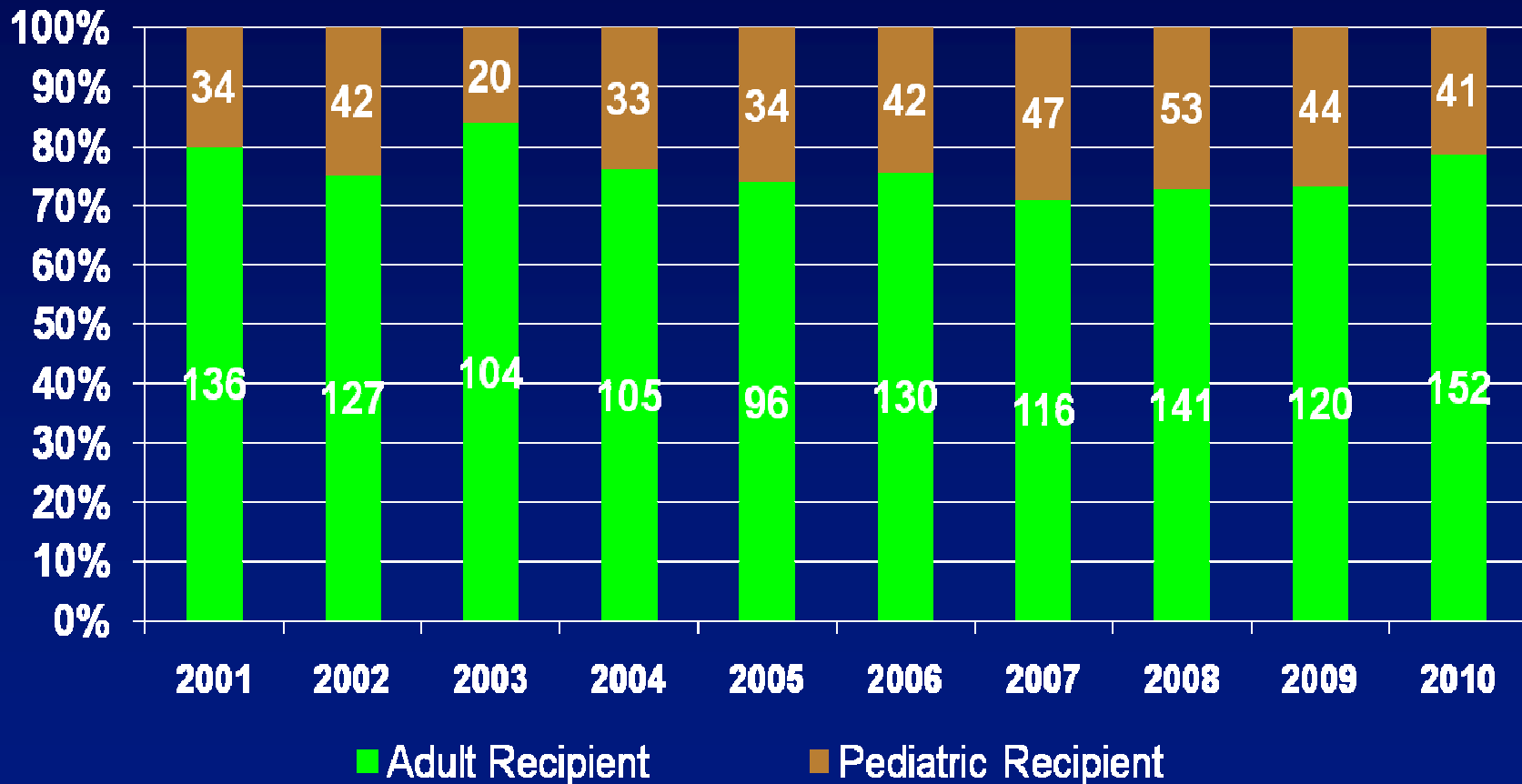
Country of Residence for Non-Resident Alien Deceased Donors 2006-2010



Non-U.S. Citizen Waiting List Registrations Added 2001-2010

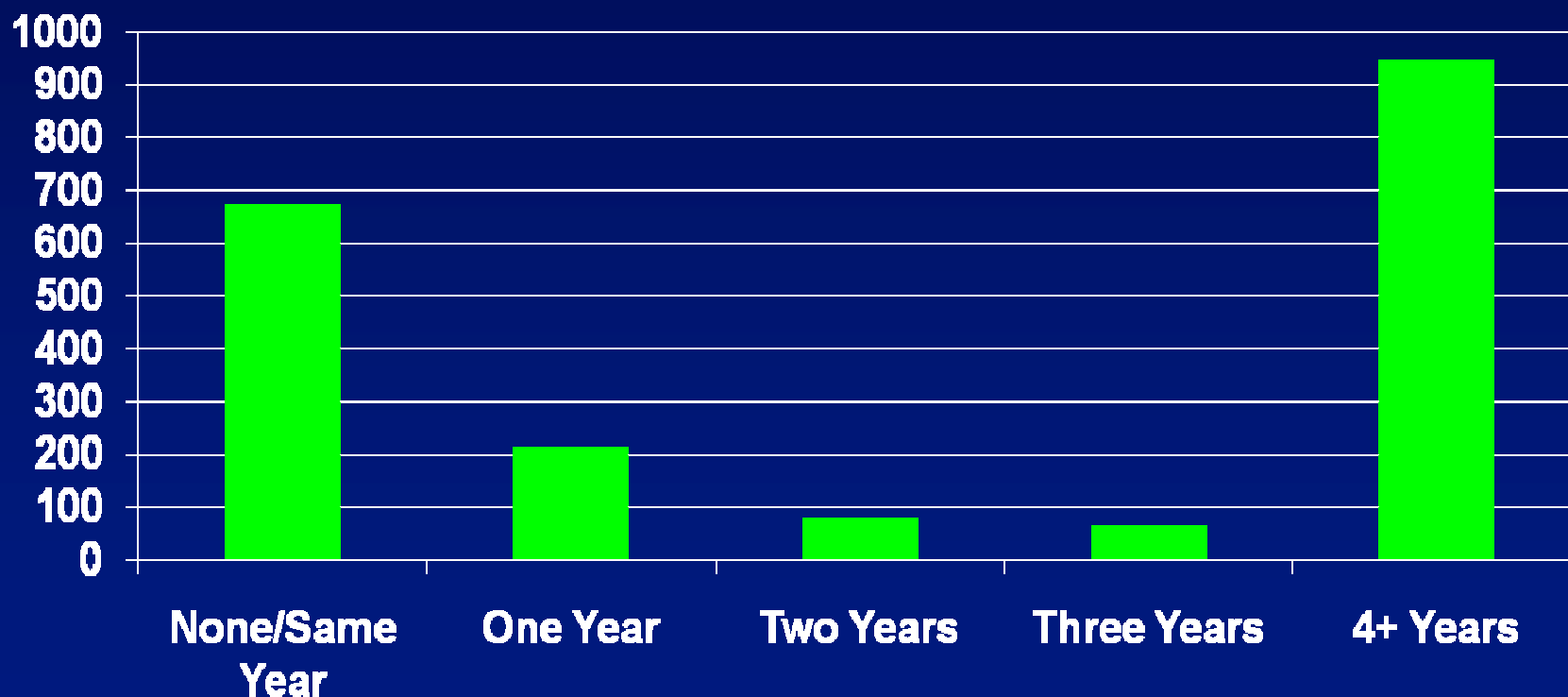


Non-Resident Alien Recipient Deceased Donor Transplants 2001-2010



Non-Resident Alien Candidate Waiting List Registrations Added 2006-2010

Years From Entry to U.S. To Listing on WL



Years From Entry to U.S. to Listing on Waiting List

OPTN

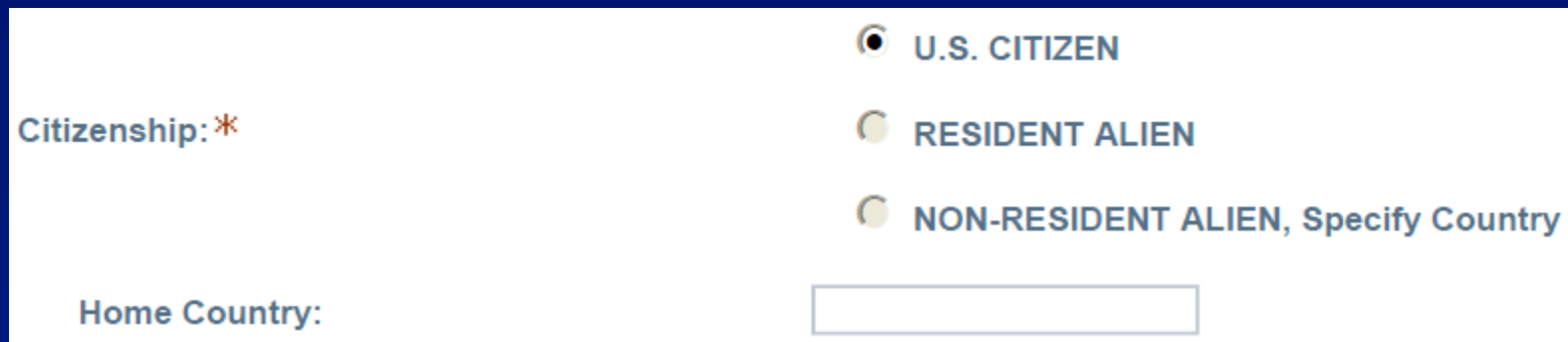


How do we Promote Transparency?

- Modify the citizenship field in the deceased donor registration (DDR), living donor registration (LDR), and transplant candidate registration (TCR) forms to:
 - Differentiate between those candidates and donors who are residents of the United States from those who traveled here for the purpose of transplant
 - *Residents are potential contributors to the donor pool*
- Data collection proposed will **not** create additional data entry burden to transplant programs, but simply change the list of choices.

Citizenship Field Categories DDR Form

- Current citizenship data field's categories
 - Entry of “non-resident alien” prompts the user to enter the “Home Country”



Citizenship:*

U.S. CITIZEN

RESIDENT ALIEN

NON-RESIDENT ALIEN, Specify Country

Home Country:

The screenshot shows a form with a 'Citizenship:' label followed by three radio button options: 'U.S. CITIZEN' (selected), 'RESIDENT ALIEN', and 'NON-RESIDENT ALIEN, Specify Country'. Below the radio buttons is a 'Home Country:' label followed by an empty text input field.

Proposed Citizenship Categories – DDR Form

- **Proposed** citizenship categories
 - US Citizen
 - Non-US Citizen/US Resident
 - Non-US Citizen/Non-US Resident

The entry of “Non-US Citizen/Non-US Resident” will prompt the user to enter the home country. Home country is currently collected for “non resident aliens.” Therefore, collecting this information for non-US residents will not create additional data entry burden to OPOs.

Citizenship Field Categories TCR Form

- Current citizenship data field's categories
 - Entry of “non-resident alien” prompts the user to enter the “Year of Entry to the US”

Citizenship: *

U.S. CITIZEN

RESIDENT ALIEN

NON-RESIDENT ALIEN, Year Entered US

Year of Entry to the U.S.

Proposed Citizenship Categories – TCR Form

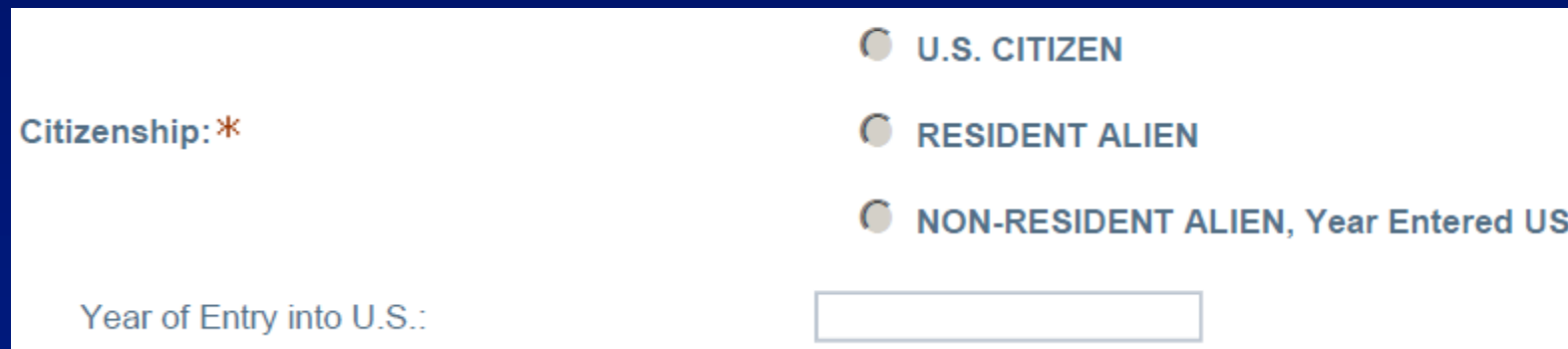
■ **Proposed** citizenship categories

- US Citizen
- Non-US Citizen/US Resident
- Non-US Citizen/Non-US Resident, Traveled to US for Reason Other than Transplant
- Non-US Citizen/Non-US Resident, Traveled to US for Transplant

The entry of “Non-US Citizen/Non-US Resident” will prompt the user to enter the country of permanent residence. (The Board previously approved the collection of country of permanent residence. There is no new data collection with this proposal.)

Citizenship Field Categories LDR Form

- Current citizenship data field's categories
 - Entry of “non-resident alien” prompts the user to enter the “Year of Entry into US”



Citizenship:*

U.S. CITIZEN

RESIDENT ALIEN

NON-RESIDENT ALIEN, Year Entered US

Year of Entry into U.S.:

Proposed Citizenship Categories – LDR Form

■ **Proposed** citizenship categories

- US Citizen
- Non-US Citizen/US Resident
- Non-US Citizen/Non-US Resident, Traveled to US for Reason Other than Transplant
- Non-US Citizen/Non-US Resident, Traveled to US for Transplant

The entry of “Non-US Citizen/Non-US Resident” will prompt the user to enter the country of permanent residence. (The Board previously approved the collection of country of permanent residence. There is no new data collection with this proposal.)

Intent, Public Comment, and Implementation

■ Intent

- Update policy, align definitions with proposed data collection
- Modifications to data elements proposed first

■ Public comment

- Not necessary, because no new data collection, but modifications to an existing field in the three forms

■ Implementation

- \$16,951 – effort is small
- Require programming in UNetSM but is **not anticipated** to impact the Chrysalis project
- Will be implemented with the Tiedi re-write project

OPTN



Resolution

- ****RESOLVED**, that the categories in the existing “Citizenship” field in the Living Donor Registration and Transplant Candidate Registration forms be modified as set forth below, pending programming:
 - US Citizen
 - Non-US Citizen/US Resident
 - Non-US Citizen/ Non-US Resident, Traveled to US for Reason Other than Transplant
 - Non-US Citizen/Non-US Resident, Traveled to US for Transplant;
- that the categories in the existing “Citizenship” field in the Deceased Donor Registration form be modified as set forth below, pending programming:
 - US Citizen
 - Non-US Citizen/US Resident
 - Non-US Citizen/ Non-US Resident
- and, that the selection of the “Non-US Citizen/Non-US Resident, Traveled to US for Transplant” category or the “Non-US Citizen/Non-US Resident, Traveled to US for Reason Other than Transplant” category will require the “year of entry to the US,” pending programming.

Third bullet: This is currently done when non-resident alien category is selected, but will require programming to maintain this data collection with the modified categories.

Questions