

# Update and Improve Efficiency in Living Donor Data Collection

*OPTN Living Donor Committee*

# Purpose of Proposal

- Improve understanding regarding barriers and access to living donation
- Expand knowledge and data collection about long-term outcomes of living donation

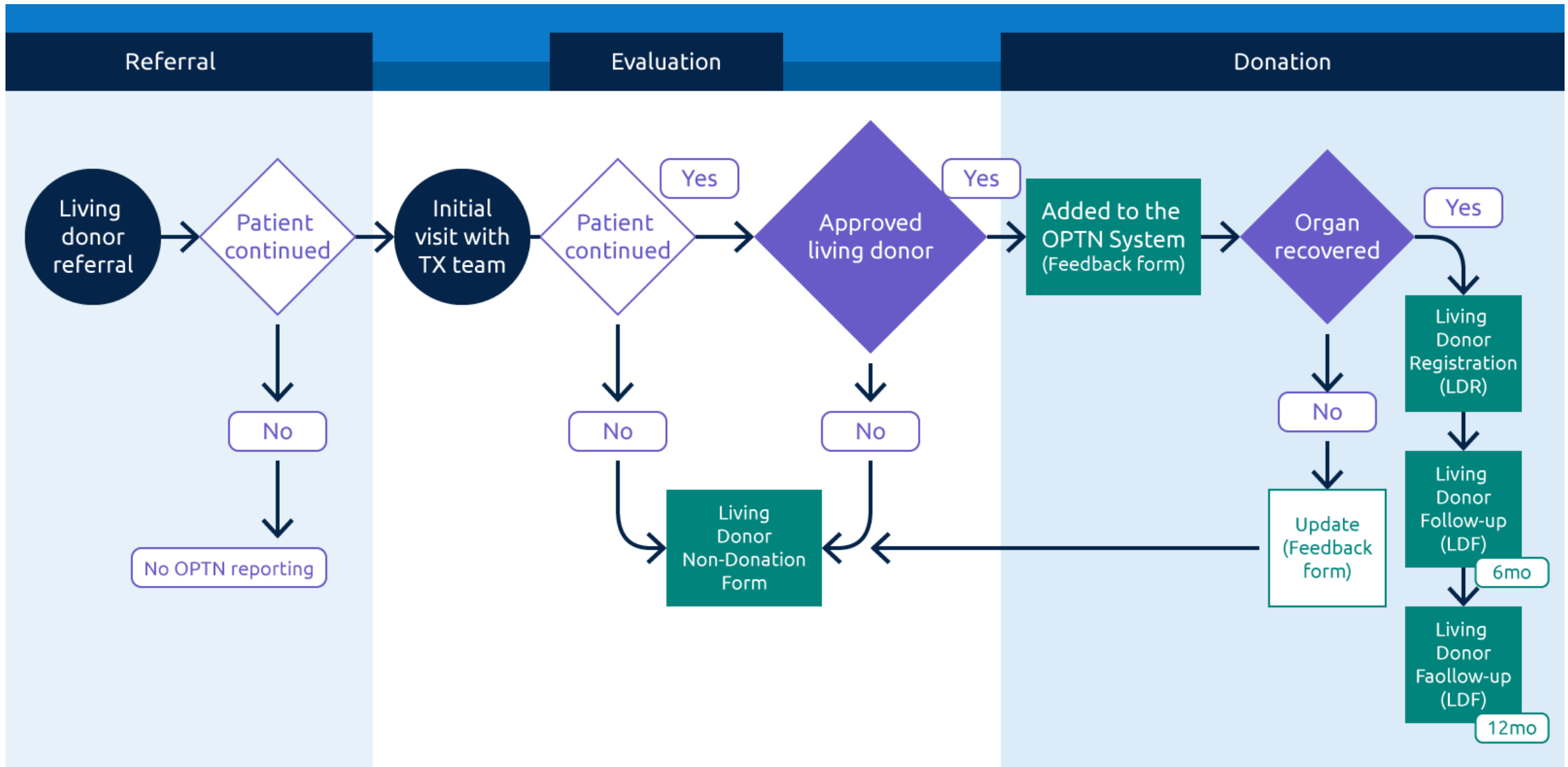
# Proposal

- Require transplant programs to submit new OPTN data collection on potential living donors who met in person with the transplant team, but did not donate. Data collected includes: demographic, clinical, and donation decision information.
- To understand why some potential living donors do not proceed with donation
- Remove the two-year living donor follow-up requirement from the OPTN and transfer voluntary follow-up to the SRTR, which follows the living donor and potential living donors long term
- To allow for annual follow up beyond the current OPTN requirements of 6 months, 1 year, and 2 years

# Proposal

- Recommend minimal additions and modifications of data elements on the Living Donor Feedback, Living Donor Registration, and Living Donor Follow-up data collection instruments
  - To align with new data to be collected on potential living donors who did not donate
- Change OPTN policy language to distinguish between living donors and potential living donors and incorporate data submission requirements for new data to be collected
  - To require the Living Donor Non-Donation form be submitted 90 days after decision not to donate

# OPTN Living Donation Collection: Proposed Future State



# Member Actions

- The new Living Donor Non-Donation form would be required for all potential living donors who meet in person with a transplant team member and who do not donate at any point after this meeting occurs
  - Start date for this requirement would be any in person meeting that occurs from the day of policy implementation onward
- Recovery hospitals will continue to submit required existing forms for living donors, but would no longer be required to complete the two-year required follow-up for living donors whose 2<sup>nd</sup> anniversary of recovery falls after the day of policy implementation

# What do you think?

- 1) *Living Donor Non-Donation Form*: Do the proposed data fields support the goals of this project?
- 2) *Reporting Requirements*: Is the 90-day turnaround an appropriate timeframe to submit the Living Donor Non-Donation form?
- 3) Any concerns related to barriers to donation or long-term outcomes not addressed among members of the living donor community?
- 4) Do you endorse removal of the current two-year required OPTN follow-up data collection and submission for living donors, to be changed to a voluntary annual follow-up administered by the SRTR (centers are still encouraged to follow up with patients, but no data submission would be required)? Do you endorse the SRTR contacting the patient directly?

# Provide Feedback

Submit public comments on the OPTN website:

- August 27 – October 1
- **[optn.transplant.hrsa.gov](https://optn.transplant.hrsa.gov)**

