

Concepts for a Collaborative Approach to Living Donor Data Collection

OPTN Living Donor Committee

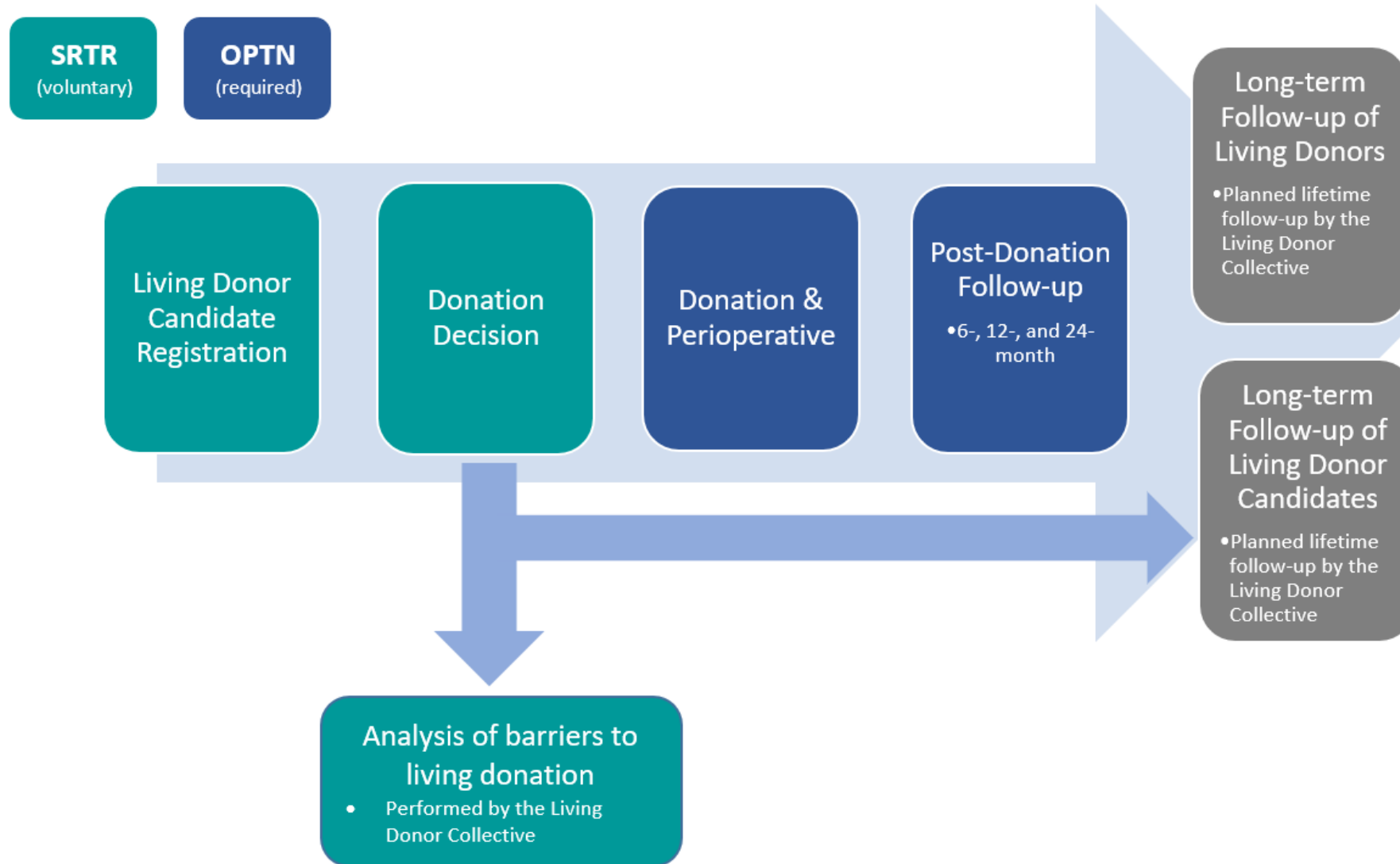
Living Donor Data Collection Overview

- **OPTN living donor data collection**
 - Transplant programs are required to:
 - Register living donors, submit perioperative data, and submit follow-up data at 6-, 12-, and 24- months post-donation
 - Meet specific reporting thresholds for living kidney and liver donor follow-up defined in policy for donor status, clinical information, and laboratory data
- **SRTR living donor data collection**
 - Living Donor Collective – a living donor registry in which transplant programs voluntarily participate
 - Participating transplant programs register individuals evaluated for living donation that do not proceed to donation (living donor candidates)
 - Seeks to examine access and long-term outcomes attributable to living donation by following up directly with living donor candidates and living donors long-term

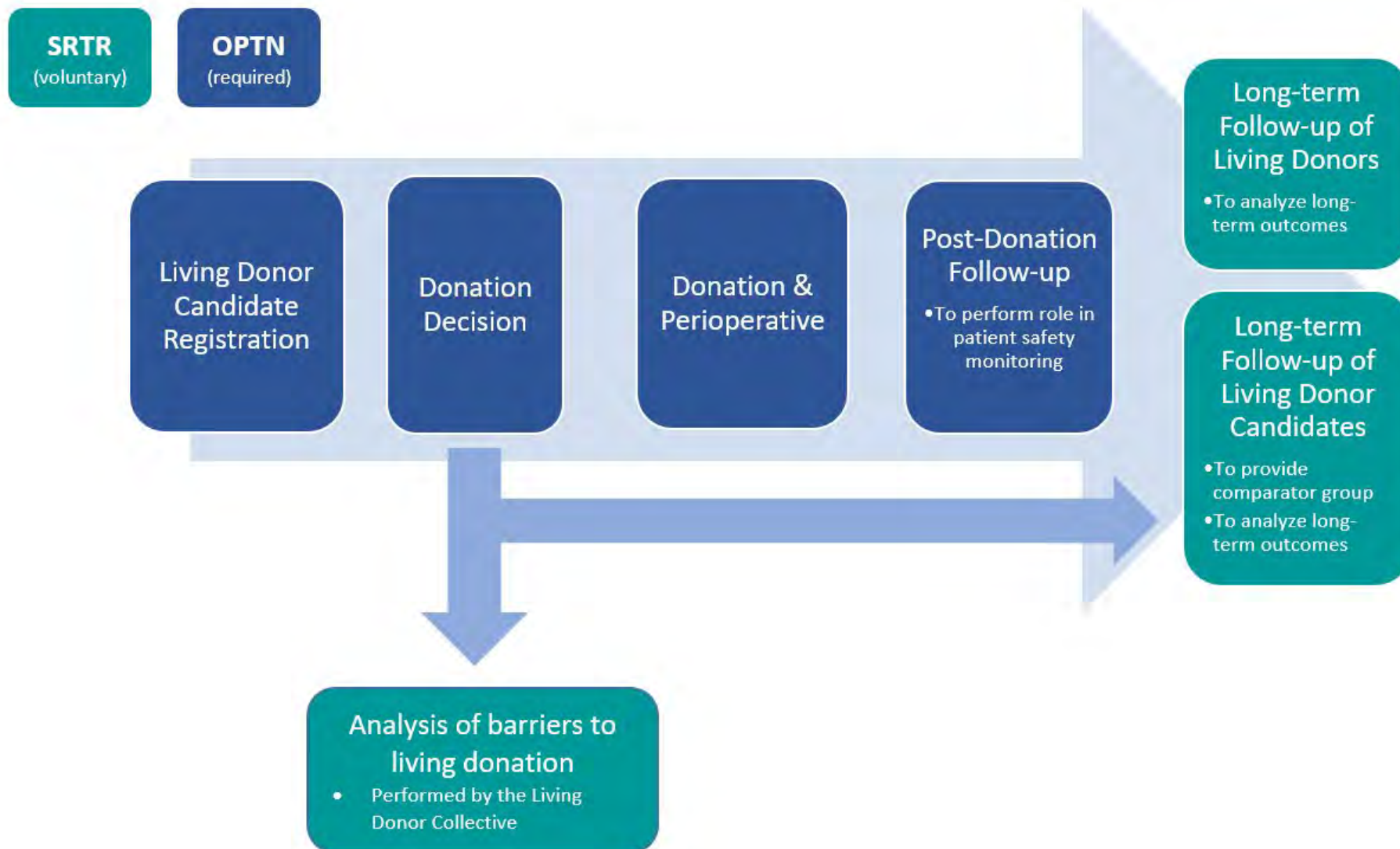
Purpose of Concept Paper

- Detail a collaborative approach to living donor data collection by the OPTN and the SRTR Living Donor Collective
 - To support data collection that fills the current gaps in knowledge related to the long-term outcomes of living donors and barriers to living donation
- Update on progress of OPTN living donor data element granular review
- Seek community feedback

Current State: Living Donor Data Collection



Concept: Living Donor Data Collection Collaboration



Concept: OPTN's Role

Living Donor Candidate

Establishes an appropriate comparator group in order to assess long-term outcomes

Donation Decision

Allows for analyses on reasons that some individuals do not proceed with living donation

Concept: OPTN's Role

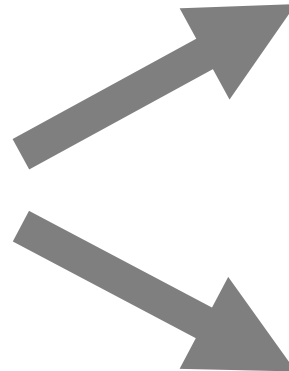
- Living donor candidate: An individual who was seen at a transplant program for evaluation
 - This is the point in time that the Committee proposes for data collection to begin
- Estimations for data that would be shifted upstream:

General
Information

Concept: SRTR's role

Long-term Follow-up

- Annual follow-up for a lifetime
- Patient-centered approach
- Self-reported data via surveys (email, phone, mail)
- Data linkages



Living Donor Candidates

An appropriate comparator group to analyze long-term outcomes attributable to living donation

Living Donors

Analyze long-term outcomes attributable to living donation

Member Actions

- There are no necessary member actions
- Proposed future state is conceptual
- Feedback is welcomed

Next Steps

- Seek community feedback
- Continue to review and solicit feedback of current OPTN data
- Project development will be determined based on community feedback

What do you think?

- Input from living donors
 - What are living donors' preferences on how to engage with long-term follow-up?
 - What data do potential living donors need to inform decision-making and post-donation health care?
- Input on definition/terminology
 - *Is living donor candidate* the correct term? Is the proposed definition appropriate?
 - How do living donor programs define *evaluation*?
- Input on data collection
 - What is the minimum amount of data necessary to collect on living donor candidates? What are the specific necessary data elements?
 - What recommendations do transplant coordinators have on updates to OPTN living donor data collection forms?
- Input on concepts
 - How do living donor programs recommend operationalizing data collection on living donor candidates and donation decision to reduce burden?