OPTN Living Donor Committee
Meeting Summary
August 12, 2020
Conference Call

Heather Hunt, JD, Chair
Titte Srinivas, MD, Vice Chair

Introduction

The Living Donor Committee (the Committee) met via Citrix GoToMeeting teleconference on 08/12/2020 to discuss the following agenda items:

1. Public Comment Update
2. Data Process and Q&A
3. New Project Discussion
4. Cross-Committee Update

The following is a summary of the Committee's discussions.

1. Public Comment Update

The Committee received an update on the Summer 2020 Public Comment period.

Summary of discussion:

Public Comment began August 4 and ends October 1. Regional meetings begin August 19.

Next steps:

Committee members received a survey to determine whether late Fall in-person committee meetings should become virtual. Results will be announced.

2. Data Process and Q&A

The Committee received an update about the Data Advisory Committee (DAC) and data process.

Summary of discussion:

Staff reviewed contract requirements which outline DAC's new role and scope of work. As an OPTN operating committee, DAC partners with other committees throughout the development of projects to endorse proposed data collection efforts. DAC ensures data collection proposals align with the OPTN Data Collection Principles and provides recommendations on improving the completeness, accuracy, and timeliness of proposed data collection.

Staff explained that data collection instruments must receive Office of Management and Budget (OMB) approval by the end of the contract period. Currently, TIEDI forms, VCA data collection, and membership applications are OMB approved. Data collection proposals, approved by the Board of Directors, which address OMB approved forms would have delay in implementation because it requires an additional step of receiving OMB approval.

A member asked for clarification about linking to other data sources. Staff explained that there is a contract task that recommends finding outside data sources which complement the OPTN data set

rather than sponsoring a project that would introduce additional data collection measures. This is to reduce instances of entering the same information multiple times.

3. New Project Discussion

The Committee reviewed potential project ideas.

Summary of discussion:

Potential project ideas:

- Evaluate exclusion criteria in living donor policy
- Living donation in multi-organ transplant
- Optimization of living donor follow-up (LDF) form

Staff explained that optimization of the LDF form would require a complete review of the form. A member asked when the last time the LDF was evaluated. Staff will check.

Another member expressed interest in the living donation in multi-organ transplant project idea. The member stated the need to better understand the processes related to each project idea in order to make a decision. A member asked how often is living donation in multi-organ transplant done. The Chair responded that research could be presented to better understand the scope.

Next steps:

The Committee will continue discussing project ideas.

4. Cross-Committee Update

A member updated the Committee on the Revise U.S. Public Health Service (PHS) Increased Risk Criteria Workgroup (the Workgroup).

Summary of discussion:

A member on the Workgroup stated, relevant to living donation, the Centers for Disease Control and Prevention (CDC) is recommending storing of living donor blood samples for ten years after donation. Another member mentioned there are changes to the risk criteria which creates modifications to how patients are counseled and how to receive informed consent.

Several members thought ten-year storage for living donor blood samples was too long. Another member stated that the cost for storing blood samples will not change due to expanded duration of storage. A member responded the cost of storage might not be a burden, but the space needed for expanded storage will become a significant issue.

HRSA staff stated that it is important to have access to blood samples from the time of transplant because of possible changes to the living donor post-transplant may result in different blood samples.

Another member asked whether there are other instances of collecting and storing samples for clinical purposes. HRSA staff responded that deceased donor samples are stored and this proposal seeks to increase storage time for living donations to improve patient safety.

A member asked the frequency of instances where there is a NAT negative test, then later found there was transmission of a virus and an inability to track down the donor. HRSA staff responded this is not common, but when it does happen there is cause for concern.

Another member expressed concerns regarding security of the storage of samples because of the genetic material they contain.

A member asked, if a concern arises and there is a need to test a stored blood sample, whose responsibility is it to determine that decision to test the sample. HRSA staff responded those details will need to be worked out.

Next steps:

The Committee will continue discussion on the September 9 call.

Upcoming Meetings

- September 9, 2020 (teleconference)
- October 14, 2020 (teleconference)

Attendance

- **Committee Members**
  - Carol Hay
  - Carolyn Light
  - Jessica Spiers
  - Katey Hellickson
  - Mark Payson
  - Mary Beth Stephens
  - Nahel Elias
  - Omar Garriott
  - Roberto Hernandez
  - Titte Srinivas
  - Steve Gonzalez
  - Vineeta Kumar
  - Heather Hunt
  - Pooja Singh
- **HRSA Representatives**
  - Marilyn Levi
  - Raelene Skerda
- **SRTR Staff**
  - Michael Conboy
  - Bertram Kasiske
- **UNOS Staff**
  - Kim Uccellini
  - Leah Slife
  - Lindsay Larkin
  - Matt Cafarella
  - Meghan McDermott
  - Sarah Booker
  - Tina Rhoades