

**OPTN Living Donor Committee  
Meeting Summary  
October 17, 2022  
Chicago, IL  
Conference Call**

**Nahel Elias, MD, Chair  
Steve Gonzalez, MD, Vice Chair**

## **Introduction**

The OPTN Living Donor Committee (the Committee) met via Citrix GoTo Meeting teleconference on 10/17/2022 to discuss the following agenda items:

1. National Academies on Science, Engineering, and Medicine (NASEM) Report
2. Living Donor Data Collection Report
3. Next Steps: Living Donor Data Collection
4. Living Donor Data Element Review
5. Open Forum

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

### **1. National Academies on Science, Engineering, and Medicine (NASEM) Report**

The Committee discussed recommendations from the National Academies on Science, Engineering, and Medicine (NASEM) report and brainstormed potential project ideas for the OPTN.

#### Summary of discussion:

The Vice Chair stated that the NASEM report highlighted areas for improving social vulnerability and health disparities. The Vice Chair stated that this highlighted area aligns with the ongoing discussions regarding living donor follow-up that the Committee has been working on. The Vice Chair stated the long-term data on living donor outcomes may offer opportunities to analyze barriers to living donation, especially for vulnerable populations. The Vice Chair suggested that the Committee may seek to review data regarding vulnerable populations in the context of access to living donation and long-term living donor outcomes.

A member stated they were in disagreement with the NASEM report suggestion to remove pre-dialysis wait time. The member stated that preemptive transplants prior to dialysis are better than having a transplant after having been on dialysis for several years.

The Chair suggested that the Committee may update living donation resources, specifically resources related to finding a living donor, on the OPTN website to address minority populations. The Chair stated that the Committee should work to help all populations access living donation.

Another member stated that socioeconomic factors are one of the biggest barriers for individuals to become a living donor. The member noted that National Living Donor Assistance Center (NLDAC) covers up to four weeks for some individuals in need. The member stated that four week coverage still leaves a gap in post-donation recovery time for the living donor. The member added that NLDAC coverage is also

linked to the recipient's income, which lends to other issues. The member suggested the Committee make a formal recommendation regarding the barriers in living donation due to socioeconomic status. The member stated that Committee work on this topic may help address some disparities within living donation.

A member stated that OPTN data collection on race and ethnicity needs to be standardized, especially for living donors. The member stated that minority populations are not all responsive to the same approach for securing a living donor, due to the variety of cultural backgrounds. The member stated that different factors need to be considered based upon the specific culture. The member explained that Micronesian populations do not have a word in their language for kidney, so trying to educate that population about kidney disease, and living donation needs completely different resources than another minority population. The member stated that resources cannot be allocated until the data is collected in order to understand the problem. The member stated that standardized race data could be correlated with socioeconomic factors to understand potential barriers in access to living donation.

Another member noted that a number of NASEM's recommendations could be extended to living donation:

- Recommendation 1: Develop national performance goals for the U.S. organ transplantation system
  - E.g. Include living donation-specific performance goals
- Recommendation 3: Achieve equity in the U.S. organ transplantation system in the next five years
  - E.g. culturally targeting educational campaigns regarding living donation
- Recommendation 8: Modernize the information technology infrastructure and data collection for deceased donor organ procurement, allocation, distribution, and transplantation
  - E.g. address any opportunities for improving technology infrastructure as they relate to living donation
- Recommendation 12: Create a dashboard of standardized metrics to track performance and evaluate results in the U.S. organ transplantation system
  - E.g. Create living donation-specific metrics such as tracking total wait time from initial evaluation of the potential living donor to donation surgery
- Recommendation 13: Embed continuous quality improvement efforts across the fabric of the U.S. organ transplantation system
  - E.g. Share best practices for living donation across the nation
- Recommendation 14: Align reimbursement and programs with desired behaviors and outcomes
  - E.g. Education for fully understanding living donation options

A member stated that ensuring that living donation surgery is cost neutral for the living donor is important. The member stated that financial coverage depends on the recipient's financial state. The member stated this was originally intended to ensure that the disparity between the recipient and living donor finances was not so great that the living donor was coerced. The member stated that this intention may no longer be necessary in the current state of living donation and suggested the Committee work to address this issue.

A member stated that there are several steps in the living donation process, and each step has its own unique barriers. The member stated that social vulnerability index measures are correlated with many of these barriers. The member suggested the Committee review data to understand the problem. The member stated if data is not available, the Committee should discuss how to create systems that provide that information and support access to living donation.

The member stated that living donor safety is the most important. The member added that the focus on living donor safety sometimes negates the importance of potential living donor's desire to donate. A member agreed and stated that the risk of declining a potential living donor is often not considered during evaluation processes. The member stated there is some literature that analyzed potential living donors who were declined and the negative impact on their life, emotional state, social state, and financial state. The member stated that the SRTR's Living Donor Collective will collect data on potential living donors who do not go on to donate. The member suggested that more data could be collected to inform what the impact of declining a potential living donor is. Another member asked whether declining potential living donors is out of concern for the individual or due to transplant program regulations. A member responded that the intent for declining potential living donors is often grounded in the concept of "do no harm". The member stated that, in their experience, if there is not a clear answer to approve a potential living donor, then the potential living donor is declined. The member stated that may not always be the correct answer and transplant teams should become more intellectually and emotionally honest with themselves when handling these types of situations.

Another member agreed and stated that cultural differences may impact approving or declining a potential living donor. The member stated that having more data to understand cultural differences would be helpful in the context of living donation. A member stated that patient navigators and community health workers are important staff because they are able to explain cultural differences and awaken the understanding across populations. The member stated that pathways need to be created to ensure that patient navigators or community health workers are incorporated into transplant teams.

Another member stated their transplant program implemented interventions to increase the number of living donors. The member noted that the number of potential living donors increased, but the number that moved forward for donation surgery did not. The member added that led the transplant program to add patient navigators to help potential living donors through the entire process.

The Vice Chair stated that many of these ideas relate to the need for more data in order to identify barriers, educate communities, and inform policies. The Chair added that this emphasizes the importance of the current data collection project the Committee is working on. The Chair stated that beyond updated data collection, additional tools are needed for the living donation community. The Chair suggested the Committee may develop a workgroup to discuss opportunities to improve living donation equity.

A member asked if the living donor registration (LDR) form collects financial status. It was noted by members that working for income, and zip code are collected.

Another member stated that the Committee should consider whether the OPTN should address some of these issues, or if it is better to afford transplant programs to make individualized decisions that support their local communities. The member cautioned to ensure that living donors are not viewed as organ banks, and living donor safety must remain paramount.

#### Next steps:

The Committee will continue to discuss potential project ideas. These project ideas will be reported by to the OPTN Policy Oversight Committee for further consideration and prioritization.

## **2. Living Donor Data Collection Report**

The Committee continued discussing living donor data collection.

#### Summary of discussion:

The Vice Chair stated that the report to the OPTN Board of Directors should clarify the different roles of the OPTN and SRTR.

An SRTR representative stated that in addition to the ongoing review of data elements, there should be consideration regarding which entity collects specific data elements, and opportunities for collaboration. The SRTR representative requested HRSA input on opportunities for collaboration. A HRSA representative stated that OPTN data collection must go through the policy development process. The HRSA representative stated that the SRTR's Living Donor Collective is collecting data in order to perform analyses on long-term living donor outcomes. The SRTR representative stated that in addition to collecting long-term data, registering potential living donors is a critical part of the program. Another SRTR representative added that these data will help analyze access to living donation. The SRTR representative stated that the Living Donor Collective is currently voluntary participation, and collaboration across organizations is needed to help support increased participation. The SRTR representative stated that the Living Donor Collective is not duplicating the OPTN's role in patient safety.

A member suggested that the report provide details on what policy changes are needed to address solutions related to long-term living donor data collection.

Another member stated that the Committee should figure out solutions that align with the scope of the Committee's role. The member stated that updating the LDR and living donor follow-up (LDF) forms is very important and the Committee should continue reviewing data elements. The member noted that the forms should be updated in a way that if living donor follow-up is ever extended through the OPTN, the data will continue to provide meaningful information. The member stated that the Committee should also discuss streamlining living donor registrations so that there are not multiple registrations that transplant programs perform. The member added that the Committee should also discuss how to ensure appropriate resources for long-term living donor data collection.

An SRTR representative stated that they are exploring whether CMS may consider living donor registration a part of organ acquisition in order to ensure financial coverage.

The Chair emphasized that there are opportunities for the OPTN and SRTR to collaborate, and the OPTN Board of Directors may have specific input on how to move forward. Staff noted that OPTN policy could not mandate participation in a specific registry. A member responded that the Committee can focus on streamlining processes across organizations.

The Vice Chair summarized that the Committee's purview is OPTN data collection and policy. The Chair stated that collecting data on potential living donors is currently out of scope for the OPTN.

Another member noted that there is difficulty in having living donors return to transplant programs for follow-up due to various reasons, such as financial coverage. The member stated that if there are issues in follow-up at two years, how can there be a way to ensure that follow-up at five or ten years would lend to any meaningful data. Another member responded that the Committee may make recommendations on what it will take to ensure living donors follow-up.

An SRTR representative stated the Committee should define what is desirable, what is possible, and what are the barriers. Staff noted that the report outlines the Committee's previous discussions regarding those topics.

*Finding: Living donors should have lifetime follow-up.*

The Vice Chair stated that the OPTN Policy Oversight Committee expressed support for the findings in the Committee's report, especially lifetime follow-up of living donors.

A member suggested the wording should read, “living donors should be followed for their lifetime”. The member suggested this clarification perhaps redistributes the onus of follow-up on transplant professionals, rather than the living donors themselves.

Another member asked who is responsible for laboratory tests and results. The member stated that it does not seem realistic for transplant programs to follow living donors for a lifetime. Staff noted this finding is to highlight consensus of the Committee for the importance of lifetime follow-up, and does not yet address the logistical issues associated with it.

*Finding: There are barriers and burdens associated with transplant programs performing living donor follow-up.*

The Vice Chair stated that the OPTN Policy Oversight Committee also agreed that burden should not be placed on the transplant programs. The Vice Chair agreed that the report summarizes the significant burden already placed on transplant programs, and extending follow-up to five or ten years is very challenging. Another member agreed and added that transplant programs have difficulty with the current six, twelve, and twenty-four month follow-up periods. The member stated that there are a lot of barriers, but the goal should be lifetime follow-up of living donors.

The Chair asked whether transplant program burden is focused on financial aspects. A member responded that burden may include cost and resources. The member stated that transplant programs have multiple responsibilities, and the primary responsibility for living donors is at the time of evaluation and donation. The member stated that more resources are needed to ensure appropriate care for living donor follow-up. A member stated that different sets of resources are needed depending on different scenarios. Another member stated that the report should be clear that the onus for follow-up is not being placed on those who do not have appropriate resources to collect the data long-term.

The Committee agreed an additional section should be added to the report to highlight that resource constraints will remain a concern no matter who performs living donor follow-up.

*Finding: A registry may be better situated to perform long-term living donor follow-up.*

A member expressed concern that report outlines reasons that transplant programs may not be the best entity for extended follow-up of living donors, yet it is beyond the scope of Committee to mandate participation in a registry. Staff noted that the report is an important touchstone with the OPTN Board of Directors to ensure alignment of goals, then the Committee can work with the community to find collaborative opportunities to work towards the end goal.

Another member noted that they would seek the opportunity to participate in a long-term follow-up registry for living donors. The member stated that engaging via a smart phone application would be beneficial. The member suggested that the Committee consider a way to be able to recommend to living donors to participate in a registry. A member agreed that there are increased ways to engage living donors via smart phone applications and text messaging. The member added it will be important to consider how to engage previous living donors.

*Finding: There are opportunities for increased efficiencies and better integration across organizations that support the transplant community.*

The Vice Chair stated that considering current technology is important. The Vice Chair explained that technology may evolve faster than policy, so any policy language should remain broad enough to allow for technological innovations.

An SRTR representative stated that collaboration between the OPTN and SRTR on the Living Donor Collective will be vital.

A member noted that as a living donor it has been difficult for them to find a primary care physician that provides appropriate follow-up health care for living donors. An SRTR representative stated that the Living Donor Collective is bringing together living donors in order to have more feedback on post-donation care.

Next steps:

The Committee will continue discussions in order to finalize a report to the OPTN Board of Directors.

**3. Next Steps: Living Donor Data Collection**

The Committee discussed how to engage the broader transplant community regarding their discussions on living donor data collection and follow-up.

Summary of discussion:

The Vice Chair stated that a regional meeting update on behalf of the Committee would be a good opportunity to engage with the transplant community and receive feedback.

The Vice Chair asked what resources can the Committee utilize to engage living donors. A member noted there is a private Facebook group for living donors. The member noted this would require permission from the hosts of the group. The member also noted that Transplant Games of America has recently begun to involve living donors. The member stated there may opportunity to present at that forum, depending on where the Committee is with the project.

The Visiting Board Member emphasized that knowing the community is critical for outreach. The Visiting Board Member stated the when appropriate community outreach is done, it will open up various avenues of connections.

A member noted that organizations such as National Kidney Foundation (NKF), American Society of Transplantation (AST), and American Associate for the Study of Liver Diseases (AASLD), who are engaged with living liver and kidney evaluation could help with living donor outreach.

Another member suggested the Committee should consider how to conduct outreach to living donors who are unengaged in the transplant system. The member stated Federally Qualified Health Center (FQHC) and the National Association of Community Health Centers (NACHC) may be important stakeholders. The member added that each state has a primary care association which generally manages the network of community safety net health providers.

A member suggested contacting local organ procurement organizations (OPOs). The member stated that OPOs often advocate for living donors and may have additional resources to share.

Another member noted the National Kidney Donor Organization may be helpful. A member stated that National Kidney Registry (NKR) may have one of the largest living donor databases. A HRSA representative suggested NLDAC as a potential stakeholder.

A member noted there are many local non-profit organizations that work with living donors. The member stated these non-profits often have community-based networks that may be beneficial to engage. The member added that additional resources will be needed to develop a project such as an app. The member suggested that outreach could include asking stakeholder organizations to contribute resources.

Another member stated that the Committee should ask identified stakeholders for feedback on how to increase resources that will aid in living donor follow-up. The member stated that there is consensus that long-term follow-up is needed, and there needs to be focus on how to achieve that goal by way of securing resources to create solutions.

The Chair stated that the living donor community should be asked to give their input on what they wish they knew before they donated. A member agreed and added that living donors should also be asked what they wish to know now. The member stated that a living donor ten years post-donation will likely seek different information than a living donor one year post-donation.

The member stated that there is a lack of education on how to provide post-donation care to living donors from the general medical community. The member stated that living donors should be equipped with information to help them seek appropriate care post-donation. The member stated that medical professionals outside of the transplant community should be educated on living donation and post-donation health care. The member noted that patients with very rare disease will present informational resources to providers in order to ensure they are receiving appropriate care. The member explained that living donors may seek similar informational resources, such as one-pagers, to provide to health care professionals.

Another member stated that the Committee should seek feedback regarding living donor reported barriers to follow-up.

A member noted that an app for living donors will also have barriers due to various levels of technological adeptness as well as access to the internet and computers.

Another member stated that when the Committee is seeking feedback from living donors it should be noted that the feedback will help inform future living donors and seek to increase rates of follow-up. The member stated that the Committee should explain why they are requesting feedback in order to ensure the feedback lends to a solution.

#### Next steps:

The Committee will continue to plan how to engage the transplant community and living donors in the next phases of this project.

#### **4. Living Donor Data Collection Review**

The Committee reviewed data elements on the OPTN L LDF form.

#### Summary of discussion:

A member stated that the *cause of death* data element is very important. The member stated that the data used from that element should be communicated appropriately. The member explained that prior living donors may die due to other reasons that are not related to the donation. The Chair agreed and stated that there are response options that indicate accidental causes of death that are not related to the donation event. The member stated that it should be made clear to potential living donors that there are rare events of death during the procedure, however the death is not related to living with one kidney. The member added it may be beneficial to analyze data to understand why the rare event of death occurs during donation.

#### *Data Element: ER or urgent care visit related to donation since last follow-up (LDF)*

A member stated it would be important to understand whether the ER or urgent care visit was related to the donation or not. The member suggested a response option should be added in which the transplant program could detail more information on the reason for the ER or urgent care visit. The member stated it may be a subjective determination whether the ER or urgent care visit was related to the donation event or not. The member suggested the LDF forms should capture all complication data related to the donation event. The Chair stated that an open text field may not be useful data. The Chair

noted that this data element also capture first readmission date, and reason for first readmission. The Chair stated this additional data would provide more information.

Another member noted that it is better to provide response options rather than adding an open text field. The member stated that open text fields are very difficult to analyze.

Another member asked if it is important to capture data on ER or urgent care visits that are unrelated to donation.

A member asked for the response rate of 'unknown' for this data field. Staff noted that entry of 'unknown' intends to capture that the transplant program does not know if the living donor has been to the ER or urgent care. Another member suggested an additional response option to capture there was an ER or urgent care visit but it is unknown if the visit was related to the donation.

A member stated this data element is redundant and likely captures a lot of data that is not relevant to the donation. The member stated that more specific data will be capture in the complication-related data elements. The member noted that data on hemorrhaging post-donation would be useful to collect.

The Committee will continue to discuss this data element after review of the other complication-related data elements on the LDF form.

*Data Element: Has the donor been readmitted since*

A member asked if the data element should clarify that it is capturing data on if the living donor has been readmitted since the last form submission.

The Chair asked what the "st" means on the data element. Staff responded that is the *status* field. Staff explained that if a transplant program is unable to answer a question on the form, the *status* field allows for the transplant program to indicate *missing, unknown, not available, or not done*. A member asked whether those response options remain relevant as they are very similar answers.

Another member asked for the response rate of 'unknown'. Staff noted that in 2019, it was 2.5 percent for living kidney donors, and 1.3 percent for living liver donors. The member suggested removing *unknown* as a response option. Staff noted that *unknown* is a necessary response option in order to have accurate data entry, even if *unknown* is not useful data.

A member suggested that this data element should specify whether the readmission was related to the donation or not. The Vice Chair suggested a drop down menu to indicate that the readmission was related or unrelated to the donation. The Vice Chair stated that collecting the date of readmission may only be relevant if the readmission is related to the donation. The Vice Chair stated that the date is important to analyze specific time frames of readmissions and complications. A member agreed that there are certain complications that are more frequent in the first thirty days after donation. The member explained being able to analyze readmissions and complications by specific dates helps with discussing overall risk with living donors.

Another member asked whether living donor events required to be reported per *Policy 18.5: Reporting of Living Donor Events* are also reported on the LDR or LDF forms. The member added that data that is reported to the patient safety portal should also be communicated to potential living donors when discussing the risks of the donation event.

*Data Element: Regularly administered dialysis as an ESRD patient*

A member suggested this data element may be beneficial to capture for all living donors, not just living kidney donors.



Another member suggested the section this data element is in may need to be restructured for a better flow.

A member suggested that data should be collected on organ failure related to the organ that was donated. The Chair stated that it may be important to capture kidney failure for living kidney, liver, and VCA donors. A member suggested that *other complications* data element should appear for all living donors. The member stated that if the living donor experiences other complications unrelated to the organ that was donated, the *other complications* section would be beneficial.

#### *Data Element: Kidney complications*

A member noted that it would be important to know whether the living donor was transplanted. Staff responded that if a living donor is added to the waitlist, there is ability to track whether they receive a transplant.

Another member asked how complications related data would be filled out for individuals who donated a kidney and a liver. The Chair noted that the LDF forms would be specific to the donation event for each organ. The Chair added that since the LDF forms are required out to 24 months, and an individual donating twice is a rare event, that the forms may not need to be modified.

## **5. Open Forum**

A member suggested reviewing social determinants of health data for living donors. The member suggested a third party could be utilized to analyze social determinants of health data on a small community of living donor.

Another member suggested the Committee consider a project to address the gender disparity in living donation. The member stated that about a third of the living donors are male, while two-thirds of the living donors are female. The member stated the Committee could identify the barriers and perhaps recommend specialized outreach in order to reduce the gender disparity of living donors.

A member noted that the onus of the burden are usually placed more on females as caregivers opposed to males. The Chair asked whether males are generally less health than females, or do males not step forward as living donors as often as females. Another member stated that if the barriers for males as living donors could be identified, then solutions could be addressed just as with other health equity issues.

A member stated that it needs to be emphasized that living donors need their own caregivers post-donation.

Another member stated that a lot of education will be needed regarding gender and gender identity before working on a project to understand the gender disparity in living donation.

Another member noted that there may be health research that already exists regarding gender disparities. The member suggested reviewing this literature to analyze what the health system already knows about gender disparities to see what interventions may be applicable.

The Vice Chair suggested the Committee create guidance for living donors to provide to their primary care providers in order to receive appropriate health care post-donation. The Vice Chair stated the guidance could provide overall best practices and then organ-specific guidance. Several members agreed with this suggestion. A member suggested creating a small card with relevant information for living donors to carry. Another member noted that this type of guidance would be beneficial to living donors and providers. The Vice Chair noted that this project idea aligns with the Committee's intention to educate and focus on long-term living donor care.

A member stated that education regarding the recently implemented OPTN policy on race-neutral eGFR calculations will be needed for living donors.

**Upcoming Meetings**

- November 9, 2022 (teleconference)
- December 14, 2022 (teleconference)

## Attendance

- **Committee Members**
  - Alexandra Shingina
  - Aneesha Shetty
  - Camille Rockett
  - Doug Penrod
  - Erik Lum
  - Henkie Tan
  - Hoylan Fernandez
  - Katey Hellickson
  - Mark Payson
  - Mary Beth Stephens
  - Nahel Elias
  - Nancy Marlin
  - Stevan Gonzalez
  - Tyler Baldes
  - Vineeta Kumar
  - Yee Lee Cheah
- **HRSA Staff**
  - Arjun Naik
  - Mesmin Germain
  - Vanessa Arriola
- **SRTR Staff**
  - Bert Kasiske
  - Katie Siegert
  - Krista Lentine
- **UNOS Staff**
  - Carol Covington
  - Carson Yost
  - Cole Fox
  - Jen Wainright
  - Kim Uccellini
  - Krissy Laurie
  - Lauren Motley
  - Lindsay Larkin
  - Meghan McDermott
  - Tina Rhoads
  - Sam Weiss
- **Other Attendees**
  - Christopher Woody