

SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

March 22, 2023, 1:30 PM – 3:00 PM CDT

Voting Members:

Ameen Tabatabai, (Co-chair), liver recipient
Dale Rogers, kidney recipient
David Rodriguez, kidney and liver recipient
Rolanda Schmidt, PhD, deceased donor family member
Katie McKee, living kidney donor
Teresa Barnes, lung recipient family member
Stephanie Mullet, pediatric liver family member

Not in Attendance:

Amy Silverstein, heart recipient
Christopher Yanakos, living liver donor

Ex-Officio Members:

Allyson Hart, MD, MS (Co-chair)
Shannon Dunne, JD (HRSA)

SRTR Staff

Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Amy Ketterer, SMS
Tonya Eberhard
Ryutaro Hirose, MD
Mona Shater, MA
Cory Schaffhausen, PhD

Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. Dr. Jon Snyder informed members that the Health Resources and Services Administration (HRSA) announced an Organ Procurement and Transplantation Network (OPTN) modernization initiative in the upcoming years to improve the transplant system and make information more accessible for patients, their families, and transplant professionals. Ms. Shannon Dunne from HRSA added that the multifaceted effort aims to increase equity in terms of access to transplant, and improve transparency for patients and families navigating the system.

Mr. Ameen Tabatabai reviewed the agenda and proceeded with the first item.

Update: Task 5 – Finalizing the “what”

Mr. Tabatabai said that the “what” (eg, metrics and information) of the Task 5 recommendations was the main focus of finalization. Dr. Hart reminded members that Task 5 is a 5-year process, which is now in the create-and-report-metrics phase, or pairing down prioritized metrics that were identified during the consensus conference. These chosen metrics can now start to be developed further. Dr. Hart also reminded members that these recommendations were narrowed down from 160 to 10 through survey input from PFAS, HSRA, and the SRTR Review Committee (SRC).

Feedback: Task 5 – Dissemination to patients, donors, and families

Dr. Hart said disseminating Task 5 information for professionals mostly consisted of papers and conference presentations. These papers include the consensus conference meeting report, the

piece on use of the term “discard” (already available online), and reports that will be published soon, including reports on focus groups done before the conference and a patient family donor perspective piece on the conference.

Mr. Tabatabai asked PFAS for feedback—specifically from a patient, donor, and family perspective—on what the community should know about Task 5 (identifying metrics and information that inform decision-making by critical audiences) and how this information should be disseminated, in particular to patients or other individuals who are not already engaged. He also brought up the possibility of disseminating Task 5 information to facilities (such as hospitals) that could distribute standard protocols or packages of this transplant information to patients; or, transplant groups with this Task 5 information that could be deployed out to a given number of hospitals to pilot the program. Mr. Tabatabai emphasized the importance of sharing Task 5 information in different transplant stages, including diagnosis, evaluation, pretransplant, and posttransplant.

Ms. Teresa Barnes pointed out there was no cohesive system for lung transplant, which may hinder attempts to use standard protocols in centers to distribute information. Because patients may be looking at SRTR data before being entered into the transplant system, they would need to be reached earlier through patient organizations and transplant advocates. Mr. Dale Rogers said patients need to be reached as early as possible (prior to entering the transplant system), so SRTR data can be used to the fullest, like in helping make decisions about where to get evaluated. Mr. David Rodriguez agreed.

Dr. Cory Schaffhausen said general dissemination may be easier in the coming year with the creation of the new patient-centered website. He asked the committee what format(s) would be appropriate to distribute information (eg, webpage, printable flyer). Ms. Barnes suggested that SRTR co-brand educational materials with other organizations for patient groups to use, and Mr. Rodriguez also recommended social media to help circulate this information. Dr. Snyder said jointly branded material was possible and already previously discussed, particularly with transplant administrators on creating a targeted document to be shared among patients. Ms. Mona Shater agreed a collaborative effort for educational material was a practical approach for the SRTR communications team.

Dr. Ryutaro Hirose pointed out that patients face many constraints when choosing a transplant center, and it may be useful for SRTR to help patients understand all the different constraints in the evaluation and referral process. Mr. Rogers agreed, saying that creating an awareness of SRTR data for patients would be beneficial. Dr. Hart brought the discussion back to what information should be available to patients on broadly disseminated transplant information. Ms. Stephanie Mullet suggested taking a humanized approach to data, focusing on a real-world application to personal experiences. In terms of dispersing information, Mr. Tabatabai proposed focusing on key points where transplant questions start to arise, such as the referral process, and inserting material (eg, infographics, data points, SRTR website link) into these areas.

Members discussed how their primary focus was more on spreading information about SRTR, as opposed to only Task 5. Mr. Tabatabai thought this shift in focus was appropriate, since patients will not be familiar with Task 5 unless they are familiar with SRTR first. Ms. Dunne agreed it may be beneficial to step back from the consensus conference and its recommendations to sharing about what SRTR is in general. Mr. Rogers proposed creating a “how to” video for the SRTR website that

different advocacy groups could distribute across their own platforms to draw attention to the SRTR website, and gain information on patient activity. Ms. Shater agreed that using more channels to promote content was a good idea. As SRTR already has an introduction video, other videos, and additional content, it was important to use additional channels to disseminate the information.

Members also discussed partnering with organizations to spread information—Ms. Barnes said this could be done at virtual patient webinars through slides and social channels, and Mr. Rodriguez recommended flyers and brochures at in-person patient events. Mr. Tabatabai emphasized that promoting SRTR as a data service for companies and organizations could help educate people about SRTR. Ms. Shater stated a “What is SRTR” brochure was a feasible idea that could be completed by mid-May. She also suggested that committee members could be ambassadors to help disperse the information. Dr. Hart made note of starting a list of patient donor family advocacy organizations and other contacts that may benefit from receiving the brochures. Ms. Katie McKee suggested making the brochure a conduit to the SRTR website, where users could scan a code to get to the website for more information. Dr. Snyder said this method would make it easier to maintain the brochure.

Mr. Tabatabai brought attention to the two paths for information distribution, being 1) transplant centers and hospitals giving information to the patient, and 2) SRTR directly delivering information to the patient. He asked if one method was better than the other, and Dr. Snyder said both options were effective and reasonable. Dr. Snyder thought a bigger challenge was reaching patients at the critical moments when they are just engaging with the system. Mr. Tabatabai agreed, and mentioned the importance of using events that happen in the transplant community to spread information, such as the Transplant Games of America.

Moving from “what” to “how”: Feedback on how these metrics would be helpful to patients, donors, and families

First, Dr. Hart noted that living donor metrics will be addressed by a Living Donor Advisory Committee, specific to the Living Donor Collective project. Dr. Hart began reviewing the 10 prioritized metrics, asking what information should be included for each. The first was A.1) providing personalized predicted waiting times. Dr. Hart said this metric was difficult, as predicted waiting times are not given due to inaccurate statistical calculations and misinterpreted outcomes. Dr. Snyder said this was a challenging concept, as waiting time is affected by allocation policies and how organs are distributed nationally. Additionally, many factors go into waitlist time, including what patient characteristics would make waiting times shorter or longer. He asked members what they thought were ideal ways for waiting times to be presented.

Ms. Stephanie Mullet preferred data that were more personally tailored to the individual, and nationally targeted at Dr. Snyder’s suggestion. Dr. Hirose pointed out that since patients want personalized predictions on which centers will list and transplant someone like them, providing broad strokes like average waiting time of an average person at an average center nationally may not be helpful. Mr. Rogers suggested regional measures instead of national, which Dr. Snyder said could be done. Mr. Tabatabai thought this was a good idea, as well as making a time range clear and factors that influence time spans understandable. Dr. Hirose commented that the metric only made sense for organs where waiting times dominate the allocation algorithm. Other organs (heart, lung, liver) are more dependent on how acutely ill a patient is. He said it was important to be careful about making sure that patients understand what actually determines how quickly a transplant is

received based on allocation models. The committee agreed personalized predicted waiting times with explanations to help provide context would be beneficial to patients.

Dr. Hart moved on to A.2) Provide survival benefit of transplant versus alternative therapies. Ms. Barnes noted the lack of alternative therapy choices for lung transplants. If a patient was being considered for transplant, that was usually the only choice. Dr. Snyder said for kidneys there was dialysis therapy, as well as a national registry for dialysis. Dr. Hirose thought this metric would have more generic information, as it largely depended on disease process and organ.

Dr. Hart went on to recommendation B.1) Provide data on which centers are most likely to refer, to evaluate, to list, and to perform transplant for a patient like me or my loved one. Dr. Hart said this could be done on the SRTR website through a user entering information about themselves and being led to certain information. A part of this process would involve creating awareness that there are different criteria at different centers. Dr. Hirose said SRTR could also provide data on who has made it onto a transplant list, but not who has not made it onto the list or presented and was denied listing. The denominator of people who went through evaluation and did not get listed is unknown. Dr. Hirose also made the distinction that centers receive referrals, while physicians and dialysis centers make referrals.

Ms. Barnes asked if it was possible to collect data on people who were evaluated. Dr. Hirose said theoretically they could request or require all transplant centers to submit data on everyone referred and evaluated, and if they were listed. He clarified that current government mandated data required to be collected by every transplant center and submitted only starts at the time that candidates are listed. Mr. Rogers brought up potential inaccuracies with referral data collection, and the importance of collecting accurate information for patients. Dr. Snyder said that the definition of being referred was not easy to define and to standardize across programs. Dr. Hirose added that terms need to be defined clearly for transplant centers to collect information accurately and precisely as possible, which was not such an easy task but the best way to do it. Dr. Hirose suggested the possibility of looking at the patient denominator that got evaluated at a center, and how many of them were listed versus not listed, along with characteristics of those patients. This information could be used to analyze how it affects patients' ability to get listed. Mr. Rogers said this information would be useful.

Ms. Barnes asked if the SRTR site lists which centers are in the same "donor pool" in regard to transplant multilisting. Dr. Snyder said the website currently does not have much information on this, but this topic was one of the metric recommendations. He said there was a common misconception among patients that listing transplant centers in the same city is not effective because they are in the same donor pool. However, each center has unique people that make decisions differently in terms of risk and acceptance patterns for organ types, which could affect waiting times. Dr. Snyder thought these nuances should be pointed out to patients.

Closing business

Dr. Hart said the next meeting would continue going through each metric recommendation. With no other business being heard, the meeting concluded. The next meeting date is to be determined.