SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

May 17, 2024, 10:30 AM – 12:00 PM CDT

Voting Members:
Ameen Tabatabai, liver recipient (Co-chair)
Teresa Barnes, lung recipient family member
Stephanie Mullet, pediatric liver family member
Marcus Simon, kidney recipient
Joseph Hillenburg, parent of pediatric heart recipient
Robert Goodman, heart recipient
Teresa Wasserstrom, family member of lung recipient

Not in Attendance:
Morgan Reid, kidney recipient

Ex-Officio Members:
Allyson Hart, MD, MS (Co-chair)
Shannon Dunne, JD (HRSA)

SRTR Staff
Jon Snyder, PhD, MS
Amy Ketterer
Tonya Eberhard
Mona Shater, MA
Cory Schaffhausen, PhD

Not in Attendance
Ryutaro Hirose, MD
Ajay Israni, MD, MS

Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. Mr. Ameen Tabatabai reviewed the agenda. The subcommittee proceeded to the first item.

Update: Patient-friendly website

Dr. Cory Schaffhausen said the patient-focused website has been live for 2 weeks, and currently exists in parallel to srtr.org. In addition, the SRTR internal team is working to do an in-depth testing of the website in different mobile environments (e.g., iPhone and Android). Dr. Hart encouraged members to submit feedback and help spread the word within individual networks. Marketing and Communications Director Ms. Mona Shater added that the website has accrued nearly 10,000 hits, with the top hits being the transplant center search, comparing transplant centers, and the transplant system map. Mr. Joseph Hillenburg said he noticed on social media that new audiences that do not typically intersect with SRTR were sharing the preview website. Ms. Teresa Wasserstrom offered to share the patient-friendly website across Facebook groups, and planned to connect with Ms. Shater on content messaging.

Update: SRTR Review Committee meeting – Washington, DC, April 30, 2024

Mr. Tabatabai summarized topics discussed at the SRTR Review Committee (SRC) meeting in Washington, DC. The committee approved the patient-friendly website, looked at new visualizations to potentially replace the bar representation, discussed enhancing organ procurement organization metrics, including looking at donor recovery and transplant rate metrics, and took a closer look at the Donation and Transplant System Explorer application.

Update: Communications – Getting the word out about SRTR

Ms. Shater said that SRTR Communications is working on a previous PFAS recommendation to reach out to organizations considered to be pretransplant related. Through research and discovery processes, SRTR Communications created a list of 57 organizations that fell into this category. Of these, 22 organizations with an even distribution of organs—lung, liver, and kidney—were contacted for website collaborations aimed at sharing resources. Ten organizations responded, and three organizations have met with the Communications team, where they reviewed the preview website and discussed the importance of patients knowing these resources are available before getting a transplant. So far, the organizations were excited about partnering with SRTR. Specifically, the Lung Transplant Foundation invited SRTR to speak at one of its "Transplant Talks," an event series aimed toward getting patients and professionals together to share transplant information. SRTR plans to include resources from these organizations on the SRTR website, and vice versa. Ms. Shater added that SRTR is looking to participate in the 2026 Transplant Games of America upon Health Resources and Services Administration (HRSA) approval.

Ms. Teresa Barnes, who has connections to the American Thoracic Society Public Advisory Roundtable, suggested SRTR speak on one of its monthly Zoom calls to educate others about the patient-friendly website. Ms. Shater encouraged all members to send any additional resources to SRTR. Members gave additional organizations to contact. Mr. Robert Goodman suggested the Transplant Recipients International Organization (TRIO), and Mr. Marcus Simon suggested connecting with the National Transplant Team at DaVita. Ms. Shater said she would send the subcommittee a list of compiled organizations and asked that other recommendations be sent to her.

Discussion and feedback: Survival after listing

Dr. Hart went over the new concept of survival after listing as a metric for transplant centers. Currently, the transplant center search function on the SRTR website includes two or three metrics (depending on the organ). These include survival on the waiting list, getting a deceased donor transplant faster, and 1-year survival. SRTR has considered what metrics matter most to patients and has begun to focus on aligning its metrics with the overall incentive to have more patients receive transplant (an effort supported by the Organ Procurement and Transplantation Network [OPTN] Expeditious Task Force).

Dr. Hart explained that the idea of giving a metric on overall survival from listing meets the incentive of successfully having waitlisted patients undergo transplant. The metric combats against the scenario of looking at the waiting list alone, in which a program can shrink the waiting list by removing people. It would also help direct patients to a metric most associated with survival. Currently, patients tend to gravitate toward the 1-year survival metric, which in many cases may not differentiate that much between programs. SRTR plans to show the overall survival after listing metric (per the instructions of the OPTN Final Rule). However, all metrics will still be shown for more detail.

Dr. Jon Snyder added that overall survival from listing has been available in the program-specific reports (PSRs), but is not at the forefront of them. One of the key questions is do patients consider a

metric that answers "what's my overall chance of survival" to be simpler and helpful. The metric generally looks out 5 years postlisting, and combines the concepts of waitlist mortality, transplant rate, and survival after transplant out to 1 year. Dr. Snyder asked if patients found it acceptable to simplify the initial search result page by showing overall survival from listing and still having the other evaluations available in the reports.

Ms. Wasserstrom preferred the three metrics because there are many variables that affect the overall survival of a patient after listing. She suggested adding an explanation next to the combined metric. Mr. Hillenburg said the process of "shopping" for a transplant center is different for the parents of pediatric patients, such as, location and distance are not as important. A 1-year metric is not as helpful either. He suggested having a different landing page for the pediatric audience than for the adult audience, because they are looking for different things. The data may also need to be different. He said the overall survival metric was probably more appropriate.

Ms. Barnes proposed listing average transplant survival rates for each organ; it varies for each. Dr. Snyder said there were resources available on this topic, and SRTR is working to add more context to overall survival, and is creating a tool to predict long-term outcomes. Mr. Simon commented that there may need to be accompanying education that explains what the survival metric means. If a metric is low compared with others, there is a risk that patients will not understand that having a lower metric is still better than not having a transplant. Or, they may not attempt to get waitlisted at a center, when it might be in their best interest. Mr. Hillenburg suggested having retransplant as a factor for metrics, for pediatrics in particular. Dr. Snyder commented on how multiple transplants are considered in the models. The first-year graft survival metric now includes both first transplants and retransplants, and has lower expected outcomes since restransplants are factored in. Similarly, for overall survival from listing, a patient's first or second transplant is considered. Dr. Snyder said there may be other ways to add retransplant information into the reports. As of now, the initial search results page tries to incorporate all of that information together in a single metric.

Discussion and feedback: Considering new icons to report program performance

Dr. Schaffhausen presented a mock-up of how SRTR currently looks with the 5-bar ratings. Common feedback from patients is that the 5-bar ratings are interpreted the same as 1- to 5-star ratings, where a 3 is considered bad. However, in the context of the 5-bar ratings, 3 bars means performing as well as the national average. He presented a project done a few years ago that tested 10 different icons in a randomized survey with questions that evaluated preferences and accurate data interpretations.

Looking at survey data from more than 1,000 individuals, results showed that the dial (speedometer/gauge) icon was more likely to be interpreted correctly. However, most individuals preferred the bars. Dr. Schaffhausen said SRTR has more interest in choosing the icon that leads to the most correct interpretations over individual preference. Dr. Hart added that the dial showed some programs are performing well by meeting the national average, without communicating that a 3 is bad.

Dr. Schaffhausen showed different color schemes for the dials, which had clear distinctions between good, average, and worse. Another example included decimal (on a scale of 0 to 1) and percentage

ratings with the colors only included in the area where the dial pointer is. The number ratings would allow sorting from top to bottom. He said the number ratings (from 0 to 1) were abstract and may not always be easy to interpret. Because of this, SRTR could instead provide an estimated actual percentage of survival so that the numbers mean after an estimated 7 years, *x* percent of patients who have been listed have survived. Dr. Hart and Dr. Snyder noted the methods used to calculate the overall survival after listing metric did not need to change. Dr. Snyder said the underlying analysis is the same, it would just involve converting numbers to a scale (actual survival percentage) readily interpretable for the user.

Members preferred the dial icon over the bars, in particular with the percentage shown. Ms. Stephanie Mullet liked the dial icon where the only colored section was where the needle pointed at. Members also discussed including a range on the dial indicating the actual low and high ends of the search results with numerical values.

Dr. Schaffhausen moved on to the next set of dial icons that had overall survival after listing, followed by being broken into other metrics including survival on the waiting list, get a deceased donor transplant faster, organ offer acceptance, and/or 1-year survival. Numbers are not included with each because the scale for each is different and may cause confusion. With the top of each dial still meaning average, Mr. Goodman suggested rethinking this word, since “average” in this context does not mean mediocre. Mr. Hillenburg suggested the word “typical.” Ms. Wasserstrom said the set of icons caused dissonance for her since they were not visually complete. She added it might be confusing to some that only one icon has a numerical value underneath it.

Closing business

Dr. Snyder explained that the Human Centered Design Subcommittee (HCDS) has a meeting in the next week after this PFAS meeting where it will review these design mock-ups. The Analytical Methods Subcommittee (AMS) will meet in July 2024 to discuss a method to convert the icon numbers back to a meaningful scale.

Dr. Hart said that SRTR is planning a follow-up consensus conference for 2025. Details are forthcoming.

With no other business being heard, the meeting concluded. The next meeting date is to be determined.