

SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

March 9, 2022, 2:00 PM – 3:30 PM CST

Voting Members:

Dale Rogers
Amy Silverstein
Ameen Tabatabai
David Rodriguez

Not in Attendance:

Richard Knight (Co-chair)
Katie McKee
Rolanda Schmidt, PhD

Ex-Officio Members:

Allyson Hart, MD, MS (Co-chair)
Adrianna Martinez (HRSA)

Not in Attendance:

Shannon Dunne, JD (HRSA)

Guest:**Not in Attendance:**

Jennifer Jones
Heather Hunt

SRTR Staff:

Jon Snyder, PhD, MS
Cory Schaffhausen, PhD
Mona Shater, MS
Amy Ketterer, SMS
Tonya Eberhard

Not in Attendance:

Ryutaro Hirose, MD
Ajay Israni, MD, MS Bert
Kasiske, MD

Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. She reviewed the agenda and began with the first item.

Update: US transplant metrics review (Task 5)

Dr. Hart updated the subcommittee on patient and family focus groups organized by Dr. Cory Schaffhausen. Twenty groups were covered between mid-November 2021 and late February 2022. Participants included kidney recipients and candidates; liver, heart, lung, and pancreas recipients; living donors; family members of recipients or candidates; pediatric family members; and family members of deceased donors. Patient demographics had less ethnic diversity than hoped, with 61% of patients being White. While Hispanic individuals were interested in participating, their availability did not align with scheduling. The next steps included finishing transcription, and systematically breaking down what the groups discussed in preparation for presenting these findings at the consensus conference.

Dr. Hart added that the Organ Procurement and Transplantation Network (OPTN) currently has an ethics committee that is working on a memo addressing an ethics framework to metrics. The framework will not be finalized before the consensus conference, although two people on the ethics committee will be attending the conference. Dr. Hart will also be attending future ethics committee meetings.

Mr. Dale Rogers voiced concerns over the latest OPTN webinar, specifically how rural America was treated regarding access to urban transplant centers and placement on the waiting list. The subcommittee agreed it was important to clarify the continuous distribution allocation framework,

which bases priority on how far a prospective donor is from a transplant facility, in terms of the negative impact transportation has on organ quality.

Dr. Hart began a breakdown of who expressed interest in attending the consensus conference. Nonprofessionals consisted of patients, living donors, family members of deceased donors, and parents of patients. Half of the patients who expressed interest are also professionals in the transplant field. Dr. Jon Snyder said 151 people were interested, not including steering committee members; 24 are solely patients, 103 are professionals, and 24 are both patients and in the transplant field.

Members had questions regarding the format and function of the conference. Dr. Snyder explained that the conference aim is to hear from various stakeholders about what transplant information would be the most beneficial. Dr. Hart added that speakers will serve as the introduction to specific transplant topics, followed by breakout workgroup discussions of the subjects. Dr. Snyder said that most of the conference will be devoted to panel and breakout sessions, with some time reserved for explaining what data the Scientific Registry of Transplant Recipients (SRTR) has available. SRTR preconference materials will also be offered.

Dr. Snyder added that the conference is designed to 1) identify all stakeholders (living donors, transplant programs, payers, etc.), 2) identify what information the stakeholders want to know or find most useful, 3) have SRTR consider what data it can present to answer these questions, and 4) take the synthesized discussions and recommendations to the subcommittees and the SRTR Review Committee (SRC), which will 5) help prioritize and implement these changes in the next 2 years and 6) reconvene in 3 years to assess progress.

Discussion and feedback: Preconference materials for patients and family members

Ms. Amy Ketterer presented the consensus conference prospectus. The draft has a rainbow palette, with the overall theme being that data are real people. Mr. David Rodriguez suggested adding more diverse images for inclusivity. Ms. Mona Shater advised circulating the images to the subcommittee for feedback. Ms. Ketterer overviewed the eight pages of content, which included a history of SRTR and OPTN, important dates leading up to the conference, COVID-19 precautions, testimonials, schedule, list of speakers, and hotel information. A full program version will be sent to those who register and will be available on a virtual platform during the conference. Physical copies may be offered, although that hasn't been decided on yet. Ms. Ketterer and Dr. Hart went over a draft of the consensus conference glossary, a list of transplant organization acronyms and transplant terms with definitions. This will also be circulated to members for feedback on what terms should be included.

Dr. Schaffhausen shared prototype drafts that outline the transplant system. The framework also focuses on creating metrics within the context of the system, which will help patients determine what information is most beneficial to them. The first was a diagram titled "Transplant Patient Journey" with a series of labels highlighting the transplant process. Members discussed if labels should be renamed or added.

Mr. Rodriguez brought up how many patients mistakenly assumed the "Referral" label is the same as being added to a waiting list. Members discussed how the label "Staying Healthy After Transplant" meant short-term outcomes, or a "survival statistic," as Ms. Amy Silverstein called it. Ms. Ketterer

explained that the SRTR metrics include 30 days, 1 year, and 3 years. Using previous SRTR terminology, short-term outcomes are 30 days and 1 year and long-term outcomes are 3 years. She added that staying healthy after transplant is important since OPTN follows patients for 1 year or 3 years posttransplant. Members also discussed how the label “Staying Healthy on the Waitlist” meant waitlist mortality. Ms. Silverstein said the label “Long-term Experiences” was important since a longer lifespan can be attributed to the methods a transplant center uses. Mr. Ameen Tabatabai said adding a label for the preparation stage prior to transplant (determining a caregiver, where a patient will stay, etc.) would be helpful. He thought the “Staying Healthy” label addressed using data to manage risks after surgery.

Dr. Schaffhausen also presented a “Transplant System” diagram. The map included patient and transplant professional components, with each line representing a stakeholder that intersects and diverges at different time points. Mr. Tabatabai compared the design to a metro transit map, analogous to which direction a patient wants to go, and what data are needed to make decisions.

Dr. Schaffhausen again showed the “Transplant Patient Journey” with summaries of what transplant information is and is not available at each point. He explained that the diagram can be used with the metrics framework, or types of metrics associated with specific parts in the transplant journey. Lastly, he shared “Patient Focused Transplant Metric Recommendations,” a way to document metric feedback from attendees for breakout sessions. Dr. Hart suggested having one more meeting before the conference, to review these materials in detail.

Closing business

Dr. Hart and Mr. Richard Knight previously discussed and proposed adding patients and family members to the subcommittee, since a few members could no longer attend. There were no objections. Dr. Hart also invited members to attend a patient-focused Task 5 Steering Committee meeting on April 21, 2022. With no other business being heard, the meeting concluded. The next meeting is scheduled for June 2022.