

SRC-PFA Subcommittee Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

December 1, 2021, 2:00 PM – 3:30 PM CDT

Voting Members:

Richard Knight (Co-chair)
Dale Rogers
Amy Silverstein
Ameen Tabatabai
David Rodriguez
Katie McKee

Not in Attendance:

Carla Smith
Rolanda Schmidt, PhD

Ex-Officio Members:

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

SRTR Staff:

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

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 gave the subcommittee an update on patient focus group development for Task 5. She said their previous feedback was incorporated to factor diversity into focus groups. This included geographic, racial, ethnic, and gender diversity, as well as pediatrics and people not directly involved in transplant research/advocacy. The subcommittee also gave feedback on the focus group guide. Dr. Hart said the guide format starts with a broad scope and narrows with specific questions. A survey at the end asks patients to rank topics by level of importance.

Patient recruitment has started with social media and patient advocacy groups. So far, 110 patients and family members are interested in participating. Dr. Hart aims to have more groups with fewer people in order to accommodate more patients. Four focus groups (living donors, kidney recipients, living donor recipients, and family members) have been populated. In order to get broad organ representation, recruitment began as nontargeted but will become targeted once missing groups are assessed in December. In addition, two short videos on SRTR and Task 5 were sent to focus groups. Mr. Ameen Tabatabai said it is important to consider the different challenges and questions of each organ recipient group. Mr. Dale Rogers said it may be beneficial to have more multiorgan recipient perspectives.

Update: 2022 Consensus Conference draft agenda

Dr. Hart reviewed a draft of the 2022 Consensus Conference schedule. The conference will have a patient and family focus, with a patient speaker starting the conference and a patient or family

member introducing each session. The conference framework will be introduced to help everyone approach tasks from the same angle. Day one will focus on describing the stakeholders and why metrics are relevant to them. Stakeholders will briefly discuss why certain metrics are important to them and their group. One group will be organized as patients (transplant candidates and recipients, living donors, and deceased donor family members), peers, Centers for Medicare & Medicaid Services (CMS), and referring physicians. The other group will consist of organ procurement organizations (OPOs), transplant physicians/surgeons transplant administrators, the Organ Procurement and Transplantation Network (OPTN) Membership and Professional Standards Committee (MPSC), the monitoring side of CMS, and donor hospitals. The last part of the day will be for discussing resources already available at SRTR and providing supplemental material on metrics in additional fields. Mr. Richard Knight suggested providing a chart of these descriptions and an acronym sheet for patients.

Dr. Hart said the framework of day two will address information of interest (eg, patient demographics on the waitlist). There will be a plenary series in which attendees will have tasks for breakout workgroups. Groups will address different topics (pretransplant, posttransplant, and access to transplant). The first plenary series will be heavily patient focused, prioritizing information of interest to patients, donors, and family members. The afternoon plenary sessions will focus on professional needs, including regulators, payers, and public health perspectives. This will follow the breakout workgroup format.

Mr. Knight suggested having a speaker from a dialysis center such as DaVita present, because it's important to address the transition from dialysis to transplant and the additional work transplant centers face in prepping dialysis patients for a kidney transplant. Dr. Ryutaro Hirose echoed Mr. Knight's comments, saying it is important to engage with referring providers for process quality improvement. Mr. David Rodriguez added that dialysis social workers should be included in the conversation because they are very involved in the steps from dialysis to transplant. Both agreed on the importance of developing a clear process that dialysis patients can understand to improve communication between them and transplant professionals.

Dr. Hart said day three will focus on how metrics can answer questions and identify information of interest. At the end of the conference, attendees will receive a summary of discussed topics and steps going forward. Mr. Rogers suggested having contacts as a follow-up method. Dr. Hart mentioned that there will be efforts to keep attendees engaged by joining workgroups in the future. Subcommittee members agreed that all the different metrics can be overwhelming for patients and that there is a need to teach patients how to identify relevant information to decide what is best for them. Ms. Katie McGee asked how conference discussion would be recorded, and Dr. Hirose suggested using graphic artists who draw group discussions in real time. These graphics could be disseminated to attendees after the conference.

Discussion and feedback: Transplant program 'carve-outs' for COVID-19

Dr. Jon Snyder went over SRTR's decision on how to handle public reporting of transplant program metrics and OPO metrics in response to COVID-19. SRTR decided to eliminate the first 3 months of the pandemic from the metrics (March 13, 2020, to June 12, 2020) and resume normal reporting thereafter. Patients who received transplants before the start data will be followed until March 13, while those who received transplants during the 3-month carve-out will not be counted. Dr. Snyder

showed United Network for Organ Sharing (UNOS) COVID-19 data (available at <https://unos.org/covid/>) that support this decision. UNOS data show that in 2020, in the pandemic's first 3 months, living donor and national weekly transplant counts fell. Inactivation codes that UNOS created for COVID-19 precautions also rose during this time. In general, counts returned to normal after 3 months, along with little use of inactivation for COVID-19 precautions after those months. The Analytics Methods Subcommittee (AMS) supported the 3-month carve-out decision, and the Human-Centered Design Subcommittee (HCDS) helped design a yellow banner that appears above individual program reports on the SRTR website stating that the COVID-19 pandemic affected outcomes during this reporting period. Though certain transplant programs were concerned about the carve-out decision, SRTR has not changed its decision. Dr. Snyder asked for patient perspectives on this decision and suggested that SRTR could add the number of COVID-19-related deaths to the public reports.

Subcommittee members agreed with the decision SRTR made and said it would be beneficial to show the number of COVID-19-related deaths in the public reports. Everyone felt that data transparency was preferable over extended carve-out periods.

Closing business

Dr. Hart said that the next meeting will focus on preconference patient education and material development. Hearing no other business, the meeting concluded. The next meeting time is to be determined.