

SRC-PFA Subcommittee Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

April 29, 2021, 1:00 PM – 2:30 PM CDT

Voting Members:

Richard Knight (Co-chair)
Dale Rogers
Carla Smith
Amy Silverstein
Ameen Tabatabai
David Rodriguez
Rolanda Schmidt, PhD
Katie McKee

Ex-Officio Members:

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

Guest

Jennifer Jones

SRTR Staff:

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

Welcome and opening remarks

Mr. Richard Knight called the Patient and Family Affairs (PFA) subcommittee meeting to order. Two members introduced themselves:

- Carla Smith, four-year post bilateral lung transplant recipient
- Jennifer Jones, kidney transplant recipient, medically retired United States Marine, board director for the American Association of Kidney Patients

Dr. Allyson Hart reviewed the agenda and proceeded with the first item.

Task 5: Identify metrics to assess national transplant system performance

Dr. Hart reviewed Task 5 and said it would involve engaging stakeholders (patients and families in particular) to identify national system performance metrics. The stakeholders would come together at a consensus conference in July 2022. The consensus conference steering committee was charged with engaging critical audiences that needed information to assess the organ procurement and transplant system. SRTR proposed using focus groups to gain more patient perspectives in preparation for the conference.

Regarding metrics, the goal was to identify what measurements should be used to monitor the transplant system (eg, deceased donor organ recovery, access to transplant). Dr. Hart said that metrics could be used for a broad range of purposes, from guiding national policy to choosing a transplant center. Patient, living donor, and family member engagement were crucial components of the metric discussion, particularly prioritizing a diverse population representation. Mr. Knight stressed the importance of having a comprehensive perspective and being well-informed when devising metrics.

Dr. Hart shared a visual explaining the who, why, what, and how behind metrics in the transplant system. Metrics were intended not only for programs and OPOs but for patients, donor families, payers, and regulators. The purpose of addressing metrics was to improve patient experiences and outcomes. Metrics are already in place for some areas, but others might be considered, such as patient quality of life, readmission rate, and others. Mr. Knight pointed out a missing metric—offers declined by providers compared with candidates. He said it is important to be aware of a patient's disposition for the organ quality they were willing to accept, because they may prefer a lower-quality organ to staying on the waitlist if their health is bad. Mr. Ameen Tabatabai said it is critical to measure why organs are declined, such as organ quality, patient health, and program standards. Mr. David Rodriguez added that organ decline often was associated with compliance, among numerous other factors.

Mr. Knight said it was crucial that patients have information on how a center is performing. He pointed out that some doctors are more conservative than others, and it was up patients to decide if they preferred a high- or low-risk center, depending on their situation. Dr. Hart asked whether a metric for the medical risk levels a center was willing to accept would address that question. Dr. Ajay Israni added that another possible metric to address this was information about patients left off the waiting list. Mr. Dale Rogers brought up complications with centers and health insurance. Mr. Tabatabai said it might be helpful to measure the percentage of insurance carriers a center accepts. Mr. Rodriguez added that many patients are declined because they have no caregiver post-surgery, and Mr. Tabatabai said it would be interesting to analyze charity or nonprofit care available at hospitals.

Dr. Hart reviewed the framework for how the subcommittee could engage in the identifying metrics task. The subcommittee would work in a synergistic effort with Ms. Jones and Ms. Heather Hunt of the steering committee. For pre-conference planning and engagement, Dr. Hart said they needed to discuss who the subcommittee should contact for focus groups (virtual) and what questions to ask. Mr. Knight said they wanted to include pediatric patients in the focus groups. Dr. Hart said focus groups were planned for liver, heart, lung, and kidney recipients, living donors, deceased donor family members, and potential candidates, if possible. Mr. Tabatabai said it was vital to cover all organs and all points of the transplant process. Dr. Hart added that they would recruit directly from transplant centers and patient organizations to reach those not yet engaged in advocacy and research.

Members moved into what questions should be asked. Dr. Ryutaro Hirose suggested asking about what is important to a patient when looking for a transplant center. Ms. Smith recommended asking if patients knew where to find information on different centers. Members discussed how to disseminate SRTR information to the public. Mr. Knight added that the SRTR website was being revised to be more patient-friendly. Ms. Katie McKee said that asking people to describe their experience would highlight patient barriers and other notable factors. Dr. Hart said targeted questions would be better due to time constraints. Ms. McKee proposed asking how much information patients seek in advance. Ms. Amy Ketterer mentioned that some people do not have Internet access and shouldn't be forgotten, to which Dr. Hart replied that the focus group process was cyclical and would be repeated, allowing time to contact those who do not have Internet access.

Dr. Hart shifted to discussing which organizations to contact. Ms. Smith mentioned different Facebook groups and other social network transplant groups. Mr. Tabatabai said he also had experience with this form of communication. He stressed the significance of educating transplant recipients through the media. Dr. Rolanda Schmidt suggested the app Clubhouse as a good communication method. Dr. Hart said she would incorporate everyone's feedback into a focus group guide, which would be sent to members for review.

Dr. Hart asked what actions needed to be taken to ensure that patients and family members attending the consensus conference felt prepared to participate. Ms. Smith suggested having any medical necessities, like oxygen tanks, on hand. Mr. Knight said a primer would be helpful, while Ms. Jones proposed an SRTR introductory video. Ms. Mona Shater commented that Ms. Ketterer created an Intro to SRTR video used for the Transplant Management Forum (TMF) that described who SRTR was, what it did, and how it supported its stakeholders. The video was scheduled to be posted to the SRTR YouTube channel, and would be shared in addition to other patient-friendly videos with the committee after the meeting.

Dr. Hart brought up potential education topics before the conference. Mr. Tabatabai advised taking a hybrid focus on introducing SRTR and transplant education, such as mortality information, waitlist size and outcomes, and others. Mr. Rodriguez said that discussing the role of blood type in transplant is important. In response to concerns about making patients feel comfortable, Dr. Hart asked whether a pre-conference patient and family meeting would be beneficial. Dr. Hart said the discussed information would be compiled into a presentation to the steering committee. She invited members to attend the meeting.

Closing business

The next teleconference meeting was not scheduled but will likely take place in summer 2021. The Metrics Steering Committee meeting is scheduled via teleconference for May 20, 2021, 3:00 PM - 4:30 PM CDT. With no further business, the meeting concluded.