

# SRC-PFA Subcommittee Meeting Minutes

## Patient and Family Affairs Subcommittee Teleconference

August 3, 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, SMS  
Tonya Eberhard

---

**Welcome and opening remarks**

Mr. Richard Knight called the Patient and Family Affairs Subcommittee meeting to order. An additional member introduced themselves:

- Heather Hunt, living liver donor, United Network for Organ Sharing (UNOS) Living Donor Committee, SRTR Task 5 group member

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

**Report: PFAS recommendations to the Task 5 Steering Committee**

Dr. Hart reviewed the Task 5 engagement framework and the subcommittee's feedback. Task 5 engagement aims to get perspectives from patients and family members at multiple levels. The subcommittee is working with Ms. Heather Hunt and Ms. Jennifer Jones, Steering Committee members, to increase the patient voice. The subcommittee stated in earlier meetings the importance of focus groups. Specifically, a group of patients, family members, and living donors made up of racial, ethnic, gender, age, and geographic diversity. Hearing patient perspectives could be most effective when followed by targeted, open-ended questions.

The Steering Committee plans to move forward with the focus groups. Recruitment will span across a range of groups including the American Association of Kidney Patients (AAKP) and liver groups. Recruitment will also be done through social media and transplant centers. Dr. Hart added there are plans for a public comment period, and a focus group education guide was recently developed. The Steering Committee is also going to plan an informal preconference social, and prepare educational material for attendees to watch before the consensus conference. Patient and family presentations will also be shown during the conference.

Mr. Knight added it was important to do a stakeholder analysis to understand the perspective and goals of the Health Resources and Services Administration (HRSA), payers, etc. This way, patients understand how sharing their experiences can help stakeholders, and the limitations of certain groups. These observations will help create a system that provides sufficient information for patients.

At the Steering Committee meeting, Ms. Amy Silverstein said patients care about metrics that measure longer survival outcomes like 5 years and beyond. She gathered from SRTR's response that it was an unrealistic request. Dr. Ryutaro Hirose said it would be challenging, but not impossible. Mr. Ameen Tabatabai added when patients are given only 1-3 years of data, the transplant feels more like an experiment instead of ensuring a longer life. Dr. Ajay Israni said SRTR worked on 5-year metrics, and it was important that the subcommittee voice interest in this topic.

### **Discussion and feedback: Task 5 next steps**

Dr. Hart reviewed the draft consensus conference schedule. The first day will be a half-day with an overview discussion for attendees. Day two will be a full day, alternating between full group sessions and smaller breakout groups. Discussion topics will include transplant centers, organ procurement organizations, and the U.S. transplant system as a whole. The third day will be a half-day where each breakout group will report back, followed by finishing the conference. Mr. Tabatabai asked how they would capture the main points of each group discussion. Dr. Hart felt it would be beneficial to have notetakers at the very least.

For the first half-day, HRSA could begin the conference by defining its goals, and SRTR could talk about the scope of the meeting. There could also be presentations that include patients and family members, donors, Organ Procurement and Transplantation Network (OPTN), and Centers for Medicare & Medicaid Services (CMS). Mr. Knight stressed the importance of understanding organization acronyms prior to the conference, and the role of each organization. Mr. Dale Rogers suggested creating a "cheat sheet" addressing that concern. Dr. Hart said this information could be reviewed in the preconference education event. She added that on the first day, a metric framework will be created to accommodate the various metrics useful for different stakeholder groups.

Members discussed the structure of breakout sessions. Mr. Knight said patients should be distributed throughout the different groups. That way, the exposure to new ideas and topics would result in patients discovering what information would be important to them. Dr. Jon Snyder said they planned for 200 conference attendees. The subcommittee discussed what was the right ratio of patients and transplant professionals. Ms. Silverstein and Mr. Tabatabai agreed the number of patients was not as important as the impact of patients being a part of the conversation.

Mr. Tabatabai and Mr. Rogers asked how patients should be distributed according to their knowledge levels. Mr. Knight felt that the focus groups would be a good indicator of patients' knowledge and comfort level. He suggested 55% of the attendees should be patients, and to have a distribution of the different organs. Mr. Tabatabai said 25% or less of the 200 as patients was a good number. Too many patients may result in a social event or a support group mentality. Ms. Hunt recommended having a patient focus group readout so the patient voice is articulated before discussion begins. Dr. Israni agreed. Dr. Hirose added liver and kidney donor patients should be included. He emphasized the primary role of patients as advocates, and education should flow from

patients to transplant professionals. In order for this to happen, there must be a fair amount of premeeting work to guarantee everyone knows who the stakeholders are. Mr. Rogers added that education also meant patients being able to bring back information to their community for widespread use.

Dr. Hart moved on to what information to share with patients at the preconference. Mr. Tabatabai emphasized the importance of focusing on what attendees will be achieving as a group, and specifying the roles of patients and professionals. He also said using a list of five key things to consider when discussing topics (possibly used as an acronym) to keep the conversation on track. Other members added clarifying who the stakeholders are and their interests. Mr. Tabatabai also suggested having this information in different formats, such as a video and a “cheat sheet.” Dr. Hart said she would send out a draft of these ideas so members could give feedback.

### **Introduction and discussion: Multiorgan transplants**

Dr. Snyder reviewed SRTR's limited reporting on multiorgan transplants. The SRTR website offers only two multiorgan combinations (kidney-pancreas and heart-lung) in the transplant selector box. While SRTR creates reports for both and there are separate waitlists for the two, waitlists for other organ combinations do not exist. A patient would instead be placed on two waitlists corresponding to the needed organs. Dr. Snyder said it was by historic accident that SRTR creates these separate reports for the two multiorgan transplants, as both are thought of as special organ types in the UNOS system. While recent data shows liver-kidney transplants are common, there is no separate report for the transplant. In addition, multiorgan data is obscurely placed at the end of data reports. The reports are also nuanced in that multiorgan transplants are included on the pretransplant side, but not in posttransplant upon evaluation.

Dr. Snyder proposed three solutions to present this data more clearly. The first option is to exclude multiorgan candidates and recipients from the main report, and create a separate one for multiorgans. The second is include multiorgan data in the main organ report, and separate the data by section. The third option is to include multiorgan candidates in the main report, state how many patients are multiorgan, include them in the evaluation for pretransplant and posttransplant outcomes, and make appropriate statistical adjustments for the risk levels of patients.

Ms. Silverstein and Mr. Tabatabai questioned the definition of multiorgan transplant. Both felt that if two transplants were several years apart, both are single organ transplants. Dr. Snyder said this definition is implemented in posttransplant evaluations. Mr. Rogers felt the data had to be split into two, as most people are listed as multiorgan, but circumstance splits the transplants. Mr. Tabatabai pointed out patients may not know when looking at data if it should be seen as two separate transplants or multiorgan. Because multiorgan data is a very small subset, he suggested keeping the data separate or as a subset of the larger report. Members agreed it would be beneficial for the transplant selector box to have a multiorgan selection option that leads to a separate set of tools to explore multiorgan data.

### **Closing business**

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