

SRC-PFA Subcommittee Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

March 15, 2021, 9:30 AM – 11:00 AM CST

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)
Adriana 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
Tonya Eberhard

Welcome and introductions

Dr. Allyson Hart welcomed subcommittee members and began with introductions:

- Richard Knight, Co-chair, president of the American Association of Kidney Patients (AAKP), transplant recipient, SRTR Review Committee (SRC) member
- Dale Rogers, AAKP secretary, kidney and pancreas transplant recipient, rural America representative
- Amy Silverstein, American Society of Transplantation (AST) member, 2-term United Network for Organ Sharing (UNOS) board member, heart transplant recipient
- Ameen Tabatabai, University of Washington patient advisory committee member, organ procurement patient advocate, liver transplant recipient, multicultural representative
- David Rodriguez, patient relations specialist, paired exchange donation recipient, Hispanic population representative
- Rolanda Schmidt, PhD, family member of deceased donor, African American population representative
- Katie McKee, organ procurement organization (OPO) employee, living donor

After reviewing conflict of interest management, Mr. Richard Knight began with the agenda.

SRTR Overview

Dr. Hart presented general SRTR information to committee members. SRTR is a contract awarded by the Health Resources and Services Administration (HRSA). SRTR is part of the Chronic Disease Research Group (CDRG), with Hennepin Healthcare Research Institute (HHRI) as the contractor. SRTR maintains a national database of transplant statistics on organ donor, waiting list candidate, and transplant recipient demographics as well as transplant and organ yield outcomes. The Organ

Procurement and Transplantation Network (OPTN) is a sister contract to the SRTR administered by the contractor, UNOS. While the SRTR contract focuses on research and policy evaluation, the OPTN contract involves policy development. SRTR data responsibilities include statistical analyses and simulated allocation modeling (eg, simulation of how organ allocation changes with policy), whereas OPTN collects data. All of these organizations are part of the US Department of Health and Human Services (HHS).

The SRTR federal contract, which is awarded in 5-year increments, consists of SRTR tasks such as producing and publishing annual data reports (ADRs), providing data to the community, and analyzing policy changes. Dr. Jon Snyder gave an example of a recent change in kidney allocation policy, in which an organ is sent for transplant within a 250-mile radius of the donor hospital.

Under the SRTR Review Committee (SRC), the Patient and Family Affairs Subcommittee aims to advise SRTR in matters relating to providing information to patients and families. This also applies to SRTR website work and printable tools. To achieve this goal, the subcommittee uses bidirectional engagement, co-learning processes, and continuous feedback.

Ms. Amy Silverstein asked if one goal is for patients to use the SRTR website to evaluate transplant choices. Mr. Knight affirmed this, but said it is important to consider its relevance for patients rather than only center ratings. Ms. Silverstein asked if SRTR staff knew the percentage of patients who visit the SRTR website. Ms. Mona Shater said that while Google Analytics provides user behavior data, it does not specify who views the pages. Information Technology is working on a pop-up survey to gather more information on website traffic. Popular user tools are the liver waiting list calculator, kidney transplant decision tool, and COVID-19 evaluation application.

In addition, Mr. Dale Rogers asked if doctors were required to inform patients about resources such as SRTR, because many patients do not know about it. Ms. Amy Ketterer said that transplant programs are required to send information such as program-specific reports (PSRs) to waitlisted candidates. However, the reports are often incomprehensible to a lay audience. Though Ms. Ketterer said she spoke with many callers who understood the value of center comparisons and multi-listing, Mr. Rogers said that this knowledge was likely the result of communication among patients rather than from doctor to patient.

Because a subcommittee task is to make metrics understandable, Dr. Hart compared the SRTR website's 2017 Center Search with the current version, which uses a 5-tier system to compare national averages. The tool has organ-specific information to help patients find information relevant to them. Dr. Snyder added that 1-month, 1-year, and 3-year outcome metrics are on the website and that SRTR is exploring the addition of a 5-year metric.

Dr. Hart showed web examples of an adapted, patient-friendly program data report and a kidney decision support tool that was dramatically improved with patient feedback. Mr. Knight stressed the importance of straightforward metrics to help patients make an informed decision pertinent to their situation. Another metric is the donor offer example, which explains to patients how the donor system works so they can use data accurately. From these focus groups, Dr. Hart learned the importance of giving context with information to adapt tools to meet patient needs.

Current tasks needing PFAS input

Dr. Hart introduced Task 5, which aims to engage stakeholders in transplantation to identify metrics to assess national transplant system performance and support informed decision-making by critical audiences. The task is slated for discussion by such stakeholders as transplant programs, surgeons, insurance providers, and medical professionals at the June 2022 consensus conference. The subcommittee needs to adequately prepare so patient voices are heard at the conference.

Mr. Knight said in order to achieve this, members need to ensure that the patient perspective is noted, starting with patient input on the steering committee. He emphasized the need to have a comprehensible patient viewpoint, and by June 2022, the subcommittee should be refining what they've already prepared. Mr. Ameen Tabatabai said it would help to know which data are available and understand the different viewpoints in a data analysis; then members could give their individual perspectives.

Members transitioned to a metric- and data-based discussion. Mr. David Rodriguez asked why waiting time varies geographically across the country. Dr. Ryutaro Hirose said a local-first mentality of distribution created a demand-supply ratio that varies by region. Political forces, in which areas don't want to see wait times increase as others decrease, are also in play.

Mr. Rogers added that it is important to inform patients of centers outside the typical organ-transportation radius. Ms. Ketterer said that though many patients request information on pre-waitlist metrics, SRTR doesn't track it or know how programs determine patient selection. Mr. Rogers asked if any metric shows how centers report so patients could see which ones used rejections to polish their records. Ms. Ketterer responded that SRTR reports transplant recipient characteristics in PSRs, but that that it is not conspicuous. Dr. Ajay Israni said that because of this, SRTR created a tool (currently in testing) with which patients can assess which centers perform transplants for patients like them.

Closing business

Dr. Hart said the next meeting will be devoted to metrics. With no other business, the meeting concluded. The next meeting date is to be determined.