

SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

February 20, 2024, 10:30 AM – 12:00 PM CST

Voting Members:

Ameen Tabatabai, liver recipient (Co-chair)
Teresa Barnes, lung recipient family member
Stephanie Mullet, pediatric liver family member
Marcus Simon, kidney recipient
Joseph Hillenburg, parent of pediatric heart recipient
Robert Goodman, heart recipient
Morgan Reid, kidney recipient
Teresa Wasserstrom, family member of lung recipient

Ex-Officio Members:

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

SRTR Staff

Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Amy Ketterer
Tonya Eberhard
Mona Shater, MA
Cory Schaffhausen, PhD
Not in Attendance
Ryutaro Hirose, MD

Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. She reviewed the agenda. New members introduced themselves:

- Teresa Wasserstrom, family member of a lung recipient
- Robert Goodman, former United Network for Organ Sharing (UNOS)/Organ Procurement and Transplantation Network (OPTN) Board of Directors member, heart recipient
- Marcus Simon, Senior Analyst at DaVita Kidney Care, kidney recipient
- Joseph Hillenburg, active in the **transportation** technology industry, parent of a pediatric heart recipient
- Morgan Reid, Director of Transplant Policy and Strategy at the National Kidney Foundation, kidney recipient

Federal contract overview

Dr. Hart explained to members that the Health Resources and Services and Administration (HRSA) holds the Scientific Registry of Transplant Recipients (SRTR) contract. SRTR is a sister contract for the OPTN, and works with this institution to analyze data and inform United States transplant system policies. The federal contract handles tasks and deliverables, like producing and publishing transplant data reports for the community and analyzing potential policy changes to inform new policy.

SRTR SRC and subcommittees

Dr. Hart said SRTR has the SRTR Review Committee (SRC), which is a multidisciplinary group (with patient representatives) that informs SRTR tasks and decisions. Smaller subcommittees like PFAS

were created for more representation and in-depth discussions with experts in that field. Content from these discussions are used to better inform the SRC.

Dr. Hart reviewed the PFAS statement of purpose, which is helping to integrate the patient, donor, and family voice into applicable SRTR work through objective review and advice. PFAS goals include members working within three phases of SRTR research and tools development. The first phase is preparatory work, or discussing and proposing patient-centered tools to improve patient decision-making. The second phase is execution, or how to get patient tools to those needing them. The third is the translational phase, or making sure tools are being used and helping the intended audience.

Dr. Hart also noted there is no hierarchy of expertise in PFAS meetings, and it is important that SRTR professionals do not dominate the conversation. Efforts are currently in place to expand PFAS to include deceased donor family member and living donor representation. PFAS aims to get more representation by keeping in mind race, ethnicity, gender, and geography.

SRTR strategic plan and 2024 priorities

Dr. Jon Snyder said that Task 2.4 of the SRTR contract calls for developing a strategic plan. At the start of each calendar year, SRTR reviews which projects will be a priority in the future with the SRC. There are top-five strategic priorities for 2024. The first is Task 5 Recommendation Responses and Patient-Friendly Website (Tasks 5 & 7). Parts of this task include the 2022 consensus conference, which gathered over 100 recommendations for data and information that would be helpful to patients and professionals. One recommendation was to create a website for patients, their families, and donors. Constructing a patient-friendly website has been underway since the conference, and a site preview will be launched in the coming months. Once launched, existing SRTR content will migrate over to the new website, and integrating a professional site into it will be the next focal point.

Dr. Snyder went over new web-based tools for patients that are actively in development. These include the Donation and Transplant System Explorer (launched 1/24/2024), Kidney Predicted Waiting Time Application, Long-Term Transplant Outcomes (particularly for parents of pediatric patients), Multi-organ Transplant Explorer Application, and Liver Offer Decision Aid.

The second priority is Support the OPTN Modernization Initiative (Task 3). Dr. Snyder explained that HRSA is currently seeking bidders to help operate with OPTN beyond the current contractor at UNOS. There are two requests for proposals (RFPs) that are out now. SRTR stands ready to engage with new contractors, making sure it is a smooth transition so patient outcomes are not affected. The third priority is OPTN Committee and Board Support (Task 3). These are UNOS committees that create allocation policies, and are working on developing continuous distribution policies for kidney, liver, and heart.

The fourth priority is Improved SRTR Data Administration and Provision (Tasks 8 & 9). This involves improving how the nation's transplant data (underlying datasets) are handled, and how data are presented to the research community. The fifth priority is Continued Expansion of the Living Donor Registry (Task 13), called the Living Donor Collective (LDC), that tracks live donor outcomes with a comparative group. The LDC expanded from a pilot phase of 10 programs, and continues to expand.

Dr. Hart runs the Living Donor Steering Committee, which represents patients and donors, considering what outcomes they think should be monitored.

Update: Patient-friendly website

Dr. Cory Schaffhausen said SRTR has been working on this new website for the past 2 years, exploring different concepts and styles, as well as meeting with patients, family members, and donors for feedback. SRTR has been working with an outside firm web developer for the past 6 months building the site. SRTR aims to launch this as a public site in March or April 2024. Once launched, users will see a prominent banner on srtr.org stating that there is a new preview available for the patient-centered website. The preview will open the patient-centered website in a new window. Future phases include migrating professional content over to the new website, and updating it for a consistent style. He hoped more feedback could be collected from brand new patients viewing the site in the future too.

Dr. Schaffhausen walked through different web page demonstrations. He showed the patients, families, and donors homepage, which features a transplant center search, and links to the key information decision aids, informational videos, and frequently asked questions (FAQs). The bottom of the homepage has the organ transplant journey, which is a simplified version of the transplant system map. The organ transplant journey has five drop-down menus, each broken down into detailed steps about the transplant process, with link to more information. Further down, there is a similar section for the living donor journey.

Dr. Schaffhausen reviewed different ways users can find information. Users can click on homepage links, or use the menu with different drop-down options under each section. He showed the website overview page (under the Getting Started section), which breaks the website down into 15-20 sections, describing who the target audience is for each (Patients, Family Members & Caregivers, Living Donors, Potential Living Donors & Donor Families, Professionals & Researchers, etc), what information is available, and a link to the page.

Dr. Schaffhausen went over the more advanced features, selecting the interactive system map under the Patients & Families section. The vertically oriented map shows different paths for different stakeholders, with points along each as their milestones in the transplant journey. Users can select an organ and journey path from two separate drop-down menus. The map updates accordingly based off of selections made. Each path has stops that users can click on for more details on each, organized in a pop-up window with a question-and-answer format. Dr. Schaffhausen said some answers contain links to data. SRTR envisions directly linking to the exact numbers in the future, and linking to outside organizations with relevant information.

Dr. Schaffhausen shared a different interface called the organ transplant journey (under the Patients & Families section). The interface is broken down into different pages by transplant step, but replicates the content from the interactive system map in a different format. The page is formatted in this way so that the content can be located by search engines like Google. Patients who enter keywords into search engines would likely find links to the patient journey pages instead of the interactive map. He also briefly showed the tool for finding a transplant center, which on the new

website will include a map view at the bottom of search results, and a transplant center side-by-side comparison option.

Members were pleased with the new website. Ms. Wasserstrom asked about what efforts were in place to educate patients that SRTR data exist. Ms. Mona Shater said SRTR has a newsletter and social media platforms to distribute information. SRTR is currently engaged in an active process of reaching out to more organ-specific areas, particularly the pretransplant phase.

Discussion and feedback: Waitlist calculator

Dr. Grace Lyden briefly reviewed the Calculate Your Risks tab on the Kidney Transplant Decision Aid tool. The tab allows users to get an estimated timeframe for waiting, based off of patient characteristics related to how long someone waits for a transplant (including blood type, years on dialysis, and years on the waiting list). Users can select up to 5 years to predict, and the tool will show the percentage of possible outcomes (received a deceased donor transplant, still waiting, and will die or become too sick for transplant) for patients with the selected characteristics.

Next, Dr. Lyden went to the new waiting list calculator, which was built with the same statistical models as the kidney decision aid. It has the same patient characteristics, with an added feature of users being able to choose a percentage range of transplant waiting times, specifically 20% to 80%, 25% to 75%, and 40% to 60% (percentage options may change in later tool versions). The tool also has layouts of a vertical and horizontal timeline. Dr. Lyden said the vertical timeline may be for mobile devices, while the horizontal timeline may be for desktops. Both layouts display the point in time when some people receive a transplant, when half of people like the user receive a transplant, etc.

Dr. Lyden pointed out the footnote at the bottom that stated 10-year predictions may not add up to 100%, since some patients die before transplant or are removed for being too sick. Also, information at the top says predictions are based on first-time kidney transplant candidates on the national waiting list from September 2020 to August 2021. Predicted waiting times for pediatric and retransplant kidney patients will be forthcoming.

Mr. Hillenburg suggested that it might be useful to have both horizontal and vertical orientations available on desktop, so users could switch back and forth if desired. Secondly, he said it would be useful to add a feature where two programs could be compared side-by-side. Lastly, Mr. Hillenburg said expanding the tool to include other organs would be helpful. Ms. Amy Ketterer agreed with his second point. She said that many people comment that they would really like to have a feature that compares centers next to each other, and three programs was a good number to start at. Ms. Teresa Barnes agreed, and suggested having templates by the number of centers users want to compare for download, populating it with information SRTR had on each center. Dr. Snyder recommended having a program comparison option at the bottom that changes the interface from a timeline to a table when selected. Ms. Wasserstrom advised adding a footnote stating the data used in the tool from September 2020 to August 2021 are still relevant.

Closing business

Dr. Hart said members will be contacted between meetings for feedback as available, and encouraged anyone with questions or concerns to email SRTR.



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