SRTR Review Committee Meeting Minutes

via Zoom

April 10, 2025, 10:00 AM – 2:30 PM CDT

Voting Members:
John Magee, MD (Co-Chair) ('26)
Sean Van Slyck (Co-Chair) ('25)
Carli Lehr, MD, PhD ('26)
Amit Mathur, MD ('27)
Emily Perito, MD ('25)
Joseph Hillenburg (PFAS) ('26)
Scott McPhee (HCDS) ('26)
William Parker, MD, PhD (AMS) ('27)

Voting Members Absent:
Deborah Mauer, RN, MBA ('25)

Ex-Officio Members:
Adriana Alvarez, MS (HRSA)
Brianna Doby, MPH (HRSA)
Shannon Dunne, JD (HRSA)
Carlos Martinez (OPTN)
Jonah Odim, MD (ARPA-H)
Jesse Schold, PhD (OPTN-DAC)

HRSA Guests:
Frank Holloman
Sarah Laskey
Jenna Smith

SRTR Staff:
Avery Cook, MPH, MSW
Earnest Davis, PhD, MHSA
Tonya Eberhard
Allyson Hart, MD, MS
Ryutaro Hirose, MD
Amy Ketterer
Sydney Kletter
Grace Lyden, PhD
Roslyn Mannon, MD
Jon Miller, PhD, MPH
Cory Schaffhausen, PhD
Mona Shater, MA
Katie Siegert, MPH
Jon Snyder, PhD, MS
Bryn Thompson, MPH
Nicholas Wood, PhD
David Zaun, MS

Introductions and welcomes

Dr. John Magee and Mr. Sean Van Slyck called the Scientific Registry of Transplant Recipients (SRTR) Review Committee (SRC) meeting to order. Roll call for voting members was taken, with quorum met. Mr. Van Slyck introduced Mr. Carlos Martinez, a new ex-officio committee member representing the Organ Procurement and Transplantation Network (OPTN) contractor from the United Network for Organ Sharing (UNOS). Mr. Van Slyck reviewed that all members' conflict-of-interest forms are up to date and reminded members to keep the team apprised of any changes to these forms.

Approval of January 2025 SRC minutes

Mr. Van Slyck reviewed the meeting minutes from the previous SRC meeting on January 31, 2025. A motion to approve the minutes was brought forth by Mr. Joseph Hillenburg and seconded by Dr. Magee. There were no oppositions, and the minutes were approved unanimously.

Performance work statement review and workgroup findings

Mr. Van Slyck presented a high-level summary of feedback from the committee members in the performance work statement (PWS) workgroup. He shared that these committee members provided feedback in a virtual meeting and individually, coordinated by Ms. Avery Cook. He said that there were a

number of detailed suggestions and summarized them for the group. He stated that key feedback themes emphasized the importance of regular engagement with SRTR under the OPTN multi-contractor landscape. He highlighted the expressed need for a centralized, streamlined analytical support structure between OPTN and SRTR. Dr. Emily Perito reiterated the need for efficiency, through the elimination of redundant data sources and processes. Mr. Van Slyck accentuated ensuring consistency and ease of access for the transplant community.

Another major point was ensuring broad representation within SRC membership, particularly increasing participation from patients, donors, and family members with lived experiences, as well as organ procurement organization (OPO) representatives. Committee members emphasized that inclusive representation enhances the transparency, accountability, and effectiveness of SRC efforts.

The committee expressed strong support for hosting another consensus conference, modeled after the successful 2022 event, to help shape future strategic priorities. Dr. Allyson Hart recommended scheduling such conferences earlier in the contract cycle to guide focus areas, and that if the SRC wanted to recommend a similar conference, the recommendation should include that the Health Resources and Services Administration (HRSA) build language about resources required to effectively engage patients, donors, and family members into the contract. Continued improvements to the SRTR website were discussed, with a focus on increasing interactivity, accessibility, and patient-centered features. Members stressed SRTR's role as a trusted source of unbiased research and emphasized the value of process improvement and data transparency.

Dr. Earnest Davis and Mr. Hillenburg highlighted the depth of trust that the public and transplant community have in SRTR, attributing it to human-centered design efforts and ongoing patient engagement beyond one-off events. They called to build ongoing channels for patient input and to act on their feedback, which resonated broadly with committee members.

Members discussed the technical and policy challenges around redundant data sets available from multiple federal and contractor sources. Dr. Ryo Hirose stressed the need for unified data sharing agreements across Department of Health and Human Services (HHS) entities to empower SRTR as a single-source provider. Transparency in methodologies, centralized access, and standardized datasets were seen as foundational for research, trust-building, and public communication. The committee supported further refining of these recommendations before submitting them to HRSA, with a target to finalize documents by the end of April.

SRC Nominations Committee process kickoff

Dr. Hart initiated discussion on the 2025 nomination process, emphasizing the need for earlier timelines to ensure adequate candidate solicitation and review. Updates were provided regarding upcoming rotations and the need to fill several roles on the Patient and Family Affairs Subcommittee (PFAS), including a co-chair position. Changes to the nomination process this year include more explicit involvement of the subcommittee co-chairs in reviewing and recommending their own members.

Volunteers were solicited for the SRC Nominations Committee, with multiple members stepping forward, including Dr. Perito, Dr. Amit Mathur, and Mr. Hillenburg. The group approved the newly proposed timeline for nominations from a motion by Mr. Van Slyck, seconded by Dr. Magee, with unanimous approval. The call for nominations will launch May 1, 2025, and close on July 31, 2025. Dr. Roslyn Mannon and Ms. Mona Shater highlighted the importance of outreach through multiple stakeholder networks,

including OPOs, transplant-specific organizations, and patient foundations, to ensure a diverse and qualified pool of candidates.

[Several recommendations for organizations to include were made through the Zoom chat.]

Donation and Transplant System Explorer updates

Dr. Nick Wood presented enhancements to the Donation and Transplant System Explorer tool. Based on prior feedback, new privacy protections have been implemented, such as limiting data to rolling 365-day windows and calculating metrics on a weekly (not daily) basis to prevent identification of single transplants at specific sites. He shared that additional feedback from transplant centers and OPOs was overwhelmingly positive, and users have requested comparison functionality. Mr. Hillenburg provided feedback on potential privacy concerns, particularly in pediatric and rare organ programs. Dr. Wood explained the proposed plan of releasing the public version of the application and updating the version on the shared site for access by transplant programs and OPOs, and he called for the committee to vote on the proposed plan. The motion to publicly release the application was brought forth by Mr. Scott McPhee and seconded by Mr. Van Slyck, with unanimous approval by the committee members. Ms. Shater and the communications team will prepare outreach strategies to ensure the transition is well communicated to stakeholders.

[Ms. Dunne noted through the Zoom chat that HRSA would like to meet with Dr. Wood and the SRTR team to review technical questions and communicate feedback prior to the launch of the Explorer updates.]

Update on inclusion of other multiorgan recipients on posttransplant evaluations

Dr. Jon Miller provided a historical overview of SRTR's efforts to evaluate multiorgan transplant outcomes, tracing the initiative back to 2014 when the Membership and Professional Standards Committee (MPSC) requested exploratory analyses for combinations beyond heart-lung and kidney-pancreas. While models for simultaneous liver-kidney transplants were developed, the initiative lost momentum by 2015 due to a lack of decision-making on accountability and methodology. With renewed MPSC interest, especially following recent discussions at the OPTN Board, the topic has resurfaced. Current reporting includes separate reports for kidney-pancreas and heart-lung transplants, with limited descriptive data appended to other organ reports. However, most other multiorgan combinations are still under-represented in formal analyses and flagging systems.

Committee members broadly supported the inclusion of multiorgan data in SRTR reports, even if not used by MPSC for performance evaluations. Dr. Jesse Schold emphasized that excluding these transplants creates gaps in transparency and understanding, particularly for stakeholders and clinical teams. Dr. Mathur and others highlighted the clinical value of such data for programs, irrespective of regulatory use. Dr. Magee cautioned against over-adjusting statistical models and stressed the importance of visibility for all transplant types. Mr. Hillenburg raised concerns about pediatric equity, with a call for more granular reporting that could inform ethical and policy discussions.

The committee discussed statistical complexities, including whether to develop separate models for multiorgan recipients or incorporate them into existing models with interaction terms. Dr. Jon Snyder concluded that SRTR can move forward independently to provide robust reporting options, allowing for both stand-alone and integrated analyses. There was consensus on advancing multiorgan transplant evaluation as a priority, with initial focus areas including kidney-liver and kidney-heart due to their

increasing prevalence. The conversation wrapped up with strong support for including multiorgan recipients in both the modeling and public-facing reports to enhance clinical insight, policy relevance, and transparency.

[Break for lunch]

Unified SRTR home-page project and professional site updates

Dr. Cory Schaffhausen provided a comprehensive update on the ongoing transformation of SRTR's digital presence, particularly focusing on the merging of two websites: the current main site (srtr.org) and the patient-focused site (preview.srtr.org). The goal is to consolidate both platforms under srtr.org with an updated design and user interface that caters separately to patients and professionals. New home-page mock-ups show a forked structure where patients and donors are directed to a more accessible, resource-rich area, while professionals can easily access tools like program-specific reports (PSRs), OPO-specific reports (OSRs), and data explorer features.

Dr. Schaffhausen emphasized that the migration process involves updating around 20 technical and content-heavy pages to fit the new design format. He also discussed new digital tools in development, including the long-term outcome tool, the kidney personalized waiting time app, and the patient-specific transplant center search tool. These efforts aim to deliver tailored and intuitive decision support resources for patients, particularly those at the pretransplant stage. In addition, the SRTR team is enhancing the site's mobile-friendliness, especially menus and footers, to ensure accessibility across devices.

A lively discussion followed about the kidney waiting time tool and the broader vision of providing personalized transplant decision-making resources. Dr. Grace Lyden clarified the methodology behind the waiting time model and how it aligns with the existing kidney decision aid, while Dr. Hart explained that multiple patient-centered tools are being staged to launch with the updated website, rather than being placed on the current platform. Dr. Will Parker raised the future potential of real-time, personalized apps integrated with patient medical records, prompting reflection on current capabilities and aspirations.

Mr. Hillenburg and others noted the longstanding discussions around offering more real-time data to patients, a topic long debated in the OPTN Patient Affairs Committee. Dr. Mannon praised the utility of the current tools, particularly the patient journey map, and emphasized the importance of promoting these tools to referring physicians and pretransplant staff. There was also discussion about future funding models for tool expansion, including possible engagement with pharmaceutical companies for nonbranded support.

Patient-specific search updates

The conversation then shifted to SRTR's plan to introduce a patient-specific search tool, similar in function to transplantcentersearch.org. This tool will allow patients to input personal characteristics like age or insurance type and see search results highlighting how many similar patients have received transplant at various centers. While this approach promises personalization, Dr. Schold cautioned about the risk of patients misinterpreting such data as indicative of a center's listing criteria. Dr. Schaffhausen acknowledged the concern and explained that their communication strategy would focus on transparency and avoid overpromising what the data can infer.

Dr. Schaffhausen went on to explain how SRTR is designing the tool to accommodate different types of users: some may prefer a simple search, others may seek deeper insight through the personalized option, and some may realize that their characteristics do not significantly affect access. He described how the side-by-side comparison tool currently available could evolve to include patient-specific filters and even referral characteristics once new prelisting data become available. Throughout the update, Dr. Schaffhausen reiterated the goal of ensuring thoughtful design and future scalability.

Town hall webinar draft agenda

Dr. Schaffhausen provided updates on the webinar follow-up to SRTR's Task 5 consensus conference held in 2022. Originally envisioned as a multiday conference, the event will now be a 1-hour webinar due to HRSA constraints. This webinar will cover key areas such as pretransplant/posttransplant insights, living and deceased donation, and a recap of progress on specific recommendations from the original conference. Drs. Schaffhausen and Snyder noted that while the webinar will highlight top achievements and tools, more granular updates, such as status on each of the 160 recommendations, could be made available via the SRTR website.

Dr. Perito and Mr. McPhee encouraged incorporating post-event feedback mechanisms and suggested using modern collaboration tools to enhance interactivity. Dr. Perito also proposed creating brief social media clips to promote the event and increase awareness of patient-facing tools. In response, Ms. Shater assured members that feedback options, either through forms or email, will be available and that recorded content will be published on SRTR's YouTube channel. The session ended with support from the SRC for continuing to develop these resources and offers to assist in distilling webinar content for maximum impact in a short timeframe.

Update on kidney-pancreas waitlist mortality following March MPSC meeting

Dr. Lyden presented a major methodological update to how kidney-pancreas transplant candidates will be evaluated in SRTR's PSRs, specifically regarding the pretransplant metrics: waitlist mortality and transplant rate. Historically, kidney-pancreas candidates were only included in their stand-alone kidney-pancreas report and not in the kidney or pancreas reports, unlike other multiorgan combinations like heart-lung or kidney-liver, where candidates appear in multiple reports. This inconsistency meant that the MPSC, which was relying solely on single-organ reports, was not evaluating kidney-pancreas candidates in pretransplant mortality assessments, creating a blind spot. After detailed analysis and consultations with both the SRC's Analytical Methods Subcommittee (AMS) and the MPSC, the approved solution was to include kidney-pancreas candidates in all three applicable reports: kidney, pancreas, and kidney-pancreas. This change brings consistency across multiorgan reporting and ensures that kidney-pancreas candidates are no longer omitted from MPSC review.

Dr. Lyden presented analytic results showing that while the change had minimal impact on kidney programs (due to their large candidate base), it had a notable effect on pancreas programs. Adding kidney-pancreas candidates significantly increased sample sizes for pancreas programs, which shifted several centers' metrics and led to new MPSC flags. Roughly the same number of pancreas programs saw their rate ratio increase as the number that saw a decrease. Discussions also surfaced around the clarity of reporting, with Dr. Perito suggesting that footnotes or summary lines be added to clearly indicate how many patients were kidney-pancreas versus single-organ candidates. While Dr. Lyden acknowledged the importance of transparency, she noted that identifying and breaking out other multiorgan combinations

(e.g., liver-kidney) remains challenging, whereas kidney-pancreas data are more accessible and could potentially be broken out for users. The implementation of this change will begin with the Spring 2025 PSR release, and the team committed to resolving final data nuances such as double-counting risks and program totals to ensure accurate and user-friendly reporting.

SRC subcommittee informational reports

Dr. Davis and Mr. Hillenburg, PFAS co-chairs, shared updates on efforts to diversify the subcommittee's representation and strengthen its role within SRTR. Two new members were added: a heart transplant recipient who is also a physician, and a nondirected donor with professional experience in finance from Texas, both selected to broaden the diversity of lived experience and geographic representation. The core mission of PFAS at this time is centered on increasing awareness of SRTR resources, especially before transplant. Members observed that many transplant recipients discover SRTR tools only after surgery. As a result, PFAS is exploring proactive outreach strategies, such as publishing articles, contributing to SRTR's newsletter, and engaging in partnerships that amplify SRTR's visibility among patients and caregivers. An upcoming April meeting will further define the subcommittee's charter, with the aim of clarifying its long-term objectives and scope of support for SRTR.

Discussion turned to SRTR's online visibility, with Mr. Van Slyck noting that searches for transplant resources do not often surface SRTR in early results. Ms. Shater explained that unlike organizations such as UNOS and the National Kidney Foundation (NKF), SRTR relies on organic search traffic rather than paid advertisements, which affects its search engine rankings. However, SRTR still sees substantial organic engagement—14,000 to 19,000 monthly visitors. Mr. Hillenburg and Ms. Shater emphasized the importance of building partnerships with patient-facing organizations and leveraging community networks. Members suggested strategies such as cross-linking with partner organizations, building search engine optimization (SEO)–friendly content, and possibly investing in paid promotion to improve discoverability. They also praised direct community outreach efforts like webinars and support group presentations, which have yielded meaningful engagement.

Dr. Lyden and Dr. Parker provided updates on upcoming topics for the AMS. Dr. Lyden clarified a prior data discrepancy from her presentation on kidney-pancreas metrics and outlined several discussion points for the next AMS meeting, including reconsidering whether transplant programs with only 6 months of follow-up should be evaluated for 1-year posttransplant outcomes, and whether programs with zero recent transplants should have public tier rankings. Dr. Lyden reviewed previous discussion regarding the concept of incorporating "historical priors" from Bayesian statistics into SRTR's evaluations, essentially allowing a program's past performance to inform its current tiering, especially for smaller centers with limited data. This could help consistently high-performing programs achieve higher tier rankings even with small sample sizes.

Dr. Schold emphasized the importance of including all available follow-up data in risk models, even when patients do not reach a full follow-up period, arguing it improves both analytical accuracy and timeliness. Dr. Miller clarified that while standard survival methods are used, the issue arises when new programs have only 6 months of data, and yet a 1-year survival estimate is presented, potentially biasing results. The group largely agreed that this practice should be reevaluated. Dr. Parker added that the Centers for Medicare & Medicaid Services (CMS) uses mixed-effects models that may better capture hospital-level effects, offering an alternative approach. He also updated the group on the approval of a manuscript on

"death after delisting," highlighting its importance for understanding patient outcomes beyond the transplant waiting list, especially with decaying data quality.

Dr. Schaffhausen and Mr. McPhee reported on recent and upcoming activities of the Human-Centered Design Subcommittee (HCDS). Their latest meeting focused on strategic implementation of the patient-specific transplant center search tool, which is being refined in partnership with Dr. Ajay Israni's development team that created the transplantcentersearch.org site. Dr. Davis attended the design session, signaling increased collaboration between the HCDS and PFAS. Future HCDS discussions may explore broader approaches to design integration as SRTR prepares for contract rebid and next-phase planning. Dr. Schaffhausen acknowledged the impact of the widely adopted SRTR "subway map" visual, which is now seen as an iconic tool for illustrating the transplant journey, and welcomed suggestions for extending it to cover posttransplant scenarios and nuanced patient pathways. Mr. Hillenburg proposed customizable versions of the map and encouraged more inclusive layers to represent long-term care trajectories.

Closing business

Dr. Snyder highlighted the productive synergy across the three SRC subcommittees and applauded their role in advancing patient-centered design, analytics, and communications. He also announced a leadership transition in the OPTN Policy Oversight Committee, with Jennifer Prinz stepping down and Erika Lease slated to take her place. The next SRC meeting is scheduled for July 8, 2025, from 1-4 pm CT via Zoom. Ms. Cook reminded attendees to complete the scheduling poll for the October meeting. Hearing no further business, Dr. Magee and Mr. Van Slyck thanked the members for their participation and adjourned the meeting.