SRTR Review Committee Meeting Minutes

via Zoom

January 31, 2025, 1:00 – 4:00 PM CST

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

Ex-Officio Members:
Rebecca Goff, PhD (UNOS-OPTN)
Jesse Schold, PhD (OPTN-DAC)

Not in Attendance:
Adriana Alvarez, MS (HRSA)
Jennifer Brock (HRSA)
Ricardo Cale (HRSA)
Brianna Doby, MPH (HRSA)
Shannon Dunne, JD (HRSA)
Jayme Locke, MD, MPH, FACS, FAST (HRSA)
Raymond Lynch, MD (HRSA)
Jonah Odim, MD (NIH)
Jennifer Prinz (OPTN-POC)

SRTR Staff:
Avery Cook, MPH, MSW
Earnest Davis, PhD, MHSA
Tonya Eberhard
Allyson Hart, MD, MS
Ryutaro Hirose, MD
Lawrence Hunsicker, MD, PhD
Amy Ketterer
Sydney Kletter
Grace Lyden, PhD
Roslyn Mannon, MD
Maria Masotti, PhD
Warren McKinney, PhD
Jonathan Miller, PhD
Caitlyn Nystedt, MPH
Cory Schaffhausen, PhD
Mona Shater, MA
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. The co-chairs welcomed new members Dr. Amit Mathur, Dr. William Parker, and Mr. Joseph Hillenburg. The members introduced themselves with a brief overview of their roles. Dr. Jon Snyder reviewed that ex-officio members from the Health Resources and Services Administration (HRSA) were unable to join today but requested the meeting be recorded. Dr. Snyder reviewed the agenda, and Dr. Magee thanked members for keeping their conflict-of-interest forms up to date.

Approval of August and October 2024 SRC meeting minutes

Dr. Snyder reviewed that for the August 14, 2024, meeting minutes, HRSA raised concerns about a detail regarding discussion of the organ procurement organization (OPO) performance metrics. He recapped that approval of the August minutes was put on hold following the October meeting. Following review of the transcript of the August meeting, the minutes were expanded to capture the breadth of the discussion. HRSA and SRC leadership have reviewed and given preliminary approval

of the minutes as edited. Dr. Magee asked for a motion to approve the edited minutes from August 14, 2024, which was motioned by Ms. Deb Maurer and seconded by Dr. Emily Perito. There were no oppositions and three abstentions from the new members who were not present at the previous meeting. The minutes were approved unanimously.

Dr. Magee moved on to the October 17, 2024, minutes from the in-person meeting in Rockville, Maryland. He called for a motion to approve the minutes, which was motioned by Ms. Maurer and seconded by Mr. Scott McPhee. There were no oppositions and three abstentions from the new members who were not present at the previous meeting. The minutes were approved unanimously.

Current SRTR operational holds

Dr. Snyder shared that on January 22, 2025, SRTR received an "operational hold" from HRSA, directing SRTR to pause all communications, including social media posts, speaking opportunities, web posts, press inquiries, and newsletters. He reported that this did not have a major impact on SRTR's day-to-day operations, as the program-specific reports (PSRs) and OPO-specific reports (OSRs) had already been updated earlier in the month, and the newsletter had already been distributed. He also noted that specific permission was received to host this meeting and The Alliance's webinar presentation on January 28, 2025. Dr. Snyder explained that the communications pause expires on Saturday, February 1, 2025, and hopefully more would be known about next steps on Monday, February 3.

Dr. Snyder also mentioned that SRTR received guidance to forward any press inquiries to the HRSA Office of Policy and Public Affairs. He reviewed that the next upcoming release is the Annual Data Report (ADR), including in the *American Journal of Transplantation*, which was targeting February 4, 2025, for publication, which HRSA was aware of and had not raised concerns about moving forward with. Dr. Mathur raised a concern about a potential delay of the ADR, to which Dr. Snyder said he would keep the SRC updated via email.

Ms. Maurer questioned the impact of the communication pause on the cumulative sums (CUSUMs), and Dr. Snyder confirmed that specific permission was received to update these metrics, likely later this evening, as they typically update once a month on the first of the month. Dr. Jesse Schold questioned whether there were any changes in access to the data for research purposes, to which Dr. Snyder confirmed that SRTR was not told to hold any type of fulfillment of research requests.

Dr. Ryo Hirose opened this up to a larger discussion with the group about being asked to comment under their institutional roles rather than as representatives of SRTR. Dr. Perito and Mr. Van Slyck cautioned against saying anything that could be misconstrued and noted the difficulty of controlling a narrative in the current media landscape. Dr. Mathur encouraged those making public statements to stick to publicly available data, while also clarifying that statements could be made from under organizational umbrellas other than SRTR. Dr. Snyder thanked the group for their input.

SRC charter review

Dr. Snyder reviewed the SRC Charter and highlighted several proposed changes to the document. Dr. Snyder reviewed the need for clarity around the ex-officio roles, including designating the SRTR director as an ex-officio nonvoting member, as is done for the subcommittees, and the designation

of three ex-officio nonvoting members representing the Organ Procurement and Transplantation Network (OPTN). He shared that, historically, someone has represented the OPTN contractor, the United Network for Organ Sharing (UNOS), as well as the chairs of the OPTN Policy Oversight Committee and the OPTN Data Advisory Committee. Dr. Snyder raised the question of how the ex-officio seat would be split among multiple OPTN contractors and pointed out the change in verbiage that HRSA can appoint ex-officio members from any federal agency with no specified number. He clarified that the Charter has been amended to state that all ex-officio positions are nonvoting. Mr. Van Slyck questioned whether this could be voted on at this time, and Dr. Snyder opened the floor up to discussion. Dr. Snyder expressed concern about having ex-officio members from each OPTN contractor, which would be approximately 15 contractors, with this concern echoed by Dr. Rebecca Goff, Mr. Hillenburg, and Dr. Magee. Dr. Magee requested a motion to approve the Charter as written with knowledge that this may be revisited at another meeting. The approval was motioned by Ms. Maurer, seconded by Dr. Mathur, and approved unanimously. Dr. Snyder thanked all members for their input.

SRTR 2025 strategic plan review

Dr. Snyder detailed the current contract that SRTR holds with HRSA, providing background about the contract term that ends in September 2025 and highlighting key initiatives that SRTR is working on completing this year. He detailed the efforts to migrate content to the new patient-friendly website and the creation of a home page that would link the patient-facing website and the existing website. He also explained that another high-priority item is to support and engage with OPTN Modernization contractors, and working with OPTN to finalize the Living Donor Collective (LDC) data capture to implement a living donor registry. Mr. Hillenburg questioned whether the scope of the LDC data capture could be expanded to include third-party organizations, such as Donate Life America. Dr. Snyder explained that Donate Life America has focused on the recruitment of new organ donors and connection of potential donors to transplant systems, while this registry would be dedicated to following the health, well-being, and safety of the living donor community. Ms. Maurer encouraged Dr. Snyder to seek out help completing these efforts if needed, citing that SRTR is a lean organization but may need more assistance to meet the goals surrounding OPTN Modernization in this timeline. Dr. Magee asked for a motion to approve as currently proposed and written, which was motioned by Ms. Maurer and seconded by Mr. McPhee. The motion was unanimously approved.

Performance Work Statement review

Dr. Snyder detailed previous discussion by the SRC at the October 2024 meeting about providing HRSA feedback on the SRTR Performance Work Statement (PWS). He noted that the end of SRTR's contract approaches in September 2025, with a request for proposal (RFP) to be released by HRSA for the next contract in early summer, typically June or July. Dr. Snyder explained that at this time, SRTR would like to provide feedback on the PWS as has been done in past contract cycles. He asked for the committee to provide feedback on the PWS and potential ways the PWS could be modified to present to HRSA. The group held a discussion regarding whether the committee would want to proceed with helping to clarify the tasks that SRTR completes and the decision to form a working group to provide feedback on the PWS. Dr. Schold articulated his support for providing feedback on

the PWS and the importance of sharing this with HRSA so this can be codified into the new SRTR contract. Mr. McPhee encouraged Dr. Snyder and the SRC to not be bound by the tasks provided by HRSA and to add any tasks that would be relevant to the next contract cycle. Mr. McPhee expressed his support and willingness to take part in a working group to provide feedback on the PWS. Dr. Earnest Davis echoed his support for a working group and proposed involving patient representatives from the Patient and Family Affairs Subcommittee (PFAS) for their input as well. Mr. Van Slyck corroborated that the efforts of the working group and PFAS should be written down with the intention of presenting to HRSA at the April meeting. Dr. Roslyn Mannon detailed the importance of presenting this information. Dr. Perito highlighted the importance of focusing on specific areas of the PWS for improvement and providing feedback to HRSA. Dr. Hirose discussed the importance of articulating the value of SRTR and its independence from OPTN, highlighting SRTR's role in improving patient outcomes as well as providing valuable data and publications. Dr. Snyder suggested a timeline of 1 month for the working group of himself and Drs. Davis, Mannon, Hirose, and Dr. Allyson Hart, as well as interest from Dr. Mathur. The conclusion was to provide HRSA with two documents: one about the value SRTR brings to this position and one of potential changes with the next iteration of SRTR.

Donation and Transplant System Explorer updates

Dr. Nick Wood reviewed the SRC's recommendation from the April 2024 meeting to add functionality to the Donation and Transplant System Explorer for allowing comparison of OPOs and transplant centers. The addition of functionality was discussed at the October 2024 meeting and, at that time, was recommended to be launched on the SRTR secure site and to collect feedback from users of the site. Dr. Wood reviewed that the current Explorer on the public site was launched a year ago and shows national trends. The updated functionality was launched on December 17, 2024, and feedback was collected from three transplant programs and one OPO.

Dr. Wood reviewed the feedback received. The first transplant program stated that this functionality was very useful but wanted to see functionality added that would allow them to benchmark, to have more ways to compare their program and national data trends or their program and other programs; the second transplant program asked questions about their own data, inquiring about what a specific metric meant; the third transplant program was also looking at their own data, but did not provide specific feedback about the additional functionality. The OPO feedback was very positive, specifically citing looking at comparisons of OPOs and national trends or comparisons between OPOs.

Dr. Wood proposed that the public version, which shows national trends, be replaced with this updated, secure version, which can be program specific. He added that updates would be added based on user feedback. The committee discussed the potential implications of presenting the updated version on the public-facing site. Dr. Schold raised concerns over the potential for identifying patients on low-numbered waiting lists due to the specificity of the data. Mr. Hillenburg echoed that concern and expanded it to include examples of pediatric programs at low-volume centers, addressing concerns over the potential for patient identification. Mr. Van Slyck commented on the amount of feedback collected, expressing disappointment and asking about the marketing and tracking methods for collecting page visits and making sure the population we are seeking

feedback from is aware of the tool. Dr. Mathur also echoed these concerns, stating that he was unaware of this Explorer and found it to be a useful tool. Ms. Mona Shater shared that the availability of the tool was broadcast to the secure site users through social media and other marketing pushes, but that the Explorer has not performed as well on the secure site as it does on the public-facing site. Dr. Perito suggested amending the tool to hide the values if less than 10. Dr. Snyder shared that SRTR is not required to do this, but SRTR could look into this if there are concerns about patient identification. Mr. Van Slyck and Ms. Maurer proposed gathering more feedback around the tool before releasing it with expanded functionality on the public-facing site. Dr. Hart asked the committee for suggestions on how to engage users to bring further awareness and feedback for the updated tool; she cited ongoing concerns toward tools available on the patient-friendly website and awareness around them.

[Ms. Maurer had to leave the meeting during this discussion]

Dr. Wood concluded the robust discussion with the determination of two separate concerns: not enough feedback to feel comfortable releasing the updated tool and potential privacy concerns with smaller programs. He suggested that SRTR continue to gather feedback and mitigate small sample concerns, which would then likely be reported to the SRC at the next meeting. The committee held a vote to approve of further mitigation and feedback. Dr. Mathur motioned for a vote, which was seconded by Mr. Van Slyck. The vote passed unanimously with no opposition or abstention. Drs. Magee and Perito remarked that this is an impressive application and praised Dr. Wood's efforts in its development. Dr. Wood thanked the committee for their feedback and agreed to keep the committee updated as feedback continues.

Long-term outcomes applications

Dr. Jon Miller revisited the topic from the October 17, 2024, meeting regarding the long-term outcomes application and the kidney tab of the calculator, which may be missing graft failures due to the loss of the Centers for Medicare & Medicaid Services (CMS) End-Stage Renal Disease (ESRD) data. He noted that the data discrepancies were discussed during the Analytical Methods Subcommittee (AMS) meeting last week, and it was found to diverge slightly with long-term follow-up; at 7 years, there was a 0.8% difference, showing 70.4% survival at the national average and 69.6% survival with the inclusion of the CMS ESRD data. He reported that the AMS voted to release this application with a note in the kidney tab of the long-term outcomes application that states that dialysis-free graft survival estimates might be slightly overestimated. Dr. Schold remarked that, given that these are long-term outcomes, spanning 7 or 10 years, to have this deviation is still surprisingly modest, but stressed the importance of re-establishing connection with the CMS ESRD data. Mr. Hillenburg highlighted that this tool was developed as a result of the 2022 Consensus Conference and the patient input was instrumental in completing this application. Dr. Miller asked for the SRC to vote to move toward launch of the long-term outcomes application. Dr. Carli Lehr motioned the vote, which was seconded by Dr. Parker. The vote passed unanimously with no opposition or abstentions.

Handling of multiorgan transplant in SRTR metrics

Dr. Grace Lyden brought forth a brief informational topic regarding the handling of multiorgan transplant candidates in pretransplant mortality rate evaluations. She explained that multiorgan transplant recipients are easy to identify, but candidates are not as easy to identify, with the exception of kidney-pancreas and heart-lung. She highlighted that the reports produced by SRTR include a kidney-pancreas report and a heart-lung report, but other multiorgan candidates appear in the concurrent reports for their respective organs. She gave an example that if someone registered for a kidney-liver transplant, they would appear on the kidney and liver reports separately, and if they died while waiting for a transplant, the death would be recorded in both the kidney and liver reports. This is also similar for heart-lung transplant candidates, who would appear on the heart-lung, heart, and lung reports because they are registered on all three waiting lists, per UNOS guidance. However, kidney-pancreas does not have that same guideline. Kidney-pancreas candidates therefore appear only in the kidney-pancreas report, not also the kidney report and pancreas report. She detailed a proposal to add kidney-pancreas candidates into kidney reports and pancreas reports, to have consistency across multiorgan evaluations. Dr. Lyden articulated that this would have the most impact on the pancreas report, as that is a very small candidate population. She explained that this was presented to the Membership and Professional Standards Committee (MPSC) in December 2024, and SRTR would be doing further analysis to determine the extent of the impact that this change would make. Dr. Lyden reiterated that nothing is changing at this time, but she wanted the SRC to be aware as this makes its way through the MPSC, because it may come to the SRC in the future—if the MPSC moves in that direction.

SRC subcommittee informational reports

Dr. Snyder reviewed that several of the SRC subcommittees have met recently and asked the respective co-chairs to give a brief update on their activities. Dr. Davis shared that PFAS has been focused on its charter to make sure that SRTR is supported by PFAS based on the PFAS charter, and Mr. Hillenburg highlighted changes in membership and speaking with members about their drive to serve on the subcommittee. Dr. Lyden shared that the AMS met last week, and Dr. Maria Masotti presented her findings on a recent uptick in survival after delisting, starting around 2014-2015 for heart, liver, and lung candidates; this uptick indicates that there may be data quality issues after candidates are removed from the waiting list and with reporting of patient deaths, which is not standardized. She shared that the AMS voted to approve a pilot study using the National Death Index (NDI) data, and they are in the process of working out logistics with this. Dr. Cory Schaffhausen shared that the Human Centered Design Subcommittee (HCDS) is planning to meet in March to continue work to migrate the existing SRTR.org and preview.SRTR.org websites. He and Mr. McPhee highlighted the priority of creating a patient-specific search for a transplant center for the migrated website.

Closing business

The next meeting is scheduled for April 10, 2025, at HRSA headquarters in Rockville, Maryland. Dr. Snyder reviewed travel planning preparations and directed members to contact Ms. Avery Cook with any questions. Ms. Cook shared that hotels must be booked by March 15, 2025. Hearing no further business, Dr. Magee and Mr. Van Slyck adjourned the meeting.