

Minutes

SRTR Visiting Committee

Date: July 16, 2018

Time: 9:00 AM-12:00 CDT

Second of Two Required Annual Teleconferences

Voting Members:

Susan Gunderson, MHA (Co-Chair)
Ken Newell, MD, PhD (Co-Chair)
Scott Biggins, MD, MAS
Jonathan Chen, MD
Richard Formica, MD
Walter Kremers, PhD
Rachel Patzer, PhD
Luke Preczewski

Absent Voting Members:

Bethany Foster, MD, MSCE

Ex-Officio Members:

Monica Lin, PhD (HRSA)
Jennifer Milton, MBA (OPTN-POC)
Jonah Odum, MD (NIH)
Darren Stewart, MS (OPTN/UNOS)

Guests:

Chris McLaughlin (HRSA)
Cory Schaffhausen, PhD (MMRF)
Joyce Hager, MPH (HRSA)
Jim Bowman, MD (HRSA)
Marilyn Levi, MD (HRSA)

SRTR:

Bertram Kasiske, MD
Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Allyson Hart, MD, MS
Larry Hunsicker, MD
Nicholas Salkowski, PhD
Andrew Wey, PhD
Laura Klein, MPH
Mona Shater, MA
Katie Audette, MS
Alyssa Herreid, MPH
Bryn Thompson, MPH

Welcome

Co-Chair Susan Gunderson called the meeting to order at 9:05 AM CDT.

Dr. Jon Snyder roll-called the participants. All voting members of the committee except Dr. Bethany Foster were present. Non-voting members and guests also introduced themselves. Numerous staff members from HRSA were present for the discussion.

Dr. Bert Kasiske informed the committee on the topic of conflicts of interest (COIs). Dr. Kasiske emphasized that SRTR must ensure management of any potential conflicts, and asked committee members to bring forward any potential COIs during deliberations and recuse themselves from related discussions.

Offer Acceptance Tool (Slides 6–18)

Dr. Andrew Wey gave an overview of the offer acceptance tool, which was introduced to the committee about a year ago but has not been on recent meeting agendas. The goal of the tool is to inform the offer acceptance decision process by estimating the potential risks and benefits of accepting an offer versus declining and remaining on the waiting list for a subsequent offer. Dr. Wey noted that an article was published in AJT this year, and SRTR is currently developing code which would be used to regularly release updated versions of the tool.

Dr. Wey discussed the following implementation questions/issues related to the offer acceptance tool:

- 1) Cohort definitions require updating for public release; it is not computationally feasible to use several years of match run data.
- 2) Update schedule: SRTR plans to update twice a year, corresponding with PSR releases.
- 3) Appropriate website: Because technical aspects of transplant are included in the tool (e.g., offer number), patients should probably use it with physicians. SRTR proposes hosting the application on the secure site and publishing a link on the secure site that allows bookmarking.

Dr. Wey then opened the discussion to feedback from the committee. Drs. Larry Hunsicker and Walter Kremers had suggestions for sampling of dates, including rotating the months or providing a probability of inclusion in each of the months, or including, e.g., every fourth day. The committee also discussed restricting the tool to physicians, or allowing accessibility to patients as well. The general consensus was that the tool is targeted to physicians and transplant coordinators and should therefore be kept on the secure site, but a few committee members felt that that it should be posted on the public site to increase its use. There was also a suggestion to incorporate the tool into UNetSM or DonorNetSM, so it is accessible when acceptance decisions are made.

A motion was made to post the tool on the secure site. The committee voted 7 in favor, 1 opposed, 0 abstaining.

A second motion was made to post the tool on the public site, in addition to posting it on the secure site. The committee voted 2 in favor, 6 opposed, 0 abstaining.

SRTR Beta Website Public Comment Period Recap and Review (Slides 39–59)

Dr. Snyder gave a brief overview of the current status of the SRTR beta site. SRTR launched updates to the beta site on May 14, 2018, following SVC approval on April 18, 2018. The site included nine major improvements made in response to feedback received previously. A 60-day comment period was open from May 14–July 13, 2018. During the public comment period, SRTR received supportive and critical comments regarding the site (documents were included with SVC meeting materials). Dr. Snyder noted that the purpose of today's discussion is to review the comments received and decide future actions for the SRTR websites.

Dr. Snyder reviewed the comments SRTR received from the general public. Positive feedback included the following: (1) grateful for the content; (2) easier to read/understand than before; and (3) presenting this tiered system and the supporting data is valuable. Critical feedback included: (1) concern over how transplant rate is explained for patients' level of understanding (changes had been made in the most recent update); (2) time-frames/cohorts should be noted (are included in the full report); (3) confusion over the meaning of the national rates table (not showing cut points for each tier, but rather the experience of an average patient who underwent transplant at an average program within in each tier); and (4) misunderstanding the metric for the assessment.

Dr. Snyder reviewed the feedback SRTR received from ASTS/AST via its Metrics Task Force White Paper. The themes from white paper included (slide 58):

- Unintended consequences of public reporting: reducing organ supply, limiting patient access, barriers to innovation.
- Skepticism about risk adjustment, data validity, and C-statistics.
- Payer Conditions of Participation (CoPs) and Centers of Excellence designations.

- Patients have little/no choice of programs.
- High rates of false positive and false negative flags (referring to CMS CoPs).
- Little difference in failure rates across programs (citing only kidney outcomes and only on the absolute survival scale, Fig. 3).
- Need for patient-reported outcomes.
- Programs may not be responsible for graft failures or deaths.

The ASTS/AST white paper also included the following recommendations (slide 59):

- Rank order by performance.
- Use symbols rather than numbers.
- Provide an overall summary measure.
- Include fewer reporting categories.
- Combine data over multiple years to increase precision.
- Aggregate data from different measures.
- Incorporate patient-reported outcomes.
- Incorporate process measures.
- Better reimbursement.
- Collection of important data.
- Work more closely with the transplant stakeholders.

Dr. Snyder opened the discussion to feedback from the committee regarding next steps for the beta and public websites. The committee felt that some of the critical comments were rooted in misunderstanding, have already been addressed, or could be applied to any new system. There was general consensus from the committee that SRTR should move toward rolling the beta site over to the public site. However, members felt that before the committee makes a final recommendation, SRTR should develop responses to the comments. Those comments would then be reviewed at the September 11, 2018, SVC meeting, and the committee would make the final recommendation regarding the path forward for the website.

The committee discussed whether SRTR should respond to each comment separately, or group them by themes and respond to the overall themes. Committee members didn't have strong feelings either way, and left the decision up to SRTR. Dr. Ken Newell noted that responding to the societies in detail would probably be valuable.

The committee also discussed the specific feedback that finding a living donor is more important than the deceased donor transplant rate, which is not taken into account on the current beta site. There was a question as to whether SRTR can change the statement that "deceased donor transplant rate is the most important" to reflect the importance of living donor transplant. Dr. Nicholas Salkowski noted that there are definite challenges to creating a living donor metric. The committee agreed that addressing all of the factors involved with living donation would not be a quick and easy process.

Dr. Snyder concluded by saying that SRTR will work on compiling and responding to the public comments, and responses will be circulated to the committee ahead of the next meeting. In addition, SRTR will prepare a statement to post on the public site stating that the comment period is closed and SRTR is currently reviewing feedback.

The Role of the C-Statistic in SRTR Model Evaluation (Slides 20-37)

Dr. Wey reported that he and Dr. Salkowski have been working on ways to address the common criticism regarding “poor” C-statistics in the risk-adjustment models. There are two different but equivalent interpretations of the C-statistic in a risk-adjustment model: (1) the probability that the model correctly identified the graft that failed first among two randomly selected recipients; or (2) the ability of the model to accurately order graft failure times by estimated risk. Dr. Wey noted that C-statistics, in isolation, shouldn’t be used to assess the accuracy of program-specific evaluations. He then provided an overview and results of the simulation study (slides 24-36). Some discussion followed about the simulation study findings, and SRTR noted that a manuscript has been submitted to AJT detailing these findings.

Delay in PSR Production (Slides 61-62)

Dr. Snyder updated the committee on the cause of and timeline for the PSR production delay. He noted that HRSA, OPTN, and SRTR are currently working to regain access to the source of supplemental death information. A decision will be made as to when PSR production will resume once OPTN has supplied the July data to SRTR. In the meantime, SRTR is moving forward with the OPO-specific reports, which will be released in early August.

Updates as Time Allows

Survival-from-listing metric: Dr. Wey informed the committee that SRTR is currently trying to develop models for survival from listing; further updates are likely at the next meeting.

Kidney waitlist outcomes (slides 64-78): Dr. Allyson Hart informed the committee that the online tool is now publicly available. She noted that presentations on the tool and the models have been well received, and that she has received anecdotal feedback that the tool is “usable.” However, no official feedback has been submitted. Dr. Ajay Israni mentioned that the tool is now being used in clinical practice.

Geography in organ allocation policies: Dr. Snyder informed the committee that SRTR continues to support OPTN’s Ad Hoc Committee on Geography. He noted that SRTR has been working with the OPTN Liver and Intestine Committee to model potential allocation scenarios that remove DSA and region, and that other organ committees are also starting to assess the best way to remove DSA and region from their allocation systems. He also informed the committee that SRTR submitted a viewpoint article to AJT describing the “borderless” system that the Geography Committee advanced as a potential framework.

AHRQ-funded project (AHRQ slides): Dr. Cory Schaffhausen provided an update on the current status of the AHRQ project. The project recently hired two new qualitative researchers to contribute to publications. One article is currently in revision, one is under review, and one is in preparation. Dr. Schaffhausen summarized the national focus group feedback on the heart and lung presentation, and discussed where future work should focus (slides 5-11), including:

- A more detailed description of what the analysis means is important to interpretation; review existing linked document, e.g. literacy consultant.
- State end point for survival analysis.
- Remove second sentence from impact note for lung.

Dr. Schaffhausen summarized feedback received on mock-ups of "Overall Patient Survival." In general, the feedback was positive.

Dr. Ajay Israni concluded by discussing next steps for the project, which include developing a stand-alone website and a prototype for the patient-specific search, and performing usability testing in the coming months.

Living Donor Collective progress update: Alyssa Herreid gave a brief update on the status of the Living Donor Collective. She noted that seven of the ten pilot sites have been trained, and currently three sites have begun entering donor candidates into the database.

Closing Business

Susan Gunderson noted that the next SVC meeting will be held in Minneapolis, MN, on September 11, 2018. More information will be supplied regarding meeting logistics. The meeting was adjourned at 11:55 a.m. CDT.