

Minutes

SRTR Visiting Committee

Date: July 25, 2017

Time: 9:00 AM-3:30 PM CTD

Second of Two Required Annual In-person Meetings

Voting Members:

Susan Gunderson, MHA (Co-Chair)
Scott Biggins, MD, MAS
Walter Kremers, PhD
David Lederer, MD, MS
Dan Meyer, MD
Rachel Patzer, PhD (via phone)
Luke Preczewski

Absent Voting Members:

John Gill, MD, MS (Co-Chair)
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)
Eric Engels, MD (NCI)

Absent Ex-Officio Members:

Joseph Kim, MD, PhD (OPTN-DAC)

Guests:

Joyce Hager (HRSA)
Chris McLaughlin (HRSA) (via phone)
Janet Kuramoto-Crawford (HRSA, via phone)
Ralene Skerda (HRSA, via phone)
Cory Schaffhausen, PhD (MMRF)

SRTR:

Katie Audette, MS (via phone)
Ryan Follmer
Allyson Hart, MD, MS
Larry Hunsicker, MD
Ajay Israni, MD, MS
Bertram Kasiske, MD
Amy Ketterer
Laura Klein, MPH
Nicholas Salkowski, PhD
Mona Shater, MA
Jon Snyder, PhD, MS
Bryn Thompson, MPH (via phone)
Andrew Wey, PhD
Jessica Zeglin, MPH (via phone)

Welcome & Introductions

Co-Chair Susan Gunderson called the meeting to order at 9:10 AM CDT.

Regarding conflicts of Interest (COIs), Dr. Bertram Kasiske reminded committee members that SRTR must ensure that they manage any potential COIs, and asked them to bring forward any potential COIs during committee deliberations and possibly recuse themselves from related discussions. Dr. Kasiske reminded the members to contact SRTR with any changes to their COI disclosures.

Ms. Gunderson roll-called the members. Participating voting members constituted a quorum. Jennifer Milton disclosed a potential conflict, her connection to XynManagement.

Multi-Organ and Offer Acceptance Reports (Slides 6-20)

Dr. Jon Snyder explained that based on previous SVC recommendations, versions of the offer acceptance tables and multi-organ tables were included in the publicly released program-specific reports (PSRs) after a preview period from April 1 through June 15, 2017. Comments during the preview period were few, and all feedback was positive. Since these data were made public, feedback has continued to be positive, with some basic questions about how to read and interpret the data.

Dr. Snyder noted that this release of offer acceptance data was provided for kidney programs only, but SRTR is working on offer acceptance reports for liver, heart, and lung programs for potential release during the January 2018 PSR reporting cycle.

The committee discussed the reports and made a few recommendations for updating the language so programs could more easily interpret the data, e.g., possibly replacing references to KDRI with approximate KDPI values.

Preview of Recommended Changes for SRTR Website and Program Summary Metrics (Slides 21-23)

Dr. Snyder presented on continuing development of the SRTR website and the summary data provided on transplant programs in response to users' searches. He began with an overview of the recommendations from the previous SVC meeting:

- Keep the 3-tier outcome assessment on the main public website (www.srtr.org) while additional changes are explored.
- Keep the 5-tier outcome assessment on the beta site (beta.srtr.org) while the SVC evaluates the following recommended changes:
 - Add a tier system for transplant rate and waitlist mortality rate to provide more context for first-year transplant outcomes.
 - Change the transplant rate to a deceased-donor-only rate for kidney and liver programs, rather than including living donor transplants in the numerator of the calculation.
 - Split volume metrics into deceased and living donor transplants for kidney and liver programs.

Dr. Snyder illustrated how the changes might look if the SVC recommendation to add a tier system for transplant rates is followed (slide 23), noting that a more detailed mock-up of the site incorporating all suggested changes will be shown later in the meeting.

Public Reporting of Pretransplant Metrics (Slides 24-85)

Given that SRTR has not published a tiered transplant rate or waitlist mortality rate metric, the methodology for constructing these tier systems had to be developed. Following the May 2017 SCV meeting, at which the recommendation was made to add tiers for pretransplant metrics, SRTR developed a potential methodology for review. Dr. Andrew Wey presented the findings and suggested solutions.

Dr. Wey organized his presentation to cover both the methodology for deriving tiers for waitlist mortality and transplant rate, and anticipated criticisms of any presentation of pretransplant metrics on the initial search results page on the website.

Dr. Wey presented data demonstrating that variability across programs is greater for transplant rate than for waitlist mortality or first-year transplant outcomes, and the statistical power is vastly greater. These issues should be considered when devising a tier system for each metric. Dr. Wey highlighted that statistical hypothesis testing in the context of metrics with more or less power would lead to an undesirable tier system. The test would place most programs in the higher or lower tiers for transplant rate due to the higher degree of power, but would place most programs in the "no statistically significant difference" tier for waitlist mortality and posttransplant outcomes, thus

motivating a tier methodology specifically developed for this purpose and tailored to each metric using a logistic-type weighting function (slides 37-39).

There was lengthy discussion on the specifics of the methodology, with emphasis on how SRTR currently determines transplant and waitlist mortality rates. Some questions were raised about how much center outcomes should improve or worsen to move a program to a higher or lower tier. Dr. Rachel Patzer reiterated the consistent concern about pediatric programs not being fairly assessed. (That issue was to be resolved in the Pediatrics in PSRs section later.)

Dr. Wey showed the committee several examples of the distribution and concluded that the methodology using the weighted logistic function tailored to each metric would distribute programs more evenly among the tiers (slides 40-55). The methodology succeeds in placing programs in the tier with more similar transplant and waitlist mortality rate ratios, and categorization of programs would be less dependent on the sample size. Dr. Wey noted as a potential drawback of the proposed tier system that it is more difficult to calculate using standard tools, e.g., Excel-based calculations; however, SRTR could provide tools to the community to help programs understand and explore the calculation.

The discussion continued, and the overall feeling was that the website and search results page should focus on information that is beneficial to patients. The committee debated whether including waitlist mortality would benefit patients in their initial exploration of transplant programs, particularly patients considering kidney programs. The committee acknowledged that SRTR should provide information that is beneficial to patients while trying to avoid the unintended consequence of programs restricting access to transplant.

Dr. Wey presented on anticipated criticism of including pretransplant metrics on the initial search results page and how SRTR is working to proactively address these concerns.

Potential criticisms identified through previous interactions with the transplant community include:

1. Transplant rates disadvantage programs in low donor supply regions.
2. Transplant rates that include inactive candidates disadvantage programs that list candidates early.
3. Kidney transplant programs do not provide the care for waitlisted candidates.
4. Transplant rate can potentially be manipulated through listing practices.

The committee agreed that to achieve the goal of providing information to patients, a transplant rate based on national experience, without adjustment for regional supply/demand, is preferred. This way, patients can readily identify areas of the country with higher/lower transplant rates. Dr. Wey demonstrated a tool SRTR could provide on the website that would allow users to compare transplant rates within a defined geographic region if they wished to more fully understand regional transplant rates.

The committee agreed that the transplant rate metric should reflect the program's rate of deceased donor transplants after adding a candidate to its list. The new models SRTR is developing will more accurately reflect this rate without making adjustment for a candidate's active/inactive status following listing.

Dr. Wey cited historical comments by kidney program personnel, e.g., during development of the composite pretransplant metric being explored by the MPSC, that kidney programs often do not directly care for the candidates on their waiting lists. Therefore, providing waitlist mortality rates in the search results for kidney programs may be unpopular with kidney programs and potentially misleading to kidney candidates. The committee debated the merits of presenting kidney waitlist mortality on the initial search results for kidney programs (all agreed it was appropriate for other organ types). The committee did not agree on a concrete recommendation, but suggested that Dr. Ajay Israni and Dr. Cory Schaffhausen explore with kidney patients the merits of including waitlist mortality on the search results page as part of their AHRQ-funded research. Drs. Israni and Schaffhausen agreed to seek kidney patient feedback on this matter. The committee agreed that the waitlist mortality rate should be presented in the more detailed sections of the report, but was unsure whether it should be prominently displayed as part of the search results for kidney programs.

The committee agreed that SRTR should proceed with implementing the updated transplant rate and waitlist mortality rate models for all organs for inclusion in the PSRs. The decision of whether to include a tiered version of the waitlist mortality rate and transplant rate will be made at a future SVC meeting.

Dr. Wey noted that the new methodology for calculating transplant rate ratios will minimize the chance that a program could affect its transplant rate ratio by timing its listing of patients.

The committee discussed the chance that some programs may restrict access to the waiting list if transplant rates were displayed in the initial search results. Dr. Patzer suggested studying the feasibility of reporting on listing practices. This would require referral data, which SRTR does not currently have, acknowledging that USRDS data could be a source of information on end-stage renal disease patients. However, the committee acknowledged that attributing listing practices to a specific program would be difficult when referral data do not likely exist. This may also be beyond SRTR's scope.

Dr. Snyder showed a developmental version of the website that implemented the following major changes as suggested by the SVC at the previous meeting:

1. Outcome tiers for waitlist mortality were added.
2. Outcome tiers for transplant rate were added.
3. Transplant rate was modified to be a deceased-donor-only rate.
4. Transplant volume data for kidney and liver programs now present deceased donor and living donor volume separately.

In addition to these major changes, the following changes were implemented for the SVC's consideration (Figure 1):

1. Sorting now defaults to sort by transplant rate.
2. Interpretive text that formerly accompanied the tiers, e.g., "worse than expected," was removed.
3. To save space after addition of waitlist mortality tiers, the tier icons were switched from horizontal to vertical bars.
4. Descriptive text for the columns in the search results was updated to better describe the column content.

Figure 1

NAME	DISTANCE	DECEASED DONORS	WAITLIST SURVIVAL	GETTING A TRANSPLANT QUICKLY	SURVIVAL FOLLOWING TRANSPLANT
The transplant rate is a measure of how quickly patients undergo deceased donor transplant at the program. Living donor transplants are not included in this metric. Click here for more information.					
Mayo Clinic Hospital Phoenix, AZ View Summary Data View Complete Report (PDF)	N/A	50			
Ohio State University Medical Center Columbus, OH View Summary Data View Complete Report (PDF)	N/A	26			

The committee suggested that the colors of tier icons should not fade out as the tier decreases, but rather remain solid colors. SRTR noted that this change would be easy to implement as alternatively colored icons have already been created. The committee again debated the merits of including waitlist mortality rates, noting that too many metrics in the search results may confuse or overwhelm patients, and reiterated the request that Drs. Israni and Schaffhausen study this with their patient focus groups.

Creating a Patient-Centered Report Card (Slides 119-175)

Dr. Schaffhausen presented findings from his AHRQ study. He explained a survey he had done, per the SCV's request in May, to obtain feedback from patients on the metrics important to them as they consider transplant programs. Dr. Schaffhausen conducted three separate surveys partnering with the National Kidney Foundation, Transplant Recipients International, and Transplant Families. The three surveys did not collect data that would directly relate to potential inclusion of a mortality rate metric. Four hundred seventy-nine survey responses were analyzed. The surveys asked the following primary questions:

1. How many centers are reasonable to consider?
2. Rate the importance of factors:
 - a. Number of transplants.
 - b. How fast patients move to top of the waiting list.
 - c. Survival after transplant.
 - d. Distance from patient's residence.
3. Certain descriptors of transplant programs might be available in the future; rate the importance of each:
 - a. Experience treating people my age or with my medical condition.
 - b. Programs that help me find a living donor.
 - c. Living donor posttransplant outcomes.

- d. Deceased donor survival outcomes.
- e. Average- or lower-quality donor organ survival outcomes.
- f. The center is willing to use average- or lower-quality organs.

Dr. Schaffhausen found that over half of respondents rated the number of transplants performed, how fast patients move to the top of the waiting list, and survival following transplant as very or extremely important, while only about 30% rated distance from home as very/extremely important (slide 98).

The committee debated how to present the various metrics (waitlist mortality, transplant rate, and posttransplant outcomes) in a way that helps patients understand what is most beneficial to their survival, and noted that SRTR should provide more education to providers to help them guide their patients.

KL2-Funded Project: Creating a Decision Aid for Kidney Transplant Candidates (Slides 176-196)

Dr. Allyson Hart presented her findings regarding the decision aid she is developing under her KL2-funded project for kidney transplant candidates. She explained her background for the committee and explained the initial study, a project to help patients look at and use data to make decisions. Dr. Hart discovered that patients knew even less than she originally hypothesized they would. This helped form new study parameters. She found that patients are driven by emotional factors when trying to make difficult decisions. When people are overwhelmed by data, they fall back on emotional decision making. They expressed the need for resources and information they can revisit later.

Dr. Hart demonstrated the calculator tool she is developing to help kidney patients make decisions. When patients enter their medical characteristics and select a program, the tool will display three metrics: percentages who undergo deceased donor transplant, who die or become to sick, and who are still waiting. Results are shown with a bar graph.

It is a good tool for physicians, because it provides data to back up what they tell patients when discussing transplant, helping to close the education gap mentioned earlier.

Pediatric Patients in the PSRs (Slides 101-111)

Dr. Snyder updated the committee on progress made in changing the way pediatric and adult patients are classified in the PSRs. Following the May committee meeting, SRTR communicated the proposed change (to define pediatric patients based on age at the time of listing throughout the PSR) to the OPTN's Pediatric Transplantation Committee. The committee had no concerns with the proposed change.

SRTR further analyzed the effect of the change. Applying it to the January 2017 PSR cycle, certain adult transplant recipients would be reclassified as pediatric patients if they were listed before their 18th birthdays. For example (slide 106), of 27,327 "adult" and 1148 "pediatric" deceased donor kidney recipients, 226 adults were aged younger than 18 years at the time of listing. Reclassifying them as pediatric recipients would decrease the adult cohort by 0.8% and increase the pediatric cohort by 19.7%. Dr. Snyder noted that this would help SRTR build better risk adjustment models for pediatric recipients by increasing the power in the pediatric population.

Dr. Snyder noted that MPSC leadership has been consulted and its primary concern was communicating this change clearly to the transplant community. SRTR will develop a communication plan and HRSA will communicate this change to representatives from the Centers for Medicare & Medicaid Services. Ms. Gunderson asked for the a motion to put this option into practice pending programming. Dr. Walter Kremers moved to implement the proposed change. Mr. Luke Prezcewski seconded the motion. There was no opposition. The motion carried.

New Liver Model Review

Dr. Nicholas Salkowski presented the new liver models for posttransplant outcomes. He demonstrated from a live datasheet. There were no slides. These models will first appear on the SRTR secure website for program review and then be implemented in the January 2018 PSR cycle, pending programming. Dr. Salkowski reviewed the covariates included in the new models. The committee asked for clarification that Dr. Salkowski provided, specifically, how MELD scores are adjusted in the model and HCV status of the donor and recipient. In response to a question about including multi-organ recipients in the models, Dr. Snyder noted that all future SRTR models will include multi-organ recipients so SRTR can begin presenting expected outcomes for them. For now, multi-organ recipients are included in model development, with appropriate indicator variables, but excluded from the outcomes metrics derived from the models.

The committee suggested that binary indicators be presented only with 1 level rather than with level 2 to avoid confusion. Dr. Salkowski said that he can explore implementing this change and would choose the less common level as the indicator variable so the reference population is always forced to be the more common level of the binary indicator.

The committee also recommended that only non-zero predictors be shown when presenting the models, to minimize confusion. SRTR includes some predictors in each model refit that may have all zero coefficients; these variables were found to be predictive during the initial model build but lost their significance during the specific model run. A future possibility would be to provide only the non-zero coefficients when displaying the model, but supply an additional table of factors that were also considered but not found to add predictive value.

Mr. Prezcewski asked if SRTR could send the model to him. Dr. Salkowski affirmed that will be done.

OPO Yield Model Update

Dr. Wey briefly demonstrated the OPO yield models through the use of a web-based model visualization tool. There were no slides. The new OPO yield models include more variables than the models currently in use, and Dr. Wey briefly reviewed the included predictors, pointing out that some variables and interactions were included at the recommendation of community members, e.g., an interaction between age and DCD downtime as recommended by the MPSC-OPO joint working group, and the ejection fraction as recommended by an attendee at the AOPO annual meeting. HIV is also included in the new models following implementation of the HOPE Act. The new models will be provided on the SRTR secure site for OPO review. Ms. Gunderson offered to look at the models in more detail following the meeting. A motion to post the models for OPO review was made by Dr. Kremers and seconded by Mr. Prezcewski. The motion carried with no opposition.

Living Donor Collective

Dr. Kasiske gave a brief update on the progress of the Living Donor Collective. SRTR is currently establishing the pilot centers and the OMB is in process of approving the data collection forms. SRTR is hopeful the forms will be approved by the end of the year.

Closing business

Dr. Snyder noted that the next SVC meeting will be a teleconference held on October 4, 2017. More information will be supplied regarding meeting logistics. There was a call for additional business. There was none and the meeting was adjourned at 3:21 PM CDT.