# SRC-PFAS Meeting Minutes

## Patient and Family Affairs Subcommittee Teleconference

August 24, 2023, 10:00 AM – 11:30 AM CDT

**Voting Members:**
Ameen Tabatabai, liver recipient (Co-chair)
Dale Rogers, kidney recipient
Amy Silverstein, heart recipient
David Rodriguez, kidney and liver recipient
Rolanda Schmidt, PhD, deceased donor family member
Katie McKee, living kidney donor
Teresa Barnes, lung recipient family member
Stephanie Mullet, pediatric liver family member

**Not in Attendance:**
Christopher Yanakos, living liver donor

**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, SMS
Tonya Eberhard
Mona Shater, MA
Cory Schaffhausen, PhD
Grace Lyden, PhD
Yoon Ahn Son, MS

**Not in Attendance**
Ryutaro Hirose, MD

### Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. The subcommittee took a few moments to commemorate voting member Ms. Amy Silverstein, who passed away from lung cancer. Dr. Hart gave a few important updates. Construction for the new SRTR website is underway, and the new Living Donor Steering Committee under the Living Donor Collective initiative had its first meeting in July 2023.

Also, SRTR has created a new nominating system for all SRTR committees and subcommittees. Dr. Hart would inform members when the call for nominations goes out. Mr. Ameen Tabatabi added that the PFAS nomination process extended out to all the different experiences within the patient transplant community, and offered people different modalities to express who they are and their interest in joining PFAS (eg, a written piece or video). Ms. Mona Shater and Dr. Jon Snyder added that a call for nominations will go out in early September 2023, with a 30-day period for application submissions. Dr. Snyder said PFAS applications will be reviewed by Dr. Hart and Mr. Tabatabai and finalized by the SRTR Review Committee (SRC). It is planned for new members to be known by November for a January 2024 start. Dr. Hart reviewed the agenda items and proceeded with the first agenda item.

### Feedback: Heart transplant calculator

Before reviewing the heart transplant calculator, Dr. Grace Lyden briefly went over SRTR decision aids on srtr.org that are separated by organ (kidney and liver calculators). Both involve inputting specific information to predict certain outcomes such as probability of transplant, probability of death or of becoming too sick for transplant, and the probability of still waiting. Users can choose

which point in time they would like to predict these outcomes. Dr. Lyden said that, in an effort to expand these tools, the patient-friendly heart calculator was made to predict personalized outcomes for patients waiting for heart transplant and to be updated as patient status evolved.

Dr. Lyden gave background information on how the heart calculator was created. She explained the cohort for modeling consisted of first-time adult, heart-alone candidates who joined the waiting list from October 18, 2018, through May 31, 2022. This start date was chosen because a new heart policy went into effect in October 2018, which affected heart statuses. The final sample size was 14,054 and a machine learning approach was used. SRTR senior staff helped decide important predictors of waitlist outcome, and current transplant policies were also considered. Standard demographic characteristics of heart candidates were measured, include height, weight, certain health conditions, transplant center, medical urgency status, and qualifying criteria for status. Dr. Lyden added that status is measured by how sick a patient is, typically by what device is needed. Extracorporeal membrane oxygenation (ECMO) is most severe, whereas left ventricular assist device (LVAD) is not ranked as urgent. Mr. David Rodriguez said this was helpful to know. For patients too sick to use the calculator, their caregivers could have access to the tools and discuss it with their doctors.

Dr. Lyden demonstrated how someone might use the heart calculator. Users can select state, transplant program, and demographic factors. All inputs are specific to heart candidates. Users can choose how many months into the future to predict. The tool updates the probabilities accordingly based off the selection. Dr. Lyden said one capability of the tool was being able to choose both status at listing and current status.

Mr. Rodriguez asked if the model gave the top-five heart transplant hospitals for posttransplant outcomes. Dr. Lyden said that would be hard for the model to determine. Dr. Hart said it was important to consider that sometimes getting the transplant faster is more important. Mr. Dale Rogers said comparisons could be done by selecting a different state and transplant program. Dr. Lyden suggested having links to other pages on the SRTR website that present the tiers of different heart programs by time to transplant.

Mr. Rodriguez suggested adding high blood pressure as one of the selecting factors. Dr. Hart said it was also important to focus on what factors will change the predicted outcome. Dr. Ajay Israni asked the members if there was a need to define medical terms listed in the model. Mr. Tabatabai thought a glossary, presented as how the model frames different diseases mentioned, would be beneficial. This could be placed near the slider at the top that adjusts for time. He pointed out to consider where the calculator fits in for patients, maybe both seeing potential outcomes and understanding why the wait may be longer or shorter based off of selected factors in the model. Guiding patients through this thought process would be helpful. Dr. Lyden added the possibility of presenting the tool as a shared decision aid between patients and clinicians. Ms. Stephanie Mullet thought an imbedded glossary would be useful. She also suggested switching two colors on the bar graph, “still waiting” from black to orange, and “death or too sick to transplant” from orange to black.

The subcommittee discussed more use cases for the model. Dr. Lyden suggested it could include comparing outcomes at different centers, and significant decision points such as whether to use an LVAD. Mr. Rogers reiterated the importance of guiding patients to these outcomes, and of patients discussing these outcomes with their doctors, leading to more doctors telling patients about the

tool. Ms. Teresa Barnes asked if the tool could highlight decision points where the patient has a choice to make that could affect their outcomes. Dr. Hart said this depended on the organ, and that the tool more so helps clinicians facilitate conversation with patients on what to expect, instead of being a decision tree. Mr. Tabatabai proposed messaging on patients looking at multiple time slots to see differences over time. He also suggested moving text describing the predicted probabilities towards the top of the page to be more visible. Ms. Barnes said that bullet points or left alignment of the user description would be better than center-aligned text.

Dr. Hart discussed adding race and ethnicity to the calculator, and when it was best to include (reveal disparities) or exclude (determine transplant access) race and ethnicity depending on the calculator's use. Dr. Rolanda Schmidt raised the question of if transparency should be important in any case. Excluded information may give the wrong perception. Dr. Hart explained that if outcomes used are from patients in the past 30 years, it is known there are disparities in outcomes based on race and ethnicity mutually exclusive biological factors. If these data are used to create a calculator that a provider used to determine poor outcomes and not list that patient or make them wait longer before listing, race and ethnicity should be excluded because it decreases access for reasons unrelated to biology. Dr Schmidt said it race and ethnicity are excluded it should be noted that disparities still exist.

Dr. Lyden gave more detail on this subject for more context. An example she cited was of recent national policy that has removed race from estimated glomerular filtration rate (eGFR) as far as determining access to the waiting list, since it had resulted in inequities. Because of this, there are more conversations around whether other algorithms should exclude race. The considerations are particular when dealing with resource allocation and policy.

Dr. Lyden outlined guidelines statisticians often use to determine if race and ethnicity should be included. The guidelines asked the questions of if predictions: improved overall by the inclusion of race and how much, and improved in each subgroup of race and ethnicity. Algorithmic fairness is also used, taking into consideration whether the same types of errors are made across all subgroups—for example, are false positive or negative rates equal across groups for those with the same outcome, and for people with the same prediction, are outcome rates equal across groups. She noted algorithmic fairness was sometimes easier to apply when it is clear what a harmful decision is. Dr. Lyden said another point to consider is what is the actual effect of race and ethnicity on model-estimated probabilities.

Mr. Tabatabai suggested in the scenario of race or ethnicity being included, to add to the glossary if a large effect is present. Dr. Lyden agreed more context on this subject could be added to the glossary, and the fact that differences have been observed. Members agreed that if race and ethnicity are going to be included in data and model presentations, transparency and making sure people have access to data about ongoing disparities should be goals. Mr. Tabatabai said it was important to consider framing and why these factors are included and in what context. Members preferred having race, ethnicity, and gender in the calculator.

**Feedback: Multiorgan transplant calculator**

Ms. Yoon Son Ahn gave background information on the multiorgan transplant calculator. Its goals were providing patient-friendly, interactive information about multiorgan transplants. This includes

number of transplants performed nationally and by program, with national level outcomes at up to 10 years posttransplant. In addition, there is an individualized risk calculator to predict posttransplant outcomes for the three most performed adult simultaneous multiorgan transplant combinations (ie, kidney-pancreas, liver-kidney, and heart-kidney).

Ms. Ahn showed layouts of the tool. The first tab contained a list of transplant centers sorted by most to least transplant performed. The panel on the left-hand side is where users can enter information on transplant combination, age group, state, and zip code. The second tab contains the national number of transplants and national outcomes. She then showed an individualized risk calculator. Users can enter certain demographic characteristics and a specific center, and select number of years to predict. Modeling for the individualized risk calculator included multiorgan transplant combinations (eg, kidney-pancreas, liver-kidney, and heart-kidney) and ages 18 years and older with transplant from January 1, 2010, through June 30, 2022. Probabilities were estimated by a mixed-effect Cox model. There were different predictors for different multiorgan transplant combinations (eg, calculated panel-reactive antibody [cPRA] for kidney-pancreas, history of blood transfusion and ventricular assist device use for heart-kidney, and model for end-stage liver disease [MELD] score for liver-kidney).

Ms. Ahn demonstrated the multiorgan transplant analysis tool, going over each tab. Mr. Rogers said this tool was very busy and not as user friendly compared to the heart transplant calculator. Ms. Barnes suggested giving the user the option to “cut tabs.” Dr. Hart recommended an earlier page with a decision tree to help navigate through the tool.

**Closing business**

The topic of creating awareness of this new content will be discussed at the next meeting. Ms. Shater will share the current efforts in place for content distribution, followed by a discussion of what can be done to enhance these connections.

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