

# SRC-HCDS Meeting Minutes

## Human Centered Design Subcommittee Teleconference

November 27, 2023, 2:00 PM – 3:30 PM CST

---

**Voting Members:**

Christopher Zinner (Co-chair)  
Harry Hochheiser, PhD  
Olivia Foss  
Sue Chu, PhD  
Kaia Raid

**Ex-Officio Members:**

Cory Schaffhausen, PhD (Co-chair)  
**Not in Attendance:**  
Shannon Dunne, JD (HRSA)

**HRSA:**

Vanessa Arriola

**SRTR Staff:**

Ajay Israni, MD, MS  
Jon Snyder, PhD, MS  
Mona Shater, MA  
Amy Ketterer  
Tonya Eberhard  
**Not in Attendance:**  
Ryutaro Hirose, MD

---

### Welcome and opening remarks

Dr. Cory Schaffhausen called the Human Centered Design Subcommittee (HCDS) meeting to order. He reviewed conflict of interest management and the agenda. Dr. Schaffhausen then began with the first agenda item.

### HCDS roster

Dr. Schaffhausen thanked the outgoing members, Dr. Harry Hochheiser, Dr. Sue Chu, and Mr. Christopher Zinner, for their time and contributions to the HCDS. He said the new nomination process resulted in three applications, with Mr. Zinner acquiring two more applicants via targeted recruitment. A nominations committee chose final recommendations, with invitations extended to the following chosen candidates: Mr. Scott McPhee, a software firm professional who manages transplant infrastructure; Ms. Bree Fouss, a member of Accenture with experience in transplant-focused work; and Ms. Bridget Huff of the Organ Procurement and Transplantation Network (OPTN), who is involved in the transplant patient field. Mr. Zinner added that all three have experience in human-centered design, and Ms. Huff gives the opportunity of creating consistency in the patient experience across the Health Resources and Services Administration (HRSA), United Network for Organ Sharing (UNOS), OPTN, and SRTR contracts. Dr. Schaffhausen said that in the future, HCDS will continue to focus on patient-centered materials in the transplant community.

### Discussion of icons for transplant center metrics

Dr. Schaffhausen said the discussion will focus on design aspects of current and future icons for SRTR transplant center metrics—specifically, designing an icon so it is interpreted as intended and comparing multiple icon alternatives. He referenced the current transplant center search on the SRTR website. The 5-bar icons are for the metrics “Survival on the Waitlist” (visible for extra-renal organs), “Getting a Deceased Donor Transplant Faster,” and “1-Year [Organ] Survival.”

The bar icons have been used for 5 years, replacing an icon that displayed the words “as expected,” “better than expected,” or “worse than expected.” Dr. Schaffhausen said 3 out of 5 bars means a center’s performance is average, 1 or 2 bars is worse relative to 3, while 5 or 4 bars are better relative to 3.

Mr. Zinner said from his perspective, the *Find and Compare Transplant Centers* feature was not only intended for and used by patients but is also used by transplant centers to monitor their tier ranking. However, Mr. Zinner felt being a 1-tier or 2-tier program does not necessarily mean a program has a “bad” performance, since the differences between the tiers can sometimes be small. Mr. Zinner thought the 5-tier system sometimes delineates very small differences. Dr. Jon Snyder noted the 5-bar system created more granularity compared with the previous 3-tier system and acknowledged that insurance companies have used the 5-tier system in contracting decisions. He noted SRTR aims to produce data that tries to highlight programs with the best outcomes, and to incentivize programs to. Dr. Ajay Israni concurred that the 5-tier system is used by private insurers and transplant centers to negotiate payment amounts.

Dr. Schaffhausen reviewed difficulties with the current tier system that prompted consideration of an icon redesign. He explained that the underlying metrics are risk adjusted. Therefore, numerical values for each metric are omitted in favor of a tiered summary since hazard ratios are difficult to interpret.

Secondly, there is variation (wide and narrow between best to worst) across centers depending on the organ type and metric. For example, for kidney transplant and the metric of 1-year graft survival, the expected outcome for a similar patient who underwent transplant at a 1-tier program compared with a 5-tier program differs by 7 percentage points. However, other organ types generally have a wider range for survival (eg, 8% for liver, 10% for heart, and 13% for lung). Dr. Schaffhausen said this creates the challenge of keeping a uniform and recognizable ranking system while acknowledging the differences across organs and metrics.

Thirdly, some metrics based on SRTR analysis have a bigger impact on survival. For some locations and organs, a fairly significant number of candidates never survive long enough to get a transplant. In this scenario, where only 1-year graft survival is looked at, it ignores the percentage of patients who died prior to transplant. Dr. Schaffhausen said in these cases, one metric is emphasized over another metric (eg, getting a transplant faster is more important than focusing on the differences in survival after transplant). Dr. Snyder pointed out that the default sort-by program sorts by the metric or column of most importance. Dr. Schaffhausen referenced Dr. Judith Hibbard’s research, which focused on designing data displays easy for patients to understand, and suggested that word icons and color coding could be helpful. He said Dr. Hibbard’s recommendations were factored into the new icon designs.

Dr. Schaffhausen said that common feedback on the flaws of the 5-bar system included that it did not convey magnitude of variation, such as one metric having 100% difference between 1 bar and 5 bars, and another metric only having a 10% difference. He also said the system can also be wrongly interpreted as the same as 5-star rating scales for consumer products. Another piece of feedback was that it was unclear if the bar color meaning was independent of bar number. Dr. Schaffhausen

explained a light blue correlated to a low bar number, and dark blue correlated to a higher bar number. However, this interpretation was not clear. He also said patients were misinterpreting bars as numerical values (eg, 3 out of 5 bars interpreted as only 60% of patients getting a transplant quickly).

Mr. Zinner agreed an overarching critique was the system can create a perception that there is more variation than there actually is for graft survival, in particular for kidney. Another critique is that national rates (eg, number of transplants per 100 years of waiting) are not easily grasped by the common user. He suggested having a scale that equates to time instead of a rate, such as 5 bars meaning 9 months or less to transplant; 4 bars, 10-15 months; etc. Mr. Zinner asked what different visualizations could work for showing unique nuances between centers. Dr. Hochheiser questioned if the current metrics shown were the right ones to display for situations where the differences are relatively small, such as kidney 1-year outcomes. If most centers are performing well, showing relative performance compared with other institutions may not be helpful.

Mr. Zinner suggested using numerical scores (such as 1 bar is 92, 2 bars is 94, 3 bars is 95, for survival metrics) paired with color coding to show users differentiations between centers can be small. Dr. Snyder said the observed survival percentage score could not be used, rather the score is based on a risk-adjusted comparison of how many people died relative to how many are expected to die. He clarified that the bar tiers represented the average national patient receiving transplant at an average program, with the predicted survival being shown in the numbers.

Mr. Zinner suggested that a numerical value that is a prediction, similar to what is shown in the existing table for "Show National Rates," could be an alternative to icons. Mr. Zinner said the right language should be used, such as predicted survival for a typical patient at a typical center. Dr. Snyder said the bars were developed to avoid numerical misunderstandings; however, Mr. Zinner said an unintended consequence of the 5-bar system was thinking a 5-bar rating means 5 times better than a 1-bar program. He posited that centers not wanting to go down a bar (versus a 94 to 92) at the expense of not accepting certain organs prevent transplant professionals from taking calculated risks to help the transplant system. However, Dr. Snyder said programs that accept harder-to-place organs actually have higher bar ratings. Mr. Zinner said how the public perceived the 5-bar system mattered too.

Members discussed positive and negative framing for numerical values. Dr. Snyder mentioned research literature showed that for positive framing, like 90% survival versus 97% survival, users may not interpret the numbers as a big difference. However, values would be interpreted differently under a negative framework, like three patients were expected to die versus ten expected to die. Mr. Zinner suggested using different numerical values for different metrics. Dr. Hochheiser said this would cause confusion, since for some metrics smaller numbers were better (eg, graft failures), while for others (survival time) bigger numbers were better. Ms. Olivia Foss suggested organizing scores based off of patient types within a transplant center. Dr. Schaffhausen said SRTR has put work into tools that provide predictions specific to patient characteristics.

Ms. Kaia Raid said a number metric display was preferable to the 5-bar system, because of the unintended mental model of the 5-star system. She also suggested keeping the system in all one color to avoid confusion. Dr. Israni reminded the subcommittee there was another metric, survival

after listing, that was not easy to show as a percentage but realistically showed what patients could expect once listed.

Dr. Schaffhausen went over a pilot study that surveyed the general public on icon alternatives and icon interpretations. There were about 700 responses. In addition to existing bars, different icon variations included circles, colored circles, dials, donuts, and pies. Participants were shown one icon at random selection and asked a series of questions about the single icon. All icons were shown at the end with additional questions. Participants were more likely to correctly interpret the meaning of the icon when they viewed the dial icon. When presented with all six icons, participants chose the bars as the best way to convey information.

Ms. Raid said the dial could be misinterpreted as communicating speed for metrics. Mr. Zinner said trading one scale system for another does not address the main critiques. While different icons are different visually, it is not functionally different. He said icon success could be measured by if an audience can correctly interpret an icon. Mr. Zinner suggested testing the icons with two different audiences: 1) patients and 2) transplant centers, the transplant regulatory community, and payers. Dr. Israni added it may be beneficial to only show metrics relevant to each audience. Dr. Hochheiser recommended doing a subject study with real users looking for transplant information, and are looking at the same designs to compare them. Mr. Zinner also advised addressing any confusion on underlying metrics beyond visualizations for each one.

### **Closing business**

With no other business being heard, the meeting concluded. The next HCDS meeting date is to be scheduled for March 2024.