

SRC-HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

September 17, 2024, 12:00 PM – 1:30 PM CDT

Voting Members:

Scott McPhee (Co-chair)
Bridgette Huff
Kaia Raid

Not in Attendance:

Bree Fouss
Olivia Foss

Ex-Officio Members:

Cory Schaffhausen, PhD (Co-chair)
Shannon Dunne, JD (HRSA)

SRTR Staff:

Allyson Hart, MD, MS
Grace Lyden, PhD
Amy Ketterer

Tonya Eberhard
Mona Shater, MA

Not in Attendance:

Jon Snyder, PhD, MS
Ryutaro Hirose, MD
Roslyn Mannon, 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 moved on to the first agenda item.

Call for HCDS nominations open

Dr. Schaffhausen said the annual process of accepting HCDS nominations is now open to the public. Applications are due September 30 and will be reviewed in October. As Ms. Olivia Foss's 3-year term ends December 1, the HCDS is looking for one new member. The new member will be announced before the end of 2024. He encouraged HCDS members to share this opportunity with individuals who might be interested. Mr. McPhee asked for suggestions on what design center communities this announcement could be shared with.

Ms. Bridgette Huff volunteered to post the nominations call to the Nielsen Norman Group. Ms. Kaia Raid suggested the University of Minnesota College of Design, or Prime Digital Academy. Dr. Schaffhausen encouraged qualified students to apply, and Mr. McPhee said to consider experience levels of all different backgrounds.

Program metric icon survey update

Dr. Schaffhausen gave an update on SRTR's efforts to create a new evaluating icon for transplant metrics. He reviewed the current Find & Compare Transplant Programs format on srtr.org, which uses the 5-bar icon rating system. Users can adjust search parameters, and compare centers side-

by-side. Mr. McPhee added that the search tool is meant to be patient-centric and clinicians can also use it to compare transplant program performance.

Dr. Schaffhausen said SRTR is replicating the 2021 study, “Design of a patient-centered decision support tool when selecting an organ transplant center” from the journal *PLoS One*,¹ as the next step. With mock-up images, participants were randomly shown one of six icon designs and answered survey questions based on this image. The first questions gauged decisions about a center and how accurately participants interpreted transplant center ratings based on the icon. Concerns with the current 5-bar system include that many users interpret 3 out of 5 bars as “bad” when it actually means “average.” The second part of the survey showed all six icons, and asked which one is the most useful in providing information to make a decision. The majority said the bars were most useful; however, the dial icon had more correct responses for interpretation.

Since the last HCDS meeting, SRTR has discussed how to best use graphic and numeric information together to provide better context for users. In the replicated version of the 2021 survey (which began August 2024), SRTR added a new section with questions about column layout. The study had IRB (institutional review board) approval, and patients were recruited through existing email lists and social media posts for the anonymous survey. The general public was not recruited. The survey iteration explored variations with the dial icon. The new survey also evaluated a metric of Overall Survival After Listing, which has been developed to reflect survival across a more complete portion of the patient journey from the waiting list until posttransplant. The new dial variations featured numbers as a unit for easier comprehension (eg, 90 out of 100) in a separate column with the heading “Estimated Average Survival.” This icon contrasted with the previous iteration, which only has a percentage number. The separate column for a survival number was preferred because the methods used to create the dial are different from the methods that would result in a survival number/percent.

Ms. Huff said the dial icon with new units, along with its chosen colors, was simplistic and easy for patients to understand. She recommended adding the word “patients” to the unit (eg, 90 patients out of 100), placing emphasis on 90, and making 100 a smaller font size. She also said to simplify the language in the information alert at the top of the page.

Next, Dr. Schaffhausen reviewed the designs (A – F) in the replicated survey. Style A replicates how the SRTR website currently looks, with B being the same format, except using dial icons. Both use three separate metrics. He pointed out the 1-year survival metric and Get a Deceased Transplant Donor Faster metric in A and B, saying the latter can be much more impactful in patient outcome (and is the primary sorting column). However, it is common for patients to pick a center based off of 1-year survival. Options C – F are dials with different color tones, and have the metric Overall Survival After Listing. F includes the additional numeric column.

The survey remained active, so results presented were preliminary. Dr. Schaffhausen presented key results, including that a majority preferred the dial plus number design (38 out of 67 total); a

¹Chu S, Bruin MJ, McKinney WT, Israni AK, Schaffhausen CR. Design of a patient-centered decision support tool when selecting an organ transplant center. *PLoS One*. 2021;16(5):e0251102. doi: 10.1371/journal.pone.0251102

majority preferred the page layout with a single Overall Survival metric and additional detail in a detailed report (33 out of 60 total).

The next part of the survey presented a random design and asked participants to pick the one with the center with the best patient outcome. All were graphically set up to have the same center with the best patient outcome. For designs with multiple metrics, most chose the center based off of 1-year survival, particularly for style A. Mr. McPhee said although SRTR aims to help patients make quicker decisions, there is the challenge of how results are interpreted. The survey results demonstrate that selections depend on what parameters a patient is looking for, as different hospitals were chosen with different styles. Dr. Schaffhausen said a patient may choose a center driven by personal circumstances, but it was important patient outcomes were understood. While style F is combined, styles A and B are not, and it is difficult to determine if certain metrics that are not combined are more important to different people.

Dr. Schaffhausen said another part of the survey showed the bars were more likely to be misinterpreted, while the dials were more likely to be correctly interpreted. The new survey differed from the original because more participants indicated that the key did not provide enough information to answer the question. He asked members about how to improve the key meant to help compare each center's performance to national rates (eg, dial pointing left means worse, pointing up means average, and right means better than national rates). Ms. Huff and Mr. McPhee agreed there should be more space for the legend. Ms. Huff suggested adding a short video to the legend, explaining what the key meant. Members discussed the use of the word "average" in the legend. Dr. Grace Lyden suggested using "as expected" instead of "average." Mr. McPhee agreed, saying this phrase set a better tone for patients. He also brought up if clinicians and nephrologists discussed SRTR data with patients, helping them determine what factors are most important. Dr. Schaffhausen said for many patients, this scenario is not common practice with clinicians.

Dr. Schaffhausen asked the subcommittee if this study should be expanded to the general population to get a large sample size. Ms. Huff said it was more valuable to prioritize direct feedback from transplant candidates, caregivers, and living donors.

Kidney waitlist predicted waiting times prototype

Early in 2024, Dr. Schaffhausen met with a small group of kidney patients to review the prototype Dr. Lyden created and discuss feedback. He reviewed the prototype, created in the standard R Shiny user interface for the statistical software being used. The tool allows users to choose transplant time ranges, patient characteristics, transplant center location, age, gender, and race. He explained that this application provided outcomes in the unit of time, in a timeline format which can be viewed vertically or horizontally. He pointed out that while the prototype makes personalized predictions for a specific subgroup of patients, the predicted waiting times have a very large variation. This was the reason to evaluate different ranges using the percent selection (20% to 80%, 25% to 75%, 40% to 60%). The timeline shows that within these ranges, the waiting time could be anywhere from 1 to 10 years, depending on the selected range. Ms. Raid said to consider more clarity in labeling between the "candidates like you" label on the right section and the selections on the left. It could be made clearer that choosing the range of waitlist times also factored into "candidates like you."

Dr. Schaffhausen said the patients he met with to review the prototype preferred the larger, holistic ranges, essentially to understand why time to transplant can vary for many patients. However, he noted that one participant preferred data tables over the timeline for easy comparison. Dr. Schaffhausen showed the subcommittee this table format SRTR already has. Ms. Raid suggesting adding this feature to the timeline via placing it underneath in a drawer format.

Next, Dr. Schaffhausen showed the new mock-up that incorporated patient feedback. This version no longer has the top question asking users what range they would like to see. Instead, the time points on the timeline reflect waiting times for 20%, 50%, and 80% of patients. Users can choose a center from the selections on the left, with a comparison center at the bottom, still done in units of time. Mr. McPhee suggested the dots on the mock-up be static years, each showing percentage points when a mouse hovered over each. The other members said this was worth exploring. Dr. Lyden pointed out that this feature is similar to what is already present in the Kidney Transplant Decision Aid, however, this information would look different on a timeline especially with different parameters selected. Mr. McPhee also suggested taking an animated approach for the time points to help differentiate results, such as for comparing waiting times at different centers.

Closing business

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