SRC-HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

May 22, 2024, 1:30 PM – 3:00 PM CDT

Voting Members:
Scott McPhee (Co-chair)
Olivia Foss
Bridgette Huff
Kaia Raid

Not in Attendance:
Bree Fouss

Ex-Officio Members:
Cory Schaffhausen, PhD (Co-chair)
Shannon Dunne, JD (HRSA)

SRTR Staff:
Ryutaro Hirose, MD
Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Amy Ketterer
Tonya Eberhard
Mona Shater, MA

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 began with the first agenda item.

New patient-friendly website launch: update and demonstration

Dr. Schaffhausen gave a quick update on the new patient-friendly website. Preview.srtr.org launched 3 weeks ago, and is a website parallel to srtr.org. Response has been positive, and SRTR is currently collecting feedback via email. Dr. Schaffhausen briefly went over the home page. He showed the interactive map, which is tailored for users to see different journey paths for each organ. Each stop in the transplant journey has a drop-down list of questions and answers. Many answers have links to other SRTR reports.

Ms. Bridgette Huff said she would send United Network for Organ Sharing (UNOS) comments on the website to SRTR. Mr. Scott McPhee expressed concern for accessibility tools being a challenge. Ms. Kaia Raid asked how the interactive map presented in mobile format, and said it would be helpful to use analytics to know how many people view the website using mobile. Dr. Schaffhausen said SRTR's information technology (IT) team is working to make continuous improvements following launch, including mobile layouts. He added that some of the interfaces designed to better support search engine optimization (SEO) may also be more accessible to users. Ms. Raid suggested adding additional arrows next to each question in the interactive map.

Dr. Schaffhausen said next steps for the preview website include migrating over existing content from srtr.org. SRTR has provided the Health Resources and Services Administration (HRSA) with various timeline proposals for this, and will continue to add more features to the preview site that will be reviewed by HCDS. He went on to a design critique discussion for future HCDS feedback—specifically, methodology feedback in how it is compiled and prioritized for future plans, such as

process discussion with IT and delivery teams. Mr. McPhee said it is important to provide proactive feedback in a timely manner to the development team. He said it may be helpful to HCDS to categorize feedback like content changes, navigation changes, additional features, etc. Ms. Olivia Foss agreed that focused feedback was excellent. However, she did not want to give feedback on issues the technical team was already addressing. Mr. McPhee said having a checklist between HCDS and the delivery team regarding challenges, questions, and so on may be beneficial. Dr. Schaffhausen said it might be best to table parts of this discussion until talks with HRSA resulted in a more clearly defined direction for the next phases. In addition, Mr. McPhee said it was important to identify and understand driving factors behind user motivation. He suggested future discussions could include additional detail on user stories that informed the design. Ms. Foss agreed and said task prioritization was more difficult when user motivation was not determined first.

Icons for transplant center metrics

Dr. Schaffhausen briefly reviewed the current 5-tier bar rating system, and the metrics survival on the waiting list, getting a transplant faster, and 1-year survival (living donor transplant in a year, getting a deceased donor transplant faster for organs liver and kidney). The metrics include a lot of statistical calculations. The icon is meant to provide a snapshot of what is ultimately a really complex calculation. He explained a 3 out of 5 bars means average or similar outcomes compared to other centers nationally.

Dr. Schaffhausen said SRTR is currently developing an overall survival for listing metric, combining all three metrics into one. The metric may also allow for outcomes beyond 1 year, and the underlying methods would allow this metric to be converted into five tiers. A second potential new metric is offer acceptance, which is largely determined by transplant centers but also influenced by patient behavior. This metric also influences factors like rate of transplant and is one way to explain variations in center outcomes.

Mr. McPhee asked if the motivation and expectation behind center scoring and comparison was allowing patients to find a different center if the one they are waitlisted with has a low score. Dr. Schaffhausen said SRTR is currently in the process of making more patient communities aware of this information before they choose a center. While it is not SRTR’s primary objective, SRTR does hear from patients who switch centers in order to undergo transplant faster. Ms. Huff asked if SRTR had tested the term offer acceptance with patients, from a plain language perspective. While SRTR has not, Dr. Schaffhausen said this was part of the larger challenge of patients not being aware that centers typically decline offers.

Dr. Schaffhausen moved into the second part of the discussion, looking at new icons to replace the 5-tier bar rating system, which is often wrongly misinterpreted as being the same as 1- to 5-star ratings—or, for example, 4 out of 5 bars meaning 80% survival. Next, he reviewed a randomized survey of 1,000 people that tested how a range of designs were interpreted. Dr. Schaffhausen focused on the dial, which had the most answers for correct interpretations. However, participants chose the bars as most helpful. SRTR has recently been focusing more on the dial since it has been the most effective for interpretation.

Dr. Schaffhausen reviewed dial mock-ups. Versions included different color palettes, dials only colored in where the dial is pointing, gradients of the color green, sets with a numeric value combined with the icon (such as a calculated score from 0 to 1), and graphics that depict a confidence interval. He added that the mock-ups have been through a color blindness simulator. All of the metrics with this icon would be risk adjusted to factor in the types of patients that centers accept.

Dr. Jon Snyder asked members what they thought of the icons with the color spectrum of green to orange and red (might be seen as bad) versus using a different color scheme. Mr. McPhee preferred the icon where non-centric colors reinforced only where the dial pointed. He suggested adding more gradients to the bottom of the icon to show the middle is still average. Mr. McPhee asked if the icon was for speeding up the decision-making process or for comparison. Dr. Schaffhausen said SRTR aimed to help make comparisons easier and complex numbers easier to interpret. Ms. Huff also suggested conducting qualitative interviews to help understand why people favored the bars.

Mr. McPhee described his preferred use of ratings for comparison shopping, where the overall rating is broken down into separate components like shipping, packaging, product, etc.

Dr. Schaffhausen decided to table the discussion on the kidney waitlist tool. He showed a few more images of the dial that included a numeric value of calculations from 0 to 1. He noted that SRTR is working on a method where the 0 to 1 scale is converted to a survival number that tries to account for complex patient populations, risk factors, etc. Then, he showed a mock-up that had the overall survival after listing metric with a survival percentage, followed by the other metrics without a numerical value because the measurements and units for each are different. Members agreed it was better to not show numbers under each icon. Ms. Raid and Ms. Huff agreed that in the header of the mock-up, the organs as icons are hard to interpret, even if the icon changed to the word when the mouse hovered over it; in addition, viewing the page on a mobile / touchscreen may not allow viewing the text. An actual list of the organs may be better. Dr. Ryutaro Hirose said SRTR plans to eventually provide data on likelihood of listing, and to consider how to graphically illustrate that.

The subcommittee gave final thoughts on the discussion. Ms. Raid said using plain language to communicate complex ideas is important. Mr. McPhee said he preferred short text explanations next to each metric. Dr. Schaffhausen summarized as follows: the subcommittee was interested in continuing to explore dials, continuing to develop reports showing the new metric of overall survival and reports showing all metrics together, exploring user testing, and focusing on using plain language.

Closing business

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