

SRC-HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

February 21, 2024, 12:00 PM – 1:30 PM CST

Voting Members:

Scott McPhee (Co-chair)
Olivia Foss
Bree Fouss
Bridgette Huff
Kaia Raid

Ex-Officio Members:

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

SRTR Staff:

Allyson Hart, MD, MS
Ryutaro Hirose, MD
Jon Snyder, PhD, MS
Amy Ketterer
Tonya Eberhard

Not in Attendance:

Ajay Israni, MD, MS
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 members and introductions

New members introduced themselves:

- Scott McPhee, Product Team Leader for transplant software Afflo
- Bridgette Huff, Design Leader at UNOS
- Bree Fouss, Design Director at Accenture

Review of 2024 projects in the works

Dr. Schaffhausen reviewed SRTR priority projects. These include building a new patient-friendly website, which began 2 years ago. The project involved design components and stakeholder feedback. SRTR has been working with an outside developer to create the website using plans and prototypes. Public launch is planned for March or April 2024.

The next project was transplant system monitoring applications. One is called the Donation and Transplant System Explorer, which is consistent with the recommendation from the 2022 conference to create a dashboard of system performance. The tool provides multiple national data reports, and has drop-down menus that give the user the option to select an organ, a rolling window, a metric, and stratification. Dr. Schaffhausen added that feedback for this tool is still incoming, and easy modifications to the data that supply the tool can be made. The second transplant system monitoring application tool is Donation and Transplantation Analytics (DATA). The

DATA tool uses the same data sources as the Annual Data Report (ADR), which is a data report sectioned into chapters by organ, for policymakers and researchers to use. The DATA is interactive, and allows users to customize the reports with line plots, bar plots, survival curves, and maps to view geographic variation.

Dr. Schaffhausen explained the system monitoring strategy is to start thinking about how these two applications will coexist, and if the focus of either will change. Mr. McPhee asked how SRTR monitored this tool and how it measured its success, such as using system use or anecdotal feedback to determine if updates were needed. Dr. Schaffhausen said SRTR did not necessarily have a systematic approach beyond reviewing online traffic to monitor the application, and it was a good idea to make evaluation of these applications more rigorous.

Next was the kidney predicted waiting time application, built around the user interface of the statistical software called Shiny. SRTR collected much feedback for this tool. Ms. Huff asked how SRTR was doing usability testing with patients to ensure a diverse sample of patients are included. Dr. Schaffhausen said there were bandwidth limitations on testing, and SRTR was balancing demands for other projects. SRTR is currently working to include patients who are not already engaged with testing, and is still defining the nature of testing with this tool. He presented members with a design and testing challenge for the tool: users can select percentage ranges for “choose range of transplant waiting times” (20% to 80%, 25% to 75%, 40% to 60%), which could be difficult to answer since there is a huge amount of variation; how could SRTR make the wide variation informative instead of confusing for users? He showed an example on the tool that demonstrated this, with the tool capturing a range that only applies to a few patients, or a huge range that applies to most patients. Ms. Foush suggested showing only a portion of the data. Ms. Huff agreed and suggested the tool default to one of the ranges and provide other options. Mr. McPhee suggested breaking the tool into a two-step process so it was easier for users to understand.

Dr. Schaffhausen went over the Long-Term Transplant Outcomes Application, also built into the statistical software user interface. The tool displays a survival curve, with survival on the y-axis and time on the x-axis. He said this may not be the best approach for the patient audience, and so SRTR will continue to test other approaches. He added another challenge of the tool is it is harder to generalize 10-year outcomes. Ms. Huff suggested rephrasing this tool and the previous tool into a patient-friendly question for patients, such as “What types of outcomes can I expect as a lung patient?”

Dr. Schaffhausen went over the Multi-Organ Transplant Explorer, a 2022 consensus conference recommendation. Built into the statistical software user interface, the tool shows descriptive data counts, and what transplant centers are doing these multiorgan transplants. He noted that for the most common multiorgan combinations (pancreas-kidney, liver-kidney, heart-kidney,) the tool did statistical modeling that can predict outcomes since the sample sizes for these are a bit larger than the others. SRTR would also like to do more outreach to recruit multiorgan transplant patients for feedback.

Then Dr. Schaffhausen briefly went over the Kidney/Liver Offer Decision Aid, which began being built 5 years ago. The tool serves as a self-guided tour of what steps take place for an organ match and offer, and how the offer is made to the patient. It is now getting additional refinement through a

grant, and will be expanding its shared decision-making features. SRTR hopes to launch this tool mid-2024. The tool will be integrated into the new website. Dr. Schaffhausen added that SRTR was also working on a one-page handout that distills the tool into a supplementary material that guides discussion between the clinician and patient.

Finally, SRTR is beginning to plan a follow-up conference in 2025 (following the 2022 consensus conference) that assesses progress on Task 5 goals. The conference may have a hybrid or more virtual format. HCDS will be a part of planning for the conference through brainstorming and discussions on methods for stakeholder engagement. The 2022 consensus conference was informed by effective human-centered design method suggestions like dot voting, and similar methods could be used again. Mr. McPhee suggested the online collaboration tool Miro for virtual conference breakout sessions where tools like dot mapping, stickies, etc are available.

New patient website demonstration and feedback

Dr. Schaffhausen first went over the patient website homepage. He said in the future, it will coexist with a professional transplant professional homepage. The patient homepage includes the tools searching for a transplant center, decision aids, informational videos, and frequently asked questions. The bottom of the homepage shows the organ transplant journey, a simplified version of the interactive system map. The organ transplant journey has drop-down menus of each step in the transplant process, each with additional information and links. There is also a similar map below it for living donors. The homepage also has an expandable menu sorted by key user groups to help orient users.

Dr. Schaffhausen briefly shared the website overview page, which separates key sections of the website and includes a description of who the primary audience is and content description with links. Then, he went to the interactive system map, where users can choose organ type and journey path with drop-down menus. The map lines update accordingly based off of selections made. Users can also choose to deactivate certain paths they do not want to focus on, and isolate ones they are interested in. The map also has stops, or steps denoting main events in the transplant journey, that users can click on for more information. A list of organ-specific questions pertaining to the stop will appear in a separate window, with expandable answers that may include links.

Ms. Kaia Raid pointed out on the homepage, the three drop down menus for transplant center search use placeholder text as the label, which should not be done according to accessibility requirements. Dr. Schaffhausen said the development team would look into it and reach out to HCDS for guidance.

Discussion: Process for future meetings

Mr. McPhee said that sometimes HCDS meetings are limited timewise, and there is not enough time to go through all the material. HCDS may want to consider setting up separate meetings for specific projects that need more time to gather feedback, like from team members who worked on the project. Mr. McPhee also pointed out that feedback needs to be gathered in a timely matter, well before launch dates. He asked members to consider if there were any current projects that needed extra attention.

Ms. Huff said in terms of prioritization, it depended on what SRTR goals and what would be the most supportive. In particular, she asked what sorts of projects in preparation for the 2025 conference would be the most valuable for feedback. Dr. Schaffhausen said SRTR would like to prioritize feedback for some of the tools discussed earlier. Mr. McPhee said if it turned out that more meetings were not needed, the six projects discussed in this meeting could be evenly distributed across the next HCDS meetings.

Closing business

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