

SRC-HCD Subcommittee Meeting Minutes

Human Centered Design Subcommittee Teleconference

December 8, 2021, 1:00 PM – 3:00 PM CDT

Voting Members:

Chris Zinner (Co-chair)
Harry Hochheiser, PhD
Kate Clayton
Olivia Foss

Not in Attendance:

Sue Chu, PhD

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
Mona Shater, MS
Amy Ketterer, SMS
Tonya Eberhard

Welcome and opening remarks

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

Update on the data query tool

Dr. Schaffhausen showed the subcommittee the improved version of the data query tool, or Donation and Transplantation Analytics (DATA) tool. It currently exists in a test environment and is in final preparation for the beta launch. The tool will be launched in January 2022.

Update on “Task 5” assessing national transplant metrics

Dr. Schaffhausen said SRTR is in the planning phase for the Consensus Conference. He highlighted 3 suggestions previously provided by the HCD subcommittee: 1) understand different audiences and their use cases before the conference, 2) plan presentation content to avoid overwhelming attendees with metric information, and 3) create opportunities for discussing aspirational goals. It will also be important to prioritize understanding what information patients are seeking and the types of questions being asked. Mr. Chris Zinner said information at the conference should help patients make informed transplant decisions and act on them. Dr. Harry Hochheiser recommended caution in how aspirational discussions are framed because the conference cannot address every topic short term. Mr. Zinner said patient needs should be prioritized according to where they are currently in their transplant journey.

SRTR metrics framework: Updated PDF

Dr. Schaffhausen displayed the who, why, what, how, and results diagram that will be used as a framework for discussing metrics at the conference. Part of the diagram was restructured to show the who and why as part of the prework phase, or identifying that information before the conference. The diagram highlighted defining metrics, which would most likely be the majority of the

work taking place during the conference. He added a “3.1 Information” section to the visual, to differentiate metric information from the perspective of a patient compared to the analytic perspective of SRTR. Then, Dr. Schaffhausen said the framework will consider where the metric is coming from and what the data source is, how the metric is analyzed, where it is reported, and how it is presented. In the future, the new metrics will be evaluated to see their effect on transplant decisions. Dr. Schaffhausen added that the goal of improving various transplant outcomes is within the scope of a 5-year project, and the conference will prioritize patient needs instead of addressing all aspects of the 5-year project at once. The conference format will have breakout sessions consisting of 200 people, with topics assigned to each. Some sessions may be combined.

Dr. Schaffhausen mentioned additional patient and family engagement planning. This consisted of virtual patient focus for collecting transplant information of interest. Another part of this process is engaging with patients who might want to join the conference, in addition to finding ways to help patients develop a baseline understanding of the transplant system before the conference.

Patient and family website development

Dr. Schaffhausen reviewed a simplified timeline for the SRTR contract. Year 2 focuses on rebuilding the SRTR secure website. There may be a future opportunity for the subcommittee to weigh in on the design effort and how to improve tools for providers. The priority for the first half of the year will be rebuilding the foundation of the database (eg, software platform) before adding new tools. In addition, SRTR received feedback about making its main website patient friendly. Although this is not officially a detailed task in the contract, there is the opportunity to spend design effort in planning for web interface updates. Mr. Zinner said, in relation to making the SRTR website patient friendly, to consider how human-centered design can converge the user experiences of professionals, patients, and family members.

Dr. Schaffhausen shared a combined timeline of Task 5 and interface design. Task 5 aims to identify information of interest—specifically, what is the information for a task and what specific metrics derived from data that could inform decisions. While Task 5 focuses on what information to present, interface design is a design effort to help patients find specific information. Dr. Schaffhausen said some amount of concept development will take up a portion of 2022, with a period of 6 months for the process of concept development, mock-ups, and patient feedback.

Interface design discussion

Dr. Schaffhausen went over high-level use cases that underline scenarios common to the patient transplant experience. These scenarios are 1) the need for transplant information but not knowing where to look, 2) finding a transplant center with good outcomes, 3) extra barriers to care due to unique cases or a rare condition, 4) looking for options while on the waiting list to increase the chances of getting an organ transplant, and 5) seeking additional support posttransplant.

Dr. Schaffhausen said it was unclear to him the best way to finalize the level of detail versus what amount of high-level summary use cases would be appropriate to begin the design process, as many cases were possible. Ms. Kate Clayton suggested defining and prioritizing what patients need to find on the website, and developing prototypes that address the design criteria. Dr. Hochheiser

pointed out that the use cases have underlying themes of uncertainty and suggested addressing what is needed to communicate to help manage uncertainty.

Ms. Olivia Foss said it was important to recognize that a patient's transplant journey is cyclical not linear as shown with the use cases. Mr. Zinner said human-centered design coaching may be a helpful method for this task. Members discussed the need for balancing the complexity of transplant information with simplicity for patients, and the importance of making distinctions between the patient and transplant professional experiences.

Mr. Zinner explained the mindset model that may help improve the SRTR website. The model considers motivation level and resource access in terms of health care to form 4 groups: 1) the empowered (people with ample motivation and resources), 2) the complacent (people with access to many resources but little motivation), 3) coachables (people with high motivation and low resources), and 4) the surrendered (those with neither). Groups with low resources are geared toward people-based solutions, and those complacent or empowered are influenced more by digital solutions. What might be helpful for one group may not be for another—something to keep in mind when making the SRTR website patient friendly.

Ms. Clayton added that the subcommittee should prioritize what groups should be addressed first, such as patients new to transplant. Dr. Hochheiser said to give people an opportunity to learn about questions they never thought of asking. Dr. Snyder brought up that patients have many questions and the subcommittee should keep in mind what is in the purview of SRTR. Dr. Schaffhausen added that there will be the opportunity to address what is unique about each organ type, and the differences between each within a scaffolding framework design.

The subcommittee discussed benchmarking or comparative analysis for the SRTR website. Benchmarking could include quantified data such as visits, time on a site, or navigation paths. Mr. Zinner described a similar process of comparative analysis thinking in terms of learning from what has been done for similar sites with multiple user groups (eg, government sites for census data). Members discussed establishing baselines and comparing them with new designs to measure improvement. Dr. Hochheiser also suggested looking at access log information.

Closing business

Dr. Schaffhausen suggested the possibility of a joint meeting of HCDS with the Patient and Family Affairs Subcommittee (PFAS). Members thought this was an efficient way to communicate design ideas, as long as the discussion was organized. With no other business being heard, the meeting concluded. The next HCDS meeting is to be scheduled for late February or early March 2022.