

SRC-HCD Subcommittee Meeting Minutes

Human Centered Design Subcommittee Teleconference

August 26, 2021, 1:00 PM – 3:00 PM CDT

Voting Members:

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

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. All voting members were present. He reviewed the agenda and introduced a new member:

- Olivia Foss, Mayo Clinic, clinical decision support and artificial intelligence projects

Update on Interactive Data Query Tool development process

Dr. Schaffhausen said that since the subcommittee gave feedback on the Interactive Data Query Tool, SRTR has been working on its development. The project aims to take a large amount of data and make it available to the public in a more interactive way. The goal is to launch the tool in a month. Dr. Schaffhausen reviewed the most actionable feedback given during the last meeting. This included separating the controls for data and report type, aligning selection menus with the data map, making headings more descriptive, replacing the hamburger menu with an icon specific to exporting, having radio buttons for date range selection, and hiding the date range slider if only the current year is selected. Dr. Schaffhausen said the subcommittee may revisit the additional navigation feedback during larger-scale changes to the SRTR public website.

Dr. Schaffhausen showed the updated mockup with the implemented feedback, which included labeled steps, narrative domain headings, and the option to group data by different types of characteristics. A new section allows users to select by OPTN (Organ Procurement and Transplantation Network) region and filter patient characteristics. Dr. Harry Hochheiser suggested rearranging one section so all filters are on one side and replacing the “select” icon with a three-dotted icon to imply more options. Ms. Kate Clayton said users wouldn’t know what OPTN regions are, and suggested labeling regions with the states in each region. Ms. Clayton and Ms. Olivia Foss said it would be better to present the data tools in a single column so they are clearly sequential.

Task 5: Assessing national transplant metrics

Dr. Schaffhausen reviewed Task 5, a five-year project to identify metrics to assess transplant performance and support informed decision making by critical audiences. At the 2022 SRTR consensus conference, stakeholders will discuss data that would meet their needs and how SRTR can provide that data. The conference, which is not an endpoint, is meant to identify realistic goals and the best approach to prepare SRTR for the next three years of work. The Task 5 steering committee has been planning for four months, with 10 or 11 months to go until the conference. The three-day conference will have 50 patient and 150 professional attendees. For the agenda, Dr. Schaffhausen said it is important to consider the kind of materials attendees will need in order to understand conference goals.

Dr. Schaffhausen introduced a double converge-and-diverge diamond, a design thinking process meant to facilitate development of a solution to a problem. Solutions are prototyped and converge into a preferred solution. In order to consider a metric as a solution, it is important to prioritize the stakeholder needs at the conference, he said. The conference won't be long enough to think of every possible solution, so Dr. Schaffhausen presented a set of prototypes that might help guide this discussion.

Mr. Chris Zinner added that the subcommittee needs to understand the different audiences and their use-cases before the conference. Ms. Clayton said the group should focus on how SRTR could help improve transplant rates by offering new metrics. Mr. Zinner asked if the subcommittee will be able to engage with audiences after the conference, to which Dr. Schaffhausen replied in the affirmative. Dr. Hochheiser suggested having participants do a couple of iterative redesign cycles to build upon each prototype during the conference.

Dr. Schaffhausen reviewed the prototype "individual metric," a general framework of who, what, why, and how for stakeholders. The "aggregated stakeholder needs" prototype addresses aggregated information from different stakeholders. He shared a categorized list of stakeholders, including patient and professional groups and government regulators. The goal is to capture information from all these groups. He also shared a list of "why: stakeholder needs" for each group. Dr. Schaffhausen suggested emphasizing overlap across groups, improving the list, and presenting it at the conference for comments. Mr. Zinner agreed that the group should highlight the overlap to create parallel tracks between stakeholders. Dr. Hochheiser suggested making the stakeholder need "whys" more concrete.

Dr. Schaffhausen shared a "what: information of interest" list exclusively focused on patients, donors, and families. He said the goal is to map "why" items to "what" items to meet stakeholder needs. He also shared options that could fit into the aggregated stakeholder needs prototype for a convergent process (eg, looking for gaps in existing structures, transplant stage, data status, feasibility, and interest). Ms. Clayton proposed focusing on desired group behaviors instead of gaps. She also suggested grouping attendees with the multidisciplinary teams addressing each user. Mr. Zinner said that mapping the "whys" and "whats" would result in four clusters: overall system performance, transplant center needs, organ procurement organization (OPO) needs, and patient and family needs.

Dr. Sue Chu recommended not overwhelming the audience and expecting too much from them. It is important to prioritize and correctly frame questions, she said. Members discussed not focusing too much on stakeholder needs. Ms. Clayton said that the scientific literature on this topic is ample. She suggested going beyond meeting basic needs (eg, an OPO reward system for incentivization), so that the benefit of an in-person conference would be to create an opportunity for discussing aspirational goals. Ms. Foss proposed the objective of not wasting viable organs.

Update on organ-offer decision support tools

Dr. Schaffhausen said that a team is working to improve the functionality of the kidney transplant decision aid and liver waiting list calculator. In the next year, it might be possible to highlight patient-centered tools separately from professional and technical tools. Once these tools on the SRTR website are rebuilt and launched, focus will shift to the SRTR secure website. SRTR will start rebuilding parts of the website in October, with the help of the HCDS. For year three and beyond, improving the SRTR public website will be the main focus. A long-term goal for the SRTR public website is to be able to select a user group with different portals for patients and family and transplant professionals. Mr. Zinner added that in the future, the HCDS will work with the Patient and Family Affairs Subcommittee (PFAS) on advocacy and representation.

Closing business

Hearing no other business, the meeting concluded. The next meeting is TBD for late November or early December.