

SRC-HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

March 10, 2022, 1:00 PM – 2:30 PM CST

Voting Members:

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

Not in Attendance:

Kate Clayton

Ex-Officio Members:

Cory Schaffhausen, PhD (Co-chair)

Not in Attendance:

Shannon Dunne, JD (HRSA)

HRSA:

Adriana Martinez

SRTR Staff:

Ryutaro Hirose, MD
Allyson Hart, MD, MS
Jon Snyder, PhD, MS
Mona Shater, MS
Amy Ketterer, SMS

Tonya Eberhard

Not in Attendance:

Ajay Israni, MD, MS

Welcome and opening remarks

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

Update on “Task 5” assessing national transplant metrics

Dr. Schaffhausen showed members the double converge-and-diverge diamond, a design-thinking process that was introduced in an earlier meeting. The diagram, meant to help find a solution to a problem, may be helpful to use during the consensus conference to explore methods for creating metrics. However, Dr. Schaffhausen was apprehensive about how this process could be described since many attendees may not be familiar with it. He also highlighted the success with focus groups—he was able discuss with a variety of transplant patients and families what transplant information would be helpful to know. These findings will be presented at the conference and published.

Patient and family website development

Dr. Schaffhausen said he hoped that in the future the SRTR website could be revamped to equally cater to patients and professionals, including a patient portion with appropriate literacy levels. He reviewed previous feedback from the subcommittee, including informing users what questions to ask, helping patients manage uncertainty, and considering digital and people-based solutions. The website project will likely occur from April through September 2022, which will involve creating concepts, forming questions to guide patients and users, and developing prototypes. He hoped a design critique from the HCDS could be given in six months.

Task 5 conference attendee materials

Dr. Schaffhausen reviewed the metrics framework the subcommittee had already been introduced to in an earlier meeting. It is hoped that the framework will guide the Task 5 process, with the first two steps (identifying stakeholders, what information they are seeking and why) taking place before the conference. Steps 3 and 4 (defining a metric) will be a main focus of the conference. Dr. Schaffhausen explained that metric importance varies by stakeholder group, and it is harder for patients to determine what transplant metrics are best for them, when they do not understand how the transplant system works. He showed the diagrams “Transplant Patient Journey” and “Transplant System,” which will be used to help patients better understand the transplant process.

Mr. Chris Zinner and Dr. Sue Chu thought the “Transplant System” diagram should be horizontal for print formats. Dr. Harry Hochheiser thought that a digital interactive version that relies on scrolling may be better with a top-to-bottom vertical format. Mr. Zinner also suggested that statements be framed as questions in the first-person patient’s voice when using diagrams from the patient’s perspective. Dr. Hochheiser said to consider which details are important when, and to show details at different levels of granularity. He also said to consider where metrics and statistics could fit in, or to give access to them in a web-based version.

Dr. Ryutaro Hirose pointed out that there are a lot of “stop signs” in the transplant process (delisting, graft loss, death, dying a year posttransplant). He suggested adding these details into the diagram. Mr. Zinner showed the Centers for Medicare & Medicaid Services (CMS) journey map, demonstrating another visual method to present medical information to patients. It outlined the process from before end-stage renal disease diagnosis to after kidney transplant. The format was digitally challenging and included copious amounts of information (details of each step, observed patient emotions, and health providers patients interacted with at each stage).

Dr. Schaffhausen returned to the “Transplant System” image. He envisioned integrating this type of system-level visualization with the metrics framework by allowing the user to focus in on any of the sections to view which stakeholders are involved, and to see specific information in that part of the diagram. Dr. Hirose said it was important to make sure the map encompassed all parts of the transplant journey, such as starting with brain death of a potential kidney donor.

Dr. Schaffhausen returned to the “Transplant Patient Journey” diagram, which had additions. One column listed current transplant information at each stage of the journey, and another column listed information patients would like but is not currently available at the Scientific Registry of Transplant Recipients (SRTR). This showcases the opportunity to collect new data, and information that can be implemented in the future.

Mr. Zinner said there needed to be prioritization with both columns, and Dr. Hochheiser suggested clustering topics that were linguistically similar to make it look less visually overwhelming. Mr. Zinner said sections could be expanded and collapsed in a digital setting (incremental reveal). Dr. Schaffhausen added that this diagram is meant to educate patients on the transplant system and data so they feel prepared for the conference. Zoom sessions may take place preconference to discuss these materials.

Dr. Schaffhausen shared a draft of the “Patient Focused Transplant Metric Recommendation” form, which is meant to guide breakout group discussions by only focusing on one topic (asking who, why, what information can fit that need, and prioritization). Dr. Hochheiser suggested that asking similar questions in a variety of ways could be helpful. Dr. Chu thought that addressing personal experiences prior to diving into the framework could be beneficial; however, these stories could end up dominating breakout group time. Dr. Schaffhausen reminded the subcommittee that each group will consist of a mix of different stakeholders who will end up giving feedback on what transplant information is important, and what SRTR can do to provide this information.

Mr. Zinner questioned the format of cross prospective groups, positing that patients may feel intimidated by transplant professionals. However, Dr. Schaffhausen said it was an opportunity for patients to speak for themselves. Dr. Allyson Hart added that a combination of critical mass, preconference education, empowerment, and strong moderation will allow patients to speak freely. She noted that patients do not want to be put in groups separated from professionals. Dr. Hart also clarified that patients will be present for the professionals’ discussion on their viewpoints of what metrics are important, and vice versa. Mr. Zinner thought that dedicating one day to the patient voice and the other to the professional voice would be valuable in making sure all voices are heard. Dr. Hochheiser suggested having different versions of the form for different stakeholder groups, or using the questions to focus on the topic at hand. Attendees should be informed what their role is for each session, and this can be added to the forms. Dr. Schaffhausen agreed different prompts could be helpful.

Dr. Schaffhausen asked members if the form format should consist of a brainstorming section where attendees list ten ideas they’d like to capture, or if topics should be prioritized and focused on individually, or a combination of both. Ms. Olivia Foss said it would be useful to have concrete steps with clear instructions, giving time to generate ideas followed by prioritization of some sort. Mr. Zinner suggested prioritization by desirability or viability, depending on the audience. He also suggested dot voting, which he has seen used in virtual meetings.

Closing business

The next meeting is to be scheduled for early June 2022. The next SRTR Review Committee (SRC) meeting will take place on April 28, 2022.