

SRC-HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

September 27, 2022, 11:00 AM – 12:30 PM CDT

Voting Members:

Christopher Zinner (Co-chair)
Harry Hochheiser, PhD
Olivia Foss

Not in Attendance:

Sue Chu, PhD

Ex-Officio Members:

Cory Schaffhausen, PhD (Co-chair)

Not in Attendance:

Shannon Dunne, JD (HRSA)

HRSA:

Adriana Martinez

SRTR Staff:

Jon Snyder, PhD, MS
Allyson Hart, MD, MS
Mona Shater, MA
Amy Ketterer, SMS
Tonya Eberhard

Not in Attendance:

Ajay Israni, MD, MS
Ryutaro Hirose, MD

Welcome and opening remarks

Dr. Cory Schaffhausen called the Human Centered Design Subcommittee (HCDS) meeting to order. He said that Ms. Kate Clayton was no longer on the subcommittee, and contacts from Optum may help identify a new potential candidate. Mr. Christopher Zinner suggested looking into transplant centers with a design team with patient experience. Dr. Schaffhausen reviewed the agenda and conflict of interest management and proceeded with the first item.

Results of Task 5 Consensus Conference

Dr. Schaffhausen said there were 140 in-person and 118 virtual conference attendees (76% professionals, 24% patients/family members). Virtual attendance skewed toward patients. The 3-day conference had plenaries, group lectures, panel discussions, and 35 breakout groups (each 10-20 people) assigned various topics to discuss (eg, pretransplant and posttransplant, living donors, organ procurement organizations, payers, insurance companies). The Scientific Registry of Transplant Recipients (SRTR) distilled the feedback from these groups down to 162 recommendations and is in the process of submitting a report of this for publication. Next steps include prioritizing with the Health Resources and Services Administration (HRSA) and the scientific advisory committee which recommendations SRTR can spearhead and continuing to facilitate patient engagement.

Website design critique

Dr. Schaffhausen reviewed the SRTR website designs and critiques from patients. Mr. Zinner asked if the website addressed the concepts considered the top transplant patient needs. Dr. Schaffhausen said some of this information was captured, including the transplant journey map from the consensus conference framework that listed key patient questions (eg, what is important when

looking for a transplant center, how long do transplants last, how long is the wait) and whether SRTR could provide this information. These questions were high priority for early implementation onto the website.

Dr. Schaffhausen showed the seven concepts the design team worked on. These were reviewed with internal staff and narrowed down to three preferred options. Using the three options, Dr. Schaffhausen hosted four Zoom sessions (each 60-90 minutes with five to six people) with patients who participated in the consensus conference giving feedback on design style and navigation. Feedback was discussed with the design team, which selected the preferred concept, created a final deliverable for the phase, and built it out. Dr. Schaffhausen said he had started to collect feedback from SRTR staff and plans to get feedback from professionals.

Dr. Schaffhausen then went over the deliverable, which included the website tour (change settings, transplant journey, data for professionals, program search, get help) and homepage. Regarding the photographs of individuals on the homepage, Dr. Harry Hochheiser suggested having the pages reviewed through a cultural sensitivity lens. Mr. Zinner also suggested using icons or illustrations as a substitution or addition. He also asked if the Spanish translation option on the tour pop-up applied to the tour only or the entire website. Dr. Schaffhausen said the goal was to translate at least a portion of the patient content, which may involve a review from bilingual participants. Ms. Olivia Foss asked if the change settings option applied to a session or account. While it would be for a session, Dr. Schaffhausen mentioned the future possibility of users having an account that included the user's location and selection history. Mr. Zinner suggested a customized cookies setting for this. Dr. Schaffhausen added that a feedback form may be built into the website.

Dr. Schaffhausen went on to review additional pages. The next section highlighted key topics of patient focus: User Guides (what's on the site), Ask Questions, Reports, and FAQs (frequently asked questions). Dr. Hochheiser and Mr. Zinner said it was difficult to differentiate between Asking Questions and FAQs. Mr. Zinner suggested a format of questions indexed by different stages in the transplant journey. Dr. Schaffhausen noted the User Guides were in a mock-up stage, and he speculated it would involve how to navigate content. He said the Ask Questions portion would be patient journey focused and Reports would link to existing tools. While Ask Questions would have data for answering questions, the FAQs section would focus on questions not answered by data. Mr. Zinner suggested making the layout clearer.

Dr. Schaffhausen reviewed a collapsed version of the organ transplant journey map, which was created in response to feedback that the entire map may overwhelm new patients. The static mock-up included five boxes representing different phases in the journey. The boxes would expand to show individual steps. Users could also explore an interactive system map below. Dr. Hochheiser suggested using color coding for navigational guidance. Dr. Schaffhausen pointed out that the static mock-up also reflected the content under "For Patients" on the homepage "hamburger" menu on the upper left. He then showed a simplified version of the organ transplant journey map without the phases. Mr. Zinner preferred the map with the phases and progressive reveal and said the other versions might overwhelm patients.

Members discussed the risk of introducing a map that could be overwhelming. Dr. Allyson Hart said the map received positive feedback from patients (including new ones), and it just needed to be

introduced the right way. Dr. Hochheiser suggested starting with a fully collapsed version of the journey stages on the website.

Dr. Schaffhausen reviewed the rest of the homepage, which also had sections for professionals and finding a transplant program. He explained that the patient page consisted of finding a center, the organ transplant system graphic, a patient video library, and possibly partnering with organizations like the United Network for Organ Sharing (UNOS) for a shared patient education library (Transplant Living Webinar section by UNOS).

Mr. Zinner asked if UNOS reached out about the organ transplant journey map as a point of collaboration and a basic framework for use across the transplant community. Dr. Jon Snyder clarified that UNOS had reached out about collaborating, although did not specifically mention the patient journey map. The recent call with UNOS was cancelled, but Dr. Snyder assumed the map would be a part of the discussion. Dr. Schaffhausen moved on to a page that showed the complete interactive system map that could be filtered by organ type and stakeholder. Users could also click on different phases for more information via a pop-up, which would display questions with a link to data. While the first build may only allow for high-priority questions, Mr. Zinner suggested adding a "coming soon" label for other questions.

Closing business

As the HCDS is at the halfway point of its 3-year term, Dr. Schaffhausen asked the subcommittee for feedback on meeting structure. Dr. Hochheiser said it would be helpful for online or supplemental materials to be sent in advance. Ms. Foss suggested that Dr. Schaffhausen follow a design critique process used for Mayo teams to walk through a series of mock-ups without pausing for questions until the end. Mr. Zinner added having the subcommittee give feedback before materials were presented to patients.

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