SRC-HCD Subcommittee Meeting Minutes

Human Centered Design Subcommittee Teleconference

May 25, 2022, 1:00 PM – 2:30 PM CDT

Voting Members:	**Ex-Officio Members:**	**SRTR Staff**:
Chris Zinner (Co-chair)	Cory Schaffhausen, PhD (Co-chair)	Jon Snyder, PhD, MS
Harry Hochheiser, PhD	Shannon Dunne, JD (HRSA)	Amy Ketterer, SMS
Olivia Foss		Tonya Eberhard
Sue Chu, PhD		Mona Shater, MS
Kate Clayton		**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. After reviewing the agenda and conflict of interest management, he proceeded with the first item.

Patient and family website development

Dr. Schaffhausen said the next meeting will focus on a design critique (Crit) of the Scientific Registry of Transplant Recipients (SRTR) website redesign. Currently the SRTR website is all the same interface, which is not ideal for patients and professionals. The Health Resources and Services Administration (HRSA) agreed to fund the concept development portion of the project, which will span from April to September 2022. SRTR has met with an external development team to discuss user profiles that prioritize patient, family, and donor users. Reviewing variations of the user interface and narrowing down concepts will be in June. SRTR will start collecting patient and family feedback in July. These concepts will be refined in July and August, with a clickable prototype being created. SRTR will take additional patient feedback in August and September.

Subcommittee members had questions about the project. Dr. Sue Chu asked what will happen after the concept development stage since funding only covers that portion. Dr. Schaffhausen said there will be another funding request made through the standard budget priority or a special project for website building in 2023. He added that the SRTR website restructure meshes well with Task 5, in that Task 5 focuses on what granular data SRTR can provide and what data stakeholders want to see, whereas this special project helps orient patients with different types of transplant information.

Mr. Chris Zinner asked if HRSA placed "guardrails" or specifications on what parts of the patient experience the project will cover. Dr. Schaffhausen said that the information will focus on the entire patient journey, from the starting point (is getting a transplant right for me?) to the end point (posttransplant and long-term survival data). Mr. Zinner suggested including other aspects like

maintaining an active status on the waiting list, or whether certain information is better suited for an SRTR patient portal or Organ Procurement and Transplantation Network (OPTN) portal. Dr. Jon Snyder said while these were important considerations for the future, the project's current scope focused on how patients can easily navigate through data. Mr. Zinner also proposed one-on-one usability testing in the coming months to determine how efficiently users can complete tasks. Dr. Schaffhausen said the logistics of sharing clickable prototypes with patients has not been discussed yet, although testing through Zoom calls and exploring placeholders for future pages are tentative planned actions.

Task 5 conference attendee materials

Dr. Schaffhausen reviewed the conference format, which will include a hybrid of in-person (200-person limit) and virtual attendees. The conference will feature standard virtual engagement platforms, including a video feed with a messaging feature for moderators to read and discuss incoming comments. He noted that patients are more likely to be virtual attendees.

The conference is organized into three 90-minute breakout session rounds. The first day (half day) will serve as an introduction. There will be a panel discussion on different stakeholder perspectives, SRTR data discussion, and a presentation of patient feedback from the past 6 months. This will be followed by breakout sessions where transplant topics will be discussed by patients (families, donors, etc) and professionals respectively. These discussions will be compiled on the final day and what can be made into a metric determined. For the final day, there will be a focus on the granular level of calculated metrics.

Each breakout session will assume a number of different topics ranging from pretransplant to posttransplant. A few groups may be discussing the same topic. Groups will be a mix of patients and professionals, with a tentative number of 15 people per group and roughly 10 groups total. In-person and virtual groups will not be mixed. Each group will have a moderator, typically someone who is involved in the Task 5 Steering Committee or is an SRTR staff member. Moderators will have step-by-step guides to help regulate the discussion.

The subcommittee discussed the breakout session format. Dr. Schaffhausen clarified that the groups for each round are apt to change. Mr. Zinner proposed that the breakout groups report back, groups could be assigned to speak after a specific round, allowing a few minutes to summarize their discussion, and subsequent groups could "add on" new comments to avoid repetition. He also suggested poster templates to guide the conversation as well as a notetaker to record all output. Ms. Kate Clayton advised providing groups with a list of topics to improve and prioritize at the start of each session to add parameters. Ms. Olivia Foss offered to help with prototyping interactions and testing sessions, in order to use these experiences to help develop a guide for facilitators.

Dr. Harry Hochheiser said it was important to be clear and purposeful when constructing groups, and agreed a notetaker with each group was important. He thought it might be a challenge to synthesize reports in-between rounds, but worthwhile. Dr. Schaffhausen said this type of synthesizing is the goal. Following the first two rounds, there will be a chance to synthesize conversations, and the report back will likely be a key deliverable. He also hoped to collect data from

individuals, identifying if the source of information came from a patient, family member, donor, or professional.

Dr. Schaffhausen reviewed the Task 5 planning and meeting process. He said that information gathered from prior patient engagement will be presented at the conference. The Task 5 Steering Committee will be doing a strength, weakness, opportunity, and threat (SWOT) analysis to help present what is already known about patient stakeholder interests. Brainstorming will follow during conference breakout sessions. Toward the tail end of these sessions, there will be a shift toward a prioritization phase, and then to solutions for developing transplant metrics.

Dr. Schaffhausen introduced a list of transplant topics for each breakout group. Since each group will be a mix of patients and professionals, he said it was important to communicate expectations, such as if a topic is patient focused, limit the amount of feedback from professionals that might be contradicting their comments, etc. This also goes for living donors, organ procurement organizations (OPOs), payors, and regulators. Ms. Clayton asked if patients wanted to be a part of discussions involving OPOs, etc, and Dr. Schaffhausen said patients strongly preferred having a seat at the table when discussing professional topics. Dr. Hochheiser reiterated it was important to have a notetaker accurately capture the dynamic of different perspectives, such as cues from facial expressions.

Dr. Schaffhausen moved onto draft materials for the moderator guide, which included a review of the who, why, what, and how framework, introducing the topic, and an overview of what is expected from patients and professionals. The guide also had rules for effective brainstorming (the Task 5 Steering Committee proposed the company IDEO, and a list from IDEO was adapted for Task 5): limit judgement, encourage aspirational ideas, build off others' ideas, stay on topic, have one conversation at a time, aim for quantity, and participate.

Mr. Zinner said "brainstorming" was an inaccurate characterization of the entire 90-minute session. He also said it was important to label the effective brainstorming list accordingly, such as requests, agreements, or guidelines. Dr. Hochheiser suggested clarifying "aspirational ideas," and going a step beyond that. He agreed with Dr. Schaffhausen's aspirational idea example of knowing what centers accept a patient to their waiting list after referral.

Dr. Schaffhausen said that for patient-focused topics it would be ideal to start with patient contributions, and give them a few minutes beforehand to write down their thoughts. These comments could be collected separately from the group report back, allowing for subgrouping across different stakeholders and idea comparison. For the data forms, Mr. Zinner suggested having participants fill out one idea per form, although multiple ideas on one list (as Dr. Schaffhausen initially proposed) would also work. Dr. Schaffhausen said individual and moderated forms would be separate, while the large poster sized notepad would be a collective. Mr. Zinner also suggested limiting quick individual brainstorms to 2-4 minutes. Members also discussed using a platform designed for virtual facilitation collaboration, such as using "virtual stickies." Dr. Hochheiser suggested jamboard.google.com, and Ms. Amy Ketterer said Cvent. Mr. Zinner added having one idea per form or sticky allowed for easy collection of common ideas at once.

Closing business

With no other business being heard, the meeting concluded. The Next HCDS meeting will be scheduled for August or September 2022.