

SRC-HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

September 15, 2023, 11:00 AM – 12:30 PM CDT

Voting Members:

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

Not in Attendance:

Kaia Raid

Ex-Officio Members:

Cory Schaffhausen, PhD (Co-chair)
Shannon Dunne, JD (HRSA)

HRSA:

Adriana Martinez, MS

SRTR Staff:

Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Mona Shater, MA
Amy Ketterer

Tonya Eberhard

Not in Attendance:

Ryutaro Hirose, MD

Welcome and opening remarks

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

New HCDS member search process

Dr. Schaffhausen said SRTR was adopting a more formalized process for selecting new subcommittee members. He explained that the SRTR Review Committee (SRC), a group heavily involved in the transplant system that meets once per quarter to give SRTR feedback, followed a 3-year cycle for selecting new members. The selection process was relatively informal, using word-of-mouth recruiting and internal discussion. However, with the transplantation field becoming more transparent, the SRC has formalized its member selection with an application process that includes listing the requirements to join and certain materials to submit by a deadline. HCDS will follow suit with a similar transparent selection process.

Dr. Schaffhausen also added that HCDS came into existence under the SRC after the Health Resources and Services Administration (HRSA) awarded the government contract to SRTR, and it encouraged SRTR to go beyond its goals stated in the contract. HCDS formed as a result, bringing together a group of designers with comprehensive experience to share different viewpoints. He said the role of HCDS will mostly likely evolve with the transplantation system field reorganizing itself as a whole. Some of this restructuring may also affect SRTR. Dr. Schaffhausen said three members would be rotating off HCDS at end of this year. If new members could not be found before then, there may be empty seats or a member's time on the subcommittee may be extended.

Dr. Schaffhausen showed members the HCDS application for critique and suggested edits. Mr. Christopher Zinner said requirements for being a HCDS member and Co-chair should be more

distinct—transplant experience should be necessary for a Co-chair (since they will also be an SRC voting member) but not required for a member. Transplant experience could supersede health care experience. Dr. Harry Hochheiser suggesting adding, under required qualifications, content about evaluation to go along with usability testing. Ms. Olivia Foss said to fit usability testing under design research, and change UI/UX to the two roles UI, UX. Dr. Sue Chu said to remove the slash from service design/design thinking.

Dr. Schaffhausen asked members what type of materials potential candidates should submit. Members favored simplicity. Mr. Zinner said only a curriculum vitae (CV) and conflict of interest disclosure was appropriate for a potential member, while potential Co-chairs should submit a cover letter and personal statement of some sort along with a CV. Members should be required to give a cover letter and personal statement only if sufficient content and context about what HCDS is is provided. Ms. Foss agreed. Mr. Zinner also proposed changing the name of “cover letter” to “required information.” Dr. Chu agreed. Ms. Foss suggested having a statement of interest, where applicants could explain why they are applying in 200 words or less. Dr. Jon Snyder added that current voting members could apply for the Co-chair role if interested.

Dr. Schaffhausen ask for suggestions on what organizations to contact for new HCDS members. Dr. Hochheiser recommended the American Medical Informatics Association (AMIA). Mr. Zinner said groups like the National Kidney Foundation (NKF) or the American Association of Kidney Patients (AAKP) for HCD leadership. He added that membership-based organizations like the American Society of Transplantation (AST) and the American Society of Nephrology (ASN) may be helpful for potential constituencies around patients. Dr. Schaffhausen said Kaiser had done design pilot work in the past and may be a good resource. Ms. Foss mentioned the Veterans Affairs National Transplant Program and Memorial Sloan Kettering. She also suggested expanding from organ to other medical modalities similar to transplant for consideration.

Review SRTR website development status

Dr. Schaffhausen gave progress updates on the patient-friendly website since the last HCDS meeting. He said the last meeting focused on design process, documenting requirements during development processes, and creating documents using mock-ups and annotations with additional details for interactive requirements. Dr. Schaffhausen said web development has started in this direction, and shared screen shots showing how this was implemented.

Dr. Schaffhausen said the development team was using the platform GitLab to track changes and new implementation cycles. The mock-ups designed in an earlier phase and tested in Zoom sessions were uploaded to GitLab (each as a page or image) for documenting interactive requirements with annotations. Dr. Schaffhausen acknowledged the importance of understanding the development team’s technical capabilities and limitations prior to giving them mock-ups and annotations to work with, so that they are not given designs that cannot be coded. He added it may be beneficial to consider a business analyst role to SRTR in the future to assist with similar projects. Ms. Foss said communicating design intent and documenting decisions to identify successful patterns were useful strategies.

Discuss future work for the interactive transplant system map

Dr. Schaffhausen said coding development is underway for the interactive transplant map. However, there will be a broader set of tools available for site navigation. These include a getting started page, and two versions of information on about patient the journey, where one page is static and the second is an interactive map with the patient and other related groups interacting with each other. He said a long-term vision is to use the map as a way to imbed more information via links, so users do not have to go elsewhere to find information they need. Dr. Schaffhausen showed the getting started page, another menu option for a broad content overview. Next, he went over main menu examples independent from the interactive map in web and mobile versions. He then reviewed the patient and living donor journey, which gives a graphic depiction of the patient journey, including a text content overview and accordion layout with each organ having a collapsible section.

Next, Dr. Schaffhausen reviewed the organ interactive map in both a web and mobile view. Users will have the opportunity to tailor organ content with dropdowns. Users can also choose which lines correspond to a certain group (patient, professional, living donor, etc) are made active. Once this information is selected, each stop will be interactive. Clicking on a stop will open a pop-up window with an organ-specific question and answer section. Users can click on a link to view an answer. Questions and answers will also be in accordion style. Members agreed the layout worked well.

Dr. Schaffhausen showed members an example of a question and answer in text about how long kidney transplants last. Mr. Zinner remarked the language was not patient friendly, did not answer the question, and may cause confusion. Dr. Schaffhausen said feedback from patients and family members was incorporated into the text. However, many of these patients are actively engaged in transplant and not necessarily new to the system. He noted it was important to simplify the language by sharing the content with brand new patients.

Dr. Schaffhausen demonstrated where a link in a question and answer pop-up window would bring a user. The link brought users to the Donation and Transplantation Analytics (DATA) tool on the SRTTR website. Users would have to make certain selections from the dropdown menus to get certain data. Dr. Schaffhausen recognized that users may not know what selections to make and go back to the previous page. He hoped that in the future such data would be queried automatically and presented to the user. Dr. Schaffhausen asked members for suggestions on how to make imbedded data more user friendly.

Dr. Hochheiser recommended a link to the most frequently asked questions that opened in a new tab. Mr. Zinner said that linking someone to a tool without passing any parameters had huge fallout—users often abandon a page when they have to complete something in order to see results. Solutions to this includes passing parameters and running the page like an Application Programming Interface (API) tool while providing most popular links, or creating interactive or static graphics using the most popular material when parameters cannot be passed. Mr. Zinner also suggested not having an empty tool, but having a scenario where the user can already see a visualization with clear parameters on how it was created. Mr. Zinner said users often preferred static or interactive graphics over a tool.

Dr. Schaffhausen said it would be ideal to direct users to a data query of a database, and having the output displayed on the tool (static or interactive). He said the feasibility of the three options Mr.

Zinner outlined would be explored given time and resources. Dr. Schaffhausen added it may be possible to present the output in a more fully integrated form so users are not being passed to the tool.

He asked members for other suggestions on how to make the map more understandable. Ms. Foss said it was a good idea to test new features if there was uncertainty around them. Dr. Hochheiser said it would be beneficial to determine what data would be most useful, and to emphasize obvious answers to transplant questions if possible. However, Dr. Schaffhausen said determining obvious answers would be difficult to do, since a variety of patient characteristics (eg, race, location, age) influence the outcome. Currently, the map only has general data although more personalized data may be available in the future through a separate tool. Dr. Hochheiser pointed out that users may not know transplant questions will be influenced by specific characteristics. Dr. Schaffhausen said there were other tools with answers that described this, and where users could see personalized data. Mr. Zinner said it was important to remember that the new website was patient-friendly for both navigating the website and finding information easy to understand. The end result of the website should not be giving users a great experience but providing confusing answers.

Closing business

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