

SRC – HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

June 13, 2025; 12:00 PM - 1:30 PM CDT

Voting Members: Scott McPhee (Co-chair) Bree Fouss

Not in attendance: Devika Patel, MS Kaia Raid **Ex-Officio:** Cory Schaffhausen, PhD (SRTR Staff Co-chair) Shannon Dunne, JD (HRSA) Heather Myers (HRSA)

Not in attendance: Adriana Alvarez, MS Brianna Doby, MPH

SRTR Staff:

Avery Cook, MPH, MSW Earnest Davis, PhD, MHSA Tonya Eberhard Amy Ketterer Sydney Sharma Jon Snyder, PhD, MS

Not in attendance: Ryutaro Hirose, MD Ajay Israni, MD, MS Mona Shater, MA

Welcome and introductions

Dr. Cory Schaffhausen and Mr. Scott McPhee called the Human Centered Design Subcommittee (HCDS) meeting to order and noted a smaller-than-usual group for this meeting. Ms. Shannon Dunne introduced Ms. Heather Myers, a colleague from the Health Resources and Services Administration (HRSA). Dr. Schaffhausen reviewed that the members of the subcommittee have changed, with Ms. Bridgette Huff having stepped off due to a career change. He also shared that Ms. Kaia Raid was unable to attend the meeting because of illness. He reviewed the agenda for the meeting and conflict-of-interest management.

Call for nominations

Dr. Schaffhausen's first item of discussion was brainstorming ways for evolution of the group to increase sustainability of members, as well as for contributing to the main SRTR Review Committee (SRC) in a meaningful manner. He shared that two seats are open for nominations at this time, as Ms. Raid's term ends in 2025 and Ms. Huff has stepped away to give her full attention to a new job outside of transplantation. Dr. Schaffhausen reviewed the nomination process and schedule. He highlighted that the call for nominations is open and that the deadline is July 31, 2025. He reviewed the application for membership, including the required and preferred qualifications and the application steps. Ms. Bree Fouss asked about the need for organ transplant experience as a qualification, to which Dr. Schaffhausen emphasized that this expertise would only be required for a co-chair applicant but not for a member. Mr. McPhee spoke about broadening the scope for applications and posed website users or patient advocates as a potential source of members.

Dr. Schaffhausen and Mr. McPhee discussed different avenues for nomination recruitment, including social media postings, design program/university alumni lists, personal member referrals, and outreach with health care and design publications. Dr. Schaffhausen also highlighted the challenge of recruiting design professionals for a role that is currently voluntary. Mr. McPhee emphasized the desire for design



background as a qualification and stated that a tangential association to the transplant field would be appropriate. Dr. Earnest Davis and Mr. McPhee discussed the implication of the inclusion of transplant patients with design experience and agreed that such applicants could provide a unique perspective and potential insider knowledge about the transplant system. Dr. Schaffhausen also revisited a proposal from a previous member, which would involve creating an ad hoc list of interested individuals to provide input as needed, rather than full members attending each meeting. Dr. Schaffhausen, Mr. McPhee, and Ms. Fouss discussed that this may be beneficial in terms of projects targeted toward specific users and filtering input based on different interests. Dr. Schaffhausen voiced his desire for further dissemination of the call for nominations but expressed his willingness to explore an additional ad hoc list in the future to help bolster membership and stoke interest in HCDS participation.

Information navigation strategies

Dr. Schaffhausen stated that there are different navigation strategies for the SRTR website, which differ based on the intended audience of the webpage. He started the discussion by sharing the Interactive System Map from the SRTR preview site. Several attendees noted a bug that occurs when trying to access the different pop-up question menus when viewing the map as a shared screen on Zoom. Dr. Schaffhausen and Mr. McPhee walked through a live demonstration of the system map, which is primarily targeted at patients and includes a list of common questions in plain language, with answers and links to further resources (eg, advocacy organizations). Dr. Schaffhausen said that the Interactive System Map is structured around highlighting where the user is in the process and tailoring the information shown based on where the user is in their transplant journey.

Dr. Davis emphasized that the questions are worded for understanding by all patients, but some of the answers provided and resources that the answers direct to may be above the degree of understanding for some patients. Mr. McPhee questioned the accessibility and optimization for mobile phone browser use, as well as the number of questions provided. Mr. McPhee expressed concerns about the scrolling capability with large blocks of text in the answers and emphasized that the content is very click-active, meaning it takes a lot of clicks to understand the information provided. This point was also echoed through the chat by Ms. Fouss, who stated that it is a lot of information throughout all the potential journeys listed. Dr. Davis also commented on the magnitude of information and that this may be too much information for patients to take in at one given point on the map. He proposed narrowing each journey to the top five questions, with further questions available as desired.

Dr. Davis also expressed concern about the lack of prompts for users visiting the site for the first time and proposed a "start here" or tutorial for how to use the site. He shared that the Patient and Family Affairs Subcommittee (PFAS) is proposing the development of introductory videos for the patient-facing site, similar to the introductory videos that are present on the professional site. Ms. Amy Ketterer shared that she is in the process of storyboarding a video tutorial aimed at helping users navigate the site for the first time, which would be shared with PFAS at a later date. Dr. Schaffhausen commented that the developers will consider the suggestion to add features that would allow filtering of the most relevant questions, as there could be a number of different approaches to streamline what the user would be looking for. He also said that the developers will work to make it clearer which components are interactive and further highlight that stops can be clicked.

Dr. Schaffhausen asked the group to consider the style for presenting information in a narrative or question-based format compared to other strategies, as the team is working to streamline navigation

across different areas of the website and has some mock-ups to share following the redesign. Ms. Myers questioned through the chat about testing with end users. Dr. Schaffhausen highlighted the ongoing collaborative workgroups with PFAS, as well as areas for improvement that were identified at the 2022 consensus conference.

[Ms. Fouss had to leave the meeting during this discussion.]

Dr. Schaffhausen shared the Donation and Transplant System Explorer, which is more of a professionally used tool, as a comparison of presentation style. He underscored that the Explorer tool does not use navigation based on a list of questions that was previously seen, but instead has drop-down lists of options that can be explored, without explanation of the metrics. Dr. Schaffhausen shared these comparisons as examples of extremes for the audiences of the tools, which broadly fall into the categories of patients and professionals.

Dr. Schaffhausen mentioned that the data reports for individual transplant centers throughout the country are more in the middle in terms of style of presentation, and could be accessed by professionals or patients. He asked the group to consider how the navigation approach could change based on the mixed audience. The current report shows tab orientation on multiple levels, including overview/summary data and more advanced data. The goal for migration is to redesign the organization and structure to be clearer and better understood. He shared several mock-ups in screenshot format, which the team is updating to make the reports easier to navigate.

One of the shared mock-ups showed bundling tabs into groups, including summary data that may be used by patients and advanced data on separate collapsible sections of the page. Dr. Schaffhausen shared several mock-ups with different styles of buttons to increase visibility of different options as well as a mock-up that uses a drop-down menu rather than tabs. Dr. Davis said that from a patient perspective, it is more useful to have simpler data up front and more advanced data that would be available if desired. Mr. McPhee thought that making the site as consistent as possible would be ideal from a design perspective, and that tabs are easier to navigate while questions would be more easily digestible by users, but that different applications can have different navigation styles. Different strategies were considered, and it seemed that the optimal layout would be the tab structure for the summarized data, with a drop-down for the more advanced data, as there are more options and filters.

Dr. Schaffhausen concluded with following up on the request for Dr. Davis to coordinate feedback from PFAS. Dr. Davis shared that he has requested the group to share their availability for the next 2 weeks and would be comparing schedules to separate patients into groups for broader feedback, which hopefully would include several PFAS members who are also health care professionals—they could give a baseline familiarity with more advanced concepts. Dr. Schaffhausen stated the aim is that designs would be pushed to the live site within the next few months.

Improving site usage analytics

Mr. McPhee spoke on identifying who the humans are that the SRTR website serves, as well as how better site usage data could be collected. He said that the first step would be to define personas of interest and their groupings, including professionals and health care teams, researchers, and family members, which could be further stratified into living donors or potential living donors, donor families, and transplant recipients and their care circles. He added that this information could then be used to define usage by persona, identifying how people are using the website, the journey that users are on, and the intent



behind their usage. He also said that this information could be used to further define access and viewing patterns, such as time and mode of viewing and tool interaction.

Mr. McPhee noted that based on the way the site is laid out, there is a good concept of whom content is written for and what is learned from each particular site page. He highlighted challenges for assessment of data without the creation of profiles, and the importance of using data that are already collected, such as IP address, time, research/patient pages, and search terms, to help define personas and cluster data to help define the journey for each user. Mr. McPhee also shared that tool usage would provide a good amount of information, as many tools have different selections, especially when logged against journey information to enrich the persona, but even without the persona, the data would still be useful to drive statistics of interest based on aggregate data (location, gender, age, race).

Mr. McPhee reviewed that Google Analytics is already in place, the site structure supports persona building, and tool coding may support logs for data mining about how tools are being used. He said that data resolution can be limited but some information gathered would be better than nothing. He highlighted the need to make sure patient identifiers and other personally identifiable information would be stripped from analysis, as well as the consideration of location identifiers and whether those should be stripped from analysis. He shared options for the adjustment of terms and conditions, to provide notice to be transparent about the data collected through cookies and the option for opting out of data collection through incognito mode.

Mr. McPhee reviewed what could be done with the data, including highlighting underserved populations and underused content on the site, and focusing tools for better usage throughout the site. Unfortunately, time was lacking for a thorough discussion, but further conversation could occur at the next meeting. Dr. Schaffhausen reviewed that the IT development contractor's scope of work is currently in development and items could be included for implementation in the future. Mr. McPhee added that he would like the data collection to be unobtrusive and done in the background, rather than asking people to fill out a survey, and proposed a mini-project for analysis of the logs that are already accessible.

Closing business

Dr. Schaffhausen thanked members for the discussion and brainstorming. With no other business being heard, the meeting concluded. The next HCDS meeting is scheduled for September 10, 2025, at 1:00 PM central time.