SRC – HCDS Meeting Minutes

Human Centered Design Subcommittee Teleconference

March 13, 2025; 12:00 PM – 1:30 PM CDT

Voting Members:
Scott McPhee (Co-chair)
Bree Fouss
Bridgette Huff
Devika Patel, MS
Kaia Raid

Ex-Officio:
Cory Schaffhausen, PhD (SRTR Staff Co-chair)
Shannon Dunne, JD (HRSA)
Sarah Laskey, PhD (HRSA)
Luke Neureiter (HRSA)

Not in attendance:
Adriana Alvarez, MS (HRSA)
Brianna Doby, MPH (HRSA)

SRTR Staff:
Avery Cook, MPH, MSW
Earnest Davis, PhD, MHSA
Tonya Eberhard
Ajay Israni, MD, MS
Amy Ketterer
Sydney Kletter
Cinthia Lozano, PhD
Warren McKinney, PhD
Jon Snyder, PhD, MS

Not in attendance:
Ryutaro Hirose, MD
Mona Shater, MA

Welcome and introductions

Dr. Cory Schaffhausen called the Human Centered Design Subcommittee (HCDS) meeting to order. Dr. Schaffhausen introduced himself as the SRTR staff co-chair of the HCDS. Mr. Scott McPhee introduced himself as the other co-chair. Ms. Devika Patel introduced herself as the newest committee member, recapping her design background and experience at The Better Lab at the University of California San Francisco General Hospital prior to attending medical school at the Penn State College of Medicine. Other committee members, HRSA staff, and SRTR staff provided brief introductions. Dr. Schaffhausen reviewed the agenda and the conflict-of-interest management guidelines, then proceeded with the first item.

Review of 2025 projects and priorities

Dr. Schaffhausen updated committee members on the status of SRTR's contract, which is set to expire in September 2025. He emphasized that the continuity of the HCDS will depend on the potential contract renewal and said that the Health Resources and Services Administration (HRSA) has included the emphasis on human-centered design and the need for feedback on design elements in previous contracts. Dr. Schaffhausen outlined website improvement projects, including the migration of professional content and development of new tools and calculators.

Dr. Schaffhausen reviewed the plans to merge the main SRTR website and the patient-friendly preview site to one main website. He explained that this is a priority and the goal is to have it completed within the next 6-9 months. He reviewed that the designs of the new home page and

patient landing page were developed in conjunction with the subcommittee at the previous meeting, and work will continue in the next few weeks for review by the next meeting. Dr. Schaffhausen reviewed the ongoing development of new tools and calculators, including the kidney predicted waiting time calculator, a long-term survival rates calculator, and the Donation and Transplant System Explorer, which gives visibility of system efficiency over different displays and metrics. He reported that feedback on the Explorer has been overwhelmingly positive and requests to expand functionality are a priority for SRTR.

Integrating external website: TransplantCenterSearch.org

Dr. Ajay Israni reviewed the Transplant Center Search tool, which was designed to help patients find transplant centers based on personalized characteristics, helping individuals receive care at facilities best suited to their specific medical needs. He explained that the website, TransplantCenterSearch.org, was developed using external focus groups with transplant patients, including sessions conducted at Hennepin Healthcare and the University of Minnesota Fairview Hospital, and a panel of national transplant recipients from each of the 11 transplant regions in the United States. Dr. Israni touched on usability testing and a clinical trial, which were conducted to compare the effectiveness of this tool against SRTR's existing website. The results demonstrated that patients using Transplant Center Search were significantly more successful in finding information about patient characteristics at transplant centers compared with those using SRTR's website at the time of the study.

Dr. Israni highlighted the key functionality of the Transplant Center Search tool, which allows patients to enter different factors, such as organ type, zip code, and relevant medical characteristics like age, body mass index (BMI), diabetes status, blood type, human immunodeficiency virus (HIV) status, and type of insurance provider. The system then generates a list of transplant centers that have experience working with patients who match those characteristics. This feature is particularly useful for patients who may face barriers to being accepted for transplant, such as those older than age 70 or with a BMI over 35, as transplant center acceptance criteria can vary widely. The tool also provides comparative statistics on center transplant volumes and patient outcomes, giving patients a data-driven approach to selecting a transplant center.

Once the patient completes their profile, the results page displays a ranked list of transplant centers, sorted by their transplant rate and patient-specific experience. The tool also highlights whether centers specialize in high-risk cases, such as older patients, high-BMI patients, or those with comorbidities. Patients can further filter results based on geographic distance and access additional metrics, such as 1-year kidney survival rates. The site also includes options for patients to email or print their results for discussions with health care providers.

Dr. Israni outlined upcoming enhancements to the tool's capabilities being developed through a new Agency for Healthcare Research and Quality (AHRQ) grant, which will include AI chatbot integration, video navigation support, long-term outcomes and posttransplant considerations, and Spanish-language support. He highlighted that these improvements will increase usability. Dr. Schaffhausen described the different use cases for patients, including those with varying levels of knowledge or

specific search needs. Dr. Earnest Davis suggested considering adding functionality targeted toward caregivers and living donors, noting that these groups have been harder to engage and have different needs than those for deceased donor transplants.

Ms. Bridgette Huff emphasized what a valuable tool this is for patients and families and asked about promotion of the tool. Dr. Israni explained that they have purposely not been promoting this tool as they would like SRTR to incorporate the functionality into their website, but after the functionality is incorporated, they would move forward with widespread dissemination. Ms. Amy Ketterer and Dr. Davis reviewed ongoing efforts to educate groups of patients to highlight the importance of various tools available on the website. Dr. Davis summarized previous brainstorming for other marketing tactics, including webinars for patient and family members in a form of "guerrilla marketing" on transplant Facebook groups, LinkedIn, and YouTube channels. Dr. Israni articulated the importance of help from the Patient and Family Affairs Subcommittee (PFAS) and the cross-stream usage that would be shared between the SRTR and the TransplantCenterSearch.org site.

Patient website

Dr. Schaffhausen shifted the discussion to how to integrate the Transplant Center Search into SRTR's main website to create a unified user experience. He emphasized that the goal is to make the tool easily discoverable through multiple navigation pathways, including direct links in SRTR's navigation menu, a home page callout highlighting the patient-specific search option, and integration with the existing transplant center search results page ("Find & Compare Transplant Programs"), which would allow patients to seamlessly transition from a basic search to a detailed patient-specific search. Ms. Huff highlighted the work that has occurred that makes the existing website easier to read, including color contrast adjustments, capitalization changes, and reduction of introductory content. She also stressed the ongoing need for targeting a sixth-grade reading level on website pages for plain-language testing. Dr. Davis raised the importance of ensuring patients clearly understand survival metrics and suggested improving the way survival data are presented, in addition to increased patient knowledge, which would introduce patients to the website prior to their transplant and potential for more interactive elements on the website. Other members of the committee agreed that accessibility improvements should be a top priority in the integration process. Dr. Schaffhausen mentioned ongoing projects to replace the bars with new icons and develop combined survival metrics. He summarized the discussion and outlined next steps, including working with an outside web development firm and seeking input from the HCDS on various design aspects in refining the user interface.

Closing business

Dr. Schaffhausen thanked members for the extensive discussion and brainstorming. With no other business being heard, the meeting concluded. The next HCDS meeting is scheduled for June 13, 2025, at 12:00 PM Central Time.