

SRC-HCD Subcommittee Meeting Minutes

Human-Centered Design Subcommittee Teleconference

June 03, 2021, 2:00 PM – 3:30 PM CDT

Voting Members:

Chris Zinner (Co-chair)
Ryan Armbruster, MHA
Harry Hochheiser, PhD
Sue Chu, PhD
Kate Clayton, MS

Ex-Officio Members:

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

HRSA:

Adriana Martinez

SRTR Staff:

Ryutaro Hirose, MD
Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Mona Shater, MA
Amy Ketterer, SMS
Tonya Eberhard

Welcome and opening remarks

Dr. Cory Schaffhausen called the Human-Centered Design (HCD) Subcommittee meeting to order. He reviewed the agenda and reminded members about conflict-of-interest management. He proceeded with the first agenda item.

Interactive data query tool development process

Dr. Schaffhausen reviewed the data query tool. He explained that the Annual Data Report (ADR) was generated once a year to monitor data trends and was used for research purposes. The goal of the new project was to place these existing data on the SRTR website for interactive use on a real-time basis. He showed a snapshot of the data structure for the website, which included transplant, deceased donation, and living donation, with subcategories within each. Other geographical aggregations included organ procurement organization (OPO), state, donation service area (DSA), and Organ Procurement and Transplantation Network (OPTN) regions. Mr. Chris Zinner emphasized that the map queried summarized data about transplant patients.

Dr. Schaffhausen reviewed the user engagement plan, which had an aggressive timeline (eight to nine months until launch date). A three-month period was carved out for the initial stakeholder phase. It was assumed that mainly professionals such as researchers use the PDF tools (nonexclusively), but there was an interest in expanding accessibility to nonprofessionals. These groups include patients and their families, regulators, payers, and the general public.

The bulk of user feedback was collected through virtual focus groups. 23 participants, including patients, researchers, government representatives, and clinicians, were recruited using contact information from the SRTR simple data request log. Four one-hour focus groups were scheduled over Zoom to discuss data query tool uses and features, followed by mockup reviews.

Mr. Zinner asked if there were any common usage patterns across the different user types. Dr. Schaffhausen said that many discussed use cases for data that might be better suited to different

SRTR tools. Use cases of interest included organ recovery performance benchmarking, tracking trends (transplant rates, mortality, wait times), and different policy factors across the United States. Patient demographics' influence on transplant outcomes was another focus. Ms. Kate Clayton commented that users seemed more interested in data insights than in data analysis. Dr. Schaffhausen said one goal of the tool was to give people insight without them having to learn statistical software to create figures like those in the new data query tool. Mr. Zinner said it was currently a general tool rather than one for a narrow topic or decision. Using a general tool, users can conduct a transplant system-wide analysis, with a patient "people-like-me" focus.

Dr. Schaffhausen moved on to mockups presented to the focus groups, the first three representing different structures of the mockup interfaces. Mockup 1A had three tabs that reflected the data map. It included pulldown menus with hierarchies for different domains and a time scale with a single point or range option. A donation-rate-per-DSA map was included.

Mockup 2A was based on the existing subjects of the print data reports. It had a tab for each organ and an output of time trends. Users could stratify results by factors such as donor type. Mockup 3A captured different data outputs that aligned with different use cases. Users could view time trends, plots, survival curves, or maps and choose different domains and subdomains. Dr. Schaffhausen remarked that, depending on the output, the options might vary. A rationale for the design was to allow the interface to be customized, depending on what features made sense with the output type.

In terms of navigation hierarchy, the focus groups were interested in combining elements from mockups 2A and 3A. This feedback resulted in mockup 4A, which included an organ-specific selection (or data type) next to different output selections (eg, time trends, plots). Mr. Zinner asked where the model specified what summarized data, such as transplant, deceased donor, or living donor, the user could access. Dr. Schaffhausen remarked how choosing optimal labels was challenging, and while the domain dropdown menu contained waitlist, transplant, and outcomes, the labels deceased and living donors were found in the data type dropdown menu.

Dr. Harry Hochheiser said that mixing different types of information would not be ideal. Mr. Zinner suggested a two-layer dropdown menu. Dr. Sue Chu pointed out that a "select organ" option was present in two places on the webpage and could confuse users. Mr. Zinner liked the idea of putting output types upfront and separating organ type from transplant, deceased and living donors.

While Dr. Hochheiser surmised these components were orthogonal, Dr. Schaffhausen clarified that they were dependent. Dr. Hochheiser suggested that the dependency would not be obvious to users relatively unfamiliar with the data. However, Dr. Schaffhausen said that the dependency was clearer for living donors (kidney and liver) but not for others. In the case of looking for living donor data, fewer organ type options would be given. Mr. Zinner proposed the idea of disabling certain options if they were unavailable. Dr. Hochheiser agreed with this approach.

Ms. Clayton recommended getting rid of the button "What do these options mean?" replacing it with guidance on the page. As the user navigated through time trends, plots, survival curves, and maps, she said it would be helpful if the "generate time trend" button was customized for the option chosen and kept on the same spot on each page. Ms. Clayton also suggested replacing the hamburger menus with exporting files with an "export" option.

Mr. Zinner inquired about the single slider option for the “data range to display” section for mockup 4D but not for the others. Dr. Schaffhausen said it was typical for maps to display a single year. In the mockup, if most recent year was selected, it would default to the end of the timeline. A second point on the slider would appear if the custom range was selected. Dr. Hochheiser suggested using a single control for consistency and agreed with Mr. Zinner that a slider shouldn’t appear unless a custom range was selected. Dr. Jon Snyder commented that limiting maps to one-year data (eg, county-level data) might not give enough information to create meaningful maps.

Dr. Hochheiser critiqued the use of the mockup language, inferring that the label “aggregation” in 4A was too vague. Dr. Schaffhausen informed the group that aggregation referred to grouping by geography. SRTR typically used aggregation for geographic context, while stratification was used for patient characteristics. The phrase “group by” was used to replace the word “stratification.” Dr. Hochheiser advised using the word “geographic” instead of “aggregation” and “group patients by” instead of “group by.” He said it was important to present understandable user language, particularly in the domains and subdomains.

Members discussed domain (waitlist, transplant, outcomes) and subdomain (dependent on the domain). Dr. Hochheiser suggested replacing “domain” with “What data are you looking for?” and “subdomain” with “What do you want to know about that domain?” Mr. Zinner proposed using less-intimidating labels such as “data type,” “data subtype,” “data subcategory,” or “data attribute.”

Dr. Schaffhausen asked how to direct users to data resources other than the SRTR website. Mr. Zinner advocated for a popup that asked what information the user was seeking, with a list of additional resources to redirect them. Dr. Hochheiser agreed. Dr. Chu said to place it in the tools section. Mr. Zinner added the possibility of a tool finder.

Task 5: Assessing national transplant metrics

Dr. Schaffhausen summarized Task 5 as a process to engage with the transplant community across the country to determine how to use data to meet everyone’s needs. Key factors include assessing national performance and supporting decision making (potentially with patients and clinicians). The task was written into the contract as a three-year cycle. Though currently in the planning phase, a consensus conference, including numerous stakeholder groups, would take place in 2022. Recommendations from the conference would be implemented into SRTR web pages and reports. Users would be asked if they found the reports helpful.

Dr. Schaffhausen said it was important to keep the patient voice a priority and understand the patient perspective on transplant data. He presented a list of current or possible data. There is a plan to hold a public commentary period on transplant data, and possibly, a survey to identify the information most important to patients. The data list contained jargon “translated” into questions that explained what could be learned from the metrics. Members discussed strategies to efficiently receive feedback. Dr. Hochheiser said it was important to eliminate derivative and redundant metrics. Mr. Zinner said that organizing the list into patient-centric categories would be helpful.

Closing business



Hearing no other business, the meeting concluded. The next meeting will be slated for late August or early September.