

Towards Reducing Health Information Inequities in the Caribbean: The Eastern Caribbean Health Outcomes Research Network Data Sharing Platform Usability Study

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Abstract

There is a dearth of health research among Caribbean populations. Underrepresented individuals are affected by structural and data inequities that limit the usefulness, availability, and accessibility to health information systems and research-generated data. To overcome this limitation, a data sharing platform was created for the Eastern Caribbean Health Outcomes Research Network Cohort Study. This study aimed to evaluate the usability of the platform. Usability testing was conducted remotely, via video conferencing, using a cognitive walkthrough and think-aloud protocol. Participants completed a self-administered web-based survey which included an adapted version of the System Usability Scale (SUS). The results showed (N=16) overall average SUS score was 73.1 (SD±21.0), translating to a 'good' usability rating. Most recommendations for improvement focused on navigation and error prevention. Participatory data sharing platforms have the potential to reduce health information inequities in the Caribbean, however, usability testing should be conducted to improve user satisfaction and increase engagement.

Keywords:

information dissemination; chronic disease; user-centered design

Introduction

The Yale Transdisciplinary Collaborative Center for Health Disparities Research focused on Precision Medicine (Yale-TCC) is a collaboration between the Equity Research and Innovation Center (ERIC) and academic, public health, policy, and community stakeholders in Puerto Rico, U.S. Virgin Islands, Trinidad and Tobago, and Barbados [1]. This collaboration expands the existing foundation and knowledge base of the Eastern Caribbean Health Outcomes Research Network (ECHORN), a unique regional research network aimed at reducing the burden of non-communicable diseases (NCDs) in the Caribbean via strengthened regional research capacity [2,3]. The ECHORN research portfolio is anchored by the ECHORN Cohort Study (ECS).

Launched in 2013 [4], the ECS is a prospective population-based longitudinal study following 3,000 community-dwelling adults, aged 40 years and older, who are permanent or semi-permanent residents of the U.S. Virgin Islands, Puerto Rico, Barbados, or Trinidad and Tobago. In the Caribbean, primary care is mainly delivered in public polyclinics, by a variety of providers, with most countries having no need for patients to

register with primary care doctors [5]. The Caribbean's unique identity is geographically and culturally diverse, with residents that speak multiple languages, follow various religions and diets, live in extremely varied community settings (from urban populace to rural village) and socioeconomic statuses, and are governed by or through different civil societies [6]. This diversity is rarely captured in systematic data collection, as the Caribbean has limited representation in large-scale surveillance programs [7].

The study is aimed at evaluating risk and protective factors for the development of cancer, diabetes, and cardiovascular disease in this population [3]. The first wave of the ECS collected data from each participant via survey tools, clinical assessment, and biological samples. Data on socio-demographics, health behaviors, healthcare utilization, medical history, and other domains were captured from participants enrolled between 2014-2018 via a confidential self-reported questionnaire which utilized audio computer-assisted self-interview to increase validity [2,3]. A paucity of health research exists amongst marginalized populations, including those in the Caribbean, with underrepresented individuals being affected by structural and data inequities that limit the usefulness, availability, and accessibility to health information systems and research-generated data [8]. Even when collected and available, the information systems may not be structured to allow for individual-level data to be assembled and relationships investigated [9].

A major goal of the Yale-TCC is to create a digital platform that can foster the sharing of de-identified and accumulated population-level data from ECS with study participants, researchers, stakeholders, and communities [10]. The field of health informatics has a research replication problem [11]. This data sharing platform will help to facilitate a culture of research replicability and validation by providing access to de-identified health data for 3,000 adults in the Caribbean. Moreover, data sharing, coupled with community-based participatory research, has the potential to increase the usefulness of data for underrepresented populations [12–15]. Some research interventions have created community-engaged informatics platforms that allow participants to manipulate their own or aggregated data, with hopes of access to health research data leading to improved health knowledge, and community cohesion [12,14,15].

In this paper, we discuss the usability testing of the ECS data sharing platform, a publicly available, searchable database of aggregated ECS data aimed at advancing the dissemination of health data throughout the Caribbean. The purpose of this study

was to evaluate the user interface on how well it supported users in the completion of basic tasks. The findings will be used to ensure that the data sharing platform is accessible and beneficial to those within and beyond the scientific community.

Methods

Development of the Data Sharing Platform

The ECS data sharing platform was developed by a multidisciplinary team which included clinical providers, clinical informaticists, and health equity researchers. A significantly upgraded version of the Web Analytics Research Platform (WARP) navigator, initially developed for the Transitions Clinic Network [15], was used for ad-hoc data queries and visualizations. Feedback from stakeholder-engaged discussions informed further development of the functions and content for the platform. The new WARP navigator provides interface elements to assist users in conducting descriptive and bivariate analysis. The interface leverages enhanced cohort-derived-metadata to generate de-identified aggregated data. Features include creating graphs (e.g., bar graph, pie chart) and tables. Users can also convert the graphs and tables to different file formats (e.g., PNG, Excel worksheet), download the results, or save the query to retrieve it in the future or share with others. A screenshot of the ECS Data Sharing Platform is displayed in Figure 1.

Recruitment and Procedures

We recruited community members age 18 years or older residing in the Eastern Caribbean to test the usability of the data sharing platform. Recruitment methods included receiving an invitation to participate in usability testing of the platform via an email sent to listservs, posts on social media (e.g., Twitter), or word-of-mouth. Purposive sampling was used to increase diversity in the sample (e.g., age, education level) and generalizability of the findings. Each participant received a gift card (20 USD value) for completion of the study.

In March and April 2021, we conducted one-on-one usability testing sessions with 17 participants. The sessions were moderated by Yale-TCC fellows (SD, DA, SW, SD) trained to conduct usability testing. Each session was completed remotely using the Zoom[®] video conferencing platform. The moderator used a script to conduct the sessions. Participants were informed of the purpose of usability testing and that the session would be video-recorded and last approximately 30 minutes. After assigning remote control to the participant, the moderator instructed them to perform a series of four tasks in the platform and, importantly, to speak aloud their thoughts and actions as they completed these tasks (Table 1). The Cognitive Walkthrough Method [16] was used to evaluate the user interface design on how well it supported users in learning to complete tasks. Specifically, this method was used to “evaluate the ease with which users can perform a task with little or no formal instruction or informal coaching” [16].

After completing the tasks, participants were asked the following open-ended questions about their experience using the platform: *What do you think about the way the website looks? What do you think about the way the website functions? What are some things that you would like to see changed? Is there anything you would like to see added to the site that is not there now? Are there things that are difficult or confusing about the website?* Moderators completed field notes for each session to document issues like sticking points, confusion, missing items, and unmet user needs. In addition, the first author independently viewed the video recordings of each session,

noted observations, and debriefed with the moderators one-on-one.

Table 1—List of Tasks for Scenarios

Scenario Tasks	
1.	Show me how you would find out the number of individuals in each location (e.g., Puerto Rico, US Virgin Islands, Barbados, Trinidad & Tobago) of the ECHORN cohort study. Display the results as a pie chart.
2.	Show me how you would find out the number of individuals that are female in each location. Display the results as a table and export the table to Excel.
3.	Show me how you would find out how many individuals ever had cancer by age group. Display as a bar graph.
4.	Show me how you would find out the percentage of individuals with high blood pressure in each location. Display the results as a stacked column graph. Save the graph.

Measures

After usability testing, each participant completed a brief self-administered web-based survey. The survey included an adapted version of the *System Usability Scale* (SUS) [17] and sociodemographic questions. The SUS consists of a 10-item questionnaire with a 5-point Likert scale spanning from strongly disagree (1) to strongly agree (5). In the SUS, ‘system’ was replaced with ‘Explore ECHORN website.’ SUS scores were calculated by subtracting 1 from the score for each odd-numbered item, subtracting the score for each even-number from 5, then summing all scores for the items and multiplying that sum by 2.5. Scores range from 0 to 100, with higher scores indicate higher usability. The 7-point adjective rating scale (from ‘worst imaginable’ to ‘best imaginable’) developed by Bangor and colleagues was used to interpret SUS scores [18].

Data Analysis

Sample characteristics were calculated as means, standard deviations, and ranges for continuous variables (e.g., age), and as frequencies and percentages for categorical variables (e.g., education). SUS scores were calculated for each participant, and the group mean score was computed to measure overall usability of the platform. Statistical analyses were conducted using SPSS[®] version 26 software.

While quantitative data such as SUS scores can provide a general sense of the usability of the platform, qualitative data collected via the think-aloud method can provide context and a better understanding for the origins of usability issues. Observations from the cognitive walkthrough sessions were noted and reported in narrative. Positive feedback and recommendations for improving the platform were categorized and summarized.

Results

Sixteen of the 17 participants recruited completed all study activities (i.e., tested the usability of the platform and completed the post-session survey). These participants ranged in age from 19 to 65 years (mean age of $34.6 \pm SD 13.9$ years), and most identified as female (13/16, 81%). The sample included participants from eight Caribbean islands, with 75% of participants (12/16) residing in one of the four islands with ECS study recruitment sites (Barbados, Puerto Rico, Trinidad and Tobago, or US Virgin Islands), and 25% (4/16) residing in

Antigua, Bahamas, Belize, or Grenada. Most participants ($n=12/16$, 75%) were college graduates. The majority had at least one computer in their home (15/16, 94%), and 63% (10/16) had three or more computers in their home. All participants had internet access in their home. The characteristics of the study participants are summarized in Table 2.

Table 2—Characteristics of Study Participants

Participant characteristics	(N=16)
Age in years, mean (SD)	34.6 (13.9)
Age group in years ^a , n (%)	
18-24	5 (31)
25-34	4 (25)
35-44	2 (13)
45-54	3 (19)
55+	2 (13)
Gender, n (%)	
Female	13 (81)
Male	3 (19)
Location ^a , n (%)	
Barbados	3 (19)
Puerto Rico	4 (25)
Trinidad & Tobago	3 (19)
US Virgin Islands	2 (13)
Other Islands	4 (25)
Education ^a , n (%)	
Some college	4 (25)
College graduate	2 (13)
Some post graduate work	2 (13)
Post graduate degree	8 (50)
Computers in home ^a , n (%)	
0	1 (6)
1-2	5 (31)
3-4	9 (56)
5+	1 (6)

^aPercentages may not sum to 100% because of rounding

SUS Scores

Among the 16 participants evaluating the usability of the data sharing platform, the overall average SUS score was 73.1 (SD±21.0), translating to a 'good' usability rating. Individual SUS scores were categorized as 'best imaginable' (4/16, 25%; SUS: 90.9-100), 'excellent' (2/16, 13%, SUS: 85.5-90.8), 'good' (4/16, 25%; SUS: 71.4-85.4), 'OK' (2/16, 13%, SUS: 50.9-71.3), or 'poor' (4/16, 25%; SUS: 35.7-50.8). No scores were in the range of 'awful' (SUS: 20.3-35.6) or 'worst imaginable' (0-20.2). Most participants (10/16, 63%) rated the platform above average (SUS score above 68). Percentages may not sum to 100% because of rounding. Older participants were more likely to rate the platform's usability lower than their younger counterparts. For example, 60% (3/5) of participants 45 years or older had SUS scores that rated the platform's usability as 'poor' compared to 9% (1/11) of the younger participants. There was no observed difference in rating the platform among participants that are college graduates and those who were not.

Qualitative Feedback

Participants completed cognitive walkthrough think-aloud sessions. Task 1 required that they show the moderator how they would find out the number of individuals in each location of the ECS and display the results as a pie chart. All participants were able to complete Task 1 with little to no assistance.

However, most participants had difficulty with the remaining three tasks, all of which required the use of more than one variable (e.g., *Show me how you would find out how many individuals ever had cancer by age group. Display as a bar graph.*) and required a little assistance to complete the tasks. Participants stated the options for selecting more than one variable were not intuitive. The participants' qualitative feedback on testing the data sharing platform is presented in Table 3. Overall, participants felt the colors and graphics were nice, the system speed was fast, the graphs were easy to read, and the interface was clean. General recommendations for improvement included adding a Frequently Asked Questions (FAQ) page and "help" button, as well as a tutorial on how to use the site. Participants also suggested adding a title and information about the purpose of the study on the main page and making the site mobile-friendly.

Regarding content and features, participants liked being able to find information on chronic diseases. Positive feedback was given about having options to save graphs as images and export tables to Excel, as well as the ability to save graphs to the site. Participants recommended allowing users to save graphs and tables by right-clicking on them or using the ellipsis button, adding a button to the 'chart' tab to save graphs, and adding hierarchical filtering capability. Regarding navigation and error prevention, participants thought the drop-down menu made things easy to find and grouping variables by category was helpful. Recommendations for improvement included relabeling the buttons for selecting the number of variables to make the functions clear and easier to apply. Participants also requested making the buttons bigger, moving the buttons to the top of the chart/table area, and adding labels above the buttons so that users do not have to hover over the button to find out its function. In addition, it was recommended to make the instructions in the text boxes a darker color, that the system highlight selected variables, moving the 'X' symbol to clear the text box to the right side of the text box, and renaming the 'island' variable 'location'.

Discussion

The ECS is the first intergenerational longitudinal cohort study in the Eastern Caribbean region focused on chronic disease outcomes. To our knowledge, the data sharing platform is one of the first to provide de-identified and aggregate population-level data from the Eastern Caribbean region to participants and community members. The results of the study showed participants perceived the usability of the data sharing platform to be good, and the average SUS score was 73.1 (SD±21.0) [18]. Older participants were more likely to rate the usability of the platform lower than younger participants. Most participants had difficulty with completing tasks requiring analysis of more than one variable. This difficulty was primarily due to lack of clarity in labeling of what buttons to use to perform the tasks, and confusion on how to navigate the platform. However, once participants figured out how to create a graph or table with more than one variable they were able to quickly complete the other tasks involving more than one variable.

Poor usability negatively affects user satisfaction and engagement, therefore the platform should be intuitive to use. Most of the recommendations for improvement focused on navigation and error prevention. Incorporating the feedback from usability testing will improve learnability of the platform (i.e., how easy it is for users to complete a task the first time they use the platform). Having a tutorial on how to use the platform would help first-time users to perform tasks and reduce the burden to learn by trial and error.

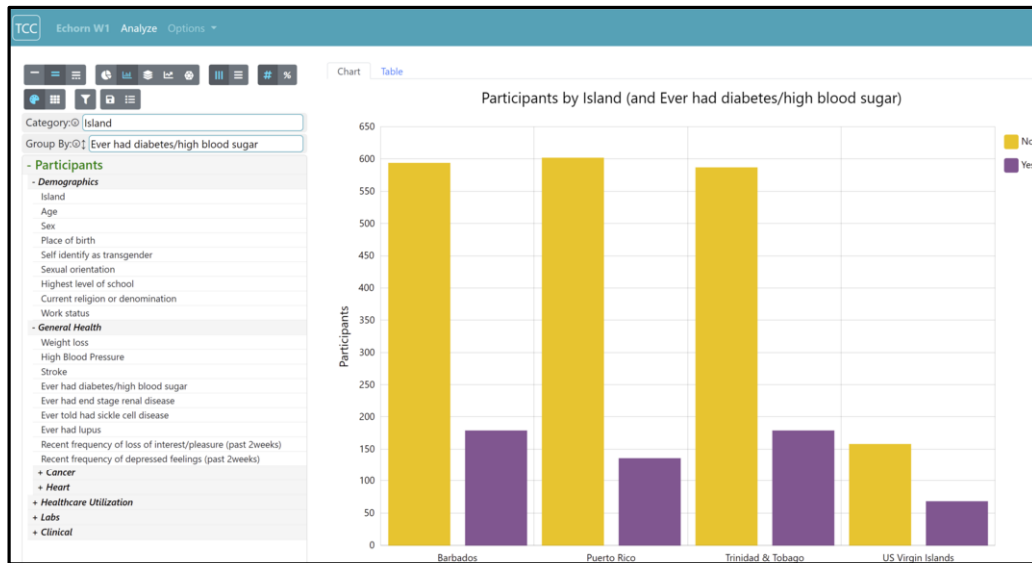


Figure 1 – Screenshot of the ECS Data Sharing Platform

Table 3– Participants' Feedback on Using the Data Sharing Platform

Themes	Positive Feedback	Recommendations
Overall reactions to app	<ul style="list-style-type: none"> Nice graphics Fast system speed Graphs were easy to read Clean interface Nice colors 	<ul style="list-style-type: none"> Add FAQ page and help button Add tutorial on how to use site Add title and information about purpose of site on main page Make site mobile-friendly
Content and Features	<ul style="list-style-type: none"> Information on chronic diseases Options to save graphs as images and export tables to Excel Ability to save graphs to the site 	<ul style="list-style-type: none"> Allow users to save graphs and tables by right-clicking on them or using the ellipsis button Add a button to the 'chart' tab to save graphs Add hierarchical filtering capability
Navigation and error prevention	<ul style="list-style-type: none"> Drop-down menu made things easy to find Grouping variables by category was helpful 	<ul style="list-style-type: none"> Relabel 'standard', 'advanced', and 'expert' variable buttons to make clear the functions Allow users to click on variable name to select Add labels above buttons Make buttons bigger Move buttons to the top of the chart/table area Make instructions in text box a darker color Highlight selected variable Move the 'X' symbol to clear the text box to the right side Rename 'island' variable 'location'

The main strengths of the usability study were its use of the cognitive walkthrough think-aloud method and administration of the SUS to obtain both qualitative and quantitative feedback on the platform. In addition, 16 participants completed the study, providing a more than adequate sample size. Prior research showed that five participants could reveal about 85% of the problems in a formative usability study [19]. Also, participants from all four study sites were included. The main limitations were that participants were mostly female (81%), and all completed at least some college studies. This may limit the generalizability of the findings, especially to those who have not completed any college studies. Also, usability testing sessions were conducted remotely (e.g., via video conferencing) due to physical distancing restrictions caused by the COVID-19 pandemic. Despite these limitations, the study yielded useful information to improve the usability of the platform.

Future work will include incorporating feedback from the usability testing to further develop the platform prior to its launch. The available variables will be expanded and new features added to increase the usefulness of the platform. Data from the second wave of data collection will also be included in the future.

Conclusions

Participatory data sharing platforms, such as the one we developed and evaluated in this study, have the potential to reduce health information inequities in the Caribbean. Improving the usability of the platform will help to increase its use and the likelihood of greater dissemination of ECS data, and other ECS related projects. With this regional sustainability, the platform can be used to inform real-world health questions and become an accessible online space for providing health information and new health insights for all Caribbean people.

The results of this study will be used to continue to refine our approaches to data integration and sharing, and inform ongoing global discussions on an informatics framework to support global partnerships for digital innovation and achievement of health equity.

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