

# Expansion of the Community Engagement Studio Method: Deepening Community Participation in Healthcare Innovation

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**ABSTRACT:**

**Background:** The Community Engagement Studio (CE Studio) method has emerged as a valuable model for community participation in health innovation research, and we advance the model by expanding the timing and number of CE Studio sessions, as well as facilitation.

**Objectives:** The authors expanded the CE Studio method first to include five sessions corresponding to five phases of innovation: (a) health experiences, (b) community readiness, (c) design features, (d) adoption, and (e) sustainability. Community experts were engaged throughout the duration of the research. Second, the authors positioned the CE Studio Team to be deeply embedded within the research team and the community of interest through Community Health Workers. **Methods:** The expanded CE Studio method was incorporated into a federally-funded research project focused on a health technology platform. The CE Studio Team held five sessions with each of four community expert panels (total of 20 sessions) based on race/ethnicity and language: African American, Asian American, English-speaking Latinx, and Spanish-speaking Latinx. **Conclusions:** CE Studio sessions revealed community experts' shared and unique evolving and deepening perspectives that show promise for expanding the model.

**KEYWORDS:** translational research; community engagement studio; community-based participatory research; health equity; information technology

As researchers look for opportunities to generate health and healthcare innovations for an increasingly diverse population, the need to understand the health and social determinants of health among diverse communities is crucial. Yet, research methods often position community members as the focus of, rather than the partner in innovation design, implementation, and dissemination [1]. In this article, we describe an adapted community-academic model that positions community members as partners in translational research to improve speed and adoption of innovation in healthcare.

### **The Community Engagement Studio**

The Community Engagement Studio (CE Studio), a method developed at the Meharry-Vanderbilt Community Engaged Research Core, is used to engage community members with lived experience with the purpose of informing a research endeavor [2]. In the CE Studio, community members are called community experts to recognize their vast and personal experiences with their own health and health services [3-5]. Community experts have also lived through the health challenges and triumphs of their loved ones, are keenly aware of the structural barriers their community faces in accessing quality health care, and have even advocated for health and healthcare issues as part of their employment or activism [6].

In the CE Studio, community experts' personal and collective perspectives and anecdotes give insight to researchers about how to improve health through a promising practice [7]. The ultimate goal is to intertwine academic and community knowledge so that the innovation can gain at the forefront how to enhance uptake, honor community self-determination, and be sustainable over time [5]. As such, the CE Studio has been associated with improved recruitment plans, survey designs, partnerships, project completion goals, and funding success, as well as community experts' increased pride and appreciation for research [5].

CE Studios differentiate from focus groups in that interaction with the community experts is sought to inform a research process, not a research question, and that researcher participation is minimal. Rather, a community-facing facilitator leads discussion with the community experts [2]. Because community experts are not considered research participants, the method is likely to be determined by institutional review boards (IRB) as exempt [2]. The CE Studio also differs from human-centered design models in which users typically test an innovation and provide input on its operability. Usually, these models work with users individually rather than collectively. CE Studios differ in their emphasis on informing, rather than testing, an innovation.

When a researcher requests a session, the CE Studio team disseminates to community networks a tailored call for nominations to an expert panel. Upon selection of members, the CE Studio team then orients the expert panel to the research project and the CE session logistics and compensation [5]. Simultaneously, the CE Studio team coaches the researcher on engaging with the expert panel and they collaborate to create a short, community-friendly presentation for the beginning of the session. The 90-minute session includes an ice breaker activity, a brief researcher presentation, and a discussion section [5].

## **Expansion of the CE Studio Method**

### **Timing of CE Studio and Level of Community Participation**

In the traditional method, a single CE Studio session can be requested at any stage of research [5]. Although this feature adds flexibility to researchers, at Dell Medical School in Austin, TX, we expanded the method to several sessions taking place throughout the duration of a project to allow for in-depth participation, and in so doing, to promote group cohesion and trust-building that comes from sustained participation, to enhance the quality of feedback sought

and received, and to further democratize the partnership between researchers and community experts. Sessions are themed thoughtfully to request input on how community experts think their community thinks about (a) the innovation and the problem it aims to reduce, (b) their appetite and readiness for the innovation, (c) their requisite design features, (d) their adoption of innovation, and (e) the payment and long-term sustainability of innovation.

### **Positionality of the CE Studio Team**

Another expansion we propose to the CE Studio method refers to the positionality of the CE team with respect to the researcher and to the community. In the traditional CE Studio, the CE coordinating team is independent from the research team and rather serves as a consultant to a time-limited piece of the research, community engagement [5]. While this arrangement facilitates CE Studio consultation to multiple research studies and in a time-limited fashion, the independence of the CE Studio team risks lacking grounding in the interests of the research and the community.

Additionally, CE Studio teams are often located in medical schools and staffed by individuals who, albeit highly trained in multicultural communication, are not representative of the communities from which expert panels are assembled. In our expansion, Community Health Workers (CHW) at our academic institution facilitate the CE Studio sessions, enhancing recruitment and retention of community experts through open and horizontal trust-building [8]. An intentional embeddedness of the CE Studio team in both research team and communities and throughout the duration of the study can strengthen the CE Studio method and better serve researchers and communities.

Moreover, by including CHWs in the recruitment and facilitation of the CE Studio

sessions, we foster continuity between the CE Studio sessions and other community engaged and community-facing efforts of the larger study, including a community advisory board, user design interviews, and community testing of an innovation. Our CHW leverages community relationships to identify the most appropriate advocates and leaders to be part of the community advisory board, highlights community interests at these meetings, suggests to the research team ways in which their research activities should align with the input provided by the advisory board and CE Studio sessions, and leverages relationships with other partners to recruit additional community members for innovation testing.

CHWs involved in our model are employed by our medical school, and work in various community initiatives, therefore, they regularly interact with researchers and community members. They are commonly recruited through community contacts (word-of-mouth), hired through a job position created specifically for the competencies of a CHW, and are supervised by an experienced CHW with national and state certification. CHWs come with training in community facilitation, motivational interviewing, power dynamics and dismantling of colonialization in practice, and language justice, among others. Their communication style is personal and engaging and they are often already known in the community for their service outside of academic walls. Moreover, they enhance community member retention by serving as a resource inside and outside of the CE Studio sessions.

CHWs at our institution received technical training in the CE Studio model, which entailed (a) a faculty member with experience in the model creating a resource library for CHWs that included the CE Studio Toolkit and process and outcome studies, (b) the team discussing CE Studio logistics and adapting materials from the Toolkit to fit the local context, (c) consulting with CE Studio contacts at Meharry Vanderbilt, and (d) participating in a national network of CE

Studio implementers that meets regularly to exchange resources, offer webinars, engage in topic discussions, and a 2-day conference.

### **Case Study Illustration of our Expanded CE Studio Method**

Researchers at Dell Medical School proposed to develop an innovative technology platform to address the problem of limited access to medical records by patients caused by each provider, payer, or pharmacy developing its own proprietary portal or app, leading patients to deal with many non-interconnected sites [9]. The idea was formed and developed by the school's Community Strategy Team that is composed of community leaders, connectors, and advocates to lead and advise researchers on community priorities. After obtaining funding for this idea, the research team proposed to reverse the order of developing innovative technologies by engaging communities first through community advisory boards and CE Studios, second by translating their preferences and needs through human-centered design with a different set of users, and third by using state-of-the-art technology to convert those ideas into a single operational digital platform called *FHIRedApp*. The community partners hence became co-designers and co-developers in this research where they learn from the researchers about the technological innovation and the researchers learn from community members about the needs, preferences, challenges, and concerns of potential end users from priority communities.

#### **Logistics of the CE Studio for *FHIRedApp***

CE Studio incorporation into the development of *FHIRedApp* was an integral part of the project. Investigators met with CE Studio developers Wilkins (personal communication, September 19, 2019) and Joosten (personal communication, December 9-10, 2019) of the original CE Studio method to discuss their ideas for expansion, which the developers expressed

enthusiasm for and shared resources. Locally, investigators first sought input from the Community Strategy Team (CST) and a community advisory board (CAB) composed of community leaders and advocates, health providers, and researchers. Investigators envisioned these advisory groups to be different than CE Studios not only in terms of group composition and background but also in terms of meeting format. For example, whereas CABs are typically led by the researcher, the CE Studio was typically led by CHWs to facilitate engagement. The function of CST and CAB members was to identify three priority racial/ethnic groups as being prominent in the Austin area that could be recruited for CE Studios, provide direction on our recruitment plan for the CE Studio sessions, and promote the call to the community and nominated members from these three communities. The CHW worked with CST and CAB members to promote the CE Studios by contacting local organizations with whom the CHW had existing relationships, presenting the opportunity at municipal committee meetings, and directly reaching out to individuals from local organizations and churches. Community members who were referred, completed a CE Studio form and discussed logistics by phone with the CHW.

Our three assembled CE Studio expert panels were defined first by race and ethnicity. The most homogenous group consisted of six African American adults ranging in age from 27-63 years. Our Latinx American group was split into two groups based on language (English speakers versus Spanish speakers), each with five adult participants ranging in age from 43-65 years. The Asian American group was the largest, consisting of nine adults ages 25-68 years identifying with the following nationalities: India, Korea, Myanmar, Iraq, Nepal, and Vietnam.

Over a two-year period, each of the three CE Studio expert panels participated in five two-hour sessions, each session focused on a phase of innovation research.



*Planning and Design Phase.* As illustrated by Figure 1, the first CE Studio session focused on community experts' description of what matters most to them when it comes to their health and to accessing and managing their health information. This information helped researchers understand the communities' priorities for the platform, launching the data integration process tailored to those priorities (e.g., security).

*Development Phase.* The second CE Studio focused on innovation readiness, with prompts following the community readiness model that outlines six dimensions of readiness: (a) existing prevention efforts, (b) community knowledge of prevention efforts, (c) leadership that could persuade adoption of innovation, (d) knowledge about the problem, (e) community climate, and (f) resources for innovation [10]. The third session explored preferred design features for the mobile health application. Community experts pointed out features they use and like on their smartphones and on other mobile apps, paying particular attention to literacy, size of text and icons, colors, primary vs. secondary content, and navigation. As shown in Figure 1, after the research team incorporated the expert panel's feedback, the newly designed application was shown individually to a separate group of community members (user design interviews) from our priority communities.

*Demonstration Phase.* In this phase, the revised mockup of the application was presented to CE Studio community experts in the fourth session. Expert panels shared their impressions of the mock-ups, suggested additional revisions, and responded to the facilitator's questions of how they would likely use or adopt the mobile application. We drew on Diffusion of Innovation to assess adoption of the designed platform, mainly the following dimensions: (a) relative advantage, (b) compatibility with existing values and current needs, (c) complexity, (d)

observability of innovation impact, and (e) trialability, or assessment of which components could be used and which ones not [11,12]. We also incorporated elements from the Unified Theory of Acceptance and Use of Technology that focus on Performance Expectancy (benefits to consumers), Effort Expectancy (ease of use), Social Influence (perception of usefulness for family and friends), and Facilitating Conditions (resources and support to use the technology) [13]. In the fifth session, we engaged community experts in a discussion about sustainability, exploring sources of data storage and continued funding for the application. We also discussed the impact on the community experts of participating in the CE Studio and ways in which their involvement in research and/or the medical school can be sustained. Simultaneously, the research team launched a pilot and test of the platform, with CE Studio members advising on recruitment and dissemination of the findings. The vast information gathered from the CE Studio sessions and research activities were presented back to the CAB and the CST and organized into oral and written reports for funders and federal agencies.

### **Analysis of CE Studio Sessions**

The CE Studio Team, composed of the faculty director, the CHW facilitator, and the coordinator, read the transcripts from each session and analyzed each session. Given that each session was structured around a theme, contextualist thematic analysis was conducted following Braun and Clarke's methodology (2006). According to this method, individuals' perspectives are defined by their personal meaning-making (e.g., preferences, coping, behavioral practices) and by their sociocultural experiences, including cultural values and national background, immigration policy and status, economic and neighborhood constraints, and interactions with the healthcare system. The first author has experience with this qualitative research method and

trained the other two coders. Training consisted of (a) describing the conceptual framework behind contextualist thematic analysis, illustrating the method's components with previously coded data from other projects, and walking through the coding phases with coders. After this instructional component, coders analyzed sessions, meeting in between sessions to compare codes, discuss discrepancies in coding, and arrive at consensus.

The phases of coding included (a) reading transcripts, reviewing summary notes taken during the sessions, and (re)listening to the recorded sessions; (b) analyzing transcripts by pulling out descriptive statements that reflect personal meanings and sociocultural factors; (c) grouping codes into themes; and (d) collapsing and refining themes, noting differences by nationality, language, and/or ethnic/racial group. We ensured the themes' trustworthiness by presenting them to all CE Studio experts during our last session, and incorporating their feedback. The coders discussed the meaning of themes based on the literature, experience with this population, and lived experience. Findings were presented to the CST for final auditing.

### **Themes from the CE Studio Sessions for *FHIRedApp* project**

Table 1 shows themes emerging from the CE Studio sessions separated by topic. In the first CE Studio session, experts across the four groups defined health holistically and viewed access to healthcare as central to health: "To me, health is spiritual health, emotional health, and mental health. Health is all of that: spiritual, emotional, and mental. But because I've been HIV positive for 26 years, I have to take medications and being able to find them and afford them is important to my health." (Debbie<sup>1</sup>, African American). COVID-19 heightened for experts how

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<sup>1</sup> Pseudonyms used throughout

important health information has been in their community, and how inaccessible it has been when it comes to accessing testing and treatment.

Although all community experts valued the idea of using health information technology, Latino experts were least likely to have used that type of technology. In part because some had limited internet access or in other cases, many did not speak English well enough to find information in English that they could navigate. Cathy, a member of the Spanish Latinx group explained, “I’ve only used watches that track your steps, but not an app. I lose papers, in the email so it would be good. I lost the immunization records. An app would be good.” Asian American experts also emphasized language justice as necessary in any platform containing their health records, if they were to use these records to communicate with their provider. In the second CE Studio session, community experts expressed enthusiasm for the *FHIRedApp* platform mainly because it is the only application they know that would integrate all of their health information into one. They provided examples of how such a platform could avoid medical errors, incentivize adoption, and improve the quality of care. Lee, Asian American, illustrated this point:

You need to know who [the] target population is. You cannot do one app and think it will work for everyone. For refugee population, you need other people to help them get care and information. But that creates a conflict with provider who doesn’t acknowledge the support networks that are needed to navigate care. Refugee populations cannot read [technical jargon]. Need someone to translate, teach them how to use the app (workshop), and allow trusted sources to be able to provide information and support.

All panels in the second session expressed that cost and access would need to be

addressed. African American and Latinx American experts also expressed reluctance to adopt the *FHIRedApp* app unless dissemination involved trusted community leaders and influence members who understood these groups' historically-rooted mistrust of the healthcare system and fear of immigration-related exposure. Asian American experts emphasized the platform's aim to coordinate medical records from different providers could be difficult for immigrant Asian communities who tend to be mobile and have medical histories in foreign countries.

With regards to design preferences, community experts in the third CE Studio session provided input on the look and feel of the app, drawing on favorite features from other mobile applications they have used. They wished for an application to be simple, usable, and tailored to their condition, where some records are more easily accessible than others. They also expressed interest in shared access so they could share their health information with caretakers and other family members. However, immigration policy gave some Latinx American experts pause about having their health information and contacts in a platform, emphasizing that no information that would identify their immigration status should be included. Older African American participants and Asian American women were also weary of privacy: "Not many people in Asian cultures talk about women's health... need to be careful of who has access to this information" (Shanti, Asian American).

Finally, after seeing a mockup of the *FHIRedApp* during session 4, experts shared ways in which they would use the app, as Alexa from the Spanish Latinx CE Studio:

I had a surgery three years ago but I don't remember exactly what it was, what is was called, what the procedure that they did is called. If I had the app now, I could say, "let

me check....” Now I would have a way to research what medical intervention it was that I had. It would be five seconds, or even if it was five minutes, that would help a lot.

A few experts asked for an added feature that would allow them to journal changes in health and the ability to share that information with their healthcare providers. In the final CE Studio session, most experts stated the belief that *FHIRedApp* should be paid by health insurance companies or local health agencies. A few were in favor of paying a small amount per month to avoid advertisements on the application, but all were cognizant that a paid membership might impede the most vulnerable community members from using it in the long term.

### **Learnings and Implications of our Expanded CE Studio method**

Our expanded CE Studio method took place in the context of a federally-funded investigation of health technology for communities hardest hit by inequities in healthcare access. Multiple sessions allowed for extended participation, which may have enhanced progression in trust-building, continuity of themes, and group cohesion for both participants and researchers. Members from various panels provided affirming examples of these effects: “I have learned so much from these sessions,” “I appreciate being involved in every stage of the project,” “I am interested in research now and want to do more,” “The researchers and the CE Studio team genuinely cared about what we thought because they listened and took notes,” and “Every session built on the one before so we were able to see the life of the project.” In the latter sessions, participants also conveyed empowerment as they described wanting to become ambassadors for the *FHIRedApp* within their communities:

If we're able to present [the slides] to my clinic... because I as well work in a medical clinic. I think we can recruit people to be able to be part of [the app], but I know they're

going to want to know more information. So is there something that we can share with them? [Ilda, English-speaking Latinx]

We compensated participants for their involvement, recognizing their expertise and time, an equitable practice advocated by others [3]. We conducted a total of 20 sessions, all online due to the pandemic. This format could have been an impediment, but community experts from the CE Studios found it convenient and a safe distraction from the isolation of being home. Outside of the sessions, community experts have co-presented with researchers' testimonials of the CE Studio, a testament to their commitment to the project and our commitment to them. This level of participation created a unique environment for ethnic and racially similar individuals to tackle community issues. Embeddedness of the team and involvement of CHWs may have provided a seamless bridge between CE Studio participants and researchers, and to represent community interests in other community-facing efforts, including community advisory boards, technology design users, and pilot testers. This approach helped to change community experts' perceptions of the medical school ("I want to be involved in other projects"; Latinx expert).

In terms of challenges, first, it is more costly to implement the expanded CE Studio method than the original, single-session model, suggesting it may not be compatible with studies with limited funding. Costs to consider are participant compensation over multiple sessions and effort for the CE team during the entirety of a project. Second, the CE Studio team had to invest time to recruit participants who were committed to a two-year project. We were successful in retaining all our Asian American and English-speaking Latinx members, but attendance was inconsistent in the Spanish-speaking Latinx and the African American panels, particularly in the last two CE Studio sessions. The historical distrust of research conveyed by members of these

panels may have contributed to challenges in participation, as well as work demands. This challenge underscores the need to include CHWs on the team to maintain contact in between sessions and to connect community members to needed social resources, but suggests that such efforts should be intensified for these panels. Improving retention would also enhance our ability to evaluate satisfaction and outcomes of participation.

Challenges notwithstanding, the expanded CE Studio method has helped us develop a *FHIRedApp* platform that is responsive to the needs of our community. We will continue to build *FHIRedApp* features with feedback from CE Studios. Moreover, as Figure 1 shows, the community was responsive to the needs of the research. They demonstrated this through their attendance, participation, and commitment to the project's success. Some experts expressed a desire to become spokespersons for the project within their respective communities. This shared participation and accountability propels us to continue and advance our innovation. For example, we are seeking funds to include health information in *FHIRedApp* to be translated to over 100 languages. We are also considering modifications that would make the information accessible to hearing or vision-impaired community members.

In terms of future directions for the CE Studio method, we plan to involve expert panels in future rollouts of the *FHIRedApp* and in other translational research projects. We have advocated for our expanded CE Studio method with national health information technology policy agencies including the Office of the National Coordinator for Health Information Technology, in the development of health information solutions to address health equity. Ultimately, we will seek funding to conduct a large-scale research study to empirically capture the impact of digital platforms developed with community input on health outcomes and equity.





## Declarations

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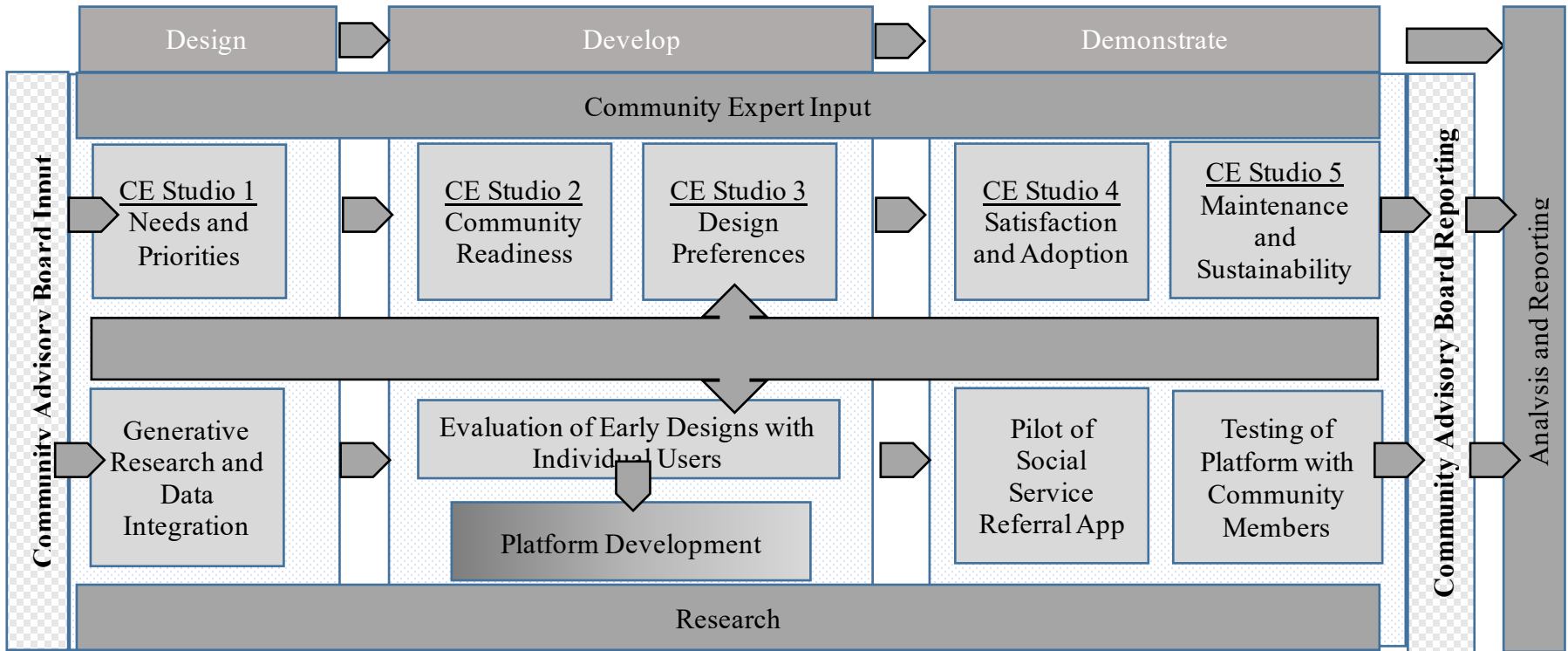
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**Figure 1:** Timing of CE Studio Sessions in Health Information Technology Research



**Table 1:** CE Studio Sessions for FHIRedApp Health Information Technology Project

Session	Topics	Sample Questions	Emerging Themes
1	Community health experiences	<ul style="list-style-type: none"> <li>• When it comes to your health, what issues matter most?</li> <li>• How could a mobile app address the health issues you have discussed?</li> </ul>	<ul style="list-style-type: none"> <li>• Health is holistic</li> <li>• Impact of racism and COVID-19 on health</li> <li>• Negative experiences with health system</li> </ul>
2	Community readiness	<ul style="list-style-type: none"> <li>• Are there efforts, initiatives or projects that you are aware of that involve sharing health information with others involved in your healthcare?</li> <li>• Who are folks that lead and influence members in your community/neighborhood?</li> </ul>	<ul style="list-style-type: none"> <li>• There is a need for innovation and no other initiatives are available</li> <li>• Factors that would promote interest are affordability, data security, language, and easy access</li> </ul>
3	Design preferences	<ul style="list-style-type: none"> <li>• What do you like about your smartphone? What features do you use the most?</li> <li>• How might we make the app easier to use for those who are not tech savvy?</li> </ul>	<ul style="list-style-type: none"> <li>• It should provide reminders and display most important items on the first page</li> <li>• Privacy key</li> <li>• Should provide shared access for caretakers</li> </ul>

		<ul style="list-style-type: none"> <li>• What would be the look and feel of the app?</li> </ul>	<ul style="list-style-type: none"> <li>• Should be easy to navigate and require little reading</li> </ul>
4	Adoption	<ul style="list-style-type: none"> <li>• How is the new app consistent with your health information needs?</li> <li>• What would you need to learn to use it?</li> <li>• What app components seem like you could use right away?</li> </ul>	<ul style="list-style-type: none"> <li>• Little training would be needed</li> <li>• Would use app right away if it combined all health information into application</li> <li>• Would like journaling feature to track health</li> </ul>
5	Sustainability	<ul style="list-style-type: none"> <li>• Thinking about value and cost, who should pay for the app?</li> <li>• Where should app data be stored in the long-term?</li> <li>• What features would allow you to continue using the app?</li> </ul>	<ul style="list-style-type: none"> <li>• Ideally paid by health insurance or local health department, not by grants</li> <li>• Language access would promote continued use</li> </ul>

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