Developing a Resource for Supporting Community-Based Health Research: Towards Considerations for Advancing Equity in Mobile Health Technology

Shaan Chopra
schopra7@cs.washington.edu
University of Washington
Seattle, WA, USA

Abril Beretta
abril.beretta@seattlechildrens.org
Seattle Children's Research Institute
Seattle, WA, USA

Miriana Duran
mdp19@uw.edu
University of Washington
Seattle, WA, USA

Katherine I. López
lopezk4@uw.edu
University of Washington
Seattle, WA, USA

Janet A. Rojina
jarojina@uw.edu
University of Washington
Seattle, WA, USA

Linda K. Ko
lindako@uw.edu
University of Washington
Seattle, WA, USA

Margaret Rosenfeld
margaret.rosenfeld@seattlechildrens.org
Seattle Children's Research Institute
Seattle, WA, USA
University of Washington
Seattle, WA, USA

Benjamin S. Wilfond
benjamin.wilfond@seattlechildrens.org
Seattle Children's Research Institute
Seattle, WA, USA
University of Washington
Seattle, WA, USA

James Fogarty
jfogarty@cs.washington.edu
University of Washington
Seattle, WA, USA

Stephanie A. Kraft
skraft1@geisinger.edu
Geisinger College of Health Sciences
Danville, PA, USA

ABSTRACT

Community-based research is essential for understanding and incorporating perspectives, values, and needs of marginalized and underrepresented communities toward creating technology that provides more equitable and accessible healthcare. However, due to differences in research and design practices across disciplines, cross-domain dissemination and translation of research insights becomes challenging. Informed by our experience with and findings of our community-based health research, we created a resource for supporting researchers and designers in questioning their assumptions about community needs and practices to develop a more community-informed lens for creating health technologies. We interviewed 18 health researchers from different domains and revised the resource based on their feedback to make it more concise, usable, and workable. As we continue to refine the resource and considerations to be more actionable and useful, we reflect on challenges of translational research and our efforts to disseminate research insights to the broader community of health technology researchers and designers.

CCS CONCEPTS

• **Human-centered computing → Empirical studies in HCI**; • **Applied computing → Life and medical sciences**.

KEYWORDS

mHealth; health technology; community-based research; community perspectives; design considerations; health equity; dissemination; translational research

1 INTRODUCTION

Mobile health or mHealth technologies have the power to advance equitable and accessible healthcare, supporting diverse individual and community needs by integrating health-tracking and healthcare delivery into everyday life activities [14] and addressing barriers to healthcare access (e.g., cost, geography) [6]. However, in order to truly reduce disparities and create more usable and culturally-responsive health technology, engaging in community-based research becomes essential for understanding and incorporating values and needs of marginalized and

underrepresented communities. Moreover, with the increased use of AI in healthcare, it is also important to integrate approaches such as community-based participatory research to improve health equity in technology design and evaluation practices, prioritize diverse representation in data, and recognize social drivers (e.g., where a person lives or works) that can affect individual and community health needs and practices [8].

HCI researchers and practitioners have examined value-based research and design practices [4, 11, 12], developing various resources (e.g., worksheets and templates [2, 13], cards [1, 4, 5], guidebooks [9]) aimed at translating academic research insights into technology design practices and at supporting designers in engaging with diverse communities in an ethical and inclusive manner. Specifically for personal health informatics applications, Kirchner et al. developed a set of design cards to support designers in re-thinking their assumptions, in turn also identifying the need to address challenges around knowledge, advocacy, and evidence in designing for health [10]. Thus, along with engaging in community-based research, disseminating resulting research insights is also vital. This includes cross-domain dissemination, such as translating learnings from clinical and public health research to design practices and sharing insights with the broader community of health technology designers and developers. However, differences in research and design practices of varying domains make dissemination and translation challenging.

This poster describes a resource we created, translating insights from one of our own projects to more general considerations for conducting community-based health research. We present our process of developing this resource, briefly describing our project and reflecting on challenges with disseminating community-based health research practices and insights. We conducted individual and group interviews with 18 health researchers from different domains (e.g., clinical health, public and community health, human-centered design of health technology) and revised the resource to be more concise, usable, and workable based on their feedback.

As we continue to refine this resource and considerations to be more actionable and useful, our goal is to support health technology designers and developers working in different contexts (e.g., industry, academic, public or clinical health research), including those who do not already/regularly engage in community-based research. This research is being conducted as a multidisciplinary collaboration drawing upon our experiences in bioethics, pediatric pulmonology, clinical research, public health, and human-centered design of technology, with these multiple perspectives being key to the success of our translational work.

2 OUR COMMUNITY-BASED HEALTH RESEARCH PROJECT

Hispanic and Latinx communities in the US bear a disproportionate burden of chronic conditions (e.g., asthma), primarily due to reduced access to healthcare and the presence of air pollution/irritants in places they inhabit [7]. Further, access barriers (e.g., cost, geography) and structural injustices in medicine and research means that these communities are often excluded from the design of health technologies [3]. This results in creation

of mHealth tools that may be unhelpful, or even harmful, potentially exacerbating existing health disparities and biases.

Our team conducted community-based research to examine the perspectives of Hispanic or Latinx-identifying individuals about mHealth and AI-based health technologies. We developed case scenarios with storyboards depicting the use of various mHealth technologies in pediatric asthma and other health contexts. We conducted focus groups, in Spanish and English, with a total of 48 Hispanic or Latinx-identifying individuals from rural and urban areas of Washington state. Findings from these community focus groups are currently under review[1] and inform the design of our resource and considerations for conducting community-based health research.

3 CREATING A RESOURCE FOR SUPPORTING COMMUNITY-BASED HEALTH RESEARCH
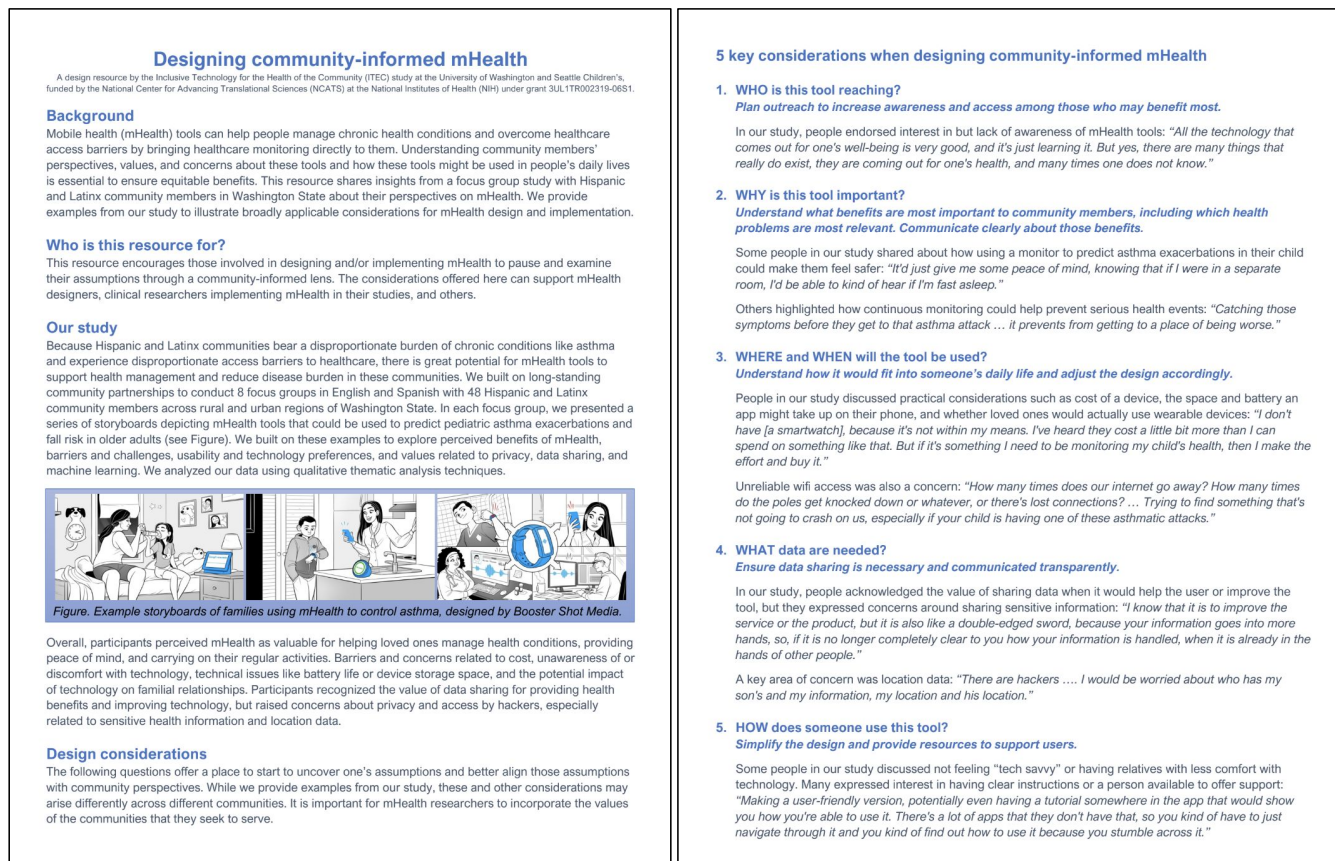
3.1 The Initial Resource

Based on the findings from our examination of Hispanic and Latinx community perspectives about mHealth, we created an initial 2-page version of the resource (see Figure 1). This version provided some details and context for our study followed by key considerations we identified for designing community-informed mHealth technologies. We translated insights from our project to form more general considerations that can support those wanting to engage in community-informed mHealth research and technology design. Each consideration is supported by quotes and findings from our study. This initial version of the resource was used to get feedback during the researcher interviews.

3.2 Feedback from Interviews with mHealth Researchers

We conducted 4 group interviews and 2 individual interviews with a total of 18 mHealth researchers (5 PIs, 13 students or research staff) from different domains, including clinical health, public and community-based health, and human-centered design of technology.

3.2.1 Tailoring the Resource to the Target Audience. A key point raised by interview participants was regarding the target audience and tailoring the resource to their needs. For example, participants felt that health technology designers in the industry might primarily care about design considerations/guidelines for creating mHealth tools and not necessarily want to read through background or study details. However, they noted that a public health or academic researcher might want more study details and to know how those informed considerations for design. Additionally, participants noted that some of our considerations might already be familiar to those deeply engaged in community-based health research, who in turn might want to use the resource as an onboarding document for new members joining an ongoing research project. One suggestion was to create a dynamic website which tailored the presentation of the resource and considerations for design according to who was using it.

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[1]Kraft et al. *Community Perspectives on Artificial Intelligence-Enabled Mobile Health Tools: A Focus Group Study of Hispanic and Latinx Community Members.* Under submission.

Figure 1: The initial version of our resource was 2 pages, providing details of our study and key considerations we identified for designing community-informed mHealth technologies. The goal of this resource is to support those involved in design and development of mHealth technologies to be more inclusive and intentional in incorporating diverse community perspectives. We got feedback on this initial version from research teams who conduct health research in different domains (e.g., clinical health, public and community-based health, human-centered design of health technology).

Although multiple participants appreciated the considerations being framed as questions, another suggestion was to make the resource more "actionable" by redesigning it in the form of a worksheet or checklist or design cards which could be used to facilitate the research and design process. Thus, depending on who is using the resource, our participants identified a need to balance conciseness and "actionability" with providing sufficient details to contextualize and understand considerations.

3.2.2   Tailoring the Resource to the Stage of Research or Design. Participants also questioned where in the process would it be most valuable to use the resource. Because most participants who we spoke with already engage in some form of community-based or human-centered research, they felt the resource could be valuable to use at each step of the research and design process, and not just during an evaluation or testing phase. They noted the considerations/questions might be differently phrased depending on the stage of research or design in which the resource was being used. However, participants noted they would prioritize using the

resource at the beginning of the research, such as when designing a study or before pilot testing/involving real participants.

3.2.3   Balancing Conciseness without Risking Tokenization of Community Perspectives. Most participants also recommended making the resource more visual (e.g., creating an infographic), reducing wordiness in the considerations (e.g., removing quotes, using bullet points to list learnings and recommendations on how to employ each consideration), and providing links to external resources and relevant publications. But although participants agreed the goal of the resource was to provide a case example for understanding and incorporating perspectives of diverse communities in technology design practices, they felt the key considerations could more directly map to cultural differences we observed in our community focus groups so that it does not feel like Hispanic and Latinx populations are just playing the role of a specific "case". However, they recognized the tensions of making the resource concise and generalizable to community-engaged work while ensuring communities' perspectives informing the considerations are not tokenized. A few participants proposed

Figure 2: The revised resource is intended to be more workable and easier to directly use. We removed all the study context and reformatted the key considerations as a checklist, also providing writing space and removing quotes. We clarify that these considerations are not prescriptive but intended to support mHealth researchers and designers in developing a community-informed lens.

highlighting limitations of using the resource for engaging in community-based or human-centered research and design practices as a potential way to navigate this tension.

4 REFLECTING ON EFFORTS TO TRANSLATE & DISSEMINATE RESEARCH INSIGHTS

A key challenge in creating this resource was balancing tensions between sharing community perspectives such that they provide sufficient context versus ensuring the considerations were general enough for others to learn from and apply in their own community-based health research practices. Although HCI and health researchers have created resources (e.g., design cards) for translating insights from academic health research to support design practice [10], challenges in creation and usability of translational research resources persist. This goes back to the question of "who do we intend this resource to be useful for?" as depending on who is targeted by the resource, they might have potentially different expectations from the resource (e.g., actionable considerations vs. evidence/context for considerations). Moreover, because methodologies differ across disciplines, the stage of research or design where the resource

would be more valuable is also questionable. Although participants recognized the usefulness of the resource at each stage, they noted prioritizing its use at the beginning of projects and as onboarding material for new researchers joining an existing community-based health project. After the researcher interviews, our team reflected on "who" and "what" this resource is intended for and made the following revisions.

4.1 Revising the Resource

We decided to revise the resource to make it more actionable and workable for those wanting to engage in community-based research and design of mHealth (see Figure 2). To this extent, we made two main changes. First, we removed all study context, just providing a citation to our under review work in case a person wants to know more about the research findings that informed the considerations. We identify the target of this resource to be mHealth designers and developers, including those who may not typically engage in community-based work. We do not intend for these changes to undermine community perspectives in any way but to highlight broader considerations informed by those community perspectives such that they can support

mHealth researchers and designers in their own projects. Second, we revised the resource to look more like a worksheet so that it could be useful for different stages of research and design (e.g., study design, onboarding new members, evaluation). We removed quotes, provided clear and concise summaries, created checklists of potential considerations, and also provided space for writing/brainstorming other considerations that might be relevant to individual projects or communities. The goal here was to make the resource more workable and easier to directly manipulate while encouraging researchers/designers to engage with the different considerations.

Moreover, while the considerations can help mHealth researchers and designers question assumptions about community needs and approach their work through a community-informed lens, it is important to understand that these considerations may arise differently across different communities and, thus, should not be treated as "prescriptive" guidelines. We clearly added this language at the very beginning of the resource.

The first author shared the revised resource with participants at the CHI 2024 workshop on "Designing (with) AI for Wellbeing"[2,3]. While the first author clarified that the resource was primarily geared towards health technology designers, including those who might not commonly engage in community-based research, workshop participants were further curious about what exact stage of design practice/development (e.g., system design, interaction design, interface design) it could be valuable for. However, all acknowledged the challenges of translational research and implementation science.

5 DISCUSSION & ONGOING WORK

As we strive for the goal of driving more community-based research in creation of mHealth technologies, we navigate tensions between providing too specific or prescriptive considerations versus risking over-generalizations of considerations for different communities or mHealth projects. Kirchner et al. navigated this tension by providing quotes and examples in their translational design cards to support designers in contextualizing the considerations [10]. However, this contrasts with our findings and revisions, wherein we removed all quotes and study context based on feedback from mHealth researchers to make the resource worksheet-like and easier to directly use. We continue to refine this resource, finding effective ways to translate learnings from clinical and public health research to industrial design practice and share with the broader community of health technology designers.

As the purpose of this poster, we also continue to look for effective ways to disseminate considerations for community-based health research to health technology designers. Would a blog post or website or other form of publication be an appropriate medium for dissemination? Or would more effective dissemination entail sharing learnings through in-person and/or synchronous workshops or discussions with mHealth researchers and designers? We look forward to presenting our poster and discussing our translational resource with the CSCW community.

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[2]Workshop: https://designingwithaiforwellbeing.github.io/
[3]Chopra et al. *Community-Informed Design Considerations for Advancing Equity in AI-based mHealth Technology: Learnings from Hispanic and Latinx Community Perspectives.* (Non-archival position paper).

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