Community-Informed Design Considerations for Advancing Equity in AI-based mHealth Technology: Learnings from Hispanic and Latinx Community Perspectives

SHAAN CHOPRA, Computer Science & Engineering, University of Washington, USA
ABRIL BERETTA, Treuman Katz Center for Pediatric Bioethics and Palliative Care, Seattle Children's Research Institute, USA
MIRIANA DURAN, Department of Health Systems and Population Health, University of Washington, USA
RUSSELL JAVAN, Department of Health Systems and Population Health, University of Washington, USA
KATHERINE I. LÓPEZ, Department of Health Systems and Population Health, University of Washington, USA
JANET A. ROJINA, Health Promotion Research Center, University of Washington, USA
LINDA K. KO, Department of Health Systems and Population Health, University of Washington, USA
MARGARET ROSENFELD, Center for Clinical and Translational Research, Seattle Children's Research Institute, USA and Department of Pediatrics, University of Washington School of Medicine, USA
BENJAMIN S. WILFOND, Treuman Katz Center for Pediatric Bioethics and Palliative Care, Seattle Children's Research Institute, USA and Department of Pediatrics, University of Washington School of Medicine, USA
JAMES FOGARTY, Computer Science & Engineering, University of Washington, USA
STEPHANIE A. KRAFT, Treuman Katz Center for Pediatric Bioethics and Palliative Care, Seattle Children's Research Institute, USA and Department of Pediatrics, University of Washington School of Medicine, USA

Mobile health technologies have the potential to advance equitable and accessible healthcare by integrating delivery into everyday life in support of diverse health management needs and to help address access barriers. It can be particularly helpful in the context of managing chronic conditions. However, toward a goal of reducing health disparities and designing culturally-responsive health technology, it is important to understand and incorporate perspectives, values, and needs of marginalized and underrepresented communities. Hispanic and Latinx communities in the US bear a disproportionate burden of chronic conditions, but are often excluded from technology design processes. We therefore conducted 8 focus groups with 48 Hispanic or Latinx individuals from rural and urban areas of Washington state, examining their perspectives on mobile health and AI-based health technologies for monitoring pediatric asthma and other health conditions. We report preliminary results around perceived benefits and barriers to use together with other considerations around data sharing, privacy, and use of data for improving device predictions. We are incorporating these perspectives to design a resource to guide designers and developers in creating more community-informed health technologies.

Additional Key Words and Phrases: mHealth, AI-based health technology, community-based research, human-centered research, Hispanic and Latinx community perspectives, pediatric asthma, design considerations, health equity

---

Manuscript submitted to ACM

ACM Reference Format:
Shaan Chopra, Abril Beretta, Miriana Duran, Russell Javan, Katherine I. López, Janet A. Rojina, Linda K. Ko, Margaret Rosenfeld, Benjamin S. Wilfond, James Fogarty, and Stephanie A. Kraft. 2024. Community-Informed Design Considerations for Advancing Equity in AI-based mHealth Technology: Learnings from Hispanic and Latinx Community Perspectives. In *Proceedings of Designing (with) AI for Wellbeing (CHI '24 Workshop).* ACM, New York, NY, USA, 7 pages. https://doi.org/10.1145/nnnnnnn.nnnnnnn

1 INTRODUCTION

Mobile health (mHealth) technologies consist of patient-facing mobile devices (or applications on mobile devices) used for medical and health-related purposes [4]. These technologies have the potential to advance equitable and accessible healthcare, particularly in the context of managing chronic conditions, supporting diverse individual needs by integrating health-tracking and healthcare delivery into daily life activities [7] and helping address access barriers (e.g., cost, geography) [4]. However, in order to reduce health disparities and create usable and culturally-responsive tools, it is key to incorporate values and needs of marginalized and underrepresented communities in technology design. Moreover, the increased use of AI in healthcare necessitates integrating foundational health equity approaches (e.g., community-based participatory research) in technology design and evaluation practices, prioritizing diverse representation in data, and recognizing social drivers (e.g., where a person lives, works, or goes to school) that can affect individual or community health [6].

In the US, Hispanic and Latinx communities bear a disproportionate burden of chronic conditions such as asthma, primarily due to reduced access to healthcare and the presence of air pollution/irritants where they live and work [5]. However, due to structural injustices in medicine and research, these communities are often excluded from the design of health technologies [3], resulting in tools that may be unhelpful, or even harmful, potentially exacerbating existing biases and health disparities. Our research therefore: (a) has examined the perspectives of Hispanic or Latinx-identifying individuals in Washington State about mHealth and AI-based health technologies, and (b) is incorporating their perspectives to design a resource to guide designers and developers in creating more community-responsive mHealth and AI-based health technologies.

We developed case scenarios with storyboards depicting the use of mHealth technologies in pediatric asthma and other health contexts. We conducted 8 focus groups (5 Spanish, 3 English) with 48 Hispanic or Latinx-identifying individuals from rural and urban areas of Washington state. Informed by learnings from these community focus groups, we drafted a resource with considerations for conducting community-based research and designing more culturally-inclusive health technology. We currently are conducting follow-on group interviews with multiple health research teams to get feedback on the resource. Our goal is to refine this resource and considerations for design so as to be more actionable and usable by health technology designers and developers working in different contexts (e.g., industry, academia, public health research). In this workshop paper, we discuss some preliminary results from our ongoing research and raise questions in going forward.

2 ABOUT THE TEAM

Our 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 work.

Fig. 1. Three of the case scenario slides used in the focus groups to explore Hispanic and Latinx community perspectives on different types of mHealth devices for pediatric asthma and other health scenarios. Left is of Diana and her 13 year old son Arturo, who has asthma. The technologies depicted in this image are an air quality monitor on the kitchen slab, a smartwatch with a cough monitor on Arturo's wrist, and an app on Diana's phone which she uses to track Arturo's inhaler usage. Middle is of 10 year old Sofia, who has asthma. The technology depicted in this image is a bed-side cough monitor. Right is of 90 year old Dolores who has trouble with her balance. The technology depicted in this image is a fall prediction and detection necklace worn by Dolores.

3 METHODS

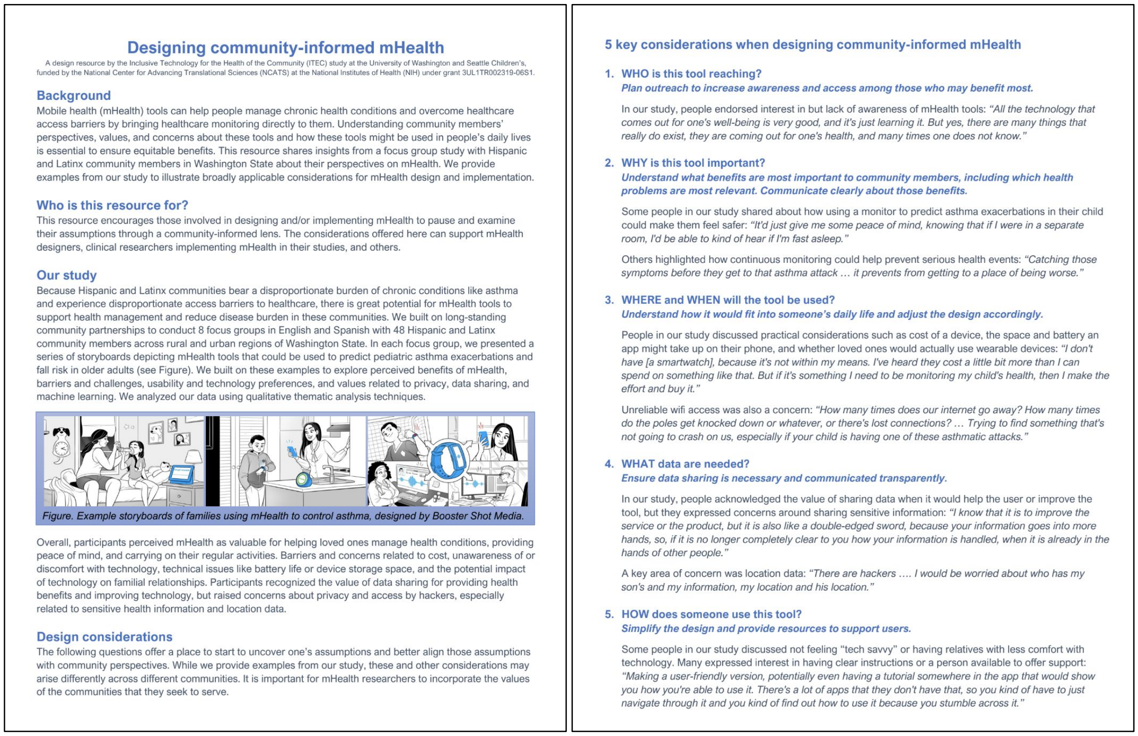
3.1 Case Scenario Creation

The research team created storyboards depicting case scenarios around pediatric asthma and other health conditions. These cases present a variety of mHealth and AI-based health devices (e.g., cough monitors, inhaler-use trackers, in-home air quality monitors, wearables for fall detection & prevention). The case scenarios were designed to be appropriate to the community in focus (i.e. Hispanic and Latinx populations), ensuring that characters and depicted scenarios resembled their experiences and environment. Figure 1 shows a snapshot of the different case scenarios and mHealth technologies.

3.2 Community Focus Groups & mHealth Researcher Group Interviews

From May to September 2023, we conducted 8 focus groups in English and Spanish via Zoom, using the case scenarios to gauge perspectives and attitudes towards mHealth and AI-based health technology for pediatric asthma and other health conditions. A total of 48 individuals participated (32 in Spanish, 16 in English, 24 urban, 24 rural, 90% women, mean age: 45 (std=14) years). Participants were recruited via long-standing partnerships with Hispanic and Latinx communities in the region. The focus groups included questions about utility, usability, burden, machine learning, privacy, data sharing, and condition- and population-specific considerations for health technologies.

We used a combination of inductive and deductive thematic techniques [1] to analyze focus group transcripts. Two team members (M.D., S.C.) used the focus group guide to develop an initial codebook. Next, they revised the codebook based on inductive coding of the transcripts, using the constant comparison method [2] to settle on the coding of each transcript. They continued this iterative process until no further revisions to the codebook were required. A.B. was trained to use the finalized codebook. S.C. and A.B. then split up the remaining transcripts for coding and M.D. reviewed them for consensus. After coding was complete, three team members (M.D., S.C., S.A.K.) worked together to identify cross-cutting themes. These themes shape our findings (currently being prepared for a journal submission) and an initial draft of our resource (see Figure 2). The resource details key considerations for designing mHealth technologies informed by Hispanic and Latinx community perspectives. We continue to refine this resource based on feedback 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).



Designing community-informed mHealth

A design resource by the Inclusive Technology for the Health of the Community (ITEC) study at the University of Washington and Seattle Children's, funded by the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH) under grant 3UL1TR002319-06S1.

Background

Mobile health (mHealth) tools can help people manage chronic health conditions and overcome healthcare access barriers by bringing healthcare monitoring directly to them. Understanding community members' perspectives, values, and concerns about these tools and how these tools might be used in people's daily lives is essential to ensure equitable benefits. This resource shares insights from a focus group study with Hispanic and Latinx community members in Washington State about their perspectives on mHealth. We provide examples from our study to illustrate broadly applicable considerations for mHealth design and implementation.

Who is this resource for?

This resource encourages those involved in designing and/or implementing mHealth to pause and examine their assumptions through a community-informed lens. The considerations offered here can support mHealth designers, clinical researchers implementing mHealth in their studies, and others.

Our study

Because Hispanic and Latinx communities bear a disproportionate burden of chronic conditions like asthma and experience disproportionate access barriers to healthcare, there is great potential for mHealth tools to support health management and reduce disease burden in these communities. We built on long-standing community partnerships to conduct 8 focus groups in English and Spanish with 48 Hispanic and Latinx community members across rural and urban regions of Washington State. In each focus group, we presented a series of storyboards depicting mHealth tools that could be used to predict pediatric asthma exacerbations and fall risk in older adults (see Figure). We built on these examples to explore perceived benefits of mHealth, barriers and challenges, usability and technology preferences, and values related to privacy, data sharing, and machine learning. We analyzed our data using qualitative thematic analysis techniques.

Figure. Example storyboards of families using mHealth to control asthma, designed by Booster Shot Media.

Overall, participants perceived mHealth as valuable for helping loved ones manage health conditions, providing peace of mind, and carrying on their regular activities. Barriers and concerns related to cost, unawareness of or discomfort with technology, technical issues like battery life or device storage space, and the potential impact of technology on familial relationships. Participants recognized the value of data sharing for providing health benefits and improving technology, but raised concerns about privacy and access by hackers, especially related to sensitive health information and location data.

Design considerations

The following questions offer a place to start to uncover one's assumptions and better align those assumptions with community perspectives. While we provide examples from our study, these and other considerations may arise differently across different communities. It is important for mHealth researchers to incorporate the values of the communities that they seek to serve.

5 key considerations when designing community-informed mHealth

1. **WHO is this tool reaching?**
   Plan outreach to increase awareness and access among those who may benefit most.

   In our study, people endorsed interest in but lack of awareness of mHealth tools: *"All the technology that comes out for one's well-being is very good, and it's just learning it. But yes, there are many things that really do exist, they are coming out for one's health, and many times one does not know."*

2. **WHY is this tool important?**
   Understand what benefits are most important to community members, including which health problems are most relevant. Communicate clearly about those benefits.

   Some people in our study shared about how using a monitor to predict asthma exacerbations in their child could make them feel safer: *"It'd just give me some peace of mind, knowing that if I were in a separate room, I'd be able to kind of hear if I'm fast asleep."*

   Others highlighted how continuous monitoring could help prevent serious health events: *"Catching those symptoms before they get to that asthma attack … it prevents from getting to a place of being worse."*

3. **WHERE and WHEN will the tool be used?**
   Understand how it would fit into someone's daily life and adjust the design accordingly.

   People in our study discussed practical considerations such as cost of a device, the space and battery an app might take up on their phone, and whether loved ones would actually use wearable devices: *"I don't have [a smartwatch], because it's not within my means. I've heard they cost a little bit more than I can spend on something like that. But if it's something I need to be monitoring my child's health, then I make the effort and buy it."*

   Unreliable wifi access was also a concern: *"How many times does our internet go away? How many times do the poles get knocked down or whatever, or there's lost connections? … Trying to find something that's not going to crash on us, especially if your child is having one of these asthmatic attacks."*

4. **WHAT data are needed?**
   Ensure data sharing is necessary and communicated transparently.

   In our study, people acknowledged the value of sharing data when it would help the user or improve the tool, but they expressed concerns around sharing sensitive information: *"I know that it is to improve the service or the product, but it is also like a double-edged sword, because your information goes into more hands, so, if it is no longer completely clear to you how your information is handled, when it is already in the hands of other people."*

   A key area of concern was location data: *"There are hackers …. I would be worried about who has my son's and my information, my location and his location."*

5. **HOW does someone use this tool?**
   Simplify the design and provide resources to support users.

   Some people in our study discussed not feeling "tech savvy" or having relatives with less comfort with technology. Many expressed interest in having clear instructions or a person available to offer support: *"Making a user-friendly version, potentially even having a tutorial somewhere in the app that would show you how you're able to use it. There's a lot of apps that they don't have that, so you kind of have to just navigate through it and you kind of find out how to use it because you stumble across it."*

Fig. 2. Our draft resource is 2 pages-long, providing details of our study and key considerations we identified for designing community-informed mHealth technologies. The goal of our 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 are in the process of getting feedback on this resource 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) and are refining the resource to make it more useful and usable for designers and developers.

4 PRELIMINARY FINDINGS

4.1 Community Perspectives of mHealth Tools

4.1.1 Benefits. Most participants found mHealth technologies to be potentially beneficial for promoting health via general monitoring (e.g., tracking steps) and preventing serious health episodes (e.g., administration of preventative intervention, early hospitalization to prevent serious illness). Participants described that mHealth devices could promote peace of mind and a feeling of safety by alerting them in case a loved one is having a serious health event: *"[A monitor] would be a safe way where we get an alert to wake up quickly and run to [our child's] room to help them [when they are having an asthma attack], since their age capacity does not give them to have that knowledge."* (Rural, Spanish-speaking participant (translated)).

4.1.2 Barriers to Use. A key barrier to use was unfamiliarity with health technologies, including lack of awareness about specific devices and how those technologies have evolved over the years. Participants noted a general feeling of discomfort with using technology, with some describing themselves or their family members as *"not tech savvy."* Other barriers included cost and insurance coverage (*"Will the insurance cover for it? Do we have to pay for it?… I would* *imagine for those who have more than one person in the family, it will cost a lot of money."* (Rural, English-speaking participant)), technical issues (e.g., not syncing, charging issues, device malfunction), inaccuracy of predicted results, and doubt about relevance or "fit" of specific technologies in an individual's everyday life and cultural context (e.g., how would using a tracking device for a child affect familial relationships, the child's school life, and other community perceptions of the child's abilities?). To overcome some of these barriers, participants noted value in individualized support, such as in the form of tutorials, to help them learn about and get comfortable with using new devices.

4.1.3 Considerations around Data Sharing, Privacy, and Improving AI-based Predictions. Participants recognized the value of data sharing, such as to access emergency services and support from family members and relevant clinicians. They were also open to sharing their data with developers of mHealth and AI-based health technologies to improve the accuracy and prediction made by the devices. However, there were concerns around privacy, such as the possibility of *"hackers"* getting access to sensitive health and location data and misuse of their data for malicious purposes. We also felt that the mental model of the participants about how AI-based technologies function was different from (or not as developed as) that of us researchers working in the domain. Thus, to not confuse participants with unfamiliar terminology, we avoided explicitly using the term "AI" or giving too much information about it. This might have influenced their perceptions of benefits and harms of predictions made by mHealth technologies.

4.2 Preliminary Learnings from Researcher Group Interviews

A key point raised by interviewed researchers was regarding the target audience and tailoring the resource to their needs. For example, health technology designers in industry might only care about design considerations/guidelines for creating AI-based health tools and not necessarily want to read through background/study details. But a public health or academic researcher might want more study details and to know how those informed considerations for design. Additionally, some of our considerations might be obvious to those deeply engaged in community-based health research and they 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. Although multiple researchers appreciated the considerations being framed as questions, another suggestion we received was to make the resource more "actionable" by redesigning it as 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, there is a need to balance conciseness and "actionability" with providing sufficient details to contextualize and understand considerations for designing AI-based health technologies.

A follow-up question was regarding where in the process would it be most valuable to use the resource. Because most researchers who we are speaking 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 that the considerations/questions might be differently phrased depending on the stage of research or design the resource was being used in. However, researchers noted that 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.

Other recommendations included making the resource more visual (e.g., creating an infograph), reducing wordiness in the considerations (e.g., removing quotes, using bullet points to list learnings and recommendations on how to employ each consideration), providing links to external resources and relevant publications, and highlighting limitations of the using the resource for engaging in community-based or human-centered research and design practices. Lastly, although researchers agreed that 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 design recommendations 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."

5 ONGOING WORK & BENEFITS FROM WORKSHOP

We are currently preparing community focus group findings for a journal submission. We are also continuing to conduct group interviews with research teams doing health work in different domains (e.g., clinical health, public and community-based health, human-centered design of health technologies) and refining our resource based on the feedback received.

At the workshop, we would love to hear additional thoughts on the resource: How valuable are the community-informed considerations for design for different types of health researchers and designers (e.g., public health researchers, UX researchers, industry designers)? Where and how in the research and design process would the resource be most useful? What forms (e.g., worksheet, guidelines, design cards) can this resource take to be more "actionable" to use in practice? What can be changed, redesigned, or included in the resource or list of considerations for design (e.g., limitations of using the resource, another consideration around assessing if there is even a need to design a technology intervention)? Should we more directly call out considerations for the AI component of mHealth technologies or is that covered by the existing considerations? Secondly, we would appreciate thoughts on how to disseminate the resource to health tech designers as well as to the CHI community. 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?

Thus, the big picture question we want to discuss and address is: **How to drive more community-based research in design of mHealth and AI-based health technologies?** More specifically, (i) **How can learnings from clinical and public health research translate to industrial design practices and be shared with the CHI community?**, and (ii) **What are some strategies to incorporate more diverse perspectives, including those of historically marginalized and underrepresented communities, into the design of AI-based health and wellbeing technologies?**

ACKNOWLEDGMENTS

This research is supported in part by NIH awards 3UL1TR002319-06S1 and R01LM012810 and by NSF award IIS-1813675. We are also grateful to Gary Ashwal and Alex Thomas of Booster Shot Media for crafting the case scenario slide presentation used in the community focus groups. We would like to thank all our participants for contributing their time and perspectives.

REFERENCES

[1] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative research in psychology* 3, 2 (2006), 77–101.
[2] Barney G Glaser. 1965. The constant comparative method of qualitative analysis. *Social problems* 12, 4 (1965), 436–445.
[3] Carmen Gonzalez, Jody Early, Vanessa Gordon-Dseagu, Teresa Mata, and Carolina Nieto. 2021. Promoting culturally tailored mHealth: A scoping review of mobile health interventions in Latinx communities. *Journal of immigrant and minority health* 23, 5 (2021), 1065–1077.
[4] Tayla Holman. 2018. mHealth (mobile health). https://www.techtarget.com/searchhealthit/definition/mHealth
[5] Tayla Holman. 2023. Asthma in the Hispanic/Latino Community. https://www.nhlbi.nih.gov/sites/default/files/publications/asthma_in_hispanic_latino_community_fact_sheet.pdf
[6] Dr. Ivor Horn. 2023. 4 ways we think about health equity and AI. https://blog.google/technology/health/health-equity-and-generative-ai/

[7] Somayyeh Zakerabasali, Seyed Mohammad Ayyoubzadeh, Tayebeh Baniasadi, Azita Yazdani, and Shahabeddin Abhari. 2021. Mobile health technology and healthcare providers: systemic barriers to adoption. *Healthcare Informatics Research* 27, 4 (2021), 267–278.

Received 20 February 2007; revised 12 March 2009; accepted 5 June 2009