

Strategies for Inclusion in the Design of Pervasive Computing for Health and Wellbeing

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■ **PARTICIPATORY DESIGN HAS** become a popular method in pervasive computing for health and wellbeing. Involving end users as participants in the design of a technology helps to ensure feasibility, acceptability, and usability—key factors that promote the uptake of pervasive computing for improving health. These factors are particularly important for emerging technologies, as we are still learning how they fit into users' lives.

Pervasive computing researchers have a unique opportunity to include many voices in influencing the design and implementation of emerging technologies. Approaching the conceptualization of pervasive systems, applications, and use cases as inclusively as possible will

ensure our innovations reach their full potential. If we do not include different perspectives in the process of innovation, we risk contributing to inequity and exacerbating existing social divides. We also limit our capacity for innovation.

Participatory design commonly involves eliciting input and inviting codesign through sketching and iterative prototyping. This process is meant to enable meaningful design experiences for both participants and researchers, but these broad activities can be difficult to apply in practice. Moreover, the activities of participatory design become more difficult to apply effectively across a variety of populations. Pervasive computing has notably tackled challenging health and social issues affecting a diverse range of populations—including children with autism, older adults experiencing physical or cognitive impairments, individuals with traumatic brain injury, individuals with limited technology

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experience, residents of low-income communities, and patients with varying literacy.

As we continue to engage diverse populations in the participatory design process, we need to critically reflect on how inclusive and effective our methods are. From the early stages of the design process, how do we engage a specific population in ideation, iteration, prototyping, and evaluation? How do we provide equitable and meaningful experiences for participants, while ensuring rigorous and innovative data collection for researchers?

There has been some population-specific guidance for applying participatory design techniques—such as cooperative inquiry, which focuses on children as partners in design.² However, once in the wild, these methods and approaches must still be tailored based on the characteristics of the population. Madsen *et al.*³ report lessons learned while conducting participatory design with adolescents with autism. Their participants were not able to articulate difficulties they had with the system being evaluated, so several methods were used to document usability issues and optimize the feedback loop during design. For example, clinicians familiar with the adolescents observed each of the participants and served as proxies to communicate feedback on the design according to what they perceived the children found engaging.

Adapting participatory design methods to the needs and preferences of specific populations is an effective strategy. Rather than relying on standards and guidelines, it has been suggested that designers develop empathy with their user groups⁵ through uniquely tailored strategies for conducting participatory design. For example, Sahib *et al.*⁶ show a scenario-based approach for conducting participatory design with blind users. Still, an open question remains as to how we can create tasks and activities that positively engage individuals from diverse populations.

ADAPTING METHODS TO EACH POPULATION

A group of 14 researchers met on May 21st, 2018, during the International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth), to share experiences and strategies for adapting participatory design

methods to fit the needs of diverse populations. The aim was to discuss the challenges that emerge when conducting participatory design with diverse populations, and share creative methods and techniques that can overcome these challenges. The researchers brought perspectives from working with populations such as low-income African-American older adults, people with vision impairments, and individuals with Down syndrome. Combining experiences with a range of diverse populations, the following aspects and challenges of the participatory design process were discussed.

- *Building rapport:* How do you introduce researchers (i.e., yourself) and the participatory design process (i.e., your work)? What phrases are effective for encouraging participants to provide ongoing, detailed and honest input?
- *Prompts:* When is it useful to provide narrative prompts such as scenarios or stories for participants to respond to? How are these prompts generated and integrated into the design process?
- *Activities:* What activities are appropriate and effective for specific populations? What types of activities can maximize enjoyment for participants while optimizing data collection for facilitators?
- *Tools/artifacts:* What tools or artifacts are helpful to participants and/or facilitators? When does high tech work well? When does low tech work well?
- *Technology experience:* How much relevant technology experience should participants have? Do different amounts of experiences lead to different types of contributions?
- *Allies:* When and how do you utilize gatekeepers, champions, or advocates for a specific population? When and how do you enlist caregivers, clinicians, or proxies for a specific population? What are the advantages of these points of view, and when do they outweigh the potential risks of not engaging the population directly?

Three themes emerged from the discussion, representing key challenges to conducting an effective and equitable participatory design

process. We were able to align these themes roughly with chronological phases of the process. We present the key challenge in each phase through an example of working with a specific population:

1. *Gaining access, recruiting, and ensuring participation* can be particularly challenging when working with stigmatized populations who may be hesitant to trust researchers.
2. *Planning for a mutually beneficial relationship before, during, and after the design process* is critical when working with underserved populations, otherwise we risk making these individuals feel used and abandoned after data collection.
3. *Creating engaging research experiences for participants while also gaining rich insights* is especially helpful when working with populations who do not perceive themselves as designers.

These three key challenges can help us all think critically about how inclusive and equitable we are in engaging a diverse range of populations in participatory design.

GAINING ACCESS

It is not always easy to recruit certain populations and engage them in the participatory design process. The reasons could be varied, but more frequently this happens due to researchers being perceived as outsiders and due to a lack of trust in their research agenda.

Example: Stigmatized Populations

It can be particularly challenging to reach individuals for the purpose of doing research around a stigmatized trait or condition. Many people are able to hide stigmatized conditions, such as depression or HIV, and are careful to whom they disclose related personal information. Privacy and confidentiality therefore become key barriers to engaging these individuals in research. Strategies for overcoming these concerns include finding community partners and using computer-mediated platforms to collect data.

Community partners are individuals already embedded within the population, such as support group administrators, advocacy leaders, care providers, and social workers who have a deep understanding of the needs and concerns

of those with the stigmatized condition. Community partners can serve as a liaison through which researchers might safely approach the population. Researchers should share the details of their research agendas with these community partners and ask for their advice and support about gaining access and recruiting study participants. Community partners can also help researchers learn how best to interact with individuals during their research (e.g., language use, privacy concerns). For instance, in the case of people living with a chronic illness like HIV, such community partners could be social workers or healthcare providers who are interacting with patients on a regular basis in a clinical or supportive setting.

In addition, methods of collecting data online may also be considered as a way of reducing the burden and risk of participation in research. For instance, one common method has been to extract posts from social media sites and perform content analysis of messages, images, or discourse. Other online methods like using asynchronous remote communities have also been employed to conduct participatory design activities remotely.⁴

PLANNING THE RELATIONSHIP

It is important to determine and communicate clearly—from the start of a relationship—the benefits for all stakeholders during the stages of the participatory design process. Researchers should be cautious not to take from the participants without giving or producing something useful in return.

Example: Underserved Populations

There can be a feeling of abandonment in certain communities once data has been collected and researchers leave a field site. This effect can be particularly destructive for individuals who live in communities that are underserved and under-resourced. Although the nature of participatory design features the collaborative involvement of key individuals that may be impacted by the development of a health technology, it may be hard for the immediate realization of these technologies, or any other potential outcomes of the participatory design process. Therefore, researchers are tasked with making research

activities mutually beneficial for the communities that they work with. Establishing the overall end goal of a participatory design experience with the research participants is one way that participants can feel a part of the research agenda and not just a subject of the study. It may be that this goal is related to the research agenda, or more closely related to the needs of the community being asked to participate in the codesign process.

Researchers can also find ways to share outcomes of participatory design work to ease the researcher-participant relationship to lessen this feeling of abandonment post data collection. This may be seen through identifying existing community resources or small-scale solutions readily available that align with participant needs. Additionally, following up on points of action to actualize brainstormed concepts past participatory design activities may be valuable to lessening participants' perceptions of abandonment.

In addition to the perception of abandonment of a community following data collection at the field site, there may be an effect of technology or intervention abandonment. Despite the potential of pervasive technologies to address health challenges, there can be significant barriers of technology proficiency, sustainability, and lack of financial access. Therefore, it is important to consider the maintenance of technologies conceptualized during participatory design particularly when working with underserved populations.

CREATING ENGAGING EXPERIENCES

The process of design can and should be engaging for participants. Not all populations may immediately perceive themselves as designers, or understand how much their lived experience can contribute to a design process. Researchers can even create research experiences that enrich communities and empower individuals.

Example: Older Adults With Age-Related Disability

Older adults (ages 65+) are often excluded from the design process with the assumption that they are uninterested in newer technologies and lack the technology proficiency to engage in participatory design. Beyond skill level and

generational differences, other considerations become critical for designing for and engaging an aging population, such as age-related disability. Researchers in human-computer interaction, pervasive computing, and accessibility spaces have discussed the importance of designing for older adults, but engaging them in the design process can be challenging. Older individuals may not feel they have the creative skills or digital self-efficacy to be designers in such a youth-dominated design space. In a participatory design environment where people are asked to make design contributions in a group space, engagement is key, yet self-imposed age stereotyping or perceptions of failure may impede upon engagement levels and contribute to feelings of disempowerment in interactions with researchers.¹ Such disempowerment may be exacerbated with older adults with age-related disabilities such as late-life vision loss or mild dementia.

One of the most important aspects of engaging older adults in the design process is to first find appropriate ways to engage with their community. To achieve this, some researchers spend several months volunteering or performing different activities with residential living facilities or care centers. These activities are not always research related, but can be influential in understanding how to engage older adults in the research process. For example, a research team could visit a senior center once a week and play card or board games with older adults. Over time, conversations during these visits could expand to other forms of gameplay and could fit well with a participatory design activity centered around a game or play-related activity. As a result, participants would feel more at ease engaging with the researcher in conversation and it would be easier for the research team to continue with codesign activities in which conversation is important.

Participatory design materials and activities can also be adapted such that older adults feel more capable of engaging in the design process. A potential barrier to this population feeling that they can be effective design partners is the perception of intimidating or unfamiliar materials or the lack of experience with design thinking. Leveraging familiar technology and using different methods of concept visualization

to explain the goal of the activities can help to overcome these barriers. Implementing design activities such as collaging or storyboarding that resemble leisure activities that older adults are familiar with (arts and crafts or storytelling, respectively), may support engagement. If the participatory design activities include using high tech concepts or devices, technical jargon should be avoided, and the tech devices must be introduced progressively.

CONCLUSION

Pervasive computing researchers should strive to include many voices in the design of emerging technologies, so the systems they create can benefit diverse populations. This paper summarizes strategies that can be applied in three phases of participatory design—recruiting, developing relationships, and creating engaging experiences:

- engage a member of the community in the research team;
- facilitate peer mentorship;
- make the mutual benefits of engaging in research clear;
- seek research advocates within communities;
- develop trust over time starting with non-research related activities;
- find methods of concept visualization that are accessible.

Designing for and with diverse populations is a challenging process. We hope that the strategies and challenges discussed in this paper can help other researchers to enrich their design work and innovation with a broader range of populations.

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