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# Designing with Diverse Populations: Sharing Experiences, Best Practices and Opportunities

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## Abstract

Participatory design is a highly valued and widely used method in the Pervasive Health community. A growing focus on health, wellness, and social good has expanded the use of participatory design to a variety of populations. From children and older adults, to patients and refugees, the CHI community is engaging in important design work to benefit diverse populations. The aims of these design activities include the development of assistive technologies, novel applications of interaction paradigms, and empowerment of vulnerable groups. This workshop will bring together researchers and practitioners to compare and contrast their experiences with engaging diverse populations in participatory design. We invite workshop participants to share best practices and innovative approaches to overcoming the challenges of applying participatory design with diverse populations. We will also discuss challenges of creating an optimal participatory design experience for participants and facilitators. The outcomes of the workshop will include generation of an edited book including the range and variety of the discussed practices, highlighting the uniqueness of working with diverse populations.

## Author Keywords

Participatory design; diverse populations; inclusive design; universal design.

### Challenges of Engaging Diverse Populations in Participatory Design

How do we sketch or ideate with individuals who have motor impairments?

How do we obtain the most nuanced feedback and input from individuals with limited or no verbal communication?

How do we engage individuals with visual impairments in design, when design tends to be a visual process?

How do we seek buy-in and motivate individuals who may not see the broader impact of a design process?

How do we create safe and nonjudgmental spaces for individuals who may be accustomed to marginalization?

How do we bridge socio-economic divides to develop trust and equitable design partnerships?

### ACM Classification Keywords

H.5.2 [Information interfaces and presentation (e.g., HCI)]: User Interfaces– User-centered Design; Theory & Methods; Standardization; J.3 [Computer Applications]: Life and Medical Sciences– Health.

### Background

Participatory design has become popular in the Pervasive Health community, and a growing number of research prototypes, products, and services are relying on this method. However, facilitators of participatory design do not always know how to apply the general principles in practice. Moreover, the general principles of participatory design become more difficult to apply effectively across a variety of populations. The Pervasive Health community is notable for its inclusivity, empathy, and commitment to tackling challenging social issues affecting a diverse range of populations, including children with autism [8, 1], people with visual impairments [6], individuals with traumatic brain injury [7], homeless youth [21], refugees [20], and patients with varying literacy [2].

As we continue to engage new and more diverse populations in the participatory design process, we need to reflect on how inclusive and effective our methods are. The aim of this workshop is to critically reflect on the suitability and effectiveness of participatory design techniques for a variety of groups. 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 facilitators?

Well-known methods and approaches for conducting participatory design (e.g., prototyping and sketching [9]) have

enabled meaningful design experiences for both participants and facilitators. Cooperative inquiry [5] is an example of a participatory design approach tailored to a specific population. Focusing on children as partners in design, cooperative inquiry has provided population-specific guidance on applying participatory design techniques. However, once in the wild, these methods and approaches must be tailored depending on the characteristics of the population. Madsen et al. [12] reports lessons learned while conducting participatory design with adolescents with autism. Their participants were not able to articulate difficulties they had with the system, so several methods were used to document usability issues and optimize the feedback loop during design. For example, clinical assistants familiar with the adolescents observed each of the participants and acted as proxies to communicate feedback on the design based on what they believed the children found engaging. On the other hand, Potter and colleagues [16] found that during participatory design, young deaf children were able to verbalize their feedback about the things they enjoyed or about the activities that frustrated them. In addition, young deaf children were able to describe their experiences when the facilitators used prompting. However, the authors expressed that over-prompting could irritate children or cause them to ignore prompts. Moreover, this work also shows that young deaf children participate and create better when working as a team rather than individually during participatory design.

These and other challenges arise when conducting participatory design with diverse populations. Rather than suggesting that designers rely on standards and guidelines, it is suggested that designers need to develop a real empathy with their user groups [15, 14], as individuals of diverse populations can have unique needs, and propose different methods and techniques for conducting participatory design. For example, the work of [17] shows a scenario-based

approach for conducting participatory design with blind users. The work of [4] presents an approach for conducting gamified co-design at primary schools. There are also work in participatory design with older adults [3], people with dementia [11], and mental health [10, 13]. However, how to design tasks and environments that positively engage wide and diverse groups of people from diverse populations still remains an open question.

In this workshop, we propose to gather researchers with experience in conducting participatory design with diverse populations, from older adults to individuals with developmental disabilities. The aim of the workshop is 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 outcome of the workshop will be the generation of an edited book documenting examples of the range and variety of best practices used by researchers to conduct participatory design with diverse populations. It will include introduction to different approaches, stages and will highlight the uniqueness of working with diverse populations, including challenges, successes and opportunities. This book will complement current literature about participatory design with diverse populations (e.g., [15, 19, 18]) with the richness of participants' experience in working with a variety of diverse populations.

### **Challenges and aspects to be addressed**

Some of the challenges we are planning to address and discuss during the workshop are the following:

**Building rapport:** How do you introduce facilitators (*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 are innovative and creative activities 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?

### **Organizing Committee**

**Karina Caro, PhD** is a Postdoctoral Researcher with a joint appointment in the College of Computing & Informatics, and the Westphal College of Media Arts & Design, at Drexel University. Dr. Caro has experience applied participatory design with children with Autism Spectrum Disorder (ASD) for designing therapeutic games and with caregivers for designing visualization systems to support institutionalized older adults. She holds a PhD and a MSc in computer science from CICESE, research center.

**Gabriela Marcu, PhD** is an Assistant Professor in the College of Computing and Informatics at Drexel University. Her research engages underserved, marginalized, and stigmatized populations in participatory design, with the aim of overcoming barriers to everyday use of mobile-based behavioral interventions. Dr. Marcu has applied participatory design for smartphone interventions such as: TreatYoSelf, for improving medication adherence among youth living with HIV; Bounce, a physical activity intervention for breast cancer survivors; and MONARCA, a self-assessment and collaborative monitoring system for individuals receiving outpatient treatment for bipolar disorder. Currently, she is embarking on participatory design projects with Philadelphia high school students at risk for truancy, and children ready to transition from behavior disorder classrooms into regular education as a result of their behavioral progress. She holds a PhD in Human-Computer Interaction from Carnegie Mellon University, and a B.S. in Informatics from U.C. Irvine.

**Kay Connelly, PhD** is a Professor and Associate Dean for Research in the School of Informatics, Computing and Engineering at Indiana University - Bloomington. Her research focuses on user acceptance of ubiquitous and mobile computing technologies where there is a delicate balance between such factors as convenience, control and privacy. Dr. Connelly's most recent work emphasizes health and wellness applications to empower both the ill and the healthy to manage and improve their own health and make healthy choices. She holds a PhD in Computer Science from the University of Illinois - Champaign-Urbana.

**Juan Fernando Maestre** is a PhD student in Informatics in Indiana University with a background in computer science and design. His research revolves around the impact and design of technology for stigmatized individuals. Ultimately, he strives for a successful integration of HCI methods in in-

terdisciplinary projects in order to create technology-based interventions that aid marginalized and vulnerable populations.

## **Workshop Plans and Structure**

### *Pre-workshop Plans*

Prior to the workshop, we will establish a steering committee by inviting researchers who have experience with engaging a variety of diverse populations in participatory design. The role of the steering committee will be to provide input on our plans for workshop activities. The steering committee will help to disseminate the call for participation to the appropriate research communities. They will also be invited to contribute to publishing the results of the workshop.

The call for participation will be distributed through steering committee members, relevant mailing lists, and word of mouth. We will also create a website to generate interest and bring together a community of researchers around the workshop topic. In the months leading up to the workshop, we will use the website to supplement the call for participation and share continuous information that will help participants to prepare for a productive workshop experience.

### *Workshop Structure*

Workshop activities will enable participants to share best practices, existing methods, approaches and successes to share their experiences and challenges in conducting participatory design with diverse populations such as older adults, children with developmental disabilities, individuals with chronic conditions, among others. The outcome of the workshop will be an outline for an editing book describing the current challenges in this area and will document different approaches among diverse populations, successes and

opportunities that can help to create an optimal participatory design experience for participants and facilitators.

This one day workshop will bring together between 12 and 20 participants. Our target audience is any student, researcher, or practitioner who has experience conducting participatory design with a diverse population. Our call for participation will invite potential participants to submit position papers 4-6 pages long, which reflect on their experiences, discuss lessons learned, outline effective strategies, and share challenges and opportunities.

The schedule for the day will involve a variety of presentation formats (e.g., short talks, posters and demos/videos) to enable participants to share a range of strategies and research areas. These presentations will promote interaction between participants and opportunities to share effective strategies and lessons learned. We will also schedule and facilitate presentations in order to maximize discussion that will focus on the challenges of conducting participatory design with diverse populations. Workshop participants will be asked to compare and contrast the challenges of working with different populations, in order to identify what works across populations, and what aspects of the participatory design process should be most malleable, flexible and tailored.

In addition, breakout sessions will allow participants to organize around key challenges and related themes that emerge during the workshop. Breakout groups will work together to identify solutions, methods, and techniques for overcoming those challenges. Finally, the breakout groups will come together and share their output with the rest of the group. The workshop organizers will take copious notes and collect artifacts in order to facilitate the preparation of a publication after the end of the workshop, based on the themes and outline generated during the workshop day.

The preliminary schedule for the workshop is as follows:

- 9:00: Welcome and introduction.
- 9:30: Short presentations and discussions on participants' work: describe population, best practices and challenges.
- 10:30: Coffee-break.
- 12:00: lunch.
- 14:00: breakout sessions: key challenges and related theme (in teams).
- 15:30: Coffee-break.
- 16:00 Sharing teams outputs.
- 16:45 Closing remarks and future plans.

#### *Post-workshop Plans*

The workshop organizers and extended program committee will edit a book on the outputs from the workshop, including the description of different approaches for working with participatory design with diverse populations, challenges, best practices and opportunities. The workshop organizers will also facilitate ongoing knowledge sharing and collaboration within the community nurtured during the workshop.

#### **Call for Participation**

One of the challenges of conducting participatory design is tailoring activities to the needs of diverse populations, such as children with developmental disabilities, older adults and people with chronic conditions. The goal of the workshop is to gather experts in conducting participatory design with diverse populations to share their experiences, best practices, challenges and opportunities.

We invite researchers, students, and practitioners with experience in conducting participatory design with diverse range populations. The goal of the workshop is to discuss the challenges that emerge when conducting participatory design with diverse populations. We will compare and contrast challenges across populations, and share successful techniques as well as lessons learned.

The workshop will include a technical program enabling participants to share and discuss different protocols and approaches they have used to conduct participatory design with diverse populations. We invite position papers 4-6 pages long, which reflect on challenges conducting participatory design with a specific population, discuss lessons learned, outline effective strategies and opportunities. The manuscript should follow the PervasiveHealth 2018 proceedings format. Authors of the accepted submissions will be invited to present and discuss their work at the workshop. For each of the accepted submissions, at least one author must attend the workshop and at least one day of PervasiveHealth 2018 conference.

To find more information about the workshop, visit the workshop website at: <http://www.empathicdesignandtech.org/ipdp>

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