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# Supporting the Voice of People with Disabilities in Kenya, Uganda and Jordan

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## **Abstract**

Research methods need to be adapted to the cultural context and traditions with which participants are familiar. Limited work has been attempted to explore ways to engage people with disabilities in low resource settings. In this paper we present methods used in two research projects that engage and actively support the voice of people with disabilities living in low resource settings. We discuss which methods have worked well and which not, with recommendations based on our experience and the research results.

## **Author Keywords**

Disability; technology; prosthesis; visually impaired; low resource settings

## **CSS Concepts**

• **Social and professional topics** ~ **User characteristics** ~ **People with disabilities** • Human-centered computing ~ Interactions design ~ Interaction design process and methods ~ Participatory design

## **Introduction**

People with disabilities are often under-represented and subjected to stigmatizing views that can hinder their ability to fully take part in society and in research and

## Challenges of Project 1

Kibera is the largest and probably the most “researched” informal settlement in Kenya. Kibera residents, including our participants, had seen numerous Westerners entering their communities, raising expectations for practical improvements and disappearing without delivering on their promises or sharing results. The scope, modalities and expected outcomes of the project had to be discussed in multiple occasions with participants. This repetition of information was necessary to facilitate participants’ trust.

We decided to minimize the collection of video and photos during observations in the community to mitigate the risk of upsetting other residents that did not explicitly consent to take part in the project.

design activities [3]. This is even more likely in low-resourced settings where disability is often intertwined with poverty and pronounced social exclusion [4]. In recent years, the HCI community has made significant progress on better engaging with people with disability utilizing participatory methods and recognizing their preferred use of language (i.e. autistic instead of with autism) [5]. However, only a handful of articles have attempted to explore ways to engage people with disabilities in low resource settings [1,6].

Enabling participants from low resourced settings to have a strong voice when they take part in HCI research requires the adaptation of different methods to the cultural context and traditions with which participants are familiar. It also requires the establishment of links with key community members to facilitate the research process [7]. These methods adaptations and co-research relationships are essential to negotiate expectations about the engagement modalities and potential outcomes of the project [2].

In this paper we present two research projects where we engaged and actively supported the voice of people with disabilities from low-resourced settings in various research activities. We will then discuss recommendations based on our experience.

### **Project 1: people with disabilities living in informal settlements in Kenya**

In this study we sought the voice of people with visual impairment who live in informal settlements in Nairobi, Kenya. We aimed to understand how they interact with their mobile phones both as individuals and with the support of their social network and to explore how they

would like their interactions with technologies and their social network to change in the future.

### *Methods*

We first engaged directly with the University of Nairobi Community Health School and the Kilimanjaro Blind Trust Association. These two local collaborations helped us to identify two influential members of the community who were interested in collaborating with the research team. Both community leaders became part of the research team as they helped us: defining the protocol for the contextual interviews and the co-design workshop, adapting questions to the local context and providing Braille translation of relevant research materials. Community researchers were also present during the contextual interviews with six visually impaired participants where they helped with: consent procedures, explaining questions when necessary and taking pictures during observation. They also took part as facilitators in a co-design workshop that involved 10 visually impaired participants, ensuring that the methods used captured what participants wanted to express.

### *Supporting voice successes*

The presence of two members of the community who were also visually impaired was crucial to ensure participants trust. This enabled them to share their experiences and voice their opinions with the research group. This collaboration gave us credibility and ensured the consideration of the unique context (Kenyan informal settlements) in the way in which we posed questions, framed activities and interpreted participant’s voice.

## Challenges of Project 2

People with upper limb absence in Jordan found difficulty in sharing their life experience with as much openness as people in Uganda. They also did not choose the media diary and chose the written version of the diary and the end of day survey. However, they did not complete a diary at all and partially completed the end of day survey, giving preference to easy to answer questions such as circling a number to rate something from 1 to 5.

People in Uganda wanted to use the activity monitors and had no trouble wearing them but found challenging to wear them due to their communities' stigmatizing attitude towards them when they wore the devices.

Similar stigmatizing attitudes were faced by participants when attempting to take photos and videos and record audio.

## Project 2: people with upper limb absence in Uganda and Jordan

There are no statistics on the incidence of upper limb loss in Uganda and Jordan. There is also no information on their needs, priorities and experiences. We only know that the current demand for prosthetics is not met and prosthetics remain unaffordable and not fit for purpose. But is it really a demand in the case of upper limb prosthetics or the industry wants us to think that people with upper limb absence cannot cope without one arm? The research project called "Fit-for-purpose, affordable body-powered prostheses" has set to design a fit for purpose upper limb prosthetic for Uganda and Jordan. We set to include the voice of people with upper limb absence before committing to a design.

### Methods

One week-long scoping studies in each country were performed consisting of informal conversations with people with amputation or congenital limb absence as well as visits to local clinics and hospitals providing prosthetics delivery services. This was only possible with key local collaborators at Makerere University and The University of Jordan. The scoping study helped to shape culturally aware semi-structured interviews which were translated into local languages. Seventeen people with amputation in Uganda and 10 in Jordan and five people with congenital limb absence in Jordan were interviewed for this project.

We piloted HCI methods: activity monitoring with wrist worn devices, experience diary and end of day surveys. Participants were asked to make a diary for 4 weeks when doing their daily physical activities and to wear the activity monitors on their prosthetic and intact arm. The experience diary and end of day survey aimed to

document their experiences related to social, physical and emotional situations. They were given the option to make a written or media experience diary (photos, videos and record audio using a feature phone).

### Supporting voice successes

People with upper limb absence in Uganda found the semi-structured experience easy to engage and shared aspects of their daily life relevant to disability stigma, support networks, access to prosthetic delivery services and information and their limb loss experience. They also chose to make media diaries and generated videos, photos and audio depicting their daily life utilizing and not utilizing a prosthesis.

## Our recommendations on supporting voice

### Communication differences

Create a steering group with local people with disabilities and ask them to review your methods to ensure that they are appropriate and to signal any improvement in the way questions are asked and understood. This was particularly important when communication with people amputations due to the traumatic nature in which these are acquired in Uganda and Jordan (violence, traffic accidents, war).

### Interpreting voice

In the prosthetics project, weekly meetings are held to ensure that data is being processed and analyzed keeping the original intended meaning of the participants. Interviews were transcribed and translated to English at each country and local researchers revised the translations to ensure that original meaning was preserved throughout.

## What it means to give voice for the communities we worked with?

The communities we have worked with are people with disabilities, living in low resource settings and facing discrimination and stigma. They have a voice and do not need to be given a voice. However, their voice is not heard, or they are not given a chance to express that voice. Being researchers, we have the ethical responsibility of making sure their voices are heard and our interpretations are true.

### *About Kilimanjaro Blind Trust Association*

NGO that provides learning opportunities to people with visual impairments in Kenya. It has a strong presence in several informal settlements around the country.

After the initial analysis of the data originated from the project in Kenya, we shared a draft version of the emerging themes with participants, community researchers and NGO's staff to ensure that the interpretation of the data was correct.

### *Facilitating*

Local junior researchers were trained to perform the semi-structured interviews in all three countries. This was key to facilitating communication between people sharing the same language and culture. Especially because discussing disability verbally was challenging, as it is a stigmatized topic. We also recommend offering non-verbal methods of expression such as taking photos.

### *Values*

Visiting the country to perform a scoping study and directly engaging with respected institutions and community members is a great way of including the voice of disabled people from the start of a research project. This can lead to culturally aware research methods as well as greater acceptance of new methods when these have not been tested before with a specific community and country.

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