Verbal Design: A Participatory Design Approach with Illiterate Patient User Groups

Kehkashan Zeb
Swansea University
Swansea, UK
806259@swansea.ac.uk
Stephen Lindsay
Swansea University
Swansea, UK
s.c.lindsay@swansea.ac.uk
Suleman Shahid
Lahore University of Management Sciences, Lahore, Pakistan
suleman.shahid@lums.edu.pk
Matt Jones
Swansea University
Swansea, UK
Matt.jones@gmail.com

DIS'18 Companion, June 9–13, 2018, Hong Kong

ACM ISBN 978-1-4503-5631-2/18/06.
https://doi.org/10.1145/3197391.3205448

ABSTRACT
This paper presents a Participatory Design approach focused on applying primarily Verbal Design techniques working alongside illiterate People with Diabetes (PWD) from low socio-economic groups in Pakistan. After gathering a set of initial findings through classic Participatory Design and encountering several challenges, we discuss the development of our Verbal Design Approach in response which uses Narrative Scoping and Persona along with Invisible Design videos to structure and drive discussion and document design. Preliminary work showed that the approach resonated with our illiterate participants.

Author Keywords
HCI4D; Participatory Design (PD); Field study; Resource-constrained community.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION
In our current project, we aim to design a technological intervention such as Interactive Voice Response (IVR) (an automated telephony system that interacts with

.

Figure 1: Researcher in Participatory Design Sessions in Faisalabad.

callers) that can help less literate PWD who have limited resources living in Punjab, Pakistan to manage their diabetic conditions. Design in this field is challenging and we opted to focus on the use of Participatory Design (PD): an established field of design that takes input from relevant stakeholders to democratize and co-determine how new systems or technologies will alter their working or living conditions. In healthcare, we see that the participation of patients in the design process empowers them and leads to the design of successful, usable systems [12].

Our PD methodology has, to date, been used as a tool to extract, describe and examine technology requirements of less literate PWD. However, as PD techniques have been developed in literate, westernised contexts, they need to be modified when employed with less literate people. In this work in progress we emphasize the importance of a *Verbal Participatory Design Approach* where participants reflect on experiences from their daily lives and this leads us to have a clear perspective on requirements of people for technology intervention. Our *Verbal Participatory Design Approach* uses Narrative based Persona and Invisible Design. Findings from these Narrative Scoping workshops showed the technological expectation of our stakeholders. These findings have been discussed alongside various possible solutions for less literate PWD in Pakistani context.

Background

In healthcare, the participation of patients in the design process empowers them and leads to the design of more successful, useful systems [1]. This process occurs as people previously dis-empowered due to health challenges and their position of relative powerlessness within the healthcare system compared to professionals are put on an even footing with them so alter technology to better suit their needs [2]. PD techniques such as low fidelity prototyping, scenario generation, and persona-based techniques all support the shared prototyping of technological solutions that respond to a user's cultural, emotional, spiritual and practical needs. Although PD techniques are developed with the focus on western countries, there is evidence that PD techniques are useful when designing healthcare interventions in developing countries and perhaps even vital [3].

However, the application of PD beyond the scope of their initial conceptualisation requires care. Projects in economically developing countries or regions show that there are numerous challenges when following PD approaches. For example, the correct identification of stakeholders is challenging at the outset of many of these processes [4,5]. Even after identification, composing PD groups in ways that encourage the engagement from all stakeholders can also prove difficult [4] as more traditional or rigid social structures inhibit some participants and researchers have observed some members of their PD groups don't respect the goal of democratization of the process. In addition, most studies focus on the PD of healthcare practices or systems of care [6] rather than designing novel or bespoke prototype technology. Language barriers can also pose a significant challenge as a diverse collection of languages is often spoken [7].

Method

Initially, we conducted interviews followed by workshops in an attempt to understand more about the lifestyle and various needs of our diabetes patients.

Persona Attributes	
	
Name	Mukhtaraan Bibi
Age	70
Gender	Female
Occupation	Housewife
Diabetes	Type 2
Technology use	The focus group participants agreed that Mukhtaraan Bibi might not be willing to attend IVR system calls but if her family members motivate her then she might get convinced that the IVR System call will ultimately benefit her by facilitating better management of her condition.

Figure 2: Example Persona arising from a Narrative Scoping Design Session in Faisalabad.

These sessions were not successful though as we encountered issues arising from the illiteracy, which made conventional PD techniques non-functional. This echoed findings from previous work [4]. The lack of literacy also made it difficult to co-create tangible design artefacts that other PD techniques rely on such as storyboards or paper prototypes which can be revisited and interrogated again later in design processes. Instead, we used the narratives we co-created and the video's we filmed as a substitute for these. However, relying solely on verbal communication still poses challenges as it makes it hard to keep participants motivated [8].

To address these issues moving forward, we chose to adapt our PD process around a *Verbal Design Approach* that emphasised discussion over all other forms of communication. Our earlier interviews showed us that the participants were eager to share their personal experiences and tell us stories so narrative scoping [10] techniques were selected to re-think the PD sessions. While stories can be defined as informal and subjective accounts of personal experience, narrative accounts are more formal and structured [9]. We used 'Persona character development' as the basis for collecting subjective accounts of personal experiences of our study participants and for formulating new ideas in relation to the established persona, developed from the results of interviews as a trigger to start the conversation with our end users focusing on telling stories or attributes about the persona and their activities. Therefore, in place of tangible co-created artefacts of the design process, personas were used to capture the results of the storytelling in the Narrative Scoping work.

When considering how to move to more concrete feature descriptions, we noticed that our participants liked to focus on the tangible and personal elements of a problem and often wanted to have more detail than we either had available or than we wanted to provide because of concerns that we would constrain the design space and impose our own concepts on the design process. To address this, we incorporated an Invisible Design approach to facilitate discussion of the more abstract community aspects of the system [11]. This entailed making a short film that depicted the usage of a system without ever showing the system itself being used. This relies on the language of film to create ambiguity about the solution being discussed in the film. This allows us to give an impression of concreteness to a design that encouraged engagement and discussion but, at the same time, does not show the system itself.

This in turn made it easier to discuss ideas with our participants and get an insight into their thinking without relying on abstract reasoning or conceptualisation. At this stage, we decided to conduct PD exercises in one-to-one setting or to conduct them with small groups of similar participants who were comfortable with each other already either being friends where we could recruit them in groups or at least drawing groups from similar demographics such as a group of all older women. This decision again emphasised the importance of the verbal elements of the design process and tried to ensure that everyone in a group could speak more freely.

Narrative Scoping Results

The basis of this session is the narrative story telling using persona as a prompt. Three PD sessions with 4, 4

.

Figure 3: Invisible Design video in which a doctor is telling Diabetes Patient aboutuse of technology for management of her diabetes condition.

and 5 participants were conducted. The participants were found through snowballing recruitment using connections in the local area. Participants were introduced to Persona work after initial narrative interview session which acted as an icebreaker and facilitated deeper discussion later in the process. We observed that our participants not only contributed actively towards the development of the Persona and its various attributes, but they even helped us to get a clear idea for developing technology interventions for PWD.

We developed 3 personas in the narrative scoping sessions, one male and two female Persona characters were co-developed. While discussing the capability of using technology, participants agreed that an older female persona would benefit from the use of IVR technology; however, a male middle-aged persona most probably already had access to a smart phone and will be happy using that for diabetes management. We initially chose female persona to make a solution as they are prevalent in greater numbers in the study. PD workshop Participants were shown the Picture of Persona and they helped in guessing various attributes like Name, Age, Gender, Occupation, Attitude towards technology, etc. Details of Female Persona ‘Mukhtaraan Bibi’ are discussed in Figure 2.

Invisible Design Results

After discussing the Persona within the Narrative Scoping, the session continued with Invisible Design where the participants watched two videos based on the Invisible Design. The approach helped to generate insights and ideas with PD workshop participants focusing on more advanced or conceptual applications of IVR systems such as community based IVR. We showed the filmed scenario of our two personas, which came out of the Narrative Scoping, where a 'Diabetes Doctor Persona' discussed with a ‘Diabetes Patient Persona’ the use of a technology that is Community IVR System, in two separate films that were each around three minutes long. After the video was shown to study participants in one-to-one PD sessions, they were quick to grasp the concept behind Community based IVR, as we explained the use of IVR with an example before showing them the video. Therefore they envisioned the system easily and were happy and enthusiastic about the idea of using a communal application where they could listen to other peoples' ideas and share their own insights. We saw that our less literate participants responded to Invisible Design technique after giving them the concept of IVR which we explained as a helpline.

Future Work

Living with diabetes is a lifetime challenge for PWD which is why they must adapt to a new life style. Technology interventions might help PWD make these lifestyle changes effectively such as using IVR technology in various forms as community Radio Program and Voice forums [13]. In the future, we plan to extend this project by incorporating existing PD techniques such as wizard-of-oz approaches to clarify our IVR solution with users in 1-to-1 PD sessions. An impact analysis will determine the success of such a solution in long-term and we plan to do it in the next round. A diabetes based IVR could be a good starting point to empower PWD in Pakistan and this could turn into a more powerful tool that can educate illiterate communities about healthcare strategies.

References

1. Lauren. Chapman "Design for Chronic Illness: Exploring Service Systems & New Technologies for Patients with Type 2 Diabetes." (2011).
2. Simon Bowen, Andy Dearden, Peter Wright, Daniel Wolstenholme, and Mark Cobb. 2010. Participatory healthcare service design and innovation. In Proceedings of the 11th Biennial Participatory Design Conference (PDC '10). ACM, New York, NY, USA, 155-158.
3. Bradley, J. E., Mayfield, M. V., Mehta, M. P., & Rukonge, A. (2002). Participatory evaluation of reproductive health care quality in developing countries. Social Science & Medicine, 55(2), 269-282.
4. Sofia Hussain, Elizabeth B. N. Sanders, and Martin Steinert. (2012). Participatory design with marginalized people in developing countries: Challenges and opportunities experienced in a field study in cambodia. International Journal of Design, 6(2) Retrieved from https://search.proquest.com/docview/1270361550?accountid=14680
5. Byrne, E., & Sahay, S. (2003). Health information systems for primary health care. In Proceedings of the IFIP (Vol. 9).
6. Arul Chib. "Research on the Impact of the Information Society in the Global South: An Introduction to SIRCA." In Impact of Information Society Research in the Global South, pp. 1-17. Springer Singapore, 2015.
7. Korpela, Mikko, Hettie A. Soriyan, and Karen C. Olufokunbi. "Activity analysis as a method for information systems development." Scandinavian Journal of Information Systems12, no. 1-2 (2001): 191-210.
8. Daren C. Brabham, Kurt M. Ribisl, Thomas R. Kirchner, and Jay M. Bernhardt. "Crowdsourcing applications for public health." American journal of preventive medicine 46, no. 2 (2014): 179-187.
9. Leah East, Debra Jackson, Louise O'Brien, and Kathleen Peters. "Storytelling: an approach that can help to develop resilience: Relating personal experiences can help participants to cope with their conditions and improve research, explain Leah East, Debra Jackson, Louise O'Brien and Kathleen Peters." Nurse Researcher 17, no. 3 (2010): 17-25.
10. Petra Björndal , Mikko J. Rissanen, and Steve Murphy. "Lessons learned from using personas and scenarios for requirements specification of next-generation industrial robots." In International Conference of Design, User Experience, and Usability, pp. 378-387. Springer, Berlin, Heidelberg, 2011.
11. Aditya Vashistha, Edward Cutrell, Gaetano Borriello, and William Thies. "Sangeet swara: A community-moderated voice forum in rural india." In Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems, pp. 417-426. ACM, 2015.
12. Lauren. Chapman "Design for Chronic Illness: Exploring Service Systems & New Technologies for Patients with Type 2 Diabetes." (2011).
13. Neil Patel, Deepti Chittamuru, Anupam Jain, Paresh Dave, and Tapan S. Parikh. "Avaaj otalo: a field study of an interactive voice forum for small farmers in rural india." In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, pp. 733-742. ACM, 2010.