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Giving A Voice Through Design: Adapting Design Methods to Enhance the Participation of People with Communication Difficulties

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ABSTRACT[1]

Many participatory design methods are heavily reliant on the presence of communication skills, with approaches often focusing on verbal or written outputs. For people with communication difficulties it can often be difficult to engage with such approaches. This workshop aims to bring together researchers, designers and practitioners to explore share both positive and challenging experiences of working with users with communication difficulties within participatory design. We will generate a description of a set of design methods which have been adapted and used with people communication difficulties, with a view to enhancing the knowledge and skills of workshop participants for the future.

CCS CONCEPTS

• **H.5.m → Information interfaces and presentation (e.g., HCI)**: Miscellaneous

KEYWORDS

Participatory Design, Methods, Communication Difficulties, Health, Participation

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1 INTRODUCTION

An estimated 18.5 million people in the USA [1] and 2.2 million in the UK [2] are living with a diagnosed communication difficulty. Communication impairments are seen in a wide variety of different individuals with varying clinical, emotional and educational needs.

In participatory design, there are a range of process-related challenges which can arise in the presence of communication difficulties. Approaches to engaging individuals in design focus often on verbal or written activities which require adequate communication skills in order to participate. In many cases this can lead to the exclusion of those with more severe communication difficulties from full participation. It is widely recognized that communities should have a say in the design of technologies to support their needs [e.g. 3, 4, 5]. However, for people with communication difficulties this is not always a simple task, and much research focuses instead on providing community representation by proxy of e.g. caregivers or clinicians [e.g. 4]. There is an emerging research base which has explicitly discussed methods for engaging people with communication difficulties in design. This work centers mainly on aphasia— an acquired disorder (following neurological damage, e.g. from traumatic brain injury or stroke) affecting spoken and/or written comprehension and/or production of language [6, 7]—although

there have also been insights drawn from Parkinson's [8], dementia [9] and children with additional needs [10]. This work shows that despite substantial issues, people with communication difficulties can participate in the design process, with adapted methods and appropriate facilitation by researchers. This workshop aims to synthesize and build upon this prior work by bringing together a diverse community to share existing knowledge and examples of best practice, as well as to, as a community, identify key challenges and possible solutions towards adapting and developing design methods to support the participation of people with specific communication needs.

2 WORKSHOP GOALS & RELATIONSHIP TO CONFERENCE THEME

The three key aims of this workshop are to 1) Explore how notions of 'communication' and 'participation' are understood within the context of designing with people of varying levels of ability; 2) Provide a space for researchers to share experiences of working with people with communication difficulties in participatory design, both successful and challenging; and 3) Generate a series of methods descriptions detailing successful adaptations of, or novel, design techniques, which facilitate the participation of people with communication difficulties. Through the establishment and subsequent promotion of these techniques, we aim to draw attention to the potential for future research which engages a larger population of citizens with varying communication difficulties. In doing this, we aim to further democratize the participatory design process by ensuring that we, as a community, can give a voice to this large group of people who might otherwise participate only via proxy or indeed not at all.

3 WORKSHOP FORMAT

3.1 Participants

The audience for the workshop will be researchers, designers and practitioners with an interest in supporting participatory design for people with communication difficulties. We envisage attendance by between 10-15 participants. In order to promote the workshop, we will disseminate our call for participation through personal contacts, professional and social media accounts and appropriate mailing lists. Within the call for participation, we will invite researchers working with individuals with communication issues to submit 1-2 page case studies that describe the challenges and successes they have encountered in their technology design practice when working alongside people with communication difficulties. They should reflect on why specific methods may have been successful and illustrate how they have addressed or responded to any challenges encountered. A submission deadline of May 18th 2018 will be set, followed by a May 25th 2018 notification of acceptance, a camera ready date of the early July and the allocated workshop date on the 21st of August 2018.

3.2 Setup of the workshop

This full-day workshop will be a balance between brief presentations, focused group discussions and practical design activities which will allow participants to visualize the design activities they have successfully used in the past. The plenary introduction session will provide insights about individual experiences of enabling the participation of people with communication difficulties in design, and will allow workshop participants to familiarize themselves with one another's backgrounds and research interests, to facilitate targeted networking during the breaks. Next, workshop participants will work in their pre-assigned reading groups to engage in structured discussion around their previously submitted case stories. Following this session, the whole group will discuss the key themes that emerged from the case study discussions. After lunch, and within teams, participants will be asked to identify a and describe specific design techniques, with a focus on technology design with a user group experiencing communication difficulties. The workshop organizers will have example methods descriptions pre-prepared to facilitate group discussion and the flow of ideas. Teams will then report on their work, considering issues including user groups, design rationale, ethical considerations and potential benefit and pitfalls of their approaches.

The workshop will conclude with an open discussion to consolidate ideas generated throughout the day and establish a future agenda. All materials will be collated and presented via the workshop website, serving as a methods reader for the wider HCI community who are planning to engage people with communication difficulties in design

4 WORKSHOP ORGANISERS

The workshop is organized by Roisin McNaney (a lecturer in digital healthcare technologies, and trained speech and Language therapist, working in the space of chronic neurodegenerative conditions), Cara Wilson (a PhD candidate researching co-design with minimally-verbal children on the Autistic spectrum), Jayne Wallace (a Professor of Craft and Wellbeing exploring how co-creative design, digital jewelry and acts of making can support sense of self, particularly in those living with dementia), Margot Brereton (a Professor of HCI who develops innovative designs, methods, and theoretical understandings by designing to support real user communities in selected challenging contexts), Abi Roper (a Speech and Language Technologist and qualified Speech and Language Therapist researching co-design and evaluation of computer based therapies for aphasia), Stephanie Wilson (a Reader in HCI focusing on digital technologies for healthcare, inclusive interaction design and user experience, including novel therapeutic technologies for people with aphasia), and Miriam Sturdee (a Research Associate interested in sketching as a communicative method and encouraging visual methods in HCI). The organizers represent the international and multi-disciplinary nature of the SIG. They have a range of experience with running

conference workshops and as members of conference program committees. They boast an impressive publication record within the space of design methods, engaging health communities, and engaging people with communication impairment.

5 OUTCOMES

The discussions forming the workshop will be used to develop a methods guide, hosted online on our workshop website, detailing best practice guidelines towards adapting and developing approaches to engaging people with communication difficulties in design. In addition, we will aim to publish a special issue journal on approaches to designing with people with communication impairment, detailing the key challenges and successful approaches to design which enable participation of individuals with varying levels of communication impairment in the design process.

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