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Involving People with Cognitive and Communication Impairments in Mobile Health App Design

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ABSTRACT

Multiple challenges face people with cognitive and communication impairments when asked to be involved in the design of technology that is appropriate for them. This population is under-represented in healthcare research and have health inequalities relative to most people. The work discussed here concerns how to adapt research processes to suit people with these difficulties when developing smartphone apps to give access to health promotion information, an area in which health inequalities arise. Strategies are identified to assist participants to understand the proposed area of work, to give consent to participation and be involved with activities such as evaluation. A combination of adaptations is proposed to engage people who would otherwise be excluded. It is clear that strategies used to make research participation accessible can assist people with cognitive and communication impairments to influence and inform the development of technology for their use.

Author Keywords

Cognitive impairment; communication impairment; health promotion; research participation; mobile app design.

ACM Classification Keywords

Human-centered computing → Accessibility systems and tools; Accessibility technologies; Accessibility design and evaluation methods.

INTRODUCTION

Emerson and Baines [10] describe the health inequalities facing people with learning disabilities and suggest these inequalities are avoidable. One reason for inequality is seen to be communication difficulty and reduced health literacy. People with cognitive and communication impairments face significant barriers to accessing and engaging with official

health literacy information designed to encourage people to care for their health, for example by eating well, staying physically fit and limiting their use of tobacco and alcohol [21,22]. Information is often presented textually and is designed for people with good cognitive skills including the ability to read and process language and retain information. This can cause accessibility barriers, creating a health inequality for people who need communication supports; health equity requires information to be presented in ways which are accessible.

One method of giving people access to health literacy is through mobile smartphone applications (apps) encouraging practice of healthy lifestyle behaviours. Smartphone apps for health promotion [1,6,7] are usually designed for people with good cognitive abilities including that of being able to process information. Such apps are typically text-based with numerical and graphical presentation of information. There is therefore a present need for health promotion apps developed specifically for people with cognitive and communication impairments which take into account their needs. The work described here aims to develop apps for this purpose while introducing some participants with these difficulties to the design process itself. Barriers faced by participants are discussed along with initial approaches on methods to overcome them. Considerations for further development of the work are also presented.

CHALLENGES IN THE RESEARCH PROCESS

The difficulties of engaging people with disabilities in research underpin their under-representation in healthcare research [12]. Similarly, this group of people are rarely involved in the design and evaluation of technology made for them because there is insufficient guidance or clarity on how to do this work [8]. People with intellectual disabilities are highly motivated to take part in research which affects them [18] however the process for engaging this group of people in developing systems raises challenges for research processes at several levels.

Iacono [13] and Cameron and Murphy [5] discuss the ethical and practical issues which affect the obtaining of consent from people with learning disabilities to take part in research. Previous work has been carried out investigating the use of participatory design as a method of engaging people with intellectual disabilities in the development of technology [3,15,23,24]. It has been used also in research

with people with acquired conditions such as aphasia [2,14,19] and dementia [9,11,16]. The populations being considered here are those who have non-acquired conditions, specifically people with intellectual disability or mild cognitive impairment associated with autistic spectrum disorders. Both groups have difficulties with literacy and processing language, which affect their access to health literacy; these are key barriers to taking part in development and evaluation. Research processes need to be adapted to accommodate the barriers to involvement that people face. In this case design procedures aimed to ensure that participants were able to:

- Understand the purpose of the research and give consent to participation
- Engage meaningfully with the evaluation process
- Communicate their views on the research output or app, using a format appropriate for them

Adapted approaches need to be incorporated into both the development process and the apps which are developed.

Mobile App Development for Special Populations

An example development for a special population is that of an app for promoting healthy lifestyle choices for people with mild cognitive impairment (MCI) [17]. This app was designed to provide health-related messages and assist users to keep track of their activities such as eating healthy foods, undertaking physical activity and drinking sufficient fluids. A further prototype app for dietary advice for people with intellectual disabilities enables a user to keep a photographic food diary and give them visual targets to aim for with their meals and snacks each day. It can offer messages with examples of healthier foods and drinks and ones to reduce or avoid, and also support interaction with a dietitian. The initial requirements were guided by advice from clinicians working with people with cognitive and communication impairments. Drawing on observation and experience in the field in initial stages meant that concepts being developed could be made concrete for the person with cognitive impairments and give them experience of using such an app. This made it easier for participants to understand the concept of the research and to offer feedback. Symbolised participant information sheets and consent forms using simplified language made information about the research process accessible. Recognised tools for evaluating interfaces [4] were simplified, augmented with symbols and used to assist participants in giving feedback on their experiences.

The feedback from participants indicated that the developed apps had good implications for encouraging positive health-related behaviour change in these populations. The strategies used thus far to make the research accessible were successful in engaging participants in the activity. Outcomes from these investigations have been positive and encourage further development of interfaces for mobile applications for people who need communication supports.

Addressing Challenges

Some approaches used thus far to meet challenges in working with these populations on app development are:

- Using appropriate language levels: researchers were trained to use simplified language to reduce information processing required by the participants
- Making information accessible: new symbol-based information sheets and consent forms were used
- Adapting tools to match the cognitive needs of the participants and the technology being used

Alternative forms of written language were used to assist participants to understand and consent to research. Symbols (e.g. Mayer-Johnson® PCS™) and simplified language were used to augment consent and information documents and usability scales.

Further aspects, relating to gathering and using participant feedback, are:

- Using observation of participant behaviour during evaluation; essential for offsetting communication difficulties
- Gathering feedback in appropriate mode, e.g. voice output communication aid, sign or gesture system
- Synthesising clinical experience and user feedback in the app development

Feedback from participants and their level of engagement at this stage of the work indicate that these approaches can be successful in supporting people with cognitive and communication impairments to engage with and participate in the research process.

CONCLUSIONS AND FUTURE RECOMMENDATIONS

As a result of implementing strategies for simplifying language at all levels of the research process, using alternative forms of language representation and using an app to enable the participant to experience unfamiliar technology it became possible to involve participants with cognitive impairments in the development process. Future research would investigate the use of symbol-based tools such as Talking Mats® [20] for identifying more deeply the participants' feedback on aspects of interface design and usability for incorporation into design iterations. Improved methods of giving participants feedback on the results of the evaluation would also be investigated.

Methods for supporting carers to enable people with more severe cognitive and communication impairments to engage in research could be investigated along with more specific tools to help them observe participant responses when using an app. In these ways health inequalities and barriers to access can be challenged for such populations.

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