Engaging Diverse Individuals in Remote Co-Design to Collaboratively Design Personalized Glucose Monitors

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1 INTRODUCTION

Mass-manufactured assistive technologies (AT) primarily address the technical needs of devices, but ignore user's individual and social needs [6, 9]. This results in the early abandonment of off-the-shelf devices [6, 9, 11], and individuals finding workarounds in isolation using do-it-yourself (DIY) and/or do-it-for-others (DFO) practices [3, 6, 8].

The notion of DIY and making in healthcare has been researched previously [2, 3, 6, 8]; however, one important challenge that remains is that *the people who want to modify their devices do not always have the necessary technical expertise or access to tools to do so*. Researchers have begun to explore the ways in which individuals want to customize their assistive technologies (AT) [1, 4, 5, 6]. Two such studies include *Diafit*, a co-design study regarding preferences when customizing Type 1 Diabetes glucose monitors [1], and *Impatient Patients*, a case study exploring one family's experience with a DIY glucose monitor [4]. These studies found three priorities for device customization - portability, feedback mechanisms, and privacy of use [1], and three usability factors missing from current devices - access to data, interoperability, and flexibility [4]. Research also shows that individuals are more likely to use their devices when they are actively involved in the design

and development of the technology [7, 9], and when the provided devices are easier to procure, use, and adapt with changing needs and preferences [6].

Building on the emerging work in medical making, we investigate how device users collaborate with healthcare professionals and product designers to design safe, effective, and personally relevant glucose monitors. We take a co-design approach [10] to gather design ideas and insights using a three-phased remote co-design study. In this workshop paper, we reflect on a series of considerations we employed while designing our study to support disability-inclusive online research.

2 CHALLENGES & CONSIDERATIONS

Designing a remote co-design study with multiple stakeholders and end-users with specific access needs is complex. In this section, we discuss some of the challenges we considered and our mitigation approaches.

2.1 Recruitment and Study Design

While designing our study, several options were considered for each phase to best accommodate our participants and study goals; two such factors included time-spent and tasks. Because of the innate nature of the domains in which our study is situated (i.e., healthcare and product design), we anticipate user groups having limited time to commit to our study due to being quite busy with long working hours or having chronic conditions that may limit their bandwidth to participate. Additionally, we recognize the differing abilities and backgrounds of each participant group. These two factors resulted in designing a multi-phase study, whereby different end-user groups are engaged at different points of the study to use their time most efficiently and still be able to gather related feedback (see Figure 1). We acknowledge that designing such a study presents its own trade-offs such as limited interaction amongst stakeholders. However, after careful evaluation of multiple options (including combinations of one-to-one and group sessions, remote and in-person sessions, and synchronous and asynchronous sessions), we determined that a remote, synchronous, multi-phase study would yield the best results and provide the greatest flexibility, while being most respectful of our participants' limitations.

Figure 1: A schematic showing the three-phase study we have designed.

2.2 Communication and Engagement

A second challenge we anticipate is successfully engaging people of different backgrounds, experiences, knowledge-levels, and abilities in a remote environment. Our study's nature raises questions such as how can we encourage all participants to actively engage in all activities, and how might we respond to situations where participants hesitate to engage. These challenges arise from the increased complexity that our co-design study faces by combining multiple end-user groups, particularly where the primary focus is on the group that includes individuals with disabilities. Challenges could include

individuals with diabetes being nervous to share their opinions as they may feel intimidated by other participants, or challenges may relate to issues of privacy where participants are hesitant to engage in discussions about personal health concerns.

To overcome these challenges, we considered how we could bring together the perspectives of various end-user groups with familiarity of a single device (i.e., one perspective is its user, another is a healthcare provider, and the last is a designer and/or developer). We developed an overarching design space that is informed by literature and highlights a set of requirements and considerations to guide glucose monitor designs. With this design space, we aim to provide a shared baseline and language amongst our diverse end-users to encourage increased comfort and understanding when taking part in discussions. We have also designed the study to allow participants to engage in one-on-one or smaller group sessions (Phases 1, 2) before interacting with all participants in a larger focus group (Phase 3) so that participants have the opportunity to ask questions and become comfortable with the language and content of the study before engaging in a larger group.

2.3 Materials

Because of the symptoms and side effects of type 1 diabetes, we anticipate that participants may have some physical limitations, such as impaired nerve-endings (and therefore, feeling) in their fingertips which could impact their ability to prototype with various physical materials. To accommodate a diverse demographic, we were cognizant of our participants abilities and limitations that may arise from their disability when determining what materials to include in prototyping kits. This led to decisions, such as including tape as an attachment mechanism instead of safety pins (which are small, sharp, and harder to work with), ensuring all materials were easy to access, and large enough to interact with easily, including squeeze scissors instead of typical scissors, and removing materials such as Play-doh from their difficult-to-open containers.

3 CONCLUSION

In this paper, we reflect on three particular considerations made in our study design to accommodate and support greater engagement of a broader participant demographic. As we continue working towards conducting this study, and collecting and analyzing data, we are interested in evaluating our choices and comparing and contrasting our approaches with other documented techniques for overcoming similar challenges in inclusive, remote co-design.

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