

iReadMore: A Reading Therapy App Co-Designed by People with Aphasia and Alexia

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Figure 1: - Screenshots of the iReadMore app in the two phases of the therapy; Exposure and Challenge.

ABSTRACT

We present the iReadMore app, a reading therapy for people with acquired reading or language impairments (known as alexia and aphasia respectively). The app was co-designed by people with alexia and aphasia, and has been demonstrated to significantly improve reading speed and accuracy in a randomized controlled trial. It is intended to be used at home without the support of a therapist. Therefore, accessibility and maintaining therapy engagement are key elements in achieving the high therapy doses required for rehabilitation of reading impairments. As such, these elements were developed in a co-design process that included 50 participants over 2 phases. This demonstration will present the flow of the application and detail how we translated a clinically validated prototype into a publicly available therapy app used by hundreds of people with acquired reading impairments since its release in March 2021.

CCS CONCEPTS

· Human-centered computing; · Participatory design; Accessibility;

KEYWORDS

Co-design, Aphasia, Reading impairment, Digital health

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1 INTRODUCTION

iReadMore is a digital therapy for alexia, an acquired reading impairment typically caused by a stroke or other brain injury. Alexia causes slow, effortful or inaccurate reading in people who were previously able readers [7]. It often occurs as part of a wider communication impairment known as aphasia where the other domains of language (speaking, listening and writing) are also affected. Presently, there are over 7 million stroke survivors living in the US and 1.3 million in the UK [1], around a third of these individuals will experience aphasia. For people with aphasia, impaired reading can result in feelings of loss, frustration and dissatisfaction and may preclude life participation, socializing and reading for information or enjoyment [5, 15]. Frequently, stroke survivors do not receive adequate treatment for aphasia; stroke survivors in the UK receive on average 8-12 hours of aphasia therapy [3, 4, 14], while a metaanalysis of aphasia therapy studies that had positive therapeutic gains averaged almost 100 hours of therapy [2]. Consequently, innovative new approaches to providing aphasia therapy are required and therapy apps offer one such solution.

iReadMore is an app that is intended to be used independently at home by people with alexia or aphasia. It is a gamified therapy that utilizes mass practice of matching spoken and written words tasks (Figure 1). The two phase therapy design begins with an Exposure Phase where users view 10 flashcards, each containing a word displayed in written and spoken forms along with a matching image. In the subsequent Challenge Phase, users are now presented with words from the previous phase, however this time, the written and spoken words do not always match. The user must decide, by clicking one of two buttons, if the written word and spoken word are the same or different. Based on the user's performance in the Challenge Phase, the therapy algorithm updates the word list and difficulty levels for the next therapy session. Before users can access the therapy, users are required to complete a registration process tests involving completing 6 baseline tests including a reading test. Some of these tests are repeated after every 5 hours of therapy.

iReadMore has been demonstrated as a clinically efficacious therapy for improving single word reading speed and accuracy in a clinical trial of 21 participants with aphasia completing 34 hours of practice [17]. This impairment-based therapy approach is evidence-based; however, this style of therapy can feel repetitive leading users to become disengaged or frustrated with the therapy [6]. Further, for a digital therapy, there are a number of barriers to accessing the therapy for people with aphasia relating to their communication impairment, co-morbidities and level of prior experience with digital technologies [10, 12].

Co-design is an approach to innovation that can improve the overall acceptability and accessibility of a product or service by actively involving members of the end-user group throughout the design process. Co-design has been applied to a growing number of aphasia therapies in recent years [8, 9, 11, 16]. A number of techniques can enable people with communication impairments to participate meaningfully in co-design research by supporting total communication. Examples include the use of drawing, writing, gesturing, visual aids, emotion scales and inviting caregivers to provide support [13]. By co-designing iReadMore, we intended to innovate an effective therapy that is also accessible and engaging.

2 THE DESIGN OF IREADMORE

With the aim of developing the initial prototype therapy into an app that could be used independently by people with aphasia or alexia, we began the co-design process focusing on developing the accessibility and maintaining user engagement throughout the therapy. Five in-person co-design sessions were held between June 2019 and January 2020 at the Institute of Cognitive Neuroscience, University College London in an accessible location familiar to many of the participants. 25 participants were recruited using stratified purposive sampling with convenience sampling through our research group mailing list and other individuals known to participants in this study. All participants had chronic aphasia or alexia, or were the partner to someone with aphasia. We aimed to get a diverse group of participants by stratifying for age, gender, experience with digital devices, and commonly co-occurring stroke morbidities; such as physical, visual, auditory and cognitive impairments.

The sessions were facilitated by a multidisciplinary team including an app developer, a medical design engineer and speech and language therapists. Each Sessions began with testing app prototypes followed by a semi-structured group discussion to generate new design ideas. These ideas were explored in more detail in the last phase of the session using paper-based prototyping. In-between

sessions, new prototypes were developed to present at the subsequent sessions. Sessions employed total communication techniques developed for inclusive co-design with people with aphasia, sessions were video recorded and all data (videos, drawings and notes) contributed to the design process.

From this process, we were able to gain insights into the barriers and enablers for a digital alexia therapy and generated several new accessibility features such as aphasia-friendly feedback graphs so users can track their own progress promoting a sense of agency (Figure 2). Additionally, menus and flows were kept minimal for ease of use and all instructions and prompts are presented in multiple formats (audio, text and pictorial) to take into consideration multiple comorbid impairments. Finally, to add a novelty and visually stimulating element to the therapy, a globetrotting postman concept was devised which changes the visualization of the therapy screens motivating users to progress in the therapy while not interfering with the therapy mechanism by using static designs during the therapy and more stimulating animations in between. The therapy algorithm remained the same as the clinical trial version of the app to maintain the efficacy of the therapy mechanism.

Following on from the in-person sessions, remote one-to-one beta testing sessions were held online via video messaging software with a further 25 participants. These were used to refine the therapy design and prepare the app for deployment. In addition to refining the app design, in this phase additional materials and the app release strategy were co-designed including the webpages, adverts, instruction guides and aphasia-friendly videos on setting up Google Play and Apple App Store accounts (available at: www.ucl.ac.uk/aphasia).

3 DISCUSSION AND FUTURE WORK

The co-design of iReadMore developed several new features that were unexpected to the researchers. In this way, co-design can be a useful tool for stepping out of the traditional paper-based or clinician-led therapy tasks and innovate new therapies that go beyond what is achievable without technology.

Some of the findings were in contrast with the existing literature on co-designed or gamified digital aphasia therapies. In our study, participants generally favored simpler, less gamified designs. This could be due to differences in the therapies themselves as the other therapies were therapist-led and iReadMore is self-led, requiring more of a focus on ease of use. This stresses the importance of case-specific co-design.

The second phase of the co-design process (involving beta testing and design refinement) had to be moved online to continue during the COVID-19 pandemic. It enabled participants to engage with the therapy over longer periods of time and at home generating a more realistic testing environment. It also allowed us to reach a wider pool of participants who lived beyond our typical catchment area or who had mobility issues that precluded them from attending inperson testing enabling the inclusion of participants who otherwise may not have been able to contribute.

Further studies and development activities for iReadMore are underway, a mixed-methods online roll-out trial has begun to evaluate the effectiveness of the app in real world settings with all data collection conducted through the app (NCT04849091). Additional





Figure 2: - Two screenshots of co-designed feedback graphs in the iReadMore app displaying the daily training time and reading accuracy graphs.

quantitative and qualitative data on the app experience and translation of therapy benefits to functional, everyday language use is being collected. This data will enable us to further refine the app design and contribute to our overall understand of best practice strategies for alexia therapies, such as optimal doses, frequency of practice and personalization of the therapy algorithm. In the future, we would like to explore the application of iReadMore therapy to other patient groups, such as people with dementia or primary progressive aphasia, as well as providing iReadMore therapy in other languages.

4 CONCLUSION

We have presented the co-design of a reading therapy app, iRead-More that enabled us to release the app publicly in an accessible and engaging format. The iReadMore app is available now to download for use in the rehabilitation of acquired reading impairments through the Google Play Store and Apple App Store. Future work will evaluate the effectiveness of iReadMore using real world data which will allow us to contribute to our overall of alexia and reading rehabilitation and further refine the app design.

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