

Evaluating the Usability of a Tablet Application to Support Adults with Mild Intellectual Disabilities during Primary Care Consultations

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Patients with mild intellectual disabilities (ID) face significant communication barriers when attending primary care consultations. Yet there is a lack of two-way communication aids available to support them in conveying medical symptoms to General Practitioners (GPs). Based on a multi-stakeholder co-design process including GPs, domain experts, people with mild ID and carers, our previous work developed prototype technology to support people with mild ID in GP consultations. This paper discusses the findings of a usability study performed on the resulting prototype. Five experts in ID/usability, four caregivers, and five GPs participated in cognitive and post-task walkthroughs. They found that the application has the potential to increase communication, reduce time constraints, and overcome diagnostic overshadowing. Nevertheless, the participants also identified accessibility barriers relating to: medical imagery; the abstract nature of certain conditions; the use of adaptive questionnaires; and the overloading of information. Potential solutions to overcome these barriers were also discussed.

CCS CONCEPTS • Human-centered computing ~ Accessibility technologies • Social and professional topics ~ Health information exchanges

Additional Keywords and Phrases: Intellectual Disabilities, Primary Health Care, Augmentative and Alternative Communication, Accessibility, Mobile Applications

1 INTRODUCTION

People with intellectual disabilities (ID) have been subjected to health inequalities that have a significant effect on the length and standard of their lives [1]–[6]. Heslop et al. demonstrated the severity of such inequalities during an inquiry into the premature deaths of people with ID [5], as well as subsequent annual reviews [7], [8]. Up to 50% of the deaths were classified as avoidable, with circa 25% directly amenable to better quality care. Many of the barriers contributing to this unsatisfactory health care [1]–[6] require significant amounts of resources to overcome, meaning benefits will not be recognized in the short-term. For example, modules on the health trends and communication needs of people with ID need to be introduced throughout a medical professional's education [9], [10] to ensure they possess the skills to conduct person-centered care [11], [12].

On the other hand, the introduction of Alternative and Augmentative Communication (AAC) technologies has the potential to overcome barriers relating to ineffective communication almost immediately [13]–[16]. They are used to enhance an individual with disabilities capacity to communicate by providing those who cannot speak a platform to convey their needs (alternative), or by supplementing the vocabulary of those who can (augmentative)

[17]. As such, AAC technologies may present personalized medical information in a format that is readily understood by both the individual with ID and the practitioner. Nevertheless, there is great variation in the research-based aids available throughout healthcare practices (e.g. [18]), meaning a large percentage of patients are unable to benefit from their use.

Consequently, we co-designed a tablet application with ten adults with mild ID [19]. The participants suggested that the completion of a questionnaire prior to the consultation will help them to practice the information they wish to convey. Yet there is a possibility that the design of the questionnaire, and its interface, are retrofitted to the needs of those involved in the original workshops and do not meet the requirements of the wider mild ID population. As such, it is important to assess the usability of the application prior to its embedment in the clinical domain. The research objectives of this paper therefore include:

1. Evaluating the design requirements for an application to support adults with mild ID during primary care consultations.
2. Extracting additional features to meet the needs of the primary stakeholders i.e. patients with mild ID, General Practitioners (GPs) and caregivers.

2 BACKGROUND

We refer to WHO's definition of ID that states that to be diagnosed an individual must exhibit the following symptoms: *"a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development."* [20] Intellectual disabilities fall on a spectrum ranging from mild to severe. People with mild ID often live independently but may struggle to complete complex tasks without support. As such, they could benefit substantially from AAC technologies that augment their vocabulary and language skills when interacting with a GP, particularly when they have limited access to caregivers.

2.1 Examples of AAC in Healthcare

2.1.1 Dentistry

Menzies et al. [21], [22] developed a computer-based tool to support patients with ID to communicate with dental practitioners and prepare for upcoming consultations. Three primary features were included to achieve these goals: (1) presenting concrete examples of what may occur during the appointment to increase the patient's expectations; (2) capturing the individuals communication preferences to enable dental staff to build a rapport quicker; and (3) presenting complex medical information in a format readily understood by the patient.

2.1.2 Psychiatry

Talking Mats™ [23] is a picture based framework used to increase the depth of information being provided by an individual who finds it difficult to discuss a topic that is unfamiliar or overly complex. The user simply places an image under the appropriate section of a textured mat in order to discern their views. Bell and Cameron [24] employed Talking Mats™ to overcome the resistance displayed by an individual with ID when discussing their mental health. The introduction of the framework helped to mitigate the social pressures that arise when directly interacting with a health professional, thereby increasing the quality of the information extracted [24]. Boström and Eriksson [25] explored the implementation of a digital questionnaire to support children with ID in reporting

their psychological health. User-centered design techniques were applied throughout the development of a 43-question survey spanning five topics of mental wellbeing. Its accessibility was measured during a quantitative study, in which 109 of the 113 participants involved were able to answer all questions without intervention from their caregivers [26]. Finally, a mixed-methods study was employed with ten children with ID to determine whether the answers provided matched their own life experiences - extracted via semi-structured interviews [27]. A good level of agreement was found between the two datasets, thus highlighting the potential of digital questionnaires in extracting accurate data from people with ID.

2.1.3 Secondary Care

Prior et al. [28], [29] explored the use of patient passports to support medical professionals to provide improved person-centered care. Their system prioritized customization to ensure a greater depth of information on the patients' needs was collected. Users had the option to select from multiple input methods and were only required to provide answers to a subset of the personal elements being queried depending on aspects such as their age and gender. Yet the information collected improves the practitioners ability to interact with patients and not vice versa, which goes against recent guidelines to focus on the implementation of two-way communication aids [30], [31].

Our project addresses some of the limitations throughout these technologies by focusing on the enhancement of both the patients and medical professionals' communicative skills within a domain that is more general in nature.

2.2 Original Design of Proposed Application

The prototype discussed throughout this paper was developed using the requirements extracted from experts [32], ID nurses [32] and ten adults with mild ID [19]. As highlighted previously, the app consisted of an adaptive medical questionnaire focusing on the health trends experienced by the ID population, including 110 questions across nine topics of health. Nevertheless, the questions presented depend on the medical context of the patient. For each of the nine categories, a core question is initially queried that determines whether sub-questions related to that topic are presented. To elaborate, the patient must answer "Yes" to the query shown in Fig. 1, otherwise the system will move on to the next topic, in this case mouth. Furthermore, sub-questions may also determine whether additional sub-questionnaires are presented. For example, the answer to the question "I have a problem with my sight" may restrict or lead to the presentation of questions relating to the individual's vision. See [33] for a full description of the questionnaire's ontology-driven structure.



Figure 1: Initial layout of the question and results pages.

The standard interface prioritizes the implementation of multiple interaction modalities. The audio playback function is activated by clicking the button located on the top left-hand corner of the screen, which highlights the question and reads out its text, prior to moving on to the options and repeating the same process. Stakeholders are also able to change the current image set displayed (from photorealistic, to semi-abstract cartoon, to basic black

and white) by clicking on the button located at the bottom of the screen. To select an answer, the patient simply taps on the option before confirming their choice via the right-hand arrow. The screen will then update based on the question returned by the ontology and this process is repeated until there are no more questions to be answered. If a mistake is made, the user may return to a previous question by tapping on the left-hand arrow. On completion of the questionnaire, a results screen is displayed that includes all answers provided by the patient.

3 METHODS

The success of the proposed application relies upon multiple stakeholder groups including caregivers, medical professionals, and people with mild ID. Consequently, we pursued feedback from these populations, as well as experts in ID and HCI due to their knowledge of accessibility barriers throughout common technologies. Unfortunately, due to Covid-19 restrictions (a condition that affects people with ID disproportionately [34]), we were unable to evaluate with patients with mild ID. Our partner charities stated that their members would have difficulty conducting online studies due to limited access to internet-enabled devices and lack of support when operating complex video conferencing software, since caregiver services were cutback during the pandemic. There were also concerns over the ability of people with ID to adhere to academic conditions virtually.

3.1 Cognitive Walkthroughs with Experts in ID and Caregivers

ISO 9241 [35] states that inspection-based evaluations may be utilized as a complement to user testing or as a replacement. They are perceived to be more cost-effective than user-based approaches and can lead to the elimination of major accessibility barriers prior to the embedment of an app in its target domain. Inspection methods are typically employed by experts in Human Computer Interaction (HCI), yet Nielsen [36] found that single experts (i.e. those with knowledge in usability or the application domain) can detect around 40% of the usability barriers present in a system, with double experts identifying 60%. As such, recruiting a range of participants can lead to a fairly accurate representation of an application's accessibility.

Cognitive walkthroughs have been shown to identify more severe usability barriers within medical systems than counterparts like heuristic evaluation ($P < .0001$) [37], meaning it is suitable for the proposed AAC application where learnability is a key factor due to its infrequent use. Such a method identifies barriers by assessing how easy it is for a new user to complete tasks within a system. This is achieved via the individual answering a set of standard questions on completion of each sub-step in a task. Polson et al. [38] recommend that cognitive walkthroughs be performed in iterations of three to five evaluators to yield a large percentage of usability errors with reasonable false alarm rates. This recommendation was therefore used to form our recruitment strategy that was implemented throughout Summer and Autumn 2020. Information sheets were initially distributed to members of academic institutions within Scotland, who had at least five years' experience in usability, with a similar period of interaction with people who have ID. Recruitment for the caregivers was led by partner charities who contacted individuals providing support to at least one adult with mild ID. Those participants who agreed to take part were required to sign a consent form digitally, prior to arranging an individual meeting on a conferencing platform of their choice.

Participants were initially briefed on the goals of the cognitive walkthrough and were shown an example of how the process works. Three scenario-based cognitive walkthroughs [37] were then performed by the lead investigator, with the participant answering the question set relevant to their demographics (see Table 1), on completion of each sub-step. Experts were required to answer the traditional cognitive walkthrough set [37], with caregivers answering the more streamlined [39], since the language used is less challenging for laypersons. The

first scenario consisted of selecting the audio playback feature, the second utilizing the image swap button, and the third involved completing the questionnaire for symptoms of a sore, tight chest. By conducting all three, the participants were exposed to each feature embedded in the prototype, thus enabling them to identify and discuss solutions for a greater number of barriers. The walkthroughs were recorded with consent and transcribed verbatim. All usability issues were then tagged, along with the potential solutions, prior to the application of Nielsen’s rating scale [40] by two separate investigators to determine the severity of the identified barriers.

Table 1: Demographics of participants involved in the cognitive walkthroughs.

Expert ID	Experience	Caregiver ID	Experience
Expert 1	8 years working in HCI, 4 years working with people with ID	Caregiver 1	21 years experience. Foster parent to an individual with ID.
Expert 2	6 years working in HCI, 10 years working with people with ID	Caregiver 2	5 years experience. Provides care to a family member and a friend with ID. Volunteers at a day center for people with ID.
Expert 3	8 years working in HCI, 3 years working with people with ID	Caregiver 3	13 years experience. Full-time carer for their three children with Autism.
Expert 4	15 years working in HCI, 25 years working with people with ID	Caregiver 4	4 years experience. Paid caregiver for four individuals with ID.
Expert 5	13 years working in HCI, 12 years working with people with ID		

3.2 Post-Task Walkthroughs with General Practitioners

GPs are key to the success of the app as one side of the communication support, however they are neither experts in usability or ID meaning they would identify circa 20% of the accessibility issues within the application [36]. Consequently, post-task walkthroughs [41] were considered to be more appropriate to enable them to envision how the app may be utilized, including whether the results page meets their needs. Post-task walkthroughs involve a participant discussing their experience with a product after they have used it to complete a task. Once again, a N size of three to five participants was set to accommodate for the increased workloads of GPs during Covid-19. Recruitment began in Autumn 2020, with an information sheet being distributed via a mailing list of professionals interested in mitigating the health inequalities experienced by vulnerable populations. No strict inclusion criteria were placed on potential GPs to ensure practitioners with a range of experience and confidence treating patients with ID were identified. Those interested in participating were required to sign a consent form digitally, prior to arranging an individual meeting on a conferencing platform of their choice. See Table 2 for their demographics.

Table 2: Demographics of participants involved in the post-task walkthroughs

ID	Experience
GP 1	26 years experience. Semi-retired, works part time as a locum practitioner.
GP 2	8 years experience. Works as a sessional GP in an urban practice.
GP 3	17 years experience. Works as a sessional GP in an urban practice and advises on eHealth services.
GP 4	7 years experience. Works as a sessional GP in a rural practice.
GP 5	Newly qualified. Works as a full-time GP in a rural practice.

The GPs were initially briefed on the goals of the post-task walkthrough, prior to completing the questionnaire for symptoms of a sore, tight chest (once again selected to demonstrate all features of the app). No support was provided except at points where the participant was unable to advance through a particular page. Areas of

indecision were noted, in addition to incorrect actions, for further investigation on completion of the walkthroughs. The sessions were recorded with consent and transcribed verbatim. These transcripts were subjected to an inductive framework analysis [42] to determine the GPs views on the key barriers and facilitators to the employment of the proposed app.

4 RESULTS: COGNITIVE WALKTHROUGH

The usability barriers discussed by the experts and caregivers are shown in Table 3. Some of the more interesting barriers will be described in greater depth under the following themes: Images; Questionnaire, Results Page.

Table 3: Usability barriers discussed by the experts and caregivers.

Usability Barrier	Discussed By	Rating
Image Change and Audio Playback icons do not accurately describe the function of the button.	E1-E4, C1, C2, C4	1
Images are not standard, i.e. they contain different characters.	E1, E2, E4, E5, C2	3
Images display characters that are of a different age and gender to the user.	E3, E4, C2, C3, C4	3
Images with positive connotations are used to represent the option no.	E2, E3, E5, C2, C4	3
The body language in some of the pictures does not accurately describe the symptom being displayed.	C3, C4	3
Some of the images used do not display abstract concepts clearly.	E1-E5, C2, C3, C4	2
Some of the more realistic photographs may be inappropriate for users with autism.	C3, C4	2
Patient may not utilize the image change button to view the range of conditions in a sub-questionnaire	E4, C2, C4	2
Potentially vague language is used to describe some symptoms.	E4, E5, C1-C4	3
Some of the questions cover components that are too complex for people with ID.	E4, C1, C3	2
Users are unaware of their progress in the questionnaire.	E2, E3	2
Patients have the potential to get lost down the wrong questionnaire branch.	E4	3
Structure of the questionnaire may be overly long for patients suffering from one condition only.	C1, C3	3
Results page is cluttered making it difficult for people with ID to locate the information they require.	E1, E3-E5, C1-C4	4
Incorrect actions are available to the user throughout the interface.	E2, E4	2

4.1 Images

The images embedded within the prototype were the same as those employed throughout the original design workshops [19], [43]. As such, there were expectations that significant usability barriers existed due to the concerns raised by the individuals with ID. Both the caregivers and experts were able to identify the same accessibility issues, which included: utilizing icons that differed to other AAC technologies; the use of non-standard characters that were a different age and gender to the user; and implementing images with unnatural body language. Nevertheless, the participants managed to identify additional barriers relating to the use of medical images to capture both the yes and no options: *Expert Two* “I don't know if people would associate no with positive. So the last one, it was like “have you been feeling sad” and it was no and it was a big happy face on the cartoon one. It might just be confusing for some people, it might throw them off.” Some of the conditions being queried lacked physical symptoms, meaning it was difficult to capture contrasting images to represent yes and no. As such, the participants advocated for an interface that highlights the question being asked, as opposed to the options: *Expert Four*: “It would be a different design that shows an image when you do have problems. So that shows symbols or pictures that try to convey that there is a hearing problem and then you have symbols for just yes and no. You're trying to illustrate yes and no answers that that are not that clear-cut. It might be better to illustrate the question.”

One of the key requirements that arose from the original design workshops was the need to offer multiple image sets [19]. This resulted in the implementation of the image swap button, yet the experts felt that it would be

inappropriate to allow the patients to switch between the embedded sets in real-time, since they are likely to have a preferred style that meets their needs. In addition, it is important to allow the individual with ID to import images they are familiar with: *Expert Four* “People have their own symbol sets they’re used to and it’s a general problem that you give people a symbol set that they’ve never seen before in a situation they’re not happy with. You exaggerate their unhappiness or their discomfort by giving them something they don’t understand because they haven’t seen before. So I would say something like this can only work if you allow the users to use their own symbol set in the first place.”

4.2 Questionnaire

Overall, the experts and caregivers felt that the questions included in the prototype were accessible to adults with mild ID. However, some of the concepts being queried (such as weight loss and increased heart rate) were deemed to be too complex for this population and may require intervention from carers. As such, Expert Five suggested that a change in the background colour may be used to highlight when this is the case. Whilst the content was deemed to be largely accessible, some of the caregivers felt that the questionnaire’s structure may be overly long for their service users. Consequently, they advocated for an alternative design that includes a tappable image of the body to allow the patient to access relevant sub-questionnaires directly: *Caregiver Three*: “If you don’t feel unwell maybe the next question should be are you sore or are you in pain? And that could be like an animated picture that you would pick where on the body and that would then take you to the appropriate question. That’s quite direct and straight to the point and it makes the full process faster. So you’ll get to your end game quicker versus going through six or seven questions that’s no.”

Patients with ID may also find the adaptive nature of the questionnaire challenging as they are unaware of the number of questions remaining and could potentially get lost down an incorrect branch: *Expert Three*: “In the last bit of that question, “are [they] making progress towards their goal,” there’s no indication I guess of how far in I am. It’s helpful to know how far in I am, how many more clicks I’m going to have to go through and questions I’m gonna have to answer...A progress bar kind of helps you combat the answer and fatigue because you know how far there is to go.” *Expert Four*: “For some reason you press the wrong answer, you might have to have some mechanism in your questionnaire that allows [you] to recover from that mistake. I’ve said something wrong five questions ago, so I’m now at the heart but it’s my teeth, there needs to be some recover that allows the questionnaire to realize I’m down the wrong tunnel here.”

4.3 Results Page

The results page was deemed to be overbearing for patients with mild ID, meaning it would be difficult for them to locate the information they wish to convey to GPs: *Expert 4*: “You would need to have it displayed in a way that on one page the person can take it in. So not scrolling through because that’s generally a difficulty to keep that all in your working memory. You’ve got like 20 images that you would have to keep in your working memory to make your story off it all.” One suggestion to reduce the cognitive load placed on working memory was to isolate the symptoms the patient is experiencing, from those they have ruled out, with GPs having access to all of the information if necessary.

5 RESULTS: POST-TASK WALKTHROUGHS

The GPs were able to visualize the potential benefits of embedding the app in current practice. All suggested that the results page may act as an effective starting point, thus enabling them to prioritize certain conditions, whilst overcoming debilitating time constraints: *GP Two*: “Sometimes people tell you about their itchy skin or broken nail

and right at the end of the ten minutes they'll say "oh and I've got chest pain." And you go "gosh I wish I knew about the chest pain before we got started." So anything that hones in on urgent symptoms would be very useful. GP Five: "If you have information like this from an app then you may be able to more effectively use a single appointment. I can't get half the history in a single appointment before I've even made a management plan or examined the person. So maybe this would facilitate quicker appointments because they've done the work themselves, you've got a lot of information about them." In addition, GP Five suggested that the app empowers patients to provide their own views, particularly when attending consultations on their own, thereby reducing the potential of diagnostic overshadowing.

In contrast to the caregivers, the GPs felt that the structure of the questionnaire was appropriate since the question, sub-question hierarchy allows the patient to select all the symptoms they are suffering from: GP Four: "Someone with a learning disability might find it difficult to go and tell the first thing, wait till that's concluded and then tell the second thing...So you've got those top-level questions at the start where they might say yes to more than one. That's really useful because, you know, the first thing they mentioned might not be the main thing that they want to talk about." Yet, some of the questions employed, such as labored breathing, were deemed to be unsuitable due their severity and subsequent need for urgent care. In this instance, it may be possible for the application to direct the patient towards more appropriate services, as highlighted by GP Two: "They are misusing [the health system] because maybe they don't know the other options, they're a little bit stuck. It's not set up for people with learning disabilities. If there was something in the app that flagged them to say if you've got paracetamol in the house take two, or call an ambulance, or speak to the pharmacist I think that would be really beneficial."

Once again, the majority of the improvements suggested by the GPs centered on the results page. Their views aligned with those of the experts and caregivers in that the structure was overly complex. Instead, they preferred to view a snapshot of the patient's major symptoms, with the option to view the remaining information if required: GP Four: "If it's really, really quick and dead obvious, you know, almost something you can see in one snap in front of you [that'd be better]. You'll find GPs are quite set in their ways and things that slot into that work well and things that kind of involve them shifting gear and go and do something else, when things get really busy they tend to not get done. So your summary sheet as it was, I think was good for maybe the person who's filled [it] out but something that's really, really snappy and painfully obvious for the GP [with] maybe the option to go and look in more detail might help."

6 DISCUSSION AND CONCLUSION

The three separate populations involved in the cognitive and post-task walkthroughs were able to identify similar accessibility barriers. This highlights the importance of mitigating such barriers prior to the embedment of the app in current practice. Some of the suggested improvements made by the participants also have implications for other domains outwith healthcare. For example, how to capture the progress of an adaptive questionnaire and automatically return from incorrect branches, may be topics of interest for artificial intelligence researchers. The results also highlight the potential benefits of the app (increase in communication, reduction of time constraints, increase in diagnosis rates), which may be measured during future randomized controlled trials. Nevertheless, prior to reaching this phase, it is important to conduct similar studies with patients with mild ID to ensure their needs are met. "Soap opera" [44]–[46] supported post-task walkthroughs [41] may therefore be carried out with this population to allow them to identify accessibility barriers unrelated to their understanding of the medical conditions being queried.

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