Exploring the Design of a Two-way Communication Aid to Support Adults with Mild Intellectual Disabilities during Primary Care Consultations

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Declaration of Authenticity and Author's Rights

Signed: Date:

Previously Published Work

Research in this thesis has been published at the following venues:

1. Gibson, R.C., Bouamrane, M.-M., Dunlop, M.: Alternative and augmentative Communication Technologies to Support Adults with Mild Intellectual Disabilities during Clinical Consultations: A Scoping Review. JMIR Rehabilitation and Assistive Technologies. In press. 35 pages.
2. Gibson, R.C, Dunlop, M.D, Bouamrane, M.-M.: Lessons from Expert Focus Groups on how to Better Support Adults with Mild Intellectual Disabilities to Engage in Co-Design. In: The 22nd International ACM SIGACCESS Conference on Computers and Accessibility. pp. 1–12. Association for Computing Machinery, New York, NY, USA (2020) (Best Paper Nominee)
3. Gibson, R.C., Bouamrane, M.-M., Dunlop, M.: Experts Views on the Use of Mobile Devices to Support Patients with Mild Learning Disabilities During Clinical Consultations. Stud Health Technol Inform. 264, 1199–1203 (2019). https://doi.org/10.3233/SHTI190416
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6. Gibson, R.C., Dunlop, M.D.: Evaluating the Usability of a Tablet Application to Support Adults with Mild Intellectual Disabilities during Primary Care Consultations. In: CHI EA '21: Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems. pp. 1–8. Association for Computing Machinery, Yokohama, Japan (2021)

The author was the principal study designer and investigator across each of the listed articles. He also led the analysis of the results and subsequent write-up. In addition, the author was responsible for the development of the artefacts included in each study, such as the easy-read information sheets and high-tech prototypes. Paper one includes content discussed in Chapter Three of the main body of this thesis, papers two and three focus on Chapter Four. Paper four discusses the user-centred design workshops conducted in Chapter Five, whilst paper five centres on the ontology-driven questionnaire discussed in Chapter Six. Finally, paper six describes the evaluation in Chapter Seven.

Signed:
Date:

Datasets

Multiple datasets have been produced during the course of this work and have been made available to the wider research community:

1. Alternative and Augmentative Communication Technologies to Support Adults with Mild Intellectual Disabilities during Clinical Consultations: Scoping Review Charted Data. DOI: 10.15129/343da1f8-593e-4f6b-a406-72314f54884b
2. Identifying Appropriate Research Methods to Embed within a Design Workshop Involving Adults with Mild Learning Disabilities. DOI: 10.15129/76f97730-a5fa-49da-973f-995373cee7ad

3. Exploring the Views of Patients with Mild Intellectual Disabilities on the Barriers to Primary Care Consultations: A Framework Analysis. DOI: 10.15129/94ca80dd-5896-4095-a56f-44ef2caf4f09
4. Patients with Mild Intellectual Disabilities Views of a Tablet Application to Support them During Primary Care Consultations: Post-Task Walkthroughs. DOI: 10.15129/71f05a5d-076a-44d2-9b6e-8f140129bb5c
5. Caregivers Views of a Tablet Application to Support Patients with Mild Intellectual Disabilities during Primary Care Consultations: Cognitive Walkthroughs and Semi-Structured Interviews: DOI: 10.15129/df697f81-c65c-414a-acab-1de446cf8302
6. General Practitioners Views of a Tablet Application to Support Patients with Mild Intellectual Disabilities during Primary Care Consultations: Post-Task Walkthroughs and Semi-Structured Interviews. DOI: 10.15129/5ca7c5d6-4a6d-4bb2-9579-81c2f2486864

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Abbreviations

AAC – Augmentative and Alternative Communication

ASD – Autism Spectrum Disorder

CHAP – Comprehensive Health Assessment Program

DS – Down Syndrome

GP – General Practitioner

HCI – Human Computer Interaction

ID – Intellectual Disability

MeSH – Medical Subject Headings

MRC – Medical Research Council

OECD – Organisation for Economic Cooperation and Development

OWL – Web Ontology Language

RCT – Randomised Controlled Trial

RQ – Research Question

UCD – User-Centred Design

WHO – World Health Organisation

WHO-ICF – International Classification of Functioning, Disability and Health Framework

XML -Extensible Mark-up Language

Abstract

People with intellectual disabilities (ID) experience health inequalities that have a significant effect on the length and standard of their lives. Many of these inequalities are preventable, particularly the breakdown in communication between health professionals and patients with ID. Communication aids have been introduced to improve the quality of medical information exchanges, yet they tend to focus on the ability of practitioners to convey their views to patients and not vice versa. Consequently, this thesis explored the design of a two-way communication aid for general practitioners (GPs) and patients with mild ID. The "Development" phase of the framework for complex interventions was used to highlight the need for the proposed aid, including how it may improve current practice. First, a scoping review on the technologies utilised throughout healthcare services was conducted, with the results highlighting a lack of two-way communication aids. Domain experts were then recruited to create an accessible design workshop for participants with mild ID. During this process, they provided their own views on the proposed aid and suggested that a tablet application that extracts medical information from the patient prior to the consultation would help improve communication. A high-tech prototype was developed using these requirements before being embedded within the design workshops. This prototype consisted of an ontology-driven, adaptive questionnaire that enables a wide range of conditions to be included, with only those relevant to the health context of the patient being presented. The ten participants with mild ID felt that the questionnaire would improve consultations yet requested features to support them in accessing appropriate health services. Refinements were made prior to the application being evaluated by caregivers, GPs, and experts. The results indicated that the app could enhance current practice in four ways: improved communication; patient independence; reduced time constraints; and increased diagnostic rates.

Chapter 1: Introduction

In spite of the implementation of inclusive health strategies such as “The Keys to Life” [1], people with intellectual disabilities (ID) continue to experience significant disparities in their life expectancy. For example, 2018’s ID mortality review [2] concluded that people with ID die on average 23 to 27 years younger than the general population [2]. With similar trends occurring throughout the developed world e.g. [3, 4], it is clear that people with ID are subjected to inequalities that have a substantial impact on their overall health. According to Emerson and Turner et al. [5, 6] many of these inequalities are a direct consequence of an individual’s social circumstance and / or genetic composition. For instance, people with ID are more likely to experience poverty and may therefore be raised in poor housing estates; undergo large periods of isolation; or have greater difficulty finding sustainable, long-term employment [5]. Furthermore, this population tend to have underdeveloped health literacy skills, which may impact their ability to: recognise and act upon medical conditions; conduct healthy lifestyle choices; and converse with clinicians effectively - a particular concern given people with ID are more prone to developing medical conditions [5, 6].

Nevertheless, the care being provided by health professionals / organisations can also contribute to the health inequalities experienced by patients with ID. In 2012, researchers at the university of Bristol completed an inquiry into the premature deaths of people with ID [7]. They examined 247 deaths across three practices in the southwest of England and subsequently classified 42% as premature, with a further 27.5% directly amenable to change providing better quality care was administered. In other words, circa 68 patients failed to receive the level of care they were legally entitled to. Moreover, patients suffered from an average of five long-term or curable conditions at their time of death, many of which were relatively straightforward to diagnose and treat e.g. constipation in 37% of cases and pressure sores in 28% [7]. As such, the quality of life experienced by people with ID is also affected, in addition to the overall length. These trends continue to the present day with the aforementioned ID mortality review [2] concluding that over half of the 10810 deaths examined failed to meet good practice standards. 11% of the reviews also reported concerns about the circumstances leading to an individual’s death and 8% (circa 71 patients) *“received* *care that fell so far below expected good practice that it either significantly impacted on their well-being, or directly contributed to their death."*

Over the past three decades, a wealth of literature has identified various health inequalities that contribute to the premature deaths of people with ID e.g. [7–11]. Recurrent themes were discussed in this literature, which highlights the lack of support available to the ID population when attempting to access effective services. First, medical professionals are less likely to carry out preventive care activities such as screening or health promotion [7–11]. Consequently, conditions may be left untreated for an excessive amount of time, since individuals with ID and their caregivers often find it difficult to recognise the presence of medical symptoms at an early stage [11]. On the other hand, caregivers can become overinvolved in the consultation process, with less-skilled staff preferring to communicate with them, as opposed to the individual with ID [11] – a process that may affect the accuracy of the information obtained.

Additionally, there was evidence to suggest that medical professionals, as a whole, fail to keep patients fully informed on the treatment options available to them [7, 10]. This information is generally disseminated via speech, yet such an approach may be inappropriate for people with ID due to impairments in literacy skills and short-term memory [12]. Rather, a variety of presentation formats, such as easy read [13], should be utilised to increase the patients ability to provide informed consent [7]. Furthermore, people with ID are often subjected to comorbidities [2, 7], meaning they require treatment across the healthcare system. Yet the general infrastructure and culture throughout this system impedes coordination between healthcare providers, which may result in patients failing to access optimal treatment in a timely manner [7–11]. Lastly, the quality and depth of education being received by medical professionals is regarded as insufficient [7–11, 14, 15]. Doctors and nurses alike tend to have gaps in their understanding of the health trends experienced by people with ID [7, 10] and this may lead to common conditions being overshadowed [16]. In addition, staff may not possess the skills required to apply reasonable adjustments, meaning the consultation techniques used could be inaccessible to the complex needs of patients with ID [8–11].

A significant amount of resources may be required to alleviate many of the inequalities previously discussed. For example, to ensure healthcare workforces are well trained on the topic of ID, a shift in culture towards more inclusive content being taught in higher-education health programs must be recognised [14]. Furthermore, calls have been made for staff to receive regular on-site training regarding the care of people with ID [17, 18], yet current workload pressures [19, 20] would prevent them from pursuing such resources, even when they recognise the need to do so. Therefore, the benefits of implementing these improvements may take years to realise, meaning patients with ID would continue to be disadvantaged in the short-term. On the other hand, Alternative and Augmentative Communication (AAC) technologies have the potential to alleviate barriers arising from ineffective communication [9–11, 21–24] almost immediately. 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) [25]. Consequently, AAC technologies have the ability to present personalised medical information in a format that is readily understood by both the patient with ID and medical practitioner.

1.1 Key Related Work

Primary examples of utilising AAC devices within the clinical domain will now be presented to demonstrate the potential advantages of such resources. Additional technologies will also be discussed in Chapter Three, where the gaps in AAC support available to both medical professionals and patients with ID will be identified.

Menzies et al. [26, 27] explored the use of computer-based tools to promote communication between dental practitioners and people with ID. A User Centred Design (UCD) process was carried out with multiple stakeholder groups (including clinical staff, patients with ID and caregivers) to determine key functionalities for the proposed tool. The results indicated that the application may help patients to better understand dental procedures, thus increasing their ability to communicate about their needs and/or symptoms. Three separate strategies were discussed that contributed to enhancing the patient’s knowledge: (1) photographs/videos of the dental environment - including potential procedures - should be presented in advance of the appointment to allow patients to better prepare for what may occur; (2) staff should have access to the patient's personal information to ensure they utilise suitable interaction techniques and build a rapport more quickly; and (3) the system should present information in the most appropriate format relevant to the patient's skills and abilities e.g. simplified sentences or via imagery. Dental staff also felt it was necessary to extract the patient's preferred method of communicating key terms such as "yes", "no" and "stop" to ensure informed consent is adhered to at all times.

Boström et al. [28–30] investigated the use of tablet technologies to support children with ID in self-reporting their psychological health. Once again, UCD techniques were utilised to develop the 43-question survey across five topics of an individual's mental wellbeing [28]. Initial requirements were identified from 14 participants with mild or moderate ID between the ages of eight and fifteen, with the results centring on aspects such as: the presentation of one question a time; the implementation of basic screens that include a limited number of possible actions; the option for audio support when receiving or responding to a query; the embedment of images to increase the user's comprehension of a question; the mitigation of technology specific actions such as swiping; and the option to pause and resume the questionnaire. A short pilot study with eight adolescents of a similar age and disability showed that the participants were able to operate the interface as intended and comprehend the meaning of the questions, despite a tendency to select the more extreme options - "yes" in particular [28].

To further assess the accessibility of the questionnaire, Boström et al. [29] conducted a quantitative study involving 113 students with ID between the ages of 12 and 16. 109 of the students were able to complete the questionnaire successfully with limited signs of response bias. Just three participants chose the most positive option for all questions presented and 18 (16.2%) provided contradictory answers to the reverse-worded control questions included within the survey [29]. Finally, to ensure the results of the questionnaire matched the views of the user, a mixed methods study was carried out with ten children who have mild ID [30]. Boström and Broberg found a good level of agreement between the results of the survey and the views provided by the participants during a series of semi-structured interviews. Nevertheless, some of the more negative experiences described were not picked up by the questionnaire, and this was attributed to such aspects being omitted from the app [30].

Boström et al’s work [28–30] indicates that a digital questionnaire can be an accessible resource for extracting reliable data from people with ID. This data may then be used to open up a discussion on how the patient is feeling and ultimately lead to medical professionals carrying out better informed care decisions [29]. Similar findings also emerged from the authors MPhil research, which aimed to explore the use of tablet technologies to promote communication between General Practitioners (GPs) and patients with mild ID [31–33]. Interviews were carried out with ten experts in ID to determine initial design requirements for the proposed application, prior to the development of a high-fidelity prototype. The resulting prototype was then presented to a subset of the experts to ensure major accessibility issues were mitigated in preparation for future studies with people with ID.

The majority of the user interface (UI) requirements discussed by the experts matched those identified by Boström and Eriksson [28]; however, there were significant differences in the structure of the surveys implemented. All of the experts advocated for a dynamic questionnaire that changes its structure based on the answers being provided by the user [31–33]. Consequently, the large range of conditions commonly experienced by people with ID e.g. [34–37] may be included without the questionnaire becoming overbearing to those with short attention spans [12], since many of the queries are not presented. Such an approach has the potential to raise awareness of the conditions being overshadowed by professionals who are undertrained on the health trends of the ID population.

1.2 Research Gap

The quality of care administered to patients with impaired communication skills (including those who have ID) remains insufficient despite the implementation of treatment guidelines e.g. [1] and the increased focus on AAC [21]. Previous literature [31–33] and Chapter Three highlights several reasons as to why this may be the case. First, clinical AAC technologies tend not be adopted on a national scale, with the availability of these resources, as well as the content included within them, varying throughout the healthcare system. Northway et al. clearly demonstrated such a variance when reviewing the patient passports utilised by individuals with ID in the United Kingdom [38]. They found that the content prioritised by health centres differed significantly, meaning key information may not be available to medical professionals as the patient is transferred from practice to practice. In addition, patients with ID are often required to defer to general purpose AAC technologies (e.g. [39]) when more specialised, research-based devices are unattainable, yet these technologies may not offer appropriate features to assist them in the healthcare domain [31]. Furthermore, they tend to be based on the opinions of developers, as opposed to the requirements identified from stakeholders, and are therefore subject to significant accessibility barriers [31].

The lack of specialised high-tech resources is a prominent issue in the domain of primary care [31], which is often a patient's first port of call into the health system. General practitioners (GPs) are typically undereducated on the specific needs of people with ID [7–11, 14, 15] and may find it difficult to conduct person-centred care [8–11], whilst potentially overshadowing the common conditions that affect this population [16]. Utilising ineffective consultation techniques can lead to professionals interacting solely with caregivers, yet such a practice may result in the extraction of incorrect or incomplete information [11]. This, coupled with a GPs lack of knowledge on the health trends of people with ID, can heighten the depth of overshadowing that may occur, meaning patients may not be forwarded on to appropriate services in a timely manner. Consequently, there is significant scope to explore the implementation of AAC devices to promote communication between patients with ID and general practitioners. This is particularly true for individuals with less severe impairments, since AAC technologies are often designed for users with complex communication needs [40].

1.3 Research Questions and Thesis Statement

As will be highlighted in Chapter Three, there is a distinct lack of high-tech, two-way communication aids available within primary care, despite the call for such resources being made as far back as 1997 [41]. This thesis therefore explores the development of a tablet application to promote the ability of patients with mild ID to communicate with GPs. The design process is approached from the perspective of patients to ensure the final prototype is better suited to their own complex needs and abilities. The decision was made to develop the app for adults with mild ID under the assumption that this population would be able to use it autonomously, meaning the extracted results should match the conditions they are experiencing more closely – see section 2.2.

Existing technologies should first be reviewed to determine how the proposed tablet application can fit into and improve current practice. Consequently, the first main research question (RQ) to be answered in this thesis is as follows:

RQ 1: What are the range of AAC technologies being used by patients with mild ID to support them to communicate with general practitioners.

By reviewing existing technologies, barriers and facilitators to the implementation of AAC devices should be identified. These lessons may then affect the design decisions made during the development of the proposed app, meaning research question one has been split into the following two sub-questions:

RQ 1.1: What are the barriers to implementing AAC technologies with adult patients who have mild ID.

RQ 1.2: What are the facilitators to implementing AAC technologies with adult patients who have mild ID.

In addition to the features identified whilst reviewing the literature, further requirements must be identified from target stakeholders. Such a process should focus on patients with mild ID, since their crucial views were overlooked during previous research [31–33]. Consequently, the primary objective of this thesis is to answer research question two:

RQ 2: What do patients with mild ID require from a clinical AAC application to support them during primary care consultations?

Additional research questions have emerged during the course of this work and will be discussed in the relevant sections throughout the thesis. Whilst addressing these questions, the following thesis statement was established:

Thesis Statement: Primary care AAC applications should focus on promoting two-way communication between adults with mild ID and GPs, informed by the personal characteristics of the patient and their current medical context.

1.4 Comparison to MPhil

As discussed in section 1.1, this thesis follows on from the body of literature published during the authors MPhil project [31–33]. The contributions made overcome the main limitations of the MPhil, including: (1) the derivation of design requirements from target stakeholders (people with mild ID, medical professionals, and caregivers) rather than experts to ensure the application better meets the needs of users [42–45]; and (2) utilising ontologies to increase the scalability and accessibility of medical questionnaires for people with mild ID. Table 1.1. provides an overview of the differences between the two projects, whilst Chapter Five and Six explains how the stakeholders' design diverged from that of the experts.

Table 1.1: A comparison of the authors MPhil project and PhD.

Characteristic	**MPhil**	**PhD**
Literature Review	Review of general AAC technologies.	Structured scoping review of clinical AAC technologies. Provides evidence on the need for improved two-way communication aids.
Design Requirements	Requirements for the application were derived from seven experts in ID and three GPs.	Requirements for the application were co-derived with 14 experts in ID/accessibility, three ID nurses, ten adults with mild ID, four caregivers and five GPs. As such, more representative design requirements have been produced. The prototype from the MPhil was incorporated in the initial design process conducted within the PhD – see Chapter Four.
Structure of Application	Questionnaire was formed from a series of linked webpages, meaning it suffered from poor scalability.	Adaptive questionnaire was ontology-driven and able to scale to ever changing health guidelines and individual practice needs. The symptoms are based on the health trends of people with ID and are therefore more comprehensive than those included in the MPhil. An accessibility model was also produced to ensure the standard user interface better meets the physical and cognitive needs of stakeholders with mild ID.

Guidelines	Expert-based design guidelines for clinical AAC technologies used by patients with mild ID	Multi-stakeholder design guidelines for clinical AAC technologies utilised by patients with mild ID. An expert and literature review approach to developing more accessible design workshops for people with ID. Guidelines to improve the accessibility of common user centred design techniques.

1.5 Contribution to Knowledge

This research makes several contributions to knowledge:

1. First, a scoping review on the existing technologies to promote communication between adults with mild ID and GPs has been conducted. Consequently, the barriers and facilitators to the implementation of clinical AAC devices for patients with mild ID were identified.
2. Barriers to the utilisation of common UCD techniques with adults with mild ID have also been identified. A novel literature review and expert based approach was used to overcome such barriers – see [46]. Appendix C discusses the adjustments made to increase the accessibility of these methods.
3. Initial design requirements for the proposed clinical AAC application were co-derived with 10 patients with mild ID, thus overcoming the limitations of [31–33] – see [47].
4. An ontology-driven approach to the development of dynamic health questionnaires for people with mild ID has been proposed. The questionnaire takes into consideration the accessibility needs of its users, in addition to their health context, and is also scalable to overcome the ever-changing guidelines on the health trends experienced by the target population – see [48].
5. Caregivers, GPs and experts in ID evaluated an initial prototype of the proposed AAC application. Such a process led to more representative design requirements, thus increasing the accessibility of the app for the wider mild ID population, as opposed to just the ten participants involved in the UCD workshops.

6. Design requirements were also derived with ID nurses (see [49]) and GPs to ensure the application meets the needs of the primary stakeholders involved in the consultation process.

A list of the literature published during the course of this thesis may found in previously published work, including the authors role within each article. In addition, the data produced during each study has been made available in Datasets.

1.6 Thesis Overview

As highlighted previously, this thesis explored the potential use of high-tech, two-way communication aids to improve information exchanges between patients with mild ID and GPs. This was achieved via the application of the “Development” phase in the framework for complex interventions [50], including a user centred design and evaluation process with multiple stakeholder groups – more specifically 14 experts in ID/accessibility, three ID nurses, ten adults with mild ID, four caregivers and five GPs. Chapter Two will provide more details on the overarching methodology and will emphasise how each research module contributed to its completion. In addition, the profiles of each stakeholder will be presented to illustrate why the proposed communication aid was designed for patients with milder ID. Chapter Three includes a scoping review on the current AAC technologies being employed throughout primary and secondary care. The review was presented after the methodology Chapter, as the findings contribute to a key phase in the framework for complex interventions [50] i.e. detailing why the proposed communication aid is needed to improve current practice. Chapter Four discusses the implementation of a novel expert/literature hybrid approach to develop a more accessible design workshop for people with ID [46, 49]. The resulting workshop was then employed with ten adults with mild ID in Chapter Five to identify initial requirements for the primary care AAC application [47]. A description of the back-end of this application is presented in Chapter Six, which includes the design of an ontology-driven adaptive questionnaire [48]. Experts, caregivers, and GPs evaluated the final prototype in Chapter Seven, thus ensuring the design requirements were more representative of the wider mild ID population. Lastly, Chapter Eight includes a discussion on the primary findings of this thesis, in addition to limitations and future work.

Chapter 2: Methodology and Project Scope

The purpose of this chapter is two-folds. First, the overarching methodological approach used to guide the research will be described, in addition to the advantages of employing such an approach. Second, the scope of the project will be introduced by highlighting the application's stakeholders via the development of personas [51] and empathy maps [52] and by providing the formal definition of ID utilised throughout the thesis.

2.1 Framework for Complex Interventions

To ensure the author followed a systematic approach that is accepted within the clinical domain, the following three criteria were given priority whilst identifying a framework for the development of the proposed application:

1. The framework must focus on the collection of evidence to inform the design of a product. As such, the final application should be better suited to the accessibility needs and preferences of target stakeholders.
2. The framework must have been applied successfully within other health-related projects for adults with mild ID, meaning the processes involved are accessible to this population.
3. The framework must be widely approved throughout the clinical domain, thus increasing the probability that the application is adopted as standard practice.

The Medical Research Council's (MRC) framework for complex interventions [50] satisfied each of these criteria. Consequently, it was the ideal choice to support the author in designing and implementing a prototype of the proposed clinical AAC application. In the context of the MRC framework, complex interventions are described as *"interventions that contain several interacting components"* [50]. The scope for the complexity of these components is wide ranging, yet crucially includes projects that encapsulate a great deal of flexibility or involves users who have intricate needs or behaviours [50]. Since people with ID are heterogeneous in nature, and may therefore have a variety of complex needs, the framework was crucial to ensuring the prototype is accessible to a series of sub-populations.

2.1.1 Overview of the Framework

The framework for complex interventions consists of four distinct stages as shown in Fig. 2.1. The initial stage, "Development", involves the collection of evidence on why the intervention is needed (in this case the proposed AAC application), as well as the potential impact it may have on current practice. Typically, the former is achieved via a systematic review that aims to identify potential gaps or weaknesses in existing processes, before being supplemented by new primary research such as stakeholder interviews or ethnography. The results may then shape the theory behind how the intervention can improve such shortcomings, in addition to further research. This thesis primarily focuses on the completion of the "Development" stage, due to restrictions in time and resources – see section 2.1.3.

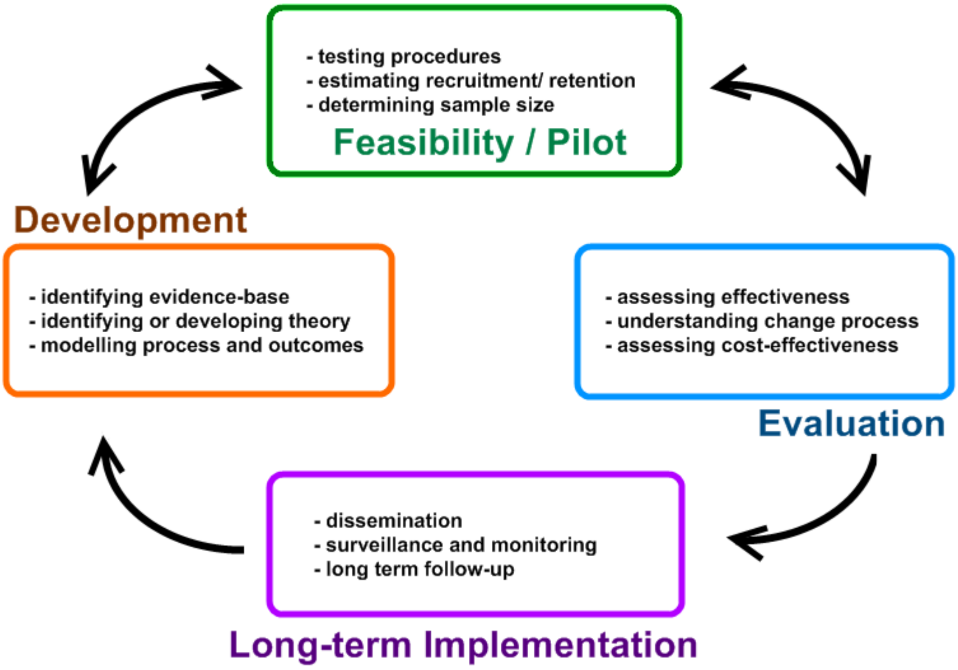

Fig. 2.1: The stages involved in the framework for complex interventions.

The second stage, "Feasibility and Piloting", includes a short-term investigation to identify factors such as: the acceptability of the intervention; the likelihood of participants engaging in and completing long-term studies; and the n-size required to measure potential effects. It is also important to assess whether the intervention had an impact on the barriers recognised throughout the "Development" stage, before scaling up to a more concrete evaluation. During the "Evaluation", researchers are expected to employ the most suitable methods to obtain the primary / secondary outcome measures previously identified e.g. whether an AAC application leads to certain conditions being diagnosed more frequently. This often involves randomised controlled trials (RCTs) to establish the true benefits of the intervention, whilst mitigating the possibility of outcomes arising from selection bias i.e. when the participants exposed to the intervention differ significantly from those who have not. At this stage, researchers should also look to evaluate how the intervention is being implemented, in an attempt to understand why it has been successful or identify ways it may be improved on. Finally, the cost-effectiveness of the intervention should be measured to ensure the results are more appealing to decision makers.

Stage four, “Long-term Implementation”, involves convincing such decision makers to translate the findings into routine practice, before monitoring the impact of the intervention once it has been widely established. The overall framework is iterative in that the results of one stage may prompt the investigator to return to a previous stage. As such, it is highly appropriate for people with ID, since it may be initially difficult to identify requirements from such stakeholders, with this process becoming easier as concrete artefacts (such as prototypes) are produced [53, 54]. Therefore, offering the flexibility to update the design of the proposed application would result in more representative requirements being embedded, with the participants views changing as the project progresses.

2.1.2 Use in Similar Projects

The discussed framework has been a key influence on the development of other health related interventions for people with mild ID. For example, Kerr et al. [55, 56] were guided by the sub-steps involved in the “Development” stage to establish an initial concept for a tobacco and alcohol reduction programme. Like the approach used in this thesis (see section 2.1.3), the authors initially focused on a review of the literature to identify the current evidence base for their proposed intervention [55]. Key databases (such as Medline, DARE, PsycINFO, CINAHL, ERIC and AMED) were searched using terms relating to: intellectual disabilities; health promotion; smoking; and alcohol drinking, amongst others. 650 papers were initially identified of which nine met the inclusion criteria defined by Kerr et al. [55] and were therefore included in the review. Each of the identified interventions were analysed using the FAME framework [57] to assess their feasibility, appropriateness, meaningfulness and effectiveness.

The results indicated that a lack of high-quality, evidence-based support was available to people with mild ID when reducing their use of alcohol and/or tobacco. Whilst assessing the effectiveness of the interventions, seven of the nine studies had serious methodological shortcomings that effected the overall conclusions being made e.g. lack of control groups and use of data collection instruments that were yet to be validated with the ID population. Of the remaining two studies, one reported a significant increase in the participants knowledge of the factors associated with smoking or drinking alcohol, and the other reported positive findings yet the differences between the intervention and non-intervention groups were not statistically significant. Meaningfulness could not be discussed due to a lack of qualitative studies identified during the data collection phase. Furthermore, just one of the papers discussed aspects relating to the feasibility of an intervention and indicated that teachers could easily incorporate relevant information into their lesson plans. In contrast, appropriateness was addressed by all of the identified studies, with some concerns being raised regarding: the verbal and interpersonal skills held by the people with mild ID in relation to group educational settings; the ability to capture participants' attention throughout informative sessions; and the participants' understanding of abstract concepts such as long-term health effects and alcohol units. Consequently, there was ample opportunity for Kerr et al. [55] to address the limitations of the interventions found throughout the literature.

The "Development" stage continued via interviews with key stakeholders to resolve the identified gap in the tobacco and alcohol related health promotion needs of people with mild ID [56]. 16 adults with mild or moderate ID, two family members and 15 health and social care professionals took part in phone interviews and focus groups, which were recorded with participant consent and analysed using a framework approach [56]. The participants discussed several factors that should be addressed by the intervention, including: people with mild ID's knowledge of the health-related consequences of smoking and drinking; their ability to discuss their own needs and views; and their motivations for quitting, along with the strategies and skills to achieve such a goal. Family/paid caregivers and health and social care professionals should also receive training on these aspects to support the individual with ID in quitting. As such, Kerr et al. [56] came to the conclusion that a joint/integrated service provision would be the most appropriate intervention for reducing people with mild ID's reliance on alcohol and nicotine. Their future work will focus on the development of this provision.

2.1.3 Influence on Proposed Application

The research modules carried out over the course of this thesis are shown in Fig. 2.2, in addition to their fit within the "Development" stage of the framework for complex interventions.

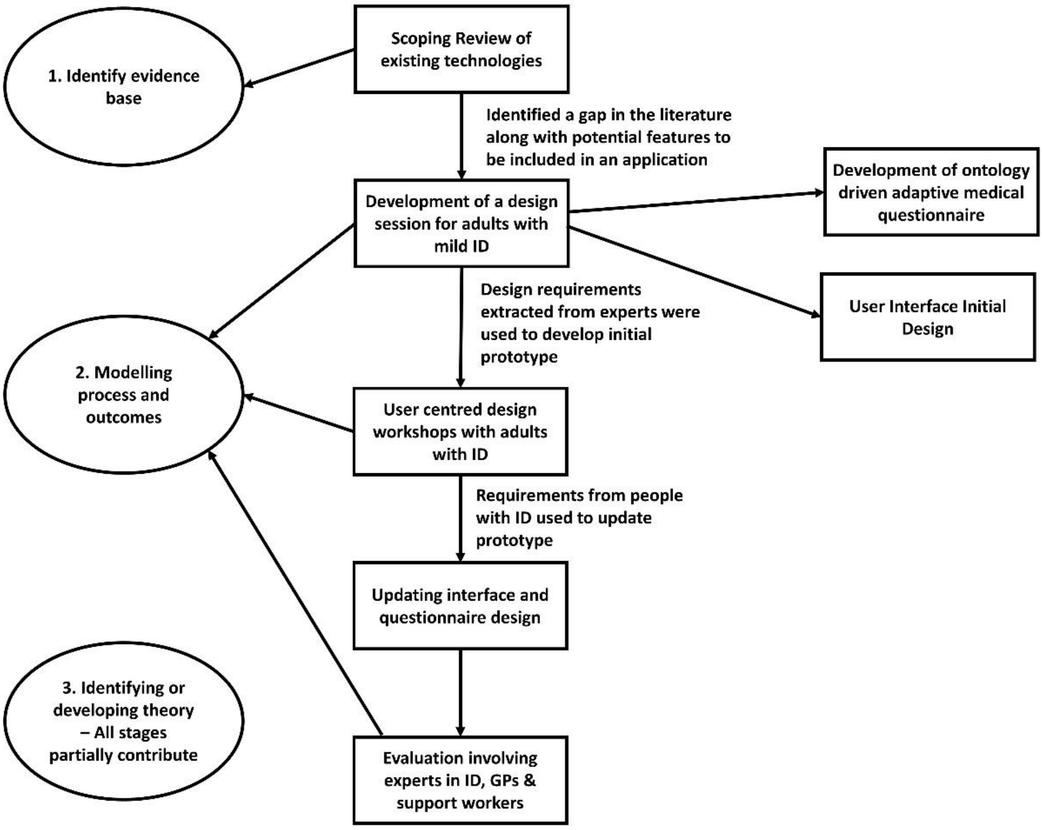

Fig. 2.2: Research modules conducted throughout the "Development" stage.

Initially, a scoping review was conducted to identify the AAC technologies available to patients with mild ID throughout primary and secondary care. The review highlighted a need for high-tech, two-way communication aids that empower patients with ID to become actively involved in their healthcare, thus establishing an evidence base for the proposed application, whilst partially answering research question one (see section 1.3). The remaining modules contributed to how the application can fit into and improve current practice. This primarily involved the identification of user needs and requirements from patients with mild ID during a series of UCD workshops. Yet due to the complex needs of the mild ID population, it was important to first ensure the methods employed were accessible to potential participants. Consequently, the UCD workshops were developed in conjunction with experts in ID, during which their own views of the application were also discussed. These views were then combined with the lessons learned throughout the scoping review to develop some of the resources employed throughout the workshops, including an initial prototype of the proposed application – see Chapter Four.

The results that were derived from the UCD sessions covered two aspects: (1) the barriers participants with mild ID face when attending primary care consultations, including the strategies used to mitigate some of these barriers; and (2) the potential use of tablets to support patients to communicate symptoms to GPs. As such, this module reinforced the findings of the scoping review - thereby formulating a complete response to research question one (see section 1.3) - in addition to partially answering research question two. The initial prototype was then updated to include the additional design requirements identified by the participants with mild ID, prior to an evaluation with three separate populations: paid/non-paid caregivers; GPs; and experts in usability/ID. This evaluation ensured that the application meets the needs of the primary stakeholders involved in the consultation process (as opposed to the sub-group of participants with ID involved in the design sessions), thereby formulating an answer to research question two. The specific methods used to complete each of the research modules will be described in the relevant chapters.

2.1.4 User Centred Design

As discussed in section 2.1.3, the principles of user centred design also had an influence on the work conducted throughout this thesis. UCD is a methodology that places the satisfaction of stakeholders needs at the heart of the design process [58], thereby complementing the goals of the “Development” phase in the framework for complex interventions [50]. ISO 9241-210 [59] lists the main objectives that need to be fulfilled when adhering to the principles of UCD:

1. Understanding and specifying the context of use.
2. Specifying the user and organisational requirements.
3. Producing design solutions.
4. Evaluating these designs against the requirements.

Such objectives should be iterated until all stakeholder requirements are satisfied (see Fig 2.3), yet implementers have the added flexibility of changing their order and/or the amount of effort put into each, based on the context of the design [59]. Prototypes should also be introduced early in the design process to assist stakeholders in determining whether their requirements are being met, before updating such artifacts as necessary [58].

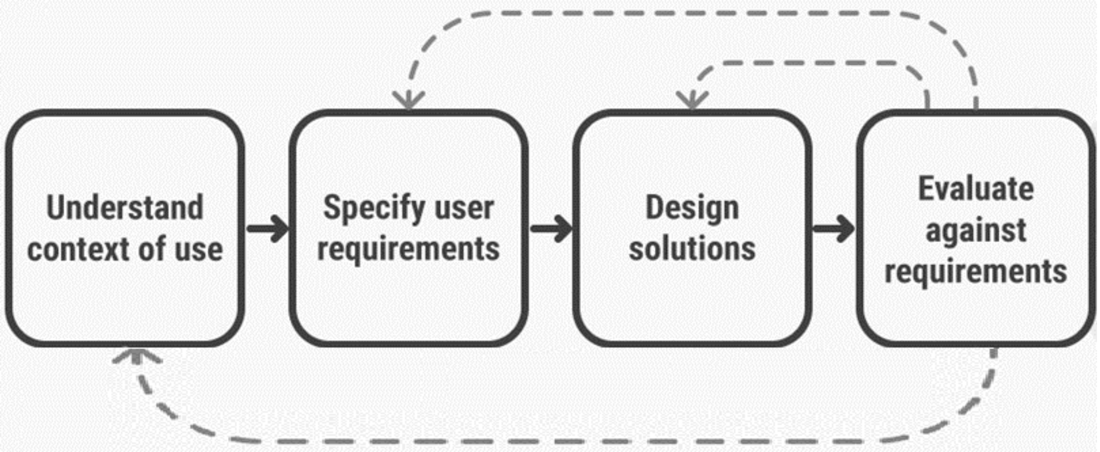

Fig. 2.3: User Centred Design Process.

The initial phase (understanding and specifying the context of use) ties in with the scoping review highlighted in Fig. 2.2. Communication was identified as a significant health inequality that may be alleviated by mobile technologies, yet there was a gap in the availability of high-tech, two-way communication aids throughout primary care. During the design workshops (module three in Fig. 2.2), patients with mild ID were encouraged to consider how they would use such an aid, which resulted in a preliminary set of design requirements. Embedded within this process was a high-tech prototype, based on the views of both experts in ID and ID nurses, to support the participants in discussing their own needs [53, 54]. This prototype was updated to reflect the patients' requirements and subsequently presented to experts, GPs, and caregivers for evaluation. As such, the final design addresses the requirements and needs of the primary stakeholders, including patients with mild ID, GPs, caregivers, and ID nurses.

2.1.5 Alternative Methods

Action research [60] is a non-clinical, alternative framework that may have been utilised to shape the design of the proposed application. Its main principles are similar to that of the framework for complex interventions, with emphasis being placed on the generation of evidence as to how the system/product can modify current practice. Like UCD, stakeholders views are placed at the heart of this evidence, with the overall process being iterative to support in the generation, validation and modification of knowledge as the project progresses [60]. The five stages involved in action research are shown in Fig. 2.4.

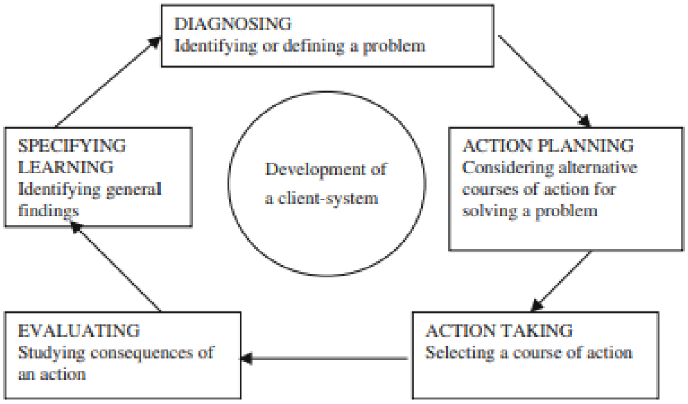

Fig. 2.4: Five stages involved in the iterative action research framework [60].

The first stage "Diagnosing" consists of identifying a problem in current practice and is therefore similar to the first sub-step in the framework for complex interventions. In stage two, "Action Planning", the investigators must determine how new technologies can have a positive impact on current practice, before settling on a specific approach in stage three. Stage four equates to the "Evaluation" phase of the framework for complex interventions [50] and focuses on recognising the true benefits of the technology as it is implemented in current practice. Stage five concludes with the dissemination of the findings recognised previously. Ultimately, the framework for complex interventions was selected for use within this thesis due to its added focus on (and acceptance within) the clinical domain.

2.2 Stakeholder Characteristics

The populations that may benefit from the proposed app were formally defined throughout the completion of the framework for complex interventions "Development" phase [50]. Their characteristics will now be described via the use of personas [51, 61, 62], in addition to the World Health Organisation's (WHO) interpretation of ID. Empathy maps [52] have also been presented to highlight the potential pain points experienced by the stakeholders during consultations that may be alleviated by the proposed application.

2.2.1 Formal Definition of Mild Intellectual Disability

As per WHO, the term "intellectual disability" is referred to using the following definition [63]: *"[an individual with ID must have] 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."*

Nevertheless, intellectual disabilities can manifest themselves via a range of aetiologies and severities, each of which have a differing impact on an individual's ability to conduct everyday tasks [64]. For example, people with mild ID are generally able to live independently but may struggle to complete complex tasks (such as describing medical conditions) without support. In contrast, people with more severe ID tend to require some sort of supervision at all times. This thesis focuses on adults with mild ID under the assumption that such a population is more likely to be in charge of their own healthcare and are able to use accessible technologies autonomously. Previous literature has suggested that caregivers (both paid and unpaid) can become overinvolved in the healthcare decisions regarding people with ID, which may lead to actions that do not meet the views or needs of the patient [24, 65]. The application can therefore overcome this barrier by improving the communication skills of people with mild ID, thus reducing the opportunity for caregivers to assert their own opinions on the consultation.

It is important to note that in the United Kingdom, intellectual disabilities are more commonly referred to using the term “learning disability.” Yet due to the ambiguous meaning of “learning disability” throughout the world – e.g. in America learning difficulties such as attention deficit hyperactivity disorder and dyslexia are grouped under this heading [66] – the author made the decision to implement the most widely used phrase throughout this thesis.

2.2.2 Personas of Target Stakeholders

Personas [51, 61, 62] are a common tool utilised by Human-Computer Interaction (HCI) practitioners to formally define the characteristics of target stakeholders. As such, they support developers to conduct design decisions based on a collective understanding of who their users are, including potential behavioural traits and accessibility needs. Typically, personas are created using data compiled from a variety of sources such as previous literature, ethnography, and interviews with users [62], yet assumptions may still be required in circumstances where relevant data is unavailable [51, 62]. They are usually developed at the beginning of a project and continue to be updated when new information is obtained [51, 62]. Consequently, the following six personas emerged from the findings of the scoping review described in Chapter Three. They were then validated by the participants involved in the application’s design and evaluation phases (see Chapter’s Five and Seven respectively) and subsequently updated to match the views of patients, GPs, and caregivers. It is important to present the personas at this stage in the thesis to allow the reader to envisage the populations that may benefit from the proposed clinical AAC application.

2.2.2.1 The Patient

Table 2.1 (presented in a similar style to Turner et al. [61]) includes a description of the traits and characteristics of a patient with mild ID, focusing on their condition, intellectual ability, social and interaction skills, medical needs and experience with technology:

Table 2.1: Persona of patients with mild ID.

	 **Jane, patient, 18** Image Source: flickr.com[1]
Condition	Jane has mild ID which affects her ability to live independently and learn and apply new skills. She also experiences an additional disorder, Downs Syndrome (DS), which often co-occurs with ID [12].
Intellectual ability	Jane's IQ is somewhere between 60 and 70. In contrast to the bulk of people with mild ID, Jane was enrolled in a segregated institution. Her overall intellect is less than that of the general population, but she can become knowledgeable in topics that are of particular interest to her. Nevertheless, Jane has a poor understanding of the human body, which affects her ability to recognise the symptoms of, and subsequently communicate about, medical conditions. Finally, her ability to learn new skills and take in unfamiliar information is significantly impeded, meaning she may not be able to understand complex information presented by medical professionals.
Social Skills	Jane is able to complete general tasks, such as cleaning, without support. Yet she requires assistance when conducting tasks that are new to her (e.g. using public transport to travel to a different location) or are complex. Jane is also able to communicate effectively with familiar partners, providing they are discussing a topic in which she is knowledgeable. However, she is less willing to converse with strangers or discuss a topic that is complex. Her receptive skills are generally better than her expressive; nevertheless, she will find it difficult to understand information that contains inaccessible language or is presented too quickly.
Interaction Skills	Jane is able to express herself verbally given the correct circumstances (see social skills). As such, she does not have a need for alternative communication aids that replace her speech entirely. However, she could benefit from augmentative aids, e.g. patient passports [38, 67], to enhance her communication skills in times of need.
Physical and medical needs	Jane has additional physical needs in the form of visual and hearing impairments and poor fine motor skills. Her medical history is typically larger than the average patients since she is more prone to developing medical conditions than the general population. As such, Jane prefers to visit the same GP when available, since they are more familiar with her health and communication requirements.
Experience with Technology	Jane owns an older model smartphone and is able to conduct a variety of complex and simple operations such as text messaging and browsing the web / social media. As such, she is familiar with touchscreen interaction procedures such as tapping, pinching, swiping etc. In addition, with the help of a caregiver, Jane has manged to adjust the default settings in her phone to meet her accessibility needs.

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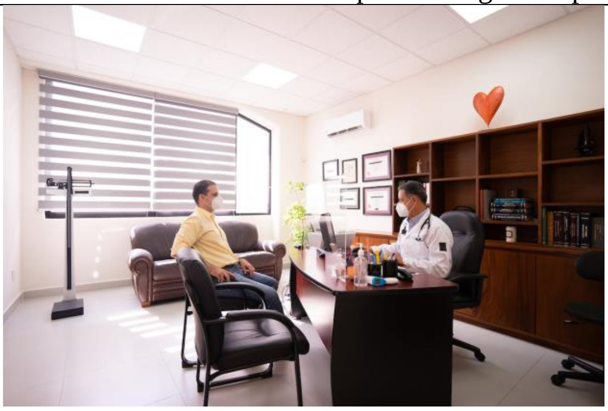
[1] https://www.flickr.com/photos/surreynews/9566922189

2.2.2.2 The General Practitioner / Primary Care Physician

The following two tables include the characteristics of GPs who are responsible for conducting consultations with adults with mild ID. Both an experienced and inexperienced GP has been presented to allow the reader to envision how the app is beneficial for a range of medical professionals.

Table 2.2: Persona for an experienced general practitioner.

	 **John, GP, 55** Image Source: pexels.com[2]
Experience	John has over 25 years' experience as a GP and works in an urban practice. He treats a couple of patients per week that are included in the practice's ID register, yet there are likely further patients who have a "hidden" disability. Through consistent engagement with this population, John feels comfortable interacting with patients who have milder ID. Yet, he still finds it difficult to treat patients with severe ID without support from caregivers and specialised professionals.
Education	John received no education on how to effectively treat people with ID during his studies. His knowledge increased via on-the-job experiences with this population and through discussion with colleagues. In recent years, John has been offered the opportunity to attend out of hours and on-site training sessions on ID, yet his motivation to attend these sessions has been low due to his previous experience and excessive workload. He is aware of some of the more general guidelines on how to treat patients with ID (such as the use of double appointments) but does not keep up to date with this information. Finally, his knowledge on the health trends of the ID population is limited to the conditions commonly experienced by his own patients, which may result in the overshadowing of others.
Interaction Skills	John's vast experience with patients with ID has helped him to develop the skills necessary to conduct a range of reasonable adjustments. These adjustments may include aspects such as: employing multiple interaction modalities to present information; utilising plain language; allowing the patient to proceed at their own pace; and having a limited reliance on caregivers. Naturally, John finds it easier to interact with patients he is familiar with and relies more on information from caregivers when treating new patients.
Familiarity	John is often the patient's primary physician and once a rapport has been established, he is able to adjust his consultation techniques to meet the individual's communication and healthcare needs, thereby providing improved, person-centred care. Nevertheless, John also has to treat patients he is less familiar with (e.g. when covering for a colleague or a new patient has registered) and could benefit from technological or caregiver support during such occasions.

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[2] https://www.pexels.com/photo/a-patient-at-a-doctor-s-office-8460095/

Experience with Technology	Touch screen technologies are becoming a part of everyday practice for medical professionals, meaning John should be well-rehearsed in using such devices. Nevertheless, AAC technologies are not commonly used in the clinical domain, and as such, he will require time to adjust to these devices.

Table 2.3: Persona for an inexperienced general practitioner.

	 **Jade, GP, 30** Image Source: pexels.com[3]
Experience	Jade is a newly qualified GP working in a rural area. She comes into contact with only a few patients with ID a month, whilst there is a limited number of individuals listed in their practice's ID register. Jade is not yet confident treating patients with ID due to her lack of education and experience in doing so. As such, she is overly reliant on caregivers to facilitate the consultation.
Education	Jade received more training on ID than John during their undergraduate and postgraduate studies. Nevertheless, she has significant gaps in her knowledge, which affects her ability to conduct person-centred care. Such gaps will primarily be alleviated via on-the job experience, with the possibility to enrol in on-site and out of hours training where possible. Jade is more likely to attend these training sessions due to her inexperience and less hectic schedule. She does not apply the recommended treatment guidelines consistently and is more prone to overshadowing the common conditions experienced by people with ID due to her ignorance of such health trends.
Interaction Skills	Jade is unaware of the range of reasonable adjustments required to treat patients with ID. Some of the common barriers to effective care conducted by her include: utilising inaccessible or potentially condescending language; adhering to strict time limits, thereby not allowing enough time for the patient to formulate a response to queries; over relying on speech to communicate; and interacting primarily with the caregiver as opposed to the patient. These barriers effect the depth and accuracy of information extracted from the patient.
Familiarity	Once again, Jade will be responsible for treating patients she sees regularly, as well as those who may be a one off. Yet due to her inexperience, building a rapport does not necessarily transition into the ability to provide person-centred care. As such, Jade may benefit more from technological / caregiver support than John, particularly during challenging consultations.
Experience with Technology	Jade is also familiar with touch screen technologies but has not come across AAC aids during her education. Consequently, she will need time to adjust to such devices and could benefit from further training.

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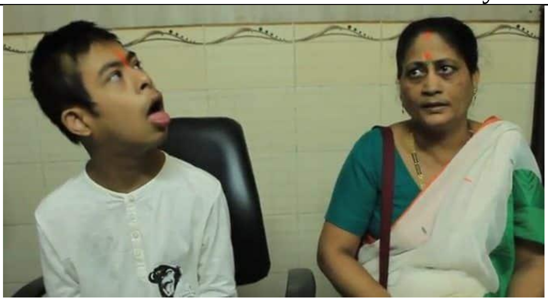
[3] https://www.pexels.com/photo/people-woman-sitting-technology-7089401/

2.2.2.3 The Caregiver

Tables 2.4 and 2.5 detail the characteristics of a family and paid caregiver respectively, thus highlighting the range of support available to patients with ID.

Table 2.4: Persona for a family caregiver.

	 **Juni, Caregiver, 48** Image Source: thehealthsite.com[4]
Relationship	Juni is the patient's mother and therefore cares deeply for the individual. She is fully aware of their needs and abilities and is able to pick up on the medical symptoms the patient experiences at home. In addition, Juni is familiar with her son's history as she assists him with his healthcare.
Interaction Skills	Juni's primary role is to support the patient throughout the entirety of the consultation process, beginning with the preparation for an appointment. She uses methods such as role play to ensure the individual with ID is well-rehearsed on the aspects they wish to communicate to the GP. Juni also steps in to mitigate any communication barriers that arise during the consultation by translating complex or unfamiliar language into a format understood by all stakeholders. In addition, she is able to recognise signs of response bias within the answers provided and therefore correct them to better match the life experiences of the patient. However, Juni can become overinvolved in the consultation, particularly when the GP is finding it difficult to communicate with the patient. As such, she sometimes provides her own views, which could lead to less accurate information being extracted.
Experience with Technology	Juni is not experienced in utilising touchscreen technologies, meaning she is unable to provide support when her son is interacting with the application.

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[4] https://www.thehealthsite.com/news/stem-cells-promises-hope-for-downs-syndrome-treatment-d0317-479022/

Table 2.5: Persona for a paid caregiver.

	 **Jamie, Caregiver, 30** Image Source: pexels.com[5]
Relationship	Jamie is a newly employed caregiver, who looks after the patient a few times a week. They have not had the time to establish a relationship with the patient, meaning they are unaware of their specific needs and medical history.
Interaction Skills	Jamie's role is to support the patient during the day. Depending on their shift pattern, this may or may not include prepping them for the consultation by using similar techniques as Juni. Since Jamie is not familiar with the interaction and health needs of the patient, they may have less of an impact in facilitating the consultation. Yet their training and past experience with other individuals with ID can help them to overcome this barrier. Jamie is also less likely to assert their own views as they are not yet accustomed to the patient's healthcare needs.
Experience with Technology	Jamie owns and regularly uses computing technologies and is therefore able to support the patient to interact with the application.

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[5] https://www.pexels.com/photo/happy-young-people-watching-on-a-laptop-4058223/

2.2.2.4 The Intellectual Disability Nurse

Table 2.6 illustrates a persona of an ID nurse. The aspects described are similar to the GPs, yet Jillian has more training and experience working with the ID population.

Table 2.6: Persona for ID Nurses.

	 **Jillian, ID Nurse, 21** Image Source: publicdomainpictures.net[6]
Experience	Jillian is well experienced in interacting with people with ID due to her training and almost daily contact with this population. Furthermore, her ability to adapt to the heterogeneity of people with ID should increase as she gains more experience.
Role	Jillian's main role within primary care is to conduct the patient's annual ID health check, which involves various preventive measures to identify common conditions early. She may also take part in the patient's consultation with the GP; however, this is to provide on-site training as opposed to administering treatment. Finally, Jillian also conducts care in the community, thus carrying out tasks such as: assessing, planning, and revising care requirements; providing education on healthy lifestyle choices; and offering support to the patient's family members, amongst others.
Education	Jillian is well educated on the communication and healthcare needs of people with ID. As such, she is more capable of adapting her consultation techniques to meet the specific needs of a wide range of patients with ID. In addition, she is able to recognise the symptoms of common conditions, as opposed to overshadowing them. Finally, Jillian is knowledgeable on the pathways available to patients with ID, thus assisting them to access optimal care.
Interaction Skills	As discussed previously, Jillian possesses the knowledge required to adjust her consultation techniques to meet the needs of patients with mild ID. This includes aspects such as: implementing accessible language; presenting information at a steady pace, whilst allowing time for the individual to respond; interacting directly with the patient as opposed to their caregiver; utilising communication modalities other than speech; and adapting to a variety of AAC technologies. Thus, Jillian is able to extract more representative information than both John and Jade.
Familiarity	Jillian's familiarity with her patients differs greatly depending on her role. For example, if she is responsible for conducting the annual ID health check, she will only see the patient once a year, yet this frequency improves drastically if she conducts care in the community. Nevertheless, her education on ID assists in mitigating any barriers that arise from lack of contact with the patient.
Experience with Technology	Jillian is familiar with a range of AAC technologies utilised by patients with ID, from general purpose smartphone applications to more specialised devices. As such, she should be able to adapt to the technologies being brought in externally by the patients.

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[6] https://www.publicdomainpictures.net/en/view-image.php?image=247244&picture=young-nurse

2.2.3 Empathy Maps

Empathy mapping [52] is another tool utilised by HCI professionals to formally capture knowledge about an individual's behaviours. They allow research teams / developers to form a deeper understanding of their stakeholders needs and can serve as a bridge between the aforementioned personas and the final deliverable. As with personas, empathy maps are traditionally developed via research data derived from the target stakeholders. Consequently, the following three maps incorporate the views of the patients, caregivers and GPs involved in Chapters Five and Seven. They include: Jane who is suffering from gallstones and is finding it difficult to describe her symptoms clearly; James, a newly employed caregiver who is not quite familiar with the needs of Jane; and Jade, an inexperienced GP who is consulting with Jane for the first time. An empathy map for an ID nurse was not developed as her primary role in a standard consultation is to educate the GP (see above).

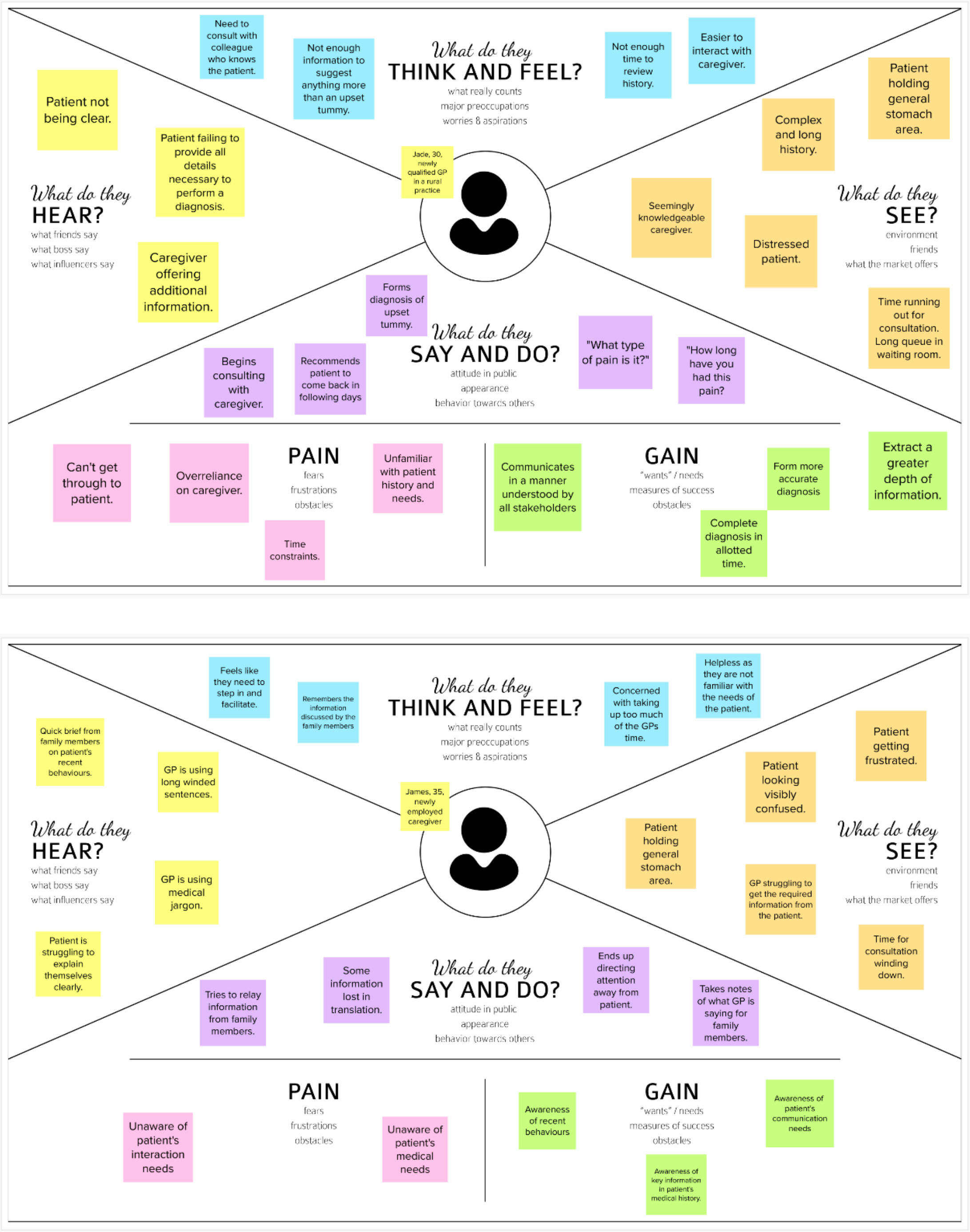

Fig. 2.5: Empathy maps for patients, caregivers, and GPs.

2.3 Conclusion

This Chapter described the overarching methodology used to develop a prototype of the proposed AAC application, which assisted in answering the research questions outlined in section 1.3. The MRC's framework for complex interventions [50] was identified as the most appropriate tool for use due to: (1) its wide acceptance throughout the clinical domain; (2) the emphasis placed on the collection of evidence; and (3) its flexibility, which enables developed solutions to be evaluated at multiple points throughout a project and subsequently updated based on the feedback received. Stage one, “Development”, [50] was the primary focus of this thesis and was supported by UCD to establish an evidence base for the application, including stakeholders views on how it may fit into and improve current practice. Finally, such stakeholders were introduced to ensure the reader has a clear impression of the populations that may benefit from this work. The next Chapter focuses on demonstrating a need for the proposed application by reviewing existing AAC technologies implemented within the clinical domain.

Chapter 3: Systematic Scoping Review of Existing AAC Technologies

The purpose of the upcoming scoping review is to provide the reader with an overview of the literature, whilst fulfilling the first sub-stage of the framework for complex interventions – see Fig. 3.1. Synthesising the evidence on existing technologies enables shortcomings in current practice to be identified, thus establishing a basis for the introduction of novel interventions. In addition, the lessons learned from previous literature can help to influence the design of the proposed tablet application by highlighting barriers and facilitators to the implementation of AAC technologies in the clinical domain. Consequently, this chapter formulates a partial response to the first research question proposed in section 1.3. A more holistic answer is provided in Chapter Five, which includes a discussion on the AAC technologies utilised by the participants involved in the applications design.

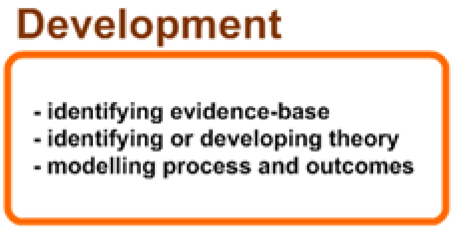

Fig. 3.1: Development phase of the framework for complex interventions.

3.1 Methods

Prior to the commencement of this thesis, the author was only able to identify one review focusing on the health literacy skills of people with ID [68]. Nevertheless, Chinn's study primarily centred on non-technical forms of support such as health-related training sessions [68]. Thus, the decision was made to conduct a novel review of the technologies and modalities used to promote communication between adult patients with mild ID and health professionals. A scoping methodology was ultimately selected based on its flexibility since it was not possible to conduct a systematic review due to the lack of a second researcher during the study selection phase. Both primary care and secondary care environments were taken into consideration to ensure interventions that have the potential to be implemented by GPs were also reviewed.

This sub-section describes the methods used during the identification and subsequent analysis of relevant literature.

3.1.1 Scoping Review Research Question

The aim of the review is to identify and synthesise the range of technologies and modalities used to promote communication between patients with mild ID and health professionals. As such, the research question underpinning this Chapter is similar to RQ1 in section 1.3: **"What technologies are being used to support adults with mild intellectual disabilities to communicate more effectively with medical practitioners?"**

In addition to the above research question, the scoping review also has the following objectives:

Sub-objective one: To determine the manner in which the identified aids were being utilised by patients with mild ID and medical professionals.

Sub-objective two: To determine the manner in which the benefits of the aids were evaluated.

3.1.2 Scoping Review Methodology

Arksey and O'Malley [69] present four common scenarios where scoping reviews are an appropriate methodology to employ, two of which align to the study objectives: (1) examining the extent, range and nature of research activity within a domain; and (2) identifying research gaps within existing literature. As such, their framework [69] was used to map rapidly the key concepts within the target domain, which consisted of the following five flexible steps:

- Research question formulation.
- Identifying relevant studies.
- Study Selecting.
- Charting the data.
- Collating, summarising, and reporting the results.

3.1.3 Overview of Search Strategy

In order to conduct a holistic search that included technological, socio-technical and disability focused communication studies, three databases were queried (PubMed, ACM Digital Library and Google Scholar) using the terms found in Table 3.1. These phrases were based on Medical Subject Headings (MeSH) relating to communication, ID, and clinical consultations, in conjunction with a variety of AAC technologies. In all, 15 queries were carried out, resulting in the identification of n=1737 articles published prior to November 2019: n=747 from PubMed; n=140 from ACM; and n=850 from Google Scholar. Separate queries were used per database due to their differing scope. For example, it was not appropriate to search for Talking Mats™ or patient passports in the ACM database since the articles returned primarily focus on high-tech interventions such as mobile applications.

Table 3.1: Search queries & search terms.

Database	**Search Query or Search Terms**
PubMed	**Query 1:** (("intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields]) AND ("communication"[MeSH Terms] OR "communication"[All Fields])) AND ("referral and consultation"[MeSH Terms] OR ("referral"[All Fields] AND "consultation"[All Fields]) OR "referral and consultation"[All Fields] OR "consultations"[All Fields]) **Query 2:** ((Alternative[All Fields] AND Augmentative[All Fields] AND ("communication"[MeSH Terms] OR "communication"[All Fields])) AND ("learning disorders"[MeSH Terms] OR ("learning"[All Fields] AND "disorders"[All Fields]) OR "learning disorders"[All Fields] OR ("learning"[All Fields] AND "disabilities"[All Fields]) OR "learning disabilities"[All Fields])) AND clinical[All Fields] **Query 3:** (("speech"[MeSH Terms] OR "speech"[All Fields] OR "talking"[All Fields]) AND "mats"[All Fields])) AND clinical[All Fields] **Query 4:** (alternative[All Fields] AND augmentative[All Fields] AND ("communication"[MeSH Terms] OR "communication"[All Fields])) AND clinical[All Fields] **Query 5:** (("communication"[MeSH Terms] OR "communication"[All Fields] OR ("personal"[All Fields] AND "communication"[All Fields]) OR "personal communication"[All Fields]) AND passports[All Fields]) AND clinical[All Fields] **Query 6:** (pictures[All Fields] OR images[All Fields] OR graphics[All Fields]) AND clinical[All Fields] AND ((intellectual[All Fields] OR ("learning"[MeSH Terms] OR "learning"[All Fields])) AND disabilities[All Fields])

	Query 7: (("communication"[MeSH Terms] OR "communication"[All Fields]) AND ((("learning"[MeSH Terms] OR "learning"[All Fields]) OR intellectual[All Fields]) AND disabilities[All Fields])) AND clinical[All Fields]
ACM Digital Library	**Query 1:** ((“intellectual” AND disability”) AND communication) AND consultations **Query 2:** (“Alternative” AND “Augmentative” AND “Communication”) AND (“Learning” AND “Disabilities”) AND “clinical” **Query 3:** (pictures images graphics "clinical" disabilities) AND recordAbstract:(+intellectual +learning)
Google Scholar	**Query 1:** ((“intellectual” AND “disability”) AND “communication”) AND “consultations” **Query 2:** ((“Alternative” AND “Augmentative” AND “communication”)) AND “learning disabilities”) AND “clinical”) **Query 3:** (“Talking” AND “Mats”) AND (“learning” AND “disabilities”) AND “clinical” **Query 4:** ("personal” AND “communication” AND “passports") AND (“learning” AND “disabilities”) AND “clinical” **Query 5:** allintitle: “clinical” AND “disabilities” AND “pictures” OR “images” OR "graphics” OR “intellectual” OR “learning”

PubMed was selected due to its focus on medical studies, including those that discuss the implementation of interventions. Each of the unique articles retrieved from PubMed had their titles and abstracts screened against the inclusion/exclusion criteria described in the next sub-section. Potentially relevant articles were then read in their entirety to identify those that adhered to the selection criteria, with more obscure articles also being analysed by a second researcher prior to their inclusion/omission. Areas of conflict between the investigators were resolved by a third researcher.

ACM was identified due to its focus on technology, particularly articles centring on the development of AAC aids. In addition, the literature returned by ACM does not overlap with that identified by PubMed, which increases the comprehensiveness of the search. Relevant articles were then chosen using the same process as above.

Google Scholar was selected as it is often used to supplement evidence searches by returning relevant articles that are catalogued in databases outwith those originally queried [70]. Google Scholar is also useful in identifying grey literature, which is considered relevant in scoping reviews providing the articles meet the defined inclusion criteria. Researchers often limit their queries to the first 50-100 articles [70] since, as a ranked retrieval system, the relevance of the literature diminishes as the search progresses. However, this limit was increased to 200 based on the following procedure. Search results for query one (see Table 3.1) were split into groups of 50. The first batch of 50 was then screened (using the same process as the previous databases), with the investigators moving on to the next batch only if a potentially relevant article was identified via its abstract; otherwise, the search was terminated. This procedure was repeated for queries two to five, with the highest batch number being used as a limit for all the Google Scholar searches. To elaborate, a relevant article was identified on the third batch of the second query, meaning the first 200 results of the other queries were scrutinised where possible. Nevertheless, some of the searches returned less than 200 articles meaning all were scrutinised, since the N size fell below the defined limit.

Finally, the articles deemed relevant had their reference lists screened using the same two-stage process described above. Yet only those that progressed to full-text screening are included in the statistics shown in Fig. 3.2.

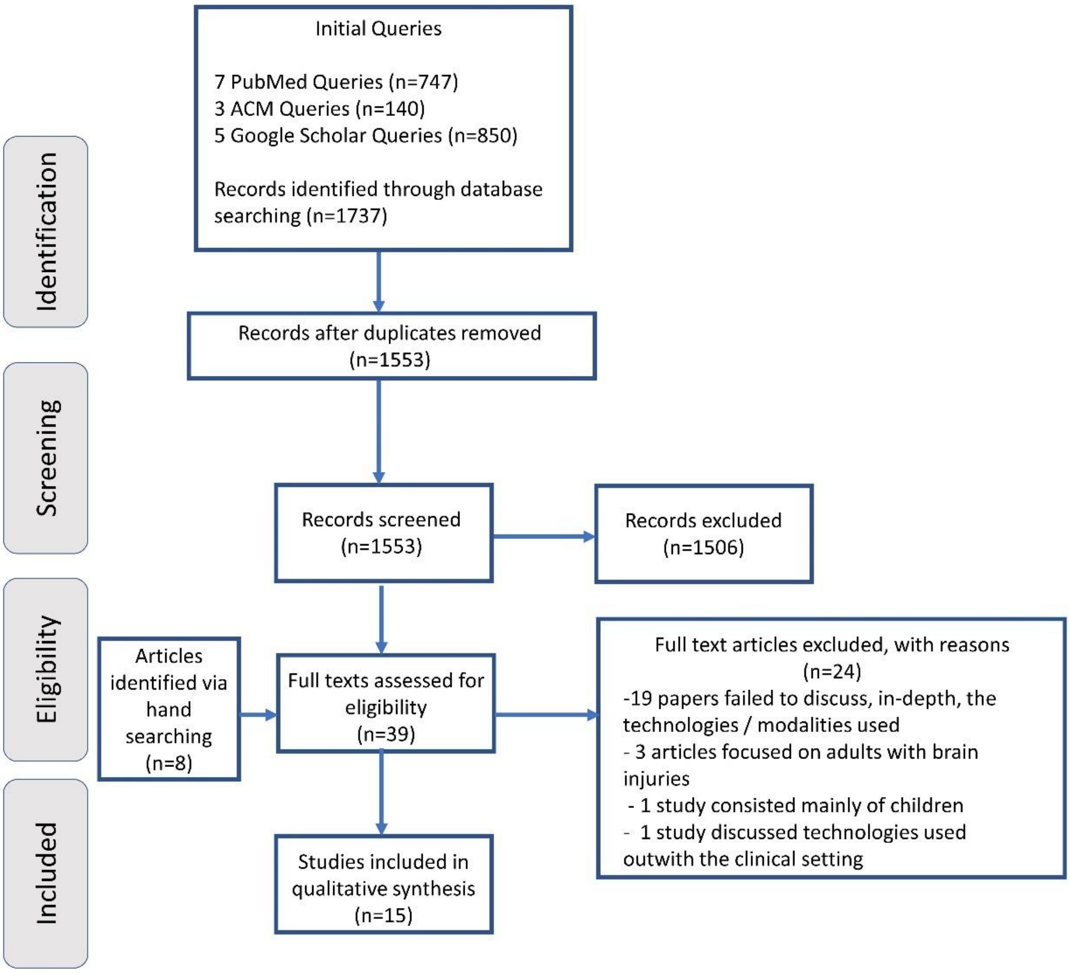

Fig. 3.2: PRISMA flow-chart of systematic scoping review.

Fig. 3.2 contains a PRISMA flow diagram [71] detailing the steps involved in identifying relevant articles. Such articles were then subjected to a qualitative framework-based analysis to synthesise the results and determine key recurrent themes (see section “Analysis”).

3.1.4 Inclusion Criteria

The review was restricted to literature that discussed the use of technology to promote communication between patients with mild ID and health professionals. Table 3.2 describes the inclusion criteria used to screen relevant articles, which was based on the PICOS search tool [72].

Table 3.2: Inclusion criteria for relevant articles.

Criteria	**Description**
Participants	Adults aged 18 or over who have mild or moderate intellectual disabilities and health professionals. Studies were also included where little information on the participants ID was provided. WHO's definition of ID [63] was used, which therefore rules out conditions linked to cognitive decline due to ageing or other neurological disorders acquired later in life e.g. dementia. Participants with physical disabilities (e.g. cerebral palsy) and no accompanying cognitive impairments were also excluded.
Interventions	A range of communication modalities or technologies used to promote the exchange of information between patients with mild ID and health professionals. Both low-tech and high-tech aids were considered relevant (see "Technological Aids"). Clinical studies with no focus on communication and those centring on the evaluation of aids used to manage a specific condition were excluded.
Comparator	The review was not limited to comparator studies.
Outcomes	Qualitative and quantitative data reporting the effects of communication aids / modalities on clinical consultations involving adult patients with mild ID.
Study Type	Primary studies only were considered relevant in this review.

Articles were also excluded if they were deemed to be of low quality by any of the investigators. This was assessed using the following three characteristics based on the aspects identified by Alborz et al. [11]:

- clarity of research questions/goals;
- appropriateness of the methods employed in relation to the research questions;
- and consideration of study limitations.

N size is often used as a proxy for the quality of a study; however, it was not considered to be appropriate for article exclusion due to interest in the development of technologies, as well as their implementation.

3.1.5 Study Selection

As shown in Fig. 3.2, a total of n=15 articles met the inclusion criteria. Of the initial 1553 articles that had their abstracts screened, 1514 were immediately excluded from the review. Consequently, 39 were read in their entirety, of which n=15 were deemed appropriate to include in the review. 20 were excluded as they did not fit the intervention inclusion criteria and a further four were excluded since they failed to meet the participant inclusion criteria.

3.1.6 Data Charting

To extract relevant information from the identified studies, a data-charting form was jointly developed with an additional investigator. The characteristics within this form were similar to those proposed by Arksey and O'Malley [69] and included: author(s); year of publication; study location; study aim; intervention; study design; populations; and key results. The same investigators independently charted the data and discussed their conclusions, with a further researcher on hand to resolve any discrepancies. A summary of the charted data may be found in Appendix A.

3.1.7 Analysis

A deductive, framework-based analysis [73] was used to synthesise the charted data. An initial thematic model capable of answering the study objectives was developed using the communication barriers/facilitators discussed within other reviews [21, 74]. This model was then discussed by the investigators introduced previously and agreed via a consensus. The framework was then applied to a subset of the articles (consisting of one study per distinct AAC aid identified) and subsequently extended where necessary, under the guidance of Gale et al. [73], to include important aspects of the data that did not immediately adhere to the original concepts. To limit bias, Gale et al. [73] also suggest that researchers must come to a consensus on the coding applied to at least the first few transcripts. As such, the additional investigators reviewed the tagged data, with any discrepancies being resolved. The remaining articles were then analysed using this framework, with additional sub-themes being created as required. The two additional investigators were consulted on the creation of new tags to ensure they were necessary and did not align with the other concepts. The final revised thematic framework may be found using the following DOI:10.15129/343da1f8-593e-4f6b-a406-72314f54884b and a summary of the themes is provided in Table 3.3.

Table 3.3: Overview of the themes that emerged throughout the scoping review.

Theme	**Summary**
Communication Barrier / Facilitators	This theme addresses the various practices that have an adverse or positive impact on information exchanges between medical professionals and patients with mild intellectual disabilities. This covers aspects such as: organisational procedures; fragmentation of care; education and training opportunities; and person-centred care.
Technological Aids	This theme identifies the various forms of communication aids used by patients / practitioners during clinical consultations and has been split into two primary sub-themes: paper-based technologies; and more complex digital technologies. An overview of the features included within each aid is provided.
Communication Modalities	This theme introduces the communication modalities employed throughout the aids, including the benefits and drawbacks of each. It also highlights the need for technologies to be adaptive due to the wide range of skills and requirements experienced by people with ID, meaning a one size fits all approach is unsuitable.
Evaluation and Impact	This theme discusses the various qualitative and quantitative methods utilised within the identified studies. It also introduces the perceived impact of the communication aids under scrutiny.

3.2 Results

In this subsection, the general characteristics of the identified studies will be presented prior to the results of the framework-based thematic analysis. An in-depth description of the relevant studies may be found in Appendix A, with a check-list summary provided in Table 3.4.

Table 3.4: Overview of the identified studies.

	Complexity		**Modalities**			**Participants**		**Evaluation**	
	High-tech	Low-tech	Text	Imagery	Speech	Mainly people with ID	Mainly other populations	Qual	Quant
Jones & Kerr (1997) [41] Paper-based checklist		☑	☑			☑			☑
Dodd & Brunker 1999 [65] Image cards		☑	☑	☑		☑		☑	
Lennox et al. (2001) [75] CHAP		☑	☑			☑		☑	
Lennox et al. (2004) [76] Health diary		☑	☑	☑			☑	☑	
Bell & Cameron (2008) [77] Talking Mats		☑	☑	☑		☑		☑	

Lennox et al. (2010) [78] CHAP & Health diary		☑	☑	☑		☑			☑
Turk et al. (2010) [79] Handheld health record		☑	☑			☑			☑
Brodrick et al. (2011) [67] Patient passport		☑	☑				☑	☑	
Bell (2012) [17] Patient passport		☑	☑			☑		☑	
Heifetz & Lunsky (2018) [80] Patient passport		☑	☑				☑	☑	
Gibson et al. (2018) [32] Tablet app	☑		☑	☑	☑		☑	☑	
Gibson et al. (2019) [33]	☑		☑	☑	☑		☑	☑	
Gibson et al. (2019a) [49]	☑		☑	☑	☑		☑	☑	
Raemy & Paignon (2019) [18] Patient passport		☑	☑				☑	☑	
Chinn (2019) [81] Easy read health information		☑	☑	☑		☑	☑	☑	

3.2.1 Characteristics of the Relevant Articles

3.2.1.1 Publication

Of the 15 articles that met the inclusion criteria, nine were retrieved from PubMed [18, 33, 41, 49, 67, 75, 76, 80, 81], five from Google Scholar [17, 65, 77–79], and one from ACM [32]. Two (13.33%) were published in the 1990s [41, 65], three (20.00%) were published in the 2000s [75–77] and ten (66.67%) in the 2010s [17, 18, 32, 33, 49, 67, 78–81]. This highlights a substantial increase in the number of studies published on the focus of the review since the turn of the millennium, and is in line with the heightened awareness of the accessibility of services for people with ID e.g. [1, 82]. Yet, despite such an increase, Hemsley and Balandin's [21] study on the quality of communication between medical professionals and patients with severe communication disabilities concluded that the use of AAC in this context remains limited. Environmental barriers were cited as negatively affecting the implementation of AAC technologies, as was the knowledge of staff who find it difficult to adapt to such resources [21].

Furthermore, all studies identified during the data collection phase were carried out in countries that are members of the OECD (Organisation for Economic Cooperation and Development), with the majority centring on the healthcare infrastructures of the United Kingdom [17, 32, 33, 41, 49, 65, 67, 77, 79, 81] and Australia [75, 76, 78]. As such, the generalisability of the findings may be limited, particularly regarding the impact AAC technologies may have on patients with ID from non-OECD nations.

3.2.1.2 Participants Involved in the Design of AAC Technologies

Six of the articles described the design/development of an intervention to promote communication between adult patients with mild ID and health professionals [18, 32, 33, 49, 67, 76]. Surprisingly, target stakeholders were not heavily involved in the design process (despite increasing expectations on the use of co-design methodologies [83]), with investigators largely deferring to the views of other populations. For example, Lennox et al. [76] relied upon an "advisory group" (consisting of two individuals with ID, two support workers, two parents, two advocacy organisation representatives and an occupational therapist) to develop a health diary for persons with ID. Their initial designs were then scrutinised, before implementation, by 101 people across 15 focus groups, yet health professionals (one GP and two psychologists) and patients with ID (eight individuals) were underrepresented during this process.

Both Brodrick et al. [67] and Raemy and Paignon [18] also followed the approach of utilising a multidisciplinary team to develop their respective interventions – a one page patient passport and an emergency admission sheet. Yet they failed to report the exact demographics of the members involved, meaning it was difficult to discern the influence people with ID had on the design processes implemented. This was particularly true in Brodrick et al's study [67] where it was unclear whether the ID population had any input on the passports design.

Finally, Gibson et al. [32, 33, 49] utilised a variety of experts in ID (researchers, support workers, health professionals and representatives from ID charities) to develop a technology probe of a clinical AAC application. The probe – described in section

1.1 – was developed for use in future UCD sessions involving participants with mild ID to ensure representative requirements for the proposed application are established. Consequently, the lessons disseminated by Gibson et al. [32, 33, 49] were premature and subject to change based on the views of target stakeholders - see Chapter Five.

3.2.1.3 Participants Involved in the Evaluation of an Intervention

In contrast, the majority of the studies focusing on the evaluation of an intervention had high involvement from patients with ID throughout [17, 41, 65, 75, 77–79, 81]. The only exceptions were: Heifetz and Lunsky's [80] evaluation of a health passport, in which the feedback questionnaire was completed by just three participants with ID compared to 25 family members/support workers; and Lennox et al's evaluation of the Comprehensive Health Assessment Program (CHAP) [75] where the views of practitioners were sought out exclusively. One study (Turk et al. [79]) reported that a high number of participants with ID (35/108, 32.4%) dropped out before completion. This was attributed to people with ID being more likely to refuse follow up interviews, as well as having a higher probability of changing GPs than the general population, meaning they were exempt from the study.

Despite people with ID being prevalent throughout the evaluations, just four of the articles offered concrete or partial statistics on the aetiology of their participants disability [41, 75, 78, 79]. As such, the author was unable to decipher the characteristics of n=375 of the n=530 participants with ID involved in the evaluation studies (70.75%). N=98 had Down Syndrome (18.48%) [41, 75, 78, 79], n=21 had Autism Spectrum Disorder (ASD) (3.96%) [79], n=16 had cerebral palsy (3.02%) [79] and n=11 were a result of other congenital factors, peri-natal birth problems or epilepsy[7] (2.08%) [79]. Lennox et al. [78] primarily measured the severity, but not the cause, of ID present in their participants and found that n=107 of their n=242 participants had mild/moderate ID (44.21%), n=62 had severe (26.52%) and n=73 were unknown (30.17%). Jones and Kerr [41] also followed the same approach with n=28 of their n=111 participants having mild/moderate ID (25.23%) and n=39 having severe (35.14%). Consequently, researchers must look to provide a consistent, in-

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[7] The author notes that cerebral palsy and epilepsy are not often a direct cause of intellectual disability but instead coincide with this condition. Nevertheless, they have been included to provide an accurate summary of the participant characteristics reported by the identified studies.

depth description of the populations targeted by their studies to increase the generalisability of their findings.

3.2.2 Thematic Analysis

3.2.2.1 Communication Barriers and Facilitators

Several of the studies performed qualitative investigations on the barriers/facilitators to effective communication between health professionals and patients with mild ID. Their findings primarily align with the wider literature, such as [8, 10, 11, 21, 22, 24, 84, 85], and have culminated in the following subthemes.

Organisational Barriers / Facilitators

Two studies [18, 41] suggested that a limited collation of healthcare data regarding ID was a major barrier to patients accessing effective services. Raemy and Paignon [18] noted that Switzerland is yet to implement a national policy regarding the health needs of people with intellectual or developmental disabilities. As a result, institutions are not expected to record the details of a patient's ID and may not have appropriate strategies in place to do so. Consequently, medical professionals are less likely to be aware of their patients' additional needs and thus fail to conduct the recommended reasonable adjustments (e.g. [86]) to their consultation methods. In addition, the recruitment pathways available to researchers are impacted considerably, as highlighted by Raemy and Paignon who were forced to identify participants via residential accommodations [18].

Jones and Kerr [41] also acknowledged that it may be difficult for institutions to recognise patients with more mild ID. Throughout their study, they expected to locate circa 150 registered patients with ID across five GP practices in the Southwest of Wales (based on national figures) yet could only identify 39. As such, there may be a hidden population of individuals with mild ID who are unable to receive the same benefits as those patients known to medical professionals.

Collaboration

In addition to the lack of guidance from national strategies, local healthcare infrastructures may impede collaboration between the medical professionals treating a patient with ID. Fragmentation of care was recognised in two of the articles [17, 80], stemming from a lack of coordination across faculties [17, 80] and between healthcare organisations and social care [80]. As such, people with ID are less likely to receive optimal care since they are more prone to developing comorbidities [87] that require treatment from a variety of specialists. Furthermore, patients might find it difficult to adapt to the procedures employed by separate institutions if they are not standardised.

In addition, Heifetz and Lunsky [80] noted that there may be some resistance to agencies moving away from their own practices and instead adopting common processes or tools, even if there are clear benefits of doing so. In such cases, it is important to establish a champion who is able to provide strong leadership in overseeing the adoption of the intervention, which may include: scheduling regular feedback meetings with stakeholders; and periodically reviewing the positive effect the intervention is having. This is particularly important during projects where the benefits are not immediately clear [80].

Time

Two studies highlighted the impact time constraints may have on consultations involving patients with ID [18, 65]. Dodd and Brunker [65] suggested that patients are often rushed to convey their health needs to practitioners, which is detrimental to people with ID due to the additional time required to process complex information and formulate an appropriate response [12]. Furthermore, a lack of time opens up the possibility of caregivers becoming overinvolved in the consultation to ensure all concerns are addressed. As such, the accuracy of the information provided may be significantly reduced - see section “Support”. Instead, caregivers should aim to remain in a purely supportive role and encourage patients to proceed at their own pace whilst interacting with a doctor [65]. Additionally, Raemy and Paignon [18] observed that time constraints prevented medical professionals from thoroughly exploring all possibilities of an individual’s condition. This included examining the patients often large and complex medical histories to gauge whether they have displayed similar symptoms in the past.

Education

As discussed previously, medical professionals tend not to be well educated on the health and communication needs of people with ID [14, 15]. Four of the identified studies discussed how this can have a negative impact on the quality of care being provided [17, 18, 32, 33]. First, Raemy and Paignon [18] suggested that a lack of knowledge regarding the health trends experienced by people with ID may result in the overshadowing of conditions (i.e. the association of a symptom with the disability itself, as opposed to some other disorder) and the poor coordination of care. Gibson et al. [32, 33] and Bell [17] also indicated that insufficient training could affect the ability of health professionals to perform reasonable adjustments, particularly when the exchange of information via verbal communication is not an option. Practitioners also complained that they were ill-equipped to overcome the challenging behaviours presented by patients with more severe ID [17].

Due to the shortcomings in undergraduate medical courses [14, 15], Bell [17], and Raemy and Paignon [18] called for the introduction of compulsory training sessions on how to effectively treat patients with ID. Bell suggested that this content should focus on the specific communication strategies employed by the ID population, including basic signing systems and the use of other modalities such as imagery [17]. Raemy and Paignon [18] developed a variety of educational resources in conjunction with people with ID to suit the specific needs and workloads of different health professionals. These resources (which ranged from a 15-minute educational session to a five-day training program) covered important aspects including: behavioural traits such as how patients express pain; common health conditions that affect the ID population; and appropriate communication strategies to ensure patients are involved in their healthcare decisions. There is also scope to explore whether training support workers and family members would also have an impact on the health of people with ID [18].

Support

The articles disagreed over the impact external support may have on consultations involving adults with ID. Turk et al. [79], Heifetz and Lunsky [80], Gibson et al. [32, 33] and Lennox et al. [76] recognised the important role caregivers play in empowering individuals with ID to provide their own views. This typically involves serving as a mediator between the patient and health professional to ensure both sets of stakeholders communicate in a manner that is understood by the other. In addition, they may be familiar with the patient's everyday needs and routines [76], which can assist in determining the optimal course of treatment for the individual with ID. The barriers that arise via the patient's impaired higher-order cognitive skills [12] (e.g. abstraction and short-term memory) may also be mitigated.

Nevertheless, the described benefits are largely dependent on the level of involvement a support worker has on the patient's life. For example, Gibson et al. [33], Turk et al. [79] and Heifetz and Lunsky [80] noted that some people with ID have to cope with everchanging support workers. As such, new staff may be unaware of the person's health history and specific communication needs, meaning they will have less of an impact on the consultation. Furthermore, there is a possibility that caregivers become overinvolved in the consultation and begin communicating on behalf of the patient – particularly when the GP is finding it difficult to interact with the individual with ID [65]. This could lead to a reduction in the accuracy of the information conveyed due to their own opinions differing from that of the patient. Finally, Raemy and Paignon [18] demonstrated the advantages of employing more specialised medical professionals to support frontline staff. Over the course of three years, an ID nurse provided on-site training to less educated professionals that improved the standard of care being provided to 1017 patients with ID.

Person-Centred Care

Lennox et al. [76] and Bell [17] noted that optimal care was administered by practitioners who went out of their way to meet a patients individual needs. This included simple adjustments like: allowing extra time for the individual to get across their views; being kind and empathetic towards a patient's situation; interacting directly with a patient rather than their caregiver; utilising appropriate communication strategies to ensure the patient understands the information conveyed; recognising that cognitive impairments may affect the patient's overall knowledge of the human body; and looking past a person's disability in order to treat them like a human-being.

Two strategies were discussed that may assist practitioners in carrying out such adjustments. First, medical professionals should be given access to the personal characteristics of their patient e.g. their preferred method of communicating the terms "yes" and "no." Second, patients should be encouraged to seek out appointments with the same medical professional, thus allowing a relationship to form over time [17, 76]. Consequently, practitioners can become increasingly aware of the specific needs of the individual with ID, yet Chinn [81] suggests this may be difficult for traditional medical professionals in comparison to ID nurses.

3.2.2.2 Technological Aids

In this section, the various technologies employed by the identified studies will be introduced using the following two classifications: low-tech communication aids; and high-tech communication aids. A low-tech aid is defined as a non-electronic tool, external to an individual's body, that assists the user in communicating a message to a relevant partner. In contrast, a high-tech aid is a complex electronic device that permits the storage and/or retrieval of messages, many of which are utilised during the formulation of speech output [88].

Low-Tech Communication Aids

Patient Passports

The bulk of the studies centring on low-tech communication aids utilised some sort of patient passport [17, 18, 67, 80]. Patient passports encapsulate an individual's characteristics to assist medical professionals in adjusting their consultations methods to provide consistent, person-centred care. They are typically short in length to allow relevant information to be accessed easily and may be maintained by all sets of stakeholders involved in a medical consultation e.g. clinicians, support workers, family members and the patient themselves. As such, they are likely to contain a range of perspectives on the optimal way to interact with a patient with ID, thus increasing the probability of doing so effectively.

The passports implemented shared common features but were often tailored to meet the requirements and infrastructures of the organisations they are employed in. This was demonstrated concretely by Heifetz and Lunsky [80] when developing passports for three institutions within the same catchment area in Ontario, Canada. Each institution requested a tool that differed in size (wallet sized vs. one full page double sided vs. four pages) and in visual appearance (plain written information vs. pictures to complement text). Yet all summarised information on the same aspects, including: the patient's medical history; their baseline behaviours e.g. potential triggers, communication strategies, or contingency plans for when the patient becomes agitated; and the emergency contact details of support workers and family members.

Brodrick et al. [67] and Bell [17] encapsulated similar details in their double sided and three page patient passports respectively. Nevertheless, they utilised colour to demonstrate the most relevant aspects required in a critical situation. For example, the medical needs of the patient (existing conditions, allergies etc.) was prioritised by both sets of authors, meaning this information was coded in red to signify its importance. Further information (e.g. the patient's environment or support needs) that was deemed to be relevant but not critical to the patient's care was coded in more neutral colours such as amber and green.

Raemy and Paignon [18] recognised that passports can only be effective if they accompany patients throughout the healthcare system – a process that may be difficult to achieve using physical resources. Consequently, they developed a digital version and integrated it within their electronic patient data system to increase the portability of the aid produced. Multiple healthcare professionals may also have access to the passport at the same time, if required.

Comprehensive Health Assessment Program / Notes Based Prompt

Lennox et al. [75, 78] and Jones and Kerr [41] explored the use of notes based prompts to support medical professionals to investigate specific areas of a patient's health. The comprehensive health assessment program [75, 78] is composed of a list of screening opportunities and preventive activities commonly employed with people with ID. Practitioners then utilise this information to determine whether the appropriate health checks have been carried out periodically with the patient. As a result, the CHAP is less likely to have a positive effect on time critical environments, such as primary care consultations, where emphasis is placed on treating the most immediate symptoms present [78]. Instead, it is more suited to interventions like the ID annual health check, since medical professionals have an extended amount of time to consider all aspects of a patient's wellbeing.

In addition to the CHAP, Lennox et al. [75] supplied health professionals with a short summary on the recent health trends of people with ID – a strategy they found most convenient to use in general practice. Jones and Kerr also followed a similar approach

[41] to encourage practitioners to be vigilant for, and follow-up on, conditions that may otherwise have been missed or overshadowed. They combined such evidence with a synopsis on the best practices to implement when interacting with a patient with ID, thus potentially increasing the amount and accuracy of information being extracted. Nevertheless, they found that the paper based nature of the aid meant it was not used prominently by health professionals [41] and could therefore be replaced by more appropriate digital solutions.

Health Diaries

Lennox et al. [76, 78] and Turk et al. [79] described the development of healthcare diaries to empower patients with ID to have a better understanding of their needs as they progress over time. Once again, all stakeholders are responsible for the maintenance of the document, meaning observations on the patient's wellbeing may be recorded by health professionals, support workers, family members or the individual with ID. Turk et al's approach [79] was to separate the diary into sections based on the common conditions experienced by people with ID, ranging from everyday ailments to more complex disorders such as epilepsy. There is also space dedicated to the treatments being received by the individual, as well as advice on how to live a healthy lifestyle.

Lennox et al's diary [76, 78] was significantly more substantial in that it contained segments on how to improve communication during the consultation, in addition to those focusing on the recording of health information. These segments were aimed at both the health professional and the individual with ID, and included: a patient passport; general strategies that may be employed by practitioners to improve the quality of care provided; and tips for the patient on how to prepare for a consultation, along with several resources to support them during this process e.g. picture symbols and pain recording tools. Consequently, the health professional's knowledge of the patient's communication/treatment preferences and specific health needs should be notably increased.

Easy Read Documents

Dodd and Brunker [65] and Chinn [81] utilised easy read documents to support patients with ID in understanding medical conditions / symptoms. Easy read is the term given to information resources that have been specifically adapted to suit the complex needs of people with ID. This is primarily achieved through the implementation of short, jargon-free sentences supplemented by identifiable imagery. In Dodd and Brunker's study [65], flashcards of various body parts, types and intensities of pain, and periods of time were issued to patients with ID to increase the accuracy of the symptoms being described. Chinn's approach [81] was different in that she directed medical professionals towards existing easy read resources on clinical conditions and monitored whether these resources had a direct impact on the communication throughout a consultation. The documents encapsulated an accessible summary on the effects and potential treatments of a condition. Consequently, they were used as a form of support during situations where a patient could not understand what the practitioner was conveying or was opposed to the course of treatment being offered [81]. Despite the documents being publicly available prior to the commencement of the study, many of the GPs were largely unfamiliar with such resources, thus potentially limiting their impact on consultations. This contrasted with the more specialised ID nurses who regularly utilised, and were involved in the development of, easy read resources [81].

Talking Mats™

Talking Mats™ [89] was identified by Bell and Cameron [77] as a potential tool to support a patient with mild ID in discerning aspects of their mental health – a process they were finding difficult to overcome using traditional consultation methods. Talking Mats™ is a communication aid that primarily relies upon imagery to form a concrete representation of an individual's views. A visual scale is first placed at the top of a physical mat. The discussion is then broken down into manageable topics and for each topic the individual must place an image that encapsulates their mindset under the appropriate section of the visual scale. Consequently, the aid is particularly effective for individuals who lack the social skills to converse with authoritative figures, since it lifts the burden on direct interactions [77]. In addition, Talking Mats™ may provide a voice for those who are unable to communicate verbally, thus increasing their participation in decisions regarding their care.

High-Tech Communication Aids

Clinical AAC Tablet Applications

Just one set of authors (Gibson et al. [32, 33, 49]) explored the development of high-tech aids to support patients with mild ID to communicate with medical professionals. They proposed a digital questionnaire based on the most common medical conditions experienced by people with ID. Each question should be presented using the easy-read format discussed above to increase the probability of users selecting symptoms they are experiencing. In addition, any information extracted from the patient should be used to influence the future questions presented, thus ensuring the questionnaire is tailored to their own healthcare needs. The application should also be customisable to account for the patients accessibility profile and may be combined with other AAC strategies, such as patient passports, to increase the quality of care being provided [49]. Extracting symptoms from patients with ID prior to the consultation may have multiple advantages: the results may be used as a referent when presenting views to a health professional; time constraints may be alleviated with the practitioner able to build upon pre-selected information; and finally, there may be increased exposure to commonly overshadowed conditions [32, 33, 49].

3.2.2.3 Communication Modalities

10 of the 15 studies described their implemented technologies well enough for the author to determine the range of communication modalities employed [17, 32, 33, 49, 65, 76–78, 80, 81].

Imagery

The bulk of the articles discussed the importance imagery has in supporting patients with ID to understand and communicate about their symptoms [32, 33, 49, 65, 76–78, 80, 81]. Nevertheless, the depth and context of use of medical images differed throughout. For example, Bell and Cameron's [77] application of Talking Mats™ resulted in a patient with mild ID providing information on their psychological health via the development of a pictorial framework. This therefore broke the reliance on disseminating information via the use of speech, with the individual only required to elaborate on those selections that were unclear or of particular importance to their diagnosis. The visual feedback offered by the mat also enabled the patient to reflect on and refine their selections, thus increasing the quality and quantity of information provided.

Lennox et al. [76, 78] and Dodd and Brunker's [65] use of imagery was less extensive in that their resources enhanced an individual's communicative abilities, as opposed to primarily replacing them. In both cases, this involved the development of colourful pictures to support a patient with ID in expressing symptoms of pain including its site, severity, [65, 76, 78], intensity and duration [65]. Heifetz and Lunsky [80] also found it beneficial to include a photograph of the patient in any resources used, to give practitioners a reference of how they should look whilst healthy.

Finally, Chinn [81] and Gibson et al's [32, 33, 49] employment of imagery was aimed at enhancing a patient's understanding of relevant medical information. In [81], easy read documents were utilised by health professionals at times when a patient was unable to understand what was being conveyed, or disagreed with the course of treatment proposed. These documents contained information on the manifestation, effects, and possible treatments of a condition, and were made more accessible to the ID population via the introduction of imagery. As such, the ability of patients to be involved in decisions regarding their care should have increased. Gibson et al. [32, 33, 49] applied a similar strategy during the design of a clinical AAC tablet application, with images being used to supplement the patients understanding of the symptoms presented as part of a medical questionnaire. Additionally, symbols were used to indicate the functionality of the buttons embedded in the applications user interface, albeit to varying degrees of success [32, 33].

Despite the reliance on imagery throughout the technologies implemented, none of the authors discussed the design decisions taken during the development of such resources. Furthermore, none of the image sets were made publicly available, which impacts the ability of researchers to reuse them or create their own. Lennox et al. [76] also noted that images can be expensive and time-consuming to produce, which could be a problem considering a one-size fits all approach is unlikely to benefit ID population [32, 33, 49]. For example, some patient's may already use Makaton symbols [90, 91] in their everyday lives, and therefore expect a similar style of image to be employed, whereas others might find realistic photographs to be more relatable.

Text and Speech

Five of the studies indicated that written information, enhanced by identifiable imagery, provided patients with an accessible means of two-way communication [32, 33, 49, 76, 81]. Gibson et al. [32, 33, 49] went one step further and suggested that the playback of textual information should also be incorporated, where possible, to ensure illiterate or semi-literate users are not disadvantaged in anyway. As such, targeting a range of modalities ensures that information is presented in a variety of different manners, with the individual able to utilise the form that makes most sense to them in each scenario [33]. For example, a patient with ID may prefer to utilise images when receiving information but also has the option to fall back on the text when a particular image is unclear.

Whilst developing textual information, Chinn [81] and Gibson et al. [32, 33, 49] emphasised the importance of following accessible language guidelines, such as [92]. This included the use of plain and simple sentences that focused on solitary ideas. Yet, Gibson et al. [33] also recognised that some complex terminology, e.g. the brand names of medication, was crucial to patient comprehension, meaning it is important to develop such resources in conjunction with target stakeholders to ensure their needs are met.

When presenting questions to patients with mild ID, different strategies were employed depending on the context of the consultation and the technologies used. For example, Bell and Cameron [77] primarily presented open-ended questions when using Talking Mats™ to establish the factors having a negative impact on the psychological health of a patient with ID. They felt that open-ended questions had the potential to improve the quality and depth of information being extracted, although recognised that the ID population may have greater difficulty constructing an appropriate response. In contrast, Gibson et al. [32, 33, 49] utilised closed questions that focused on a narrow range of medical symptoms, thus enabling them to break the consultation process down into manageable steps, whilst building up an overall picture of the patient’s healthcare needs.

Training

Bell also suggested that healthcare professionals remain undereducated on the communication strategies employed by patients with ID [17]. Consequently, she called for the enhancement of existing training programs to include information on how to effectively target a range of communication modalities, as opposed to just utilising speech. This included basic signing systems such as Makaton [90, 91], in addition to simplified language and imagery.

3.2.2.4 Evaluation and Impact of the Technologies

Finally, the evaluation techniques employed will now be presented to demonstrate the perceived impact the interventions may have on current practice. The techniques discussed are split into qualitative based evaluations and quantitative based evaluations.

Qualitative Evaluations

Most of the identified studies utilised qualitative methods to evaluate the effect their technologies had on current practice [17, 18, 32, 33, 65, 67, 75–77, 80, 81]. This included: interviews / focus groups and questionnaires [17, 18, 65, 67, 75–77, 80]; the analysis of a reflective journal [17]; post-task walkthroughs [32, 33]; and a conversational analysis of the interactions between health professionals and patients with ID [81].

Interviews, Focus Groups and Questionnaires

Comprehensive Health Assessment Program

Lennox et al. [75] initially assessed the benefits of their Comprehensive Health Assessment Program – which included a checklist of screening opportunities / preventive activities, a synopsis of the literature on the current health trends of the ID population, and a health record audit tool – by issuing a self-evaluation form to the practitioners involved in the study. Of the 45 GPs that agreed to participate, just 15 (33.33%) completed all components of the study. This, combined with the lack of involvement of the 38 patients with ID, significantly restricts the strengths of the conclusions made, as highlighted by the fact that only descriptive results were reported. In terms of effectiveness, the GPs reported that all interventions were beneficial in assisting their provision of care. Nevertheless, the synopsis of the literature was most productive in improving their knowledge of the health demographics of people with ID and was considered to be the most practical to use [75]. The checklist was most likely to raise awareness of the health needs of the patient and therefore prompted the greatest amount of action that may not have been carried out otherwise. Communication was reported as having increased between carers, hospitals, and specialists, as were consultation times – although no quantitative measures were carried out to confirm this [75].

Ask It Health Diary

Lennox et al. [76] employed a similar evaluation form to determine the appropriateness of an educational session that preceded their implementation of a health advocacy diary. Once again, the finer details of the form were not disclosed, yet the feedback indicated that the session was useful in reinforcing the responsibilities of both the patient and health professional. Furthermore, the session also introduced the steps involved in becoming an effective advocate. To evaluate the health diary, a short pilot study was carried out with two groups: (1) 19 parents of adults with ID who use a non-governmental support service; and (2) seven people with ID who use a non-governmental accommodation service. The participants took part in the above educational session and were then issued with the health diary. Next, they were required to familiarise themselves with the tool over a two-week period prior to completing an interview over the phone or in person – the protocol of which was not described. The qualitative data indicated that the diary improved the advocacy skills of two-thirds of the participants and improved their relationship with the GP in 50% of cases. The results were also used to improve the technology before a more thorough evaluation was carried out in [78].

Talking Mats™

Bell and Cameron [77] performed two separate interviews to validate the health information extracted from a patient with mild ID using Talking Mats™. The patient’s concerns extracted during these interviews were collated into a single document, with arrows being included to show how they had changed. This information was then passed on to the individuals support worker to ensure actionable change was carried out to improve their mental health. Bell and Cameron [77] found that the Talking

Mats™ framework makes it possible to *"extend the use of therapies that rely heavily on verbal communication to those people who not only find verbal communication difficult in a general sense but also in a specific situational sense."* The visual feedback, along with the open-ended questions presented, may also increase the depth and quality of the information being extracted.

Easy Read Communication Cards

Dodd and Brunker [65] issued a questionnaire at the start of their project to determine the health advocacy skills of ten patients with ID. After six months of using the easy read communication cards, and participating in the accompanying training sessions, participants were required to redo the questionnaire to determine if their skills had improved. Brief multiple-choice questionnaires were also completed by the participants, GPs, and caregivers each time a participant fell ill or was in pain and visited their doctor. In total, three follow-up evaluation cards were completed by the participants involved, meaning the authors were only able to provide tenuous remarks regarding the feedback received [65]. The reported benefits included: an increase in knowledge on how to recognise the signs of being unwell, along with what to do when ill; an increase in two-way communication using the pictorial aids issued; and an increase in the ability of the patients to become involved in the decisions regarding their care. Nevertheless, there was some variance in the results extracted, with only those participants who used the aid regularly with their caregiver or doctor demonstrating increased retention of healthcare information.

Patient Passports

Heifetz and Lunsky [80] also utilised both questionnaires and interviews to evaluate patient passports across three institutions in Canada. Their descriptions of the protocols employed were more complete, thus increasing the replicability of their findings. 18 semi-structured interviews were conducted over the phone with a variety of stakeholders, including: hospital clinical staff, community health and ID service providers, community-based health care coordinators, and one parent. Participants with ID were not initially included, since the focus of the interviews was on the implementation of the passports, as opposed to their use. Rather, the ID populations views were extracted using a questionnaire, along with support workers and family members, to determine the fit and user-friendliness of the passport, as well as its potential benefits. Both closed and open-ended questions were used to achieve this.

Overall, 75% of the participants involved in the questionnaire felt that the tool provides healthcare professionals with relevant background information on the patient. 65% suggested that such an approach can assist practitioners in carrying out reasonable adjustments to their consultation methods, with 80% recognising an improvement in communication between all stakeholders involved in a consultation. Consequently, the tool has the potential to support practitioners in conducting better informed healthcare decisions. Nevertheless, these results may be speculative, since just three of the participants who completed the questionnaire had ID, in comparison to 25 without, and 82% had no experience in using the aid within a healthcare context. The interviews also highlighted the variable degree in which the passports were adopted across each institution. Strong leadership in monitoring and educating professionals on the use of the tool was reported as increasing community awareness and buy-in [80].

Brodrick et al. [67] conducted a short pilot study of a one page patient passport across two sites in England in October 2009. Residential managers from each service were trained in using the passport before introducing the aid to frontline care staff. Over the course of the month 150 passports were produced, with both the researchers and residential managers remaining on hand to provide additional training and support. Quality checks were carried out on these resources and a final round of focus groups were conducted at the end of the pilot phase to obtain feedback from the healthcare staff. Nonetheless, the components being reviewed throughout the quality checks, along with the tasks employed in the focus groups were not reported. The potential benefits of the passport were similar to those reported by Heifetz and Lunsky [80] in that it provided staff with the necessary information to deliver person-centred care. The passport also increased the continuity of care as patients moved across departments whilst promoting collaboration between health care providers. However, their initial quality was extremely variable and only improved once extra training and support was provided, along with example passports deemed to be of high calibre.

Reflexive Journal Analysis

Bell [17] employed multiple methods to evaluate their own version of a patient passport. As such, a variety of perspectives were extracted, thus improving the strengths of the findings made via data triangulation. First, 12 family carers and health and social care staff participated in a series of semi-structured interviews to determine their experiences of using the passport. In addition, a focus group involving eight adults who have ID was conducted, with emphasis being placed on aspects that had, or had not, helped them to feel comfortable in a hospital context. Nevertheless, only one participant had experience in using the passport employed, which potentially limits the impact of the findings made from this part of the study. Finally, Bell [17] observed and recorded notes on the passport being implemented in practice, which was analysed using a reflexive process. As with Heifetz and Lunsky [80] and Brodrick et al. [67], increased collaboration and continuity of care was recognised across multiple healthcare providers.

Conversational Analysis

Chinn [81] video recorded the interactions between health professionals and patients with ID to determine the effects easy read information sheets had on consultations. A total of 41 recordings were made, 32 of which involved a patient with ID attending a health check with primary care clinicians, and nine with specialist ID nurses. Conversational analysis was then used to examine the interactional micro-practices that framed the literacy events involving easy read resources. Reflective interviews were also conducted with a subset of the participants (nine patients and nine health professionals) to determine the reasons behind certain actions. Chinn's study [81] was carried out in the context of annual health checks to ensure the identification of appropriate participants. Yet this environment restricted the opportunity for health professionals to introduce easy read information sheets, as highlighted by their visibility in just 22% of the appointments recorded. The ID nurses involved were also far more likely to utilise the information sheets (due to their specialised skills) despite Chinn's best effort to educate the GPs on the benefits of such resources. When used, the easy read information sheets were effective in supporting the medical professional to offer unsolicited advice, particularly when the patients were resistant to change.

This was due to the aid reinforcing the practitioner's views and reminding them of important aspects to forward on to the patient.

Post-Task Walkthroughs

Gibson et al. conducted post-task walkthroughs with four experts in ID to ensure a technology probe of a clinical AAC tablet application was accessible to the target population [32, 33]. The experts were required to select various symptoms within the probe, before answering questions on their experience with the app. Particular attention was paid to any areas of interest noted by the investigators during the experts' interaction. The benefits of the application listed by the participants included: an increase in communication via the use of an accessible list of symptoms as a referent; raising awareness of the conditions commonly overshadowed by practitioners; and the mitigation of time constraints by providing information to the GP prior to the consultation. Nonetheless, such benefits may be premature, with Gibson et al. [32, 33] revealing their intentions to consult with health professionals and adults with mild ID during future work, before carrying out a pilot study within the clinical environment.

Quantitative Evaluations

Just three studies [41, 78, 79] employed quantitative methods, via RCTs, to determine the effect their interventions had on current practice.

Ask It Health Diary and Comprehensive Health Assessment Program

Lennox et al. [78] followed on from their earlier studies [75, 76] to perform a clustered RCT with people with ID living in private dwellings throughout the Greater Brisbane area of Australia. They examined the effect of these interventions using a $2 \cdot 2$ factorial design with the units of randomisation being assigned to clusters of participants interlinked via sharing a GP practice. These clusters were organised into blocks of four according to size. One cluster from each block was then assigned to a factorial group by a statistician using computer generated random numbers. The effects of the interventions on clinical activity (e.g. health promotion and disease prevention) were measured over a 12-month period and compared with the same activities in the preceding year.

The comprehensive health assessment program had a statistically significant effect on health promotion, disease prevention and case finding activities across a number of components. Outcomes related to sensory systems (e.g. hearing and vision tests) increased as did all five of the immunisations highlighted by the program. There was also a substantial increase in the number of patients receiving weight measurements. There were no strong changes in the measured outcomes of the group who were assigned to the Ask It health diary alone, with only modest effects being noted on epilepsy review and constipation investigation. This contrasts with the findings of [76], which suggested that the health diary could lead to an improvement in the patient’s health advocacy skills, and as such, increase the number of conditions being identified. Lennox et al. suggested that the trial may have been too short to recognise the true benefits of the diary [78].

Notes Based Prompt

Jones and Kerr [41] also utilised a RCT to evaluate their notes based prompt – a tool which was similar to the CHAP program described above. Five primary care practices participated in the study and identified 88 patients with ID who were randomly allocated into the active or controlled group. The active group had access to the prompt immediately, whilst the control group endured an embargo for six months. After the initial six-month period, data was collected on a wide range of variables related to health promotion, consultation patterns, and physical, psychological and social well-being. This was compared with information on consultation patterns during the previous four years, as well as life-long records of general health issues. In contrast to Lennox et al. [78], no significant differences were observed on consultation patterns (location, nature and outcome) or on health promotion. Jones and Kerr [41] attributed the lack of positive outcomes to the paper-based nature of the aid, with medical professionals preferring to use digital resources. In addition, they suggested that without statutory regulations, and considering the current workloads experienced by GPs, screening opportunities are unlikely to be carried out on an opportunistic basis.

Handheld Health Record / Diary

Finally, Turk et al. employed a RCT to evaluate their hand-held health diary [79]. 40 primary care practices were randomised to the control or implementation groups, with a total of 163 patients with ID completing all stages of the trial. Initial interviews were carried out with patients and caregivers to determine aspects such as: basic background information; their knowledge of health problems and medical terminology; information on GP visits over the past year; and whether specific health checks were up to date. Follow up interviews were then conducted one year after the study's starting date and were identical to the initial interviews, except that additional questions were asked about the individuals experience with the health diary where appropriate. On completion of the study a nurse researcher accessed the medical records of the patients from a year before the initial interviews up to the time of the follow up interview, in order to measure a number of health-related outcomes.

Similar to Lennox et al. [78], no statistically significant outcomes were achieved by the hand held health diary [79]. Yet there were some improvements in relation to the number of GP visits per year (an increase of 1.4), the ability of patients to report health related problems, and the ability for them to recognise medical jargon. The qualitative data extracted during the follow-up interviews indicated that only 18% of the patients with ID involved in the intervention group used the diary and 39% of caregivers used it on behalf of the patient. This may partially explain the limited impact the diary had on consultation patterns and was attributed to a high turnover in support staff, as well as other factors such as carers forgetting it, being too busy or being concerned about taking up the GPs time. Nevertheless, those who had utilised the diary generally expressed satisfaction with it and suggested that it helped them to know more about the patient's health and was useful during visits to the GP or hospital.

Raemy and Paignon's [18] evaluation phase is currently in process, therefore no concrete results were reported. In addition, Gibson et al's study [49] only focused on the extraction of design requirements, meaning no evaluation was conducted.

3.3 Discussion

Despite communication barriers being well recognised within the literature e.g. [8, 10, 11, 21, 93], little is known about the use of technology to support the exchange of information between patients with mild ID and medical professionals. This review therefore maps the literature within such a domain, whilst exposing potential gaps that may be addressed by the proposed application. Just 15 studies focusing on the development and/or implementation of AAC devices were identified, with the majority investigating one-way communication aids [17, 18, 41, 67, 75, 78–80]. Notes-based prompts [41, 75, 78] were statistically significant in increasing the number of targeted checks being performed by medical professionals in problematic areas e.g. hearing difficulties [78]. Passports and health diaries [17, 18, 67, 79, 80] aimed to increase the practitioners knowledge of their patients' medical and communication needs, therefore facilitating reasonable adjustments, as well as the recognition of commonly overshadowed conditions. Yet these interventions centred on the way medical professionals present information to their patients, as opposed to empowering the individual with mild ID to take an active role in their care. This goes against Chinn's [68] view that the best outcomes for consultations occur when both parties receive support to enhance communication.

In contrast, the interventions described in [32, 33, 49, 65, 76, 77, 81] aim to facilitate improved two-way communication. Images of symptoms and body parts were used in multiple ways by Dodd and Brunker [65], Lennox et al. [76] and Bell and Cameron [77] to promote discussion on such topics. Easy read resources were also embedded in consultations to enhance patients with mild IDs knowledge of certain conditions / procedures, thereby improving their ability to provide informed consent [81]. Finally, Gibson et al. [32, 33, 49] investigated the use of digital questionnaires to produce an easy-read summary of the main symptoms being experienced by an individual with ID. Both the patient and medical professional may then build upon this summary throughout the consultation. Ensuring all stakeholders share a mutual understanding of the clinical information being discussed is likely to lead to more accurate diagnoses being carried out. As such, the author agrees with Chinn [68] that greater emphasis should be placed on the development and evaluation of two-way communication aids.

Nonetheless, one-way communication aids, particularly patient passports, still have a role in environments that are time critical (e.g. accident and emergency) or are difficult to navigate (e.g. large-scale hospitals with multiple wards), to ensure consistent care is administered [17, 67]. Yet Hemsley and Balandin [21] recognised that overly long summaries of an individual's needs may result in medical professionals ignoring such information, with the patient having to repeat themselves on multiple occasions. This could therefore explain the change in focus towards one page patient passports e.g. [17, 67, 80].

3.3.1 Systemic Change

The bulk of the communication barriers discussed within the review match the findings of Hemsley and Balandin [21]. Yet not all may be alleviated via the simple introduction of AAC technologies and require much more systemic change. Hemsley and Balandin [21] note that governmental and healthcare agencies must do more to reduce the inequalities being experienced by patients with complex communication needs. One instance in which this is abundantly clear is Switzerland’s failure to implement a national ID strategy, meaning institutions lack the appropriate guidance and resources to treat patients with ID effectively [80]. Additional services, systems, and policies [21] must therefore be developed on a national scale to encourage improved person-centred care. Hemsley and Balandin [21] highlight various aspects that must be considered during this process: (1) increasing the knowledge of healthcare staff on effective communication strategies; (2) extending the time available to consult with patients with complex communication needs: (3) increasing interagency collaboration to ensure patients are able to take the optimal pathway throughout complex health systems; (4) clearly defining the role of caregivers; and (5) increasing access to and encouraging the use of AAC devices within consultations. The studies identified within this review also suggested that targeted health checks [41, 75] and the employment of specialised professionals to support frontline staff e.g. ID nurses could have serious benefits for the wellbeing of the ID population. Introducing statutory regulations should also help to ensure interventions are utilised within practice – a problem identified by some of the studies reviewed e.g. [17, 41]

Finally, the health inequalities experienced by patients with milder ID may be exacerbated due to the “hidden” nature of their disability [41]. Their symptoms are not as prominent as those with moderate or severe ID, meaning their diagnosis could be delayed or missed entirely. As such, medical professionals may continue to employ inappropriate consultation techniques due to their ignorance of their patient’s additional needs. Consequently, practices should look to employ intellectual disability registers [94] to ensure medical professionals are aware of their need to conduct reasonable adjustments. In addition, greater emphasis must be placed on strategies to identify people with mild ID.

3.3.2 Review Limitations

This review is the first to explore the type of AAC technologies available to patients with mild ID during clinical consultations. It has highlighted the limited extent of research being carried out in this area despite the abundance of evidence detailing the health inequalities being experienced by patients with ID. Further investigations into the potential of two-way communication aids to increase the health advocacy skills of this population must be conducted, with emphasis being placed on the use of high-tech aids, since they can adapt to the working routines of medical professionals. Quantitative measures must also be employed to determine their clinical advantages. Nonetheless, the review is a scoping review, as opposed to a systematic, and therefore has some limitations. First, the searches were restricted to three primary databases meaning relevant literature may have be omitted. Second, only articles published in English were considered, which may explain why the identified studies were carried out in members of the OECD. There is also scope to explore the use of AAC devices in improving the health of other populations, such as those with more severe ID (as in [26]) or children (as in [28–30]).

3.4 Conclusion

This Chapter summarised the technologies and modalities used to support adults with mild ID to communicate with medical professionals. As such, it has partially answered the initial research question presented in section 1.3, whilst fulfilling the first sub-stage of the framework for complex interventions (i.e. identifying an evidence base for the proposed application [50]). Both the high-tech and low-tech interventions focused on two main strategies to promote care: (1) capturing the personal characteristics of the patient to support medical professionals in carrying out reasonable adjustments; and (2) raising awareness of commonly overshadowed conditions. Nevertheless, there was a lack of high-tech, two-way communication devices identified, despite Jones and Kerr [41] recognising the need for such technologies as far back as 1997 - due to their increased fit within the practices employed by medical professionals. There is also evidence to suggest that people with ID prefer to implement digital solutions when required to use AAC technologies on a regular basis [95]. The high-tech devices identified, primarily [32, 33], failed to include the views of target stakeholders meaning they may not cater to the preferences of end users. Consequently, there is a clear need to conduct further research into the benefits of high-tech AAC devices within the clinical domain.

With the need for the proposed AAC application already established, the next Chapter will focus on gathering evidence for the second substage of the framework for complex interventions – determining how the aid will fit into and improve current practice [50]. This will be achieved via the identification of design requirements from both experts and medical professionals, in addition to patients with mild ID. How these requirements translate into a concrete application will be described in Chapter's Four to Six via the development of a high-fidelity prototype. The resulting prototype will then be evaluated in Chapter Seven prior to its embedment within the clinical domain, thereby completing the "Development" stage of the framework for complex interventions.

Chapter 4: Developing Accessible Requirements Gathering Workshops

The research conducted up to this point in the thesis centred on establishing an evidence base for the proposed clinical AAC application. Since there is a clear need for the implementation of high-tech, two-way communication aids, the remaining Chapters will focus on co-designing an application that may fit into and subsequently improve current practice - as per the “Development” stage of the framework for complex interventions [50]. This process primarily involved understanding and capturing the needs of patients with mild ID to ensure the final application addresses their accessibility requirements [42–45], thereby supporting them to overcome the communication barriers that exist throughout primary care. In addition, such a process overcomes the limitations of previous work [31–33], and can help to alleviate device abandonment rates (which may rise as high as 53.3%[44]) by focusing on the specific requirements of target stakeholders, as opposed to the assumptions made by developers.

Nevertheless, prior to conducting research studies with participants with ID, investigators must guarantee that all resources employed are accessible to stakeholders. Those who are unfamiliar with the needs of people with ID are therefore faced with significant challenges, due to the lack of guidelines on how to include this population within research [96, 97]. Fig 4.1 details the steps employed by the author to overcome such a barrier. Initial design tasks suitable for the goals of the patient workshops were identified from the literature, yet the protocols for these tasks were incomplete, meaning not all of the authors accessibility concerns were addressed. As such, the tasks were presented to experts in ID for review, with improvements being made in preparation for their utilisation with adults with mild ID. A pilot workshop was then conducted with two patients, before an additional two workshops involving eight participants with ID in total.

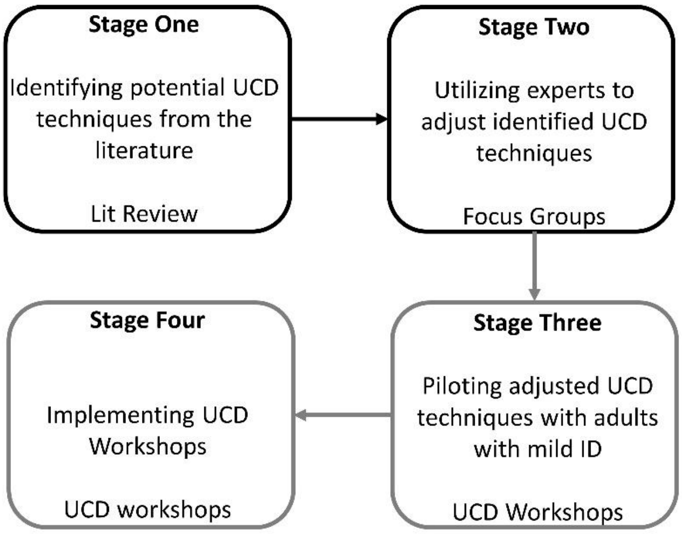


Fig 4.1. The stages involved in deriving design requirements from experts and adults with mild ID.

Chapter Four will focus on the development of the patient workshops, meaning results from the initial two stages shown in Fig. 4.1 will be presented. This includes the identification and subsequent adjustments of UCD techniques, as well as the experts' views on the proposed clinical AAC application. Chapter Five will then discuss the results of the final two stages of Fig. 4.1, which includes the design requirements identified by the patients with mild ID.

4.1 Literature Review of Potential Design Tasks

As introduced previously, the author had limited experience working with people with ID and was therefore unaware of how this population responds to traditional HCI processes. Nevertheless, prior literature has been successful in identifying common impairments that may have an effect on the results identified. For example, speech is often at the heart of design methodologies, yet adults with mild ID may find it difficult to present their views using this modality, particularly when complex or unfamiliar topics are being discussed [44, 53, 96, 98, 99]. Consequently, they may be more inclined to answer closed questions, which could limit their overall contributions, whilst opening up the possibility of response bias occurring more prominently [100]. In these circumstances, it may be more appropriate to utilise resources that target other modalities, such as the picture based Talking Mats™ framework introduced in section 3.2.2.2. Short-term memory impairments [101] can also affect an individual's ability to follow verbal instructions and operate intricate technologies. In addition, people with ID tend to have impaired higher-order cognitive skills, such as abstraction, conceptualisation, and creativity [12, 53, 99, 102–105], meaning they are unlikely to be able to envisage the potential use of novel technologies. Finally, people with ID are more prone to developing physical impairments (e.g. motor impairments or short-sightedness [35, 37]) that may limit their ability to participate in hands-on tasks.

Despite a clear understanding of the barriers to implementing user-centred design tasks with people with ID, there exists little guidelines on how to overcome such barriers [96, 97]. Hendriks et al. [96] recognised this dilemma in 2015 and proceeded to develop a dedicated methodological approach to enhance the participation of people with ID in co-design. Yet, after consulting with experts, they quickly concluded that their goals were over ambitious due to the heterogeneous nature of this population. As such, Hendriks et al. [96] now advocate for an individualised approach to the adjustment of design techniques based on the skills and impairments of participants. Key lessons learned whilst carrying out these adjustments should also be disseminated widely to increase the knowledge of other researchers [96]. However, this body of work is in its infancy, meaning investigators currently have to rely upon other forms of support.

Consequently, the author conducted a two-stage process (see stages one and two in Fig. 4.1) to develop a UCD workshop that was better suited to the accessibility needs and preferences of participants with mild ID. First, previous literature was searched to gauge techniques that had been successfully implemented with people with ID, and may be altered to address three aspects of the proposed clinical AAC application: (1) its functionality; (2) the design of the user interface; and (3) pictures of medical symptoms, since there is evidence to suggest that imagery can support people with ID to better understand complex concepts [39, 106]. Nevertheless, some of the decisions made by the researchers were not clear, hence the decision was made to pilot the emerging tasks with experts to ensure any remaining accessibility concerns were addressed. The expert workshops will be presented in section 4.2.

4.1.1 Literature Review Methods

The review was carried out in April 2018 and began with the author querying three databases (PubMed, Google Scholar and ACM Digital Library) using the phrase "*co-design AND intellectual disability*." As with the scoping review conducted in the previous Chapter, these databases were selected to ensure appropriate studies from the domains of health and human computer interaction were identified. In line with previous literature [70], the first 100 articles only had their abstracts screened by the author since the relevance of the results diminished as the search progressed. Eight papers (see Table 4.1) met the inclusion criteria, which consisted of employing design techniques with adults who have mild ID, and were subsequently reviewed in full. All discussed potential design tasks that may support adults with mild ID in addressing the three aspects of the application highlighted previously and were therefore considered relevant. A data charting form (consisting of the following characteristics: author; study aim; design techniques; and adjustments) was applied to the eight papers in order to extract relevant information – see Table 4.1 for a summary. The author and an additional researcher then came together to tag and discuss the key differences between the extracted research methods. These differences are presented in the next subsection and helped to shape the initial design workshop presented to the experts in ID.

Table 4.1: An overview of the design studies considered relevant.

Article	**Aim**	**Design Techniques**	**Discussed Adjustments**
Dawe (2007) [53]	Develop a picture based remote communication system.	Interviews with proxies; ethnography; paper mock-ups; technology probe evaluations; nightly voicemail diaries.	Iterative probing process where additional features were implemented as participants gained experience with the artefact.
Francis et al. (2009) [107]	Co-design digital assistive technologies for people with high functioning autism and Aspergers.	Video ethnography; self-photography; think-aloud; role play	Use of concrete examples.
Prior (2010) [44]	Develop a digitised hospital passport for patients with complex communication needs.	Focus groups; storyboard walkthroughs; paper prototyping; medium-fidelity prototype evaluation.	Research materials (questions etc.) issued in advance of study. Example features provided during paper prototyping.
Zisook & Patel (2014) [108]	Understand the most important aspects of communication to improve the design of assistive technologies.	Ethnography; individual interviews; image boards; iterative prototyping ranging from paper-based to high-fidelity.	Live capture of key topics being discussed via the placement of sticky notes in full sight of participants.
Brereton et al. (2015) [54]	Develop an app to support users with ID to express their goals.	Ethnography; High-fidelity prototype testing.	Initial requirements were gathered from proxies familiar with the needs of the target population.
Wilson et al. (2016) [109]	Develop a goal-setting app for young adults with ID.	Participant and environmental observations; semi-structured interviews; technology probes.	Iterative probing process where additional features were implemented as participants gained experience with the artefact. Use of proxies to facilitate interviews.
Sitbon & Farhin (2017) [98]	Develop an app to support people with ID when using public transport in large cities.	Initial prototype evaluations; non-finito features (features with no defined action) to promote creativity.	Caregivers used as proxies to facilitate tasks but also included as full research participants, meaning they were able to provide their own views.
Sitbon (2018) [100]	Develop applications to support people with ID in using public transport in large cities and using search engines.	Low and high-fidelity prototype evaluations.	Initial prototypes developed using requirements from the literature. Caregivers used as proxies and research participants.

4.1.2 Literature Review Results

Some key similarities and differences emerged from the literature that helped to shape the protocol employed within the second sub-stage i.e. the expert focus groups.

4.1.2.1 Ethnography Vs. Interviews

Many of the studies [53, 54, 107–109] used some sort of ethnographic technique to identify initial requirements from their participants. Such methods enabled researchers to bypass traditional interviews in favour of recognising problems that occur naturally in their stakeholders' lives. Prompts on how technology may be used to overcome these problems could also be made in real-time [54], thus alleviating potential higher-order cognitive impairments such as abstraction. From there, concrete probes [110] / prototypes were developed and subsequently evaluated by potential users to identify whether the assumptions made during the ethnographic observations were accurate. Additional methods of eliciting requirements for the prototypes included interviews with proxies (e.g. family members or caregivers) [53] and the review of previous literature [100].

In contrast, some researchers implemented focus groups and interviews with people with ID to determine how technology can enhance the lives of this population [44, 108, 109]. A variety of adjustments were made to ensure these techniques were appropriate to the needs of the participants involved. Prior [44] interviewed several individuals who relied upon alternative devices to communicate and therefore issued resources in advance of the study to allow participants to prepare in-depth answers. Zisook and Patel [108] overcame potential short-term memory and communication impairments by capturing important themes live via the use of sticky notes. Such a process reminded participants of the topics being discussed and allowed them to challenge any misconceptions made by the researchers.

In the context of this thesis, there is a wealth of literature on the potential communication challenges faced by patients with ID e.g. [18, 21, 22, 24, 68, 81, 111]. As such, it was unnecessary to observe this population interacting with GPs. Instead, emphasis was placed on determining how AAC can assist participants to overcome the barriers faced previously, meaning a focus group session was developed for the second sub-stage – see section 4.2.1.

4.1.2.2 Low Vs. High-Fidelity Prototypes

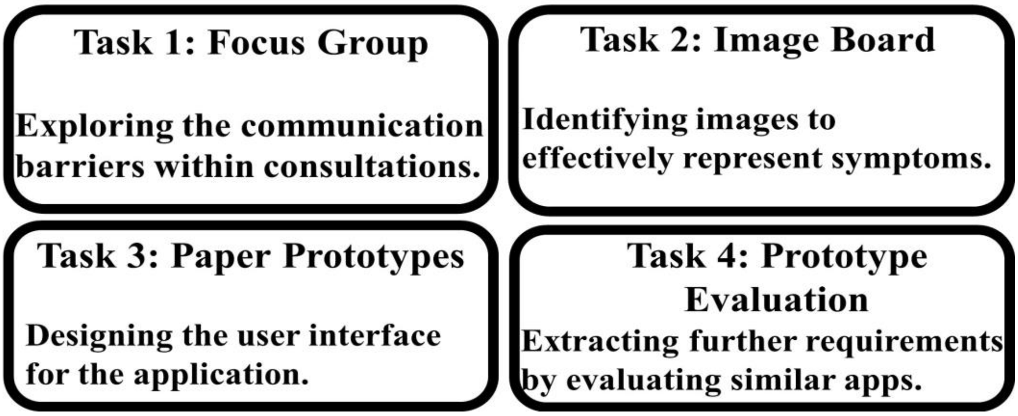
As highlighted in the previous section, some of the identified studies discussed the use of high-tech probes / prototypes to derive initial requirements from participants with ID [53, 54, 98, 100, 109]. This literature therefore followed the approach of "design after design" advocated by Brereton et al. [54] who suggest that people with ID become better engaged and more enthusiastic when interacting with pre-developed prototypes, as opposed to starting from scratch. Nevertheless, there is a possibility that the introduction of prototypes early on in the design phase may restrict or bias the views of the participants. In contrast, other researchers focused on the elicitation of requirements via the co-production of paper prototypes [44, 53]. Standard user interface objects (e.g. buttons) were provided to support participants during this process. In addition, Prior [44] utilised storyboards to provide participants with example scenarios of when the proposed technology may be required, therefore assisting them to envisage its overall functionality and design. Since there were pros and cons to both approaches, the author made the decision to present a paper prototyping task and a high-fidelity evaluation in order to maximise the potential requirements identified – see section 4.2.1.

4.1.2.3 Image Boards

Imagery was used as a main source of feedback in just one of the studies [108]. Zisook and Patel [108] implemented the image board methodology to determine potential solutions for an everyday AAC application. The participants were required to select images of interest from a series of magazines before combining these artefacts together to form a collage representing their views. This approach could therefore be adapted to assist people with mild ID in identifying effective medical imagery. Consequently, task two (see section 4.2.1) was presented to the experts in the next stage to determine whether such an approach was accessible to the target population.

4.2 Expert Evaluation of Selected Design Tasks

As shown in Fig. 4.2, four tasks emerged from the literature review that were deemed to be appropriate for inclusion within the UCD workshops. Yet, despite adjustments to these tasks being described throughout the literature, not all of the author's accessibility concerns were addressed. For example, during the prototype evaluation, it was not clear whether a "Think Aloud" procedure would be suitable for the cognitive skills of people with mild ID. Thus, the identified tasks were piloted with experts in ID, during a series of focus groups, to ensure any remaining accessibility barriers were mitigated prior to the introduction of people with mild ID.



Task 1: Focus Group

Exploring the communication barriers within consultations.

Task 2: Image Board

Identifying images to effectively represent symptoms.

Task 3: Paper Prototypes

Designing the user interface for the application.

Task 4: Prototype Evaluation

Extracting further requirements by evaluating similar apps.

Fig 4.2: The four UCD tasks identified from the literature.

4.2.1 Expert Focus Groups Methods

Guest et al. [112] suggest that 80% of all themes are discovered within the first two to three focus groups. This recommendation was therefore used to form the expert recruitment strategy, which was implemented during the months of June and July 2018. Invitations to participate were distributed via email to appropriate members of academic institutions and ID charities within four cities across Scotland. During this procedure, potential participants were issued with information sheets to support them in their decision to take part. Enough individuals from two cities (Glasgow and Dundee) were recruited to meet the goal of five to eight participants per focus group – see Table 4.2 for demographics. A separate focus group was conducted in each city in a venue and date that was convenient to the participants involved. To be eligible for the study, the experts had to have five+ years of experience working with or caring for the target population.

Prior to the commencement of the focus groups, participants were reminded of the goals of the study, as well as their individual rights. They then signed a consent form before completing each of the four tasks listed in Fig 4.2. Whilst conducting these tasks, the experts were asked to identify potential accessibility barriers for people with mild ID, along with ways to mitigate such barriers. The study then concluded with a discussion on how to overcome common obstacles to conducting research with the mild ID population. The use of focus groups in this context enabled a range of experts to approach the problem from different viewpoints, thus increasing the number of potential barriers identified. Institutional ethical approval to conduct the study was obtained from the department of computer and information sciences ethics board: ID 747. The average length of the focus groups was 78 minutes.

Table 4.2: Expert Demographics.

Focus Group	**Profession**	**Sex**
1	Researcher in the health and wellbeing of people with ID.	F
1	Researcher in the health and wellbeing of people with ID.	F
1	Researcher in the health and wellbeing of people with ID.	F
1	Employee of an advocacy charity for people with ID. Has mild ID.	F
1	Employee of an advocacy charity for people with ID.	F
1	Former ID nurse. Manager of ID activity centre.	F
1	Digital inclusion assistant – Teaches basic digital skills to people with disabilities.	M
2	Community ID nurse.	F
2	Employee of an advocacy charity for people with complex communication needs.	F
2	Community ID nurse.	F
2	Employee of anonymous ID charity. Supports people with ID in pursuit of employment.	F
2	Community ID nurse.	F

4.2.1.1 Description of Tasks

Task one aimed to establish the way in which technology can be used to overcome the communication barriers grounded throughout the literature. As such, it consisted of a semi-structured focus group centring on four main themes: preparing for consultations; positive and negative communication encounters with GPs; the use of touch screen technologies; and the implementation of AAC to support patients with ID during primary care consultations. Appendix C contains an amended list of the questions presented based on the accessible language feedback received from the experts. The sticky note process employed by Zisook and Patel [108] (see section 4.1.2.1 and Fig. 4.3.1) was also utilised to capture the key concepts being discussed.

Fig. 4.3: Example outputs from the design tasks.

Task two involved the image board methodology discussed by Zisook and Patel [108] to identify appropriate pictures to represent medical symptoms. The experts were required to individually critique pre-existing images of medical symptoms and separate them into one of two categories: those that accurately represented the symptom conveyed; and those whose meaning was more obscure. All symptoms were conveyed via three or more image sets (including basic black and white symbols, coloured cartoons, and real-life photographs), with each image incorporating a short textual description to ensure the participants know what it was trying to depict – see Fig 4.3.2 and Appendix C. A group discussion then occurred on why some images are more accurate in describing symptoms than others, before the pictures deemed effective were collated to form an image board. Images that had similar reasons for their inclusion on the board e.g. clear facial expressions, were grouped together to allow the investigators to form themes on aspects that accurately depict medical symptoms.

Task three aimed to develop an appropriate interface for the proposed application by utilising paper prototypes. The experts were required to nominate a leader who was responsible for describing initial features to include in the interface. Once the group came to a consensus, mock-up objects were then placed onto a paper representation of a tablet to demonstrate their needs. Similar to Prior and Dawe [44, 53], the objects included general usability features such as skip buttons, as well as those more specific to the application. Blank objects were also provided to allow the inclusion of elements unforeseen by the author. Participants developed a paper representation of each screen and described what actions occur when certain elements are selected, for example a potential symptom.

In task four, participants were required to evaluate a previously developed tablet application [31–33] to discern requirements that may not have been identified during task three. A "think-aloud" [113] protocol was implemented where the participants were asked to complete two exercises using the application and describe the reasons behind their actions during real-time. Once again, the group nominated a leader to initiate a discussion on what action should be conducted, yet progress was only made once a consensus was reached. The task then concluded with a discussion on the features considered to be accessible to people with mild ID and those that are missing or make the application less usable. A more in-depth protocol for the tasks is shown in Appendix C, which describes the eventual workshops conducted by the patients with mild ID. The reader should note that a post-task walkthrough procedure is discussed in task four, as opposed to a think-aloud, and the reasons for this will become clear in section 4.2.2.4.

4.2.1.2 Analysis of Tasks

All tasks were recorded with participant consent and transcribed verbatim by the author to further their understanding of the data. During this process, a summary of their key thoughts was logged into a research diary to support in the development of an initial codebook that was applied throughout an inductive framework analysis [73]. Key findings in the transcripts were tagged by the author in Microsoft Word by highlighting phrases and assigning an appropriate code under the following format "<code>". The codebook was extended where necessary, with comments being added to the transcript to explain the application of certain codes. This process was repeated until the author was confident in their interpretation of the data, at which point a second researcher reviewed the tagged transcripts and made note of any codes that required adjustment. The two researchers then came together to resolve their discrepancies and subsequently updated the codebook to reflect their conclusions. Similar codes were then grouped together to form themes, with the tagged transcripts being revised to conform to the final framework. Relevant data was then charted into the framework analysis table, which included a structured summary of the barriers and facilitators to conducting design activities with adults with mild ID. In addition, the table includes initial requirements for the proposed application - see DOI:10.15129/76f97730-a5fa-49da-973f-995373cee7ad.

4.2.2 Expert Focus Groups Results

The experts' views on the accessibility of the tasks will now be presented, along with their recommended adjustments to overcome the potential barriers. Quotes from the resulting framework analysis table will be provided (using the format "Focus Group ID.Participant ID" - see table 4.2) to strengthen the conclusions made.

4.2.2.1 Focus Group - Exploring Participants Views on Primary Care Consultations

Accessibility

Overall, the experts found focus groups to be accessible to people with mild ID. In particular, three key themes emerged that may assist adults with mild ID to disseminate their views within a group setting.

Appropriate Use of Language

Experts across both focus groups stressed the use of accessible language guidelines (such as NHS England's [92]) to increase the participants' ability to both comprehend and answer the questions presented. The use of simple and plain language was disclosed as being particularly important within the proposed focus group due to the complexity and unfamiliar nature of the topics being discussed. Questions that are concise, focus on solitary ideas and avoid the use of jargon should assist in easing the cognitive load placed on participants, which may increase their ability to provide in-depth answers that accurately match their views.

Supportive Caregivers

Support workers and family members are often familiar with the individual traits of people with ID. As such, they should be able to recognise when inappropriate communication strategies are implemented by the researcher and subsequently suggest alternative approaches. For example, a caregiver may rephrase overly complex passages of speech or advise the investigator to avoid specific perceptions. They may also be able to recognise when the participant fails to mention an important concept or has conveyed an experience that is not entirely factual. Nevertheless, it important that the caregivers input on the study is limited and that the bulk of the views discussed are from the participants with ID.

Sticky Notes

The experts were also optimistic about the use of sticky notes to capture the views of participants in real time. They suggested that the notes may act as a concrete referent for the topics being discussed, thus helping to alleviate any short-term memory impairments. Participants are also able to elaborate on or challenge any of the produced notes, meaning the spontaneity of discussion may be increased, which matched the findings of Zisook and Patel [108].

Barriers

The experts identified three barriers to the implementation of focus groups, two of which centred on the questions proposed and one focused on the involvement of caregivers.

Response Bias

The participants involved in focus group two revealed that response bias tends to be prominent within the ID population. They suggested that adults with ID are often "*people pleasing*" and may provide answers they believe are expected, rather than their own views, as discussed by participant 2.3: *"One member in particular, he went to the doctors and say he had pain in his shoulder but also had pain in his knee…He gets across that it was in his shoulder and the doctor was like "oh is there anything else" and he'd be like "no I'm good" even if he had this horrendous pain in his knee."*

The above example highlights response bias occurring in open-ended questions; however, the experts also suggested that it may be a prominent issue within closed questions (such as rating scales) where the most extreme options tend to be selected. Caregivers may therefore play a positive role in pinpointing response bias, since they are familiar with the life experiences of the individual with ID and can recognise when erroneous answers are provided.

Complex Concepts

It was not possible to avoid complex concepts within all the questions presented. One instance was the use of the word "*symptom*", where many of the experts in focus group one felt that its meaning could be difficult to comprehend for people with ID. Another example was the concept of time. Each of the ID nurses revealed that their patients had issues determining when a symptom first occurred and suggested a similar barrier could emerge throughout the focus group. Strategies to overcome these barriers will be discussed in the Adaptations section.

Caregiver Barriers

The positive impact caregivers may have in supporting people with ID to complete design tasks has previously been discussed. However, the experts also highlighted the potential dangers of incorporating carers within research: participant 2.5: *"You'll get some [caregivers] who will take over or direct them [the participant] more and others will be very supportive…I would try to get them to just sit back."*

As shown in section 2.2.2.3, carers can range from family members who have known the individual for the entirety of their lives, to paid employees who have been hired for a short period of time. They may therefore differ in terms of their familiarity with the needs of the participant, as well as their enthusiasm to get the best outcomes for the individual. For example, family members often care deeply for the participant and this may lead to them becoming overinvolved. As a result, the study may be skewed with caregivers providing opinions that do not match those of the individual with ID: participant 1.3: *"I think you need to think about whose perception is it you want to capture during your research. Is it people with intellectual disabilities or is it carers? Cause you might get quite different outcomes."* Consequently, it is important to clarify the role in which the caregivers have and enforce that they stick to this role.

Adaptations

The experts advocated for the implementation of concrete examples across three scenarios to help ease the cognitive load placed on participants. First, those in focus group two suggested shortening any Likert scales used to a maximum of five points and further supplementing them with symbols to clearly define each option, thus matching the findings made by Hartley & MacLean [114] . Concrete examples should also be employed to assist in the clarification of difficult language. For example, a diverse range of symptoms may be presented to support participants in processing what a symptom may entail. The ID nurses also suggested that this strategy may be used to help an individual overcome complex concepts such as time: participant 2.5: *"Things like how long have they had this problem [for] is hard for our clients. So, this is where we use, right, if it's the summer was it there before Christmas time?"*

4.2.2.2 Image Board – Exploring Effective Medical Images

Accessibility

The experts found this activity to be less cognitively challenging than developing images from scratch: *Participant 1.3: "I think it's better to have these to work with rather than [coming up with your own]"* - *Participant 2.5: "I couldn't draw what some of these look like."* This was particularly true when more abstract symptoms, such as numbness of a limb, were presented. As mentioned previously, people with ID tend to have impaired higher-order cognitive skills such as abstraction and creativity [12, 102–105]. Consequently, their ability to describe how certain symptoms may look could be affected, especially if they have not experienced such symptoms before. It was therefore considered to be more appropriate to present potential options to the participants and have them share their needs by critiquing these options.

Barriers

Two potential accessibility barriers were identified: the labels placed on the images; and the heterogeneity of the participants.

Labelling Images

The experts in focus group one advocated for the use of labels to assist participants in critiquing the accuracy of the image: *Participant 1.3: "I think it's good with that and then you have headache at the bottom. And I think if it didn't have headache at the bottom it would be quite confusing 'cause it could be is she burned, has she burned her face?"* However, this quote suggests that the participant initially found the image to be ambiguous, and its intention only became clear after they had read the label. As such, there is a possibility of response bias occurring and this was a concern raised by the experts in focus group two: *Participant 2.2: "if you have the words there it would be very much what answer you're looking for rather than what they actually think or what [they would see] without guidance."* The use of labels may therefore detract from the natural first impressions of the participant and could potentially lead to the development of images that are less effective in describing symptoms.

Heterogeneity

The experts were unable to agree upon the style of image that best represents medical symptoms. Those involved in focus group one preferred the more photorealistic images. Whereas the ID nurses involved in focus group two revealed that they are familiar with the simplistic black and white line drawings and believe that such a style would be more effective. Participant 2.5 predicted that this scenario would occur throughout the UCD workshops: *"You're going to get different people saying different things. Be prepared for them disputing the best one 'cause everybody has got their own things as to what they like."*

Adaptations

The experts also suggested implementing an image board on which to capture the ineffective pictures (versus simply discarding them), as a way to promote discussion on features of the pictures that the people with ID find inaccessible. Additionally, researchers must be wary of the heterogeneity of the ID population and adjust various resources to account for this heterogeneity. An example was the inclusion of several image sets within task two, as opposed to just one.

4.2.2.3 Paper Prototype - Design of User Interface

Accessibility

The experts believe that the low-fidelity prototype process is more accessible to people with ID in comparison to high-fidelity prototypes. Those involved in focus group two explained that many people with ID come from a household affected by poverty and, as a result, may not interact with tablet technologies frequently: *Participant 2.2: "We understood that you meant "click on that and it'll go to the next section" but for people who are not familiar with iPads or apps, that would just blow their mind."*

As such, it may be initially daunting for the participants to interact with an application or device they are unfamiliar with. Additionally, people with ID often require support from their caregiver when interacting with technology, meaning they can be entirely dependent on their carer being tech-savvy to complete the task. Some participants may therefore be more comfortable when interacting with paper prototypes, yet the findings from Chapter Five suggests that most people with mild ID have access to smartphones (due to their declining costs), with up to 50% also owning tablets. Ramsten et al. [115] came to a similar conclusion, therefore indicating that digital exclusion may not be a prominent barrier within this population.

Barriers

In addition to digital exclusion one further barrier was proposed by the experts. Originally, abstract elements were used to represent objects, such as simple "*Answer*" and "*Question*" options. However, all experts felt that this approach would be cognitively challenging. They suggested that the participants would find it difficult to relate to the objects, which could impact their ability to identify their needs. For example, they may believe that the inclusion of six options on the screen could be accessible, when in reality it is overwhelming and hinders their ability to answer a question.

Adaptations

Once again, the concept of using concrete examples was brought up by both sets of experts. They stated that the inclusion of example questions and answers within the paper prototype could reduce the cognitive load placed on the participant. This will then allow them to convey their needs accurately as described by participant 1.1: *"It might be better if you give them examples of questions. So rather than "question" and "answer" you can give them your choice of two answers or examples like "do you feel cold." Or if you had six choices with real life examples they could say "oh it's too much I can't decide between these ones."*

Participant 2.2 also discussed using examples to overcome the potential issues that arise from digital exclusion. She revealed that a short demonstration of tablet technologies could be provided to give the participants with ID an idea of how they function. This could also include some time for them to interact with similar accessible health applications. In addition, participant 2.2 also proposed a minor improvement to the paper prototyping process to make technology specific actions explicit to the participants: *"if you just got flip chart paper and put it along the wall, then it was like [the changing of screens]."* The experts in focus group two agreed that this was a good suggestion and believe that the flip chart would be able to mimic such actions. To elaborate, flipping over the paper may symbolise the changing of screens, with existing elements being replaced by newer ones once an action has occurred. This may help the participants to visualise the consequences of tapping on certain objects.

4.2.2.4 Think Aloud – Critiquing Existing Touchscreen Prototype

Accessibility

Overall, the experts found the Think-Aloud session to be inaccessible to people with mild ID. They suggested that the need for the individual to describe their actions is cognitively challenging and will distract them from performing the exercise to the best of their ability: *Participant 2.4: "It might be a little bit too much. It would probably be too much for me, oh, how do I touch that and speak at the same time. I think afterwards would probably be [better], like a talk through review type thing."* Consequently, the process had to be adapted to ease the cognitive load being placed on the individual and this will be discussed in further detail in the Adaptations section.

Barriers

Two main accessibility barriers were cited by the experts when completing this activity: complexity and digital exclusion.

Complexity

As discussed in the Accessibility section, the experts believe that the Think Aloud process is too complex for the mild ID population. Combining the need to describe an action with the need to complete a task using the prototype was deemed to be cognitively excessive and may limit the amount of feedback received. As such, these two processes should be separated, and this will be deliberated further in the Adaptations section.

Digital Exclusion

Digital exclusion could also have a significant impact on the results obtained since the needs of people who are unfamiliar with such technologies may differ from those who are. Consequently, investigators must be prepared to develop products that accommodate for the requirements of a wide range of users. In exceptional circumstances some may be unaware of the specific actions required to interact with tablets, such as swiping and scrolling. This is one scenario where the benefits of allowing the participants to interact with the technologies beforehand may be of use.

Adaptations

To increase the accessibility of this task, the experts suggested separating the prototype interaction phase from the evaluation phase. As such, a post-task walkthrough methodology e.g. [116] should be more appropriate, with the participants answering questions about their actions on completion of the task. One downside to this, however, is the opportunity for the individual to justify their decisions, since they have time to think about what they have done rather than being prompted immediately.

The experts in focus group one also discussed the need to change the accessibility settings contained within the tablet to suit each individual's preferences: *Participant 1.7: "I think one thing that might take a bit of time as well is the setting up. Like if it's on the tablet, then setting the tablet up for their [accessibility] needs, [for example], maybe a screen reader so they can tap on things for [the interface] to speak to them."*

Such a process may include aspects like: changing button activations to occur on the end of a tap; updating colour schemes to account for colour blindness; increasing contrast etc. Yet, identifying and setting up accessibility settings for a large focus group may be an extremely time-consuming process, meaning investigators could benefit from completing this task in advance of the study. Nonetheless, it may be crucial to the participants ability to use the prototype effectively.

4.3 Initial Design of the Proposed AAC Application

The experts also discussed their views on how the application should function whilst evaluating the four design tasks. Consequently, the framework analysis process described in section 4.2.1.2 resulted in the conceptualisation of design requirements, along with the accessibility barriers discussed previously. Such requirements were used to update the prototype from the author's MPhil [32, 33] in preparation for the design workshops with patients with ID. This prototype will now be discussed and compared with its predecessor.

4.3.1 Simplifying the Consultation Process

Both sets of experts concluded that the consultation process is too complex for people with mild ID. Patients have to comprehend information on aspects that are difficult to understand, whilst navigating procedures unsuited to their needs – for example, medical information is rarely disseminated via easy read resources [117]. As a result, the experts advocated for technologies that help to break consultations down into manageable steps: *participant 2.5 "Could you not have something like that saying* *what part of the body the pain is in first of all? Once you've narrowed it down, have a different set of cards to say what type of pain is it? Is it hot pain? Does it [feel] cold? Is it sharp like a needle or something?"*

They felt that supporting patients to identify the symptoms they wish to highlight could increase their ability to communicate about their health, whilst easing potential time constraints, since GPs have the option to build on areas of interest as opposed to starting from scratch. Nevertheless, participant 2.5 recognised that centring on symptoms of pain would result in the omission of conditions frequently experienced by the target population: *participant 2.5 "I suppose the problem is if [you] start with body parts and then go on to what's wrong with that body part, general symptoms of tiredness [for example] wouldn't be [picked up]. Do you know what I mean? 'cause they might just feel totally drained all the time."* Consequently, the experts identified a potential model that assists GPs in exploring the holistic health of patients with ID, as shown in Fig. 4.4.

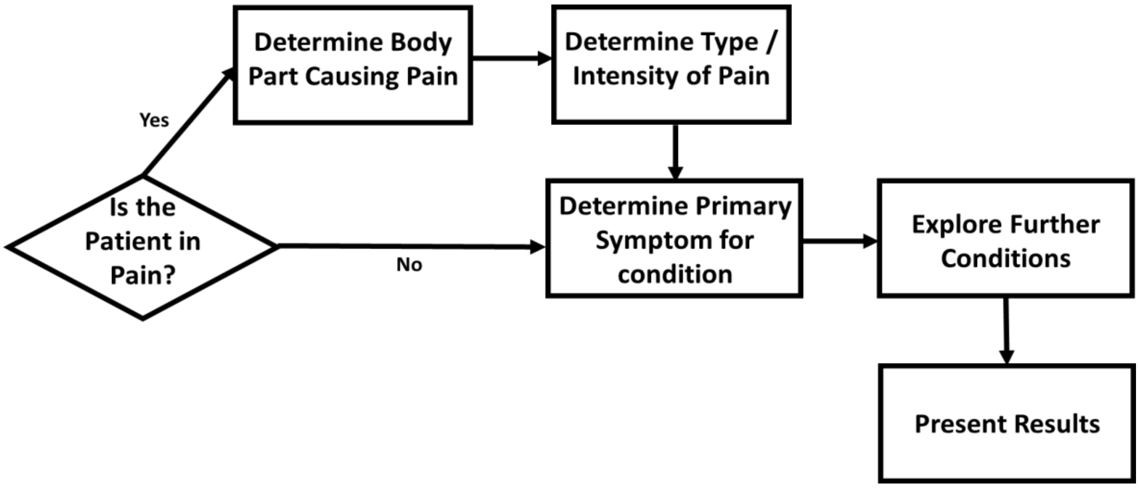


Fig. 4.4: Experts suggested model for diagnosing patients with ID.

The first image in Fig. 4.5 shows how this model is captured by the prototype. Initial yes/no queries are administered to determine whether the individual has an issue with a particular symptom and/or a body part. If they answer "yes" to any of the primary questions, a sub-questionnaire relevant to that body part or condition is then presented to extract further symptoms, with this procedure being repeated until the questionnaire is complete. Consequently, people with ID are expected to consider smaller, more manageable components of their health, as opposed to their overall wellbeing.


I have a problem with my mouth

no

yes

Results

I feel generally unwell

no

I have been feeling sad.

Fig. 4.5: The question and results pages embedded within the first prototype.

The application described in [31–33] takes a slightly different approach, with the user tapping on an outline of a body to indicate the potential area causing them distress e.g. the head for a migraine. Some of the experts involved in the workshop development process also advocated for a similar feature, in contrast to the yes/no queries, yet this was not implemented due to the following reasons: (1) people with ID are prone to developing motor impairments [35, 37] and may find it difficult to tap on smaller sections of the body; (2) some conditions span over multiple body parts meaning it may be difficult for the user to pinpoint a certain area; and (3) presenting a similar style of question will result in a more standard user interface, thus increasing the learnability of the system.

4.3.2 Limiting the Number of Options Displayed

The previous application [31–33] centred on multiple choice questions in which four different symptoms may be presented for selection at any one time. Yet the experts suggested that an excessive amount of choice may be cognitively challenging for people with mild ID and could lead to less accurate answers. Instead, the number of options available should be limited, preferably to two: *participant 1.2 "I think as much as possible if you could have yes/no questions or like a tick and a cross to say is it painful? I think they might struggle if there's too many options."* Consequently, this version of the application focused solely on the use of yes/no questions and was later expanded to accommodate for the views of people with ID – see Chapter Five.

4.3.3 Combining Multiple Modalities

As with the previous application [31–33], the prototype combined three modalities to present medical information in a more accessible manner. First, the experts advocated for the implementation of accessible writing guidelines (e.g. [92]) that includes aspects such as: utilising plain and simple language, along with short sentences that focus on solitary ideas; employing a minimum font size of 12; offering the ability to playback textual information; and making use of concrete examples. These guidelines assisted in the development of the questions presented at the top of Fig. 4.5, which should therefore be suitable for stakeholders who possess the necessary literacy skills. Nevertheless, the language employed can be considered as placeholders, since it is important to evaluate the text with people with mild ID to ensure the meaning is understood as intended. For example, the word "problem" may be interpreted in a range of different ways by this population. There is also evidence to suggest that people with ID are familiar with certain medical expressions (e.g. brand names) [117], which goes against the accessible writing guideline of utilising the most simple/clear term.

On the other hand, people with mild ID have lower literacy rates than the general population [12], meaning there is no guarantee patients will be able to respond to textual information. As such, the ability to playback text has been implemented via the button embedded in the top left-hand corner of Fig. 4.5. When pressed, the question/title bar will be highlighted and read aloud, followed by the options from left to right or top to bottom as shown in Fig. 4.6. The previous application [31–33] utilised a single audio button per phrase; however, this was considered to be unnecessary and potentially confusing to patients with mild ID.

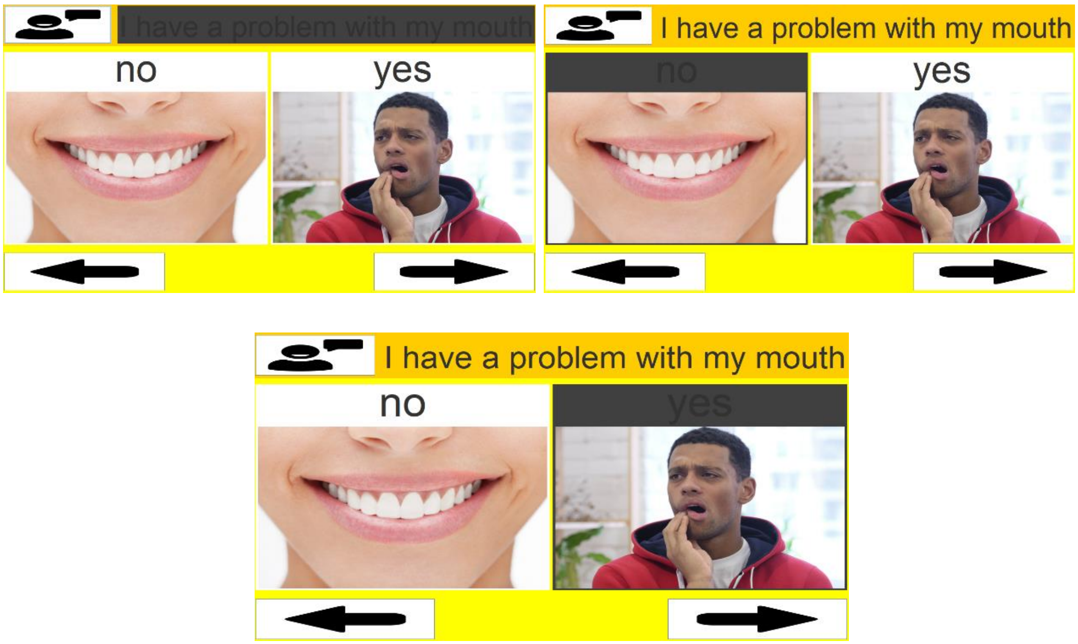


Fig. 4.6: An example of the audio playback process. The text is highlighted until the phrase is read out at which point the system moves on to the next section of the screen.

Some of the more obscure symptoms, e.g. numbness, may require terminology that is outwith the patients' impaired health literacy skills, meaning it is unlikely they will be able to understand this information via text alone. In such circumstances, the experts suggested that imagery may be used as an alternative representation, one that enables the patient to form a visual comparison with their own symptoms. Nevertheless, they were unable to agree upon the style of image that would better suit the needs of people with ID. For example, the participants in focus group one found that the photorealistic images were clearer: *participant 1.3: "I thought this tired one was quite good it was quite realistic - better than the sort of drawing of someone lying in their bed. I suppose that's a bit more cartoony, I think I prefer the actual person."*

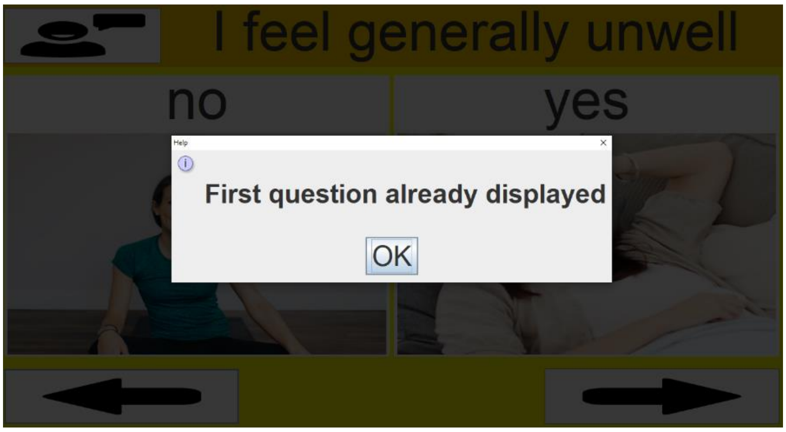
In comparison, the experts in focus group two advocated for the use of simplistic black and white drawings: *participant 2.3: "I prefer the egg head kind of ones 'cause they're not male or female. You know you might get a female with autism who's like that's not me 'cause [the picture is of a man]…And also, less colour - just the black and white (colours) I think is more effective."* Consequently, a range of images may be necessary to cater to the needs of different sub-populations and this was implemented in the prototype via a keystroke. Fig. 4.7 shows the different image sets available to the user based on their individual preferences: real-life photographs; in-depth coloured cartoons; and simplistic black and white drawings. These images were retrieved from hosting websites (such as www.flickr.com) under the CC-BY copyright licence and were the same as those implemented in the previously discussed image board task. As such, they may also be viewed as placeholders since they were not developed with the target population, meaning significant accessibility barriers remain – see Chapter Five. Images were also used to denote the functionality of buttons to ensure those with impaired literacy skills understand their intention.

Fig. 4.7: An example of the interface changing image sets based on individual preference.

Combining these three modalities (text, speech, and imagery) provides an optimal solution to increasing the accessibility of medical information. Patients are able to utilise the modality that makes most sense to them when presented with each question, thus increasing the likelihood they understand the information presented. For example, an individual with mild ID may generally rely upon pictures to process complex information but can fall back on the text when the meaning of a particular image is obscure.

4.3.4 Selecting an Answer

Patients may confirm their answer by tapping on the appropriate image, which is then highlighted (see Fig. 4.5), prior to selecting the right-hand arrow on the bottom of the screen. Such a strategy may assist in preventing accidental activations, particularly for users with impaired motor skills, and can accommodate for the implementation of future questions that allow multiple answers to be chosen. This contrasts with the pervious application [31–33] in which the interface moves on to the next question after the first tap. The left-hand arrow simply allows the user to return to the previous question if a mistake has been made. Help menus will appear if the individual attempts an action that is not viable, for example selecting the left-hand arrow when presented with the first question, as shown in Fig. 4.8. Automatic playback of the text will also occur for those who are unable to read the help message.



First question already displayed

Fig. 4.8: An example of the help menus displayed when the user attempts an incorrect action. Focus will be placed on the help menu until the user exits onto the main screen.

4.3.5 Displaying the Results

On completion of the questionnaire, the experts suggested grouping all selected answers onto one page. This includes the questions in which patients replied “no”, with the ID nurses in particular stating that the absence of conditions can support medical professionals to form a diagnosis. Each of the three modalities previously discussed (text, speech, and imagery) should be utilised to display this information to ensure the GP and patient with mild ID can build on the results throughout the consultation. At this stage, the results page simply mirrored the order in which the questions were presented to the user – see Fig. 4.9.

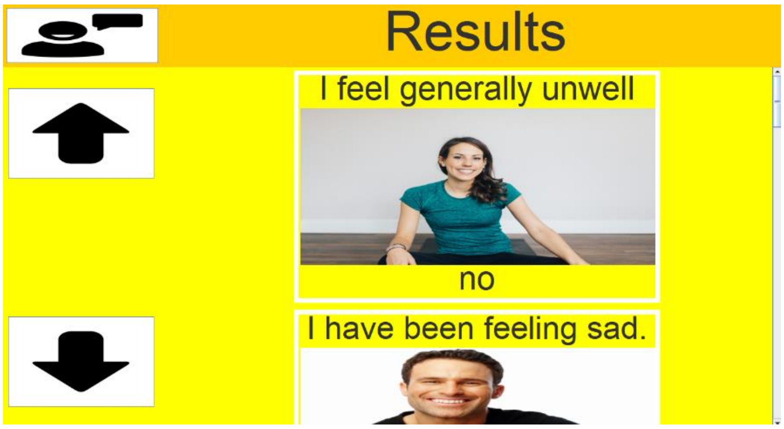


Fig. 4.9: The results page displayed on completion of the questionnaire. It simply lists all answers selected by the patient, with the arrows being used to navigate through the symptoms.

4.3.6 Guiding the Patient

Finally, the ID nurses involved in the second focus group discussed two common scenarios that generate a heavy burden on healthcare services. First, participant 2.4 suggested that some patients book medical appointments for the social experience, as opposed to actually requiring treatment: *"So [sometimes] they use health professionals inappropriately. You know, they make appointments with the doctor and they don't have any symptoms, they just want to talk to somebody. The doctor won't find the symptom 'cause there's not one there."* The second involves patients prematurely booking appointments for conditions that have just occurred and will heal in due course: *participant 2.3: "For some of our clients, I don't see any point in [them] going to the GP. Sometimes it's something that's just happened, and we expect it to be like that so [they shouldn't] go to the doctor."*

To overcome these issues, the experts discussed implementing a feature that makes use of the extracted information to suggest a course of action, as explained by participant 2.5: *"Whether you can have solutions at the end to say well how long have you had a headache for? Right, try [taking] paracetamol or try drinking some water or a lie down or something. You know go and tell your care worker or your family first of all. So, it could almost be like a filter."*

Consequently, the application could be used in the patient's home, before directing the individual to treatments outwith primary care for minor ailments such as short-term headaches. More serious symptoms would require medical interventions, at which point the app can be used as a referent to support the patient in disseminating their views. Nevertheless, such a feature was not included as the app's purpose is not to diagnose the patient but instead help them to communicate more clearly with general practitioners.

4.4 Conclusion

Due to the lack of established guidelines on how to create accessible research methods for people with ID [96], a two-stage process was implemented during the development of the UCD workshops described in Chapter Five. Initially, a review of the literature was carried out to identify techniques that had been successfully applied in other HCI related studies and may be altered to suit the workshops goals. This step resulted in a basic structure for the workshop, yet there were still concerns over certain elements in the identified tasks, hence the need for their application with experts. In addition to mitigating potential accessibility barriers, the experts were able to provide their own views of how the proposed application should operate. Such an outcome was crucial, as the identified requirements were used to update a prototype prior to its embedment in the UCD workshops, thereby following the design after design approach advocated by Brereton et al. [54]. The success of the adjusted methods will be discussed at the end of Chapter Five.

Chapter Five: User Centred Design Workshops with Adults with Mild Intellectual Disabilities

Chapter Four detailed the results from the first two stages of Fig. 4.1 - identifying potential UCD techniques from the literature and utilising experts to adjust these techniques to better meet the needs of adults with mild ID. The findings from the resultant workshops will now be discussed (i.e. stages three and four in Fig. 4.1), including the aspects the participants found helpful, as well as those that caused barriers.

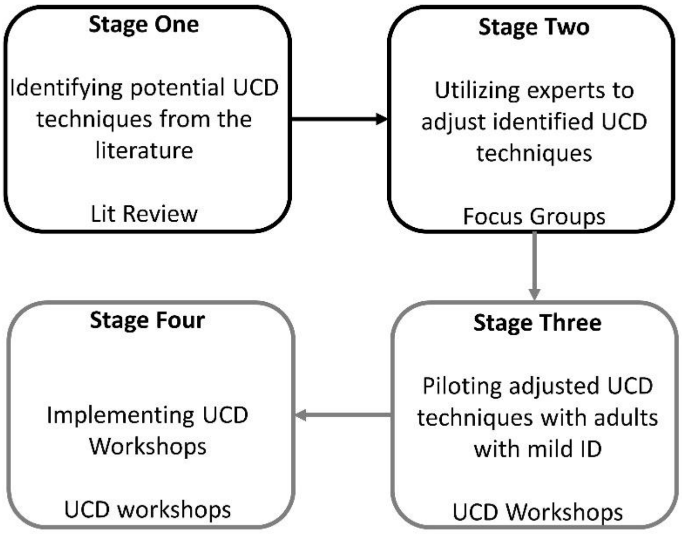


Fig 4.1. Repeated for Convenience.

5.1 UCD Workshop Methods

5.1.1 Pilot Workshop – Stage Three

As with the expert focus groups, the aim was to conduct two to three workshops under the guidance of Guest et al. [112] who suggest that 80% of all themes will be discovered within this period. Rather than recruiting the traditional five to eight participants per study [118], the experts involved previously indicated that four to six participants would be more appropriate. This was to ensure the participants felt comfortable in a group setting and had equal opportunities to present their views. Initially, one charity in Glasgow was contacted to identify participants who had adhered to the following inclusion criteria: adults aged between 18 and 60 (to reduce the presence of age-related cognitive diseases) who have mild ID; individuals who can communicate via speech (including with the use of AAC devices) and can understand verbal partners; and those with the visual capabilities to process imagery.

Easy Read Information sheets (see Appendix B) were disseminated to possible candidates to enable them to gain an understanding of what the workshop entails, with an in-depth version being sent to their caregiver to promote discussion. Potential participants were invited to take part if they could demonstrate their ability to provide informed consent, by answering the six questions proposed by Horner-Johnson & Bailey [119]. Four individuals consented to participate in August 2018; however, two dropped out unexpectedly on the day – see Table 5.1 for the demographics of all participants involved in the design workshops. Each participant had an unspecified range of disability that adhered to WHO's definition of mild ID (confirmed by the charity employee in charge of recruitment). Further information regarding their aetiologies was not collected as it was inappropriate to ask the participants about the specific nature of their disability. One charity facilitator was present during each workshop to assist the investigator in solving any challenges that arose. The participants also had the opportunity to attend with a caregiver for support, although this option was not adopted by any of the ten individuals.

Table 5.1: Demographics of participants with mild ID. "-" replaces information that the participants preferred to keep confidential.

Participant ID	Gender	Age
3.1, 3.2	F, M	41, 29
4.1-4.5	M, M, F, F, M	-
5.1-5.3	F, F, M	28, 29, -

5.1.1.1 Workshop Procedure

Before the workshop commenced, the participants were briefed on the structure of the study and had any concerns addressed by the author. They were then required to sign the easy read consent form shown in Appendix B, prior to engaging in an ice-breaker session to help them feel at ease with their peers. The four tasks that emerged from the expert focus groups were then presented for completion – see Appendix C for a more complete protocol.

The first task was essentially unchanged and involved a discussion on the following topics: preparing for consultations; positive and negative communication encounters with GPs; the use of touch screen technologies; and the implementation of AAC to support patients with ID throughout primary care consultations. Appendix C contains a list of the questions presented, which were adjusted by the experts to adhere to accessible language guidelines. Throughout the task, the participants views were captured via the sticky note methodology proposed by Zisook and Patel [108] and placed in full view to encourage further deliberation.

The image board [108] task was an extended version of that conducted by the experts. Once again, the participants with ID were required to individually critique images of medical symptoms and separate them into one of two categories: those that accurately represented the symptom conveyed; and those whose meaning was more obscure. The decision was made to initially pilot the three image sets (basic black and white symbols, coloured cartoons, and real-life photographs) with textual descriptions, despite concerns of response bias occurring. A group discussion then occurred on why some images were more accurate in describing symptoms than others, with the images being collated to form an ineffective image board, as well as an effective one. Those that had similar reasons for their inclusion on each board were grouped together for further analysis.

The penultimate task was also largely unchanged from the expert focus groups, since the participants were familiar with digital technologies. Tablet templates were placed on a flipchart, with the participants required to add mock-up objects depending on their views of what each screen should entail. This process involved a nominated leader driving the discussion, yet artefacts were only included on group consensus. Similar to Prior and Dawe [44, 53], the objects included general usability features such as skip buttons, as well as those more specific to the proposed AAC application. All artefacts were concrete to alleviate any barriers that may arise from impaired higher-order cognitive skills. To elaborate, example questions and answers were provided, rather than the “Question” and “Answer” cards previously used in the expert focus groups. Any elements unforeseen by the author were hand drawn on the prototype.

Task four involved a post-task walkthrough [116] evaluation of the prototype that emerged from the expert workshops – see section 4.3 for an in-depth description of artefact presented. Once again, a leader was nominated to select symptoms from two conditions (one involving pain and one without) on census of the group. During this process, the author observed the actions being performed and any areas of interest were discussed on completion of the task, along with features the participants liked/disliked.

Comfort breaks were administered between each task, with the participants being reminded of their right to withdraw during this time frame. Each workshop lasted approximately three hours, at which point the participants were debriefed on the initial results obtained and reimbursed for the travel expenses they had incurred. They also received a £5 lunch voucher for their participation. All studies were conducted under ethical approval from the Department of Computer and Information Sciences ethics committee, University of Strathclyde (ID: 915).

5.1.1.2 Workshops Analysis

Tasks one to four were audio recorded with participant consent and transcribed verbatim by the author to further their understanding of the data. Initial thoughts and key findings were captured in a research diary during this process to assist with future analysis. Task one was then subjected to a largely deductive framework analysis [73], with an initial codebook being developed using the concepts captured within the aforementioned sticky notes. This codebook was applied to the transcripts of task one by highlighting relevant excerpts in Microsoft Word and assigning them the appropriate tag under the following format "<tag>". The codebook was extended when important aspects of the data did not conform to any of the previous tags and comments were added where necessary to explain the application of certain codes. Such a process was repeated until the author was confident in their interpretation of the data. An additional researcher then reviewed the tagged transcripts and made note of any tags that required adjustment. The two researchers involved in the analysis then discussed their discrepancies and updated the codebook to reflect their conclusions. Similar codes were then grouped together to form themes, with the tagged transcripts being revised to conform to the final framework. The data was then charted into the framework analysis table, which subsequently included a structured summary of the barriers faced by the participants within the clinical context, as well as the strategies used to mitigate these barriers – see DOI:10.15129/94ca80dd-5896-4095-a56f-44ef2caf4f09.

Task four underwent an inductive framework analysis [73], as opposed to a deductive. The steps involved were largely the same as those described above, except that an initial codebook was derived from the notes produced during the transcription/familiarisation stage. The resulting table therefore contained a structured summary of the aspects of the prototype that were accessible to adults with mild ID, as well as those that hinder the communication process – see DOI:10.15129/71f05a5d-076a-44d2-9b6e-8f140129bb5c

During task two, the participants were required to group logically related images together whilst forming the (un)clear boards. For example, images that depicted the wrong facial expressions were placed in a similar area on the unclear board. These groupings were tagged with phrases suggested by the participants, which were used to form the themes discussed in the results section. All excerpts from the transcripts that centred on an image within the groupings were also tagged with the same phrase. As such, the characteristics that improve the clarity of medical images for patients with mild ID have been identified, with the findings being strengthened by direct quotes from the participants.

During task three, the author proceeded to tag each distinct feature generated by the participants. These features were then transferred to a spreadsheet, which included a column detailing the number of workshops in which they were discussed and the reasons behind their inclusion - extracted directly from the transcripts. This allowed the author to sort the spreadsheet by the frequency column, thus giving developers an idea of the requirements prioritised by adults with mild ID. The depth of discussion placed on each feature may also be determined.

5.1.2 Primary UCD Workshops – Stage Four

As will be discussed, the initial pilot study was a success and required no amendments prior to the implementation of further UCD workshops. Consequently, the findings from stages three and four of Fig. 4.1 will be reported together. During stage four, three additional charities (from the cities of Edinburgh and Glasgow) were contacted throughout June and July 2019 to assist in recruitment. The charity members utilised the recruitment strategy described in stage three, which resulted in two further workshops being conducted – see Table 5.1 for participant demographics. Five adults with mild ID were involved in the second workshop, with a further one dropping out on the day, and three were involved in the third workshop. Participants were required to conduct the same tasks described in stage three, with the collected data being subjected to the same analysis. They were then issued with an easy-read summary of the results on completion of the analysis – see Appendix B.

5.2 UCD Workshop Results

The results from the three UCD workshops will now be presented, which includes the barriers to effective care experienced by the participants, in addition to how AAC can alleviate such barriers. Tables 5.2 and 5.3 include a summary of the design requirements for the proposed application that were derived from these findings.

5.2.1 Task One – Focus Group

Throughout the focus groups, the participants discussed several barriers they face when attempting to access effective healthcare services. In addition, they introduced the various technical and non-technical strategies used to mitigate such barriers.

5.2.1.1 Access to Healthcare Services

The participants experience with primary care practices varied widely. For example, participant 4.1 had only attended in recent months to undergo their yearly ID health check, whilst others made regular appointments to manage chronic conditions or mental illnesses (participants 3.2, 4.1, 4.3, 5.2 & 5.3). Despite this range, all reported experiencing barriers when accessing services from their GP, the most prevalent of which was the availability of appointments. Participant 4.3 revealed that it can take up to three weeks to arrange a consultation within her practice, leading to detrimental effects on both her mental health and ailment: *"For a normal appointment you've got to know three weeks in advance what you've got… if there's not an appointment for three weeks you could be worrying unnecessarily till you find out whether it's something serious or whatever."*

This waiting period is prolonged even further if the patient requests to be treated by a preferred GP. Nevertheless, due to the seriousness of their condition, participants 3.1 to 4.3 have settled for treatment by doctors they are unfamiliar with. This has led to participant 3.1 falsely claiming that their condition is an emergency to ensure they receive a timely appointment with their favoured practitioner.

The participants also reported a large variance in the organisational procedures used to disseminate information and book appointments. Furthermore, these procedures were often static, with employees unable to adjust the methods employed to meet the complex needs of people with ID, as described by participant 5.3: *"I got my [diabetes] diagnosis over the phone which more or less just didn't work. There was no face-to-face sort of contact, that sort of thing. And it ended up me just basically ignoring my diabetes for quite a few years. There wasn't really much in the way of clear communication."*

Despite participant 5.3's practice being aware of his ID, he received a life-changing and complex diagnosis over the phone without access to immediate or future support. This was clearly unsuitable to his needs as he continued to live a normal life thus potentially heightening his condition. Instead, it would have been more appropriate to conduct a face-to-face consultation whenever his support worker was available, to ensure he understood his condition to the point where it could be successfully managed.

Finally, the participants also indicated that they were not always aware of their need to see a doctor and instead rely on family members to facilitate this process. Nevertheless, they often withhold crucial information regarding their health, as they do not want to overburden their loved ones: *Participant 3.2: "My family do a lot of caring work within the family. So to give them information that I'm not well then I'm probably going to feel a wee bit over[whelmed]... Normally a family member [will] say "right you need a doctor" and that's about it [in terms of preparation]."*

5.2.1.2 Practicing GP

The participants had conflicting views regarding the quality of care received from their GP, which often leads to them dealing exclusively with certain doctors. Their complaints largely centred on the lack of adjustments being made by a medical professional to accommodate their specific needs. Terminology was a major factor in this, with the GP regularly employing complex terms, or language inappropriate to the patient's level of ID: *Participant 5.2: "Because I speak so well doctors think that*

I understand more than what I do…and I'm like "what? Can you simplify that?"" Participant 4.3: "If they see the word learning difficulty, they just think that's it, obviously they've got the mental capacity of a two-and-a-half-year-old so I'll just talk to her like that when there is different levels."

Furthermore, the participants felt that some medical professionals lacked empathy towards their situations. This meant that an insufficient amount of time and effort was expended on diagnosing the health complaints made, which may ultimately lead to severe consequences: *Participant 4.3: "I just felt that they weren't interested. They were running late, and they were just wanting me in and out the door. They weren't interested in sort of me or what was wrong with me. Which luckily, if I was somebody that didn't have kids that was on the brink, that could have serious repercussions."*

In contrast, the positive experiences discussed by the participants centred on their preferred GPs ability to meet their complex needs. Language was also a major part of this, with the medical professional being aware of the best way to communicate with the patient, whilst breaking complex concepts into simpler terms: *Participant 3.2: "They don't use the complicated language or if they do they then say it in simpler terms for you as well." Participant 4.3: "He sort of asked loads of questions but, like, it was simple short questions, it wasn't a case of big, long winded [sentences]."*

Being treated by the same doctor also helped the participants to establish a relationship with a figure who is often seen as authoritative. This assists in easing anxiety issues and in turn enables the patient to be more open about their health conditions. Additionally, people with ID are more prone to developing a vast range of diseases than the general population [7]. As such, their medical histories can become complex, meaning it may be difficult for GPs unfamiliar with the patient to perform a complete diagnosis: *Participant 4.5: "If you get to use the same doctor, you get friendly with them and they get friendly with you, so you are able to speak to them more." P5.2: "I can go to the GP without my mum because she knows me that well. I've got the confidence to not go with support…I try and see the same doctor for anxiety reasons but also for the doctor's sake 'cause my history is so complicated."*

5.2.1.3 Time

The amount of time afforded for appointments was also reported to be a major barrier that effects the quality of consultations. Less than half of the participants (4.3, 5.1, 5.2 & 5.3) would adequately prepare for an upcoming consultation as they do not wish to burden their support network with their problems. Nevertheless, several had utilised internet enabled devices to research their symptoms and prepare a list of concerns to be discussed with the GP. Yet getting through these lists proved to be quite a challenge: *Participant 5.1: "Sometimes I have questions, but the problem is you don't get very long in the GP…You try to get all those questions [answered] in the ten minutes, it's quite a struggle."*

In addition, the participants believe that time constraints prevent medical professionals from thoroughly exploring all routes leading to the cause of a symptom, including familiarising themselves with the patient's history: *Participant 4.4: "You go in and you talk about what you want and then they get up and open the door and you're told that's it, it's time to leave" Participant 1.2: "They just don't have time to read your record. They go in and they say, "well what's wrong with you" [patient] "Oh I've got…." [doctor] "oh we'll give you Co-dydramol.""*

Consequently, patients with ID could benefit from double appointments. Yet when probed on this, only participant 5.2 revealed that they regularly use such an option, with the rest unaware of their right to do so. This suggests that practices are not adhering to international guidelines on consultation length e.g. [120]; nevertheless, there were some GPs willing to overextend on appointments to ensure their patients had all concerns addressed: *Participant 3.2: "If I'm having trouble with my diabetes then the doctor that I go to see in the practice, he makes time. He'll deliberately go behind his schedule so that he can make sure that everything is back okay and, you know, figure out why I'm having trouble with my diabetes."*

5.2.1.4 Support

Surprisingly, the majority of participants reported that they attend GP appointments with support workers, despite previously indicating they value their privacy. This may suggest that their willingness to share personal issues with paid caregivers differs from that of their family members to limit the amount of stress placed on loved ones. The primary responsibility of the caregiver was to act as an intermediary between the patient and GP to ensure the stakeholders understood what was being communicated. This was particularly true during appointments of a complex nature. *Participant 4.3: "As soon as they found out I had learning difficulties and I started taking my support worker they explained more to my support worker. So even if I didn't get it then and there, when I went away, she's going to explain it in a way I would understand."*

Participant 4.3 also felt that her complaints were taken more seriously by medical professionals in the presence of a support worker. In contrast, participants 4.4 and 5.2 reported having negative experiences when attending appointments with support, as their own views had less value in this situation: *Participant 5.2: "They look as if they're looking at my mum and I'm like "I'm here."…because mum's tried to support me it's like "well have you asked this or what can we do for this" and I'm like just sitting listening with them. If I'm on my own I will have the guts to sort of say "what's this or why are we doing this or would this be helpful?" Like I will ask the questions and I think my mum sort of has the best intentions but she kind of overrules a little bit."*

Finally, participant 4.2 spoke about how they require support during consultations but cutbacks in funding meant that this was not feasible. Paper notes therefore had to be taken to update their support network on what was discussed, meaning vital information may be lost in translation.

5.2.1.5 Technological Aids

The participants reported a high usage of memory aids (primarily pen and paper) to support them in recalling facts that require further scrutiny outwith the consultation. Strikingly, this contrasted with their use of communication aids, with only participant 5.2 having utilised a low-tech form in the past: *Participant 5.2: "So I've written maybe a page long [summary] of what I find useful, what's rubbish....I'll just write a little summary saying "well doctor's need to keep an eye out for this or if somebody struggles to speak in this way, [this will] make it easier."* Participant 5.2s use of a patient passport was due to the insistence of her mother who was involved in the development of such aids for children with severe illnesses. This may suggest that the availability of communication aids, as well as their effectiveness, must be promoted in greater depth to ensure they are adopted on a wider scale.

Nonetheless, all participants felt that a digital aid could assist both themselves and patients with other/more severe disabilities to better prepare for a consultation, thus enabling them to communicate effectively with GPs: *Participant 3.2: "It [the app] should gather symptoms and then send them to the GP. [Because] for us with mild learning disabilities, sometimes we find it difficult to describe symptoms. Thinking about physical disabilities it's also a good idea because with a tablet it [would] quite literally be a case of boom into the doctors, right this is what it is…right that's a chest infection, here's some antibiotics."*

One major barrier to the adoption of high-tech aids, however, is this populations familiarity with tablets, since just five of the participants own or use a tablet on a regular basis. On the other hand, all had access to a smartphone with participant 5.3 stating that these devices are more accessible, in terms of availability, than tablets: *Participant 5.3: "You're probably more likely to get people having smartphones these days than you would, well than having no phone. I mean [some might] not [be] used to tablets. In saying that I used the tablet for everything."*

5.2.2 Task Two – Image Boards

Previous literature has shown the importance effective imagery has on the use of AAC devices by people with ID e.g. [26, 32, 33, 106]. Nevertheless, there is little guidance into the factors that increase the accessibility of medical images for people with ID – see section 3.2.2.3. During task two, the participants identified several characteristics that may support designers in developing more appropriate resources.

5.2.2.1 Facial Expressions

The emotions expressed by a character had a significant impact on the clarity of images. For example, two of the three workshops originally concluded that the man in Fig 5.1.1 was not experiencing pain since his facial expressions alluded more to happiness. Moreover, the participants in the second workshop were unable to associate the emotion of sadness with the image shown in Fig. 5.1.2: *Participant 4.4"I think he was in a dream or something. Participant 4.3: "He looks like he's playing with his tablet…I think I'd like tears, like maybe one of those things with like tears or* *something."* Participant 4.3 suggested that the inclusion of tears would improve this image's clarity since it may demonstrate that the person has been crying. Consequently, these views may imply that it is more appropriate to capture the extremity of an emotion to ensure it is understood by the ID population as intended.

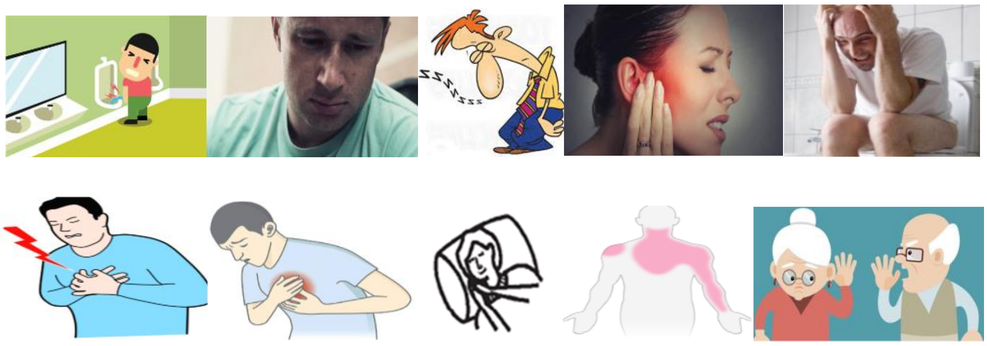


Fig. 5.1: A subset of images critiqued by the participants during task two.

5.2.2.2 Body Position

There were multiple instances in which the position of the body was considered the most important aspect of an image. Participant 3.2 was generally able to grasp the meaning of Fig. 5.1.1; however, they questioned the location of the character's head since he associated the action of looking up with being in pain. Furthermore, the participants in the second workshop failed to agree upon the clarity of the image displayed in Fig. 5.1.3: *Participant 4.1: "He's sort of dozing off there, he can't keep his eyes open. Participant 4.5: "No, he's standing up." P2.3: You couldn't sleep standing up. It's a weird one."* Despite the facial expression and presence of "z's" making the image clear to other participants, participants 4.3 and 4.4 could not see past the character standing up. Consequently, they were more inclined to select images that depicted the character lying in bed - an action they found more natural for this scenario. Finally, participants 4.3 and 4.4 were able to recognise that the woman in Fig. 5.1.4 was in distress but felt that the area of pain was emanating from her cheek due to the position of her hand. As such, designers must ensure that their images naturally capture the body language experienced by an individual suffering from the condition displayed.

5.2.2.3 Colour

Colour was shown to both effect the clarity of an image and differentiate between similar types of pain. For example, participant 5.2, who is short sighted, failed to identify that the man in Fig. 5.1.5 was sitting in a restroom: *"I had to really look closely to see because he's wearing a white outfit on a white toilet so I couldn't even identify the loo. I was thinking more headache because he's holding his head."* This image may therefore have benefited from the use of contrasting colours to enable people with visual impairments to recognise its finer details. Participant 3.2 also raised this point and stated that the black and white pictures are appropriate for those who are colour blind but may be less aesthetically pleasing for those with normal vision. Additionally, the participants preferred using colour (as opposed to other methods such as Fig. 5.1.6) to indicate the area and intensity of pain, like that shown in Fig. 5.1.7. In general, they found warm colours such as red or orange to indicate more intense pains, with cooler colours such as green and blue representing a numb or tingling feeling: *Participant 4.3: "Maybe a peach circle for like pain but not like a burning pain. And then like a deeper red for a burning pain….Blue just gave me the impression more of numbness if anything."*

5.2.2.4 Lifelike

The participants routinely found the real-life photographs to be clear as they reminded them of conditions they had previously experienced. This was due to the amount of detail that may be conveyed: *Participant 3.2: "It says what it needs to say but to me the one that we've picked over there said it more…Sometimes actually seeing the physical side of it and the emotional side of it does work better than the drawing."* Moreover, the participants felt that even less detail could be captured by the black and white drawings. For example, in Fig. 5.1.8 they found it difficult to establish whether the woman's eyes were open. As a result, participant 3.2 explained that the black and white image sets may be more appropriate for users with severe ID but are too simplistic for their own abilities. This was also true for those drawings that captured the outline of a body (Fig. 5.1.9) since no distinguishable features were included.

5.2.2.5 Graphic

Throughout the three workshops, the participants found at least one image to be too graphic to include in the app. Participant 5.2 suggested that colour drawings should be used to capture these concepts as they are less realistic and may be altered to obscure the graphic nature of a condition: *"I think that is a little bit too real looking. Whereas the other one [coloured drawing of someone being sick] that's like a green colour, it's a little bit of a distraction."*

5.2.2.6 Personalisation

The final concept discussed by the participants in relation to the images reviewed was personalisation. There were multiple instances in which a participant hesitated to declare that an image was clear since the traits of the character displayed were completely different to their own. This included both gender (Fig. 5.1.1) and age (Fig. 5.1.10): *Participant 4.5: "I prefer this one cause that's just showing you male and that one's showing both." Participant 3.1: "I liked the picture, but I didn't pick that one 'cause it just says that old people are deaf whereas young people can [also] be deaf."*

In addition, images may have multiple meanings based on the communication system the user is familiar with: *Participant 3.2: "People with more severe learning disability who are used to PECS* [121] *will pick out things like the person with the lines round him is cold, the person with the arrows is dizzy. They'll pick that out because that's what they're used to."* Consequently, this suggests that AAC technologies must provide the functionality to support users in switching between multiple image sets based on their own needs.

5.2.3 Task Three – Paper Prototypes

The participants identified a plethora of design requirements to be embedded within clinical AAC tablet applications for patients with mild ID. These are summarised in Table 5.2 and generally fit into four themes: pre health questionnaire; health questionnaire; post health questionnaire and interaction modalities.

5.2.3.1 Pre Health Questionnaire

In advance of providing medical information, the participants requested two features to assist them in attending the consultation. Participants 4.3 to 4.5 revealed that they had issues remembering the exact details of an upcoming appointment and could therefore benefit from a screen that displays this information: *Participant 4.5: "A reminder about your doctor, when you've got to go. 'Cause quite a lot of people, they do forget about their appointments. Now if they have something there to remind them* *about it [that would be helpful].”* The time and location of the appointment, along with the practicing GP were considered to be the most important aspects within this process.

During workshop three, the participants also discussed the difficulties they have in contacting and accessing appropriate services: *Participant 5.2: “If you put in like your post code that way it can identify [your] closest GP. Near me I’ve got three different GPs, so it can direct you to the [details of the] nearest one. You could have sort of like the top five [services] dentist, mental health, hospital, A&E, and GP…A lot of us do need public transport because I can’t get to <anon> easily. Maybe a little corner bit on that front page to say “here’s the link to these forms of transport.””*

Hence, the app could enable them to identify the most appropriate local service to treat their condition, ranging from dentistry’s to accident and emergencies. In addition, participant 5.2 felt that it was paramount to provide public transport links for these services, thus breaking their reliance on caregivers to gain access to the healthcare system. Fig. 5.2 includes a paper mock-up of the features proposed by the participants to assist patients with mild ID in attending medical appointments. The button on the top left side of the screen would be used to highlight and playback the information contained in the interface.

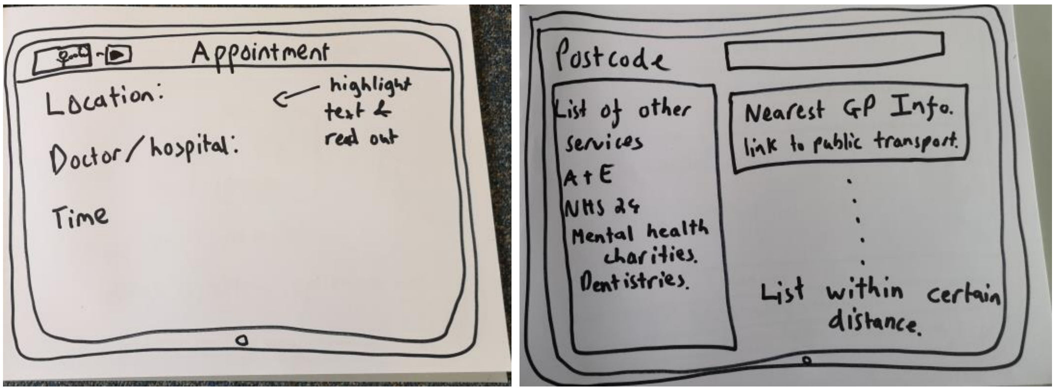


Fig. 5.2: Suggested features to assist patients with mild ID in accessing healthcare services.

5.2.3.2 Health Questionnaire

All participants agreed that the most effective way to improve communication with a GP was to supply them with a list of pre-selected symptoms. This should be achieved via an accessible questionnaire whose structure follows a hierarchical route similar to the one discussed by the experts. First, a body part causing the user distress, or the primary symptom of a common condition, should be identified. Further options related to that selection should then be explored: *Participant 5.2: "Maybe you had something that said like different parts of your body. So head, chest, arms, legs, you have the headings like that and [then] you go into the subheadings for like symptoms."*

Participant 5.2 suggested that the body parts and primary symptoms (e.g. weight loss) could be displayed in a colour coordinated, textual list. Nevertheless, this may be inappropriate for those who are illiterate or require more visual methods of displaying information. As such, the three workshops suggested an alternative approach by first presenting an image of the body to enable the user to tap on the area causing them pain. The app would then move on to displaying sub-symptoms in an accessible format or if the person was not in pain display the primary symptoms described previously. The paper mock-ups of the body and symptoms screens may be found in Fig. 5.3, whilst Chapter Four included a discussion on why the body image approach was not implemented.

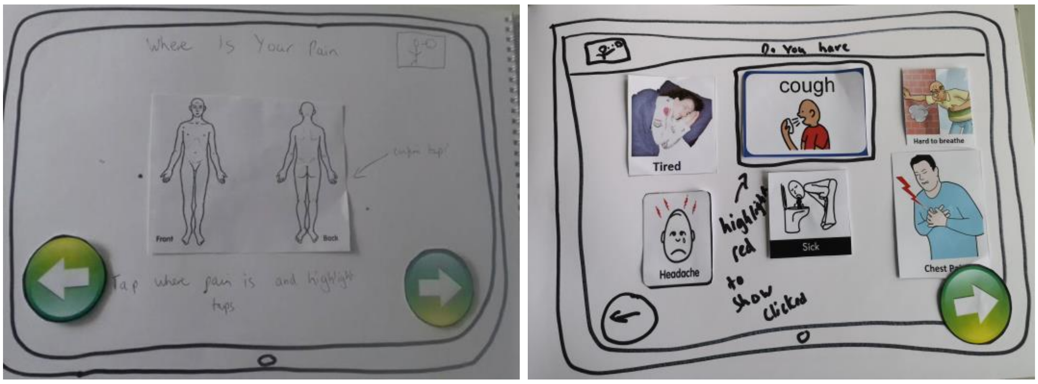


Fig. 5.3: Possible methods of extracting symptoms from patients with mild ID.

5.2.3.3 Post Health Questionnaire

Once the questionnaire is complete, the participants requested that the results be displayed in a single screen using the modalities discussed in the next sub-section. As such, the stakeholders involved in the consultation may refer to this information when elaborating on their views. To facilitate this process, a save and review feature must be implemented, as well as the option to print the results for those who are using publicly accessible tablets: *Participant 4.3: "I think there should be a bit where if it's your tablet you can just sort of download it and keep it in a certain section for when you go to the doctor. But, if it's not your tablet, if you're going to the library there should be like a button where you can print [it] out and then basically you can [take the] sheet of paper to the doctor."* Fig. 5.4 shows a possible way of displaying the results extracted from the questionnaire. Participant 5.2 felt that the results page should also link to a patient passport where possible to support medical professionals in employing more appropriate consultation techniques.

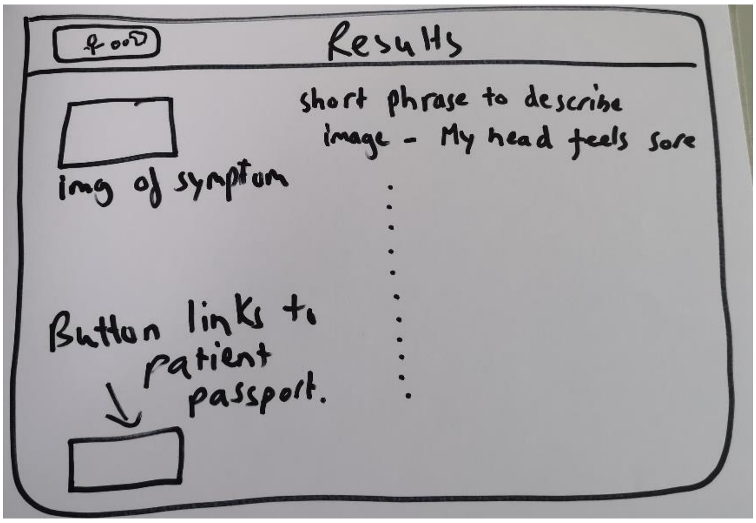


Fig. 5.4: Participants views on how to display the symptoms selected.

5.2.3.4 Interaction Modalities

All participants discussed the need to capture the information displayed via three modalities. The first, accessible language, entails describing the symptoms and questions in the simplest terms possible. This includes avoiding medical jargon where appropriate; however, such a strategy may not be suitable for patients with visual problems or insufficient literacy skills. Consequently, the option to highlight and play back excerpts must be provided, as described by *Participant 3.2: "This [audio] button would [first] say [the question] "are you in pain" and then highlight the yes [option before] saying "yes" and then highlight no... Three separate buttons [for each option] would make it more difficult for somebody with a LD."*

In addition to speech and text, the participants believe that imagery would help them to understand the more complex symptoms. This was also true for representing the function of buttons, as described by participant 3.2: *"See thinking about it the guy with the speech bubble would probably be better cause that's saying that it [audio button] can read it for you."*

5.2.3.5 Summary of Requirements

Table 5.2 includes a summary of the requirements discussed by the ten participants with mild ID. The number of workshops in which each requirement was mentioned is provided, as well as how they relate to the views of the experts involved in Chapter Four.

Table 5.2: Primary design requirements extracted from participants with ID. * indicates that all workshops discussed the requirement with 1, 2 and 3 used otherwise.

Requirement	**Relation to Experts Views**
Personal profiles must be facilitated to enable features such as saving symptoms in a patient history. (*)	Same feature discussed by experts.
The application should initially determine whether the patient has a problem with a body part or some other common condition e.g. diabetes. (*)	Same feature discussed by experts.
Question sets should form a hierarchy with selected symptoms leading to relevant sub-symptoms. (*)	Same feature discussed by experts.
Patients may select more than one option at a time. Selected options should be highlighted to distinguish them from those unselected. (*)	Experts disagreed. Felt that allowing more than one option to be selected could be cognitively challenging to patients with mild ID.
Patients should have the option to show where their pain is by tapping on an image of the body. (*)	Same feature discussed by experts.
A maximum of 4-6 options should be presented at any one time. (*)	Experts disagreed. Felt that a maximum of four options would be more accessible. Preferably two should be presented.
The language embedded within should follow accessibility guidelines. Medical jargon should be avoided where possible. (*)	Same feature discussed by experts.
Audio playback of text should be supported within all pages. (*)	Same feature discussed by experts.
Images should be included to enhance an individual's understanding of a medical condition, as well as an embedded button's functionality. (*)	Same feature discussed by experts.
An accessible list of the symptoms selected should be displayed on completion of the questionnaire. (*)	Same feature discussed by experts.
Left (back) and right (forward) arrows should be used to navigate from a page. (*)	Same feature discussed by experts.

Patients should be able to view the details of upcoming appointments. (2)	Feature not identified by experts.
Users should be able to view public transport routes to local services. (3)	Feature not identified by experts.
The app may be used to manage a list of medication being taken by the user. (3)	Feature not identified by experts.
Selected symptoms should be saved for future use. The ability to print these results must also be offered. (2)	Same feature discussed by experts to allow a questionnaire to be resumed at a later date thus combating short attention spans.
Colour can group logically related items together. (3)	Feature not identified by experts.
Scrolling should be avoided if possible. (1)	Same feature discussed by experts.
The app should provide access to the user's patient passport if available. (3)	Same feature discussed by experts.

5.2.4 Task Four – Post-Task Walkthrough of High-Fi Prototype

In the final task, the participants were required to select symptoms using the digital prototype that emerged from the expert focus groups – see Chapter Four for a description of the application. The feedback received during this process will now be discussed and is summed up in Table 5.3.

5.2.4.1 Tutorial Screen

Despite the prototypes symptom selection process being similar to that identified in the task three, workshops two and three were initially unable to grasp the concept of the questionnaire hierarchy. Once it was explained that answering yes to a primary question would lead to its sub-questionnaire being presented, the participants were able to progress through the application without support. As such, multiple participants suggested that it would be necessary to include a tutorial to enable users to familiarise themselves with the app: *Participant 5.2: "That [the questionnaire hierarchy], I think you would have to like explain a little bit beforehand because that was a bit confusing there until you got to that point."*

5.2.4.2 Customising Features

Yellow was utilised as the primary background colour to accommodate for users who experience dyslexia [122]. Nevertheless, the participants felt that a range of colours may be more appropriate for other medical conditions or to simply meet individual preferences. As such, they requested the ability to customise the colour schemes employed. Participant 5.2 also felt that it may be advantageous to customise the voice used to play back text to a more local dialect. Finally, the experts in Chapter Four suggested that the utilisation of a single image set would lead to accessibility issues for users with ID. Consequently, a feature was developed to allow an individual to switch between three styles of images and this was well received by all participants: *Participant 4.3: "I like the fact that you can change it. Some images aren't as clear but then the other ones are a bit clearer, so if you are confused you can change the image and understand [it] better."*

5.2.4.3 Usage of Results

All participants felt that the app could improve communication by providing a building block of symptoms that may be elaborated on throughout the consultation. This may also empower patients with limited verbal skills, as discussed by participant 4.3: *"It sort of would be good to have something like that for, like, people who maybe aren't as good at communicating, that can just point to it and have a limited conversation. Like for me, I'm reasonably alright, so therefore I can sort of explain reasonably well if I'm not well. Whereas not everybody is like that so having this I think is a good idea cause then you've got the basics, so you just have to polish it up kind of thing."*

One final approach to utilising the captured results was discussed by the participants in workshop three. They suggested that sending the list of symptoms to the practice in advance of the consultation could assist in overcoming the various access barriers introduced previously: *P3.2: "If you could scan that result and send it to your GP and they said, "oh you don't need to come in cause it's [not serious]." So it would also make it beneficial to the actual service of the thing because you don't actually want to go unless you have to."* This process would enable the practice to arrange an appointment date relative to the seriousness of the symptoms selected. Consequently, they may also be able to free up consultation times by forwarding on patients with less serious illnesses (e.g. a normal headache) to other services such as a pharmacy.

Table 5.3: Further features identified by the participants when completing task four. * indicates that all workshops discussed the requirement with 1, 2 and 3 used otherwise.

Requirement	Relation to Experts Views
Users have access to a tutorial on how the app works. (*)	Not identified by experts.
Users can switch between different image sets. (*)	Same feature discussed by experts.
Users can customise the colour schemes employed. (*)	Same feature discussed by experts.

Users can customise the style of voice played back. (3)	Not identified by experts.
Results should be sent to the practice in advance of the consultation to ensure appointments are made within a suitable timeframe. (3)	Experts disagreed. Felt that the app itself should make the decision on the best course of action, as opposed to forwarding on the results to medical professionals.

5.3 Updated Design of the Proposed AAC Application

As highlighted in Tables 5.2 and 5.3, the bulk of the requirements discussed by the participants with mild ID were similar to those identified by the experts in Chapter Four. In particular, the paper representations developed in task three broadly matched the design of the prototype that emerged from the expert focus groups. Nevertheless, the patients discussed some improvements to this prototype that were subsequently implemented prior to the evaluation in Chapter Seven. The reader should note that only those features that have a direct effect on the consultation were embedded due to time constraints. For example, those used to help alleviate access barriers were not included.

5.3.1 First Time User Tutorials

Some of the participants had difficulty understanding the structure of the questionnaire and could only advance once assistance was received from the investigator – section 5.2.4.1. They suggested that first time users would benefit from a tutorial explaining how the application works, to ensure they know what is expected of them, as well as the functionality of each button. Consequently, the option to view a tutorial should be presented on start-up of the application. The video should cover: the accessibility features of the application; how an individual answers questions; when help menus occur; and the presentation of the results on completion of the questionnaire. Nevertheless, this feature may be frustrating for those who regularly utilise the application and may be moved to a separate menu once a log-in feature has been implemented. User profiles will enable the app to store whether an individual has watched the tutorial and subsequently prevent the video from automatically playing on log-in.

5.3.2 Swapping the Style of Pictures

As highlighted in section 5.2.4.2, the adults with mild ID felt that swapping the style of images displayed could be advantageous when the meaning of a symbol is more obscure. However, this feature was implemented via a keystroke, which may not be accessible to a large bulk of the target population due to the reliance on an external keyboard. As such, a further button was added to the interface to facilitate the image exchange functionality and was subsequently denoted via a face-swap symbol – see Fig. 5.5.


I have a problem with my ears or hearing

Fig 5.5: The implemented image swap button. Clicking on the button will change the image sets used to display the potential options.

5.3.3 Increasing the Number of Options

The participants suggested they were able to process questions with a greater amount of choice – up to six options, see table 5.2. Additional question formats were therefore implemented to extract a more comprehensive history from the patient, with Fig. 5.6 underlining how the duration of a condition is captured. Chapter Six will discuss the exact question types available to the user in greater depth. Additionally, the background colour of the potential options was changed to yellow, as opposed to white, under the guidance of participant 4.3 who indicated it would help to mitigate the accessibility issues that arise from dyslexia. A white border was also added to make explicit the area in which the user should tap on to select an answer.

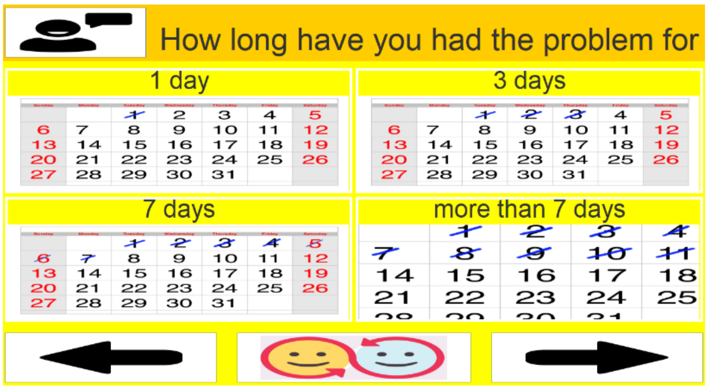


Fig 5.6: An example of non-binary multiple-choice questions.

5.4 Relating the Design Requirements to the Personas

Visualising the potential benefits of the updated prototype may be best achieved by linking the identified design requirements to the personas listed in Chapter Two. This subsection therefore compares the characteristics of the application's stakeholders against the requirements highlighted in Tables 5.2 and 5.3.

5.4.1 Patients

As discussed in section 2.2.2.1, Jane's knowledge of the human body is significantly impaired, meaning she finds it difficult to recognise and subsequently inform others of medical symptoms. The structure of the questionnaire included in the prototype, as well as the design of its content helps to alleviate such a barrier. First, the patient is prompted to consider smaller aspects of their health (split into significant conditions and body parts), as opposed to their overall wellbeing, which may assist them to hone in on important symptoms that may have otherwise been overlooked. Questions are presented via a combination of modalities including accessible language, speech, and imagery, which helps Jane to form a better understanding of concepts that she is unfamiliar with. Offering the ability to switch between different image sets also assists in overcoming the heterogenous nature of the ID population, since users are likely to employ different types of images in everyday life e.g. PECS [121].

Restricting the number of options available to Jane once again encourages her to focus on a more manageable set of symptoms. Yet it is important to allow her to select more than one of the options providing they are relevant to her health context. The questionnaire should then respond appropriately to these selections by exploring the symptom pathways of each answer. This will be discussed in further depth in Chapter Six. Selecting a symptom involves the user tapping on the desired image prior to the right-hand arrow, with this process better suited to the impaired motor skills of Jane, thereby reducing the number of accidental activations that may occur. The return arrow is also useful for Jane to revert back to a previous question if a mistake has been made. Only basic touchscreen actions have been implemented, with the tutorial available to Jane when needed to reinforce how to navigate the application's interface.

Collating the symptoms into a single page provides the patient with a resource to refer to at times when they are struggling to describe how they feel. They may utilise the range of modalities that convey these symptoms to provide a more accurate representation of their current health context. The results page is particularly useful for Jane who finds it difficult to converse with strangers on topics she is less familiar with and may provide her the confidence to become actively involved in her healthcare as opposed to deferring to caregivers.

The participants with mild ID discussed several features to alleviate potential access barriers, yet not all can be considered useful for Jane. The ability to view upcoming appointments can overcome short-term memory impairments, which may lead to a reduction in the number of "did not attend's" that occur, especially if such details are distributed regularly via push notifications. In addition, forwarding the results page on to the practice can support patients to better navigate the appointment scheduling process and therefore lead to more timely consultations. Finally, offering accessible public transport routes can break the reliance patients have on caregivers to attend primary care consultations. Nevertheless, Jane is visibly vulnerable and unlikely to travel on her own, meaning this feature would be better suited to other patients with mild ID.

5.4.2 Caregivers

James has only recently become a caregiver for Jane and is therefore unfamiliar with her medical and communication needs – see section 2.2.2.3. Consequently, he could benefit from Jane's patient passport being linked to the application to try and help the GP to conduct the necessary reasonable adjustments to their consultation techniques. James is a paid caregiver, meaning he has limited opportunities to observe the patient's medical symptoms prior to the consultation. As such, he is likely to be reliant on information that has been passed on from Jane's family members, which in itself could be inaccurate. The results page offers an alternative source, one that has been extracted directly from Jane and can be used to reinforce her views during the consultation. In addition, focus should be directed back towards the patient, as opposed to James interacting with the GP on their behalf.

Juni on the other hand is the patient's mother and is responsible for helping her child to prepare for an upcoming consultation. She therefore has the opportunity to embed the application in this process to improve the number of symptoms covered. Although Juni is less rehearsed than James in operating touchscreen technologies, she is still able to help her child understand the questions presented and can use her own observations to answer queries involving abstract concepts. During the consultation, Juni can encourage her child to make reference to the results page, rather than answering questions for her, thus increasing direct communication between the practitioner and patient.

5.4.3 Medical Professionals

Jade is likely to benefit more from the application than John since she is also unfamiliar with the needs of the patient. As such, the linked passport may once again help her to adjust her consultation techniques to better meet the needs of the patient, yet this is questionable due to Jade's lack of experience with the ID population. In contrast, the results page provides a building block of symptoms that Jade can explore during the consultation. This information is presented in a format that is accessible to all stakeholders, meaning it is a shared resource that both the patient and practitioner can use to elaborate on their views. The time constraints placed on the consultation may also be alleviated since the GP is not required to start from scratch. John's primary benefit from using the application also stems from the results page. The questionnaire is based on the health trends of the ID population (see Chapter Six), meaning it may pick up on symptoms that would have otherwise been overshadowed by John as he is not familiar with this literature. He also finds the app helpful when building a rapport with a new patient due to the inclusion of the patient passport and the produced set of symptoms. Finally, Jillian the ID nurse has the skills needed to implement the application in practice when she deems necessary or when brought in externally by the patient.

5.5 Discussion

All participants with mild ID discussed having negative experiences with healthcare services that matched the barriers identified during the scoping review (see section 3.2.2.1), thus strengthening the need for the proposed clinical AAC application. Many centred on static organisational procedures that failed to meet international guidelines or the complex needs of patients with ID. For example, the ten individuals with mild ID felt that they rushed through their medical concerns with GPs (similar to [18, 65]), yet just one indicated they were aware of their right to book double appointments [120]. In addition, the participants cited that medical professionals often lack the knowledge required to employ appropriate consultation techniques, as well as recognise conditions common to the ID population (like [17, 18, 32, 33, 49]). This led to them dealing exclusively with GPs who had become familiar with their personal needs and were able to present information in an accessible manner. Furthermore, the participants acknowledged that establishing a relationship with a GP resulted in more accurate diagnoses, due to the medical professional becoming familiar with their complex medical histories.

In contrast to previous literature [17, 80], the participants with mild ID did not view insufficient communication between medical professionals as a major barrier. Instead, their discussions centred around how medical professionals were disseminating information to them or their caregivers. Nevertheless, this may have been due to the workshops scope focusing on primary care consultations, as opposed to the entire healthcare system where greater collaboration is required. Moreover, the participants with mild ID had greater concerns regarding accessing appropriate services in a timely manner. This suggests that the aids identified within the scoping review neglected to consider the entire consultation process and instead concentrated on alleviating the barriers between patients and medical professionals. There was also some evidence to support Jones and Kerr's [41] view that mild intellectual disabilities are frequently overshadowed, with participant 4.3 stating that her practice remained unaware of her condition for an extended period of time.

5.5.1 AAC Technologies

Surprisingly, just 10% of the participants with mild ID indicated they had used some form of AAC (patient passport) during a clinical consultation. As such, the availability of these technologies, including how they benefit patients, must be disseminated more widely to ensure adults with mild ID are able to take advantage of them. Increased awareness of the guidelines on how to treat patients with ID is also required to ensure patients have regular access to procedures such as double appointments [120]. Despite not using AAC technologies in the past, all participants recognised that they could benefit from a newly developed tablet application.

Both the experts in Chapter Four and the participants with mild ID agreed upon the best approach to increase communication with GPs. They suggested that a digital questionnaire that breaks the consultation down into manageable chunks could help to extract more reliable information from patients and stimulate conversation on the symptoms identified. The proposed solution is therefore similar to that of Boström et al. [28–30], who utilised a tablet questionnaire to determine the psychological health of adolescents with ID. Nevertheless, the structure of the questionnaire advocated by both sets of participants was wholly different to that implemented in [28–30]. Boström et al. [28–30] developed a 43-point survey across five topics of an individual's mental health, with the user required to answer all of the questions presented. Yet this approach was deemed to be unfeasible within the proposed clinical AAC application, since the question sets employed must be based on the health demographics of the ID population. As such, presenting queries on every possible symptom a patient may encounter would result in an overly long and unmanageable questionnaire that is unsuited to the cognitive skills and short attention spans [12] of people with ID. Instead, the participants recommended that the application first identifies the primary symptom being experienced by the patient prior to extracting related sub-symptoms. Consequently, a large range of conditions can be ruled out from the offset. Chapter Six includes an ontology-based approach to facilitating such a process.

Despite the discrepancies in the employed questionnaires, the bulk of the design requirements derived from the participants matched those identified by Boström and Eriksson [28]. This included: utilising a range of modalities to adhere to the heterogeneity of the ID population e.g. complementing text with identifiable imagery; implementing simplistic screens with a limited number of possible options; reducing the use of technology specific actions such as swiping; allowing for customisation of the interface to suit personal preferences; and implementing a pause and resume feature. Furthermore, the participants intended use of the application was also similar to the requirements identified by Menzies et al. [26, 27] when designing AAC technologies to promote communication between dental practitioners and people with ID. The experts in Chapter Four suggested that the application could assist individuals to better prepare for the consultation by practicing what they wish to convey prior to the appointment. This process could help to raise the awareness of commonly overshadowed conditions (similar to the notes-based prompts described in section 3.2.2.2), whilst increasing the patients' ability to recognise symptoms, since they have a referent to compare their conditions to. Embedding digital passports within the results page will also help to ensure the medical professionals are aware of the patient's communication preferences (like [17, 18, 26, 27, 67, 80]).

Finally, the participants recognised that AAC technologies can also assist them when accessing healthcare services. First, they suggested that pushing the details of upcoming appointments on a regular basis could mitigate short-term memory impairments, thus reducing the number of cancelled consultations. In addition, providing a list of contact details for local services, along with public transport routes, may break the patient's reliance on caregivers to gain entry to the healthcare system. Second, both the experts and participants with mild ID proposed that the results of the questionnaire can be used to determine a possible course of action. The experts advocated for the application to provide a potential diagnosis, in addition to what the patient should do next – for example, collecting medication from a pharmacy or booking an appoint with a GP immediately. Nevertheless, this strategy could have serious repercussions if an incorrect diagnosis is made and the wrong advice is given - especially since many of the conditions affecting people with ID are commonly overshadowed. As such, the participants with mild ID suggested sending the results to the GP practice to enable a medical professional to book an appointment within a reasonable timescale.

5.5.2 Caregivers

Previous literature e.g. [11, 22, 24, 65, 68] suggests that caregivers can have a negative influence on consultations by providing their own views that may not match those of the patient with ID. This was evident in the design workshops with participant 5.2 stating that her own opinions had less value when her mum was present. Additionally, some of the participants discussed how they preferred to keep health concerns private from their family members to avoid inducing an unnecessary sense of worry. As such, it is imperative that medical professionals attempt to extract symptoms directly from the patient, as opposed to interacting solely with a caregiver. Nevertheless, other participants felt more comfortable attending consultations with a paid support worker to ensure they had a mediator who was able to present information in an accessible manner. Yet participant 4.2 revealed that they had experienced cutbacks to their funding, meaning it was not possible to receive such support. Instead, he resorted to writing key information on paper notes to update his support network outwith the consultation, which may result in data being lost in transition. These scenarios suggest that the proposed application could play a fundamental role in increasing the health advocacy skills of people with ID when caregivers are unavailable or overbearing. Presenting an accessible summary of potential symptoms should assist patients in getting across their main concerns, whilst the embedded passport can help GPs to utilise more appropriate information extraction techniques.

5.5.3 Effectiveness of UCD tasks

On the whole, the four tasks were successfully employed throughout the design workshops. This subsection discusses aspects of the tasks that worked well with the participants with mild ID, in addition to those that may be improved on, to demonstrate: (1) common adaptations that may be applied to other projects; and (2) the experts' (see Chapter Four) ability to increase the accessibility of research protocols.

5.5.3.1 Targeting a Range of Modalities

It was clear throughout that the experts advocated for a mix of different tasks to be used within the workshops. People with ID are highly heterogenous and therefore respond to information in different manners. As such, utilising workshops that rely heavily upon a single modality is an ineffective strategy and may severely limit the amount of feedback being received by participants. For example, several of the participants took a back seat in the more verbal tasks (i.e. the focus groups and think alouds) due to being less comfortable in a group setting. Yet their feedback was well-received in the tactile image boards and paper prototypes. Additionally, targeting a range of modalities assists in capturing the participant's attention, particularly during extended studies. Such a practice was evident throughout previous literature [44, 98, 106, 108], with researchers combining a range of techniques such as storyboarding, interviewing and prototyping etc. to extract the needs of their participants.

5.5.3.2 Providing Equal Opportunities

One participant tended to dominate the conversations within two of the three design workshops. In such cases, it was important to involve the other participants by deflecting the views of the dominant individual to the others. For example, forwarding on their comments to another person by asking if they agree with what has been said. Another strategy may be to have a set order in which the participants can express their individual views before coming together to have an overall discussion. Nevertheless, it is important to refrain from singling out a participant who is less outgoing, whilst having a heightened awareness of response bias, since individuals are likely to accept the views of the majority using yes or no responses.

5.3.3.3 Use of Concrete Objects

Throughout the focus group tasks, the participants appreciated the use of sticky notes to keep track of what was being discussed yet were unlikely to challenge any misconceptions made. Instead, the author had to prompt the participants to review the accuracy of the sticky notes on completion of the task, at which point some errors were rectified. For individuals who are illiterate, it may also be more appropriate to utilise other modalities such as imagery. Within the image board task, the decision was made to pilot images that included short descriptions of the symptom being depicted, with the majority being assigned to the ineffective board. As such, the author was confident that response bias had not occurred. Overall, concrete examples could help people with ID to: understand complex language; overcome potential digital exclusion barriers; comprehend abstract concepts; and answer questions with greater accuracy.

5.3.3.4 Prototypes

Several alternatives to extracting requirements from participants with ID were discussed by the literature, including ethnography [53, 54, 107–109] and the evaluation of pre-developed prototypes that increase in fidelity [54, 98, 100, 109]. Potential methods of creating such prototypes ranged from the lessons learned from previous literature [98, 100], to the knowledge held by proxies who are familiar with the needs and abilities of the people with ID [54]. This research highlighted that proxies may be successful in recognising the needs of people with ID, since the paper prototypes that emerged from the design workshops broadly matched the requirements discussed by the experts. Nevertheless, it is still important to pilot any technologies with target users, to ensure all requirements are identified.

5.3.3.5 Experts and Caregivers

The most knowledgeable experts across the two focus groups in Chapter Four were the ID nurses. They were able to consistently envision how the design tasks would assist or hinder participants with ID to discuss their clinical experience. Nevertheless, the experts who had knowledge in HCI and digital inclusion also made significant contributions to the identification of potential accessibility barriers - for example, the need to change the user interface settings on tablets before use. As such, a variety of experts should be employed within the focus groups to ensure design tasks are approached from different viewpoints and the optimal number of accessibility barriers are addressed before implementation with target stakeholders.

Previous literature suggests that caregivers may have two distinct roles within research: (1) supporting people with ID to complete tasks to the best of their abilities by performing appropriate adjustments [96]; or (2) actively contributing to tasks due to their familiarity with the experiences and needs of people with ID [98–100]. This research, however, indicates that a combination of these two strategies may be most appropriate. The experts initially agreed with role one to ensure the information obtained is the true views of the participant and not those of the support worker/family member. Nevertheless, they later realised that caregivers may have a positive influence on recognising the presence of response bias and could therefore rectify the answers provided to match the life experiences of the individual with ID. There may also be scope to employ design tasks with caregivers in addition to people with ID, to extract the similarities and differences that occur between these two populations.

5.3.3.6 When to Include Experts?

One possible drawback of the proposed expert approach (see Fig. 4.1) is the over-reliance on domain experts to evaluate and adjust potential design methods. As such, it may not always be appropriate due to the overheads involved in recruiting specialist participants who have restricted free time. Researchers should first look to the literature to gauge whether suitable techniques have been used in the past, including those that have been implemented with other populations who have similar needs – for example, participants with limited cognitive functioning due to dementia. Experts may then be contacted if any accessibility concerns remain, particularly when the study focuses on novel technologies in which similar products do not exist.

5.5 Conclusion

Throughout Chapter Five, design requirements for the proposed AAC application have been identified via the employment of UCD tasks adults with mild ID. As such, a partial answer to the second research question presented in section 1.3 has been formulated. The participants agreed with the experts in Chapter Four in that the completion of an accessible questionnaire prior to the consultation could help promote discussions on the symptoms identified, whilst alleviating potential time constraints. The questionnaire should be based on the demographics of people with ID e.g. [34–37] to increase the diagnosis of commonly overshadowed conditions and should adapt to the users health and accessibility context. In addition, the participants with mild ID indicated that AAC technologies can assist them to overcome potential access barriers by highlighting the contact details of local healthcare services, along with potential public transport routes. The results of the questionnaire may also be shared with the GP practice to ensure a timely appointment is made relative to the seriousness of the symptoms identified.

The participants also discussed their experience with AAC in the clinical domain. Surprisingly, just one participant regularly used such technologies (a patient passport), which establishes a more holistic answer to the first research question, along with the resources identified in section 3.2.2.2. The next Chapter discusses an ontology driven framework used to capture the structure of the proposed questionnaire, prior to a formal evaluation of the prototype in Chapter Seven.

Chapter Six: Ontology-Driven Adaptive Health Questionnaire

Chapters Three, Four and Five have resulted in the identification of design requirements for the proposed clinical AAC application via: (1) a review of existing technologies; and (2) the implementation of UCD workshops with target stakeholders (ID nurses, patients with ID) and experts. The results partly establish how the application can fit into and improve current practice as per the "Development" stage of the framework for complex interventions [50]. The forthcoming Chapter will discuss the structure of the questionnaire that emerged from the design process i.e. the backend of the application. The interface that links up with this questionnaire was described in section 5.3.

6.1 Motivation

All participants involved in the requirements gathering process advocated for a questionnaire based on the health demographics of people with ID, since their needs differ significantly from that of the general population [34, 37]. Nevertheless, the implementation of such a questionnaire may cause three main challenges for developers: (1) people with ID are prone to developing a range of medical conditions, which could result in an overly long and unmanageable survey; (2) the guidelines surrounding the health of people with ID are everchanging, meaning the questionnaire must scale well to include future conditions; and (3) the ID population is heterogeneous by nature and will not engage with an interface in a standard manner. An ontology driven framework will now be presented that overcomes the aforementioned barriers, whilst capturing the questionnaire structure discussed throughout Chapter's Four and Five e.g. by first identifying the underlying problem, prior to extracting further symptoms.

6.2 Background

Ontologies offer the necessary structure to model the characteristics of real world concepts (e.g. medical conditions), including the relationships that exist between such elements (e.g. excessive thirst is a symptom of diabetes and dehydration etc.) [123]. Separate fragments of meaningful information are linked together under a portable data format - essentially extensible markup language (XML) – that promotes ease of use within different platforms. As such, they are widely implemented throughout the medical domain, where critical information is often shared across departments or hospitals utilising different technological systems. Furthermore, ontologies are typically straightforward to extend since new relationships/concepts may be added without impacting dependent processes or systems. Consequently, an ontology driven questionnaire was considered to be the optimal solution to overcoming potential portability constraints, as well as everchanging healthcare guidelines.

6.2.1 Adaptive Health Questionnaires

Computer-based information collection systems are becoming increasingly popular within the medical domain due to the range of benefits they provide over traditional data extraction practices. More accurate, structured, and detailed information can be retrieved from patients whilst ensuring the medical professional remains free to focus on other tasks such as person-centred care [124]. Yet, as first highlighted by Bouamrane et al. [125–127], there remains a challenge in designing medical questionnaires that are general enough to meet the needs of the bulk of patients but specific enough to extract important individual information. To overcome such a dilemma, Bouamrane et al. [125–127] proposed the use of ontologies to drive the adaptive behaviour of questionnaires during preoperative assessment. Existing paper-based forms contained a host of questions that may be unrelated to the health context of the patient (e.g. presenting multiple questions on chest pain[8]). In contrast, the proposed ontology-driven questionnaire can update its structure based on the input received from the patient, thus mitigating questions that have no relevance to the risk assessment, whilst expanding on those deemed to be important [125–127]. As such, the system can capture finer-grained information with each successive step providing it is appropriate to the patient's current condition.

One drawback to Bouamrane et al's approach [125–127], however, was the "hard coding" of questionnaires to a specific domain. Benmimoune et al. [128] overcame this limitation by introducing a Data Type ontology that gives meaning to a specific

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[8] http://www.cardiffandvaleuhb.wales.nhs.uk/sitesplus/documents/1143/Surgical%20Booking%20form%2012-16_Fillable.pdf

question by relating it to a concept within a domain (e.g. "what type of surgery has the patient received?" may be related to the "type of surgery" concept within the digestive surgery domain [128]). This is useful as it assigns added meaning to the collected data that may be used for further analysis purposes. For example, a set of rules may be implemented to derive the body mass index from "weight" and "height" concepts. The patient's interactions with the system (i.e. the questions presented / answers received) are also captured via an Interrogations History Ontology to support future processing.

6.2.2 Accessible Interfaces

Ontologies can also assist in the adjustment of standard user interfaces to better meet the accessibility requirements of people with disabilities. Yesilada et al. [129] developed a semi-automated annotation tool that uses an ontology to translate web elements into "travel" concepts. These concepts support individuals with visual impairments to navigate quickly and accurately across internet content. For example, annotated "identification" points (those that represent an object, place, or person in an environment e.g. a header) may be collated to form a table of contents detailing the various sections of a webpage [129].

Obrenovic et al. [130] employed ontologies to assist researchers in the creation of multimodal interfaces – a process they believe requires knowledge from several domains: medicine and biology, cognitive sciences, and computer science. Three sets of logically related ontologies were developed to capture basic concepts that may influence how an interface is utilised, including: the computing environment; the capabilities of the user; and the context of the user's surroundings. A fourth ontology imports and connects these concepts together to allow the developer to view the potential effects their design choices may have on various human factors.

Castillejo et al. [131] designed a similar ontology to adapt the settings of mobile devices based on three sets of properties: the user's characteristics, the environment's characteristics, and the device's characteristics. Rule sets are then executed to make the necessary adjustments depending on the concepts extracted. For example, ambient light sensors may detect that the surrounding environment is dark, meaning the devices screen brightness is reduced to counteract this condition. Karim and Tjoa [132, 133] also proposed using ontologies to formally describe a mapping between a user's impairments and the available interface characteristics (e.g. low visual acuity to text size). Class-subclass hierarchies were used to achieve this, with formal logic statements facilitating automatic interface adaptations. Finally, in contrast to the previous work, Marino et al. [134] focused on the enhancement of a user's capabilities as opposed to simply mitigating the impact of disabilities.

6.2.3 Context of People with Intellectual Disabilities

Bouamrane et al. [125–127] and Karim and Tjoa [132, 133] provide an adequate structure for the development of accessible health questionnaires for people with ID. Nevertheless, their work may not be used directly since the concepts included within the ontologies are modelled on other populations, as opposed to those with mild ID. For example, Bouamrane et al. [125, 126] focused on the domain of preoperative assessment for general, everyday patients and therefore included answer types such as "past or present" to determine whether an individual has, or is, suffering from a particular condition. Yet as described previously, people with ID have impaired memory skills [12] and may find it difficult to recall past events in great detail. The quantification question type is also used to determine aspects such as the length of time a symptom has been present, a task people with ID find difficult to achieve as highlighted by the ID nurses in section 4.2.2.1.

Karim and Tjoa's ontology [132, 133] centred on mapping physical impairments (hearing, motor, mobility, and vision) to changes in an interface; however, no concepts have been modelled to capture potential cognitive impairments and their associated adaptations. Consequently, a novel information collection system was developed that builds on the work of Bouamrane et al. [125–127] and Karim and Tjoa [132, 133] to adapt to both the health context and accessibility needs of patients with mild ID. As shown in Figure 6.1, aspects from the International Classification of Functioning, Disability and Health framework (WHO-ICF) and the Web Content Accessibility Guidelines were also utilised to ensure the application takes into consideration a range of cognitive and physical impairments. WHO-ICF[9] is a framework that encapsulates the health components of functioning and disability and is organised around the following three concepts: body functions and structure; activities and participation i.e.

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[9] https://www.who.int/classifications/icf/en/

how an individual executes a given task; and environmental factors such as geographical features. The classification is employed internationally to assess an individual or population's degree of disability and places emphasis on bodily functions, as opposed to conditions or diseases.

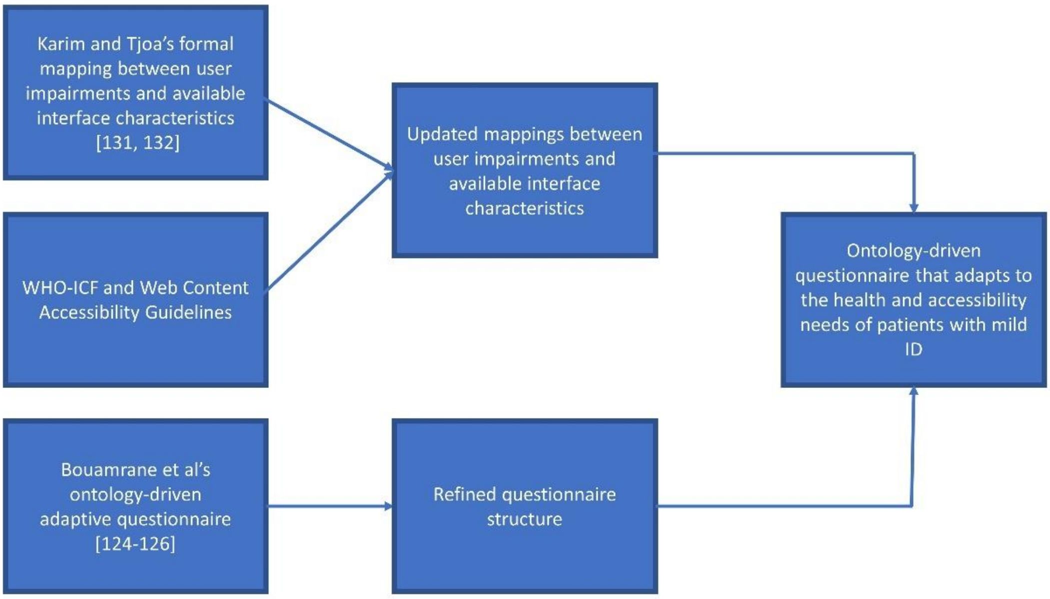

Fig. 6.1: Resources used to develop the ontology-driven adaptive questionnaire.

6.3 Methods

The proposed system consists of three main components, as shown in Fig. 6.2: an ontology to model the accessibility needs of the patient; a second ontology to model the medical needs of the patient; and a Java Adaptive Engine to accept user input and interact with the ontologies as appropriate. A deliberate design decision was made to separate the two ontologies (despite sharing common functionality) to ensure they are used and maintained as distinct resources, which is considered best-practice design in software engineering [135]. Both the accessibility preferences and medical questionnaire ontologies were modelled using the Web Ontology Language (OWL), and the Protégé-OWL development tool [136]. The Java Adaptive Engine was implemented using the OWL API [137] to facilitate interaction with the user interface, which was written in Java.

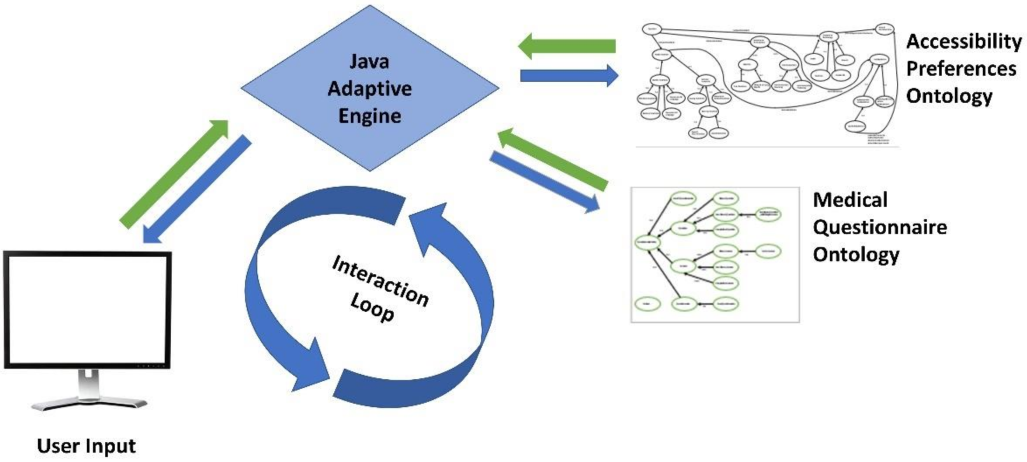

Fig: 6.2: System Architecture for the adaptive questionnaire.

6.3.1 Accessibility and Medical Ontologies

Common impairments that effect people with ID (both physical and cognitive), are extracted by the accessibility preferences ontology, prior to suggesting potential interface adaptations - like that of Karim and Tjoa [132, 133]. Nevertheless, it is important to note that the functionality to incorporate the suggested changes within the standard interface has yet to be implemented. The International Classification of Functioning, Disability and Health framework (WHO-ICF) was used to identify and subsequently model the impairments, as it is a widely endorsed classification of health and disability throughout the 191 member states of the World Health Organisation[10]. Forward engineering was utilised to semantically link the impairments to appropriate changes in the interface based on the Web Content Accessibility Guidelines[11]. This ontology requires the user to input their accessibility needs via a questionnaire (as opposed to an automated process that utilises other resources) meaning it should be completed in conjunction with a carer or care assistant e.g. practice nurse.

Published guidelines regarding the health needs of people with ID were utilised to model the queries included within the Medical Questionnaire Ontology. The “Learning Disability Health Toolkit” [37], developed by Turning Point UK, was selected since it contains ordered information on the most common symptoms experienced by this population (grouped by medical conditions). Once again, forward

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[10] https://www.who.int/classifications/icf/en/

[11] https://www.w3.org/WAI/standards-guidelines/wcag/

engineering was used to model the symptoms contained within the toolkit, including their relationships to other body parts and conditions. Symptoms relating to a single condition were initially captured, with their properties being iteratively refined as further ailments were added to the ontology. The final concepts were modelled as classes and subclasses, instead of instances, to aid in maintenance since they are subject to change as new guidelines are released.

6.3.2 Java Adaptive Engine

Rather than utilising a reasoner to classify the behaviour of the ontologies, a rule-based Java Adaptive Engine has been developed to decouple the handling of the user-input and the traversal of the questionnaires from the ontologies themselves. This strategy promotes convenient maintainability, as changes may be made to the questionnaires without affecting the Java Adaptive Engine and vice-versa. Consequently, the system allows for less complexity and higher modularity under the recommendations of best practice software engineering [135].

6.4 Development of Ontologies

A high-level overview of the ontologies will now be presented. Their basic compositions are similar to one another, with modifications being implemented to capture the appropriate medical conditions or disabilities.

6.4.1 Medical Questionnaire Ontology

The ontology models two distinct aspects: (1) the structure of the questionnaire; and (2) the adaptive behaviour of the questionnaire. These fundamental principles are based on the work of Bouamrane et al. [125–127] and have been adapted to encapsulate the concepts identified within the Learning Disability Health Toolkit [37]. A high-level overview of the developed classes may be found in Fig. 6.3.

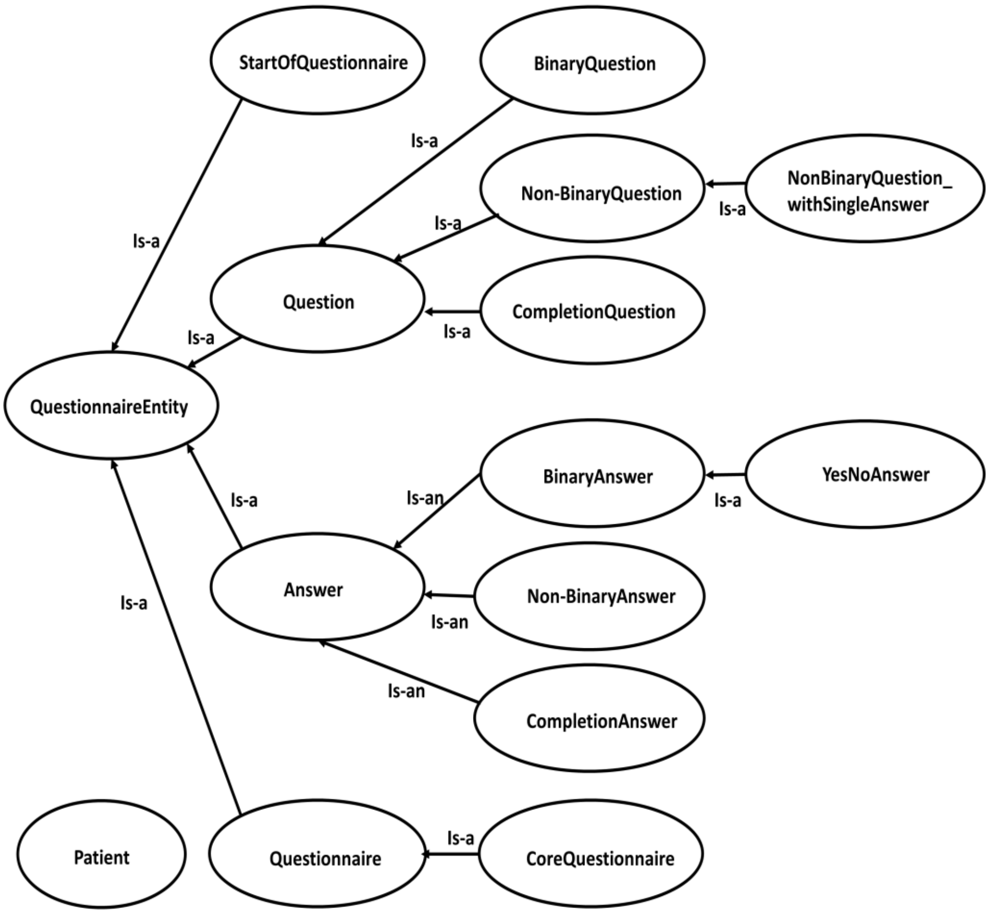

Fig. 6.3: Overview of the classes contained in the medical questionnaire ontology.

- ***Questionnaire:*** Comprised of thematically related *Question* classes.
- ***CoreQuestionnaire:*** Comprised of *Question* classes that are used to determine whether the primary *Questionnaires* (equating to the body parts and conditions found in [37]) are presented to the patient. An example shown in Appendix E is the question "I have a problem with my ears or hearing." All *Questions* contained within are adaptive thus heavily restricting the number of *Questionnaires* parsed.
- ***StartOfQuestionnaire:*** Points to the *Questionnaire* class containing the first *Question* to be presented to the user - primarily *CoreQuestionnaire*, see section 6.5.
- ***Question:*** Captures the information used to determine the runtime behaviour of the questionnaire implementation. This includes: the set of possible *Answers* for a *Question*; and the set of potential actions that may occur upon

receiving user input. Three types of *Questions* are included: (1) *BinaryQuestion* provides exactly two *Answers* to the user, with the option to select one of these *Answers.* This is the main question type presented due to the patient with ID's preference to answer yes/no questions; (2) *NonBinaryQuestion* presents three or more *Answers*, with *NonBinaryQuestion_withSingleAnswer* permitting the user to select just one of these *Answers* (used for duration questions); and (3) *CompletionQuestion* requires the user to input free text when answering *Questions* that have no defined *Answers* (used to determine age*)*. All *Questions* are characterised by a questionContent property to display the question text and a questionPriority property to determine the order in which the *Questions* contained within a *Questionnaire* are presented.

- ***Answer:*** Mirrors the *Question* classes whilst encapsulating the information required by the user interface to display the *Answer* i.e. an answerContent property.
- ***Patient:*** Encapsulates the patient's personal information (gender, age, impairments) which facilitates the restriction of a specific *Question* or *Questionnaire*.

6.4.1.1 Medical Questionnaire Properties

Object properties are fundamental in defining both the structure of the questionnaire implementation and its run-time behaviour. As such, two main sets of properties have been defined, structural and adaptive, and these are described in Table 6.1 using the acronyms S and A respectively. Examples of their use are provided in section 6.5.

Table 6.1: Object Properties Included in the Medical Questionnaire Ontology.

Property	Type	Domain	Range	Description
containsQuestionAbout	S	*Questionnaire*	*Question*	Determines which *Questions* are contained within a *Questionnaire* class.
hasExpectedAnswers	S	*Question*	*Answer*	Links a *Question* class to its *Answer* classes
hasAlwaysRelatedQuestion	S	*Question*	*Question*	Links two *Question* classes provided one is always followed by the other.

ifAnswerToThisQuestionIs	A	*Question*	*Answer*	Declares *Question* is adaptive. Links *Question* to further *Question* classes depending on the *Answer* received.
thenGoToQuestion	A	*Answer*	*Question*	Links a follow-up *Question* to a specific *Answer*.
hasAssociatedQuestionnaire	A	*Question*	*Questionnaire*	Links a *Question* to a follow-up *Questionnaire*.

Three specialised adaptive properties have also been defined to restrict the presentation of *Questions* based on the user’s age (onlyIfAgeIs), sex (onlyIfSexIs), and impairments (onlyIfImpairmentIsNotApplicable). The latter depends on the information extracted from the Accessibility Preferences Ontology described in the next sub-section.

6.4.2 Accessibility Preferences Ontology

A wide range, and combination of, adjustments must be made to the standard interface described in Chapter Five to ensure the application is accessible to people with mild ID. The Accessibility Preferences Ontology achieves this by extracting the cognitive/physical impairments experienced by the patient, before mapping them to a model of interface changes to mitigate their effect - similar to [132]. A high-level overview of the ontologies structure may be found in Fig. 6.4. As described previously, its composition is similar to that of the medical questionnaire ontology, with adjustments being made to capture the concepts included in the WHO-ICF framework. The following new classes emerged as a result of this process:

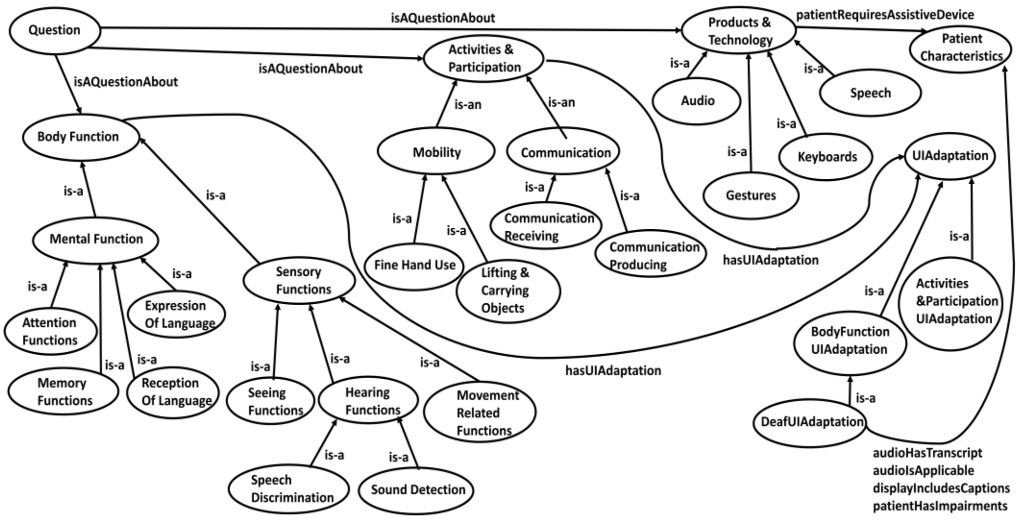

Fig. 6.4: Overview of the Accessibility Preferences Ontology. The hearing functions concept has been extended to demonstrate the effect a *UIAdaptation* may have on *PatientCharactersistics*.

- ***BodyFunctions:*** Captures the potential options (impairments) that may be presented to the user related to an individual's functioning of the body. This includes both mental functions, and sensory functions. An impairmentDescription annotation is used to describe the impairment in a textual format.
- ***ActivitesAndParticipation:*** Essentially the same as *BodyFunctions* except that it captures impairments that may affect an individual's ability to complete everyday tasks. This includes mobility and communication.
- ***ProductsAndTechnology*****:** Captures the potential assistive devices required by the user to operate digital technologies. Such devices were extracted from Marino et al. [134] and grouped under the following concepts: Audio, Gestures, Keyboard, and Screen.
- ***UIAdaptation*****:** Models the interface adaptations that should occur once the user has indicated that they have an impairment or that they require an assistive device e.g. increasing text size for an individual who is short sighted.
- ***PatientCharacteristics*****:** Encapsulates the individuals user interface preferences, which have been previously captured via the *UIAdaptation* classes.

6.4.2.1 Accessibility Preferences Properties

Two sets of properties have been defined: object properties that determine the structure and run-time behaviour of the accessibility questionnaire; and data properties that capture the individual's user interface preferences. Table 6.2 contains a description of the newly developed object properties, with examples of their use being found in section 6.5.

Table 6.2: Object Properties included in the Accessibility Preferences Ontology.

Property	**Domain**	**Range**	**Description**
isAQuestionAbout	*Question*	*BodyFunctions*, *ActivitiesAndParticipation*, or *ProductsAndTechnology*	Links a *Question* to a relevant option class i.e. a subclass of *BodyFunctions*, *ActivitiesAndParticipation*, or *ProductsAndTechnology*
hasUIAdaptation	*BodyFunctions*, *ActivitiesAndParticipation*, or *ProductsAndTechnology*	*UIAdapatation*	Links an impairment i.e. a subclass of *BodyFunctions* or *ActivitiesAndParticipation* to an appropriate *UIAdaptation*.

In addition, the ifAnswerToThisQuestionIs and thenGoToQuestion properties found in section 6.4.1 are also included and operate in the same manner. The user characteristic data properties identified by Castillejo et al. [131] have been extended to capture the individuals interface preferences – see Table 6.3. Consequently, a variety of impairments commonly experienced by people with ID may be catered to by the employed user interface.

Table 6.3: PatientCharacteristics data properties extended from [131].

Subclass	**Property Name**	**Description**
Audio	audioHasTranscript	A Boolean value that describes whether an accompanying transcript should be provided in addition to audio feedback.
Interface	interfaceEnablesScrolling	A Boolean value that indicates whether scrolling is enabled.
	interfaceEnablesSwiping	A Boolean value that captures whether swiping is enabled.
	interfaceTouchStrategy	This property models the preferred touch input method with the following possibilities: "default" and "end-tap".
	interfaceTracksAttention	A Boolean value that indicates whether an eye-tracker may be utilised to determine if the system is in possession of the user's attention.
Patient	patientRequiresAssistiveDevice	A list of assistive devices required by the individual to operate digital technologies effectively.

	patientHasImpairments	A list of impairments that effect the individual.
View	viewIncludesCaptions	A Boolean value indicating whether videos should include captions.
	viewIncludesGIFS	A Boolean value describing whether GIFs are appropriate to the individual.
	viewIncludesProgress	A Boolean value that captures whether an individual's progress should be monitored and returned.

6.5 System Implementation – Java Adaptive Engine

As highlighted in Fig. 6.2, the Adaptive Engine is decoupled from the underlying questionnaire models, meaning there was a significant amount of discretion regarding its implementation. Ultimately, the questionnaires were processed as a last-in-first-out stack similar to the approach adopted by Bouamrane et al. [125–127]. First, the engine calls the method required to traverse the Accessibility Preferences Ontology, prior to conducting the following five stage process:

(1) The initial *Question* classes are loaded into the stack in order of priority.

(2) The *Question* at the top of the stack (see Appendix D for an example) is popped and presented to the patient, along with the potential options that the user may select from. These options are identified via the direct subclasses (point one in Appendix D) of the object contained in the current *Question's* "isAQuestionAbout" superclass (see point two). As such, they may be a subclass of *ActivitesAndParticipation*, *BodyFunction*, or *ProductsAndTechnology*.

(3) An appropriate *Answer* is extracted from the user and subsequently mapped to changes in the interface via the filler contained in the selected *Answer's* "hasUIAdaption some *UIAdaptation*" superclass (see point three). The properties held in the *UIAdaptation* class (point four) are then used to update those in *PatientCharacteristics*.

(4) The engine checks to see if the current *Question* is adaptive i.e. whether it is a subclass of "(ifAnswerToThisQuestionIs some *Answer*) and (thenGoToQuestion some *Question*)" – see point five in Appendix D. If the *Question* is not adaptive, or the input received from the user does not trigger further questions, the system moves on to stage five. Otherwise, an additional

Question is added to the top of the stack via the "thenGoToQuestion some *Question*" superclass.

(5) Steps two to five are repeated until the stack becomes empty.

Next, the Java Engine calls the method used to traverse the Medical Questionnaire, prior to passing in the information held in the *PatientCharacteristics'* patientHasImpairments data property. This parameter is used to update the hasImpairments property contained in the Medical Questionnaire's *Patient* class, which facilitates the restriction of *Questions* based on the user's physical or cognitive disabilities – see section 6.5.1. The following five steps are then carried out.

(1) The initial *Questionnaire* is identified by examining *StartOfQuestionnaire* and extracting the filler from its superclass "hasAssociatedQuestionnaire some *Questionnaire*" – see point six in Appendix D.

(2) The *Questionnaire's* "containsQuestionAbout some *Question*" superclass (point seven) is then examined with all direct subclasses of the filler (point eight) being added to the stack in order of priority, provided they satisfy all restrictions e.g. a *Question* may not be added if it is a subclass of "onlyIfSexIs some Female" and the patient is male.

(3) The *Question* at the top of the stack (point nine) is popped and presented to the patient along with the set of possible answers the user may select from. These options constitute the direct subclasses (point ten) of the filler included in the *Question's* "hasExpectedAnswer some *Answer*" superclass (point eleven).

(4) Once an appropriate *Answer* has been received from the patient, the Java Engine stores the *Question/Answer* pairing and subsequently checks to see if the current *Question* is adaptive i.e. whether its superclass's include "ifAnswerToThisQuestionIs some *Answer*" (point twelve). If the *Question* is not adaptive or the *Answer* received by the user does not trigger its adaptive properties, then the system moves on to stage five. If the current *Question* is adaptive and requires a single *Question* to be added to the stack, then this is pushed to the top via "thenGoToQuestion some *Question*", provided it meets all restrictions placed on it. If multiple *Questions* are required to be added e.g. those contained in a *Questionnaire* (point 12), then this is done in a similar process to that described in stage two.

(5) Stages 3-5 are repeated until the stack becomes empty.

6.5.1 Dynamic Changes to the Stack

An example of how the Medical Questionnaire stack reacts to user input will now be discussed to demonstrate the importance of *CoreQuestionnaire* and onlyIfImpairmentIsNotApplicable in reducing the number of irrelevant Question classes presented.

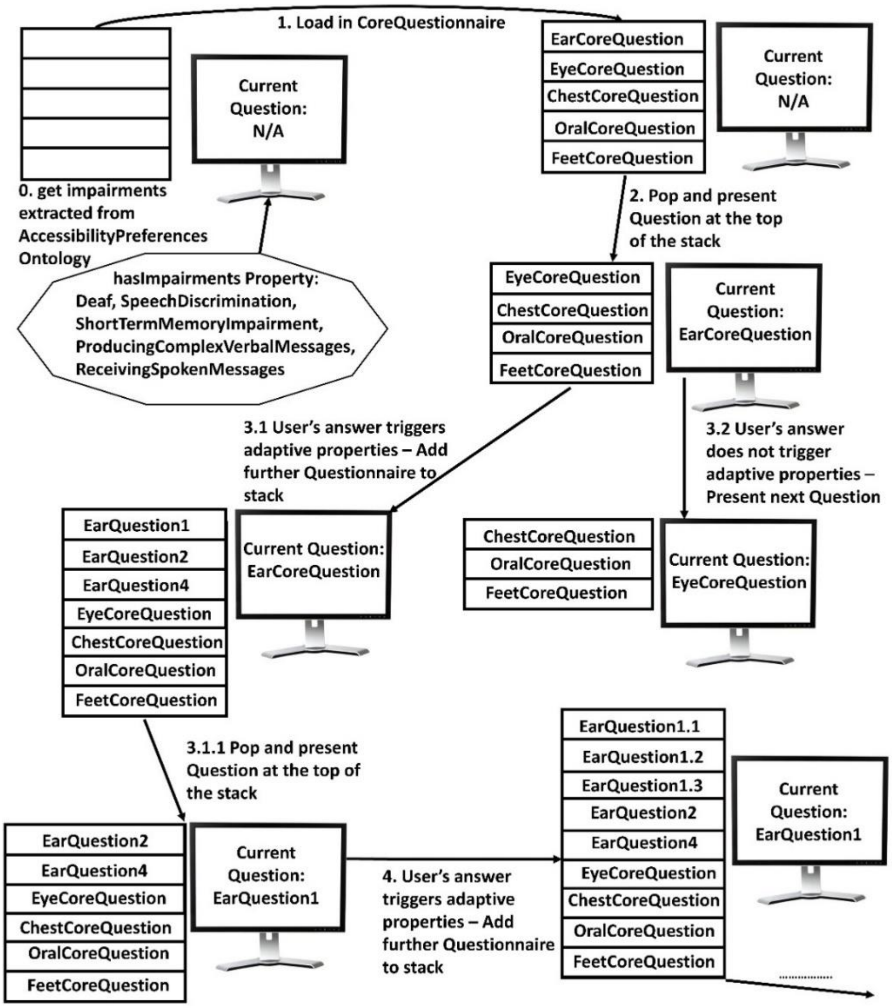

Fig. 6.5: Changes to questionnaire stack based on user's input & accessibility needs.

The initialisation phase is shown in step zero of Fig. 6.5 and involves updating the *Patient* class's hasImpairments property to include the impairments identified by the Accessibility Preferences ontology. The Java Engine then pushes all *Questions* contained in *CoreQuestionnaire* (step one) to the stack in order or priority, since this is identified as the starting *Questionnaire*. *CoreQuestionnaire* encapsulates the

Question classes that link to further *Questionnaires* on the specific body parts and conditions described in [37]. All *Questions* are adaptive meaning an entire *Questionnaire* may be bypassed based on a single response received from the patient. For example, in step three of Fig. 6.5 the user is required to answer the current *Question* displayed - in this case *EarCoreQuestion*. The questionContent annotation attached to this class is presented on the screen along with the possible answers. If the user selects the option "No", the system simply presents the next *Question* at the top of the stack, see step 3.2 in Fig. 6.5. Consequently, the class *EarQuestionnaire* is never parsed by the Java Engine or presented to the user. Step 3.1 in Fig. 6.5 demonstrates what occurs if the patient's answer triggered the adaptive properties of *EarCoreQuestion*. All *Questions* contained in *EarQuestionnaire* is added to the stack except from *EarQuestion3*. *EarQuestion3* is not parsed as it is a subclass of "onlyIfImpairmentIsNotApplicable some Deaf" and the condition "Deaf" is included in *Patient's* hasImpairments property. *Questions* that are not a subclass of *CoreQuestionnaire* may also cause additional *Questions/Questionnaires* to be added to the stack, as shown in step four of Fig. 6.5.

6.6 Scenario Based Evaluation

As will be described in depth in Chapter Seven, it was not possible to conduct an evaluation of the developed prototype with adults with mild ID. Consequently, a scenario-based approach (similar to [131]) was utilised to demonstrate the scope of adaptation that may occur when the Medical Questionnaire Ontology responds to the health and accessibility needs of an individual. Two separate scenarios were developed to accommodate for the range of impairments/conditions experienced by people ID, as opposed to recruiting stakeholders who are potentially suffering from the conditions included within the ontology. At the time of the scenario-based evaluation, the Medical Questionnaire Ontology was populated with 110 *Questions* across 9 distinct *Questionnaires* capturing conditions of the mouth, feet, chest, ears and eyes, as well as the patient's mental wellbeing, toiletry habits, weight trends, and general health – see Appendix E for the full list.

6.6.1 Scenario One

June currently works for a national advocacy charity. The left-hand side of her vision is impaired meaning she finds it difficult to interact with applications that have been developed in the standard, justified format. June has a slight motor impairment; however, this does not affect her ability to interact with digital technologies on an everyday basis. Nonetheless, when she becomes tired her touch accuracy reduces significantly, at which point she prefers to interact with the user interface via speech.

Table 6.4 captures the most relevant interface changes proposed by the Accessibility Preferences Ontology based on June's physical impairments. The main adaptation to the default interface is captured via the viewHasPageLayout property, which aligns the elements to the right-hand side of the screen. Since her visual acuity is unaffected the default text-size is reduced from 12 to 10 to assist this process. Regarding Jane's motor impairments, the model has suggested that touch input should only register once an action has been completed, whilst audio input is also a recommended interaction modality.

Table 6.4: Important sections of the proposed user interface model for scenarios one and two.

Scenario One		**Scenario Two**	
Property	Value	Property	Value
viewHasPageLayout	Right aligned	viewHasTextSize	14
patientRequiresAssistiveDevice	SpeechRecognition	viewIncludesCaptions	True
interfaceAcceptsAudioInput	True	patientRequiresAssistiveDevice	ScreenMagnifier
viewHasTextSize	10	interfaceAcceptsAudioInput	True
interfaceTouchStrategy	End-tap	interfaceTracksUserAttention	True
patientHasImpairments	ComplexMotorFunctions, LeftFieldLoss, TappingAccuracy	patientHasImpairments	Deaf, SpeechDiscrimination, ShortSighted, AttentionDeficit, ShortTermMemory, Producing&ReceivingVerbalMessages
		audioIsApplicable	False
		viewIncludesProgress	True

6.6.1.1 June's Medical Needs

June has recently secured a promotion at the advocacy charity meaning her responsibilities have increased substantially over the last few weeks. This increased workload is becoming overwhelming and has had a significant impact on three areas of June's life – her social routine, relationship with peers, and mental wellbeing. She is currently experiencing the following primary symptoms: difficulty sleeping due to heightened stress and anxiety; a decrease in attentiveness; irritation; and isolation.

In this instance, just one of the *Questions* contained in *CoreQuestionnaire* has its adaptive properties triggered - *MentalWellbeingCoreQuestion*. Consequently, only the mental wellbeing *Questionnaire* is presented to June, in addition to the initial nine *Questions* contained in the *CoreQuestionnaire*. The mental wellbeing *Questionnaire* includes a total of 15 *Questions* of which six are dependent on the adaptive properties of two separate *Questions* – *SocialRoutineQuestion* and *SleepingRoutineQuestion*. These adaptive properties are triggered, meaning a total of 23 *Questions* from a possible 110 (20.91%) are presented to Jane.

6.6.2 Scenario Two

Jamie is deaf and therefore has a dependence on visual methods to receive information. Despite this reliance, he is short-sighted and finds it difficult to read small text. In addition, the patient's ID affects their capacity to understand obscure or abstract information and significantly impedes their attention span and short-term memory. He is able to express simple or familiar concepts - such as yes or no - via the use of speech yet struggles to convey more complex words/sentences coherently.

The primary adaptations that occur (see Table 6.4) relate to the user's inability to detect sounds. The audioIsApplicable property states that sound is not a viable method used to provide feedback. Despite this, Jamie has indicated that he is able to use speech to communicate simple needs, hence why the interfaceAcceptsAudioInput value is True. viewIncludesCaptions expresses the need to provide captions alongside any media content. Several adaptations also occur to combat Jamie's short attention span, along with an increase in text size to overcome his short sightedness.

6.6.2.1 Jamie's Medical Needs

Regarding Jamie's current health status, he has been confined to his bed over the last few days with a high fever and a feeling of nausea. When active, the patient has been experiencing dizzy spells and cannot stay on his feet for too long. Jamie has found it hard to sleep due to an aching pain emanating from his inner right ear, yet he finds it difficult to communicate this pain.

In this instance, two of the nine *Questions* contained in *CoreQuestionnaire* have their adaptive properties triggered – *GenerallyUnwellCoreQuestion* and *EarCoreQuestion*. The generally unwell *Questionnaire* includes seven *Questions*, of which none are adaptive, meaning all are parsed by the system. On the other hand, *EarQuestionnaire* is made up of nine *Questions*, with four of these being dependent on the user's ability to hear. Since Jamie has indicated that he is deaf, these four *Questions* are not presented. Therefore, Jamie was required to answer a total of 21 *Questions* (19.09%).

6.7 Conclusion

This Chapter described the development of the accessible health questionnaire advocated by the participants within the UCD workshops. In contrast to the front-end of the application (see Chapter Five), the back-end is much more sophisticated in that it drives the adaptation of both the standard interface and the questionnaire based on the patient's accessibility and health needs. The Accessibility Preferences Ontology suggests a model of potential interface changes that mitigate the cognitive/physical impairments experienced by the patient, thus ensuring the application is usable for a wider range of stakeholders. Symptoms are captured via the Medical Questionnaire Ontology in a manner that enables the patient's input to shape the future questions presented. As such, the range of conditions prevalent throughout the ID population may be included within the questionnaire, whilst limiting the queries presented to those that have a direct influence on the patient's individual health context. For example, the core question "do you have a problem with your ears or hearing" may restrict or grant access to the ear sub-questionnaire based on the patients answer. Chapter Seven will discuss an evaluation of the final prototype with target stakeholders (GPs and caregivers) and usability experts. The results obtained will formulate a comprehensive answer to the second research question (see section 1.3) with the feedback being used to update the prototype in preparation for a randomised controlled trial within the target domain.

Chapter Seven: Post-task and Cognitive Walkthrough Evaluations

Chapters Four, Five and Six described the identification and implementation of design requirements for the proposed application. The resulting prototype assists patients with mild ID to better prepare for primary care consultations via a medical questionnaire that hones in on the information they wish to convey. The aim of this Chapter was to evaluate whether the implemented design requirements meet the needs of the wider mild ID population, in addition to the other primary stakeholders. Consequently, an answer to the second research question presented in section 1.3 has been established i.e. What do patients with mild ID require from a clinical AAC application to support them during primary care consultations? Cognitive walkthroughs [138–141] and post-task [116] walkthroughs were conducted to identify usability barriers within the prototype, in addition to absent features, thereby contributing to the completion of the "Development" phase in the framework for complex interventions [50]. Three separate populations were involved in the walkthroughs: experts in ID/usability (who took the place of people with ID due to the Covid-19 pandemic); caregivers; and GPs. The introduction of caregivers and GPs resulted in the identification of features specific to their needs, thus ensuring the app is well rounded prior to entering the feasibility stage of the framework for complex interventions [50]. Conducting this extra step in the design phase should therefore lead to better outcomes from a feasibility study, with more interventions being carried onto long-term implementation.

7.1 Cancelled Study with Patients

Individual "soap opera" [142–144] supported post-task walkthroughs [116] were to be employed with participants with mild ID who had not taken part in the UCD workshops. This would ensure the prototype's design better meets the needs of the mild ID population as a whole, rather than being retrofitted to address the requirements of the participants involved in Chapter Five. Ethical approval to conduct the study was awarded by the Department of Computer and Information Sciences, University of Strathclyde Ethics Committee, ID:1021. Recruitment began in January 2020, with the intention of conducting a minimum n=12 post-task walkthroughs to account for data saturation [145]. Three charities agreed to assist with recruitment, with five participants consenting to take part by the end of February 2020. Unfortunately, this time period aligned with the initial outbreak of Covid-19 cases throughout the United Kingdom – a condition that affects people with ID disproportionately due to a higher prevalence of comorbid health problems, in addition to lifestyles that rely on others [146]. After consulting with the charities, it was decided that in-person studies would unnecessarily put participants at risk of contracting a potentially deadly virus. As such, a virtual version of the post-task walkthroughs was proposed, yet the charities also had concerns over the ability of people with mild ID to complete tasks using such a medium. First, they stated that some of their members have limited access to the internet in their own homes and would have to travel elsewhere to participate, thereby increasing their risk of infection. Second, people with ID may require support when operating complex video conferencing software, yet their access to caregivers was cut throughout the pandemic. Finally, those who are able to operate the necessary technologies may still find it difficult to adhere to academic conditions virtually. Consequently, the soap opera supported post-task walkthroughs were cancelled and subsequently replaced by virtual cognitive walkthroughs with experts in usability/ID.

7.2 Evaluation with Experts, Caregivers and Medical Professionals

As stated previously, the main purpose of the evaluation was to assess the usability of the developed prototype for the primary stakeholders, including patients with ID, medical professionals, and caregivers. Nevertheless, it was not feasible to incorporate patients within the final evaluation, with experts instead acting as "proxies" for this population during a series of cognitive walkthroughs [138–141], which were conducted alongside walkthroughs with GPs and caregivers. Cognitive walkthroughs come from a series of evaluation techniques called "inspection methods," which will now be described to make the reader aware of their suitability as a replacement methodology.

ISO 9241 [59] states that inspection-based evaluations may be utilised 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 usability barriers prior to the introduction of target stakeholders. Inspection methods are typically employed by experts in Human Computer Interaction, yet Nielsen [147] found that novel users (i.e. those with no expertise in the application domain or usability) can detect circa 20% of the usability barriers present, with single-experts (those with expertise in one of the domains) detecting around 40%. Furthermore, double experts (those with knowledge in both usability and the application domain) can identify around 60%, meaning the recruitment of a range of participants can lead to a fairly accurate representation of an application's usability. Consequently, an inspection-based evaluation was considered to be an appropriate alternative to the aforementioned post-task walkthroughs.

Zhang et al. [138] lists cognitive walkthrough and heuristic evaluation as two of the most widely employed inspection techniques. Both differ in terms of the outcomes achieved. Cognitive walkthrough is used to establish the ease in which novice stakeholders can learn to operate a system, whereas heuristic evaluation is utilised to assess an interface's compliance against a set of usability principles i.e. heuristics. In addition, Khajouei et al. [139] demonstrated that these techniques result in the identification of different usability barriers throughout health information systems. Heuristic evaluation managed to capture a greater number of barriers (although the result was not significant), whereas cognitive walkthrough was able to identify more severe ($P<.0001$) [139]. Since the proposed clinical AAC application is unlikely to be used on an everyday basis, cognitive walkthrough was deemed to be more suitable due to its focus on learnability, as well as its capacity to mitigate barriers crucial to the systems misuse. Furthermore, it has been streamlined in the past [140], meaning it is suitable for non-experts in usability. As such, cognitive walkthroughs were carried out with two populations: (1) caregivers who were able to act as proxies for people with mild ID; and (2) experts in ID and usability.

7.2.1 Methods

Two studies were conducted to identify potential usability barriers within the proposed application. Virtual cognitive walkthroughs were performed (individually) by experts in ID/usability, as well as caregivers who were able to act as proxies for the omitted patients. In addition, post-task walkthroughs were completed by GPs (following on from the original evaluation plan) to determine their views on the appropriateness of the application for their own needs and working routines.

7.2.1.1 Cognitive Walkthroughs with Experts and Caregivers

Polson et al. [141] recommend that cognitive walkthroughs be performed in iterations of three to five individual evaluators to yield a large percentage of usability errors with reasonable false alarm rates - the proportion of errors identified in a walkthrough but not observed in stakeholder testing. This recommendation was therefore used as a target N size for both of the populations involved in the cognitive walkthroughs i.e. the experts and caregivers. To be eligible for participation, experts had to have at least five years' experience in usability, with a similar period of interaction with people who have ID. Invitations to participate, along with information sheets, were distributed via email in the months of July and August 2020 to members of academic institutions throughout Scotland. Those 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. Recruitment for the caregivers was led by a partner ID charity throughout Autumn 2020. The charity sent emails and information sheets to their members who were actively providing support to at least one individual with mild ID. A suitable date and platform for the study was then arranged in a similar manner to the experts. Table 7.1 includes the demographics of all participants involved in the cognitive walkthroughs. Ethical approval to conduct the study, along with the post-task walkthroughs, was provided by the Department of Computer and Information Sciences ethics committee, University of Strathclyde ID: 1195.

Table 7.1: Demographics of participants involved in the cognitive walkthroughs.

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

Description of Cognitive Walkthroughs

Prior to the commencement of the study, participants were briefed on the goals of the PhD, including the rationale behind the evaluation. Those who were not familiar with cognitive walkthroughs were also shown an example of the process to ensure they were aware of what was required. Scenario-based cognitive walkthroughs [139] were then performed using the narratives listed in Table 7.2, which were designed to evaluate all features of the application. The author was responsible for conducting the sub-tasks involved in the scenarios, with the participant answering the question set relevant to their demographics on completion of each action. Experts were required to answer the traditional cognitive walkthrough set [139] shown below, with caregivers answering the more streamlined [140], as they were deemed to be less cognitively challenging for laypersons. Participants were also asked to suggest solutions for any barriers identified whilst completing the study.

Table 7.2: Scenarios completed by the experts during the cognitive walkthroughs.

ID	**Scenario**	**Sub-Steps**
1	A user is unable to read the text currently displayed on the screen and therefore requires audio feedback.	- select audio playback feature located on the top left-hand side of the interface.
2	A user does not understand the image currently displayed on screen.	- select the image swap button.
3	A user is finding it difficult to convey symptoms of a sore, tight chest.	Note that all tasks involved selecting the appropriate answer, prior to the right arrow button to confirm the selection. - select no to generally unwell question - select no to feeling sad - select no to ear question - select no to eye or vision question - select no to mouth question - select no to feet question - select no to toilet question - select yes to chest question - select appropriate time answer for duration question - select yes to sore chest question - select no to burning feeling question - select no to cough question - select yes to tight chest question - select no to faster heartbeat question - select no to gained weight question - select no to lost weight question

Traditional [139]

- Question 1: Will the user try and achieve the right outcome?
- Question 2: Will the user notice that the correct action is available to them?
- Question 3: Will the user associate the correct action with the outcome they expect to achieve?
- Question 4: If the correct action is performed; will the user see that progress is being made towards their intended outcome?

Streamlined [140]

- Question 1: Will the user know what to do at this step?
- Question 2: If the user does the right thing, will they know that they did the right thing, and are making progress towards their goal?

Since the caregivers had an added interest in the application, due to being a potential stakeholder (see Chapter Two), their studies concluded with a semi-structured interview. The following question set was presented during these interviews, which focused on how patients with ID prepare for consultations, how the application can enhance communication, and how it may be improved.

(1) Do you help the individual with ID to prepare for upcoming consultations? What does this involve? What are the barriers to this process?
(2) Do you attend the consultation with the individual with ID? What is your role in this process?
(3) What are the main barriers for people with ID during primary care consultations?
(4) Would you recommend this app to the individual with ID? What are the benefits of using it?
(5) Could they complete the questionnaire on their own? What are the barriers to this process?
(6) How may the application be improved?
(7) Does the individual with ID own or have access to a tablet? Are they familiar with these technologies? What about mobile phones?

(8) Is there anything else you would like to add?

Analysis of Cognitive Walkthroughs

The cognitive walkthroughs were recorded with participant consent and transcribed verbatim by the author to increase their familiarity with the captured data. All usability issues were then tagged, along with the discussed solutions, before being transferred to a table containing the following columns: usability barrier; justification; frequency i.e. the number of walkthroughs the barrier was mentioned; and proposed solutions. Nielsen's rating scale – see below [148] – was then applied separately by two investigators to determine the severity of the identified issues. These investigators met virtually to discuss their ratings, before coming to a final consensus – see Table 7.4. Tagging the usability barriers, as well as the solutions, enabled the author to provide participant quotes whilst discussing their conclusions, thus strengthening the validity of the results.

- 0 = not a usability problem
- 1 = Cosmetic problem only, need not be fixed unless extra time is available
- 2 = Minor usability problem, fixing this should be given low priority
- 3 = Major usability problem, important to fix, so should be given high priority
- 4 = Usability catastrophe, imperative to fix this before product can be released.

The semi-structured interviews were transcribed verbatim by the author to further their understanding of the data before being subjected to an inductive framework analysis [73]. An initial codebook was developed using the author's notes produced during the familiarisation stage and was subsequently applied to the transcripts by highlighting key phrases in Microsoft Word and assigning the appropriate tag. Further codes were created where necessary and comments were included to explain the application of certain tags. This process was repeated until the author was confident in their interpretation of the data. An additional researcher reviewed the tagged transcripts and made note of codes they did not agree with. The two researchers involved in the analysis then discussed their interpretations and a consensus was met, at which point the codebook was updated to reflect their conclusions. The transcripts were then revised to meet the final framework. Relevant excerpts were charted into the framework analysis table, which included a structured summary of the key barriers and facilitators to the employment of the proposed app - see DOI:10.15129/df697f81-c65c-414a-acab-1de446cf8302.

7.2.1.2 Post-Task Walkthroughs with General Practitioners

General practitioners are neither experts in usability or ID, meaning they would identify a minimum number of usability issues within the application (circa 20% [147]). Consequently, post-task walkthroughs [116] were considered a more appropriate method to apply with this population to enable them to envision how the application may be utilised, including whether the results meet their own needs. Traditionally, a minimum of n=12 post-task walkthroughs would need to be conducted to account for data saturation [145]. Nevertheless, the author was aware of the additional burden placed on medical professionals during the Covid-19 pandemic and therefore aimed to recruit a N size that aligned with the cognitive walkthroughs. 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. Recruitment was carried out in Autumn 2020 via a mailing list of medical professionals interested in mitigating the health inequalities experienced by vulnerable populations. An invitation to participate was sent to the mailing list facilitator, along with an information sheet, who then forwarded the resources on to the members. Potential participants contacted the author to arrange a suitable date and platform to complete the virtual study, prior to signing a digital consent form. Table 7.3 includes the demographics of all GPs involved in the post-task walkthroughs.

Table 7.3: Demographics of the GPs involved in the post-task walkthroughs.

ID	Experience
GP1	26 years experience. Semi-retired, works part time as a locum practitioner.
GP2	8 years experience. Works as a sessional GP in an urban practice.
GP3	17 years experience. Works as a sessional GP in an urban practice and advises on eHealth services.
GP4	7 years experience. Works as a sessional GP in a rural practice.
GP5	Newly qualified. Works as a full-time GP in a rural practice.

Description of Post-task Walkthroughs

Once again, the participants were briefed on the goals of the PhD, including the rationale behind the evaluation. They were then asked to use the prototype to select symptoms from the final scenario listed in table 7.2. 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. Since the views of General Practitioners had not been identified up to this point in thesis, the participants were also asked to complete a semi-structured interview centring on their experience treating patients with ID, as well as the potential of the application to improve consultations. The questions presented are listed below:

1. How confident are you treating patients with mild ID without technological support?
2. What are the barriers to treating patients with mild ID?
3. Do you think this app would improve consultations involving patients with mild ID? How will it achieve this? Would you use the application regularly with this population?
4. What are the barriers to using the application?
5. How could you improve on the application?
6. Is the results page easy enough for you to understand? Would you trust the results produced? Would you like them stored for future use?
7. Do you use tablet-based applications within consultations? Are there barriers to this? What alternatives are there?
8. Is there anything else you would like to add?

Analysis of Post-task Walkthroughs

The post-task walkthroughs and semi-structured interviews were transcribed verbatim by the author to further their understanding of the data. The transcripts were then subjected to the same framework analysis [73] process used in the cognitive walkthroughs to determine the GPs views on the key barriers and facilitators to the employment of the proposed app. The resulting table may be accessed via the following DOI:10.15129/5ca7c5d6-4a6d-4bb2-9579-81c2f2486864

7.2.2 Results

The results for each of the three sub-populations involved will be presented separately in order to compare the similarities and differences between them.

7.2.2.1 Experts in HCI and Intellectual Disability

In all, the experts identified 20 potential usability barriers, which have been summarised in Table 7.4. The key barriers will now be discussed under the following headings: Modalities; Results Page; Navigation; and Additional Functionalities.

Table 7.4: Usability barriers identified by the experts in ID.

ID	Usability Barrier	Discussed By	Rating
1	Audio icon does not accurately describe the function of the button.	Expert 1, 2, 3	1
2	Image change icon does not accurately describe the function of the button.	Expert 1, 2, 3, 4	1
3	Images are not standard, i.e. they contain different characters.	Expert 1, 2, 4, 5	3
4	Images display characters that are of a different age to the user.	Expert 3	3
5	Images display characters that are of a different gender to the user.	Expert 4	3
6	Images with positive connotations are used to represent the option no.	Expert 2, 3, 5	3
7	Some of the conditions captured by the images are not obvious at a glance.	Expert 1, 3	2
8	Some of the images used do not display abstract concepts clearly.	Expert 1, 2, 3, 4, 5	2
9	Patients may not utilise the image change button to view the range of conditions contained within a sub-questionnaire.	Expert 4	2
10	Potentially vague language is used to describe some symptoms.	Expert 4, 5	3
11	Some of the questions cover components that are too complex for people with intellectual disabilities.	Expert 4	2
12	Audio confirmation of the selected answer is not provided for those users who are illiterate.	Expert 4	1
13	Results page does not clearly highlight the symptoms the patient is experiencing.	Expert 1, 2	4
14	Results page is cluttered making it difficult for people with intellectual disabilities to locate the information they require.	Expert 1, 3, 4, 5	4
15	Users may be unaware of the purpose of the results page.	Expert 3	2
16	Users are unaware of their progress in the questionnaire.	Expert 2, 3	2
17	Patients have the potential to get lost down the wrong questionnaire branch.	Expert 4	3

18	Confirmation of previous answer not provided when navigating back to previous questions.	Expert 3	3
19	Incorrect actions are available to the user throughout the interface.	Expert 2, 4	2
20	Button positions may require additional effort from users with physical disabilities.	Expert 1	2

Modalities

Non-standard Image Sets

As highlighted in Chapter Five, the pictures embedded within the prototype were considered as placeholders until a common image set is developed with people with ID. These images were the same as those used in the UCD workshops, meaning there were expectations that significant usability barriers exist due to the concerns raised by the individuals with ID throughout the image board task (see section 5.2.2). The most notable barrier identified by the experts was the employment of non-standard images, as highlighted by Expert Two: *“The picture sets are good but they sometimes show different things. So, for example, the no’s, the first one was a thumbs up with a random guy. The second one was a child getting their ear examined by a doctor and this one is a lady with I think a light coming out her ear.”*

The use of multiple characters may therefore result in patients having difficulty relating to the conditions displayed. Consequently, Expert Four advocated for the embedment of standard image sets, with the ability to customise the set based on the needs and familiarities of the patient e.g. they may already be utilising Makaton or the Picture Communication System. This process should occur prior to the first question being presented, at which point the option to swap images should be removed: *Expert Four “It's a general problem [when] you give people a symbol set that they've never seen before in a situation they're not happy with…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. If you allow people to personalise the symbols, I would then probably not allow them to switch in while they're doing it because all the symbols will be what they normally use.”*

Non-Representative Characters

Similar to the results of the UCD workshops (see section 5.2.2), the experts had concerns over the implementation of characters that differed in age and gender to the patient: *Expert One "I'm not sure about using older adult images [with] young people. When you click, it [should] display images that kind of match their ages. There is a young person, nice eye, I'm guessing not a problem and the second image, someone touching their eye, having an older person does not make much sense." Expert Two "The other thing would be trying to get a balance, a ratio of like male and female images because obviously there's one female out of the six images and like the second set [toilet problems], they would not apply to most females I imagine."*

Consequently, it is also important to personalise the image set based on the characteristics of the patient: *Expert Two "It might just be that when you start the app it asks would you like to see male or female pictures and it just then…even two separate sets of images, like you've got a female set and a male set."*

Images with Positive Connotations being used to Represent No

In Fig. 7.1, an image of a man smiling and holding his thumb up was used to convey a lack of problems with an individual's ears or hearing. Some of the experts felt that people with mild ID would have difficulty aligning an image that has such positive connotations with the option "no": *Expert Two "I don't know if people would associate no with positive. So the last one as well it was like "have you been feeling sad" and it was no and it was a big happy face on the cartoon one. And with this one it's a thumbs up but it's no. I think that might be an understanding thing for people, it would be like "Yes", "oh wait, that say's no and he's got his thumbs up."*

I have a problem with my ears or hearing

Fig 7.1: Determining whether the patient with mild ID has a problem with their ears or hearing.

To overcome this barrier, Expert Four suggested illustrating the question when there is no obvious difference between the yes and no answers: *"You're illustrating the* *answer, which is quite difficult because although there's no, the chap looks very happy. So it would be a different design 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."*

Nevertheless, it is still appropriate to convey both options when there are clear differences, for example in the bunion question shown in Fig. 7.2. Highlighting the symptom via contrasting circles was also considered to be important by Experts One and Three to ensure the user is aware of what is being conveyed.

Fig 7.2: Determining whether the patient with mild ID has a bunion.

Replacing the Image Swap Button with an Image of the Body

Some of the experts suggested that the image swap button may not be used to cycle through the conditions that a primary question may lead to. An alternative structure for the questionnaire was therefore proposed, with an image of the body being utilised to navigate to a sub-questionnaire directly: *Expert Five "Could you do something like having a body image, so they select the body part because most of those were related to body parts…Even if they could select something on the head and then that breaks down to the eyes, ears and mouth."* Such a strategy was also raised by the participants with ID during the UCD workshops and the reasons for not utilising a touchable image of the body was discussed in section 4.3.1.

Use of Vague Language

In terms of the language employed, some of the experts indicated that the first two core questions (general wellbeing and mental health) were non-descriptive and could lead to patients incorrectly triggering their adaptive properties. Co-designing the language with people who have mild ID was considered to be a potential solution, as was a feature to return from incorrect questionnaire branches: *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…So just to [check] that you're not on the right path and then allow [them] to get back on to the right path."*

Questions Better Suited to Caregivers

Overall, the questionnaire was considered to be appropriate for patients with mild ID as it supports them to hone in on the symptoms they wish to convey *Expert Five: "Getting into the nuances of what the actual issue is can be quite tricky, I mean it can be tricky for anyone particularly for your patients with intellectual disabilities. So I think the main kind of thing that I like about this is it's breaking it down to the smaller problems and really being able to target what the particular issues are. And I think it's not intimidating either so it would be easier for them to complete this and then the GP look at it, whereas you know the GP saying well what about this, what about this, what about this could be quite off putting."*

Yet several of the concepts included within the questionnaire (weight change, duration of symptoms, heart rate) were deemed to be too complex for the ID population without caregiver intervention: *Expert Four: "How do they know that they've put on weight? So that means they either weigh themselves every day or they have a very good body image that allows them to decide that they have put on weight...There are answers and questions that the person with the learning disability will always have difficulties answering so you would need somebody else to."*

Expert Five therefore suggested utilising colour as an indicator to the patient that they may need some assistance when answering complex questions. Such a process also mitigates the reliance placed on the clarity of medical images, particularly since it is difficult to capture abstract concepts accurately using this medium.

Results Page

Order of Results

The bulk of the experts stated that the results page was overbearing for patients with mild ID, since they would need to keep a large set of images in their working memory in order to describe their condition. Isolating the symptoms they are experiencing should help to reduce the cognitive load placed on their working memory, as described by Expert Five *"They could just see the yes ones possibly in maybe more of a grid layout or something so they're not scrolling… I think if the GP can go back into it and see the details, more of the extra details, but for the actual patient I would concentrate on what the main one was and the duration and then possibly the other yeses."*

Expert Four also advocated for a feature to allow the patient to confirm whether the symptoms selected are an accurate description of how they are feeling. The medical professional may then build on these symptoms if so or explore other routes if not: *"You would probably have to summarise that in a more sophisticated way. That you actually take all the answers and create a little report that says this is what [is wrong]. It's a tool to help the GP communicate with the patient isn't it? So you will always have after that the GP talking to the patient. So at least if they have an option to say yes that's actually a good summary of how I feel, or it didn't work out that's not really what I'm here for then that can still be a starting point for the GP."*

Emphasising Severe Symptoms

In addition to reducing the amount of information contained in the results page, the experts felt it was necessary to emphasise more severe symptoms to ensure they are discussed within the consultation: *Expert Two: "I feel like the yellow colour theme is consistent but obviously if they say yes to a question that indicates a problem doesn't it? Yeah, I think you need a slight difference, maybe it's a colour so that yeses are flagged up with, I don't know orange or red or something."* Subtle colour changes may be used to achieve this, with orange representing common symptoms such as a cough and red representing more severe e.g. chest pain.

Navigation

Fatigue and short attention spans were identified as major barriers to the completion of the application. Such aspects were heightened by the adaptive nature of the questionnaire since the patients have no insight into how many queries remain: *Expert Three: "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. But at the same time if it's difficult, you know like there's a mobility issue or each question is effortful, [the] idea that "oh my god I have 19 questions or so in front of me" is daunting."*

Providing a progress bar may therefore help the individual to carry on with the questionnaire as they know the amount of effort required for completion: *Expert Three: "The progress bar, it kind of helps you combat the answer and fatigue because you know how far there is to go. But equally it's an easy set of interactions so if they want to use the tool then it's not like it's particularly complicated it's very doable."* It may also be useful to implement a summary of the questions that have been answered at the point the user quits since this information may be valuable to the GP.

Additional Functionalities

Preventing Incorrect actions

Whilst navigating the prototype, stakeholders may perform incorrect actions that are mitigated via the presentation of error messages. For example, Fig. 4.8 highlighted what occurs when an individual selects the back button on the first question. In addition, a further error message was presented if the forward button was selected prior to a yes or no option. Experts Two and Four suggested that such steps are unnecessary, and the interface would be easier to use if buttons were hidden until they were required: *Expert four: "If you can't use a button like forward and backward, I would grey them out. That's something you can avoid [error messages] by not showing the back button when it's not needed."*

Button Positions

Expert One observed that the position of the buttons may be demanding for stakeholders with physical disabilities: *"Do you think most of the people are left-handed? It's [audio button] on the left. So if I use any devices, I use my right hand, right finger [to tap]. So I would like things on the right hand side because most of the people are right handed."* Reorganising the interface based on the dominant hand of the user should mitigate the physical exertions place on the individual. As such, a further property should be added to the Accessibility Preferences Ontology (see Chapter Six) to drive such customisation.

7.2.2.2 Caregivers

Overall, the four caregivers identified a similar set of usability barriers to the experts. These will be presented in the following subsection, with a particular focus placed on the barriers that differed between the two groups of participants. The second subsection will then describe the results of the semi-structured interviews, in order to compare the caregivers' perspectives with those of the GPs in section 7.2.2.3

Usability Barriers Identified by Caregivers

Table 7.5 provides a summary of the usability barriers discussed by the caregivers. Those that diverged from the opinions of the experts will subsequently be discussed in greater depth.

Table 7.5: Usability barriers identified by the caregivers.

ID	Usability Barrier	Discussed By	Rating
1	Audio icon does not accurately describe the function of the button.	Caregiver 1, 2	1
2	Image change icon does not accurately describe the function of the button.	Caregiver 1, 2, 4	1
3	Images are not standard, i.e. they contain different characters.	Caregiver 2	3
4	Images display characters that are of a different age to the user.	Caregiver 2	3
5	Images display characters that are of a different gender to the user.	Caregiver 2, 3, 4	3
6	Images with positive connotations are used to represent the option no.	Caregiver 2, 4	3
7	The body language in some of the pictures does not accurately describe the symptom being displayed.	Caregiver 3, 4	3
8	Some of the images used do not display abstract concepts clearly.	Caregiver 2, 3, 4	2
9	Some of the more realistic photographs may be inappropriate for users with autism as they do not respond well to facial features.	Caregiver 3, 4	2
10	Patients may not utilise the image change button to view the range of conditions contained within a sub-questionnaire.	Caregiver 2, 4	2
11	Questions are posed as statements meaning some patients may not realise they need to provide an answer.	Caregiver 1	1
12	Potentially vague language is used to describe some symptoms.	Caregiver 1, 2, 3, 4	3
13	Some of the questions cover components that are too complex for people with intellectual disabilities.	Caregiver 1, 3	2
14	Structure of the questionnaire may be overly long for some patients who are suffering from one condition only	Caregiver 1, 3	3
15	Results page is cluttered making it difficult for people with intellectual disabilities to locate the information they require.	Caregiver 1, 2, 3, 4	4
16	Users may be unaware of how to navigate through the questionnaire.	Caregiver 2	2

Image Change Functionality

Three out of the four caregivers aligned with the views of the experts in that common icons should be used to indicate the functionality of the image change and audio playback buttons. Nevertheless, Caregiver One felt that the former was unnecessary since the three image sets employed may be displayed on the screen at the same time: *"You might even just put up three different [image sets] rather than have somebody select another one, just have three different [sets displayed]."*

Such a process, however, may be cognitively challenging due to the abundance of choice present on the screen at any one time. In addition, it is an inefficient use of space, particularly for a population that is prone to developing eye and motor impairments. Consequently, it may be best to utilise a single image set that is pre-selected by the patient prior to the commencement of the questionnaire, as discussed previously by the experts and by Caregiver Two: *"Photo symbols is usually what we use for images when we're doing easy [read] documents. So they're quite familiar with those, and also when we're doing easy read, if we are talking about the same thing, we always use the same image. So yeah I wouldn't swap the images out, I would use the same consistent ones because I think people might get a bit confused if [they] keep seeing different pictures or might get too hung up at looking at the different pictures."*

Gender Related Images

Once again, the caregivers indicated that certain symptoms, e.g. toiletry habits, require gender specific images. Yet in contrast to the experts, Caregiver Three felt that it may be more appropriate to employ gender neutral image sets to accommodate for user groups with less knowledge of the opposite sex: *"I would actually even say, like, the people one, [it is] completely inappropriate for any young person to be seeing a man or woman sitting on a toilet…I'd probably make them a bit more gender neutral is what I would say as in not make it obvious whether it's a boy or a girl because that would cover both. A stick person sitting in a toilet isn't offensive, it just shows you an action. You can still show the type of pain versus a very descriptive picture of a man or a women sitting in a toilet."* As such, the experts' suggestion of selecting an appropriate image set at the start of the application may be extended to include gender neutral pictures.

Realistic Images

Following on from the inclusion of gender-neutral images, Caregiver Three proposed that certain sub-populations, such as those with autism, can find it difficult to associate with realistic expressions: "*My children with autism don't actually understand facial expressions but in a cartoon form, for some reason it's different, don't know why it just is…Maybe two, three choices [of images] would be your best bet, you don't want to overwhelm them because if they have six or seven buttons that they have to click through, they're going to lose interest after a point.*" This further highlights the importance of personalisation, including the ability to embed and utilise image sets that best meet the needs of individual patients.

Structure of Questionnaire

Two of the four caregivers agreed with the views of Expert Five, stating that the structure of the questionnaire may be simplified via the introduction of a touchable body image: *Caregiver Three: "If you don't feel unwell maybe the next question should be are you sore, or are you in pain so that if it was a pain that they were feeling that would then maybe move them back on to the yes track, which we could then narrow down what type of pain they've got…If it was a touchscreen, you would pick where on the body and that would then take you to the appropriate question…So you'll get to your end game quicker versus going through six or seven questions that's no then one that's yes."*

In section 7.2.2.3, the GPs indicated that they prefer the current structure as it enables a greater depth of information to be extracted from the patient. It may therefore be advantageous to offer both strategies, with the body image process acting as a fallback for individuals who find the original laborious or overbearing.

Complex Concepts

Two of the four caregivers were open-minded over the ability of people with mild ID to provide information on abstract concepts, such as increased heart rate: *Caregiver Two: "I think they would know if their heart was beating faster than it normally does. Even if they didn't know what the normal one was like. In fact one of my friends, he describes his symptoms when he's not well and he often says things like my hearts* *beating too fast. So he recognises that that's a problem and he knows it's not normal, so I think in general people would get that."*

Nevertheless, they agreed with the experts that an indication may be necessary for caregiver intervention if the individual is unable to recognise such symptoms: *Caregiver Four: "For when a service user [needs to] step in [you could] have like a key at the start and then have something in the corner that the carer can look out for when to step in."*

Results of Framework Analysis

On completion of the cognitive walkthroughs, the caregivers discussed their own responsibilities during consultations as well as the potential barriers/facilitators to the implementation of the proposed app. The next section presents the results of the latter discussion, since the collected data has a direct influence on how the app may be embedded within current practice. Nevertheless, Fig. 7.3 includes an overview of the main barriers to effective primary care highlighted by the carers, in addition to the strategies used to overcome them. Appendix F describes these barriers in greater depth, thus strengthening the conclusions made throughout the scoping review and UCD Chapters.

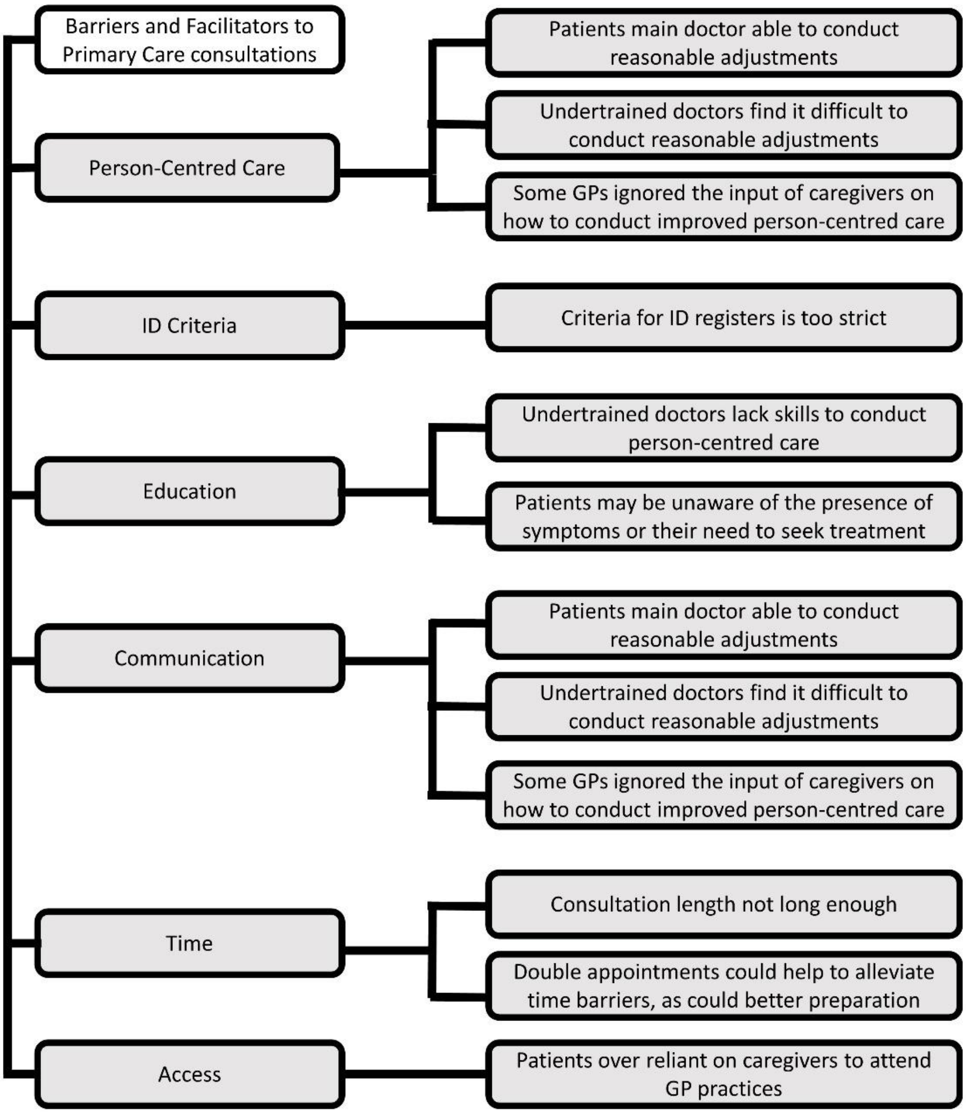

Fig. 7.3: Overview of the barriers to primary care identified by the caregivers.

Digital Advantages / Disadvantages

All four caregivers had little experience utilising technologies during primary care consultations, yet the majority (Caregivers Two to Four) were open to doing so providing the benefits were clear. Nevertheless, there was some concerns that a greater reliance on technology could create further inequalities for people with ID due to limited access *Caregiver Two: "But now of course we've got new things, so it's phone calls or video calls. The video call concerns me a bit because obviously people have trouble getting access to things online anyway. I'm not sure how well that would work for people with learning disability. But if that's the only option then they will also need help to get online to do things like that. And a phone call can be difficult unless you're* *on speaker because your caregiver doesn't hear necessarily what's coming from the other end but face to face is always the easiest."*

However, mobile technologies are becoming more accessible due to declining costs, with Caregiver Two suggesting that majority of people with mild ID will be able to access and run the application, providing they receive some sort of support: *"I think because more and more people are using technology now, they're getting used to how it works. They've got phones, they've got tablets, they've got computers and I think if it helps them communicate better with primary care then yeah, I'd be up for it. Obviously, there are people who will not use it and people who don't use any kind of technology but there are fewer and fewer of those now and especially, you know, from 18 and upwards, most of them have got some kind of device."*

Application Barriers

Two further usability barriers were identified by the caregivers during the semi-structured interviews. First, they appreciated the use of the audio playback feature since many of the individuals they care for have difficulty reading text. Yet the style of feedback was deemed to be inappropriate, particularly for people who are feeling unwell: *Caregiver Three: "I think the voice is okay but [I'd prefer] if it was a little bit more humanized rather than so robotic because I think that's a bit weird. It's not comfortable if you're not feeling well...I think it would need to be quite a soothing, calming voice."*

Furthermore, several of the caregivers had concerns over first time users knowing how to traverse the interface due to the obscurity of the icons. Implementing a tutorial to combat such a barrier was therefore raised, yet this feature was deemed to be potentially overbearing: *Caregiver One: For some, maybe a tutorial would be a bit heavy. But if there's some other way [to show their functionality]…I mean these concepts are quite commonly used in, you know, in lots of things*. Caregiver One therefore suggested that the interface employ a similar layout to other AAC applications to ensure quicker uptake.

Advantages of the Proposed Application

The caregivers identified four positive effects the proposed application may have on primary care consultations, ranging from an increase in autonomy to a reduction in time.

Communication

First, the application was judged to help patients identify and better describe their symptoms. This was particularly true for individuals who find communication challenging in both general and situational circumstances, since they are able to point to symbols that represent their views: *Caregiver Three: "I think something like this could be a complete game changer for a lot of families like mine, not just with people with learning disabilities but it would help with people with autism a million percent because they could point to it on a visual aid or something like that. That would verbally be able to express what they can't."*

Autonomy

Increasing the patient's ability to communicate may also break their reliance on caregivers to facilitate the consultation, as described by Caregiver Three: *"It gives that person with additional needs their own independence and they don't have to rely on an adult. I think that's really important when you become a young adult, if you don't have those skills, if there's another option for you."* Extracting symptoms from the source may also help to enhance the accuracy of diagnoses being carried out, whilst fulfilling the GPs expectations of interacting directly with the patient.

Time

Caregiver Three suggested that a list of pre-determined medical symptoms can also help to alleviate time constraints: "*If they had a tablet with visual aids or some form of communication that my children would get and just hit what it [was], it would make the world of difference. Because it would be quicker, which would save everybody a lot of time and stress and the doctor would be able to diagnose them with the right thing.*" Furthermore, the GP will be free to focus on areas of interest for longer, which may help in diagnosing more complex conditions.

Finally, Caregiver Three revealed that her children's anxiety levels rise dramatically when attending medical practices. As such, she would prefer to utilise virtual appointments where possible and believes that the proposed application would assist in making such a process easier: *"Now we don't have to go into the doctor's surgery and we're doing everything via phone calls or like this [video call], they [her children] prefer it much better and you get a much better, honest answer off them…So I actually think unless they had to be physically examined then these type of things should be an option [because]a doctor could get all the information they need and see them visually and then maybe determine right actually you need to come in and we need to actually check you out."*

Questionnaire

Overall, the questions included within the app were deemed to be appropriate for people with mild ID. Caregivers Two and Three particularly appreciated the embedment of symptoms that patients often fail to recognise as a medical problem: *Caregiver Three: "I like the thing like with the toenails because I don't think a person with a learning disability would think that was something you would go to a doctor to say about."*

Nevertheless, there were concerns over the omission of a sexual health sub-questionnaire since GPs tend to overlook such queries during consultations: *Caregiver Two: "Actually one of the main issues is we need to be talking to them about sexuality and all those kind of things. So you know dodging it [isn't appropriate] because if it was a problem with their genitalia they're going to have to tell the doctor that. Or they might not feel well in that area and there's no question there about it so they're just like well I'll not bother."*

In addition, a reordering of the sub-questionnaires was also proposed by Caregiver Two to ensure the most serious conditions, such as chest problems, are presented first: *Caregiver Two: "I think if it's eight questions that's quite long and that's an important question [chest pain] so you want them to get there. So yeah, maybe a review of the order of the questions and maybe ones that are more important should come up first. I would categorise them in order of potential severity."* Moving common conditions closer to the start of the questionnaire may also help to retain the attention span of the patient, with the queries directly relating to their current medical context.

Modalities

Sound

The bulk of the caregivers conveyed that the individuals they support have difficulty reading text, particularly when the language is complex or unfamiliar. As such, they appreciated the text to speech functionality, yet in contrast to Expert Four, felt it should remain as an option to the user: *Caregiver Three: "I think the option is good because you know only someone that needs it read out would touch that button. When they're not well you might find that the last thing they might want to do is read it out."* Caregiver Three also went on to suggest that their children would primarily utilise the images when understanding the question presented, meaning persistent auditory feedback would be inappropriate for them.

Finally, Caregiver Four suggested that sound may be used to help patients understand some of the more abstract conditions by providing additional information such as the rhythm of a heartbeat: *Caregiver Four: "I don't know how much you're developing this app but sounds as well would aid there quite a lot, so they could, like, compare it to the beat of their heart."*

Language

Most of the language embedded throughout the app was considered to be accessible to patients with mild ID. However, in line with the experts, the caregivers were unable to agree on the phrasing used within the chest pain duration question: *Caregiver One: "I don't think number of sleeps is necessarily a good thing. I think you just express it in days, number of days or give them a calendar…I mean personally I don't like that kind of language because I think that's something you would say to a kid." Caregiver Three: "I would say sleeps is the best way rather than a calendar like this because my kids, you ask them the date and they can't tell you. For somebody with a learning disability that's just a whole lot of numbers."* This difference in opinion highlights the importance of allowing patients to personalise the interface to ensure the concepts included meet their own needs e.g. utilising beds to highlight duration, as opposed to a calendar.

Images

Caregiver Two further emphasised the importance images may have in increasing the usability of technologies. She revealed that the person she cares for is illiterate and is therefore wholly reliant on symbols to navigate user interfaces: "*One of the guys I care, for the family friend, he can't read or write and over the years he's co delivered easy read training with me. So he was one just a couple of months ago [that] got on Teams and Zoom [because] he [can] recognise logos and he knows what pictures mean. So words like yes and no he might recognise but he would use the images rather than the text."*

Consequently, there is a great importance in ensuring the final images clearly portray the medical symptoms being queried. This process is likely to involve the user embedding their own image sets, as described in the usability barrier section. Caregiver Three also suggested that the standard set should focus more on cartoon drawings due to the level of detail that may be included in them: *"I would go more with the drawing aspect of it because I think you can get more description in a drawing than you can with an actual physical picture of a real person…You can target whereabouts in the chest whether it be high up, low down, round the back in an arrow to show that it's wrapping around about you. You can be much more descriptive about what they're seeing for them to then understand."*

Finally, the caregivers suggested that GIFs are more appropriate when conveying symptoms that involve movement: *Caregiver Three: "The laboured breathing ones really good. Because that's a slight animation - to me she's doing yoga there and she's fine but that one looks as if she's pain and it's sore…I would say more animated ones for certain types of illnesses, like the breathing one that was really very helpful, because it shows what laboured breathing actually is versus you couldn't do that in a drawing."*

7.2.2.3 General Practitioners

Throughout the post-task walkthroughs, the five GPs discussed their own experiences of consulting with patients with mild ID, in addition to how the application can help promote communication. Following on from 7.2.2.2, the results presented focus largely on the latter discussion since the collected data has a direct influence on how the application may be embedded within the clinical domain. Yet Fig. 7.4 highlights the main barriers experienced by the GPs when treating patients with ID, in addition to the strategies used to overcome them. Appendix F describes such barriers in greater depth, which again strengthens the conclusions made throughout the scoping review and UCD Chapters.

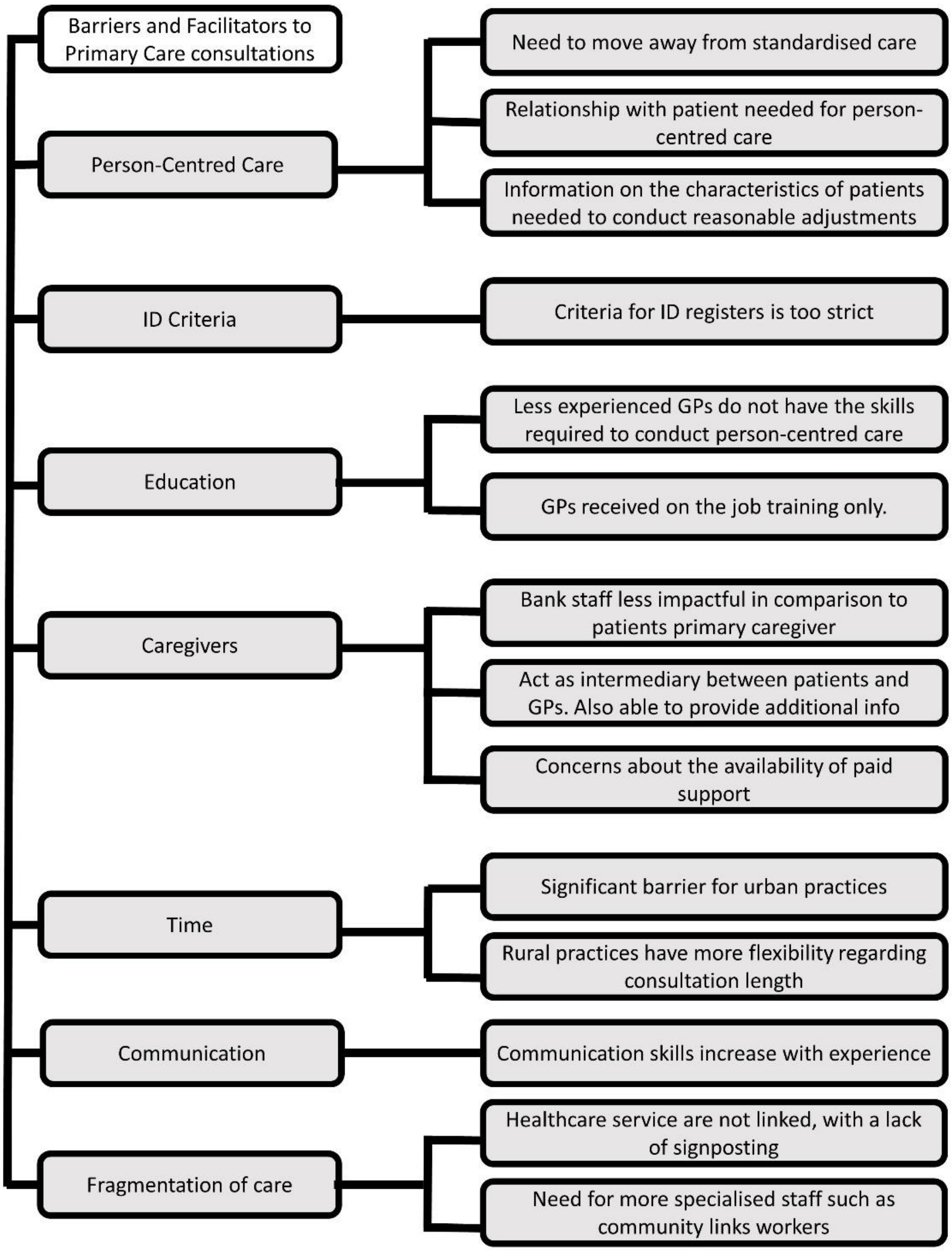

Fig. 7.4: Barriers to primary care identified by the GPs.

Digital Advantages / Disadvantages

On the whole, the GPs recognised the potential role technology may have in mitigating the health inequalities experienced by patients with ID. Yet there were concerns surrounding its overuse, with valuable occupations such as community link workers being replaced by cheaper, less effective alternatives.

Resistance

GP one was passionate about the role educated professionals have in the care of patients with ID and therefore suggests that the overreliance on technology may create further inequalities, as opposed to increasing the accessibility of health services: *"The problem that I fear for the health service at the moment is that IT's seen as some sort of solution to all the problems that they didn't sort beforehand and it's not going to do that. We're very concerned about I.T platforms creating a bigger inequality gap…People in <anon> and all, you know, educated people will be able to access IT no problem and then everyone else will have to struggle with the systems…There's a real danger people having to access us with apps will exclude people with health inequalities or any sort of issue that makes them less IT literate."*

It is therefore important to ensure new technologies supplement the ability of professionals, as opposed to simply replacing them: *GP One: "When you're speaking to someone, you can't actually have algorithms for every single thing you talk about because consultations can be extremely complex…So your clinical skill is filtering out whether that chest pain is actually just muscle damage or whether their breathlessness suggests something else. So I think if you try to design a clever algorithm for that you'd be there all day and it just wouldn't work. So I think that's why the IT is so important to see it as augmenting but not replacing."* Furthermore, strategies must be implemented to ensure patients with ID have access to such technology, including the support required to operate them effectively. This will be deliberated in greater detail in the next Chapter.

Technological Barriers

The other GPs welcomed the use of technology to improve communication with patients with mild ID. Surprisingly, their previous experience was positive and their only concerns centred on patient access and confidentiality, as opposed to the added responsibilities technology may place on them. Nevertheless, they were wary of recommending aids to their patients that had not been validated in the clinical domain: *GP Four: "With any of these things, clinicians [will] usually be uncomfortable unless things are at least safe in some ways. It's not until they're tested that we know….If a patient is using something and are able to use that to communicate what their needs are, that's fine. I would be more uncomfortable with recommending something to patients if we don't know how it works, if that makes sense?"* This highlights the importance of completing the framework for complex interventions cycle [50], to ensure evidence is collected on the impact the proposed application can have on current practice.

Furthermore, an implementation strategy must be set to ensure medical professionals receive adequate training on the technology, thereby increasing its uptake. Such training may be carried out by medical champions: *GP Five: "In order to go through and learn how to use something effectively, it takes time. I genuinely don't have that much time. So then to add something else on to that, I'm not used to using, I'm like "how beneficial is it going to be?" Usually it will be somebody saying "oh actually I used that recently, that was really good or that was easy."...So I think yeah if it's gotten really quickly and without the proper implementation and no sort of proper guidance, then yeah it just puts you off wanting to use it."*

Advantages of the Proposed Application

The GPs views on the advantages of the app largely mirrored those discussed by the patients (Chapter Five) and caregivers. All felt that the summary page is an effective starting point for the consultation and allows medical professionals to prioritise the symptoms to be brought up during the discussion: *GP2: "Sometimes people, not just with mild learning disabilities, come in with five or six things. They 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 and I looked at your verruca." So anything that hones in on urgent symptoms would be very useful."*

Such a process may also help mitigate the debilitating time constraints placed on consultations, with patients discussing a greater depth of information: *GP5: "If they* *were able to come in having looked at those [results], I think it would just make the consultation easier. There's things that if they forget or they're not sure that day how they're feeling, then I think if they had that before they come in then that would be helpful...Maybe this would facilitate quicker appointments for people because they've done the work themselves, you've got a lot of information about them beforehand."*

Providing a list of the symptoms could also help increase the diagnosis of conditions commonly overshadowed by medical professionals. In addition, GP Three felt that the results of the application could help empower the patient to provide their own views, therefore reassuring them that their concerns have been met: *"I think there's an issue in that sometimes you're making assumptions that you haven't actually tested and also patients find it much more reassuring to be listened to. So even though I have a very good idea what I'm dealing with possibly long before they do, it's not necessarily therapeutic for them if I just cut them off....So again, I think something like this could be quite useful in making people feel reassured that the clinician has listened and understood."*

Finally, the GPs also suggested that the application can be a valuable form of support for those who lack access to caregivers – a frequent problem during the Covid-19 pandemic: *GP Two: "We are at the moment trying to reduce footfall into the surgery. So in certain circumstances we of course allow a caregiver to come and give the history if we feel that the patient can't give the history. But it may be that for mild learning disabilities some practices might feel that having an extra carer in might not be appropriate and if the caregiver is able to do the app beforehand then that would save them actually having to come out or come down." GP Five: "It improves their autonomy so they don't have to just go through the caregiver, you know, they can tell us what's wrong with themselves."*

Barriers to the Proposed Application

The GPs main concern was the results page forming an inaccurate description of the patient's medical context: *"GP Four: My worry would be if the app misses the mark, would it take you down the wrong path too early and like the GP thinks it's about something when actually it's just not quite grasped what it is? Rather than doing what you'd normally do and just start off with a really open mind it might just even* *subconsciously kind of marry you off the wrong path."* Consequently, evidence on the benefits of the application must be composed to alleviate medical professionals' unease over the accuracy of the questionnaire. Furthermore, continuously monitoring the use of the questionnaire in practice will allow problem areas to be identified and amended.

Nonetheless, despite this concern, four of the five GPs suggested that they would regularly employ the app in their consultations. The other, GP One, insisted that her skills did not warrant the need for communication aids; however, they envisioned a use for the app further down the consultation process: *"There's a lot of work being done in general practices, particularly deprived practices with community links workers. It sounds like this is the kind of work that would sit with community links workers when people register patients with the practice…What I would envision the receptionist doing is putting it in as a phone consultation with the link to the summary of their presentation. So before we start speaking we have an idea of what's going on. That'd be helpful that way."*

Questionnaire

Overall, the GPs felt that the structure of the questionnaire was appropriate, since the question, sub-question hierarchy allows the patient to select all symptoms they are suffering from: *GP Four: So I've been having lots of consultations with people who have more than one problem. And often people will, you know, have their list or they'll remember and so on but 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 were considered to be unsuitable due to their seriousness or their relevance to other professions: GP Four: *"I think laboured breathing is a really hard one…Because actually that's something that at the point they're filling it out might actually change what [you would do]…You know if that's genuinely a yes, they're sitting there panting away, you're going to change what you do at that stage."* *GP One: "Well that's interesting. In <anon> everyone that's got a* *problem with their eyes should be going to their optician. They shouldn't be phoning the GP actually and that's a triaging pathway."*

In addition, some of the GPs felt that important queries were omitted from the questionnaire, particularly those relating to genitalia: *GP Five: "One thing that I would be interested in that we often get, that are quite challenging are like male and female problems. So women period problems and men testicular problems and then that's also difficult for people to speak to the caregiver and then sort of speak to you."*

The language used to convey the questions was considered to be accessible to patients with ID, apart from the word "generally" in the first core question i.e. "I have been generally unwell." The embedment of images was appreciated by all of the participants as it enables complex information to be presented in a format more suited to the abilities of people with ID. They particularly liked the feature to change the image set displayed, as there were concerns over the effectiveness of the photorealistic pictures: *GP Three: "I really like the switch from the pictures to the sort of cartoon characters. Because I think a lot of people with learning disabilities are quite familiar with this. A lot of learning disability services use kind of smiley faces and pictures like this to express concepts."*

As with the views of the experts and caregivers, GP Five felt that the images should be gender appropriate to ensure patients are able to relate to their meaning: Finally, GIFS were considered to be an advantage over paper-based resources when displaying symptoms that require movement: *GP Three: "I like what you're doing here but a lot of it can be approximated using a paper-based questionnaire. Whereas using the animation is that it brings something different."* Nevertheless, some of the options required more exaggerated differences, as highlighted by GP Four: "*You said the pictures were placeholders which is fair enough. So some of them like the feet ones, they wouldn't maybe be clear what was the good foot, what was the bad foot. And the breathing, I appreciate what you've done with the GIFs and the heart and things. I think those differences were subtle."*

Further Features

The majority of the improvements suggested by the GPs focused on the results page. All felt that the current structure was overly complex and instead preferred a snapshot of the patient’s major symptoms, with the option to view the remaining information if required: *GP Four: “[The results page should] almost [be] something you can see in one snap in front of you. 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 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.”*

GP Two also suggested that it may be beneficial to colour code the symptoms based on their severity, to ensure the most significant are explored first: *GP Two: “I can't quite work out how it would work but maybe if the yeses and no's were color-coded. So if all the no’s were sort of like green and all the yeses were red, like if something was really bad you would go yeah it's red and it might just be a bit easier to take [interest in].”*

The same GP then went on to describe how they would like additional information to be presented if the patient had been consistently complaining of the same condition: *GP Two* “*Sometimes it's very hard to pick out the wood from the trees because people often come in with three or four different complaints and sometimes it's really quite difficult and challenging to pick out actually what's the important thing here. And I think if the app was able to identify we've done this before you can either go right have I really looked at this properly because this is the fourth time they've come in saying they feel sick.”*

Finally, in line with the patients’ views in section 5.2.4.3, GP’s two and four felt that the application can support individuals with ID to identify the most appropriate health service to attend, thus alleviating some of the burden placed on general practice: *GP Two:* “*It's not set up for people with learning disabilities. If you think of all the options if you hurt your toe, what would you do? Would you go to a and e, would you go to minor injuries, would you speak to your doctor, would you call NHS24, would you speak to the pharmacist? 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. Not everything would then need to* *go to the GP…It wouldn't be a massive step for the contents of the summary page to be uploaded to the duty doctor via email and a decision then made."*

7.3 Discussion

Chapter Seven approached the quality of primary care consultations from the perspective of both caregivers and GPs. The main barriers presented in Appendix F (e.g. time, education, fragmentation, communication and complexity) broadly match those discussed within the wider literature [8, 10, 11, 21, 93, 111, 149], thus highlighting the urgent need to reduce the health inequalities experienced by the ID population. The participants also recognised the important role technology may have in achieving such a goal but only as a supplement to other policies such an increase in specialist staff, e.g. community link workers [150], and an overhaul of the medical education system. The proposed app was deemed to be beneficial in terms of reducing time constraints, promoting autonomy and communication, and enhancing the diagnosis of commonly overshadowed conditions. Nevertheless, there were some barriers to its implementation, which will now be discussed.

7.3.1 High Quality, Personalised Imagery

Imagery is often used as a key modality to assist people with ID in navigating interfaces, as well as processing complex concepts [151, 152]. Such a sentiment was furthered by the participants with mild ID in Chapter Five, who suggested that some of the medical concepts being queried were too abstract to capture via text alone. In addition, the caregivers and GPs discussed instances when they were caring for individuals who are illiterate. This therefore highlights the importance of developing an image set that accurately portrays the symptoms being conveyed - a process the current placeholders fail to achieve. Identity was considered to be a major barrier, with each of the three sets of participants suggesting that people with ID may be unable to relate to characters that are of a different age or gender. In addition, Caregiver Three indicated that people with autism may be unable to process realistic photographs and would instead prefer the implementation of cartoon images. Yet, to be truly effective, the participants agreed with the views of Keskinen et al. [152] in that the user must have the option to introduce image sets they are familiar with such as PhotoSymbols, Widgits and Makaton. Consequently, further research is required on how to effectively support adults with mild ID to achieve such a process. In addition, a standard set must be produced (in conjunction with target stakeholders) for those who do not have access to the relevant medical imagery.

7.3.2 Automating the Adaption of User Interfaces

Versatility has been considered throughout the design of the application to ensure the clinical and accessibility needs of a wide range of users are met. These features were appreciated by the participants, with some of their suggested improvements also moving away from a standard interface e.g. making components visible only when required or changing an elements colour to emphasise its selection. Nevertheless, (semi) automated alterations are not common practice and actually contradict one of the main accessibility guidelines that states that consistent interfaces are easier to use for people with cognitive disabilities [151]. As such, applications often employ a settings page to facilitate customisation, yet this approach is traditionally difficult for people with ID to navigate without support. More automated approaches, such as [151], should therefore be considered in the future to enable the mitigation of accessibility barriers without the need for caregiver intervention.

7.3.3 Adaptive Questionnaires

Overall, the participants felt that the questionnaire was appropriate for patients with mild ID in the primary care domain. Yet, there was scope to include further conditions, such as those related to genitalia, as well as an additional traversal strategy i.e. the use of a touchable body image to indicate areas of pain. The omission of potentially relevant queries highlights the need to evaluate the questionnaire with medical professionals to ensure their information requirements are being met. Moreover, the participants identified two novel functionalities that may help to overcome the barriers related to adaptive questionnaires. First, a recovery feature will assist patients to return from incorrect paths if they have misunderstood a particular question or image. Second, a progress bar may help to combat short-attention spans by providing users with information on the amount of effort required to complete the questionnaire. Such features may be useful across a range of adaptive questionnaires e.g. [125–128], meaning further research is required to recognise how they may be implemented effectively.

7.3.4 Covid-19 and Beyond

Despite the lack of questions surrounding Covid-19, the current pandemic was raised repeatedly by the caregivers and GPs. This is not overly surprising, since care workers were perceived as a high-risk group due to their inability to isolate. Both sets of participants recognised that the lockdown measures implemented in the UK resulted in further health inequalities for the ID population. First, the preference to conduct consultations online, via services such as Attend Anywhere, could result in a delay in care due to a lack of access to, or experience with, the appropriate technology. In addition, important caregiver services were cut during the height of the pandemic, meaning patients were unable to receive the necessary support when utilising potentially inaccessible technologies or when able to attend in-person consultations. This builds on the findings of Courtenay and Perera [146] who stated that an increase in isolation may negatively impact the mental health of a population traditionally reliant on others. This is a significant problem since people with ID already have higher rates of undiagnosed mental health problems [153].

Courtenay and Perera [146] also highlighted the important role accessible technologies can play in overcoming such barriers, which matches the conclusions made during the evaluation study. They proposed that *"new ways of working are likely to be adopted optimising the use of technology in delivering clinical care that could lead to more efficient and streamlined services."* Yet the technologies implemented may only be effective if they have been developed in conjunction with people with ID and are supported by the appropriate personnel: *"It will be necessary for paid carers and family carers to have a workable level of IT literacy when interacting not just with health services but care services too. Technology will need to ensure that it is accessible to people with cognitive impairments and limited communication using software applications. Research into the utility of adaptive technology will be required in order to learn what is effective and what people with ID prefer to use and how. Their participation in research in technology will be essential that should help to empower them in the long term."*

The work carried out in this thesis, including the evaluation, contributes somewhat to the questions raised by Courtenay and Perera [146]. The proposed application can be embedded within a more hybrid healthcare service, where people with ID have the option to attend consultations online if physical examinations are unnecessary. Such an approach also alleviates the pressure on caregivers (providing the app is accessible), which may be extremely beneficial when paid services are limited. It is also interesting to note the importance Courtenay and Perera [146] placed on the depth of adaptation that must occur in healthcare technologies for people with ID, an aspect achieved by the application's ontology driven framework. New symptoms may also be added to the questionnaire relatively easily, meaning it can adapt to upcoming pandemics if and when they occur. Future work could focus on the potential benefits of this hybrid service for the ID population.

7.4 Conclusion

The original requirements identified in Chapter Five have been evaluated by experts, caregivers, and General Practitioners. As such, the application should better meet the needs of the wider mild ID population, as opposed to being retrofitted to the participants involved in the UCD workshops. In addition, a concrete answer to the second research question proposed in section 1.3 has been formulated. Each of the sub-populations who participated in the evaluation agreed that an accessible questionnaire can help to promote communication, the diagnosis of commonly overshadowed conditions, and patient autonomy, whilst also reducing debilitating time constraints. The Covid-19 pandemic also highlights the potential role AAC technologies may play in easing the barriers that arise from sudden and drastic changes to the healthcare system. Suggestions for improvements primarily centred on increasing the clarity of the images displayed, restructuring the layout of the results page, and improving the use of adaptive questionnaires. Chapter Eight will discuss the key lessons learned throughout this thesis, including how the research has fulfilled the "Development" phase of the framework for complex interventions.

Chapter Eight: Discussion and Conclusion

The conclusions made throughout the Evaluation Chapter further constitute how the proposed application can fit into and improve current practice. As such, sufficient data has been collected to progress to the “Feasibility/Pilot” stage of the framework for complex interventions [50], since the need for two-way communication technologies was already identified within the Scoping Review and UCD workshops (see Chapters Three and Five respectively). In addition, concrete answers to the research questions presented in section 1.3 have been established. The purpose of this Chapter is to discuss the formulation of these answers, whilst linking significant findings to the wider literature. The limitations of the research conducted will also be presented, as well as opportunities for future work.

8.1 Response to the Research Questions Proposed

As stated previously, the “Development” stage of the framework for complex interventions [50] centres on establishing an evidence base for the introduction of new technologies, including how they may be adopted within the healthcare system. Such goals clearly align with the research questions presented in section 1.3:

RQ 1: What are the range of AAC technologies being used by patients with mild ID to support them to communicate with general practitioners?

RQ 1.1: What are the barriers to implementing AAC technologies with adult patients who have mild ID?

RQ 1.2: What are the facilitators to implementing AAC technologies with adult patients who have mild ID?

RQ 2: What do patients with mild ID require from a clinical AAC application to support them during primary care consultations?

Consequently, the investigator was able to formulate a response to these questions using a systematic process that is widely accepted throughout the clinical domain. Following the framework to its conclusion may therefore increase the probability of the application transitioning from research to current practice – a problem that is prolific throughout the clinical AAC domain.

8.1.1 Response to Research Question One

RQ1 aimed to explore the range of AAC technologies being utilised by patients with mild ID during clinical consultations. A scoping review was therefore carried out in Chapter Three to determine the communication aids available to this population in both primary and secondary care. Surprisingly, just 15 articles discussed the design and implementation of AAC technologies, therefore highlighting a serious lack of research being conducted in this area, despite the recognised need for such aids [21]. Those that were identified focused largely on increasing the general practitioner's ability to convey information and included: notes-based prompts to promote discussion on commonly overshadowed conditions [41, 75, 78]; and patient passports / health diaries [17, 18, 67, 79, 80] to increase their knowledge of the patient's health and communication needs, thereby facilitating reasonable adjustments. Technologies that empowered the patient with mild ID to have an active role in their care were less frequent and generally involved the use of imagery to help them understand and communicate about complex medical concepts e.g. Dodd and Brunker [65] and Lennox et al's use of flashcards [76]; Bell and Cameron's implementation of the Talking Mats™ framework [77]; and Chinn's employment of easy read resources [81]. Gibson et al.'s [32, 33, 49] adaptive questionnaire was the only high-tech aid found during the literature search, despite Jones and Kerr advocating for the adoption of such technologies since 1997, due to their increased fit within the working routines of medical professionals [41]. The questionnaire aims to produce an accessible summary of the patient with mild ID's symptoms prior to the consultation, to enable stakeholders to build upon this information throughout [32, 33, 49]. Nevertheless, the design of the application, as well as the conclusions made, were restricted due to the lack of input from the ID population.

There was also limited evidence of AAC technologies being embedded within current practice. During the UCD workshops (Chapter Five), just one of the ten participants with mild ID disclosed that they use communication aids on a regular basis. This participant had access to a patient passport (at the insistence of her mother who was involved in the development of such resources) and found it to be particularly useful when interacting with unfamiliar medical professionals. As such, the availability of clinical AAC technologies may have to be disseminated more widely, to ensure people with ID have access to them. Similar trends also occurred with the GPs and caregivers involved in the evaluation (Chapter Seven). Three of the five General Practitioners had utilised symptom flashcards and pain scales in the past; however, they were not implemented consistently with patients with ID. In addition, just one caregiver had knowledge of the clinical AAC technologies available and regularly employed the Talking Mats™ framework to determine the views of the individual they were caring for.

To summarise, the range of AAC technologies discussed throughout the literature was limited, as was their use in current practice. This matches the conclusions of Hemsley and Balandin [21] who suggest that greater access to, and use of, AAC devices is needed to improve the quality of care being provided to patients with complex communication needs, including those with ID. Such a perspective has been heightened by the current pandemic, with the ID population at a greater risk of Covid-19 due to a higher prevalence of comorbid health problems and lifestyles that rely on others [146]. Consequently, they have an increased reliance on medical services, yet their access to effective healthcare may be restricted due to the recent shift towards telehealth technologies – a solution that exacerbates barriers such as ineffective communication [154]. AAC therefore has a major role to play, with the author proposing that future research be conducted into the use of such technologies during telehealth appointments with vulnerable patients, including those with cognitive disabilities.

8.1.1.1 Research Question 1.1

Research question 1.1 focused on the barriers affecting the implementation of clinical AAC technologies with people with mild ID. Once again, these barriers were identified during the scoping review and design / evaluation stages.

Lack of Stakeholder Involvement

Surprisingly, the majority of the literature focusing on the development of clinical AAC technologies (Chapter Three) lacked input from people with mild ID e.g. [41, 75, 78, 79]. Instead, the investigators employed the views of proxies, such as experts and caregivers, which goes against the underlying principles of codesign [83] and could lead to less usable technologies for a population that is traditionally difficult to design for. Some of the other studies tried to circumvent this barrier by including target stakeholders within the evaluation of their aids, yet their protocols restricted the conclusions that could be made. For example, in [17, 65, 80], a limited number of participants had actually used the intervention in the desired context, whereas Lennox et al.'s [75] completion rate was relatively low (33.33%). Furthermore, the aetiologies of the participants disability were not described, which makes it difficult for others to judge how well the intervention can scale across the entire ID population. Finally, quantitative methods were used scarcely, meaning the true benefits of the aids may not have been realised. Consequently, the AAC technologies that emerge from such processes may not meet the needs of target stakeholders and will subsequently have less of an impact on current practice.

Organisational Procedures

Developing an accessible aid that caters to all stakeholders is only one half of the problem. Researchers must also consider the challenges that arise when attempting to embed technologies in a healthcare system that is resistant to change [80] and fails to prioritise the needs of the ID population [18]. Raemy and Paignon recognised that some countries have yet to employ a national intellectual disability strategy [18], meaning institutions do not receive the incentives or support to begin using AAC technologies. In addition, the presence of a national ID strategy does not guarantee that funds are made available to those who need it, as highlighted by participant 4.2 (Chapter Five) who revealed that their access to paid caregivers had been cut drastically in recent years. Finally, resources such as ID registers often exclude people with less severe disabilities, which results in medical professionals failing to conduct reasonable adjustments, including the employment of AAC [41]. As such, greater effort must be placed on ensuring patients with more mild ID also benefit from any improvements being made to healthcare routines e.g. by changing the assessment criteria for ID registers.

Education and Access

Medical professionals are often undereducated on the health and communication needs of people with ID, which affects their ability to conduct person-centred care [14, 15, 17, 18, 32, 33]. This includes a lack of knowledge on the various AAC devices available to ID population, meaning GPs may fail to adapt to these resources when brought in externally by patients, or recommend their use when finding it difficult to communicate. As highlighted by the participants involved in the UCD workshops (Chapter Five), patients are also unaware of the options available to them, since just one utilised a patient passport on a regular basis. Her use was at the insistence of a parent heavily involved in the development of these resources, which suggests greater time and effort has to be placed on the promotion of an aid to ensure its uptake in current practice. Some of the participants with mild ID had also received cutbacks in their support funds and may therefore be unable to afford paid services.

Medical Professionals

Even if medical professionals are aware of the AAC technologies available, they may still decline to use them throughout the consultation. One GP involved in the evaluation (Chapter Seven) stated that her own skills did not warrant support from a tablet app and also suggested that the overreliance on technology could end up excluding certain patients. In addition, several other GPs were wary of recommending interventions that had not been scrutinised in the past or the benefits of doing so were not clear. This highlights the importance of utilising frameworks that emphasise the collection of evidence (such as [50]), as well as conducting quantitative evaluations within the target domain.

Time

Both the participants with mild ID (Chapter Five) and GPs (Chapter Seven) suggested that they were heavily restricted by time and this matches the findings from the wider literature e.g. [18, 65]. Such restrictions may therefore hinder the implementation of AAC technologies, which are traditionally time heavy to utilise [155]. As such, it is crucial to ensure patients are aware of their right to book double appointments, which will prevent them from rushing their views and lead to more holistic diagnoses being carried out.

8.1.1.2 Research Question 1.2

Research question 1.2 focused on the facilitators to the implementation of clinical AAC devices for patients with mild ID. These facilitators largely mirrored the barriers discussed in the previous section and were also identified during the scoping review and design / evaluation phases.

Adaptive Technologies and Recommended Guidelines

As stated previously, the involvement of people with ID in the design and evaluation process should increase the accessibility of the final product. Yet, due to the heterogeneity of the ID population, the resulting interface will only meet the needs of a subset of stakeholders. It is therefore important to enable the user to personalise the application via automatic, semi-automatic, or manual adjustments, thus extending the range of individuals who can operate it as intended. The methods of adaptation available will be discussed in the upcoming sections of this Chapter. In addition, medical practices should look to consistently implement national and international guidelines [120] for the treatment of people with ID, such as the use of double appointments. This is particularly true for people with less severe ID who often miss out on reasonable adjustments due to the hidden nature of their disability [41].

Training

Bell [17] and Raemy and Paignon [18] called for the introduction of regular training sessions to improve medical professional’s knowledge of ID. Both suggested that the content should centre on aspects such as: the patient’s behavioural traits e.g. how patients express pain; common health conditions that affect the ID population; and appropriate communication strategies to ensure patients are involved in their healthcare decisions, including the use of AAC technologies. These sessions should come in a variety of formats to suit the working schedules of GPs (ranging from a 15-minute educational session to a five-day training program) and should involve people with ID [18]. Finally, there is scope to explore the implementation of training sessions with caregivers [18], which should help promote access to new aids, and equip them with the technological skills to provide support when needed.

Medical Professionals

As discussed by GP One in the evaluation (Chapter Seven), AAC technologies should assist medical professionals in coming to a decision, as opposed to forming a diagnosis outright. There also needs to be an implementation plan in place to support them in the uptake of the aid, with this process being driven by medical champions [67, 80] who should monitor its progress and provide feedback / support where necessary. This is particularly important during projects where the benefits are not immediately clear. Practices should look to match patients with the same GP to ensure they become familiar with the individual's communication needs, including any AAC technologies in use, whilst passports can help to alleviate such a barrier with first time patients. Finally, there is scope to explore the widespread employment of more specialised professionals (such as community link workers and ID nurses) [18] who should have the skillsets and experience to adapt quickly to the AAC technologies in use.

8.1.2 Response to Research Question Two

RQ2 investigated the views of patients with mild ID on the use of tablet technologies to promote communication with general practitioners. The decision was made to approach this question from the perspective of the patient, since their opinions had been omitted from previous literature e.g. in Gibson et al's work [32, 33, 49] and during the design of the aids identified throughout the scoping review e.g. [18, 67, 76]. A UCD approach was therefore adopted in Chapter Five, to ensure the resulting prototype was better suited to the accessibility needs and requirements of patients with mild ID.

Following on from Gibson et al. [32, 33, 49], the participants suggested that answering a questionnaire based on the health needs of the ID population could assist them in a number of ways. First, the app is a useful resource to help patients practice the information they want to convey to the GP and subsequently increase their confidence to convey their feelings. The results page also acts a shared referent, which is accessible to all stakeholders involved in the consultation, thereby promoting two-way communication. In addition, the collected symptoms should help GPs to identify commonly overshadowed conditions, whilst enabling them to focus on areas of interest for longer, thus alleviating debilitating time constraints. Finally, the implementation of patient passports can result in more appropriate communication strategies being employed by medical professionals. Table 8.1 provides a complete list of the identified requirements for the proposed application, which contains the balanced views of experts, medical professionals, caregivers, and people with mild ID.

Table 8.1: Final design requirements discussed by the participants with mild ID (patients), GPs, caregivers, ID nurses and experts. The requirements have been grouped by the populations who identified them.

Requirement	**Discussed By**
The application should initially determine whether the patient has a problem with a body part or some other common condition e.g. diabetes.	All.
Question sets should form a hierarchy with selected symptoms leading to relevant sub-symptoms.	All.
Patients should have the option to show where their pain is by tapping on an image of the body.	All.
The language embedded within should follow accessibility guidelines. Medical jargon should be avoided where possible.	All.
Optional audio playback of text should be supported within all pages. It is important to allow individual symptoms to be played back separately in the results page.	All.
Images should be included to enhance an individual's understanding of a medical condition, as well as an embedded button's functionality.	All.
Left (back) and right (forward) arrows should be used to navigate from a question.	All.
The patient should be able to customise the image sets employed prior to the commencement of the questionnaire.	Caregiver, experts.[12]
The symptom in question should be captured by imagery, as opposed to the yes and no options.	Caregivers, experts.
Patients should be able to view their progress in the questionnaire.	Caregivers, experts.
Incorrect actions should be unavailable for selection until they are needed.	Experts.
Functionality should be provided to allow patients to return from an incorrect questionnaire branch.	Experts.
Patients should have access to an accessible list of the symptoms they are experiencing. GPs should also have the option to view the symptoms the patient has ruled out.	GPs, caregivers, and experts. [13]

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[12] The patients felt that it would be appropriate to change the images displayed during the questionnaire.

[13] Patients suggested all answers should be displayed on the results page.

Scrolling should be avoided if possible.	Patients, GPs, caregivers, experts
GIFs may be used to display symptoms that involve movement.	GPs, caregivers, experts.
The app's interface should adapt to the accessibility needs of the user.	GPs, experts.
The images should contain characters of a similar age and gender to the patient.	Patients, Caregivers, Experts.
First time users should have access to a tutorial prior to progressing to the questionnaire.	Patients, Experts, Caregivers.
Colour can group logically related items together. For example, a change in the background may be used to highlight questions that require caregiver support. Red may bring emphasis to potentially harmful symptoms on the results page.	Patients, GPs, caregivers, experts.
Personal profiles must be facilitated to enable features such as saving symptoms in a patient history. This history may be used to highlight persistent symptoms affecting the patient.	Patients, GPs.
Selected symptoms should be saved for future use. The ability to print these results must also be offered.	Patients, GPs.
Results should be sent to the practice in advance of the consultation to ensure appointments are made within a suitable timeframe.	Patients, GPs.[14]
Patients may select more than one option at a time. Selected options should be highlighted to distinguish them from those unselected.	Patients.
The app should provide access to the user's patient passport if available.	Patients.
Patients should be able to view the details of upcoming appointments, as well as the contact details of local health services.	Patients.
Users should be able to view public transport routes to local services.	Patients.
The app may be used to manage a list of medication being taken by the user.	Patients.
A maximum of 4-6 options should be presented at any one time.	Patients.[15]

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[14] ID nurses felt that the app could suggest a course of action without human intervention. This was deemed to be potentially harmful.

[15] Experts disagreed and felt it would be more appropriate to present a maximum of four options, preferably two.

Such requirements focus on the need to implement a simplistic interface that displays medical information in an accessible manner and is offset by a more complex back-end. They broadly match those implemented by Boström et al. [28–30], who demonstrated that digital questionnaires are a viable option to extract accurate psychological information from children with ID. Yet there were major differences in the amount of adaptation employed by the two systems. Boström and Eriksson [28] utilised both a static questionnaire and interface, meaning stakeholders had to answer the same questions in the same manner, regardless of their accessibility needs or health context. This thesis highlights that a similar strategy would be unsuitable in primary care due to the heterogeneous nature of people with ID, and the large range of medical conditions they are susceptible to developing [34, 37]. The ontology-driven adaptive model presented in Chapter Six offers a potential solution for these barriers. First, the Accessibility Preferences Ontology extracts the physical and cognitive disabilities that affect the patient's capacity to interact with the proposed application and subsequently recommends potential adaptations to mitigate their impact. Second, the Medical Questionnaire Ontology provides the functionality to include questions on a wide range of conditions, but limits those presented to the specific health context of the patient. This is achieved by updating the structure of the questionnaire based on the information already extracted from the patient.

Lastly, the participants with mild ID suggested that AAC technologies should focus on the entire primary care process, as opposed to just the consultation – a limitation of the aids identified during the scoping review (Chapter Three). Their recommendations largely centred on easing access to medical services and involved the following four aspects: (1) reminding patients of appointments; (2) providing the contact details of nearby health services; (3) offering accessible public transport routes to the practice; and (4) directing the patient to the most appropriate service based on the severity of the symptoms extracted. Nevertheless, the latter may cause potential harm to the patient if the identified symptoms result in the application suggesting a less serious course of action e.g. attending the pharmacy as opposed to calling an ambulance. Consequently, it may be more suitable to forward on the results of the questionnaire to the practice, who then decide what steps are required, as highlighted by GP Two (Chapter Seven)

8.2 Discussion of Key Results

8.2.1 Stagnating Health System and Systemic Change

During the investigations with patients, caregivers, nurses and GPs, it became clear that the health system is stagnating in terms of the support provided to individuals with ID. Each sub-population discussed barriers that are well embedded throughout the past three decades of literature e.g. [8, 10, 11, 21, 93, 111, 149], which may explain why mortality reviews, such as [2], continue to report high rates of insufficient care.

The GPs involved in the evaluation stated that they received little to no training on ID and instead relied upon on-the-job experiences to increase their knowledge of this population. Consequently, some felt that they were unequipped to conduct the necessary adjustments to their consultation methods to address the individual needs of patients with ID. Trollor et al. [156] came to a similar conclusion when reviewing the ID content currently taught in Australian medical schools, compared to that of the 1990s. They found that little progress had been made to address the gap in ID education, despite such knowledge being critical to reversing poor health outcomes [156]. As such, there is a systemic need for medical schools to introduce more inclusive content to ensure future workforces are equipped to provide person-centred care. In the meantime, Raemy and Paignon [18] advocate for flexible, educational resources that better fit the schedules of medical professionals, ranging from 15 minute sessions to five day training programs.

Organisational barriers were also discussed frequently by the caregivers, GPs, and participants with mild ID. Time was the most widely cited barrier that effected the quality and depth of information being extracted from patients. Yet despite the availability of double appointments [120], both the GPs and participants with ID stated that they do not utilise this option on a regular basis, with all but one of the patients unaware of their right to do so. This further highlights the need to educate individuals with ID on their rights when attending healthcare services. Being treated by the same professional may help to overcome time-related barriers, due to the GPs familiarity with the patient’s history, as well as their communication needs. Nevertheless, some of the participants with mild ID had difficulty booking appointments with their regular GP, which exacerbated the communication barriers present.

The complexity of the healthcare system also impacts the ability of patients to access optimal care, particularly those who have difficulty recognising the presence of symptoms. Yet technology may only have a limited impact in alleviating such barriers, as highlighted by the GPs involved in the evaluation. Most were wary of the application suggesting a potential course of action and instead preferred that the results of the questionnaire were forwarded on to a member of the practice for further deliberation. Moreover, GP one passionately advocated for the introduction of community link workers [150] to help identify patients who misuse the system, prior to developing more appropriate care and wellbeing programs.

All of the aspects discussed indicate that significant resources are required to increase the accessibility of the healthcare system. National ID strategies, such as the Key's to Life [1], are a great start; nevertheless, they need to be met with the appropriate financial backing and personnel to ensure actionable change is achieved. In addition, countries such as Switzerland are yet to develop ID strategies [18], meaning health organisations lack the incentives and support required to improve their services. The views of people with ID must be incorporated at all stages of change to ensure the measures made are suitable to their needs and abilities. Technology may help drive the impact of such measures, yet specialised personnel (e.g. community link workers [150] and ID nurses [18]) must be employed more broadly to take the burden off general practitioners as a gateway into the healthcare system. The widescale implementation of ID registers may also assist GPs to recognise the need for reasonable adjustments. Nevertheless, as highlighted by GP one, the criteria for inclusion needs to be revised to ensure those with more mild ID are identified and have access to benefits such as the annual health check – a problem also identified by Jones and Kerr [41].

8.2.2 Lack of AAC Use in Current Practice

As highlighted previously, little research is being carried out in the domain of clinical AAC technologies for people with mild ID, despite the widescale presence of communication barriers e.g. [8, 10, 11, 21, 93, 111, 149]. One possible reason for this gap may be the assumption that such patients are unable to make autonomous decisions regarding their healthcare and therefore do not require communication aids.

However, Werner [157] stressed the importance of people with ID having an active role in their treatment and suggested that further work is required to develop this populations decision-making skills, as well as steering medical professionals towards shared, person-centred planning. This thesis builds on Werner's view [157] and indicates that AAC technologies can increase people with ID's ability to convey their medical needs, providing they have been designed to cater to the patient's accessibility requirements. For example, the participants with mild ID suggested that the proposed application can support them to home in on, and practice, the information they want to confer, thus increasing their confidence to overrule the views of both the GP and caregiver. Furthermore, GPs three and four suggested that the app can help reassure patients that their concerns were considered by the doctor prior to the diagnosis being made.

Surprisingly, the bulk of the technologies identified in the literature review [17, 18, 41, 67, 75, 78–80] focused on enhancing the medical professionals ability to convey information, thereby conflicting with Chinn [68] and Werner's [157] recommendations on the need for improved two-way communication. Furthermore, there was a tendency for researchers to explore paper-based technologies, despite evidence to suggest that people with ID [95] and medical professionals [41] prefer high-tech devices when used on a consistent basis. These reasons opened up scope for the exploration of high-tech, two-way communication aids, with the participants with mild ID advocating for the adaptive questionnaire approach described in Chapter Six.

More worryingly, there was a lack of transition from research to practice, since few of the participants throughout this thesis stated that they had access to, and regularly utilised, clinical AAC technologies. Furthermore, several of the studies identified in the scoping review that focused on the implementation of communication aids, reported limited use of their interventions in the healthcare context [17, 65, 75, 79–81]. Inappropriate or inaccessible designs may be a major factor in this lack of use, as the scoping review highlighted a tendency for researchers to employ the views of proxies when designing clinical AAC technologies [18, 32, 33, 49, 67, 76], as opposed to implementing co-design methodologies. Jones and Kerr [41] also suggested that medical professionals are unlikely to utilise new technologies/processes on an opportunistic basis and will only do so on the introduction of statutory regulations. Medical Champions (professionals interested in improving healthcare services) could therefore help drive the implementation of such technologies by monitoring and disseminating their impact, particularly if the benefits achieved are not immediately clear [80].

The lack of involvement of people with ID in the design of clinical AAC technologies [18, 32, 33, 49, 67, 76] may be due to insufficient literature on how to include this population in research [96, 158]. As such, there is a need for investigators to share the design decisions made whilst employing co-design activities with participants with ID, along with a discussion on their success. This enables a corpus of literature to be built over time to support researchers in identifying the most appropriate techniques to employ. Meanwhile, experts in ID may be a suitable resource of support, if any accessibility concerns remain after consulting the literature, as highlighted in Chapter Four.

Finally, since the medical domain is data driven, there is an increased need to evaluate AAC technologies via the use of quantitative methods to determine their true impact on clinical consultations, thereby potentially increasing adoption. Just three of the articles identified in the scoping review utilised RCTs [41, 78, 79], with one recognising that their aid had a statistically significant impact on health promotion, disease prevention and case finding activities [78]. Additionally, researchers should aim to clearly describe the populations involved in their studies to ensure more transferable results – an issue that was identified prominently within the scoping review.

8.2.3 Towards Questionnaire Based Clinical AAC Technologies

Few of the participants involved in the UCD workshops disclosed that they prepare for primary care consultations. Those who did, suggested that they browse online health resources to obtain more information on their symptoms, which matched the findings of Oosterveld-Vlug et al. [149]. Yet such information is often too complex to understand [149], thus explaining why the participants advocated for an aid to support them in preparing the information they wish to convey to the GP. The developed prototype utilises an ontology-driven adaptive questionnaire to provide this support, which responds to the accessibility needs and health context of the patient. Currently, changes to the user interface are suggested based on the disabilities extracted from the patient via a questionnaire. Yet this approach is reliant on the individual with ID's caregiver to ensure the survey is completed correctly; otherwise, they may still encounter significant accessibility issues. Since the objective of the app is to support patients to autonomously discuss their medical symptoms, further approaches may have to be explored for the adaptation of the interface, when the caregiver is unavailable. Potential options may include: utilising the accessibility settings already embedded within the device; and automatically adjusting the interface as the user interacts with it. The latter is incredibly time dependent, since stakeholders are likely to abandon technologies they are unable to use fairly quickly. There is also scope to explore adapting the interface based on the capabilities of the user, as opposed to their disabilities [134].

Most of the requirements discussed in Table 8.1 lend themselves towards inclusive design, as does the concepts included within the Accessibility Preferences Ontology. This is not wholly unexpected, with the experts involved in the evaluation, and in previous literature [33], suggesting that technologies developed for people with ID are also suitable for the bulk of other populations. The design requirements specific to users with cognitive impairments centred primarily on the amount of choice available and the depth of information displayed on the screen at any one time. Stakeholders are only able to access the question immediately prior to/after the one displayed, rather than skipping to specific queries, thereby overlooking potentially relevant symptoms. The number of options presented is also limited to ease the cognitive load placed on the patient when making decisions, therefore increasing the accuracy of their answers. Finally, during the evaluation, the participants suggested that only key symptoms should be displayed, to aid the patient in conveying the information that is most crucial to their diagnosis.

8.2.4 Relevance of Results

The findings made throughout this thesis offer several contributions to knowledge, which can help change the way investigators approach the design of clinical AAC applications for patients with mild ID, in addition to improving current practice. First, the scoping review highlighted a gap in the amount and quality of two-way communication aids being employed in primary care, which should help to bring further scrutiny to this area. Common pitfalls being made in the design and implementation of clinical AAC technologies (e.g. the lack of stakeholder involvement and overuse of qualitative evaluations) were also identified and should result in the development of more effective aids.

A novel literature review / expert evaluation cycle has been created to assist less knowledgeable investigators in improving the accessibility of their research methods, thereby overcoming the lack of guidelines on how to do so. The protocol presented in Appendix C contributes to the agenda raised by Hendriks et al. [96], since it makes explicit the design choices and adaptations made during the development of the UCD workshops described in Chapter Five. Whilst these adjustments may not necessarily scale to other contexts, they provide a building block for researchers to base their initial studies on prior to the evaluation with experts if such a stage is deemed necessary.

Design requirements for a two-way communication aid to support adults with mild ID during primary care consultations has been derived from patients, caregivers, experts, ID nurses, and GPs. As such, they are the most holistic available to researchers in the field of assistive technologies, since the key literature [31–33] lacked input from several stakeholder groups. Investigators may then use this information to take the prototype beyond the "Development" stage of the framework for complex interventions [50] and into evaluations within the target domain. The potential effects discussed by the participants throughout this thesis (an increase in communication, the diagnosis of commonly overshadowed conditions, and patient autonomy and the reduction in time constraints) can then be measured to determine the true impact of the proposed application, at which point it may be embedded in the target domain. The requirements also highlighted the need to combine patient passports, with strategies that explore the health context of the patient, which supports the thesis statement discussed in section 1.3: Primary care AAC applications should focus on promoting two-way communication between adults with mild ID and GPs, informed by the personal characteristics of the patient and their current medical context.

Building on from the thesis statement, Chapter Six presented a framework for developers in artificial intelligence to help drive the live adaptation of questionnaires and user interfaces. Some questions were raised during the development of this framework (e.g. how to convey the number of questions remaining or help users return from incorrect branches), which if explored, should help to improve the usability of adaptive questionnaires.

Finally, the results obtained throughout the evaluation reinforce the use of digital technologies in helping patients with ID to overcome potential access barriers to healthcare services. Some of the experiences discussed by the participants during the Covid-19 pandemic align directly with the commitments made by the Scottish Government in their 2018 Digital Health Strategy [159]. This includes: the use of triaging tools to direct patients to more appropriate services; a preference to utilise telehealth services on demand; and the need for appropriate training services to ensure patients are able to operate new and existing services. Yet the digital health strategy does not go far enough since there is a lack of commitments focusing on accessibility, particularly for those with cognitive disabilities. On the other hand, the recently released discussion document on the need to update Scotland's digital strategy [160] highlights that much more effort is required to ensure the countries technological infrastructure is accessible to all, particularly during times of enforced use. The document highlights steps that ensure geography, background, and ability do not become barriers to the benefits achieved from digital technologies. In addition, the commitment to accessibility means that stakeholders should be directed to alternative ways of accessing services for those who cannot or do not want to use digital routes. This blending model of service matches the views of the participants in Chapter Seven and could shape the basis of primary care consultations going forward.

8.3 Limitations

Overall, the employment of the framework for complex interventions [50] was beneficial due to its alignment with the research questions proposed in section 1.3. Emphasis was placed on the collection of evidence for both the need for the proposed application, as well as how it may influence current practice. Moreover, the "Development" phase of the framework is fairly flexible in terms of how this evidence is composed, which was advantageous at the start of the Covid-19 pandemic when it was no longer feasible to conduct an evaluation with additional participants with mild ID. Nevertheless, there were limitations to the research conducted throughout this thesis.

The scoping review described in Chapter Three was the first to explore the types of AAC technologies available to patients within the clinical domain. This included both primary and secondary care to ensure aids that are not currently employed by GPs, but may be of use, were also considered. However, the review followed a scoping methodology [69], as opposed to systematic, with the databases searched being limited to PubMed, ACM Digital Library, and Google Scholar. As such, key literature may have been missed that could have had a significant influence on the design of the final prototype. Furthermore, the scope of the search was limited to English, which impacted the identification of literature from countries outwith the OECD. This, combined with the primary data collection being carried out in a country with a high-quality, publicly funded health system, restricts the portability of the findings to nations that employ different frameworks or have less advanced technological infrastructures.

The number of participants with mild ID involved in the UCD workshops met the recommendations of both the literature [112] and the experts who helped to design them. The results obtained overcame the shortcomings of previous work (e.g. Gibson et al. [31–33, 49]) and led to the development of an initial prototype of the proposed application. Yet the lack of involvement of people with ID in the prototype’s evaluation can be viewed as a potential limitation, since the requirements may be retrofitted to the needs of those involved in the original design workshops. To get around this, experts in HCI/accessibility and caregivers were employed to act as proxies, thus ensuring the application is more accessible to the wider mild ID population – both sets were successful in identifying a range of potential barriers. Nonetheless, there is still a need to assess the design of the application with additional participants with mild ID, once the changes from the evaluation have been implemented.

Finally, GPs had a limited impact on the findings made, due to the design of the application being approached from the perspective of patients. Just five were involved in the evaluation, with four of the participants working as sessional GPs, as opposed to full-time. Most had greater exposure to people with ID due to the location of their practice, as well as their interests in mitigating the health inequalities experienced by disadvantaged populations. Consequently, the views of a wider variety of GPs must be explored to assess the feasibility of the application being implemented on a national scale.

8.4 Future Work

A set of design requirements for the proposed clinical AAC application was established during the UCD workshops and cognitive/post-task walkthroughs – see Table 8.1. Nevertheless, further research is required on how the application will be implemented in practice. For example, four out of the five GPs involved in the evaluation were supportive of discussing the results of the questionnaire with the patient during the consultation. However, GP one felt that their own skillset was sufficient enough to treat the individual with ID without support, yet suggested the application would be beneficial further down the consultation process e.g. when booking an appointment. In addition, the GPs demographics were similar in that they worked part-time in practices frequently exposed to patients with ID and had added interest in reducing the health qualities of disadvantaged populations. As such, the views of medical professionals who are less rehearsed in treating these patients must be established to determine whether they would utilise the application, along with the extra benefits of doing so. As highlighted in section 8.3, the current prototype should also be evaluated by further participants with mild ID to ensure the wider needs of this population are addressed.

Additionally, there needs to be a dialogue on how the proposed intervention is introduced to GP practices, with two primary options available: the application may be licenced as a specialised service or brought in externally by the patient. Both strategies will require significant support from third sector and caregiver organisations to ensure stakeholders are aware of the app's availability and are to operate it as intended. The latter may also be subject to some resistance from medical professionals due to the establishment of unsolicited technology. One solution may be to complete the remaining stages of the framework for complex interventions [50], thereby collecting concrete evidence on the benefits of the application in practice e.g. reducing consultation times; enhancing communication; or increasing the recognition of commonly overshadowed conditions etc.

Chapter Six presents a potential solution to implementing the adaptive interface and questionnaire listed in Table 8.1. Yet, as highlighted in section 8.2.3, the approach implemented is reliant on the availability of caregivers to input the disabilities experienced by the patient. Consequently, alternative strategies must be identified to drive the adaptation of the interface when the caregiver is otherwise engaged. This may include extracting the accessibility settings already incorporated in the device and/or other applications; and automatically adjusting the interface as the user interacts with the app. A switch in emphasis towards enhancing the patients abilities, as opposed to mitigating the impact of their disabilities, may also be explored [134]. The queries implemented in the questionnaire should be evaluated by medical professionals and subsequently monitored during implementation to identify problematic pathways or missing symptoms. There is also scope to explore the implementation of the app in more specialised services (such as diabetes clinics) or during a hybrid approach to healthcare where patients can utilise virtual consultations unless a physical examination is required.

Finally, the characteristics identified in Chapter Five to increase the clarity of medical images for the ID population should be embedded in further co-design sessions. This will enable an image set to be developed with the target population and subsequently employed alongside existing resources, such as Makaton or the Picture Communication System, which may not cover all symptoms included within the questionnaire.

8.5 Final Conclusions

Design requirements for an evidence-based tablet application that promotes communication between adults with mild ID and GPs have been produced throughout this thesis. First, a review of the literature was conducted to establish the need for the proposed intervention, which highlighted a gap in the high-tech, two-way communication aids being employed within the clinical domain. A hybrid literature review / expert evaluation approach was then utilised to develop an accessible design workshop for patients with mild ID, thus enabling them to provide their views on the design and implementation of such an app. 10 adults with mild ID participated in the UCD workshops, with the outcomes being used to enhance an initial prototype of the communication aid. This prototype was evaluated by experts in HCI/accessibility, caregivers and general practitioners. The results of these studies indicate that AAC technologies can help to promote communication by extracting information on the personal characteristics of the patient, in addition to their current medical context. This data should be used as a referent during the consultation, thereby potentially reducing time constraints and highlighting commonly overshadowed conditions. Both the interface and the medical questionnaire employed should be adaptive to accommodate to the wide-ranging accessibility and health needs of the ID population and ontologies have been shown to support this necessary adaptivity.

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APPENDIX A: SUMMARY OF SCOPING REVIEW PAPERS

Study	Aim	Intervention	Design	Population	Results
Jones & Kerr 1997 [41]	To evaluate an intervention that assists GPs in checking for common health conditions experienced by patients with ID.	A paper-based checklist containing information on appropriate health promotion activities i.e. whether they have been carried out in the past three years. GPs also received educational packages on the best practices to employ when treating patients with ID.	Randomised controlled trial. Information was collected on a range of variables including health promotion activities; consultation patterns; and patient well-being over a 6-month period.	29 GPs from 6 practices identified 111 patients with ID to take part in the study. 56 of the participants with ID were male and 55 female (mean age 41 years). 28 had mild ID, 39 had severe and the severity of 44 was unknown. 30 participants had Down Syndrome.	No significant difference was observed in consultation patterns between the control and intervention groups across several factors including: location, nature and outcome. No significant difference was observed across various health promotion activities. The intervention identified some deficiencies in the frequency of recommended tests being carried out e.g. 15 of the 30 participants with Down Syndrome had not received a thyroid function test.
Dodd and Brunker 1999 [65]	To investigate whether it is possible to increase the health advocacy skills of people with ID.	An educational package designed to increase an individual with ID's awareness of the human body, including common medical symptoms that may occur. Computer generated images are also distributed to assist the patient in discussing site, type, severity and duration of pain, as well as basic medical symptoms such as sickness.	Pre and post intervention questionnaires on bodily functions and medical conditions.	Five men and five women aged between 31 and 46 years old. Their verbal skills varied widely – British Picture Vocabulary Test Scores ranged from 28 – 94. No information on type or severity of ID was provided.	Improvements were observed in the participants' knowledge of bodily processes and what to do when ill during 6-month follow-up period (although some reductions in retention occurred). The highest degree of information retention was demonstrated by the participants who had visited their doctor and had used the communication aid resources within a clinical context.
Lennox et al. 2001 [75]	To pilot the Comprehensive Health Assessment Program and collect descriptive data regarding GPs views on the proposed strategies to	The Comprehensive Health Assessment Program (CHAP) is a booklet that contains the following resources: A section to capture the medical history and screening activities of the patient with ID; A section that provides information to assist the GP in carrying out an assessment of	GPs were asked to recruit three patients with ID from their registers and utilise the CHAP booklet within consultations involving these patients over a 12-month period. The intervention was then assessed via a self-evaluation form.	15 GPs from 45 practices completed all components of the study. 38 patients with ID participated (21 females, 17 males) and were aged between 22 and 68 years old. The type and severity of ID experienced by the participants was not described in depth, yet four participants were reported as having Down Syndrome.	Providing information on the medical history and screening activities of a patient can help medical professionals become aware of previously unknown conditions and keep up to date with health maintenance tasks. The medical and screening information of the patient was considered a more valuable resource than the synopsis of the literature.

	improve the care of adults with ID. As a by-product, the authors were able to determine the current health-related activities being conducted and the health problems detected as a result of such activities.	the patient's overall health; And a section to educate medical professionals on commonly missed or poorly managed conditions experienced by the ID population.			
Lennox et al. 2004 [76]	To develop an advocacy tool that can be used by people with ID during a medical consultation.	The Ask It Health Diary which is a package containing a 5-year long diary and a brief advocacy educational session. The diary contains the following sections: Personal information about the patient such as communication preferences, health registrar details etc. Resources to assist the patient in preparing for a consultation e.g. images of the human body and pain recording sheets. Information on effective practices for clinical staff to use when treating patients with ID. The medical history of the patient.	The intervention was piloted with two separate groups of individuals with ID over a 2-week period. Feedback was then obtained during a phase of in-person or telephone interviews.	An advisory group met regularly throughout the project to provide feedback on the design of the intervention. It consisted of: two2 people with ID, two support workers, two parent advocates, two advocacy organisation representatives and an occupational therapist. Further feedback was sought from 22 professionals throughout the researchers' network. To determine the overall format and content of intervention, focus groups were carried out with eight people with ID, 85 support workers, three parents, two psychologists, one GP, one volunteer friend and a sister. The final package was piloted by two groups: 19 parents of adults with intellectual disability who use a non-government support service; and seven people with intellectual disability who use a non-government accommodation service.	66% of the participants interviewed felt that the diary would help them to become better advocates. 50% also felt that it would help them to improve their relationship with their GP. GPs envisioned using the intervention with other populations.

Bell and Cameron 2008 [77]	To demonstrate the clinical advantages of employing the Talking Mats™ framework with patients with ID.	Talking Mats™ is a pictorial based communication aid. A visual scale is presented at the top of each mat, with the user required to give their views by placing relevant picture symbols under the appropriate section of the scale.	Talking Mats™ was used at two separate psychological consultations involving an individual ID. The produced mats were then compared for similarities / differences and a report was created detailing the patient's needs. This report was then approved by the patient and her social worker.	A woman in her 40s with mild ID. Her understanding of spoken, single words was similar to an individual aged between 14 years 9 months and 16 years 6 months.	Talking Mats™ took the pressure off the patient directly addressing her psychological concerns thus improving the quality and depth of information provided. The information received was used to form a person-centred plan of action to improve the factors affecting the mental health of the patient. Talking Mats™ can extend the use of therapies that rely heavily on verbal communication to those who find verbal communication difficult in a general sense, as well as a specific situational sense.
Lennox et al. 2010 [78]	To investigate whether 2 health assessment tools, the Ask health diary and the simpler CHAP tool, improved healthcare for people with ID.	Comprehensive Health Assessment Program - see details in row three (Lennox et al. 2001 [75]) Ask it diary – see details in row 4 (Lennox et al. 2004 [76])	A cluster randomised controlled trail was conducted with people with ID living in the Greater Brisbane area of Australia. A 2 · 2 factorial design was used to examine the effects of the CHAP and Ask it health diary over a 12-month period. Health promotion, disease prevention and case finding activities were compared with those from the previous 12 months.	272 individuals from 140 GPs agreed to participate in the baseline interviews. Participating individuals were allocated into one of four factorial groups: usual care (77 participants), Ask only (57 participants), CHAP only (61 participants), or CHAP + Ask (77 participants). 89% (242) of the participants were involved in the follow-up stage. The participants with ID's mean age was 35 years, range 18-75. 107 had mild/moderate ID, 62 severe and 73 were unknown.	"Increased health promotion, disease prevention and case-finding activity were found in the intervention groups using the CHAP. It had a positive impact on Pneumococcus vaccination (OR 7.4; 95% CI: 1.5–37.1), hearing testing (4.5; 1.9–10.7), Hepatitis A vaccinations (5.4; 1.8–16.3), vision testing (3.4; 1.4–8.3), and weight measurement (3.1; 1.5–6.4). There were no strong changes in the measured outcomes in the group who used the Ask health diary alone. [78]" The study period may have been too short to recognise the true benefits of the Ask it health diary.
Turk et al. 2010 [79]	To assess the impact of handheld health records (a form of patient passport) on GP consultations involving adults with ID. To determine if the proposed	The personal health passport consists of 50 double-sided pages separated into three sections. The first is a brief introduction, with the second encapsulating chapters on the health of the individual e.g. medication being taken, mental health symptoms etc. The final section contains information on	Randomised Controlled Trial in which consenting GP practices, containing patients with ID on their registrars, were randomly allocated to the control or intervention group. Primary outcome measures were obtained from GP records and included: basic demographic information; degree and type of	Forty GP practices were randomised to the intervention or control group. 201 people with ID were interviewed at baseline and 163 followed up after 12 months intervention. People with ID and carers were also employed as research interviewers. Baseline interviews were completed for 102 participants with ID in the PHP intervention group and 99 in the control	No significant outcomes were achieved by the intervention. Annual consultation rates in the intervention and control groups at baseline were low (2.3 and 2.6 visits respectively). A slightly greater increase occurred over the year in the intervention group 0.6 ()0.4 to 1.6) visits per year compared with controls. People with ID in control group reported more health problems at follow-up 0.9 (0.0 to

	technology increases the health knowledge of people with ID and / or their carers.	ID for use by carers or medical professionals.	disability; the completion of the OK Health Checklist – considered to be the most comprehensive health assessment tool; a newly devised Knowledge of Health Problems and Terminology Checklist (KHPT) to measure the number and type of health needs known by the patient with ID and/or their carer; the Client Services Receipt Inventory to measure the number of GP visits; and questions relating to the satisfaction of primary care consultation including communication with their GP. These measures were repeated during the follow-up interviews (conducted a minimum of 12 months after the commencement of the study), with additional questions being presented on the use of the health record where appropriate.	group. 89 carers out of the 168 involved in baseline interviews with people with ID knew the cause of the participants disability. This included: Down syndrome – 27 (16%), autism spectrum disorder – 21 (12.5%), cerebral palsy – 16 (9.5%), another syndrome – 12 (7.1%), and other congenital factors, peri-natal birth problems or epilepsy – 11 (6.7%).	1.8). People with ID liked their health record (92%) but only 63% reported usage.
Brodrick et al. 2011 [67]	To improve the health experiences of people with ID using services in East Cheshire via the development of a one-page patient passport.	The passport contains personal information about the patient that will assist medical professionals in performing person centred care. It is split into four sections in order of priority: medical information; communication needs; support needs; and environmental needs. A personal information page (on the reverse) also encapsulates information deemed important by administrative and clinical staff from the emergency and outpatient departments.	A pilot study was carried out in October 2009 in Macclesfield District General Hospital and two independent service providers: David Lewis and The Rossendale Trust. Residential managers were trained to use the passports, who then introduced them to frontline staff. Circa 150 passports were produced over the trial period, although no additional information was provided on the manner in which they were developed.	"A working group was established with representation from East Cheshire NHS Trust; Cheshire and Wirral Partnership NHS Foundation Trust; East Cheshire Advocacy (an organisation that provides professional and volunteer advocacy support to people with learning disabilities); and the local independent sector, including David Lewis (a registered charity providing education, therapy, support and life skills development to people with epilepsy and complex learning disabilities) and The Rossendale Trust (an organisation that supports people with learning and physical disabilities)." [67]	The pilot study shows that the passport has the potential to improve the quality of support being provided to patients with ID on admission to and during their stay in hospital. The initial quality of the passports was extremely variable, with some not containing the information required to be effective. This improved when additional support and training was provided, as well as example templates. "Staff found the patient passport to be a useful document because it enabled them to provide pertinent, person-centred information about the service user in a simple, clear format. This saved time on admission." [67]

			The quality of the passports was reviewed by the researchers during the pilot stage and initial feedback was gained from discussion groups held by working group members and staff.	Working group members initially sought guidance from administrative and clinical staff at Macclesfield District General Hospital's emergency and outpatient departments to ascertain the essential information required when a person with learning disabilities accesses their services A pilot study was carried out in October 2009 in Macclesfield District General Hospital and two independent service providers: David Lewis and The Rossendale Trust. Residential managers were trained to use the passports, who then introduced them to frontline staff. Circa 150 passports were produced over the trial period, although no additional information was provided on the manner in which they were developed.	
Bell 2012 [17]	To evaluate a hospital passport tool and examine its effects on communication between patients with ID and staff.	The passport is an A4 sized, coloured booklet that includes red, amber and green sections detailing personal information that may assist in providing person-centred care. There is also a Vital Information Sheet to clearly emphasise potentially lifesaving information, for example, if the person has dysphagia (swallowing problems) and how to manage this safely.	Semi-structured interviews involving family members and health and social care staff who had supported an individual with ID when using the passport. A focus group that involved people with ID discussing their experiences of staying in hospital. A reflexive journal analysis that included the researcher's views on a recent example of the passport in practice. The 3 separate studies allowed for triangulation.	"12 participants including health, hospital and social care workers as well as family carers, were asked a series of five questions about their experiences, both positive and negative, of using the Traffic Light Hospital Assessment. Additionally, eight participants, all of whom were adults with learning disabilities attending a self-advocacy group, took part in a focus group discussion about their experiences of going into hospital." [17]	The passport was a useful resource in improving communication and the continuity of care across multiple agencies involved in the treatment of patients with ID. Passports can help improve communication between patients, carers, and medical professionals, which can have a direct impact on the quality of care being provided.
Heifetz and Lunsky 2018 [80]	To evaluate the use of health passport communication	Patient passports were locally tailored and implemented throughout three regions of Ontario. All contained	The intervention was evaluated through interviews with those responsible for implementing the passports in each region, as well	28 questionnaires and 18 interviews with stakeholders (e.g., hospital staff, community agency representatives,	21 participants who completed the questionnaire (75%) reported that the tool "definitely" provides background information about the patient, and

	tools by people with ID in psychiatric and general emergency departments throughout Ontario, Canada.	information on: the patient’s medical history; and their baseline behaviours e.g. communication preferences, signs of distress, behavioural triggers etc. Nevertheless, each regions’ chosen passport differed in terms of size (wallet sized vs. one full double-sided page vs. four pages) and in aesthetics e.g. plain written information vs. picture based.	as interviews with stakeholders and surveys. Each of these stages were carried out between 6 and 12 months after the implementation of the passport.	families) were completed throughout the regions. The questionnaire was completed by: three individual clients / patients (11%); seven family members (25%); and 18 support staff / paid caregivers (64%). 82% of questionnaire participants failed to use the passport within a clinical setting. 18 semi-structured interviews were conducted over the telephone with: hospital clinical staff, community health and ID service providers, and community-based health care case coordinators.	~50% felt that the tool “definitely” makes the patient more comfortable. Benefits were also discussed in regards to: helping the caregiver feel more involved and respected (n = 13, 65%), helping hospital staff to adapt their care approach (n =13, 65%), helping in improving communication with hospital staff (n= 16, 80%), and helping make decisions with better information (n = 16, 80%). The levels of adoption of the passport varied by region. Strong leadership or “medical champions” are required to increase use by front-line care staff.
Gibson et al. 2018 [32]	To demonstrate the potential use of mobile technologies to meet the communication needs of patients with mild ID during primary care consultations.	A hi-tech, clinical alternative and augmentative communication tablet application. The application intends to extract medical information from the patient, using an accessible questionnaire, prior to the consultation. As such, the primary symptoms the patient is experiencing may be available - in an accessible format - to all stakeholders thus potentially improving communication.	Requirements gathering interviews were carried out with ten experts in ID, which included: two GPs; three Governmental advisor’s involved in the development of Scotland’s national ID strategy; four academics in the fields of social work, cognitive psychology, inclusive education, and aging, fragility and dementia; and a full-time support worker. A hi-fidelity prototype was then developed using the identified requirements and subsequently presented to a subset of these experts during a usability study.	10 experts with ID were involved in the requirements gathering interviews including: two GPs; three Governmental advisor’s involved in the development of Scotland’s national ID strategy; four academics in the fields of social work, cognitive psychology, inclusive education, and aging, fragility and dementia; and a full-time support worker. Four of these ten experts then participated in a usability study to determine if there were major accessibility issues in the developed prototype prior to introducing additional participants with mild ID.	The proposed application has the potential to alleviate those issues that arise from cuts in funding to support workers by increasing the health advocacy skills of patients with mild ID. The GPs interviewed were open to including AAC technologies within the consultation process despite their lack of experience in using such technologies. The application has the potential to highlight the conditions commonly overshadowed by professionals undereducated on the health needs of people with ID. Providing medical information in advance of the consultation can help reduce debilitating time constraints. It also enables medical professionals to concentrate on areas of interest for longer.
Gibson et al. (2019) [33]	To assess the feasibility of utilising tablet applications to	A hi-tech, clinical, alternative and augmentative communication tablet application.	Requirements gathering interviews were carried out with ten experts in ID.	10 experts with ID were involved in the requirements gathering interviews including: two GPs; three Governmental advisor’s involved in the development of	Three primary advantages of the proposed application were discussed by the experts: (1) promoting communication by presenting medical information in a manner that is accessible to all

	increase the quality of communication between GPs and patients with mild ID.	The application intends to extract medical information from the patient, using an accessible questionnaire, prior to the consultation. As such, the primary symptoms the patient is experiencing may be available - in an accessible format - to all stakeholders thus potentially improving communication.	A hi-fidelity prototype was then developed using the identified requirements and subsequently presented to a subset of these experts during a usability study.	Scotland's national ID strategy; four academics in the fields of social work, cognitive psychology, inclusive education, and aging, fragility and dementia; and a full-time support worker. 4 of these 10 experts then participated in a usability study to determine if there were major accessibility issues in the developed prototype prior to introducing additional participants with mild ID.	stakeholders; (2) alleviating time constraints by collecting medical information prior to the consultation – this enables medical professionals to concentrate on areas of interest for longer; and (3) highlighting medical conditions that are commonly overshadowed by practitioners.
Gibson et al. (2019a) [49]	To investigate the use of AAC applications to promote the exchange of information between GPs and patients with mild ID. This was achieved by identifying initial requirements that cater to the needs of patients with ID.	A hi-tech, clinical alternative and augmentative communication tablet application. The application intends to extract medical information from the patient, using an accessible questionnaire, prior to the consultation. As such, the primary symptoms the patient is experiencing may be available, in an accessible format, to all stakeholders thus potentially improving communication.	2 focus groups were carried out with 12 experts in ID to: first determine the accessibility of a future user-centred design workshop for adults with mild ID; and second, identify the experts views on how the application should look and function. The activities included: a focus group to explore the communication challenges experienced by patients with mild ID, as well as how technology can be used to overcome these challenges; an image board exercise to identify factors that constitute effective medical images; a paper prototyping process to identify the features to be included in the app; and a post-task walkthrough of a similar application.	Focus group one was conducted in the city of Glasgow, Scotland and included: three academics in the health and wellbeing of people with ID; two employees of an advocacy charity, one of which had mild ID; a former ID nurse who is now manager of a support centre for people with ID; and a digital inclusion officer. Focus group two was conducted in the city of Dundee, Scotland and consisted of: three community ID nurses; one employee of an advocacy charity; and one employment support officer.	Similar advantages to the above two studies were discussed by the experts involved. Additionally, the experts in focus group two discussed the importance of including personal information on aspects such as the communication needs of the patient. This will assist medical professionals in adjusting their consultation methods to improve the quality of care provided.
Raemy and	To demonstrate the extent of adjustments	To improve communication throughout different sections of the hospital, an emergency	In 2012, 60 working group sessions took place to determine the most common health needs of	Multidisciplinary teams consisting of nurses, medical doctors, physiotherapists, senior nurses, social	The emergency admission sheet has been filled in by almost every registered individual with ID in Geneva. It is systematically used throughout the

Paignon (2019) [18]	required to provide high-quality care to patients with ID in an acute care setting in Western Switzerland. These adjustments focused on: patient care pathways; the education of professionals about ID; the employment of communication aids to standardise care; the accessibility of the hospital's environment; and the employment of specialised ID health staff.	admission sheet (similar to a patient passport) was developed. The admission sheet is an A4 sized, double-sided document that includes information deemed crucial to the care of the patient including: their disability; challenging behaviours and the presence of additional impairments; legal representation; capacity to consent; and communication abilities such as how they express pain, comfort, discomfort and anger. This admission sheet is standardised in the electronic patient data system to ensure it is available to all health professionals involved in the patient's care.	the ID population, the barriers to effective care, and the prioritisation of adjustments that may be made to improve this care. Multidisciplinary teams consisting of nurses, medical doctors, physiotherapists, senior nurses, social workers, representatives of families, associations, architects, representatives of the main supported residential accommodations and lecturers from the Nursing department of the University of Applied Sciences were then set up to address the most important issues identified in the working group sessions. The multidisciplinary teams were responsible for improving 4 aspects: Patient care pathways and best practice; communication; human resources; and environment. Annual reviews then occurred between 2012 and 2017 to share the progress / challenges that occurred during the implementation of the reasonable adjustments. An overall evaluation of the project started in 2016 and is still on-going. Patient satisfaction questionnaires regarding the efficiency of the adjustments made and the overall quality of care received is the primary means of evaluation being collected.	workers, representatives of families, associations, architects, representatives of the main supported residential accommodations and lecturers from the Nursing department of the University of Applied Sciences were then set up to address the most important issues identified in the working group sessions. An overall evaluation of the project started in 2016 and is still on-going. Patient satisfaction questionnaires regarding the efficiency of the adjustments made and the overall quality of care received.	hospital and has resulted in improved communication. Nevertheless, there is an estimated 10% of people with ID who have not been diagnosed meaning they cannot benefit from the admission sheet. An ID-physician and ID-nurse have also been employed to assist medical professionals in improving the care being provided to patients with ID and to educate them on best practices etc. This has resulted in improved care being administered to approximately 100 patients over the year 2016, over 400 in 2017 and 517 in 2018.

Chinn (2019) [81]	To determine the impact easy read information has on the literacy events present in consultations involving patients with ID.	Easy Read is the term used to describe written resources that have been adapted to cater to the needs of people with ID. They typically include short, jargon free sentences supported via the use of immediately identifiable imagery. One such resource used within the study was a leaflet on blood tests that both described and highlighted the steps involved in the procedure.	32 ID health check procedures involving primary care clinicians who had access to easy read resources were video recorded, as well as 9 health appointments with ID nurses. These recordings were then analysed using conversation analysis to examine the interactional micro-practices that frame literacy events involving easy read texts. Using conversational analysis ensures that the data is captured from naturally occurring interactions as opposed to post hoc interviews or surveys. Reflective interviews were also conducted with nine of the health staff and nine of the patients. They were required to watch the recordings of the consultation and elaborate on the actions performed during areas of interest.	The full data set comprised video and audio recordings of 32 ID health checks conducted by GP staff and 9 video and audio recordings of health consultations between people with ID and specialist ID nurses. Four patients attended health checks by themselves, and others were accompanied by supporters who were either family members or people in paid support roles. Recruiting staff involved in performing the health checks of people with ID meant that the presence of the target population was guaranteed. The rationale behind recruiting community ID nurses was that they might use different communicative strategies based on their more extensive experiences with patients with ID compared to the primary care staff, and also that they were more likely to routinely use easy read resources.	Easy Read health information was visible in only 7 (22%) of the primary care health checks (though not always shared with the patients). Easy Read health information was used in sequences where clinicians offered unsolicited health advice and were met with degrees of resistance from patients, though its potential for shared decision making was also evident. The specialist intellectual disability nurses were more likely to use Easy Read formatted resources of all kinds in their recorded interactions. Such resources were part of the interaction with patients with ID in four of the nine recordings made. The easy read texts were also more varied than those evident in the GP settings.

APPENDIX B: EASY READ RESOURCES ISSUED TO PARTICIPANTS WITH MILD ID

Easy Read resources will be provided on request. Please forward the request to ryan.gibson@strath.ac.uk.

APPENDIX C: PROTOCOL FOR THE UCD WORKSHOPS

1 Objective

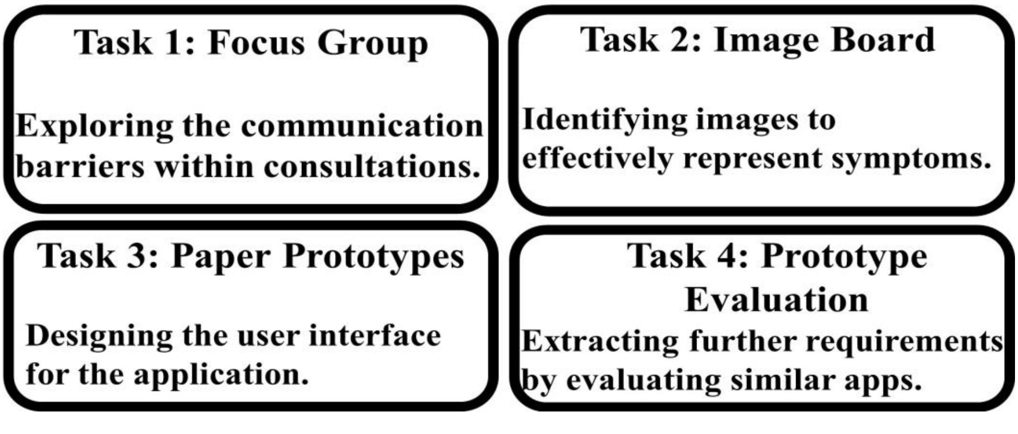
The research question for this study is as follows:

- What do adults with mild intellectual disabilities (ID) require from a tablet app to support them in conveying their medical needs to a general practitioner (GP).

Whilst answering this research question, a series of user centred design (UCD) workshops will be carried out with participants with mild ID, thereby culminating in the identification of design requirements better suited to the needs of the target population.

2 Workshop Overview

The aim of the workshops is to determine: (1) the functionality of the application; (2) the design of the user interface; and (3) aspects that increase the clarity of medical images for people with ID, since there is evidence to suggest that such a modality can support this population to better understand complex concepts [39, 106]. Four distinct techniques have been identified from the literature to support patients in fulfilling these objectives – see Fig. 1.



Task 1: Focus Group

Exploring the communication barriers within consultations.

Task 2: Image Board

Identifying images to effectively represent symptoms.

Task 3: Paper Prototypes

Designing the user interface for the application.

Task 4: Prototype Evaluation

Extracting further requirements by evaluating similar apps.

Fig 1: Co-design techniques to be employed within the workshops.

The first task includes a focus group to discuss the communication barriers experienced by the participants during primary care consultations. In addition, they will outline how technology may be used to overcome these barriers. Two main techniques from the literature were deemed to be appropriate to extract this information: ethnography and interviews. Ultimately, ethnography was disregarded in favour of focus groups since there is a plethora of studies that identify the communication barriers present in healthcare. Consequently, there is no need to spend excess time observing patients during consultations to pinpoint opportunities for the introduction of a communication aid. Rather, this may be achieved whilst the patients reminisce about their past experiences, with the findings being related back to the previous literature. As will be discussed, it is important to ensure the questions presented have been developed using accessible language guidelines. Furthermore, capturing concepts live via sticky notes can help participants to remember what has been discussed so far and presents them with the opportunity to challenge any misconceptions made by the investigators.

The second task involves the participants developing two separate image boards: one that encapsulates medical images they find clear; with the other capturing images whose meaning is more obscure. There was a lack of alternative, image specific methodologies employed in the literature; however, this technique was deemed to be accessible to people with ID, whilst encouraging them to think about the finer details of the images being presented. The image pool will be divided equally amongst the adults with mild ID, with time being set aside to enable them to appraise their own images individually. They will then be asked to present their stance on each image to the group, before a consensus is made on their inclusion on the appropriate board. It is important to encourage the participants to group similar images together to form themes e.g. images with vague facial expressions.

Tasks three and four aim to determine the participants' views on the design of the proposed application. Live creation of prototypes, as well as their evaluation, have been widely implemented in the literature to achieve such a goal and both have their advantages and disadvantages. Evaluating predeveloped artefacts helps to overcome impairments in abstract thinking since participants are required to critique an existing solution, as opposed to coming up with their own. Nevertheless, the conversation is likely to be restricted to this prototype, meaning not all of the participants needs may be identified. Developing paper prototypes from scratch alleviates this issue, yet the participants may find it difficult to envision their needs for more novel technologies. The decision was therefore made to conduct both tasks since their advantages complement one another. The paper prototyping task should be presented first to ensure it is not affected by the results of the evaluation. Prior to its commencement, the group of participants will nominate a leader to identify initial features for the prototype, which will be included on consensus. Potential artefacts, such as images of symptoms and common buttons, should be made available to assist in this process. The participants will have to create a design for each page they deem essential in the application. A post-task walkthrough protocol was deemed to be the most suitable method for evaluating the prototype described in Chapter Five of the main body of the thesis. This was due to the interaction phase being separate from the feedback phase. Once again, a leader will be nominated to drive the interaction with the prototype, but any actions carried out will be on consensus of the entire group. The participants will be required to select symptoms relating to two conditions before providing their views on the experience with the application. An in-depth description of the steps involved in each of these four tasks will included in subsection 4.

3 Participant Demographics

All participants involved in the workshops should adhere to the world health organisation's definition of intellectual disability [63]:"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."

Intellectual disabilities can manifest themselves via a range of aetiologies and severities, each of which have a differing impact on an individual's ability to conduct everyday tasks. For example, people with mild ID are generally able to live independently but may struggle to complete complex tasks (such as describing medical conditions) without support. In contrast, people with more severe ID tend to require some sort of supervision at all times. This study focuses on adults with mild ID under the assumption that such a population is more likely to be in charge of their own healthcare and are able to use accessible technologies autonomously.

All participants should have their ability to perform informed consent assessed prior to being invited to the design workshops. This assessment will be conducted by the charity members involved in recruitment, who will issue the questionnaire proposed by Horner-Johnson and Bailey [119]. Rather than the traditional six to eight participants per study, the n size for each workshop should be restricted to between four and six. This will allow the participants sufficient opportunity to provide their views, without the group size becoming overbearing for individuals who are less outgoing. In addition, it will be more manageable for the investigators to cater to the individual needs of the participants, such as setting up their accessibility settings on the tablet.

Participants will be afforded the opportunity to bring a caregiver with them to provide support during the workshops. Nevertheless, it is important to make it clear to the caregivers what their role is i.e. helping participants with mild ID to understand what is required of them, as opposed to providing their own views.

4 Workshop Protocol

This section describes the steps involved in each of the workshop tasks. In addition, the ice breaker and debriefing stages will also be discussed.

4.1 Welcome and Ice Breaker session

- Investigators should aim to arrive at least 15 minutes prior to the commencement of the workshop in order to arrange the environment into a suitable workspace. Chairs should be placed around a table in a circular fashion, with the researchers situated at the head of the table in full view of the participants. As such, they should be able to recognise when participants are in distress and offer the necessary support.
- On arrival, participants will be greeted by the investigators and handed a copy of the easy read information sheet and consent forms. They will be asked to disclose any additional needs, with the researchers performing reasonable adjustments to cater to these needs e.g. placing participants with restricted hearing closer to the lead investigator.
- Refreshments should be offered to the participants once they have taken a seat.
- When all participants are ready to begin, the lead investigator should remind them of the purpose of the study, in addition to their rights, by taking them through the information sheet step by step.

- Participants will then be asked to sign the easy read consents forms, thereby confirming their involvement in the study, as well as agreeing to be audio recorded.
- If any caregivers are present, they should be reminded that their involvement in the study is to support the participant with ID to understand what is required of them, as opposed to providing their own views.
- Prior to commencing the workshop, the participants will be asked to share three interesting facts about themselves. This will ensure they feel comfortable with each other and are more likely to discuss personal experiences within the design tasks. The investigators should first present facts about themselves to show what is required, with the participants taking turn in clockwise order. During this process, it is important to recognise who is more outgoing since such individuals may be targeted as leaders during tasks three and four. The icebreaker session should last 10 to 15 minutes.

4.2 Task One: Focus Group

- Participants will be reminded about their right to pass on any of the questions. The focus group centres on an extremely personal topic (i.e. an individual's medical experiences), meaning it is important to highlight that the participants do not need to answer these questions if they feel uncomfortable doing so.
- Participants will also be reminded about their views being recorded and subjected to anonymisation procedures before being shared with anyone outwith the study.
- The Dictaphone will be set up in the centre of the table to ensure the audio captured from each participant is of high quality. A sticky board should also be placed at the end of the table, in preparation for capturing the live views of the participants.
- The lead investigator will then present each of the following questions to the group in order, yet the question set may be expanded where necessary due to the semi-structured nature of the focus group. It is important for the researchers to keep track of what is being discussed to prevent the repetition of questions, particularly for a population that is difficult to keep within the remit of a study. Investigators should also be wary of certain individuals dominating the conversation and could perhaps deflect their views to the other participants. There is also scope to introduce a set order in which the participants are permitted to answer questions if an individual continues to interrupt their peers. The question set was developed in conjunction with experts in ID to ensure the language was accessible to the target population. Nevertheless, it may be useful to include people with ID in this procedure to ensure the language is being interpreted as expected.

(1) How many times have you seen a doctor this year?

(2) How do you prepare for going to the doctors?

(3) Do you talk to the same doctor each time?

3.1 If not – Was the other doctor as helpful?

3.2 What did they do differently?

(4) Do you like your doctor? What do you like about them?

4.1 Do you understand what they say?

4.2 Do they try to reword sentences you don't understand?

4.3 Does the doctor give you time to think about what they're saying?

4.4 Can you think of a time when the doctor really helped you?

(5) What don't you like about them?

5.1 Does the doctor spend most of their time talking to you or the carer? Are you okay with them talking to the carer?

5.2 Do you understand what they say? (If not answered in 3.1)

5.3 What could the doctors do differently so you understand what they are saying?

5.4 Do they spend enough time with you? Do they give you enough time to say what you are thinking? Do they give you enough time to understand what they are saying? (if not answered in 3.3)

5.5 Can you think of a time when the doctor was really unhelpful? How could this be improved?

(6) Have you ever used a communication aid during a doctor's appointment? An example maybe a speech generating device, basic images, or communication booklets.

6.1 Did the aid help to make your views clear to the doctor? How did it do this?

6.2 What do you like about the aid? What don't you like about the aid?

(7) How could a tablet application help you to tell the doctor what is wrong with you?

7.1 Where would you use it? Home or in the practice (before or during the appointment)

7.2 Do you use tablets (or touch screen mobile phones) at home?

7.3 What do you find hard about using touch screen devices?

- People with mild ID often have impairments in their short-term memory and therefore find it difficult to track what has been discussed over the length of a session. In addition, some find it hard to express themselves clearly, meaning researchers can incorrectly interpret their views. Zisook and Patel's sticky note methodology [108] may help to alleviate these barriers and should therefore be employed by a second investigator during task one. As discussed previously, a notice board will be placed in full view of the participants, with this investigator adding notes to the board to encapsulate the topics being discussed. The language embedded in these notes should adhere to accessible language guidelines, whilst it may also be necessary to draw complimentary images for those participants with impaired literacy skills. As such, it could be useful to determine the participants literacy skills prior to the workshop and subsequently hire appropriate personnel to draw the images if needed.
- Participants may not directly challenge the produced sticky notes during the focus group. Consequently, the task should end with the lead investigator describing the contents of each note (in the order they were produced) and offering the opportunity for any participant to disagree with this content.
- The Dictaphone will then be switched off, whilst the participants have a refreshment break. In all, the focus group session should last approximately 45 minutes.

4.3 Task Two: Image Boards

- During the refreshment break, the investigators should set up the image board task. This procedure will involve placing two sticky boards (one for clear images and the other for unclear) at the head of the table where the primary investigator is situated. In addition, the images included in section 5 should be split equally amongst all participants, with those representing similar conditions being distributed to the same individual. Three separate image sets have been sourced: photorealistic images; semi-abstract cartoons; and basic black and white pictures. Investigators may want to limit the number of images given out to a smaller group of participants yet should ensure every medical condition is represented at least once.
- The lead investigator will brief the participants on what the image board task entails, prior to switching on the Dictaphone.
- Participants will have fifteen minutes to separate their own image sets into two piles: one containing clear images and the other more obscure. During this process, the investigators will go around the group ensuring everyone knows what to do and provide support where necessary. For example, some participants may not be able to read the description of the images or understand what a particular condition is.

- Each individual with ID will then be asked to present their conclusions back to the group. They will first describe their reasons for including the images in the clear set, with the remaining participants being afforded the opportunity to agree or disagree. The investigators should look out for potential signs of response bias at this point such as the group agreeing with all of the explanations presented. Once a consensus has been reached on each image, the participants will select a spot on the appropriate board to place them. They should be encouraged to group similar images together such as those with incorrect facial expressions. This process will then be repeated for the unclear set, before moving on to the next individual with ID.
- Once all images have been placed on the relevant boards, the participants will be asked if they wish to make any last-minute changes. They will then be prompted to suggest appropriate tags for the subgroups of images included on each board.
- The Dictaphone will be switched off once the image boards have been finalised, in preparation for the second refreshment break. The image board task should last approximately 50 minutes in total.

4.4 Task Three: Paper Prototype

- A flipchart will be placed at the head of the table in full view of all participants, with each page containing an outline of a tablet. The resources shown in section 6 should also be placed in the centre of the table to support them in developing their paper prototypes.
- The lead investigator will then brief the participants on what task three entails. People with mild ID should consider how a tablet application can support them during primary care consultations and come up with a design that matches their views. They may utilise the resources provided or come up with their own.
- The group will nominate a leader whose role is to propose initial features to include in the prototype, yet the features will only be added on consensus of the entire group.
- The Dictaphone should be turned on at this point to record the participants reasons for their design.
- The nominated leader should suggest what the first page in the application will focus on. If the remaining participants agree, the leader will then move on to the features of this page, which will be added to the tablet outline if deemed appropriate and useful by the others. One page on the flipchart equates to one screen in the application.
- The above process will be repeated until the participants are satisfied that they have covered all potential screens to include in the application.
- The lead investigator will then flip through the design and describe the major features, whilst offering a final opportunity for the participants to tweak their design.

- The Dictaphone will then be turned off in preparation for the final refreshment break. The paper prototyping task should last approximately 30 minutes.

4.5 Task Four: Post-Task Walkthrough

- In the final task, participants are required to evaluate the prototype developed by the experts (see Chapter Five in main body) via a post-task walkthrough protocol. Prior to commencement, the lead investigator should identify any changes that need to be made to the tablet's accessibility settings and carry them out accordingly. The tablet will be placed at the top of the table and all actions will be performed by the investigator.
- The lead investigator will describe the symptoms to be selected by the participants when using the application. The first set of symptoms involve those experienced by someone with the flu and the second involves a sore, tight chest. These conditions were selected to explore all features in the prototype.
- Once again, the group will be asked to nominate a leader to suggest initial interactions with the prototype, but they will only be performed on consensus of the group.
- The Dictaphone will be turned on at this point to record the participants interaction with prototype.
- The participants will then be asked to work through the prototype for symptoms of flu. The lead investigator will perform the suggested actions but will only provide assistance when specifically asked. The other researcher will monitor the interactions being made and will make note of any areas of interest.
- The above process will then be repeated for symptoms of a sore, tight chest. Any features that were not explicitly used by the participants will then be demonstrated by the lead investigator.
- Finally, the participants will be asked the following question set to determine their views on the application. They will also be quizzed on the observations made by the second researcher. The post-task walkthrough is estimated to last 30 minutes.
  (1) Would you use this app when going to the doctors?
  (2) What did you like about the app?
  (3) What did you not like about the app?
  (4) What would you change about the app?
  (5) Is there anything else you would like to add?

4.6 Debriefing

- The lead investigator will briefly cover the main findings from each task using the produced resources as a referent.

- They will then explain that an easy-read version of the results will be forwarded on to them via the charities in due course.
- The participants will then be reimbursed for the travel costs and supplied with a £5 lunch voucher.

5 Images used in Task Two

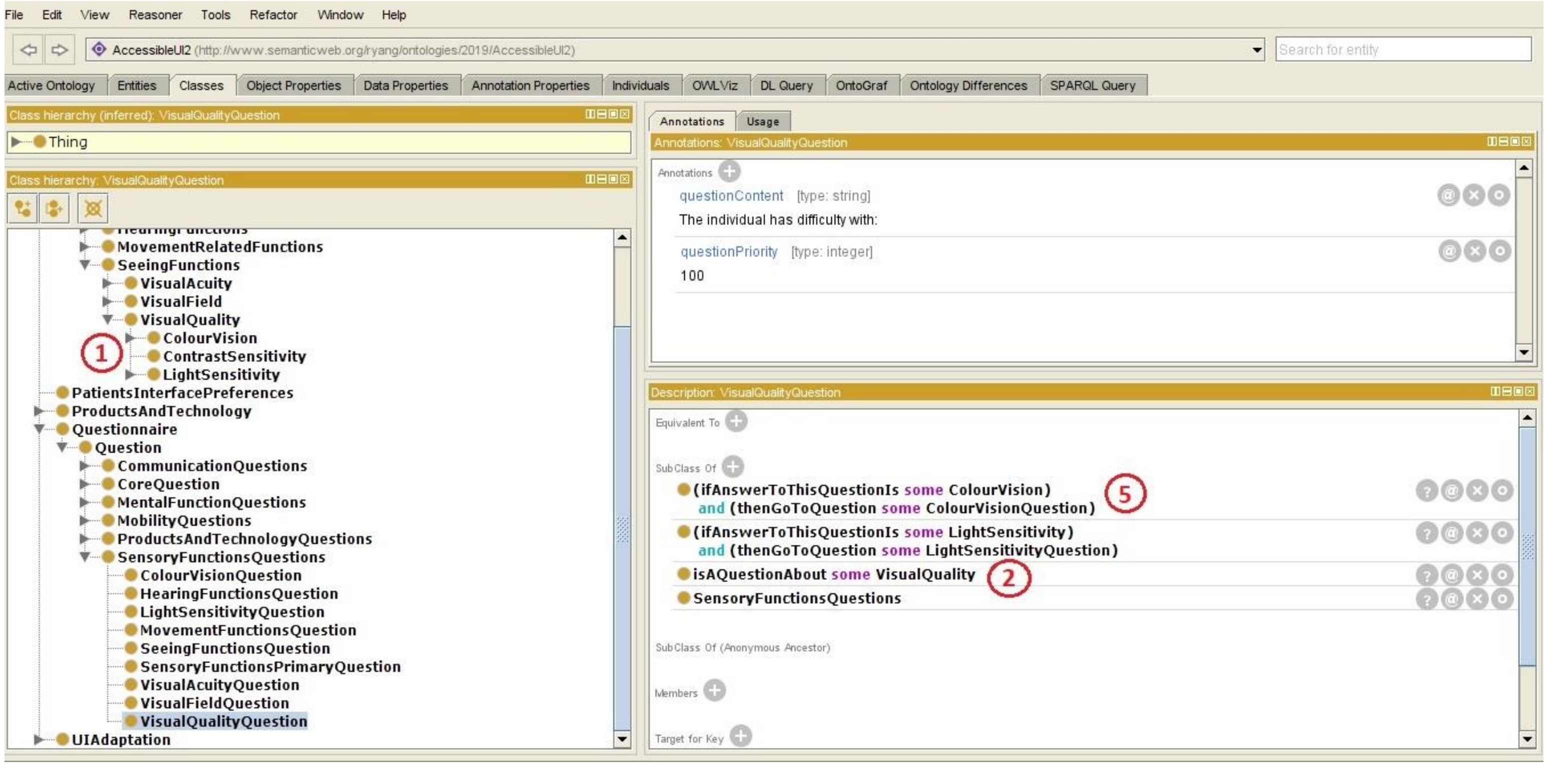
The pictures to be evaluated by the participants will cover a range of symptoms, thus enabling common themes to be identified that may assist in the future development of medical images for this population. Images to be used can be provided on request. Please forward this request to ryan.gibson@strath.ac.uk

6 Images used in Task Three

Both general user interface objects, as well as those more specific to the application, will be offered to the participants during the paper prototyping process. Images to be used can be provided on request. Please forward this request to ryan.gibson@strath.ac.uk.

APPENDIX D: SCREENSHOTS OF THE PROTÉGÉ INTERFACE DETAILING THE STRUCTURE OF THE ONTOLOGIES

The first three images highlight the structure of the Accessibility Preferences Ontology. The first captures a question about the patient's visual quality, the second demonstrates an answer for that question, and the third illustrates potential interface changes if that answer is selected.



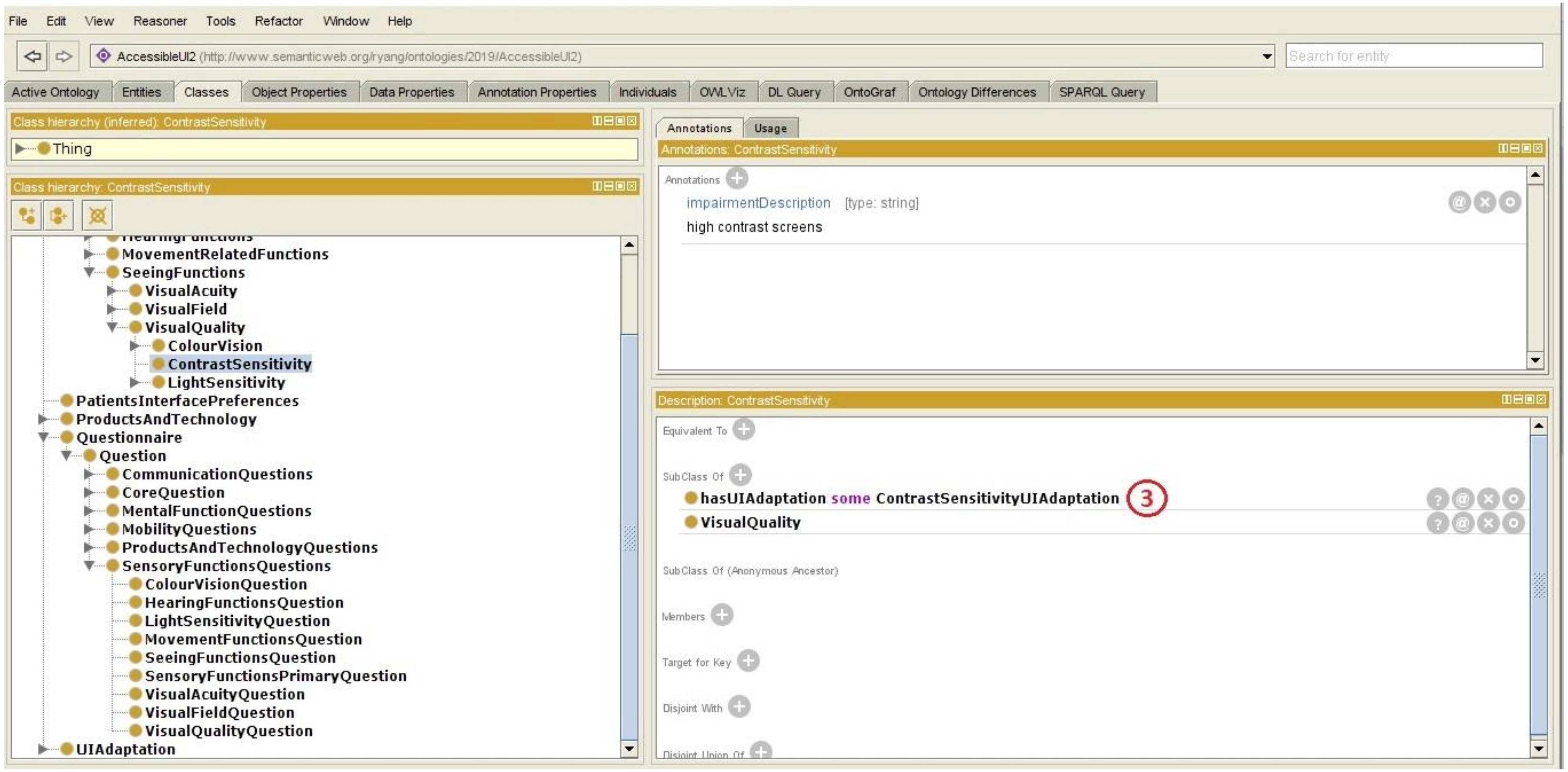
questionContent [type: string]

The individual has difficulty with:

questionPriority [type: integer]

100

```
(ifAnswerToThisQuestionIs some ColourVision)
 and (thenGoToQuestion some ColourVisionQuestion)
(ifAnswerToThisQuestionIs some LightSensitivity)
 and (thenGoToQuestion some LightSensitivityQuestion)
isAQuestionAbout some VisualQuality
SensoryFunctionsQuestions
```



Annotations

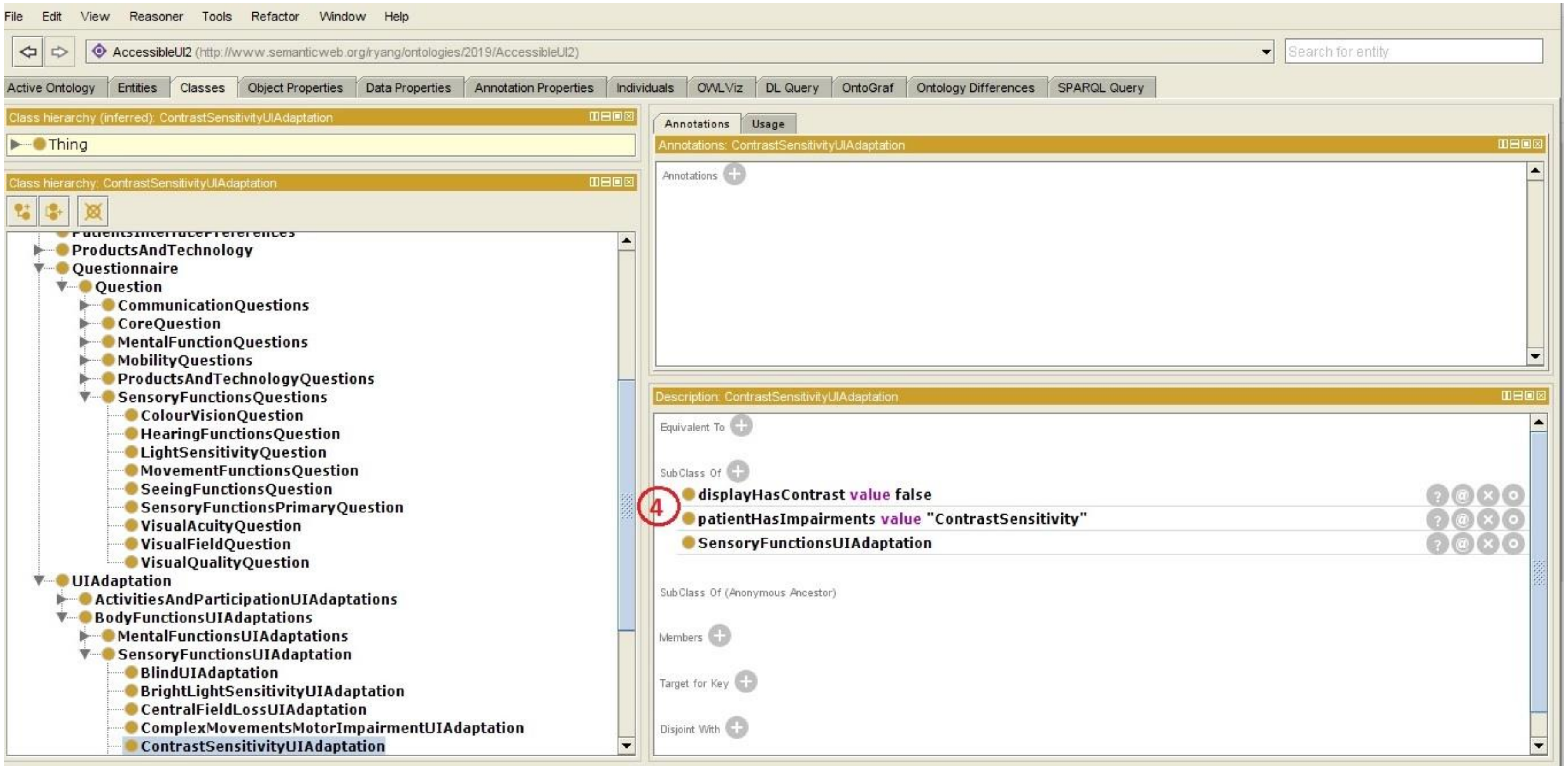
impairmentDescription [type: string]

high contrast screens

SubClass Of

hasUIAdaptation some ContrastSensitivityUIAdaptation

VisualQuality

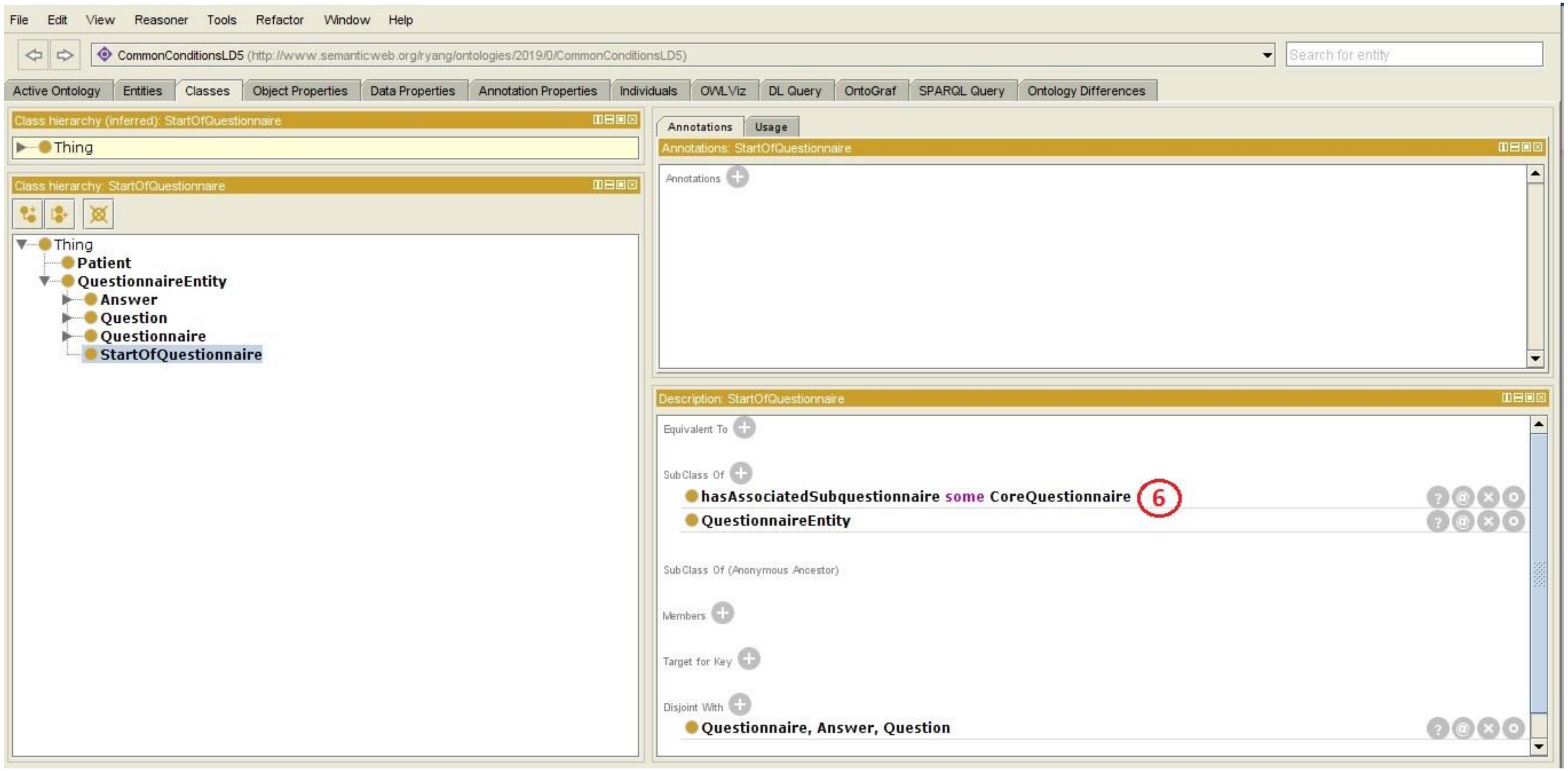


```
PatientsInterfacePreferences
ProductsAndTechnology
Questionnaire
    Question
        CommunicationQuestions
        CoreQuestion
        MentalFunctionQuestions
        MobilityQuestions
        ProductsAndTechnologyQuestions
        SensoryFunctionsQuestions
            ColourVisionQuestion
            HearingFunctionsQuestion
            LightSensitivityQuestion
            MovementFunctionsQuestion
            SeeingFunctionsQuestion
            SensoryFunctionsPrimaryQuestion
            VisualAcuityQuestion
            VisualFieldQuestion
            VisualQualityQuestion
UIAdaptation
    ActivitiesAndParticipationUIAdaptations
    BodyFunctionsUIAdaptations
        MentalFunctionsUIAdaptations
        SensoryFunctionsUIAdaptation
            BlindUIAdaptation
            BrightLightSensitivityUIAdaptation
            CentralFieldLossUIAdaptation
            ComplexMovementsMotorImpairmentUIAdaptation
            ContrastSensitivityUIAdaptation
```

SubClass Of

```
displayHasContrast value false
patientHasImpairments value "ContrastSensitivity"
SensoryFunctionsUIAdaptation
```

The second set of images highlights the structure of the Medical Questionnaire Ontology. Image one demonstrates how the initial questionnaire is identified and loaded into the stack, image two captures the design of a questionnaire, and images three and four display an individual question and answer respectively.



CommonConditionsLD5 (http://www.semanticweb.org/ryang/ontologies/2019/0/CommonConditionsLD5)

Class hierarchy (inferred): StartOfQuestionnaire

- Thing

Class hierarchy: StartOfQuestionnaire

- Thing
  - Patient
  - QuestionnaireEntity
    - Answer
    - Question
    - Questionnaire
    - StartOfQuestionnaire

Annotations: StartOfQuestionnaire

Annotations

Description: StartOfQuestionnaire

Equivalent To

SubClass Of

- hasAssociatedSubquestionnaire some CoreQuestionnaire
- QuestionnaireEntity

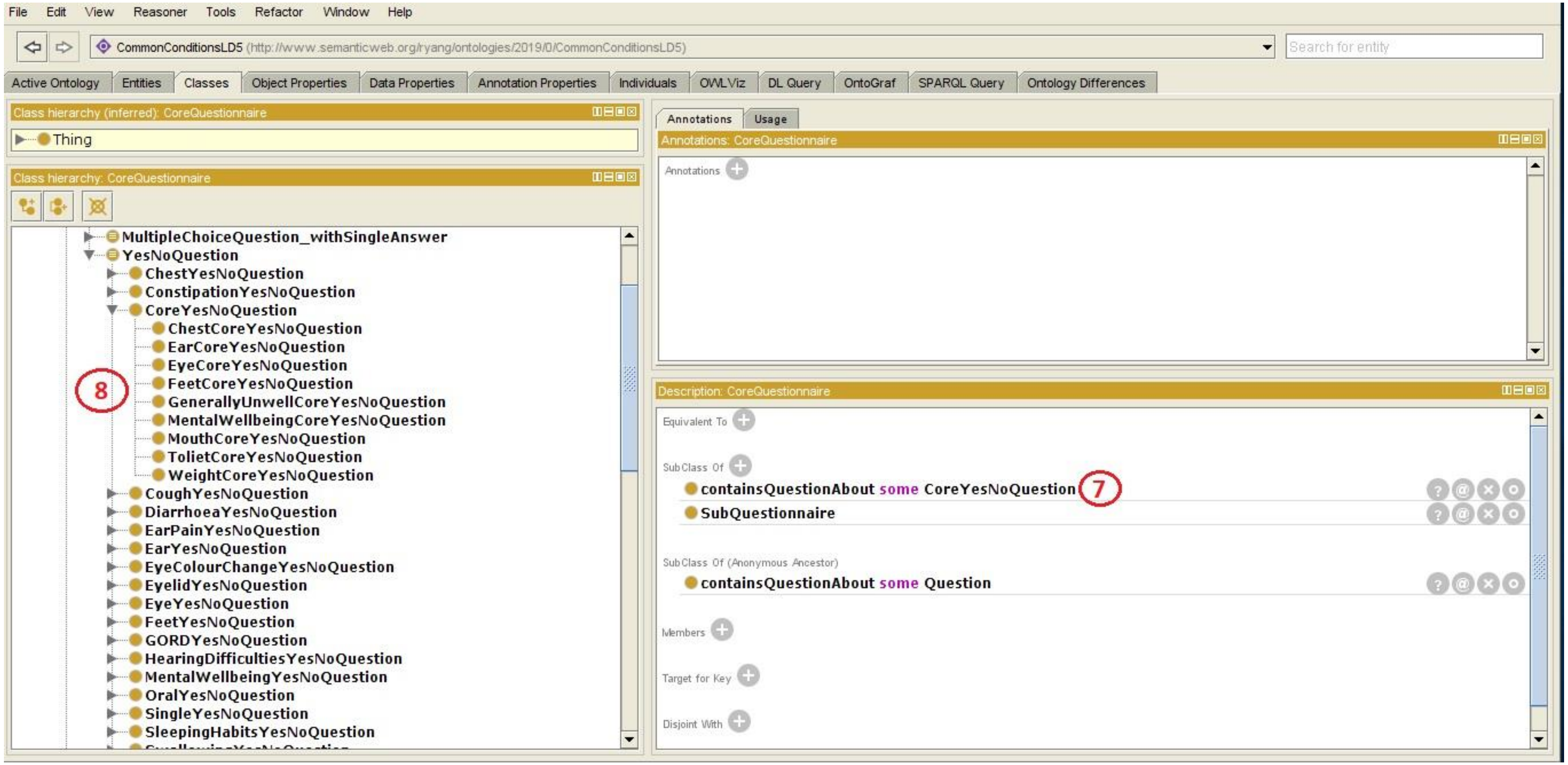
SubClass Of (Anonymous Ancestor)

Members

Target for Key

Disjoint With

- Questionnaire, Answer, Question



- MultipleChoiceQuestion_withSingleAnswer
- YesNoQuestion
  - ChestYesNoQuestion
  - ConstipationYesNoQuestion
  - CoreYesNoQuestion
    - ChestCoreYesNoQuestion
    - EarCoreYesNoQuestion
    - EyeCoreYesNoQuestion
    - FeetCoreYesNoQuestion
    - GenerallyUnwellCoreYesNoQuestion
    - MentalWellbeingCoreYesNoQuestion
    - MouthCoreYesNoQuestion
    - ToiletCoreYesNoQuestion
    - WeightCoreYesNoQuestion
  - CoughYesNoQuestion
  - DiarrhoeaYesNoQuestion
  - EarPainYesNoQuestion
  - EarYesNoQuestion
  - EyeColourChangeYesNoQuestion
  - EyelidYesNoQuestion
  - EyeYesNoQuestion
  - FeetYesNoQuestion
  - GORDYesNoQuestion
  - HearingDifficultiesYesNoQuestion
  - MentalWellbeingYesNoQuestion
  - OralYesNoQuestion
  - SingleYesNoQuestion
  - SleepingHabitsYesNoQuestion

Equivalent To

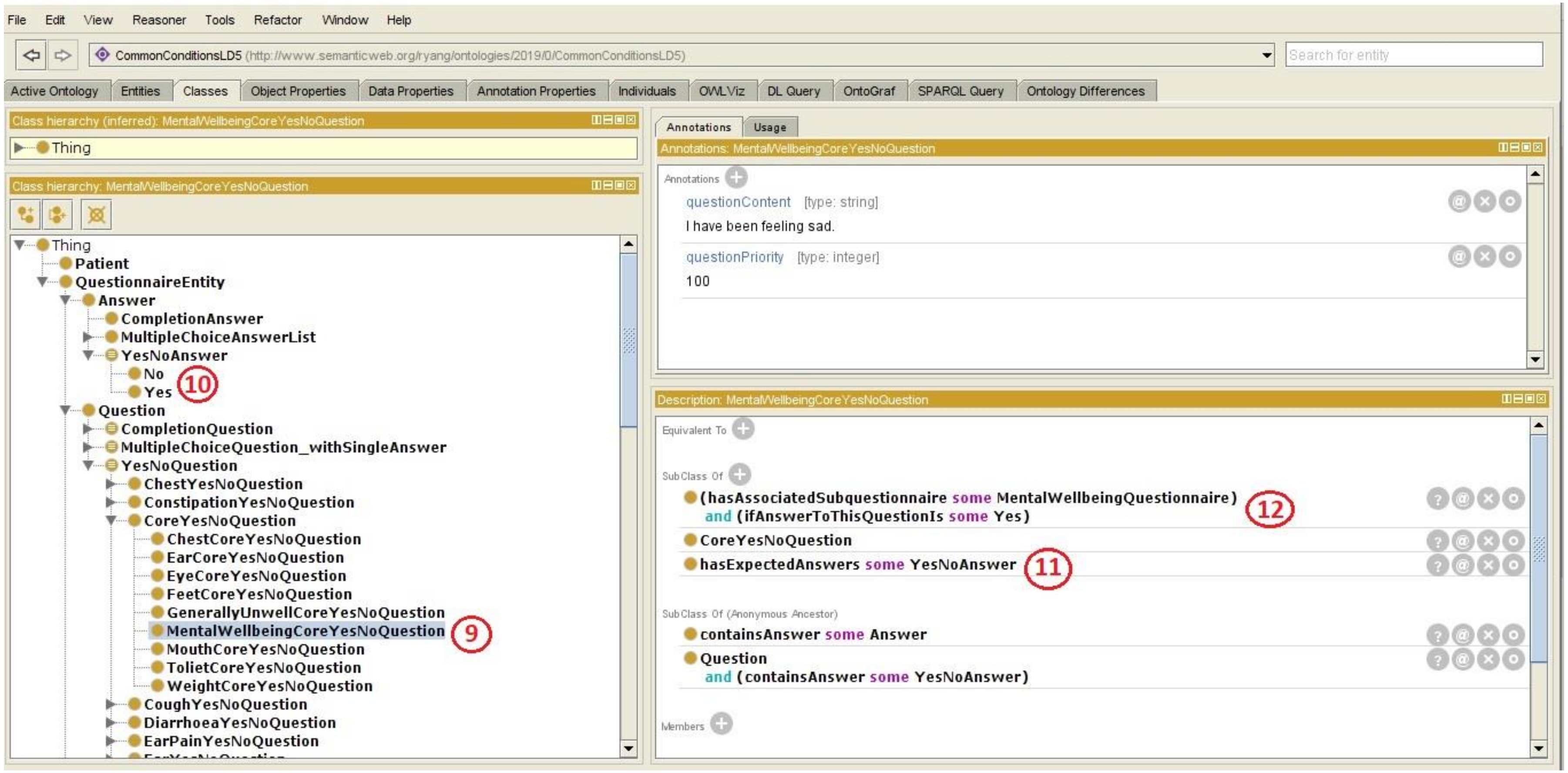
SubClass Of
containsQuestionAbout some CoreYesNoQuestion
SubQuestionnaire

SubClass Of (Anonymous Ancestor)
containsQuestionAbout some Question

Members

Target for Key

Disjoint With



CommonConditionsLD5 (http://www.semanticweb.org/ryang/ontologies/2019/0/CommonConditionsLD5)

Class hierarchy (inferred): MentalWellbeingCoreYesNoQuestion

- Thing

Class hierarchy: MentalWellbeingCoreYesNoQuestion

- Thing
  - Patient
  - QuestionnaireEntity
    - Answer
      - CompletionAnswer
      - MultipleChoiceAnswerList
      - YesNoAnswer
        - No
        - Yes
    - Question
      - CompletionQuestion
      - MultipleChoiceQuestion_withSingleAnswer
      - YesNoQuestion
        - ChestYesNoQuestion
        - ConstipationYesNoQuestion
        - CoreYesNoQuestion
          - ChestCoreYesNoQuestion
          - EarCoreYesNoQuestion
          - EyeCoreYesNoQuestion
          - FeetCoreYesNoQuestion
          - GenerallyUnwellCoreYesNoQuestion
          - MentalWellbeingCoreYesNoQuestion
          - MouthCoreYesNoQuestion
          - TolietCoreYesNoQuestion
          - WeightCoreYesNoQuestion
        - CoughYesNoQuestion
        - DiarrhoeaYesNoQuestion
        - EarPainYesNoQuestion

Annotations: MentalWellbeingCoreYesNoQuestion

Annotations

questionContent [type: string]
I have been feeling sad.

questionPriority [type: integer]
100

Description: MentalWellbeingCoreYesNoQuestion

Equivalent To

SubClass Of

(hasAssociatedSubquestionnaire some MentalWellbeingQuestionnaire)
and (ifAnswerToThisQuestionIs some Yes)

CoreYesNoQuestion

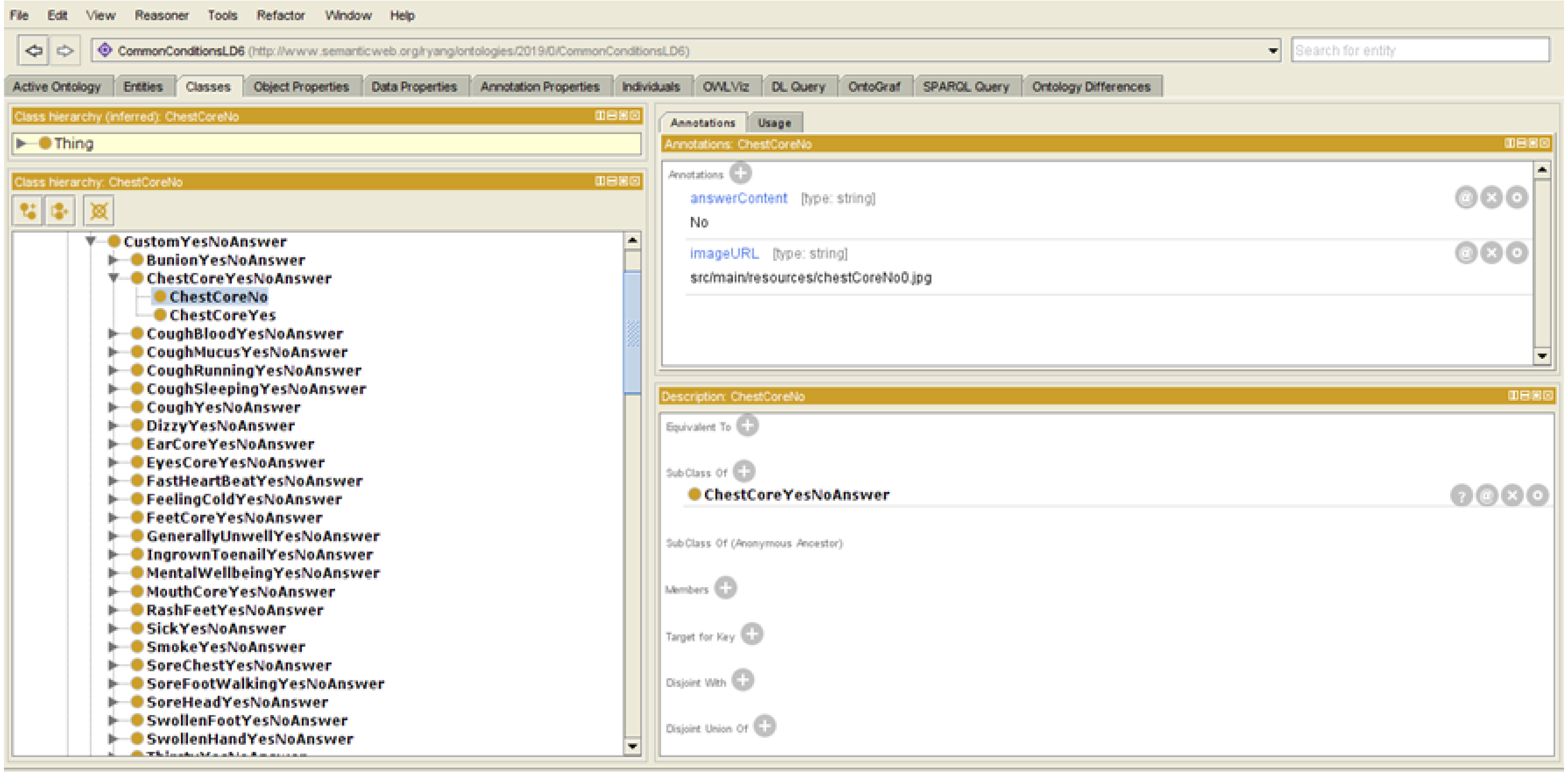
hasExpectedAnswers some YesNoAnswer

SubClass Of (Anonymous Ancestor)

containsAnswer some Answer

Question
and (containsAnswer some YesNoAnswer)

Members



CommonConditionsLD6 (http://www.semanticweb.org/ryang/ontologies/2019/0/CommonConditionsLD6)

Class hierarchy (inferred): ChestCoreNo

- Thing

Class hierarchy: ChestCoreNo

- CustomYesNoAnswer
  - BunionYesNoAnswer
  - ChestCoreYesNoAnswer
    - ChestCoreNo
    - ChestCoreYes
  - CoughBloodYesNoAnswer
  - CoughMucusYesNoAnswer
  - CoughRunningYesNoAnswer
  - CoughSleepingYesNoAnswer
  - CoughYesNoAnswer
  - DizzyYesNoAnswer
  - EarCoreYesNoAnswer
  - EyesCoreYesNoAnswer
  - FastHeartBeatYesNoAnswer
  - FeelingColdYesNoAnswer
  - FeetCoreYesNoAnswer
  - GenerallyUnwellYesNoAnswer
  - IngrownToenailYesNoAnswer
  - MentalWellbeingYesNoAnswer
  - MouthCoreYesNoAnswer
  - RashFeetYesNoAnswer
  - SickYesNoAnswer
  - SmokeYesNoAnswer
  - SoreChestYesNoAnswer
  - SoreFootWalkingYesNoAnswer
  - SoreHeadYesNoAnswer
  - SwollenFootYesNoAnswer
  - SwollenHandYesNoAnswer

Annotations: ChestCoreNo

Annotations

answerContent [type: string]
No

imageURL [type: string]
src/main/resources/chestCoreNo0.jpg

Description: ChestCoreNo

Equivalent To

SubClass Of
ChestCoreYesNoAnswer

SubClass Of (Anonymous Ancestor)

Members

Target for Key

Disjoint With

Disjoint Union Of

APPENDIX E: QUESTIONS INCLUDED WITHIN THE MEDICAL QUESTIONNAIRE

In this context, an adaptive question is defined as follows: a question in which a particular response will result in further questions being added to the stack / presented to the user.

A "*" represents the primary question of the stack – generally adaptive.

Questions with two or more stars are dependent on the user providing a specific answer to the nearest question with one less star. For example, those questions with two stars will only be asked providing a certain response is received for the primary question. Those with three stars are dependent on a certain response being received for the nearest two-star question and so on.

The questions were modelled from the Learning Disability Health Toolkit [37] and were presented in accordance with accessible language guidelines – People with ID tend to prefer to read statements that are written in first person.

General Wellbeing

* I feel generally unwell

    ** I feel sick

    ** I have a sore head

    ** I feel thirsty all the time

** I feel dizzy

** I feel colder than normal

** My hands are swollen

** My feet are swollen

<u>Mental Wellbeing</u>

* I have been feeling sad

** I have been unable to relax.

** I have been crying a lot recently.

** I have been getting mad with people.

** My social routine has changed.

*** I have stopped seeing a family member or friend.

*** I have stopped doing a hobby.

        *** I have stopped going to a social club.

    ** I have been forgetting things.

    ** I have been getting distracted.

    ** My sleeping routine has changed.

        *** I have been sleeping more than normal.

        *** I have found it hard to get to sleep.

        *** I feel tired after waking up.

    ** I have been sweating a lot.

Ears

* I have a problem with my ears or hearing.

** I have a sore ear.

*** My ear is red.

*** My face is swollen.

*** Red or yellow liquid has been coming out of my ears.

*** I hear a constant ringing noise.

*** I cannot sleep at night.

** I find it hard to hear people.

*** I have been getting frustrated with people.

*** I have earwax in my ear.

Eyes

* I have a problem with my eyes or vision.

** A part of my eye has changed colour.

*** The white part of my eye has turned red.

**** The white part of my eye has turned yellow.

*** The coloured part of my eye has turned pale.

** I have a problem with my sight.

*** Things that are far away are blurry.

*** Things close to me are blurry.

*** I see black spots all the time.

*** I see flashing lights.

*** I need to cover one eye to see clearly.

** I have a problem with my eyelids or eyelashes.

*** I have a lump on my eyelid.

**** The lump is just above my eye.

*** One of my eyelids is hanging lower than the other.

** My eyes have been watering.

*** My Eyes feel dry.

** I have been rubbing my eyes a lot.

** I have been staring into lights.

** I have yellow liquid coming out of my eyes.

<u>Oral</u>

* I have a problem with my mouth.

** I have a problem with my teeth.

  *** I find it hard to eat because my teeth hurt.

  *** My teeth are sore when drinking hot or cold drinks.

  *** I have a loose tooth.

  *** I have brown holes in my teeth.

** My gums have been bleeding.

** I have a problem with my tongue.

  *** I have white patches on my tongue.

  *** I have a burning pain in my tongue.

  *** I have a salty taste in my mouth.

** I find it hard to swallow my food.

  *** I have been coughing a lot when eating.

        *** I have been coughing food up.

    ** I have bad breath.

        ** I have a dry mouth and feel thirsty.

<u>Feet</u>

* I have a problem with my feet.

    ** My feet hurt when walking.

    ** I have a lump at the bottom of my big toe.

    ** I have a small rough lump at the bottom of my foot.

    ** I have red itchy skin on my toes.

    ** have yellow/green toenails.

    ** I have a nail growing into my skin.

        *** My toe is red and swollen.

***I have green liquid coming out of my nail.

Toiletry Habits

* I have a problem going to the toilet.

** I have a problem when pooing.

*** I find it hard to poo.

**** My poo is hard and lumpy.

**** I have pooped less than 3 times this week.

**** My tummy is sore.

**** My tummy is swollen.

**** My poo is soft and watery.

***** There is blood in my poo.

***** My poo is black.

***** I need to poo suddenly.

***** My tummy is sore.

***** I have been sick.

** I have a problem when peeing.

*** I am in pain when peeing.

**** I have pain in my side.

**** I have pain in my back.

**** I have pain in my tummy.

*** My pee is a different colour.

**** My pee has blood in it.

**** My pee is cloudy.

*** I need to pee suddenly.

*** I have been wetting myself.

*** My pee smells bad.

*** I have been feeling confused.

*** I have been shaking.

Chest/Breathing

* I have a problem with my chest or breathing.

** How long have you had the problem for?

** I have a sore chest.

*** I have a burning feeling in my chest.

**** I have been bringing up stomach acid.

**** I have been burping a lot.

        **** I have been choking on my food.

        **** My throat is sore.

** I have a cough.

    *** I cough a lot when trying to sleep.

    *** I cough a lot when exercising.

    *** I have been coughing up green liquid.

    *** I have been coughing up blood.

    *** I smoke.

** My chest feels tight.

** My heart is beating faster than normal.

Weight Change

* I have put on weight

** I have lost weight

APPENDIX F: CAREGIVERS AND GPS VIEWS ON THE BARRIERS TO EFFECTIVE PRIMARY CARE CONSULTATIONS

As highlighted in Chapter Seven, the caregivers and GPs also discussed their views on the barriers and facilitators to primary care consultations involving patients with mild ID. The main themes that were derived will now be presented, beginning with the experiences of caregivers and ending with the GPs.

Barriers/Facilitators Discussed by the Caregivers

ID Criteria

Caregiver Two recognised that primary care practices had systems in place to make medical professionals aware of an individual's ID. Nevertheless, these systems did not scale well across the entire spectrum, with patients who have mild ID and/or additional conditions such as Aspergers, missing out on their potential benefits: *Caregiver Two: We have something here, it's a flag system, so if people have a learning disability it should be on their health notes. Although I don't know if they only do that for people who are registered with the learning disability service or whether they also do people with learning difficulties. I suspect it might only be people that are supported by the learning disability service though…Somebody that has Aspergers for instance is on the spectrum and may also have a learning disability that might not be picked up [on] because the Aspergers is the overall condition…It can be hard to tell because if there's another underlying condition or whatever people who have a mild learning disability, it may be missed and overlooked.*

Greater efforts must therefore be made to identify and embed patients with more "hidden" disabilities in ID registers, particularly those who do not qualify for caregiver support. This should alleviate the health inequalities being experienced by such patients, due to an increase in specialised treatment practices such as reasonable adjustments.

Person-Centred Care

On the whole, the caregivers were confident in the ability of GPs to conduct person-centred care. The only exception was Caregiver Three, who found that the quality of treatment received by her children was variable: *"My twins specifically, they've got very high pain threshold. So if they're crying and in pain, then you can be sure that any other person would probably need morphine. But for my child to say that it's that sore means that it's excruciatingly sore for any other person and trying to explain that to a doctor, they'll go "yeah I get it" [and] "I'm like no you don't". They're not used to having this kind of feedback and this amount of pain, so you actually think it can't be that bad, but when I see that reaction I think "oh shoot he's in a lot of pain" and I can tell them that's the case."*

In this instance, Caregiver Three felt that they were a valuable source of information as they held knowledge on the behavioural habits of the patient. Nevertheless, there was some resistance to this information, since the medical professional preferred to speak directly to the individual with ID: *"When a child hits a certain age regardless of the conditions they've got, they will always ask that child over the parent even though I'm their full-time carer and that's very frustrating. Generally a younger doctor will get it a lot more than somebody that's been doing it longer, is what I tend to find. They're a bit more empathetic towards you and understand that a little bit more and I'm assuming that might be because there's more training…"*

Education

Caregiver Three suggested that the lack of person-centred care was due to the gap in training medical professionals receive on ID. This included effective consultation methods, in addition to the health trends of people with ID: *"Staff as soon as you mention autism they go oh yeah and it really doesn't mean anything. So they know the symptoms of autism as in it can mean that they don't like loud noises, they don't like to be touched, their vocabulary might not be great and they know all that but they don't know exactly how drastic it affects the child because to them it's just a list of symptoms. They don't see how it affects our daily life and how it alters their daily life and how their perception of things through the way they think is altered by this. You add that with maybe like a speech impediment, global development delay and the possibility of either dyspraxia or dyslexia or any of those, you know, other conditions, then it's a complete mine field for a parent and a child to go into a doctors."*

Caregiver Three continued *"[One Time] I was in hospital all day and everything's [supposedly] great, we can't see anything wrong. If it doesn't get any better come back and I'll be back three consecutive days in a row before they'll even do any tests and even when they do the tests, they're not being very forthcoming. Well he's got autism, he's got global development delay, you're not going to get any more from him than you've got from him already and there's some questions I can't answer. So in my opinion they should do all the tests rather than just hearsay because what if they send them away and it's something really bad…Now a GP's touching our children and examining the children but when your child doesn't feel pain the way any other would, they're making the [assumption] that means it doesn't hurt because they're not reacting the way any other person would."*

Providing additional training may ensure medical professionals are able to relate to the behavioural traits and communication needs of the ID population. Furthermore, GPs should become familiar with the common conditions affecting people with ID, thereby reducing the possibility of symptoms being overshadowed. Yet, as highlighted by Caregiver Two, the outcome of the consultation can also depend on the ability of the patient to recognise and describe their feelings – a process they may find extremely difficult: *"People just not understanding themselves, what it is they feel [is also a barrier]. So they might not be able to actually explain what's going on and that's where the carer really needs to be in there with them to either help them get their words out or explain what it is they're trying to say."*

Consequently, the caregivers suggested that a lot of their effort is spent on preparing the patient for the consultation and would therefore benefit from support during this process: *Caregiver 4: "[My role is to] speak them through why they're attending, maybe give them a brief in some of the things that we'll need to talk about. If it's personal information just prepare them for that, the time that we will be there, if we need to bring anything with us. I'd speak to them and let them know their kind of rights, like, I need to share this information, I'm allowed to share it, I will reassure them it's going to be confidential and I'm not going to pass it on and the doctor's not going to pass it on. Some of the service users don't understand and accept that I need to pass on this information and they don't realise the consequence if I don't. So they maybe say I don't want you to say that, the barrier is that they doctor will not get the* *information they need and they may lack the information and make the wrong diagnosis because the service user doesn't want me to speak about things…I think [the app can] try to pull out that information before the actual appointment because if they're sitting in the appointment and they're anxious they might hold off information. But if they can do this from the safety of their home, I don't know if that's what it's intended for, to then take to the GP, they're maybe going to be a bit more relaxed and they've got their support worker there to help them through it. So they've maybe got a bit more accurate symptoms before going in to see the GP."*

If enough information has not been extracted then the caregiver can step in and provide their own views; however, if a diagnosis is still not feasible it may be appropriate to rely on extra testing as highlighted by Caregiver Three.

Communication

Ineffective two-way communication was the barrier most widely cited by the caregivers. They suggested that the GPs often utilised language that was too complex for the individual with ID, with the patient also finding it difficult to describe their symptoms clearly: *Caregiver Two: "Not understanding the language, so jargon is a huge barrier. Say they had to go to a clinic and they had to go to gastroenterology, what's that? Clear, simple plain English is what's needed to have a conversation and to check that they're understanding what they're being told. So yeah, language is a huge barrier." Caregiver Three: "There always has to be this big explanation rather than just the basic form. They just don't have the words, just don't have the ability to be able to give [the GPs] the adjectives they need to say "oh it's more likely to be this than this." They'll just say it's sore because that's just how they feel. But then I mean you do come across some practitioners and they do get it."*

Consequently, the caregivers stated that their role was to facilitate the exchange of information between the GP and patients, since they are familiar with the needs of both populations: *Caregiver Two: The carers role to me would be ensuring that the person that they're caring for gives all the information that they need to give and also to listen to what the GP is saying and to take a note of that because chances are, we all do, we go to the doctors [and] can't remember what they said. In terms of if there's any medication, you encourage the person, or the carer [themselves] speaks to the GP* *about the medication, finds out what it's for, how long should [it] be taken and everything you can find out about it. And if there's a concern about the cared-for person being able to do that themselves then the carer would need to take on responsibility to make sure they get their medication."*

Access

Another major barrier discussed by the caregivers was the ability of patients with ID to gain access to healthcare services. Some of the individuals being cared for were visibly vulnerable and therefore wholly reliant on carers to attend appointments: *Caregiver One: "It's a walk or a bus ride [to get to the GP surgery] and my person is not self-traveling. He would probably know how to get there but he's vulnerable and visibly vulnerable. And if he's so ill that he's got to go to the GP then [he needs support]*."

Such patients may therefore miss appointments on a regular basis if they do not have access to paid support. This may be one reason why the participants with ID requested features to assist them in attending primary care consultations – see section 5.2.2.3.

Time

Consultation length was also believed to have a negative effect on the quality of care received by patients with ID: *Caregiver Two: "The usual kind of appointment time, it's quite often harder to communicate well and effectively with a person with a learning disability whether it's mild or not. They need to be given time and they need to not feel they're rushed because then they may panic and, you know, they'll give up because it's quite difficult sometimes. It can be very frustrating for people if they think they're not getting the message across or they're not being listened to properly."*

Thoroughly preparing the individual with ID prior to the consultation may help to alleviate such a barrier, as could the regular implementation of double appointments: *Caregiver Two: "[Preparation] involves trying to make sure that you've got all the information about how the person's feeling and what kind of symptoms they might have, how long it's been going on, that kind of thing. Then encouraging them to be clear when they go to the doctor, tell the doctor what's been going on, for how long has it been going on, if anything you've done that might have caused it…So basically prepping them so that they can actually talk to the GP themselves but also in most* *cases somebody would be in with them if they did forget anything. But some people do find it very hard to express themselves and be clear and sometimes the language lets them down a bit because they're not able to put into words exactly how they're feeling. So kind of practicing is quite useful just to try and make sure that they know what they have to say and how they explain things and point to areas."*

Barriers/Facilitators Discussed by the GPs

All of the medical professionals were aware of the health barriers being experienced by the mild ID population. Once again, the factors they discussed broadly matched those identified in the scoping review and by the caregivers and patients with ID (see section 5.2.1), therefore triangulating the urgent need to overcome such inequalities.

ID Criteria

In line with the findings of Jones and Kerr [41], GP One revealed that some patients with mild ID are unable to access the support they need due to the severity of their condition not meeting strict criteria: *"There probably needs to be an honest conversation about that label of learning disability and your medical records and what it actually means. When we coded people quite some time ago in the practice there were some strict criteria we had to meet to code them but we knew that we had a lot of patients with mild learning difficulties, whether they were borderline IQ, had gone to mainstream schooling, whatever, but still would struggle with literacy and all sorts of other things that you and I would take for granted. [They] would need in any sort of definition extra support but won't get it because they're not coded as such. And that, I think causes a lot of issues with forward planning or trying to get support services into people."*

Consequently, greater funds should be made available across the entire ID spectrum to ensure people with more mild ID also have access to the support services they desperately need. For example, participant 4.2 in the UCD workshops (section 5.2.4.1) stated that they recently had their funding for external support cut, meaning they had to attend consultations on their own. This led to them taking notes whilst interacting with the GP in order to update their support network; nevertheless, vital information may be lost during this process.

Easing the criteria used to diagnose an individual's ID will also result in a greater percentage of this population having a formal record of their disability. General Practitioners may then be aware of their need to conduct reasonable adjustments, thus leading to increased health outcomes: *GP Three: "When you say to me somebody with mild learning disabilities, I know they're not into IQs and things these days but I'm sort of thinking of an IQ around 70. So somebody like that is actually reasonably functional in society and with a bit of time patients can negotiate receptions and appointment systems stuff like that. [However,] it is easy to assume that they understand more than they might've led on. But I think most GPs and most of society are guilty of assuming a higher level of function than people perhaps have. Partly because that makes life more straightforward."*

Person-Centred Care

GP Four stressed the importance of moving away from standardised care and instead adjusting consultation techniques to meet the individualised requirements of patients with mild ID: *"To be flexible as well to kind of be able to adjust the way we do things to meet their needs. Most people [that] don't have a learning disability kind of [have] an idea of what the doctor involves and they kind of play that game almost. Whereas I think with people with a learning disability, you need to be a bit more flexible in just making it work for them and, you know, go along with how they would present themselves."*

Yet the medical professionals felt it was difficult to conduct reasonable adjustments, particularly when they are treating a patient for the first time: *GP1: "If you know patients very well that continuity of care which is often very understated in general practice is really important because you know[when] your patient's well, you know when they're not well. In out of hours it's slightly different because they're not your patients, they're somebody else's patients, registered patients, so you're having to risk managing a patient you don't really know that might have complex multi-morbid conditions. It's history, the history taking is really, really fundamental to general practice. You take a really good history, you quite often can manage the case very appropriately and it also helps you to risk manage as well.*"

Continuity of care should therefore help the medical professional to form a relationship with the patient, thus increasing their knowledge of the individual's communication preferences. In addition, the GP should become familiar with their potentially complex medical history, which should lead to more accurate diagnoses. This matches the patients views in section 5.2.1.2, meaning primary care practices should increase their efforts to schedule appointments with the individual's preferred medical professional.

Nevertheless, some practices may not be able to accommodate such requests, in which case access to information on the personal characteristics of the patient may be crucial: *GP Five: "[If] an LD [learning disability] patient has been put to me that I don't know, I usually go to speak to the GP that sees them more regularly. Because that's the way it is, you know, [on] emergencies I will have a chat and be like right you know this person, what are they like, what's their capability? An example for that was I had a cp, so cerebral palsy patient with LD who was coming in to see me for a gynaecological issue. But I didn't really know how able she was to do things. I didn't know how, if I even suggested an examination, how that was going to go. So I went and spoke to my colleague and it was just very clear that the anxiety levels were very high in her and that we should really just tread very carefully and take things over several weeks to build a rapport before we could actually get down to the nitty-gritty of getting things looked at."* The widescale use of patient passports may also facilitate practitioners' access to their patients' characteristics, thereby increasing their ability to provide person-centred care.

GP Education

None of the five GPs had received any formal training on ID and instead relied upon on-the-job experience to increase their knowledge of this population: *GP Four: "Probably not, well not directly. You know training through experience reflects [the bulk of our education]. So a lot of our training involves, kind of, discussing challenging cases with our trainers and that kind of stuff. So that kind of teaching yes, although there probably wasn't any kind of normal training."*

Some of the less experienced GPs therefore found it largely challenging to treat their patients (including individuals they were in frequent contact with) due to a lack of understanding of the health trends of the ID population, as well as how to conduct reasonable adjustments. Seasoned GPs, particularly those exposed to an above average number of patients with ID, were more confident in their abilities to consult with such patients: *“GP One: I think communication is something you learn throughout your medical career but it's really the fundamental building block of general practice and I think we are used to dealing with, if you're experienced you get used to people who cannot articulate [their symptoms].”* This further highlights the need to introduce modules on ID throughout a medical professional’s education to ensure they are equipped with the necessary skills to conduct person-centred care from the offset.

Fragmentation of Care

As described previously, people with ID are more prone to developing conditions and comorbidities than the general population [2, 7]. Consequently, they often require treatment from a range of health specialists, which may result in fragmented care, as discussed by GP One: *There's always a danger that we become ever more fragmented. We think we're being very clever of joining things up but actually it's not technology that joins up systems it's actually people who join up systems. Technology should not be thought of as replacing that, it's still a human endeavour. So patients who don't know where to go will often come to the GP actually because we’re the centre of everyone's referral...I think we have to work on the kind of referrals that social work and other services will accept from us because there's a constant frustration that patients don't meet thresholds of intervention or criteria for intervention. And I think that people forget that GPs are generalists so any problem whether it's housing, your sore foot, your sore head, your sore chest whatever it is and whatever combination we will still deal with you and still see you as a GP because we are generalists. So we have to get other services to work as generalist and that is a challenge for systems at the moment.*

GP One therefore believes that technology has a role to play in linking up the various services involved in the treatment of patients with ID, but only as an extension to specialist professionals e.g. social workers and mental health workers. Additional funding must therefore be released into these sectors to ensure the future demand for such personnel is met. Furthermore, the workload placed on primary care may be reduced, since specialists, such as community link workers, possess the skills required to forward on individuals to appropriate health services – a process people with ID find difficult to complete, hence their overreliance on GPs (see Complex Healthcare Systems).

Complex Healthcare Systems

As stated, patients with mild ID find it hard to manage the healthcare system. First, they may not seek treatment in a timely manner due to difficulties in recognising and acting upon the presence of symptoms [11]. Even on completion of this process, patients with mild ID face challenges identifying and gaining access to healthcare services: *GP One: I think the [main] barriers are just their own lack of ability to manage the systems. I mean managing the medical system, the health system is actually very complex. So I think the lack of support to navigate the systems is always a problem. With someone [who has] learning disabilities, you can imagine they can't read their appointments or they'll get no prompts about their appointments. They don't know where they're going, they don't know how to get there, there's a whole load of issues…I think that they maybe not realise they're unwell. So that can be a barrier but that's a health inequality issue that stops deprived patients wherever they are in [anon]. Accessibility is still an issue no matter what, so them knowing that they should contact the GP if they believe they're unwell and we have to be a general practice open to that. GP Three: The figure that always used to get mentioned is the reading age for our general population, so never mind our population with known learning issues, would be about nine. So you think about all that stuff around shielding with Covid-19, the letters that came out they were reasonably complicated for me to understand as a highly trained, middle class health professional rather than somebody who's struggling with a mild learning disability, you know. I think it permeates every bit of the health service; it makes you annoyed.*

These views strengthen the need to include features in the application that support patients throughout the entire consultation process. For example, in sections 5.2.3 and 5.2.4, the patients requested features that assist in booking appointments and accessing their practice via public transport. In addition, the GPs also recognised that the app may help patients to attend more appropriate services based on the severity of their symptoms.

Communication

Following on from the Education section, the most experienced GP felt that their communication skills were adequate enough to not warrant support from tablet technologies: *GP One: "I mean do you think that an experienced GP would need that with the consultation skills that they have because we often speak to people with disabilities and difficulty in articulating what they have, they don't have the language to articulate the symptoms. That doesn't actually happen just with people with disabilities actually, sometimes it's quite a common thing, people don't quite know how to describe what their symptoms are."*

Yet, as discussed previously, the less experienced had difficulty performing reasonable adjustments, despite their awareness of the importance of effective communication: *GP Four: "Being really clear with communication, making sure you're communicating directly to the person and giving them the chance and the space to express that [is really important]…Communication can be tricky, just making sure that you're accurately getting to the problem and how it affects them. You need to make sure you're kind of getting that this is not always obvious to us exactly what they're coming [in] about sometimes."* Consequently, the remaining four GPs were in favour of the wide-scale implementation of communication aids, particularly for more challenging patients such as those they are not familiar with.

Time

Time was a significant barrier for medical professionals depending on the location of their practice. GPs from less burdened practices were able to consistently employ double appointments or take longer than their scheduled ten minutes: *GP One: "This [double appointments] is what we were doing for patients who were complex, not just learning difficulties but other issues as well, mental health problems etc. If we felt they needed longer appointments that's what we would give them because there's some very good work done by <anon> if you give GPs more time there's better enabling, better empathetic consultations and there's better outcomes for patients. So that is absolutely key and that's a key argument actually in how we're going to provide services and particularly in deprived communities to address health inequalities and manage conditions. We do need extra time for some patients and it's probably about 10% of* *the patients need that extra support, it's not the entire population in the general practice."*

Nevertheless, GPs who were responsible for a larger cohort of patients had limited opportunity to allocate extra time to individuals with ID: *"GP Three: As a GP, the practice gets about 150 quid per patient per year. It's not a lot. It's very easy for all kinds of interest groups and politicians and whoever to say of course everybody should get as much time as they need. But then the reality is, particularly in a deprived city, you're required to get through between five and ten percent of your practice list every week. Sometimes, you know, with three or four doctors. So, [we] would always choose to give our more vulnerable patients longer but it's not always practical."* The medical professionals in this position were thus advocating for technologies that reduce debilitating time constraints, as discussed in the digital advantages section.

Caregivers

In contrast to the literature [79, 80], all but one of the GPs were positive about the impact caregivers can have on the consultation, by facilitating the appointment and providing a greater depth of information on the health context of the patient: *GP One: "If someone does have a carer that acts as their intermediate, that can be helpful, but you still need to speak to the patient as well. I think during Covid-19 it has been quite interesting because the volunteering sector, community support groups really stepped in where the state was failing and so there are gaps. And we must go back to that I think and find out how can we fund that sector better to keep going for work because obviously it is a gap." GP Four: Also seeking clarification, be that from relatives or you know other people that support them [can be helpful], but also not relying on that all the time."*

GP Five had a more diverse relationship and found many caregivers to be overcontrolling or uninformative. This was due to the dependence on "bank" staff, who were yet to form a connection with the individual with ID: *GP Five: "I think it's entirely variable. It depends on the caregiver; it depends on the relationship they have with the patient as well, if they're quite a controlling caregiver, or how regularly they see them. So in some of our places where we maybe have, like, a lot of staff are bank, so that caregiver might not be the one that sees them the most frequently. And if they* *come into the appointment, you're pretty much just not getting the information that you need adequately. So I just think it's people, some people can be a hindrance when they think they know what's going on and they don't want to let the person talk. Or they tell them to be quiet."*

Nevertheless, primary caregivers were considered to be much more helpful and would often go out their way to provide information on individual patients. Such a process was made easier due to the practice being situated in a rural location: *GP Five: "The caregivers are normally quite a small population here. I think it'd be easy to [get their] input. I think we probably have that benefit to be fair. You know, we have a small community hub. We know who the carers are and I can make one phone call and I guarantee I will get a phone call back today about that specific person. So it probably is a lot easier in a small community."*

Finally, in parallel with the views of the patients in section 5.2.1.4, the GPs were concerned about the availability of paid support: *GP Four: "I think particularly with people with milder learning disability where they're not perhaps always relying on a caregiver or you know they've got a degree of independence and they're able to do a lot of things for themselves, there's a risk that they then become isolated and don't have access when they should because they don't have that support."* It is therefore important to identify other forms of support for such patients, to ensure their medical concerns are recognised and addressed.