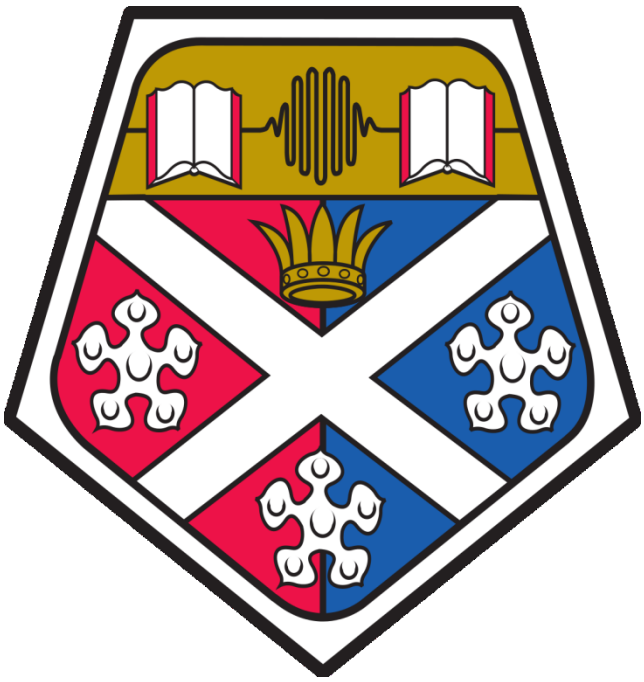

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A Digital Aid to Support Adults with Mild Learning Disabilities during Clinical Consultations

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This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signed:

Date:

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First, I would like to thank the many participants who shared their views throughout this thesis. Without the range of knowledge and expertise held by these professionals, it would not have been possible to develop a specialised interface that has the potential to address the complex needs of adults who have mild learning disabilities.

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Abstract

Some of the factors that explain poor health outcomes for people with learning disabilities (LDs) include multi-morbidity and underdiagnosed health conditions. Previous studies have suggested that this population face significant communication barriers when interacting with health professionals and this is a major contributing factor to such diagnosis complications. Consequently, such health barriers are often preventable. However, there is a surprising lack of research-based technologies available that intend to promote this communication. We aim to address this gap by investigating the potential of using mobile technologies to support adults with mild LDs during clinical consultations. To achieve this, we interviewed a number of domain experts including government advisors, academics, support workers and General Practitioners. We then developed a technology probe to inform the information extracted and subsequently created a set of design guidelines for the development of Augmentative and Communicative technologies that target the clinical needs of adults with mild LDs.

Table of Contents

List of Tables

List of Figures

Acronyms

AAC – Augmentative and Alternative Communication

AMD - Age-related Macular Degeneration

ASD – Autism Spectrum Disorder

CHD - Coronary Heart Disease

COPD - Chronic Obstructive Pulmonary Disease

DS – Down's syndrome

DVT – Deep Vein Thrombosis

GORD - Gastro-Oesophageal Reflux Disease

GP – General Practitioner

IBD - Irritable Bowel Disease

IBS – Irritable Bowel Syndrome

LD – Learning Disability

MLD – Mild Learning Disability

MRC – Medical Research Council

PCP – Personal Communication Passport

PECS – Picture Exchange Communication System

PVD - Posterior Vitreous Detachment

RSI – Repetitive Strain Injuries

SGD – Speech Generating Device

STI – Sexually Transmitted Infection

VOCA – Vice Output Communication Aid

Chapter 1

Introduction

Latterly, there has been an increase in focus towards improving the quality of life of those who have learning disabilities (LDs), by both the UK and Scottish Governments [1-2]. For example, a number of policies have been introduced (such as expanding the number of patients eligible to receive a learning disability annual health check [3]) that have serious health benefits for the learning disability population. However, the overall standard of care being provided to these patients is still far from adequate considering men who have learning disabilities within the UK have up to a 13-year lower life expectancy than that of the general population, with this figure rising to 20 for women [3]. Such a wide discrepancy may be observed throughout the developed world [117], thus highlighting the need to address the standard of care being provided to the learning disability population.

Many of the health inequalities faced are potentially avoidable, and thus addressing these may improve the overall health of such patients. Some of these barriers include: difficulties in identifying the need for and accessing health care services; care-givers acting as intermediaries between staff and patients; health care professionals lacking the skills required to effectively manage the health needs of patients with learning disabilities; inadequate facilities; and inappropriate and inflexible processes or procedures [4-5].

Nonetheless, the most widely cited reason for ineffective healthcare is the breakdown in communication between professionals and patients. Howells suggests that the "art of general practice lies in the ability to communicate with patients" [6]. However, adults with learning disabilities tend to have sub-par languages skills and/or deficits in their abstract thinking [7], and this has an adverse effect on their ability to convey or identify symptoms that may be relevant in the formation of a diagnosis. This may significantly hinder the flow of information between the General Practitioner (GP) and the patient and therefore cause serious strain on the 10/20 minutes afforded to such consultations. Furthermore, GPs tend not to possess the knowledge required to

overcome communicative barriers [4], meaning there is significant scope within the field to explore how digital technologies may be used to aid this process.

1.1 Related Work

As highlighted in the upcoming scoping review, little research has been conducted into how digital technologies may assist patients with learning disabilities during clinical consultations. However, some similar innovative practices intend to overcome such barriers.

Firstly, Jones and Kerr [8] developed a notes-based clinical aid to be used by General Practitioners when consulting with patients who have learning disabilities. Essentially, the aid aims to provide GPs with vital advice on how to carry out consultations with this population, before listing common conditions that tend to be overshadowed throughout. The general idea was to increase the knowledge held by health professionals on both the communication and health needs of those who have learning disabilities, to ensure consultations are more fruitful. However, an evaluation of the aid concluded that it had limited impact on the consultation process, with the preference to use a digital aid, as well as the limited time on offer to explore screening options, highlighted as key reasons for the lack of success.

Aids have also been developed that aim to provide information on a more personal basis. For example, Brodrick et al. introduced a novel version of the Personal Communication Passport (PCP) into Macclesfield District General Hospital [9]. The passport consisted of a single page of information that aims to supply hospital staff with crucial guidance on how best to care for an individual with learning disabilities. The patient's medical information, communication needs, support needs, and environmental requirements are captured by the staff and subsequently arranged in order of importance. However, the success of the passports relied heavily on the accuracy and depth of information being provided, and this was proven to be extremely varied without continuous access to effective training resources.

The idea of segregated care has also been explored in the past [10]. Specialised walk-in clinics were trialled within two hospitals in the north of Scotland, where the services of a learning disability nurse were provided on an on-demand basis. Participants with

learning disabilities were encouraged to attend to receive a general health check or advice on a specific problem. Results from the study suggested that patients were able to discuss their health needs in greater depth due to the absence of time restrictions and the expertise of staff. Furthermore, the nurse was able to assist the patients in overcoming multiple conditions, thus reducing the strain placed on traditional health care services. Despite the benefits on hand, recent policy emphasises the need for people with learning disabilities to access mainstream practices [1-3], meaning segregated services are unlikely to be promoted in the future [5].

1.2 Research Gap

Each of the potential interventions listed in section 1.1 have one common drawback; they are not implemented on a national scale. A variety of reasons has contributed to this including: inappropriateness; ease of use; time constraints; lack of appropriate training facilities; and cost. Common technologies, such as Augmentative and Alternative Communication (AAC) devices, have the potential to overcome a number of these issues. However, as described in Chapter 2 they tend not to be based on evidence but rather on the opinions of developers, and are built for everyday use meaning they may not be suitable within the clinical environment. Consequently, there is clear scope to implement a device that intends to overcome the communication challenges that exist between patients with mild learning disabilities (MLDs) and GPs, but one that may also be adopted on a national scale. Helmsley and Balandin have recognised that the standard of care being provided to those with communication impairments has failed to improve of the years despite recommendations being made to overcome this issue [133]. The aid described in this thesis aims to change this and will target the needs of adults with mild learning disabilities on the assumption that they will benefit most from such a service.

1.3 Research Questions

Adults with mild learning disabilities face a variety of communication difficulties throughout consultations that hinder their ability to effectively describe the conditions they may be experiencing. These include a restricted knowledge of the human body, an inability to perceive that an illness may have a number of causes and symptoms,

limitations in their abstract thinking and long-term memory, and sub-par language skills, which may also affect their ability to understand any information being conveyed by the physician [7, 11]. In order to develop an aid that is successful in overcoming these issues, a number of research questions must be addressed.

Firstly, the current technologies used to assist adults with learning disabilities during clinical consultations must be identified. This includes those that are used to aid stakeholders' in general day-to-day activities but may also be of use during specialist activities such as attending a doctor's appointment. As a result, the strengths and weaknesses of such devices may be used to develop a technology probe [118] of the proposed intervention. Therefore, the first research question intended to be solved is as follows:

Research Question 1: What current technologies are used to support adults with mild learning disabilities during clinical consultations?

To ensure that previous interventions are taken into consideration when developing a probe of the proposed application, this question has been broken into two further sub-questions:

Research Question 1.1: How do current technologies succeed in supporting adults with mild learning disabilities during clinical consultations?

Research Question 1.2: How may these technologies be improved upon to further support adults with mild learning disabilities during clinical consultations?

The information obtained by solving the first set of research questions may only partly contribute to the requirements of a digital aid used to support adults with learning disabilities during consultations. Therefore, another primary objective of this thesis is to establish the key requirements of a tablet application to support stakeholders in overcoming the communicative issues:

Research Question 2: What are the requirements for a tablet application that assists adults with mild learning disabilities during clinical consultations?

Once again, this question may be broken down into two further sub-questions, to ensure the needs of all stakeholders involved in the consultation process are met:

Research Question 2.1: What features do adults with mild learning disabilities require in a tablet application that aims to support them during clinical consultations?

Research Question 2.2: What features do General Practitioners require in an application used to support consultations involving adults who have mild learning disabilities?

The research carried out within this thesis is highly significant since it lays the groundwork for developing digital aids that address the complex needs of adults with MLDs in the medical environment. The results obtained whilst answering the proposed research questions will contribute to this greatly.

1.4 Research Contributions

This research makes several contributions:

- Firstly, a scoping review has been carried out that identifies the current technologies used to support adults with mild learning disabilities during the consultation process. This further highlights the need to develop a suitable aid before discussing the many features that help or hinder these technologies in achieving their goals.
- A series of steps to follow during the co-development of AAC technologies aimed at adults with mild learning disabilities have been identified.
- Initial requirements for an application that aids consultations involving adults with mild learning disabilities have been extracted from GPs.
- Additionally, the requirements of patients with mild learning disabilities have been identified for the proposed application. This was achieved by interviewing learning disability experts.
- A set of design guidelines for the development of clinical AAC technologies targeting the needs of adults with MLDs have been proposed using the aforementioned requirements.

1.5 Thesis Overview

In the next chapter, a scoping review of the existing technologies used to support adults with mild learning disabilities is presented. This provides the reader with an idea of the various challenges that materialise throughout the consultation process, and how existing technologies fail to address such issues. A discussion on various other aspects such as the communication modalities used by patients with learning disabilities and the attitudes held by health care staff towards the LD population will also be presented. Chapter 3 outlines and justifies the methodology used to design the proposed intervention. Chapter 4 provides the various requirements for the intervention that were extracted throughout the course of this research - primarily through a series of semi-structured interviews conducted with experts in learning disabilities. Chapter 5 addresses how these requirements were used to design a specialised interface that accommodates for the complex needs of adults who have mild learning disabilities. A series of user evaluation studies conducted with further learning disability experts will be presented in Chapter 6. This enabled key design flaws to be identified and subsequently addressed before the probe is presented to its intended stakeholders. Chapter 7 provides a discussion on the research conducted and presents future opportunities to build upon this research. Finally, Chapter 8 concludes with a summary of the research carried out.

Chapter 2

Scoping Review

As of July 2016, no high-quality scoping reviews were available on the technologies used by patients with mild learning disabilities during clinical consultations. Instead, reviews tended to focus on how AAC devices are being used in general day-to-day activities [12-13]. Consequently, the author conducted a scoping review in order to detail the communicative challenges present during consultations and the technologies used to alleviate such issues. The methods used to achieve this, along with the results obtained, will subsequently be presented.

2.1 Introduction

People with learning disabilities generally require a higher level of care than that of the general population, due to their poorer health [4]. Despite this, General Practitioners find it difficult to address the health care needs of this population. These difficulties may include a lack of experience in working with people who have LDs, concern over their competence for examining such patients; the time constraints present, and ability to overcome the resistance of some patients to diagnostic, preventive, or therapeutic procedures [14].

However, as introduced in chapter 1, the main challenge GPs must overcome when providing effective healthcare is communication [14-15]. Practitioners rely heavily on their ability to extract accurate information from their patients; however, those with LDs may find it challenging to express themselves and thus find it difficult to explain their symptoms accurately. Furthermore, they tend to have restrictions in their knowledge of the human body and this may hinder their ability to recognise when such conditions transpire [5]. With the time constraints [16] already placed on consultations, GPs may find it difficult to overcome these communication/knowledge barriers and could benefit greatly from the support of digital aids.

Recommendations to improve the health care services of people with learning disabilities have previously focused on enhancing the knowledge staff, rather than working directly with patients to extract and implement their views [17]. However,

recent legislation such as "The Keys to Life" [2] promotes the need for the co-development of future interventions. As a result, you would expect more appropriate health resources being developed for those who have LDs. This review intends to explore whether this is true by identifying the current technologies/modalities used to extract medical information from adults with mild learning disabilities.

2.2 Background

Effective communication is particularly important in the clinical setting since exchanges between the patient and General Practitioner are vital to producing an accurate diagnosis. However, patients with learning disabilities are generally affected by communication difficulties. As a result, they are largely recommended augmentative and alternative communication (AAC) systems to assist them in generating comprehensible dialect [18]. AAC systems are designed specifically to complement the person's 'natural' communication modalities, such as facial expressions, when producing speech [18].

The needs of people with communication difficulties can vary widely. Some may be unable to use speech in order to express their views, and thus rely on alternative devices as a means of communication [19]. Others may possess the ability to use speech but may have problems expressing their views in an intelligible manner. Such users require an augmentative device in order to enhance and support the language skills they currently possess [19].

A diverse range of both alternative and augmentative communication technology is readily available, due to the unique requirements of those who have a disability. These technologies may be categorised as either aided or unaided. Unaided communication systems do not require any instruments external to the body and instead usually involve gestures such as signing [20]. Aided communication systems on the other hand use external devices and typically involve objects such as photographs and symbols [20]. An overview of the AAC systems used in the papers reviewed can be found in 2.4.4.3.

Low technological and high technological aided AAC devices are available depending on the needs of the individual. Low-tech devices do not require a battery to operate and can include approaches such as communication booklets that make use of symbols,

photographs and simple phrases. In contrast, high-tech devices require electricity to operate and typically involve the production of artificial speech. Both sets of devices may vary in terms of their complexity, portability, input method, output method, and vocabulary representation format [19].

Traditionally, AAC devices were dedicated i.e. their sole objective was to supply a means of communication for those who struggle to do so unassisted [19]. Presently, there is a trend developing where AAC technology is being embedded into systems that have multiple purposes such as mobile phones, laptops and tablets. The advantages and disadvantages of following this approach will be discussed in section 2.4.4.4. With so many different options available to those who require augmentative and alternative communication, great care must be taken when selecting an appropriate device for the user. The necessities and characteristics of the individual must be fully considered in order to ensure the selection of an AAC device that is most suited to their needs [19, 21]. For example, those who have poor fine-motor skills may require the use of eye-gaze technology in order to operate a device. The views of knowledgeable professionals, family members, and ultimately the end user should be considered when selecting such a device [22].

2.3 Method

The author carried out a systematic scoping review between the months of July and December 2016, to identify the current communication technologies and models used to extract medical information from patients with mild learning disabilities. This section describes the methodology used to identify the relevant literature included.

2.3.1 Review Question and Scope

The initial review question was "What technologies can be used to support communication between patients with mild learning disabilities and doctors during a medical consultation?" This area of research is in its infancy meaning a lack of relevant studies were identified. Therefore, the original review question was split into two sub questions: "What technologies can be used to support communication for people with mild learning disabilities?" and "What technologies can be used to support

communication during a medical consultation?" This enabled a broad range of strategies that may aid in the consultation process to be included in the review.

The diagnosis of "learning disability" may be applied to a patient if they satisfy the following three criteria [23]:

(1) The patient has an impairment of intellectual functioning;
(2) The patient has an impairment of adaptive/social functioning;
(3) The aforementioned symptoms occur before adulthood i.e. before 18. This therefore excludes conditions such as dementia, since they primarily develop in the latter stage of one's life.

There are several categories of learning disabilities ranging from mild to severe. Those who have mild or moderate learning disabilities can convey most of their needs, but have trouble understanding abstract or complex ideas. In contrast, people who have severe or profound learning disabilities have limited communication skills and tend to use basic words or gestures to get across their needs [23]. This review focuses on those with mild or moderate learning difficulties on the basis that this population will benefit more from potential aids developed in the future. An in-depth description of the potential characteristics of an individual with mild learning disabilities may be found in section 5.2.

2.3.2 Inclusion / Exclusion Criteria

Articles were included in the review if they adhered to the following criteria:

(1) Participants were primarily individuals with some sort of mild or moderate learning disability;
(2) The article discussed the communication technologies/modalities used by people who have learning disabilities;
(3) The article included examples of technology that may be used in the general consultation process;
(4) The article was published in the English language.

In addition, articles were included in the review if they:

(5) Discussed the communication challenges that occur between physicians and people with learning disabilities;
(6) Reviewed current guidelines on HCI for people with cognitive disabilities;
(7) Discussed Guidelines on Web Accessibility; and
(8) Discussed the inclusion of people who have learning disabilities in the development of guidelines/aids.

Articles that primarily discussed the following were excluded from the review:

(1) Individuals who mainly have severe or profound learning disabilities;
(2) Individuals who have conditions that develop in adulthood such as dementia;
(3) The medical conditions rather than the modalities/technologies used;
(4) Physical conditions rather than cognitive;
(5) Telemonitoring;
(6) Platform architectures such as workstations.

In addition, articles that were deemed to be lacking in quality were also excluded from the review. To assess the quality of the literature, the author used the following criteria:

(1) Were the research questions / goals of the study clearly defined?
(2) Were the research methods used appropriate and clearly described? Do they assist in answering point 1?
(3) Has the study included an evaluation of the methods / technologies used?
(4) Have the authors discussed the limitations of the research conducted?

The number of participants included within a study may also contribute to the quality of the research being conducted. However, since adults with mild learning disabilities are typically a hard to reach population (in comparison to undergraduate students for example), this was not regarded as being a primary factor when judging the quality of a paper. Instead, the methods being used and the evaluation process that occurred was deemed to be more important.

2.3.3 Search Strategy

The identification of relevant literature adhering to the inclusion criteria consisted of three distinct stages. Firstly, two searches were conducted on PubMed (www.pubmed.com, 292 results in total) to ensure relevant studies from the health domain were included. The second stage involved performing two searches on the Association for Computing Machinery Digital Library (http://dl.acm.org/, 191 results in total). This ensured that relevant literature from the technology domain were also included in the review. All search results had their abstracts screened in order to identify potentially relevant papers. Those that were deemed potentially relevant were then read in their entirety to confirm that they adhered to the inclusion/exclusion criteria and could be included in the review.

During stage three, eight Google Scholar (www.sholar.google.com) searches were carried out in order to identify literature omitted during the previous two rounds. The first 100 articles identified within each search were screened by title to ensure irrelevant papers were excluded at a glance. The results returned by Google Scholar were deemed less relevant than those identified by ACM and Pubmed, meaning it was important to reduce the amount of time spent reviewing irrelevant articles. From the searches listed in table 1, 143 papers were deemed potentially relevant after having their titles analysed. These papers had their abstracts and content scrutinised in the same manner as those returned by the ACM and PubMed Searches. The search strategy used was modelled around that discussed by op den Akker et al. [24].

A list of all search terms used in each stage may be found in Table 1. These consisted of mesh terms relating to the environment, populations and technologies affected by the research questions proposed meaning terms consisting of participatory or user-cantered design were omitted.

Table 1: Search queries & search terms

Database	Search Query or Search Terms
PubMed	**Query 1:** ("communication"[MeSH Terms] OR "communication"[All Fields]) AND mild[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]) **Query 2:** ("communication"[MeSH Terms] OR "communication"[All Fields]) AND ("technology"[MeSH Terms] OR "technology"[All Fields]) AND mild[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])
ACM Digital Library	**Library Query 1:** ("communication") AND ("learning" AND "disabilities") AND ("medical" AND "consultation") **Query 2:** ("Human Computer Interaction" OR "HCI") AND (("learning" AND "disabilities") OR ("medical" AND "consultation"))
Google Scholar	("Technology" AND "consultation") OR ("communication" AND "learning" AND "disabilities") OR (("Visual support " AND "consultation") AND (("learning" AND "disabilities")) OR ("Talking Mats" AND ("learning" AND "disabilities")) OR (("Augmentative" OR "Alternative") AND " Communication")) OR (("Human Computer Interaction" OR "HCI") AND (("learning" OR "cognitive) AND "disabilities")

2.3.4 Thematic Analysis

The search strategy presented in section 2.3.3 identified a number of papers adhering to the inclusion criteria. A thematic analysis of this literature was carried out to determine the characteristics, strengths and limitations of the technology used to extract information from people who have learning disabilities. Thematic analysis is a method of qualitative synthesis that involves the identification of key and recurring themes and concepts from a body of literature [14]. This analysis enables priori concerns to be addressed but ensures that any results produced are significantly shaped

by the data being scrutinised. Eight key themes were identified, and the nature of these themes will be discussed in the results section.

2.4 Results

This section discusses the process of analysing the relevant literature returned by the search strategy described in section 2.3.3. Figures relating to the communication models covered by the relevant papers along with the population involved in the studies conducted are presented. In addition, the results of the thematic analysis conducted will be discussed.

2.4.1 Articles Screened

Of the initial 626 articles that had their abstracts analysed, 532 were excluded from the review. 205 of the excluded articles failed to address the communication modalities or technologies used by people who have learning disabilities. They also failed to address the challenges that arise during consultations involving the target population. 226 studies addressed the wrong population and 83 were omitted due to discussing medical conditions. 14 papers were excluded due to duplication and a further 4 focused on telemonitoring or workstations.

Additionally, 33 potentially relevant articles that had been read in their entirety were also omitted. 22 were judged to be poor quality and consisted of posters for conferences or short overviews of projects. 7 papers involved studies that primarily consisted of participants who had severe and profound learning disabilities and a further 4 studies focused on those who have physical disabilities. A total of 61 articles from the original 626 screened (9.74%) were deemed relevant and were included in the review. A flow chart of the selection process can be found in Figure 1. Of these papers, 4 were published in the 1990s (6.56%), 32 were published in the 2000s (52.46%) and 25 were published in the 2010s (40.98%), thus depicting an increase in focus towards the LD population since the turn of the millennium.

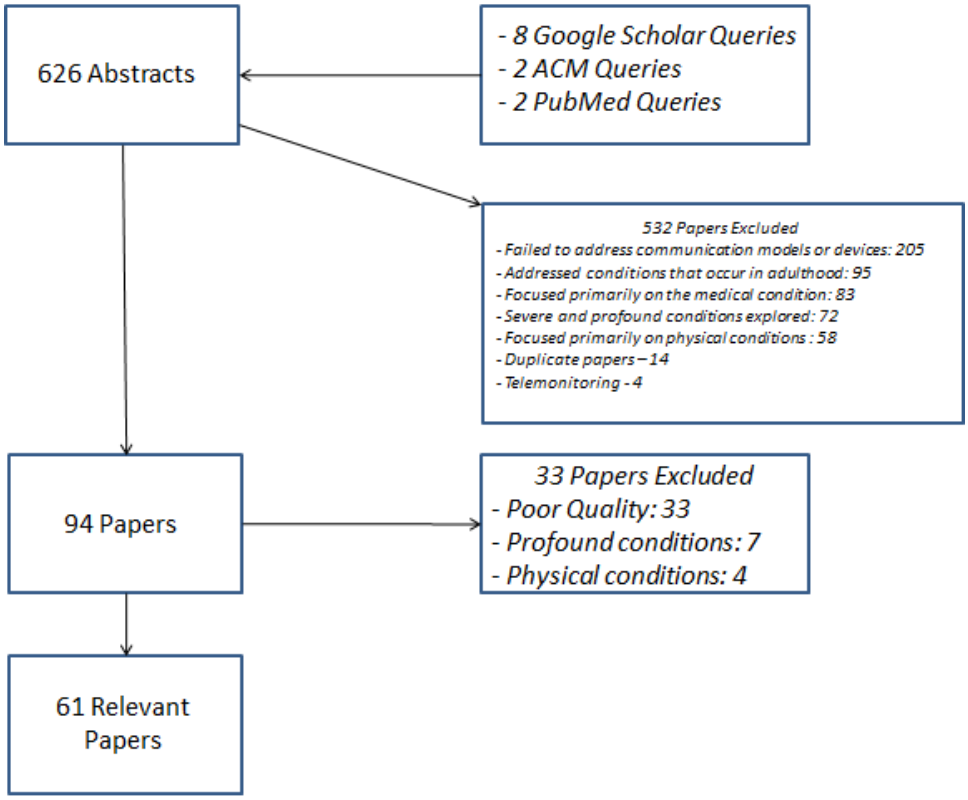


Figure 1: Scoping Review Flow Chart

2.4.2 Communication Models

The relevant papers included in the review covered a wide range of communication models and devices. The bulk of the literature focused on using symbols/objects of reference not related to a specific communication model (19.67%). 10 further papers reviewed the use of mobile technology and AAC applications by those who have cognitive impairments (16.39%). 7 articles included reviews on HCI for the cognitively impaired but did not involve mobile devices or applications (11.45%). 7 articles used Talking Mats, or adaptations of, to extract information from subjects. A further 7 papers focused on the inclusion of people with learning disabilities, including the barriers and facilitators to effective health care. 4 articles concentrated on the Picture Exchange Communication System. 3 conducted general AAC device reviews (4.92%). 3 papers focused on Voice Output Communication Aids/Speech Generating Devices (4.92%). 2 papers addressed general ICT and desktop reviews (3.28%). Personal Communication Passports, or adaptations of, were used in 2 papers (3.28%). A further 2 papers focused on the use of tangibles. 1 paper used video review sessions

to extract the views of people with learning disabilities (1.64%) and 1 paper focused on using a questionnaire to extract views on psychological health.

2.4.3 Population

From the 61 relevant articles, 29 contained reviews of technology or communication models and involved no original experimentation (47.54%). The remaining 32 papers carried out studies that involved 1498 participants. Of these people, 864 were professionals, carers or family members (57.68%); 191 people have unspecified learning disabilities (12.75%); 166 participants have Autism Spectrum Disorders (11.08%); 159 people have unspecified mild/moderate/borderline learning disabilities (10.61%); 88 have cerebral palsy (5.87%); 24 have aphasia (1.60%); 2 have downs syndrome and unspecified severe learning disabilities (0.13%); and 1 participant each have foetal alcohol syndrome and hydrocephalus (0.07%).

2.4.4 Thematic Analysis

Overall, eight individual themes were identified during the thematic analysis process. An overview of the themes can be found in table 2. A more in-depth overview of each theme may be found in Appendix A.

Table 2: Overview of Identified Themes

Theme	Summary	Citations
Communication Challenges	This theme identifies the communication challenges experienced by those have learning disabilities, focusing on those that have an adverse effect on the consultation process.	10 studies were identified which included communication challenges that may affect consultations [4, 12-13, 19, 21, 27-28, 32, 33, 35]
Communication Modalities	This theme identifies the different modalities people with learning disabilities use to communicate including speech, gestures, pictures and eye	24 studies included discussions on different modalities and the benefits and disadvantages of each

	gazing. The advantages and disadvantages of each are discussed.	[19-21, 32-33, 37-42, 45, 47-58]
Communication Aids	This theme identifies the various communication aids reviewed including their advantages and disadvantages. The suitability of using each aid within the medical domain is also discussed.	24 studies reviewed specific aids or features of certain aids such as symbols etc. [9, 20-22, 35, 37-42, 47-49, 55, 58-59, 62-67]
Barriers to Technology / Accessibility	This theme identifies the barriers to effective AAC use including those prevalent in AAC applications on mobile phones and tablets. The accessibility issues of the Web are also addressed.	13 studies addressed traditional AAC devices, AAC applications, or web accessibility barriers [12-13, 18-19, 21, 33, 45, 56-57, 66, 69-71]
Professionals' Attitude	This theme addresses professionals' attitudes towards people who have learning disabilities including any stigmas that they may hold.	9 studies discussed issues relating to professionals' attitudes towards people with learning disabilities [12-13, 19, 28, 36, 38, 47, 66, 75]
Individualisation	This theme recognises the need for individualised communication aids due to the heterogeneous nature of people with learning disabilities. It also discusses the need to tailor Web pages to suit each user's needs.	9 studies recognised the need for AAC devices and Web pages to be tailored to suit the needs of their users [18, 21-22, 33, 39, 45, 53, 76-77]
Co-Design	This theme addresses the need to include people who have	9 studies discussed the inclusive design process

	learning disabilities throughout the lifecycle of a system.	[18, 22, 34, 56, 69-70, 76, 78, 82]
Evaluation	This theme discusses the various evaluation techniques used in the studies reviewed.	30 studies involved some sort of evaluation [4, 17, 19, 26, 28, 31, 33-38, 40-42, 45-46, 51, 53, 55, 66, 74-75, 77, 81, 85-87, 89, 115]

2.4.4.1 Communication Challenges

A variety of communication challenges that affect people who have learning disabilities were identified, and a great deal of these may influence the consultation process. First of all, people with learning disabilities are heterogeneous in nature. Disabilities such as Autism Spectrum Disorders (ASDs) have a range of manifestations that may or may not include additional impairments [26]. As a result, these people may share some symptoms, but may differ in terms of the severity and number of symptoms present [27]. This requires the physician to have a great deal of knowledge about learning disabilities, in order to adapt to the individual needs of the patient. However, physicians tend to lack the skills required to communicate effectively with patients who have LDs, meaning their conditions may remain unidentified [28].

The willingness of people with learning disabilities to communicate and their abilities to do so can also vary dramatically. For example, people with ASDs tend to be self-absorbent and refrain from initiating conversations, whereas people who have Down's syndrome (DS) are generally highly motivated to communicate with others [29]. Those who are unwilling to engage with practitioner will present additional challenges to extracting accurate medical information [4].

People with learning disabilities may be entirely non-verbal and take advantage of AAC devices to communicate. As a result, GPs will have to accommodate for each individual device and these may require specialised knowledge, which the physician does not possess, in order to operate. Additionally, AAC devices require large

amounts of time to produce the views of the user [12-13, 21] and this is not ideal considering the short amount of time allocated to consultations. Staff may therefore rush these consultations and fail to provide the patient with a high level of care. Most AAC technologies are built for everyday use and may not contain the language required to describe medical symptoms. This causes severe problems for the physician, as they will have to develop another strategy to extract the information required to make an accurate diagnosis.

The majority of people with learning disabilities tend to develop some speech and language skills but not to an average level of ability, with the Royal College of Speech and Language Therapists reporting that up to 90% of the population have issues with communication [30]. Furthermore, the progress of development is also generally skewed, where the person may build a strong vocabulary in areas of interest but fail to grasp basic concepts in other areas [31]. Due to their sub-par language skills, people with learning disabilities may fail to describe symptoms accurately thus leading to an erroneous diagnosis [29].

The target population also have trouble in understanding information being presented to them. They tend to have issues in understanding language that is overly complex or is presented too quickly. They also require more time to deliberate what was said before constructing an appropriate response [29]. Patterns such as the use of rigid language (using phrases that have no meaning or that seem to be out of context) may help in identifying the patient's lack of understanding.

To overcome these problems, physicians must find a way to break the consultation into small, manageable chunks and avoid using complex medical terms that may confuse the patient. They must also find the time to allow the patients to consider fully the information being presented. However, this may be difficult to achieve based on the length of time currently afforded to consultations and may be the motivation behind GMCs proposal to extend consultations involving patients who have learning disabilities [16]. These patients also tend to have poor non-verbal communication skills and may not recognise or understand information presented via body language or facial expressions. Physicians should ensure that all information is shared directly in a clear format and not via the use of secondary cues such as body language.

Not all people with learning disabilities will respond to information presented to them via the use of speech. In these cases, physicians will be required to present information in other formats such as pictures or text [19, 32-35]. This may be time consuming especially when no existing resources are available for use. Information presented on prescriptions, packaging etc. should also be presented in a variety of ways to aid in comprehension. This introduces the problems associated with conveying information via the use of imagery, which will be discussed further in section 2.4.4.2

The aforementioned challenges contribute to a plethora of obstacles that the physician must overcome. Inadequate communication may result in a wrong diagnosis occurring or unsuitable medication being administered, and this may potentially be life threatening [36]. Communication challenges may also affect the accuracy of a patient's medical history and this can have negative connotations during future consultations [28]. The main solutions to overcoming communication barriers are for the physician to increase their knowledge on learning disabilities, [28] and to increase consultation times in order to extract clear and reliable symptoms from the patient.

2.4.4.2 Communication Modalities

Speech

Due to their heterogeneous nature, people with learning disabilities can have a wide range of verbal communications skills. Some may only be able to use short utterances to request attention; however, others utilise an extensive vocabulary in order to construct complex sentences. This may produce a variety of problems during the consultation process and these issues were discussed in section 2.4.4.1. Several studies revealed that those who have learning difficulties tend to rely on speech even when using alternative forms of communication [37-40]. This suggests that the participants have become frustrated whilst utilising AAC technologies and have reverted to traditional forms of communication.

Despite this, studies have shown that the use of alternative forms of communication can develop speech. By using the Picture Exchange Communication System (PECS), people with Autism Spectrum Disorders were revealed to increase their use of spontaneous speech dramatically [41]. Others were also shown to increase both the

accuracy and length of their answers when provided with aids such as pictures [42]. Speech Generating Devices (SGD) offer people with learning disabilities the ability to produce artificial speech at the touch of a button, thus enabling them to make their needs known to unfamiliar communication partners. Therefore, the continued use of alternative forms of communication may benefit people with learning disabilities. An example of a simple SGD may be found in figure 2.

Figure 2: An example of a simple Speech Generating Device

Much of the content on the Web is represented by text and many people with learning disabilities have difficulty in understanding such language. UNESCO found data pertaining to the literacy rate of those who have learning disabilities to be scarce; however, a case study conducted in Uganda enabled such rates to be compared to the general population [43]. They found that around 40% of young people with no physical or cognitive impairments are illiterate compared to 62% of those who have mental disabilities. These figures may differ in more developed countries, but they reveal that text may not be solely relied upon to convey information to adults with MLDs.

As a result, many Web users require a text-to-speech synthesiser (screen readers) that converts text into audio [24]. However, there are several barriers to the use of such technology. Firstly, dynamic web content may not be appropriately addressed by the device due to a number of reasons including lack of support, and stakeholder preference to suppress screen updates. This may result in users accessing out of date information. The content within pages may also be inaccessible for such devices, thus

preventing stakeholders from benefiting from their use. For example, Flash objects rely on alternative text to ensure those who require screen readers understand their purpose. Web developers however, may fail to include such features or make use of non-descriptive text to convey their meaning [44]. Additionally, support for the device may not be offered depending on the browser being used [45]. Such software is often complex and difficulty to use for those who have learning difficulties making them a less than perfect solution [33].

Gestures

Communicating via the use of gestures can range from simple acts of pointing to complex uses of sign language [46]. Facial expressions and body language are the most natural forms of communication and may enable non-verbal users to make their needs known. For example, a person may nod their head and smile when enjoying an activity [47]. Others may resort to aggression or self-harm to express their frustrations or to request an object. Paying particular attention to a person's body language may provide cues to their needs or overall mood.

Pointing is a particularly powerful form of communicating one's needs and can accommodate for a number of disabilities. For example, adults who have significant motor impairments may make use of eye-gazing software to ensure they are able operate technologies effectively [48]. This is particularly relevant since there is evidence to suggest that a large number of adults with learning disabilities are affected by poor motor coordination [20]. People who are not able to share their needs via speech can simply point to an object they desire, and the communication partner can respond appropriately. This requires less physical effort than other communication methods such as signing [20] and does not necessitate the need for the partner to understand the language used in order to respond.

The most complex form of communication via the use of gestures is signing. Signing combines gestures, facial expressions, and body language to provide a means of communication for those unable to use speech and is primarily employed by people who have hearing impairments. Sign languages are not universal and can even differ

within the same country. As a result, people with learning disabilities may not be able to understand partners due to subtle differences in the language used.

Several studies have suggested that the use of manual signing, in conjunction with speech, results in faster and more complete receptive/expressive vocabulary acquisition than speech alone [20]. However, this is not true for the entire LD population and one factor that appears to be related to the effectiveness of manual signing is fine motor ability [20]. On top of this, people with learning disabilities tend to have poor memories and have trouble learning new skills. These factors may account for Layton and Watson's view that "even after intensive training with signs, a significant number of nonverbal children continue to be mute and acquire only a few useful signs" [20]. Hence, it may only be beneficial to teach stakeholders a limited number of simple signs such as eat and drink. They may also require further aided communication techniques to be effective in conveying their needs.

Pictures

Pictures have been proven particularly effective in aiding communication for those who have learning difficulties. First of all, pictures assist in processing the concepts that are to be considered [19, 32, 48-51]. People with learning disabilities tend to have complications in reading and processing text and speech, particularly when complex vocabulary is used. However, pictures provide an alternative means of representing this language in a fathomable manner, providing the illustrations directly represent the concepts being symbolised. Illustrations that are not immediately identifiable will further hinder the individual's comprehension of the information conveyed [52-53]. Symbols also provide a concrete representation that speech cannot. As described previously, people with learning disabilities may have difficulty in retaining information and therefore may struggle to remember what was being said to them [49]. Pictures on the other hand provide a physical referent that the person can allude to when required.

Pictures also provide an alternative approach to answering questions, either by selecting symbols that directly represent a concept or by placing images into certain categories. Personal photographs are especially fruitful with Cambridge et al.

describing them as the most effective resource used to elicit views. Participants have been shown to enjoy conversations relating to personal photographs [54], and this has led to an increase in the accuracy and depth of answers provided [55]. Young et al. were particularly impressed with the views provided by people with learning disabilities when using personal photographs and have called for the development of this form of consultation [54].

On the downside, conversations may be limited to the symbols that are available thus potentially restricting the answers provided by the individual [40]. Systems that use large amounts of images may become confusing or unmanageable and may result in the user resorting to their traditional form of communication [40]. That being said Poulson and Colette estimate that half of the population could benefit from symbols or symbol-related text [33]. This is particularly true in the clinical context where the vocabulary used is notably complex, even for the general population.

Eye Gazing

Eye gazing is a developing form of communication that is primarily used by people who have poor fine motor abilities. Those who have impaired fine motor skills may be unable to use their hands to point, swipe, pinch or carry out signs successfully, and can become tired quickly when carrying out such actions [20, 56-58]. In order to accommodate for their impairment, these people may be able to use their eyes in order to communicate.

The most basic form of eye gazing requires no technology and simply involves the person looking at objects to bring attention to them. Developing forms involve using cameras that are attached to a screen to track the eyes of the user. Software then determines where the user is looking at in order to select the options located on that area of the screen. Eye gazing software enables people with learning disabilities to select and navigate through options contained within an AAC device, simply by looking at the answer in which they wish to select. They may then take advantage of the benefits provided by AAC devices, even if they do not possess the fine motor skills required to use them. Bradshaw has called for the future development of eye gazing

technology and the need to make it more accessible for people who have disabilities [21].

2.4.4.3 Communication Aids

Talking Mats™

A variety of communication models that aid in extracting the views of people with learning disabilities were reviewed. By far the most frequently scrutinised low-tech communication model was Talking Mats™ [37, 48-49, 59-62]. The Talking Mats™ framework consists of an inexpensive, textured mat 60 × 30 cm in size and a series of picture symbols with Velcro™ attached to the back [48-49]. The symbols are normally split into three sets with the first set being composed of images relating to the topic being investigated, for example activities or relationships. The second set is comprised of potential options relating to these topics, for example music or friends, and the final set is comprised of a visual scale that enables each user to express their general feelings about these options [48-49].

Once a topic has been agreed upon, the participant is given each option separately before being asked a question, for example "How do you feel about….?". The participant must then place this symbol under the relevant section of the visual scale located on the mat. There are no constraints on the time afforded for the individual to respond, and they may change the position of symbols to ensure the mat symbolises their views. Once completed, a digital photograph of the mat can be taken to provide a permanent record of the participant's views. One topic is chosen per mat and "sub-mats" can be used to examine options in more detail if required [48].

By using images extensively, Talking Mats™ takes advantage of the benefits described in section 2.4.4.2. On top of this, the Talking Mats™ framework has also been proven to provide its users with a means of expressing views in which they would have had difficulty doing otherwise [49, 59, 62]. This is particularly useful during consultations, since people with learning difficulties may encounter problems whilst trying to describe their symptoms. The Talking Mats™ framework also aids in the comprehension of a task by dividing the strands of issues into manageable chunks [48]. An example of a completed mat may be found in figure 3.

Figure 3: An example of a completed talking mat.

Personal Communication Passports

Personal Communication Passports (PCPs) may also aid people with LDs during the consultation process [9, 63]. PCP booklets consist of a series of symbols and short sentences that disclose essential information about the views and characteristics of a person [63]. Instead of simply listing the owner's likes and dislikes, the short sentences should contain more data pertaining to the person's communication habits. For example, a passport could contain information on how the owner reveals what activity they wish to participate in, rather than listing some activities they enjoy. This enables conversation partners to interact with the person in a consistent manner, thus helping them to comprehend the situation and make the most out of the communication abilities they do possess [63]. This would allow physicians to gather knowledge at a glance on how to communicate best with the patient, thus enabling them to extract the information required to make a diagnosis.

The passport belongs to the person who has communication impairments rather than their family or carers. However, the person's peers may be responsible for helping them to use the passport accordingly and to update it. As a result, PCPs contain information from many people who come from various backgrounds (e.g. nurse, carer, parent or teacher), and are able to provide a different perspective on what the most effective means of communication is. All information recorded on a passport assumes

no prior knowledge of the subject, meaning they are extremely useful to unfamiliar communication partners [63]. An example of a PCP may be found in Figure 4.

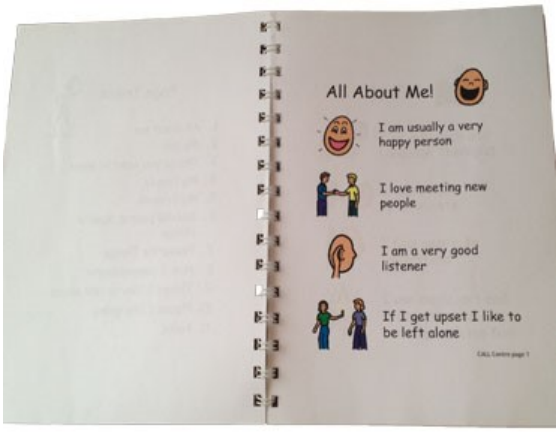


Figure 4: An example of a Personal Communication Passport.

Brodrick et al introduced an adapted version of the personal communication passport into the clinical setting in 2011 [9]. Overall, the passports were found to be useful since they enabled staff to share pertinent information about the patient in a simple and clear format. However, when first introduced the quality of the passports were poor leading to the conclusion that without proper training, passports may contain unreliable information that could adversely affect clinical decisions made by healthcare professionals. Prior also developed an electronic version of a hospital passport that extracts information crucial to the care of those with severe communication impairments during their admission to hospital [134]. Helmsley and Balandin have recognised the need for patients who have severe communication impairments to provide hospital staff with key information on their needs [133].

Picture Exchange Communication System

Several papers reviewed the effectiveness of the Picture Exchange Communication System [40-41, 55, 64]. PECS applies basic behavioural principles and methods such as differential reinforcement, successive approximation, and transfer of stimulus control via delay to develop the communicative abilities of a person, by using illustrations as a referent [41]. The illustrations are stored on a PECS board with the use of Velcro™ in a similar fashion to Talking Mats™. The subject is then trained to

use their PECS board by selecting various picture cards (e.g. “I want to” card plus “play outside” card) in order to create a sentence, before distributing the collection to a communicative partner as a request for a specific item. PECSs may also be used to make social comments or to answer specific questions.

As with Talking Mats™, PECSs use images extensively and therefore inherit the advantages and disadvantages discussed in section 2.4.4.2. However, PECSs are unique in the manner that they depend upon the user approaching a listener in order to begin the communication process [40]. Various studies have shown that PECSs can be taught quickly, meaning people can profit from their services almost immediately [64]. This could be advantageous in the clinical setting since patients with learning difficulties may be trained to use a PECS to approach a member of staff with potential problems/symptoms. However, no papers included in the review discussed such an approach. An example of the Picture Exchange Communication System may be found in figure 5.

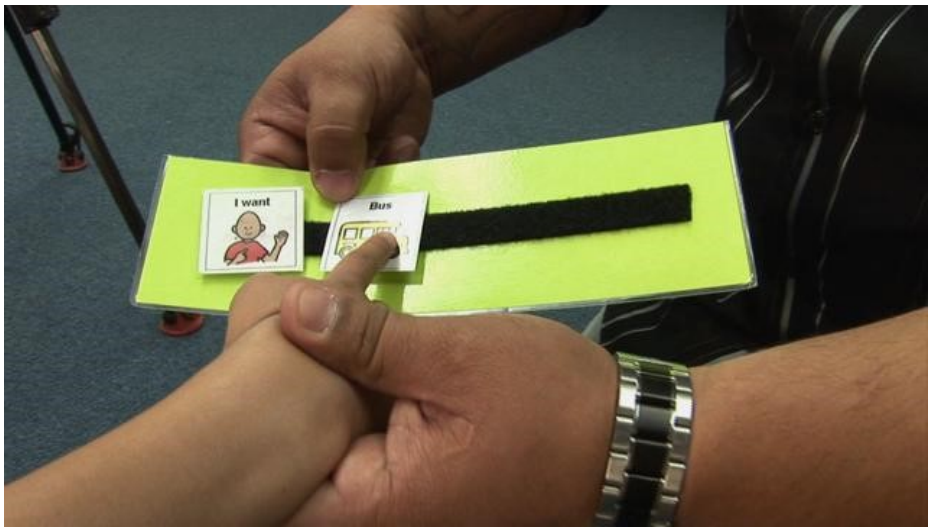


Figure 5: Picture Exchange Communication System

Voice Output Communication Aid / Speech Generating Device

Voice Output Communication Aids (VOCAs) are high-tech communication devices that have been proven particularly effective in teaching people with learning disabilities to request attention [20, 64-65]. VOCAs are typically small, lightweight electronic devices that are used to supplement speech or writing by producing artificial

dialogue at the touch of a button. A wide range of graphic symbols can be used along with VOCAs to represent directives that are initiated when a user selects an option from the display [20]. VOCAs come in various forms depending on the needs of the user. These range from complex touch screens that contain an abundance of phrases and symbols spanning numerous pages, to simple remote controllers that contain only a few buttons and options.

The content, organization, and updating of the vocabulary on a VOCA is also dependent on the needs of the user, along with the context in which the device is used. For example, the vocabulary required for a device being used in a clinical setting would be vastly different from that required by a device being used at home. The development of methods to enhance both the vocabulary used and the speed in which speech is produced is currently on going. However, the consensus is that vocabulary terms should be relevant to the user, be regularly applicable, have various meaning, and be pragmatic in functionality [22].

As with the Picture Exchange Communication System, none of the papers reviewed discussed using VOCAs in the clinical setting. However, the simplistic nature of VOCAs (entire requests can be made at the touch of a button) combined with the relatively short time frame required to become proficient in using these devices [20, 64] suggests that a VOCA could be developed in order to assist people who have learning disabilities within medical environments. For example, a VOCA could be used to alert staff to common symptoms that the patient is experiencing. The success of these devices depends largely on the symbols that represent the vocabulary used and therefore are subject to the advantages and disadvantages of using images described in section 2.4.4.2.

Mobile Phone and Tablet Applications

By far the most frequently reviewed high-tech communication model was mobile phone / tablet applications [21, 35, 42, 47, 56-58, 66-68]. AAC applications are becoming increasingly popular due to a number of reasons including their low cost compared to traditional AAC devices, increased portability, and increased availability since they are readily obtainable in both the Google Play Store and the Apple App

Store [21, 56-57]. The advantages and disadvantages of using AAC applications will be discussed in more detail in section 2.4.4.4.

Prolquo2Go is the most popular AAC application available on the Apple App Store and offers much of the services available in the technology previously described. Proloquo2Go focuses on the creation of sentences by offering a symbol grid system that enables the user to navigate through a variety of categories in order to develop text that is played back as synthesized speech [57]. The consumer may also utilise these symbols to create and save daily schedules, or storyboards that may be passed on to communicative partners. The grid system can be customised to suit the user's preferences, by allowing frequently used phrases to be saved and offered for selection first. However, there is great difficulty in adding entirely new symbols to the application [57], a feature that is easier to achieve in other applications such as iCommunicate. An example of the proloquo2go interface may be found in figure 6.

Figure 6: Proloquo2go – A mobile AAC application

There is a clear gap in the market for AAC applications designed specifically for use in the clinical environment. Of the 265 AAC applications listed on appsforaac (http://appsforaac.net/), 3 have been developed for this purpose. However, it is unclear whether they were built in-line with the views of developers rather than the use of evidence obtained through research. Therefore, there is scope to develop a research

based AAC application that effectively addresses the complex needs of adults who have learning disabilities within the clinical setting.

2.4.4.4 Barriers to Technology/Accessibility

AAC Devices

Common barriers to the use of high technological communication models were discussed in an abundance of papers reviewed. Operational difficulties [12-13, 18, 69] were found to be the most common barrier. People with learning disabilities tend to have problems in learning how to use intricate technology as well as remembering instructions [33]. Therefore, if the device is difficult to use and the interface is overly complex, these people may revert to their traditional communication methods such as pointing. This leads to high rates of AAC device abandonment with Riemer-reiss & Wacker suggesting that such rates may rise as high as 53.3% [119]. Leading on from this, the time taken to generate a message was also perceived to be a major barrier [12-13, 18]. The rate of message transmission is quite slow in comparison to normal speech, particularly for those people who use text-based devices [13]. However, to be particularly effective, Lund and Light state that the device should be able to 'produce' the message in time with the thoughts of the user [21].

The use of alternative and augmentative devices appears to affect how their users perceive themselves. Clarke et al. found that children tend to think of AAC devices as uncool and boring and as a result feel uncomfortable when communicating with unfamiliar partners [18]. Bradshaw took this ideology one-step further when she described that the voice or language of a device causes particular embarrassment for users. This is due to several reasons including limitations placed on the vocabulary produced, and the sound output not representing their own voice [21]. The foreign nature of a traditional AAC device may also discourage unfamiliar partners from initiating a conversation with the user [21].

AAC devices are generally expensive to purchase and a lack of funding to access services or devices is often a primary obstacle [12, 19, 21]. Such devices often require to be tailor made for each user [19], meaning there may be a lack of cheaper second-hand devices available that suits the needs of specific users. There also seems to be a

lack of technical support available in the event that something goes wrong [13, 21, 66]. Despite this, the frequency of breakdowns appears to be high [13, 21] with a survey conducted by Angelo concluding that 11% of parents felt that their children's AAC devices broke down too often [23].

Web Accessibility

Web technologies also contain key flaws that limit their use by people who have learning disabilities. Firstly, not all browsers conform to the User Agent Accessibility Guidelines, which is a set of protocols used to improve accessibility to those who have disabilities. This may result in situations where users are not able to take advantage of the accessibility features promised by a Web page developed using such guidelines due to the browser being used [45, 70].

Another major flaw concerns the tools used to evaluate online resources. Many tools cannot wholly evaluate accessibility in regard to such aspects as scripting, the suitability of alternative texts that aid in the description of graphics for the visually impaired, or the accessibility of audio and video files. Such tools are also ineffective if the web content designers have insufficient knowledge on the accessibility guidelines that require human judgement. This is also true for web pages that have their content altered by all types of users such as blogs and online learning environments. The sites may proclaim to be developed in an accessible manner, but the content placed on the platforms may not [71]. The need for accessible technologies can be reduced if accessibility guidelines are implemented from the front end instead of attempting to retrofit accessibility measures [71].

Mobile Technology

Mobile technology and AAC applications mitigate some of the barriers described previously; however, they introduce some of their own. First of all, the use of tablet or mobile phone applications as a form of AAC may alleviate the issues of self-image [21, 56]. Mobile technologies are socially valued and as a result, people can use AAC applications without the stigma that is often associated with the use of traditional assistive technologies. Traditional devices tend to contain technical operations that apply menus, layouts and commands that differ considerably from mainstream

technologies, thus imposing new learning demands on communication partners [56]. The operational requirements of AAC applications are similar to those used in traditional apps, meaning communication partners have less of a learning curve when interacting with such technologies.

The introduction of tablet and mobile phone AAC applications has made assistive technology more accessible. Tablets and mobiles are cheaper and more portable than conventional devices [21, 56]. On top of this, AAC applications are themselves relatively inexpensive making them far more affordable to purchase. However, this may result in applications being introduced prematurely, before the needs of the user are evaluated [21]. Some individuals who use appropriate AAC solutions may also be advised to switch to cheaper alternatives since many adhere to the belief that "one size fits all". This may be troublesome as those with learning disabilities have issues learning new operational skills and may not have access to personnel who can provide adequate support.

The main downfall of using mobiles as AAC devices is screen size. The demand for small screens causes problems for those users who have significant motor impairments. Many interactions with a phone require an array of highly coordinated fine-motor movements to carry out such as swiping and pinching [56-57]. Motor impairments may seriously affect the user's ability to carry out such operations on small screens. However, tablets tend to be larger, meaning they have the potential to mitigate these problems. iOS and Android operating systems also enable adjustments to be made to touch input [72] and this may result in the frequency of accidental activations being reduced.

2.4.4.5 Professionals Attitude

Several papers revealed that professionals have to become more knowledgeable about AAC devices, and the ways in which people with learning disabilities interact with such technology [12-13, 47, 66]. For example, if a speech and language therapist has insufficient knowledge about AAC devices, then they may overlook devices that could potentially be of benefit to an individual with communicative impairments. If a

teacher, physician or carer has inadequate knowledge, then they may lack the skills required to engage successfully in a conversation with the user.

In order to significantly improve a professional's education of AAC, intensive training is required [13, 19, 38]. However, a number of studies revealed that professionals have insufficient access to appropriate training [13, 19]. This is particularly true for GP staff as a survey conducted by Murphy found that "none of the staff had received any training on communication disability" [36]. On top of this, professionals realise that further education and training would be beneficial [28, 36], but time constraints prevent them from taking advantage of such opportunities when they arise [28]. Lennox et al. found that a majority of GP staff would prefer access to a short handbook on learning disabilities, rather than receiving intensive training [28].

GP staff are usually unaware of the range of communication disabilities that exist and the various forms of technology on offer that aid these disabilities. As a result, they tend to rely on carers to facilitate conversations between themselves and the person with communication problems [36]. This may ease potential time restrictions placed on such consultations, as caregivers are likely to use strategies that effectively extract information from the patient. However, these carers may provide answers that they believe to be true but are not the views of the actual patient. Additionally, people with learning disabilities tend to object to the GP bypassing their own views in order to speak to their carer [36]. A far better approach would be for staff to update their own knowledge of communication disabilities in order to address the patient directly. The General Medical Council's recommendation to increase the amount of time afforded to such consultations [16] may also alleviate some of these issues.

Negative attitudes held by medical professionals can affect the standard of health care provided [28]. General practitioners may experience frustration when consulting with people who have learning disabilities, and as a result subconsciously provide a poorer level of healthcare for all patients with similar conditions. This may also explain why GPs tend to interact with the carers rather than the patients.

The AAC technologies used by people who have learning disabilities are changing rapidly [73]. Consequently, there is a wide range of AAC systems on offer and

choosing the most appropriate device for an individual may be difficult [22]. This may result in the patient being unable to express their views due to the type of AAC device in use. Furthermore, this change will require professionals to continuously update their knowledge on such technologies and this may not be feasible for those who have hectic work schedules.

Physicians tend to be reluctant when interacting with new technology. The main reason for this is the perceived negative impact learning how to use such technology may have on a physician's workflow [74]. Some believe that learning how to operate new technology or follow new guidelines requires a significant amount of effort that instead may be directed towards important tasks such as updating health records. This is particularly true when the system has been poorly developed [75]. However, if a physician cannot extract the information required to perform an accurate diagnosis, then there is a high chance of that patient returning to the clinic in the near future. Valuable time and effort will then have to be expended on an issue that should have been solved during the initial consultation. Therefore, it is beneficial for the physician to ensure they are able to interact effectively with patients who have LDs to ensure their needs are catered for. Support staff should be made available when implementing new technologies to enable the transition period to run as smoothly as possible [74].

2.4.4.6 Individualisation

The need for individualisation was highlighted by an abundance of authors in the papers reviewed. Several studies found that, although certain communication models are effective for some users, not all benefited from their use [18, 33, 39, 45, 53]. People who have the same learning disability may still have disparities in their cognitive, linguistic, and motor abilities [27]. Therefore, you should not assume that the inclusion of alternative forms of communication, such as symbols or photographs, would be sufficient to make the experience beneficial to all participants [76]. Instead, using a wide range of consultation methods is deemed a more effective approach in extracting the views of those who have learning difficulties [39]. These methods should make use of different forms of auditory, touch, and visual processing.

The AAC market as a whole is small, but the requirements of its consumers are highly diverse. As a result, no device can conceivably satisfy the needs of all AAC consumers [22]. Instead, greater attention to the necessities and characteristics of an individual is required in order to determine the type of AAC device that is most suited to their complex needs [21]. A combination of the views from knowledgeable professionals, family members, and ultimately the end user will result in the most appropriate AAC device being chosen [22]. However, this will not guarantee that all of the user's requirements will be fulfilled due to the heterogeneous and ever-changing nature of people with learning disabilities.

Today's multimedia technologies tend to focus on accommodating for the larger "able" population and leave those who have disabilities as an afterthought. Rather than incorporating the principles of accessibility as a fundamental system component at the conceptualisation and design stages, these features tend to be introduced once development has concluded [77]. As a result, websites tend to be designed around generalisation, and this is not a legitimate approach for people with LDs since they need fully configurable platforms that are able to adapt to their specific needs [53].

To be compliant with UK law, web services must meet level AA of the Web Accessibility Guidelines 2.0. However, WCAG recognises that "even content that conforms at the highest level (AAA) will not be accessible to individuals with all types, degrees, or combinations of disability particularly in the cognitive language and learning areas." [45]. A set of guidelines that enables a web developer to create an environment that adapts to each user's needs and preferences would be preferable, [45] but may ultimately be unachievable. The potential to customise the functionality of medical AAC technologies will be addressed in chapters 4 and 7.

2.4.4.7 Co-design

The penultimate theme that was identified was the need to involve end users in the design of the communication model. Several studies emphasised the need to include representative users in the design of a system, to ensure that it succeeds in achieving its intention and becomes successful [18, 22, 70]. Eghdam et al. took this idea a step further and suggested that representative users should be involved in the early design

stages and continue to be involved throughout the entire development process and system lifecycle [78]. This is particularly true for a system that is being developed for people with learning disabilities, since the needs of the user may be difficult to extract or even change throughout the development process. Testing the product continuously with representative users will ensure that their complex needs are being met and that they can navigate the user interface with relative ease.

Systems that have been developed collaboratively with representative users are far more likely to be easy to use and look 'good' in the eyes of the consumer [18]. Systems, which have not been developed in conjunction with the views of end users, are more likely to have major accessibility flaws. This may result in the target user group abandoning the device since it does not contain the required features that allow them to operate the technology effectively [69]. For example, the buttons may be too small to be used by someone who has significant motor problems. Despite this, AAC applications tend not to be based on research evidence or include end users in their design, and as a result they may not address the needs of the individuals using them [56, 67]. Developers instead tend to make assumptions on the needs of the end users and build their systems based on these assumptions. This also seems to be the case for more traditional AAC devices with the rate of abandonment being reported as high as 53.3% [119].

There are several reasons as to why developers may not include people with learning disabilities in the design of a system. The most substantial reason alludes to the lack of studies available that detail the involvement of people who have cognitive disabilities in usability tests [34]. As a result, there is a lack of guidelines on how to include such users. This appears to be a solvable problem since academics may come together and develop such guidelines [34]. In stark contrast, strategies and guidelines to include those who have dementia within research [79-80] seem to be readily available and some of these recommendations could potentially be adapted to suit the needs of those who have learning disabilities.

The difficulty in extracting the views of people with learning disabilities is another significant factor. Such people tend to have problems in understanding new or complex information [23] so may not understand what is required of them. They may

also experience problems in expressing their own opinions [23] and therefore are not able to convey their needs in a comprehensible manner. Their heterogeneous nature provides significant challenges since the researcher has to adapt to the specific needs of each participant. Researchers themselves tend to feel ill equipped in extracting the views of those who have learning disabilities and instead rely on the services of in-demand experts [81]. Blackstone et al. suggest that an important research need is to explore the ways in which the views of consumer groups can be extracted reliably [22] and this may result in less people relying on the services of such experts.

Developers who include people with learning disabilities in the design of a system must ensure that their subject's right to discontinue their involvement is regularly exercised [76]. Individuals who consent to take part in the design process must fully understand how they can contribute and what is to be expected of them [76]. However, this information may not be clear and can result in the subject agreeing to participate without fully understanding what is required of them. Therefore, a series of decision points should be provided as the research unfolds, in order to allow the subject the chance to opt out if circumstances change. A variety of aids (audio, symbols etc.) should be included in the consensual process in order to make the most out of the language and communication skills owned by each individual.

2.4.4.8 Evaluation

From the 61 relevant articles, 29 contained reviews of technology or communication models and involved no original experimentation (47.54%). The remaining 32 articles used a variety of research techniques within their studies. The vast majority of these studies took the form of qualitative interviews. Communication models, such as Talking Mats™, were used extensively within semi-structured interviews and focus groups, in order to include and extract the views of people who have learning disabilities [17-18, 36-37, 39, 42, 48-49, 54-55, 60-61, 82]. Such information extracted via the use of communication aids included: people's views on AAC [17], people's perspective of the quality of health and social care being provided [36, 39, 54-55], the issues students faced when moving schools [42, 48], and people's views on their quality of life [48-49, 82]. Interviews were also used in order to identify vocabulary that could be added to the Talking Mats™ framework [37].

Qualitative interviews were also conducted where no explicit communication aid was specified to have been used by the participants who have learning disabilities [52, 66, 69, 83-84]. These interviews were conducted in order to extract the requirements of people with learning disabilities in the creation of information leaflets and questionnaires [52, 83], extract people's experiences of cognitive behaviour therapy [84], elicit people's perspective of the quality of health being provided to them [69], and to extract people's views on AAC technology used in iOS operating systems [66]. Professionals and family members who are involved in the lives of people with learning disabilities also participated in qualitative interviews [17, 28, 36, 58, 60, 66, 85]. Such people's views were valued when discussing the care of those who have learning disabilities [17, 28, 36], when discussing the requirements of mobile phones and tangibles [58, 85], and when discussing the appropriateness of using iOS applications as a form of AAC [66].

Qualitative observations were used extensively as a form of evaluation [47, 64, 83, 85-87]. Observations were used to evaluate the use of iPod touch devices and the Picture Exchange Communication System in the education setting [48, 64], how people with learning disabilities use Web facilities [87], how effective a questionnaire was in the self-diagnosis of mental health problems [83], how effective a health education course was in teaching those who have cognitive problems the basics of health [86], and the effectiveness of tangible in facilitating independent exploration [85].

Quantitative analysis techniques were used scarcely [32, 38, 41, 50, 59, 64, 68] in comparison to qualitative techniques. Murphy et al. compared subjects understanding of questions, engagement in conversations, satisfaction of answers given, range of topics discussed, and time taken to complete an interview when using Talking Mats™ compared to the subjects' traditional communication aid [59]. The frequency of challenging behaviour, requesting of items and occurrence of correct pronouns before and after the use of Voice Output Communication Aids was measured using quantitative techniques [64]. Charlop-Christy et al. measured the number of trials required to master each phase of the Picture Exchange Communication System along with the time taken [41].

Comprehension questions that followed symbolized text were compared with questions that followed plain text by using quantitative techniques [32]. A structured questionnaire was used to accompany video segments, in order to evaluate the effectiveness of video applications as an educational tool by recording the accuracy of answers provided [68]. Bailey et al. used quantitative techniques to measure how effective visual aids are in relation to financial decision-making and temporal discounting exercises [50] and Joleff et al. measured aspects such as initiation of conversations and response rates before and after the use of AAC devices [38]. No randomised control trials were carried out. There is a clear need for further use of quantitative analysis to determine the true effectiveness of communication aids in areas such as engagement, language development, accuracy of answers provided etc.

2.5 Discussion

The purpose of this scoping review was to identify the technology and communication modalities used to support clinical consultations with people who have mild learning disabilities. Presently, there are no research-based models developed for such a purpose and are in use on a national scale. However, the problems encountered during consultations with those who have learning disabilities have been well documented [4, 6, 11, 14-15, 28, 36], so why is there a lack of clinical aids being developed for such a group? This may be down to the absence of available guidelines to assist in the creation of such aids. Despite this, several steps were identified throughout the review that should be followed by AAC developers and an overview of these may be found in table 3.

Table 3: Overview of steps to follow during the creation of AAC applications

Step	Description
1. Identify Communication Challenges	The communication challenges of the target group should be identified. These challenges may vary widely due to heterogeneous nature of people with learning difficulties. Contingency plans

	should be developed in order to overcome each individual challenge.
2. Update Knowledge of AAC	Developers should update their knowledge of the current AAC devices being used by their target group. The advantages and disadvantages of each should be noted. This will enable them to successfully engage in a conversation with potential stakeholders and learn from the success and failures of past technologies.
3. Involve End Users throughout the Project	Developers should make an effort to involve end users throughout the lifecycle of the project
4. Account for Individualisation in the Design of the Product	People with learning disabilities are heterogeneous in nature. Therefore, an effort should be made to enable the consumer to customise the product to suit their specific needs.
5. Plan appropriate ethics	The developers should continually exercise their subjects' right to dissent from participation in the project. The resources used to acquire consent from the subjects should be presented in a variety of formats in order to make the most out of the language skills owned by stakeholders.
6. Use Quantitative Analysis Techniques	Whilst testing the product, quantitative analysis techniques should be used to determine the true effectiveness of the device. People with learning

	difficulties should be involved heavily within the testing process.

First of all, the key communication challenges of the target group should be identified and contingency plans should be put in place to overcome these. The recognition of such barriers will enable developers to design an intervention that appropriately addresses the consumers' communicational needs. Developers should then update their knowledge of the current AAC technologies used by their target group, since this will enable the strengths of such devices to be identified and may result in similar features being incorporated into product. The weaknesses of such devices should also be identified in order to avoid key features that have been unsuccessful in past technologies.

The previous two steps enable developers to include representative users throughout the development process of the aid. By identifying possible communication challenges between themselves and people with learning disabilities, developers can devise strategies that will enable them to get the most out of the conversation skills owned by the subjects being interviewed. This may be achieved by including additional resources such as pictures or objects of reference etc. within the interview process. By updating their knowledge of AAC technologies, developers will equip themselves with the skills required to engage successfully in a conversation with people who use a wide range of AAC devices. As a result, they may find it easier to extract the requirements and views of those who have learning disabilities.

Representative users should be involved throughout the products lifecycle [78], beginning with requirements gathering and ending with extensive testing. By involving such users in the early design stages, key features may be identified that are crucial to the person's ability to operate the aid. For example, objects used within a system may be increased in size to accommodate for those who have poor fine motor skills. Developers should focus on extracting the specific communication modalities used by their target group and any possible limitations of these modalities, the subject's views of current AAC technologies, and the specific needs of the user when interacting with the aid that is to be developed. This information should form part of the

requirements of the aid. Prior demonstrated in the design of CHAMPION [134] that people with complex communication needs are both able and willing to participate in the design of a system. The participants also believed that their direct involvement results in being identified and appropriately catered for.

When designing the product, developers should account for individualisation where possible. Due to their heterogeneous nature, people with learning disabilities have disparities in their cognitive, linguistic, and motor abilities [9], and may require a wide range of consultation methods to communicate. Therefore, you should not assume that the inclusion of alternative forms of communication, such as symbols or photographs, would be sufficient to make the experience beneficial to all participants [76]. A far better approach would be to identify sub-groups of users who have similar needs and then provide a service for each sub group. For example, some users may respond better to text when it is accompanied by images, whereas others may require some sort of speech feedback to be embedded within the system. Therefore, the product could be developed to include both options and allow an individual to select the appropriate option according to their specific needs.

Once the design stages have been completed, end users should continue their involvement within the project. During the development process, representative users should continuously test the product, particularly when prototyping is being used. Allowing people with learning disabilities to test the product regularly ensures that major accessibility issues are identified and subsequently addressed. This may result in the aid being easy to use and attractive to its consumers [18]. Quantitative analysis techniques should then be used to evaluate the effectiveness of the developed product. This enables the benefits of the aid to be presented in a clear statistical manner. Qualitative analysis techniques should also be utilised to provide stakeholders with the opportunity to provide feedback on their experience with the aid.

Throughout the lifecycle of the product, the developers must continually exercise their subjects' right to assent or dissent from involvement [76]. Individuals who consent to take part in the research being carried out must fully understand the purpose of this research and its outcomes and know what is expected of them [76]. However, this information may be complex and the subject may agree to participate without fully

understanding what is required. Therefore, a series of decision points should be provided as the research unfolds, to allow the subject the chance to opt out if circumstances change. The consensual process must also include the use of a variety of aids (symbols, photographs, audio etc.) in order to make the most out of the language and communication skills owned by each individual. Even those individuals who make use of proxies must heavily involve themselves in the consent process to ensure that they are indeed willing to participate [76].

The scoping review highlighted several communication aids that are used within everyday situations (such as Proloquo2go) as well as those that have been adapted for more specialised environments e.g. Brodrick et al.'s one-page patient passport. However, some key AAC practices failed to be acknowledged within the papers identified. Makaton [125] is a language programme that combines the use of signing and symbols to assist in enhancing an individual's spoken language. Prior research has indicated that a limited number of symbols and signs are easier to learn than spoken words [20, 126]. Consequently, this system is extremely beneficial to children who are in the process of developing their speech and for individuals who have significant impairments that affect their ability to communicate. They may simply use a sign to convey their needs (for example the sleep sign shown in Figure 7) or in turn respond appropriately to a sign carried out by a communication partner. If they are unable to carry out, or fail to recognise the actions of a sign, then relevant symbols may be used to clarify an individual's intent.

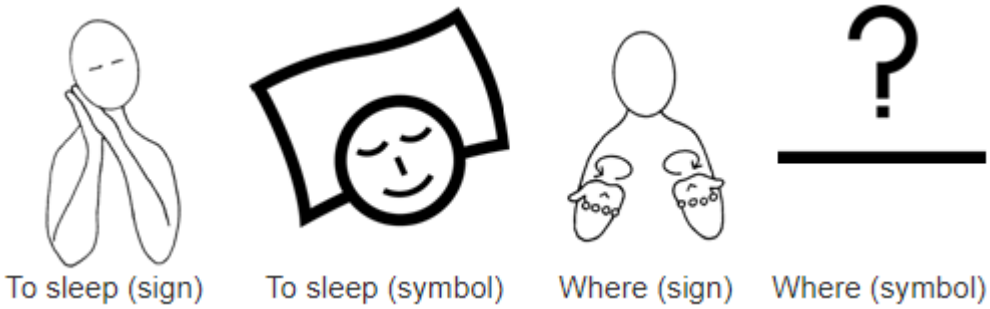


Figure 7: Makaton resources for sleep and where [126].

The Makaton process may be utilised by an individual until they are confident in their own ability to communicate via the use of speech. However, for those with significant

communication impairments, Makaton may be an essential part of making their needs known. As such, the system is extremely flexible and may be personalised for an individual's needs across a number of circumstances. It may be used when: sharing thoughts, choices and emotions; labelling objects, people or places; listening to, reading or telling stories; creating lists or plans; and writing letters/messages amongst other purposes.

Makaton has even developed symbols and signs for use within the clinical environment [127]. The developed resources intend to improve the exchange of information between medical staff and the individual with communication difficulties on aspects crucial to the patient's care. This includes information on: the medical environment; the medical procedures that may occur; the equipment used; and the symptoms that the patient may be experiencing. Other symbol sets have also been developed that intend to ease the communication between health professionals and patients with communication difficulties (including LDs), such as PCS [128] and Widgit [129]. This highlights the important role images, including those used within easy read resources, can play within clinical consultations involving this population.

2.6 Conclusion

The needs of people who have learning difficulties are highly diverse due to disparities in their cognitive, linguistic, and motor abilities [27]. As a result, there is a wide range of communication aids on offer for these people. When selecting an appropriate AAC device, great attention to the necessities and characteristics of an individual is required [21]. This includes any limitations in their bodily functions that prevent them from executing certain actions (for example pointing), and the ways of representing language in which they respond to best i.e. text, audio or pictures.

In order to be successful when developing communication aids for those who have learning disabilities, stakeholders should be involved throughout the lifecycle of the product. By including consumers in the design of the project, developers may be able to extract their complex needs, thus ensuring a higher probability of developing a product that the users can operate effectively. However, as described previously, those

who have learning disabilities are unique and therefore not all requirements may be catered for by one device.

Instead, developers should try to include as wide a range of potential users as possible within the design process, including those who have different disabilities. From here, developers should try to establish common needs across the range of participants and may even identify sub groups of users that have similar requirements. Individual features may then be created to suit the needs of each sub group and users may then choose to apply these features depending on their requirements [81]. A number of alternatives to textual information should be used within the design process in order to make the most of the language skills owned by the participants and extract a wide range of user requirements. By conducting extensive tests that involving stakeholders, developers ensure that major accessibility issues are addressed, and that the user can operate the product effectively. These tests should be carried out using quantitative techniques to demonstrate clearly the benefits of using the aid.

Many papers outlined the challenges physicians face when dealing with patients with learning disabilities. Despite this, only one paper reviewed the use of communication aids in the clinical setting [9]. Brodrick et al. evaluated the use of a modified personal communication passport within a hospital in East Cheshire; however, no widespread studies took place that involved a number of practices. This demonstrates the need to evaluate how communication aids perform in the clinical setting on a widespread scale in order to determine their true effectiveness

The need to develop a communication aid that may be used in the clinical setting is only part of the problem. Physicians tend to have a lack of knowledge on learning disabilities [36] and as a result are ill equipped when attempting to extract the needs of such patients. Knowledge on how to interact with this population, including how to accommodate for AAC technologies, should be an essential part of the GPs education. At the very least, physicians should have access to a short handbook on learning disabilities, which they can refer to when needed [28].

Chapter 3

Methodology

The purpose of this Chapter is to introduce the methods used to identify the requirements for, and develop a technology probe of, a digital aid that may assist adults with mild learning disabilities during the consultation process. The project primarily involved the use of qualitative techniques and these will be discussed in further detail within their relevant chapters.

3.1 MRC Complex Intervention Framework

To ensure that the probe was developed in a structured way, the author primarily followed the Complex Intervention Framework developed by the Medical Research Council [88]. Complex interventions may be described as "interventions that contain several interacting components" [89]. The scope for complexity is very wide, but crucially includes projects that may involve a high degree of flexibility to ensure its goals are met, or those that are intended to overcome the intricate issues or behaviours experienced by the target population [89]. Therefore, the framework provided crucial guidance on how to develop an application intended to overcome the complex and highly individual requirements of adults with mild learning disabilities in the clinical setting.

The complex intervention framework emphasises the need to collect ample evidence as to why current practice may be improved upon, before the design process is carried out. This ensures that researchers understand the problem at hand before developing sufficient theory on how a novel intervention may fit into and improve current practice. The product is then piloted in order to evaluate how effective it is in achieving its goal before the results are disseminated and potential improvements are made. The final product is then introduced into current practice at which point a long-term follow up study is performed to ensure the intervention is having its desired effect. This emphasis on evidence gathering is highly appropriate for the research proposed, since adults with mild learning disabilities are heterogeneous in nature and require a number

of complex needs to be met. Thereby, providing multiple opportunities to evaluate and update the probe may result in a more appropriate interface being developed.

Furthermore, similar projects that aim to improve the health of people with learning disabilities have made use of the Complex Intervention Framework. For example, Kerr et al. intend to develop evidence-based tobacco and alcohol-related interventions for adults with learning disabilities. To achieve this, they first gathered evidence as to why such an intervention is required, by identifying the current practices used to promote the health benefits of quitting smoking or drinking via a scoping review. The results of the review confirmed that there is a sufficient need to explore such material for the learning disability population [90].

The same authors then proceeded to explore the tobacco and alcohol-related health promotion needs of adults with learning disabilities to ensure a suitable intervention is developed. A focus group involving adults with mild/moderate learning disabilities was used to achieve this and the various questions presented centred on: why the participants use tobacco and alcohol; their understanding of the health risks associated with smoking and consuming alcohol; and their health promotion needs [91]. The data collected will subsequently be used to develop the intervention, meaning the project follows a similar to structure as the research carried out in this thesis.

Figure 8 presents an overview of the four stages involved in the complex intervention framework. This research primarily focused on the implementation of the first stage (Development) where evidence was gathered as to why the intervention is required and an initial probe was developed. The probe was also evaluated by a number of learning disability experts meaning stage 2 (Piloting) was also partially completed. The procedures involved within these stages will be discussed in more detail throughout the chapter.

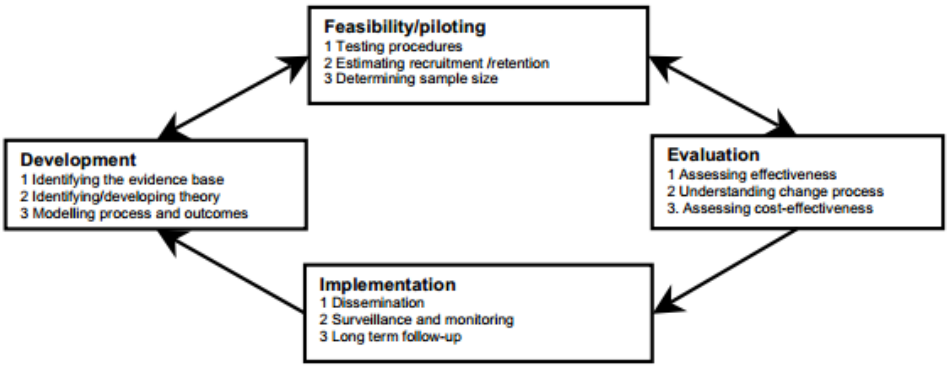


Figure 8: MRC framework for complex interventions [88]

3.2 Development

To ensure that the intended intervention is effective in achieving its goal, the framework emphasises the need to develop a good theoretical understanding of how it may positively affect current practice before any implementation occurs [88]. The following two subsections were used to achieve this:

1. Identifying the evidence base
2. Identifying / developing theory

3.2.1 Identifying Evidence

Identifying the evidence base involves reviewing how successful similar interventions were in changing current practice and identifying the evaluation techniques used to recognise this [88]. No high-quality literature reviews were evident at the end of June 2016 that addressed the existing communication technologies used to support adults with mild learning disabilities during clinical consultations. Instead, the reviews identified focused on the everyday use of AAC technologies [12] and their associated barriers [13]. Therefore, the author proceeded to conduct their own between the months of July and December 2016. A full explanation of the methods used to conduct this scoping review was discussed in Chapter 2; however, a summary will subsequently be provided.

Potentially relevant literature was identified by searching the PubMed, Association for Computing Machinery Digital Library, and Google Scholar databases, thus ensuring that literature was included from both the medical and technological domains. Papers

were then included within the review if they addressed a number of key issues ranging from: the potential communication challenges between physicians and patients who have learning disabilities, to the communication aids or modalities used by this population. The papers that focused on these issues were collated and subjected to a thematic analysis to identify the key concepts emerging across them.

Within the themes identified, it was clear that practitioners must overcome a number of communicative challenges when consulting with patients who have MLDs. The review also revealed that there is a lack of research-based technologies widely available to support stakeholders in overcoming these challenges. Instead, general Alternative and Augmentative Communication devices tend to be used and these may be unsuitable for such a specialised environment. Consequently, sufficient evidence has been produced that highlights the need for the proposed application, as well as the potential impact that it may provide.

3.2.2 Developing Theory

Developing theory involves furthering your knowledge on how the intervention can achieve its goals by drawing on existing evidence and supplementing this with primary research [88]. This was achieved in the following two ways:

A Framework Analysis of the Thematic Document

Throughout the thematic analysis document produced during the previous stage, a number of key concepts were raised that aided the author's understanding of how an application may assist clinical consultations. A framework analysis [92] of the document was subsequently carried out, in order to produce a structured summary of the potential requirements discovered during the scoping review.

The framework analysis was conducted using the themes and consequent sub-themes that emerged during the thematic analysis process as codes. Key excerpts from a copy of the document were highlighted and coded appropriately. These excerpts were then transferred to an entirely new document and placed within a table containing 3 columns: a summary of the excerpt to ensure that no contextual meaning was lost during the transfer process [93]; the excerpt itself; and the code. The table was sorted

by the tag column to ensure that similar statements were grouped together, and that an analysis of an entire theme/sub-theme could occur.

Table 4: A representation of the framework analysis table used to structure the findings from the thematic analysis

Summary	Excerpt	Tag
Tablet AAC applications are becoming ever popular due to them being more accessible than traditional AAC devices.	Mobile phone and tablet AAC applications are becoming increasingly popular due to a number of reasons including: their low cost compared to traditional AAC devices; increased portability since most can fit in your pocket; and increased availability since they are readily obtainable in both the Google Play Store and the Apple App Store	Accessibility

The resultant table provided valuable information relating to the challenges experienced by those who have learning disabilities, as well as General Practitioners. On top of this, it also contained a host of information describing where strategies have succeeded in overcoming the communication barriers between people with mild learning disabilities and the general population, and where strategies have failed. As a result, the framework analysis provided a structured account of existing evidence that highlights the possible features an application must have to assist those who have learning disabilities during the consultation process.

A number of key requirements for the intended application were identified during the analysis. This information was then used to develop the first of two technology probes, in preparation for the semi-structured interview stage. Technology probes may be considered as an early representation of a product that is utilised by stakeholders within the target environment to inspire the design process by exposing them to new experiences [118]. They enable radically new technologies to be field-tested early in the design process which in turn helps to discern the true requirements of stakeholders. Statistical analysis features, such as interaction or eye-gaze logs, may also be built into the probe that unobtrusively monitor the actions of users. As such, potential user interface problems (for example frequent taps being made on a non-clickable object) may be readily identified and mitigated.

Norman [95] suggests that stakeholders are typically unsure of what they require from a product during its conception and early design phases. People with learning disabilities tend to have impaired higher-order cognitive skills such as abstraction and imagination [121-123] meaning this scenario may be amplified. Consequently, they may be better of interacting with existing technologies to determine what features assist them in achieving the goals of the product and those that don't. Since there were no existing technologies similar to the proposed the application, the decision was made to develop a number of probes in preparation for a design-after-design process like the one utilised by Brereton et al. [124]. To achieve this, the probe was built using the requirements identified by experts in learning disabilities. Target stakeholders may then contribute to the design process by interacting with the probe, having their actions monitored and subsequently analysed, and then suggesting any potential issues they have or additional requirements that need to be met.

By following the Complex Intervention Framework, probes would not have been evaluated until the end of the Piloting stage. However, since a number of key requirements were identified during the scoping review, the author decided to develop a lightweight probe containing the basic features and potential layout of the application and present this to the experts involved in the semi-structured interviews. Presenting probes early on in the process provided multiple opportunities to receive feedback on the system and address key design flaws, thus ensuring the final probe is better suited to the complex needs of adults with mild learning disabilities.

Semi-Structured Interviews

In order to triangulate the data extracted during the scoping review, and to obtain further possible requirements for the application, semi-structured interviews were conducted. Ethical approval to carry out these semi-structured interviews was obtained from the department of Computer and Information Science Ethics Committee at the University of Strathclyde on the 8th of December 2016.

Invitations to participate in the study were issued in Spring 2017. These invitations were sent out to a purposive selection of experts in learning disabilities including governmental advisors, academics, support workers and General practitioners. As

described previously, people with learning disabilities have impaired higher order cognitive skills [121-123] and this may significantly affect their ability to recognise their needs for a system during its early design phases. As such, the author originally interviewed experts in order to gather initial requirements for the system and to develop a second more substantial probe that the stakeholders may utilise in order to make their needs known. This process also involved the evaluation of the lightweight probe discussed previously.

Overall, the target number of experts to be interviewed was set at between 10 and 15 people. This figure was based on the number of interviews (12) suggested by Guest et al. in order to achieve data theme saturation [96 in 97]. 9 interviews were conducted between the months of March and June 2017. One of these interviews involved two people, since the person originally contacted felt that their colleague could contribute to the project and invited them to participate. 21 emails were sent out to various organisations to accommodate for those potential participants who would not respond. Recruitment ceased once appropriate time had been given for all potential participants to respond, and the number of those who consented to participate fell within the sample target size. This occurred in June 2017.

The duration of the interviews ranged between 20 minutes and 1 hour. The mean duration was approximately 34 minutes. By conducting semi-structured interviews containing open-ended questions, there were opportunities for both the interviewer and the interviewee to raise, and expand on, unforeseeable topics [98]. These open-ended questions aimed to validate the information collected during the scoping review. As a result, questions were based on: the challenges involved in the consultation process, the communication challenges between people with learning disabilities and the general population, communication modalities, communication aids, the aesthetics of the intended application, and the features that should be included in the application.

Once all initial questions had been answered, the author presented the initial lightweight probe (developed using the requirements extracted during the scoping review) to the participant(s). They were then prompted to give their views on the overall look and feel of the probe, the features that may support or hinder the patient to provide medical information and any further features to be included. This

information was used to develop a second more complete probe, which was presented to further experts during the study described in Chapter 6. The individual questions involved in the interviews may be found in Appendix B. Separate question sets were developed for the GPs and the remaining interviewees, since their areas of expertise differ dramatically.

All but one of the interviews was conducted face to face at a location convenient to the participant. One interview was carried out with the use of Skype in order to overcome geographical challenges. Interviews were recorded with participant consent and subsequently transcribed by the author to enhance their understanding of the data. 4 of the participants were male and 6 female.

3.2.3 Modelling Process and Outcomes

This stage involved using the data collected previously to design the intended intervention, including revealing how the application fits into current practice. Section 3.2.2 partially contributed to this with the creation of the initial probe. However, further requirements were identified throughout the semi-structured interviews, along with potential features that may be improved upon. As a result, the initial probe had to be updated to reflect these requirements.

To develop an updated design of the proposed application, the author made use of the data collected throughout the scoping review and semi-structured interview stages. As described in section 3.2.2, a framework analysis of the scoping review was conducted in order to produce a structured summary of the key requirements gathered throughout. Since the questions asked during the interviews were intended to validate the data discovered during this review, it was a natural decision to conduct a framework analysis of the transcripts based on the themes and sub-themes identified within the review. This enabled a structured summary [92] of the key requirements identified during the interviews to be produced. An in-depth analysis of the steps involved in the process was discussed by Parkinson et al. [93]

As mentioned, the codes used throughout the framework analysis primarily reflected the themes and sub-themes produced during the scoping review. However, due to the semi-structured nature of the interviews, a host of information was produced that did

not fit into these themes. Therefore, a number of new codes were created in order to address these key points.

Relevant excerpts throughout the copies of the transcripts were highlighted and tagged appropriately by the author. Some excerpts addressed a number of themes and were therefore tagged multiple times. Once all transcripts had been coded, the highlighted excerpts were transferred into their appropriate positions in the framework analysis table contained within a separate Excel document. This table was comprised of codes, which represented the columns, and individual cases which represented the rows, as shown in table 5. This allowed the author to scrutinise specific interviews by reading across rows, but also analyse how specific codes were addressed across multiple interviews by reading down columns [93].

Table 5: A Representation of the Framework Analysis Table used to Structure the Findings from the Semi-structured Interviews

	Theme A	Theme B	Theme C
Case 1	Summary	Summary	Summary
Case 2	Summary	Summary	Summary
Case 3	Summary	Summary	Summary

The excerpts contained within the framework analysis table were then combined with those extracted during the previous stage in order to justify the decisions made when designing the second probe. This ensured that the requirements implemented were based around the collective knowledge held by the experts interviewed, as well as those who authored the papers included within review. As a result, the application has been designed to better suit the complex needs of those who have mild learning disabilities, and therefore has a higher chance of being successful in changing current practice.

Data saturation was explored during this process by analysing the codes that were developed. The final transcript of each sub-group involved in the interviews was analysed and any new codes created were noted. If these codes were determined to have a significant impact on the development of the proposed application, then the author acknowledged that saturation did not occur.

3.3 Feasibility and Piloting

The objective of the framework's Piloting stage is to test the feasibility of delivering the intervention and to determine how accepted it may be by the stakeholders [99]. Essentially, the intervention is piloted with a number of stakeholders before being implemented into practice and a large-scale study takes place. To accomplish this, the initial probe developed in section 3.2.2 was updated using the requirements gathered during the previous semi-structured interviews. Rather than involving adults with mild learning disabilities at this stage, the probe was presented to further learning disability experts during a round of usability studies. This ensures that all glaring design flaws are addressed before the application is presented to the vulnerable learning disability population.

These evaluations were modelled around usability tests, a process that is described in more detail by Dumas and Redice [100]. Ethical approval to carry out this study was obtained from the Department of Computer and Information Science Ethics Committee at the University of Strathclyde on the 3rd of August 2017.

Invitations to participate in the study were issued at the beginning of August 2017. These invitations were sent out to those experts who originally participated in the requirements gathering process, since they had prior knowledge of the project and understood what the application's goals were. Three evaluation studies were conducted throughout the month of August, one of which involved two people as it was convenient for them to meet at the same time and place. Initially the sample size was set at between 3 and 5 participants since Dumas and Redice suggested that this number enables key design and usability flaws to be identified and subsequently addressed over a short period of time, rather than having to carry out an extensive number of studies in order to obtain similar information [100]. Once the probe has

been updated, a further 3-5 studies may then be carried out to refine the design if necessary.

Participants were required to complete two scenarios that had been designed to explore the various features embedded within the probe. These scenarios will be described in detail in chapter 6. No assistance was provided during the completion of these scenarios except at stages where participants were unable to complete a given task, at which point appropriate feedback was given. This ensured that the author did not influence the actions of participants and that key design flaws were identified [100]. Any points of indecision were also observed and noted by the author in order to be explored further at the end of the interview. The total time taken to complete the tasks was over 1 hour, with each session averaging 21 minutes.

On completion of the scenarios, the participants were asked a series of questions that extracted their views on their overall experience with the application along with whether it is appropriate for adults with mild learning disabilities. This enabled features to be identified that may succeed in aiding patients with mild learning disabilities in describing medical symptoms as well as those that may hinder the process. Once again, the evaluation studies were conducted on a semi-structured basis to ensure all participants had the chance to discuss issues that were unforeseeable [98]. The questions asked throughout may be found in Appendix C.

The sessions were recorded with consent and transcribed by the author to further aid their understanding of the data captured. These transcriptions were once again subjected to a framework analysis process similar to that described in section 3.2.3. Since many of the requirements used to develop the application stemmed from the scoping review conducted in chapter 2, a large proportion of the feedback received reflected the themes identified throughout the review. Therefore, a framework analysis of the transcripts was once again conducted using these themes as codes. However, due to the semi-structured nature a number of issues were raised that did not

of views, as well the scrutiny of individual interviews [93]. Overall, the data captured may be used to update the most recent probe to ensure it addresses the needs of the

target population before being presented to adults with mild learning disabilities for further testing. Data saturation was measured in a similar way to the previous section.

3.4 Evaluation

3.4.1 Assessing Effectiveness / Understanding Change Process

The evaluation stage within the MRC Complex Intervention Framework would require the application to be embedded within the environment it was designed for and is therefore out of scope for this project. Essentially, this would involve having adults with mild learning disabilities use the application during consultations with GPs. On completion, both the GPs and patients would be asked questions that aim to extract their views on their experience with the application. On top of this, other factors such as the return rates of patients, the accuracy of the diagnoses being made, and consultation duration may be measured. The quantitative and qualitative data captured would then be analysed, in order to determine the overall effectiveness of the application. The sample size of this study should be large in order to capture the unique views of adults with learning disabilities. Due to the iterative cycle of the framework, data from this stage may prompt a return to the feasibility/piloting stage in order to make significant changes to the intervention. This ensures that the intervention has every opportunity to be successful in achieving its intended purpose.

3.4.2 Assessing Cost-effectiveness

Determining how cost-effective the application may be is also out of the scope of this project. However, the costs potentially inflicted by general practice organisations may include acquiring a licence to use the application, the initial purchase of suitable tablet devices, replacing damaged devices, and internet services. The potential benefits to the organisations include, an increase in the number of accurate diagnoses being made thus resulting in the correct medicines being prescribed, a reduction in patients returning for a second consultation, and a reduction in consultation times meaning more patients may be seen throughout the day.

3.5 Implementation

The implementation stage is similar to that of the evaluation stage, except that the studies are carried out over an extensive period. Consequently, this stage is also out of scope for the project. Similar factors to that mentioned in section 2.4 will be measured including how cost effective the intervention may be. The duration of study should be around 3 years with detailed information being recorded and analysed at various stages throughout.

Overall, the MRC Complex Intervention Framework is an iterative process where results from one stage may prompt researchers to return to a previous stage. Consequently, future studies conducted with stakeholders may prompt the author to return to the Development stage in order to update the initial requirements that were gathered. Nonetheless, the research conducted throughout this thesis has resulted in the development of a strong initial specification for an application that assists adults with mild learning disabilities during clinical consultations.

3.6 Alternatives

The Complex Intervention Framework prioritises the collection of evidence to ensure the developed technology/guideline/process etc. achieves its goal of improving patient care. This is achieved through an iterative process where the results from one stage may significantly affect those obtained during previous stages. As such, the researchers must return to these stages and act appropriately and the author believes that this process is highly suitable when developing technologies that cater for stakeholders with learning disabilities. The LD population is heterogeneous in nature meaning users will require a combination of needs to be met to operate the product effectively. These needs may be difficult to extract initially and may only become apparent when the technology is embedded within the target environment. Consequently, it was appropriate to first develop several iterations of a probe based on the requirements extracted from experts before piloting it with target stakeholders, at which point they may significantly affect the look and functionality of the application by utilising a design after design process similar to Brereton et al. [124]. The probe can then be updated to form an intervention that aims to promote communication between patients with mild LDs and medical professionals. This may ultimately

increase the probability of an accurate diagnosis occurring, thus improving the health of patients with learning disabilities.

The main alternative to this process would have been to include target stakeholders from the offset. As such, user-centred design techniques would have been crucial to the success of the proposed application and may have been combined with the action research [130] process shown in Figure 9. This cycle begins with identifying a problem that needs to be solved and planning how this may be achieved. The scoping review process described previously may be instrumental in attaining this. For example, the review revealed that ineffective communication is a serious problem within consultations involving patients with LDs and highlighted the potential impact high-tech AAC solutions may have in promoting such communication.

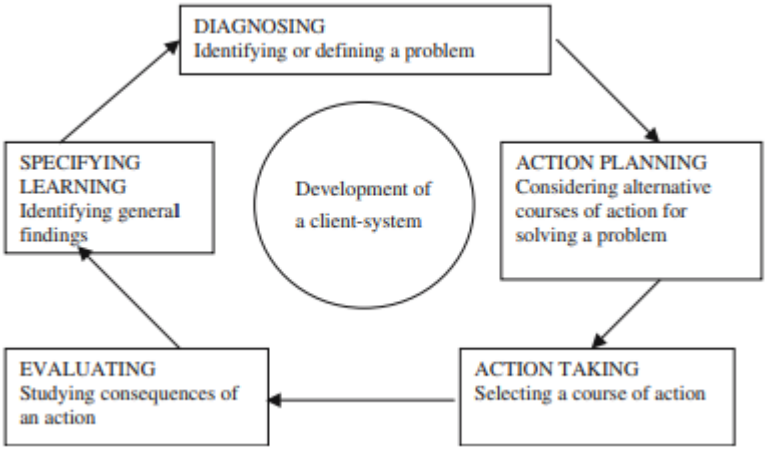


Figure 9: Cyclic process of Action Research. [130]

Process mapping [131] may then be used to understand how consultations are carried out and how AAC technologies can fit into and improve current practice. This may include observing a number of consultations and detailing the steps involved and interviewing the various stakeholders to identify their roles within the process. Requirements gathering interviews and co-design workshops may then be utilised to try and discern the look, feel and functionality of the technology. A rapid prototyping process may then be employed to translate the extracted requirements into design features before evaluating whether these features meet the needs of the stakeholders. The overall cycle may then be repeated until the prototypes are built up to form the

final product. This process is similar to the Complex Intervention Framework in that it places emphasis on the collection and reporting of evidence to ensure a developed intervention / technology achieves its goal. The author ultimately went with the approach used due to the lack of existing technologies that may have been utilised within the co-design workshops to help ease the load placed on the stakeholder's higher-order cognitive skills such as abstraction and imagination. The time restrictions placed on the research in comparison to the time required to identify, set-up and carry out studies with such a hard to reach population was also a significant factor.

Chapter 4

Requirements Gathering

The scoping review conducted in chapter 2 enabled the author to collect evidence on the potential impact the proposed intervention may have. Furthermore, a number of requirements were identified that could potentially shape the design of the application. The purpose of this chapter is to present the most significant findings from a series of interviews, carried out with learning disability experts, which aimed to triangulate these requirements. As a result, evidence as to how the proposed intervention may overcome the communication challenges that exist between GPs and patients with learning disabilities has been produced. The data collected during these interviews has contributed to the completion of the "identifying/developing theory" stage of the Complex Intervention Framework.

Due to the wide range of expertise possessed by the participants, a variety of requirements were gathered during this stage - many of which catered for the needs of an individual. Rather than trying to build a more complex application that caters for all of these requirements, the author decided to implement only those that occurred as common themes across a number of interviews and would accommodate for a large proportion of potential stakeholders. Those requirements supported by the literature identified during the Scoping review were also included and will be discussed throughout.

The chapter will begin with a recap of the methods used to conduct the interviews. The requirements that were discovered during the scoping review, and subsequently triangulated throughout the semi structured interviews will then be presented. Finally, additional requirements that emerged during the interviews will be discussed.

4.1 Methodology

In order to triangulate the data extracted during the previous framework analysis process, and to obtain further possible requirements for the application, semi-structured interviews were conducted. A purposive selection of experts in learning disabilities was invited to participate within the study including governmental

advisors, academics, support workers and General Practitioners. An overview of the professions held by the experts interviewed may be found in table 6 to give an idea of the validity of the data captured.

Table 6: Professions of the experts interviewed.

Profession	Job Description
1	Governmental advisor – Gathers evidence for the Scottish Government on the health inequalities experienced by those who have learning disabilities. Previous support worker for people with severe and profound learning disabilities.
2	Governmental advisor involved in the coproduction of policies affecting those who have learning disabilities. Previous support worker.
3	Full time support worker for a learning disability charity.
4	Academic in social work and social policy.
5	Governmental advisor involved in promoting Scotland's "Keys to life" strategy.
6	General Practitioner
7	General Practitioner
8	Academic in inclusive education. Previously involved with a special needs school.
9	Academic in cognitive psychology. Developed accessible information resources for the NHS
10	Academic in aging, frailty and dementia. Previously involved with a national LD charity

As described in chapter 3, experts were originally interviewed in order to gather initial requirements for the system and to develop an appropriate probe that may address the needs of adults who have mild learning disabilities. The more vulnerable learning disability population will then be invited to evaluate this probe (during future studies) to confirm these requirements and to suggest further features to be implemented. This

approach may ultimately result in the development of an interface that addresses the complex needs of adults with MLDs.

The interviews were recorded with consent and transcribed verbatim. A framework analysis of the transcriptions was conducted in order to produce a structured summary of the views held by the participants. The codes used to conduct this analysis primarily consisted of the themes and sub-themes identified throughout the scoping review since the questions presented to the participants aimed to validate this data. The resulting framework analysis table may be found using the following web link: http://dx.doi.org/10.15129/7fed3a65-9ac4-4152-953b-b606376b64b5. The cell rows are organised to reflect the participant ID's found in table 6 with the exception that participant 1 and 2's views have been combined into the one row (2), since they participated in the same interview. All ticks and stutters contained within the excerpts presented throughout this thesis have been removed.

4.2 Triangulated Requirements

This subsection presents those requirements identified during the scoping review and subsequently triangulated by the semi-structured interviews. The section will be organised to reflect the themes that emerged during the review.

4.2.1 Communication Challenges

The primary reason identified during the scoping review [4, 17, 28, 36, 54] for the challenging nature of consultations involving adults with mild learning disabilities was the breakdown in communication between patients and GPs. Both GPs interviewed agreed with this statement and suggested that the inability to describe symptoms in a clear manner, both on the physician's part as well as the patients, may contribute heavily to this breakdown; as discussed by participant seven, *"the persons understanding of their condition for instance, their interpretation of symptoms may be different, their ability to communicate symptoms may be different. Our ability on the practitioner's side to elicit those symptoms may be different or more challenging. Our ability to conduct an examination may be more challenging. People, ultimately a consultation is based around communication, two-way communication and at times*

aspects of that communication can be difficult whether it be to do with comprehension or to do with abstract thinking or just basic communication."

To try to accommodate for this, developers must be mindful of the language used to present symptoms to stakeholders, be that through text or speech. Due to their sub-par communication skills, adults with learning disabilities may not possess the ability to convey or understand complex information, particularly when medical terms are used. Instead, text should be presented in its simplest form where appropriate and avoid the use of medical jargon; as summed up by participant four, *"just in terms of language, making sure you keep the language as simple as possible, not using jargon and things like that."* Nevertheless, participant 10 revealed that any language used throughout the application would unlikely be suitable to all users *"Sometimes the terms that are used so if we say to someone "can you tell me where you are in pain" the term "in pain" might actually not be the right term to use and sometimes that's more down to local kind of colloquialisms. So "where are you hurting" might actually be the right term to use rather than "are you in pain"."* Further requirements that ease the burden placed on adults with mild learning disabilities when reading text will be discussed in sections 4.2.4 and 4.2.6.

As discussed in chapter 2, adults with learning disabilities may be illiterate and have great difficulty reading text. Several of the experts mentioned easy read as a possible alternative for this population, which involves the combination of simple language and pictures in order to make information more accessible. Easy read will be discussed in more detail in section 4.2.2. Helmsley and Balandin [133] cited several strategies to improve communication with patients who have severe impairments including the need to: "*the need to: consider the patient as an individual, gain the patient's attention, talk directly to the patient using the patient's preferred communication mode, use clear, jargon-free explanations, check that the patient understands, observe the patient closely, respond to non-verbal communication, and attempt to paraphrase and rephrase messages that are not understood."*

4.2.2 Communication Modalities

Adults with mild learning disabilities are highly heterogeneous and therefore may not respond to information in the same manner as others [4, 26-27, 29, 53]. The experts interviewed agreed heavily with this and revealed that they use a variety of modalities in order to accommodate for an individual's needs. The most common modality used by the experts was pictures. Pictures enable information to be represented in a format that is fathomable for those who are unable to read, providing they are immediately identifiable. They may symbolize options from which the user can choose from or simply act as a "visual record" during face to face conversations, as described by participant 9, *"it was just extra prompts to help deal with memory deficits and have a kind of visual record in front of somebody so they can keep track of where they are. And concrete things are very helpful if there's something there that can be pointed to as a reminder or help, sort of, keep a focus I think that helps."* As a result, using images to represent symptoms may enable those who have deficits in their memory, as well as those who are illiterate, to provide further information to General Practitioners. This may ultimately result in an increase in accurate diagnoses being carried out.

Overuse of pictures however, may have detrimental effects as conveyed by participant 4, *"I think sometimes what people have a tendency to do is when they're trying to make something accessible they're just trying to replace words with pictures and sometimes I don't think that's always helpful because I think there's a process isn't there in trying to kind of figure out what the picture actually means. So sometimes, I think the more words you replace with pictures that you're speaking, you'll be overcomplicating things. So only use pictures where it's appropriate I think is what I would say."* Therefore, a balance must be struck in relation to the cognitive abilities of potential users and the number of images displayed on each page. This will be discussed in more depth in section 4.2.4. Text must also be used as a contingency plan for those stakeholders who are unable to comprehend the meaning conveyed by the picture. This follows participant eights expectations of the application, *"for something like a sore thumb it might be like a thumb with a kind of throbbing picture or something like that on it. It's that kind of thing but you could have the word underneath it as well.*" This combination of images and clear, concise language has been incorporated within previous low-tech resources [127-129] that aim to improve the information exchange

between medical professionals and patients with communication impairments, thus highlighting the important roles these modalities may play.

The second main communication modality discussed by the experts is speech. One major problem identified during the scoping review was the dramatic variance in the verbal skills possessed by adults who have learning disabilities, as described by participant 3 *"We have people who have quite complex needs and with no verbal communication. And then we have people who are quite vocal and like to be involved in things and help with the decision making, so, and they're able to express themselves quite easily."* Trying to accommodate for this range may be problematic, but by using the advice disclosed in the previous section, conversations may become more fruitful. Further requirements that ease the burden placed on adults with mild learning disabilities during conversations will be discussed in section 4.3.4.

Speech may be incorporated into the probe by allowing the user to playback any text displayed on the screen. This accommodates for those users who are illiterate and unable to understand the meaning conveyed by a particular image. However, several of the experts revealed that in order for this verbal feedback to be effective, the pace at which it is returned must be altered to suit the needs of each individual; as summed up by participant two, *"I think being really clear, being really structured and taking time is really important to going at the pace of the person rather than at your own, at your pace."* Therefore, the pace at which speech is returned should be made customisable and the option to playback speech at any time must be implemented, to ensure that the user may fully understand the information being presented.

Two of the experts revealed that a combination of these two modalities may provide the most effective strategy in communicating with the target population; as outlined by participant four, *"I think verbal communication is best where possible and then following it up with writing and pictures."* However, they also discussed the need for repetition, *"I think repetition actually is really important so if you have something in a written format that you want to give someone it's probably important to talk to them about it first and then give them the information away with them so they've got something they can use to kind of jog their memory".* Therefore, within the application, both images and text should be used to represent all symptoms displayed.

An option to playback this text must also be provided for those who fail to grasp the meaning conveyed by the previous modalities.

In summary, the experts have triangulated the requirement to ensure a number of modalities are targeted throughout AAC devices. This may enable a wide range of users to utilise the application effectively, since potential stakeholders can make use of the modality that makes most sense to them during each individual case.

4.2.3 Communication Aids

Both GPs revealed that they were yet to come across patients who had used communication aids in the past. However, they believed that they would be open to this providing the aids were accessible, as summed up by participant seven, *"in theory if it was easy for the individual to use and they were going to use it I can't see any reason why that wouldn't be beneficial."* Previous research has indicated that the use of communication aids within the clinical setting can greatly improve the care provided to people who have serious communication impairments [132]. 55% of the nurses interviewed by Helmsley et al. directly attributed the use of AAC strategies to the successful communication experiences they have been involved in. However, the nurses suggested that they were far more familiar with the use of ow-tech resources such as symbol boards (95%) and alphabet boards (85%) as opposed to high-tech communication devices (55%). In stark contrast, many of the other experts interviewed discussed experiences where they have used communication aids. These tended to be pictorial based, with Talking Mats being discussed prominently throughout.

The primary reason identified during the scoping review for the success of Talking Mats was the ability to break down complex information into more manageable chunks [49, 59, 62]. Participant two explicitly agreed with this statement and believes that small, straightforward questions are key to extracting information from the learning disability population, *"you have a problem which you need an answer to and the process of deconstructing that problem into lots of different component parts and that provides a useful framework for people to think about. So, I think that structured framework, breaking things down into very small straightforward questions [would be*

useful]". Furthermore, four experts went one stage further and revealed that the information contained within these questions should focus on solitary ideas in order to avoid confusing the user; as summed up by participant 1, *"so we'll take some more detailed information and we'll break that down into what we call accessible language. So, if a sentence has got for example lots of clauses in it you break it down and use just one idea to make a sentence."*

However, since Talking Mats makes extensive use of images it may not suitable for all potential users, as discussed by participant 10, *"I've used pictorial communication in research but not as a starting point. I would always get to know the person first and then try to work out what the best method of communication might be."* Instead, a range of modalities should be targeted to ensure that a variety of needs is catered for.

4.2.4 Barriers to Technology/Accessibility

Simplicity

As discussed in Chapter 2, operational difficulties lead to high rates of AAC device abandonment [119]. Adults with learning disabilities tend to revert to traditional forms of communication, such as pointing, if a device is overly complex and difficult to use. Several of the experts disclosed the need for simplicity to ensure that stakeholders are successful in using the proposed application; as outlined by participant ten, *"Again it would depend on how easy they were to use but the quicker the better I would say. The shorter the better in terms of how much time someone would have to [complete it]. So, if it's, so easy to use absolutely, reduce [the] number…. limited…. as few kind of steps in the process, as few clicks in the process as possible."*

Therefore, reducing the number of clicks required to complete a process may increase simplicity. Consequently, reducing the amount of questions presented to stakeholders may increase their ability to complete the questionnaire and thus provide significant information to their GPs. As a result, a static questionnaire would be unsuitable for the proposed application, since patients will be required to answer a large number of irrelevant questions whilst trying to provide meaningful information about the condition. Instead, future questions presented should be shaped by the information submitted previously, thus closely mimicking the consultation process as described by

participant seven, *"I think the first question would be hi how can I help you today? How are you getting on? How, how are you managing? You know how are things? And then it really, each subsequent question depends on that."*

To ensure that future questions are shaped by the data submitted previously, a stack based questionnaire may be implemented. This process will be discussed in depth in Chapter 5, but a summary will subsequently be provided. A main questionnaire stack will be used to present questions to the patient and this stack will vary depending on the initial symptom selected by the user. For example if the user selects that their primary symptom is pain in their eye, then the questions relating to eye pain will be loaded into the stack. Questions will be popped sequentially from the top of stack and presented to the user if they fulfil the required conditions; otherwise they will be discarded and the next suitable question will be presented. The questionnaire has been completed when there are no more questions to be popped from the stack.

Further questions may also be added to the top of the stack depending on the answers selected by the user. If the patient reveals that they have itchy red eyelids before the above questionnaire has been completed, then this may suggest that they are suffering from blepharitis. As a result, the questions designed to extract the symptoms of blepharitis are added to the top of the questionnaire stack in order to be presented. Consequently, the application has the potential to limit the number of irrelevant questions being presented to the user, since only those deemed relevant to the patient's condition are added to the stack. This may also be advantageous to those stakeholders who have limited attention and working memory spans as reducing the number of questions presented decreases the cognitive load placed on such users.

One other method for reducing the cognitive load placed on potential users would be to reduce the number of options presented. Overall, the experts agreed that the amount of choice available to adults with mild learning disabilities should be limited in order to avoid confusing the user, and this was aptly summarized by participant four, *"if there's too many choices things get really confusing and complicated but if it's completely open-ended someone might find it difficult to think of the words that they need or, so having options but not too many I think is important."* However, there was a lack of consensus regarding the number of options that should be presented to the

user. Participant nine found that this population tends to be excluded from the decision making process and consequently are indecisive when presented with choice. As a result, the number of options available to them should be reduced to a minimum, *"we did a project on choice. We found that when you give people with learning disabilities a choice, they're not used to getting a choice, they're not really sure. So maybe keeping options kind of limited and that, building it out in a kind of, you know, kind of structure so that when you get to the end point you might have to go the long route rather than the shortcut."*

Participant four also agreed with this perspective to an extent by revealing that "yes or no" questions should be implemented in order to keep the application as simple as possible, *"so keeping it simple I think is important. The other thing that's probably be important, well I don't know, I'm thinking giving people yes/no options, things to choose between."* The nurses interviewed in Helmsley's study stated that establishing a system to convey yes or no is a process crucial to communicating with those who have sever communication impairments [132]. Prior also found that the participants involved in her study preferred to answer yes/no questions as opposed to those with a greater amount of options [134]. However, several of the other experts were of the opinion that adults with mild learning disabilities would be able to cope with more choice and stated that up to 3 and 4 options could be used. Participant eight took this a stage further by discussing the potential of altering the number of options available to stakeholders, *"the amount of information that appears, the amount of words, the amount of detail will vary from, so it can be tailored. And I, I think it's quite a useful thing because again you know some person might cope with quite a large volume of information and some people might need very, cope with very little you know two or three items so again I keep coming back to you know it depends on what the individual needs. So I think if you were developing something my recommendation would be to develop something that was very flexible that you could adapt to the individual needs of a person."*

Evidently, the experts had conflicting views in this area. However, there was an agreement that the maximum number of options displayed on the screen should not exceed four. If a potential condition has a range of symptoms surpassing four, then

the application must break these down into related sets. The excess options may then be presented in the future pages. Not only does this accommodate for those who have cognitive impairments, but also for those who have visual deficiencies. By limiting the number of options displayed on the screen, the elements used to represent these can be increased in size, thus enabling those who are short sighted to see the text and images used to convey symptoms more clearly.

By presenting potential symptoms in sets of four, the number of clicks required to complete the application will increase since the user will be required to answer a larger number of questions. This actively contradicts the advice described previously; however, the author believes that the advantages described above outweigh the need to restrict the number of clicks required to complete the questionnaire.

Screen Size / Motor Problems

Screen size was another significant problem identified throughout the scoping review [56-57]. Many interactions with mobile phones require an array of highly coordinated fine-motor movements such as swiping and pinching. If the screen size is too small then the user may not be able to perform the required movement successfully. By using tablets these issues may be mitigated since clickable elements may be expanded in order to increase their surface areas and the probability of users with motor impairments clicking on the objects they intended to. However, this may result in devices being much too large and heavy for certain users.

To accommodate for this contrast participant eight revealed that the overall size of the tablet should not be set and instead should vary depending on the specific needs of the user, *"if it's a tablet for example are you going to ask them to hold it? Is it going to be mounted or whatever? I also, like I think you know it goes beyond just learning difficulties, [it's] to do with for example for people with say a visual impairment or people who have got problems with motor skills but may not necessarily have learning difficulties. So there's a kind of [an] overlap in those areas. I would do it around the basis of the individual you know, what works for that particular individual."* As a result, the author believes that the application should be developed in a way which

ports readily across different operating systems and screen sizes. Stakeholders may then run the application on the device that is most suited to their complex needs.

Cost

As disclosed in Chapter 2, traditional AAC devices tend to be inaccessible to adults with mild learning disabilities as they are expensive and there is a lack of funding available to access such services [12, 19, 21]. Tablets and their subsequent applications tend to be much cheaper; however, several of the experts revealed that many potential stakeholders still suffer from digital exclusion; as summed up by participant two, *"So it's access to the actual hardware. So a lot of people with learning disabilities experience poverty and probably don't have the iPhones and the iPads and the touch screen stuff. They maybe you know, I suppose the consideration for you is the impact of digital exclusion on this population whether they have access to the actual technologies in the first place".* This highlights the need for the simplistic user interface described previously as many stakeholders may be unfamiliar with how to operate such technology.

Since many potential stakeholders experience poverty, a large number will be unable to gain access to the technology required to run the application. Therefore, the practice may be liable to supply such devices to those who are in need, providing the correct funding is accessed; as described by participant seven, *"I've never seen anyone come in with a tablet to aid in communication. Unless there was ring-fenced funding for general practice to, for instance we have things called locally enhanced services or LES, you know hypothetically there could be a LES for people with learning difficulties. And if that included funding for training and extra time and a lap, a tablet with practice, familiarity in training in how to use the tablet that could be worthwhile".* Helmsley and Balandin have also called for practices to provide a range of communication aids to help support patients with a variety of communication impairments [133]. To aid the chances of securing such funding, the application should be relatively inexpensive and be able to operate effectively within cheaper models of tablets to ensure that broken devices can be replaced easily.

4.2.5 Professionals Attitude

The literature identified during the scoping review revealed that GPs rely heavily on carers to facilitate communication between themselves and patients with learning disabilities [36]. Both GPs interviewed agreed with this statement and believe that these carers play a key role in consultations involving patients who have communication difficulties; as discussed by participant six, *"The only difference I would say is if a person has got severe difficulties with communication and you are not able to understand what the symptoms are or how long they've been there you sometimes do have to rely on their overall behaviour which you can ask the carers. You know, have they been distressed, and are they eating well? Are they, what are they sleeping well, what their toilet habits are, and that may give, that may become more relevant in this particular scenario than in the general population."* However, the views provided by these carers may not necessarily match those of the patient. Additionally, people with learning disabilities tend to object to the GP bypassing their own views in order to speak to their carer [36]. Therefore, a far better option would be to address the patients directly in order to extract accurate information about the symptoms they are experiencing.

This reliance on carers may be down to a lack of awareness on the range of communication disabilities that exist and the various strategies that may be used to overcome them [133]. Participant seven discussed the lack of training they received on learning disabilities during their studies and this may be a primary factor in the gaps of knowledge held by GPs, *"I wouldn't say we've ever had or I've ever had any specific training around that [learning disabilities]. I mean there's the odd bit and piece over the course both undergraduate and postgraduate. So for instance I remember at medical school we had sections with, around communicating with people who either have hearing impairments or were visually impaired. So there was an element of that awareness and some of the specific issues there. And then again during my GP training I would say it was more on the job rather than sort of dedicated training. But for instance you know how you might conduct a consultation using written notes or using the computer was discussed but I wouldn't say it's done certainly not in any great detail."* This may contrast to the training received by nurses, with a study by Helmsley et al. [132] suggesting that the majority of nurses interviewed (90%) had received training around a number of disabilities that may affect

communication, including LDs. Nevertheless, the type of training received may have been inappropriate with none of the participants stating that they had been trained by a speech language therapist to communicate effectively with a patient who has severe impairment [132]. Such training should also be carried out in *"naturalistic situations with the opportunity for modelling, targeted feedback, cues, and practice."* [133].

Even though the General Practitioners are aware that they require further training on learning disabilities, participant six revealed that they are unwilling to seek out such facilities since only a small proportion of patients they treat have such conditions, *"I would say that it has, that the training resources has to, you know, has to be proportionate to the scale of the problem. It does vary, it is not a scenario you come across very frequently. So I have not particularly looked for any training resources so I'm not aware how many training resources are available."* As a result, the author believes that the application should support GPs in diagnosing the patient by supplying accurate medical information obtained directly from the patients. This has the potential to alleviate time constraints by presenting GPs with information that may then be used to shape the questions presented throughout the consultation.

4.2.6 Individualisation

As described in Chapter 2, alternative and augmentative communication devices are unable to satisfy the complex needs of all potential stakeholders, due to their heterogeneous nature [4, 26-27, 29, 53]. Instead, greater attention to the necessities and characteristics of an individual is required in order to select the most appropriate device available to them. Seven of the experts interviewed explicitly agreed with the fact that communication strategies must be altered depending on the abilities and needs of the individual, and this was aptly summed up by participant one, *"I think just to highlight one of the things that was said is that it's not a one size fits all approach, it is a tailored, you can tailor it to each individual needs. So that's something that's quite important."*

This excerpt revealed that to be effective for a wide range of stakeholders, AAC devices must be customisable in order to accommodate for a multitude of complex needs. The user may simply select the settings that they find to be most useful to

them. However, participant eight urged developers of AAC technologies to be wary of customisation, *"I do worry about things getting too individualised, you know, like, you know it's so that it can't be shared in any way"*. Therefore, a balance must be struck between customisation and the ability to share common functionality between a large range of users. As a result, the author believes that the aesthetics of the application should be made customisable by the user in order to satisfy background colour requirements, audio preferences etc.; however, the content should remain the same for all users. This will be discussed in further detail in chapter 7.

Over-customisation was taken into consideration when developing the requirements for the proposed application. The experts discussed a multitude of requirements due to their diverse background in working with people who have learning disabilities. Rather than trying to incorporate all of these into one application, the author extracted those identified as common themes. This ensured that the proposed application has been designed to address the most common needs and that the user interface is not overly complex by trying to accommodate for more individual requirements.

4.2.7 Co-design

Several studies within the scoping review emphasised the need to include representative users throughout the lifecycle of a system, to ensure that it succeeds in achieving its intention and becomes successful [18, 22, 70, 78]. Many of the experts partially agreed with this statement, and proposed that potential stakeholders should be involved within the design and testing stages of the application. However, the initial design of the proposed application was conducted with the use of experts before the more vulnerable learning disability population is introduced during future studies. Norman suggests that stakeholders are initially unsure of the features and functionality required by a system and their views only become clear once they have interacted with early prototypes [95]. Therefore, the author gathered initial requirements from experts in learning disabilities before developing a probe that may be presented to stakeholders during future studies. This will enable the target population to triangulate these requirements and reveal if any of their complex needs are currently not met.

Overall, the advice given by these experts on including adults with mild learning disabilities within research differed dramatically. Participant two believed that a wide range of abilities should be involved in order to give a true representation of how well the application performs across subgroups, *"obviously the more diverse that group is the better because you can the start to say well that works with that group of people but maybe not for that group of people. So it's really essential I think that when you developed your, I suppose you've developed some early prototype you might take an opportunity to get a group of people together."*

Conversely, participant nine believed that a specific sub group within the learning disability community should be targeted, since it is unlikely that the application will be able to scale across the entire population, *"in my opinion, you go down one route you make, you target one particular population so down syndrome, autism, whatever you chose."* Initially the application will be designed to accommodate for the most common needs throughout the entirety of the mild learning disability population. During future studies, subgroups will be explored in order to determine those that respond to the application best. Further functionality will then be embedded into the application that addresses the specific needs of these groups.

4.3 Further Requirements

Due to the semi-structured nature of the interviews, an abundance of requirements were discussed that were not identified within the scoping review. This section subsequently presents the requirements identified by the learning disability experts interviewed.

4.3.1 Content

Conditions

The experts revealed that a variety of questions should be explored by the proposed application. Firstly, the symptoms presented to stakeholders should be informed by the specific health needs of adults with learning disabilities, rather than that of the general population since these differ greatly. Participant two strongly believed that this should be a key requirement, *"the content needs to be informed by the specific*

health experiences of people with learning disabilities. So people with learning disabilities have different patterns of diseases to people in the general population so more, different kinds of cancers for example are more prevalent in the population of learning disabilities. Similarly you know different other physical health conditions are more prevalent."

It may be safe to assume that the majority of patients with mild learning disabilities will be attending consultations to seek treatment for one of these conditions. Thereby focusing on these disorders, the application has the potential to further reduce the number of irrelevant questions being presented to the user. Participant ten discussed in detail the types of conditions that the application should target, *"cancers for example in people with learning disability are often quite progressed and advanced when things are picked up because of the overshadowing. And it's often, someone is perhaps taken later to a GP because staff or family don't realise that there's other things going on as well. I would tie in with that not just health but sensory people use as well then I think professionals whether health or social care are not so good at that picking up. A lot of things are perhaps due to failing eye conditions, difficulty with failing eyesight or eye conditions associated with getting older and hearing loss that again are not picked up. And so we sometimes think there's things going on more serious than, actually it's just a case of it's an eye condition, it's cataract so I would perhaps tie sensory awareness with health conditions as well. Gastrointestinal is a particular issue for people with a learning disability. We obviously know of like dementia at a younger age in people with downs syndrome who also have narrower ear canals so hearing loss is an issue as well, along with certain sight conditions and epilepsy as, particularly as related with dementia as well. [There was a] study that was done in a few health boards that looked at reasons for death in people with learning disability and the figures they came up with about reasons for premature death in people with learning disability and certainly dementia came up highly in that. Pneumonia came highly in that, breathing difficulties that lead to aspiration pneumonia".* Further conditions to be included within the application will be discussed in Chapter 5.

Questions

Besides the types of conditions the application should attempt to extract, the experts also discussed further questions that should be presented to the user. Participant six described briefly the first five questions they would ask during clinical consultations, including those involving adults with mild learning disabilities, *"The first thing I'd ask is why are they here today? Then whatever they describe, what their perceived problem is you ask for duration, if that has happened before and if there are any other symptoms and, and how they generally."* Four distinct categories of questions were extracted from this excerpt and should subsequently be embedded within the probe where appropriate:

1. Questions designed to extract symptoms experienced by the patient.
2. Questions designed to extract the duration of specific symptoms.
3. Questions designed to extract the history of symptoms.
4. Questions designed to extract the overall health of patients, particularly focusing on their mental well-being since NICE reports that up to 40% of adults with learning disabilities have undiagnosed mental health problems [101].

In order to avoid confusing the user, these questions should be presented one at a time. They should also refrain from being open-ended in order to afford stakeholders the best possible chance of being able to answer them accurately; as described by participant 4, *"Sometimes I think if you leave it really open ended that's a bit more challenging for people so maybe having the conversation or sorry the communication, something that's quite structured so it gives people options to choose between is slightly easier than something that's just completely open ended."* Instead, a variety of options should be presented to the user along with the ability to skip those questions that provide no suitable symptoms.

Feedback

Participant nine discussed the need to be wary of the language used when providing feedback to adults with learning disabilities, due to their general lack of self-esteem, *"I think we, you've got to be really careful in terms of the feedback you provide 'cause self-esteem is generally quite low and if you kind of knock that self-esteem then your*

interaction is not really going to go particularly well. You're not going to get the best out of the individual there." This may partly contribute to the high rate of abandonment discussed in Chapter 2 [119]. Therefore, all feedback provided within AAC technologies should not only be simple but also constructive in order to encourage stakeholders to continue using the intervention.

4.3.2 Content Presentation

Fonts

Two of these experts agreed that a minimum font size of 14 should be incorporated to accommodate for stakeholders who have visual impairments. Additionally, a further two experts suggested that all text should be made as large as possible, in order to ensure that the user has the best possible chance of being able to read and comprehend its meaning. One way of accommodating for this was proposed by participant five, *"generally people prefer large print over small print and so I guess the larger the screen the better".* However, rather than limiting the types of devices used by stakeholders, a function may be developed that stretches text to fill their respective containers. This guarantees that all text contained throughout the application is as large as possible and ensures that flexibility is maintained, since stakeholders may use the tablets that are most suited to their complex needs. Several of the experts also disclosed that some fonts are more accessible than others; however, none were able to specify which families are most effective.

Colours

Six experts revealed that colours are an effective method of aiding adults with mild learning disabilities in the comprehension of text. The most basic way of incorporating colours into the application was discussed by four of these experts, who revealed that contrasting schemes should be used in order to ensure text stands out. Participant five pertinently summed this up, *"[You should use] quite contrasting colours I would say because obviously there's people who have kind of visual impairments so nothing too pastel or, like you know, if like black, white or blue and white would be fine but if it was colours quite similar to one another then it wouldn't be clear enough for a lot of people to see."*

Several of the experts interviewed highlighted the fact that a yellow background has been proven to be effective in aiding those who have dyslexia whilst reading. Adults with learning disabilities may also have dyslexia and therefore providing a yellow background for this population may be advantageous. However, as described in Chapter 2, learning disabilities have a range of manifestations [26] and as a result, stakeholders may react differently to certain colour schemes. To accommodate for this, four of the experts proposed that the application should include a function that allows the user to select the colour scheme implemented; as summed up by participant four who revealed, *"I think different people depending on the kind of condition they have perhaps have different requirements but yellow is the kind of standard one. But normally if someone needs a different colour for whatever reason they'll tell you. So I don't know if there's something that you can change".*

However, the context in which colour is used is extremely important; as summed up by participant 10, *"I tried using the kind of emoticons, smiley faces, sad faces for someone on one occasion and they only saw the colour so they weren't able to recognise the facial expressions."* Therefore, user testing must be conducted when colours are implemented in novel ways.

4.3.3 Setting

Several of the experts believed that an application that provides medical information in advance of consultations, would be the most effective way of aiding GPs during appointments with adults who have mild learning disabilities; as summed up by participant four; *"anything that would help to boost their confidence in terms of making the interaction within the consultation more appropriate and perhaps having the information in advance of the consultation would help with that because then they can actually focus on the kind of questions they want to ask rather than having a blank canvas with no idea of what their issues are."* Essentially, the application may be used as a starting point, since the medical information supplied can be used to shape the questions asked throughout the consultation. This may alleviate some of the time constraints placed on consultations involving adults with learning disabilities.

Not only will this be beneficial to those who have learning disabilities, it may also be advantageous to the general population; as disclosed by participant five, *"I thinking having it available in a GP waiting room might be helpful. And I think actually with a lot of things what we're finding is if you get it right for someone with a learning disability you get it right for everybody. You know in terms of clear communication and so on so maybe that if you do develop this app and having a tablet in the waiting room that's available for anybody is a good idea and because lots of people struggle to articulate what's wrong, where the pain is, what kind of pain it is you know across whole range of symptoms. So there might actually be a better demand, quite a high demand for something like that. I don't know, it's worth testing out."* This may make the application seem more financially viable since participant six revealed that they treat only a few patients who have learning disabilities a month. Thereby, making it available to anyone, and not exclusively to those who have learning disabilities, should increase its usage.

Participants six and seven revealed that this is something they have not come across before but may be beneficial when patients are suffering from more complex conditions, as illustrated by participant seven, *"I think it depends [what] the consultation is for at that particular time. You know certainly for some problems getting information brought to the consultation, so for instance if someone has a history of headaches keeping a headache diary can be useful so you get a sense of what their symptoms are like you know in the preceding week, so that may be beneficial. I mean, I guess it's not the sort of thing which as yet has become routine practice. I don't know if anyone's ever come to me in a consultation with symptoms from an app but in theory if it was easy for the individual to use and they were going to use it I can't see any reason why that wouldn't be beneficial."*

However, there is still some concern over how symptoms deduced by an algorithm will be accepted by physicians, as discussed by participant 7, *"I guess you, you're getting potentially into the territory of using you know computer algorithms on symptoms to more or less tell you what's going on based on computer probabilities and that might be useful but I think it might be met with some resistance from the profession I suspect. I think because there's a limit to what a computer can do I think*

it can be very helpful but ultimately people exist in a social context and many of their symptoms are socially patterned in social form and an understanding of that context is crucial to interpreting those symptoms and you might not get that from a computer algorithm." Consequently, the application should not aim to diagnose the patient but instead provide information that the GP may use to assist them in forming an accurate diagnosis. The intervention must be thoroughly tested to ensure that its benefits are clear and that the GP does not bypass the results produced in favour of forming their own opinion.

4.3.4 Symptom Storage

Besides effective communication, the success of consultations involving adults with mild learning disabilities also relies heavily on the use of patient histories, as described by participant six, "*the second thing you tend to utilize is previous records. Anything in particular for example if they have a particular health problem then you can anticipate certain problems. And, the third thing you try to utilize is history from their carer or family members which often gives you cues to work beyond."* From this excerpt, you may assume that all symptoms selected throughout the application should be stored for subsequent retrieval. However, participant seven believes that this is not necessary and instead only significant symptoms should be stored, *"I tend to think of the GPs role as being in helping to interpret symptoms. So our role is largely often an interpretive role translating people's symptoms alongside any investigations, alongside what we know about probability of conditions prevalence etc. into a formulation of what things going on and addressing any concerns that the individual might have about their symptoms. So to that extent you know I don't always document every single symptom that someone mentions in the consultation and I don't know how helpful that might be if we started going down that route."* Therefore, the application should store more complex and significant conditions within a patients overall history in order to be retrieved during future consultations. General practitioners may also use this information to defend any decisions made throughout consultations which resulted in a misdiagnosis.

To enable the retrieval and storage of symptoms, the application must extract personal information from the patients to act as identifiers within the database. These details

include the date of birth and full name of the patient. However, they must be kept secure to ensure that stakeholders are willing to use the application; as discussed by participant ten, *"Confidentiality in where the information goes would be important particularly in terms of someone filling it in with someone. If it's saved somewhere? How is it used? So someone might be hesitant to use it with someone with a learning disability if they didn't know where the data would go, what it would be used for, how it would be, if it was wiped when they finish their visit or is it stored somewhere? Is it recorded? So I think that would need to be clear."*

4.3.5 Assistance

Many of the potential stakeholders will be unable to use the application without assistance, particularly if it is their first time using touch screen technologies; as described by participant nine, *"I think, depends on the individual, it depends on the experience but I, my gut feeling is the vast majority when unless, there, you know they use, they're used to things like that wouldn't be able to use it as a stand-alone resource. Not particularly the first time. I mean if, if they come back and they use different things, can be used, or they've used it more than once then that would be okay but I think initially there's going to be a bit of investment in supporting its use."*

Five of the experts suggested that this assistance may be provided by carers/family members since many of these caregivers accompany patients to consultations. Participant two also revealed that these caregivers play an important role in the effective health care of adults with mild learning disabilities, due to being familiar with the patients' overall health and needs, "*well the other thing probably you'd need to think about is the role of carers in facilitating the people's access to that. So there's quite a lot of research on you know, on the important role that carers play in either facilitating or yeah in advocating for you know people accessing health and health care. So you know in lots of cases the likelihood is that person in that waiting room will be with a carer so you probably want to think about that as well."*

This may suggest that caregivers are the ideal population to assist in the completion of the application. However, as described in Chapter 2, many of these carers tend to provide information during consultations that they believe to be correct, rather than

directly involving the views of the patient [36]. As a result, misleading information may be provided to the General Practitioner, and this is an issue that participant nine anticipates occurring with the application, *"it's a really tricky one in terms of carers do a wonderful job but they do sometimes overstep the mark and more generally because they care. Because they're trying to look out for that individual and also just to kind of make things easier I think on the individual that's there. And also I think that they are aware of the fact that there's a bit of time pressure within appointments and they're trying to kind of speed it on."*

Furthermore, participant five revealed that due to a lack of funding adults with mild learning disabilities progressively have to make do without access to support from care workers, *"I'm not sure there will be exceptions to this but I would imagine that the hardest population would be the ones that don't have support. You know a, increasingly this is something that might, maybe worth noting, increasingly support isn't available. For adults with learning disabilities, the eligibility criteria tightened in most parts of the country and some places it's like life and limb. You know unless you've got some kind of critical risk to your health, you don't get support. So [it's happening] more and more that the folk who are living on their own are just having to manage and so they'll be turning up at GPs without a support worker. So I can see why it would make sense to try to facilitate communication between doctor and patient but I don't think you could assume that in the majority of cases they'll be, the person will have a carer that could support them to use the app. That's maybe something you'd want to see what other options there are."* Consequently, further scenarios must be explored in relation to providing support for patients using the application, since there is no guarantee that a caregiver will be present to offer the required assistance.

Nonetheless, the application must be simple enough to ensure that person providing support is efficient in doing so; as described by participant ten, *"a lot of it comes down to how confident the staff is, staff are to support people to use it and family members as well. If someone's living at home with perhaps parents who are older and who don't use this type of technology themselves then support won't be there for the person either."* A set of instructions may also be provided that detail how the application is

to be used. An easy read version of this can be made available to those patients with mild learning disabilities who attend consultations alone.

4.4 Summary

A number of requirements have been identified and triangulated during the semi-structured interviews and to ensure that features for the proposed application can be viewed at a glance, a summary will be provided in table 7. These requirements are listed in the order they appear throughout the chapter. The references used to support the requirements identified will also be provided.

Table 7: A summary of the requirements identified during the semi-structured interviews.

Requirement Number	Requirement Description	Literature References	Participant ID
1	Text used to convey symptoms should be presented in its simplest form and avoid the use of medical jargon where possible.	[29, 33-34, 51-52, 61, 83]	[2, 3, 8, 10]
2	A variety of communication modalities should be targeted. As a result, symptoms should be represented by text, speech and images where appropriate.	[19, 33-35, 40, 51, 53, 61, 76, 116]	[1, 3-5, 7-10]
3	Any images used should be immediately identifiable to the user.	[18, 20, 33, 42, 47, 52-53, 55, 59, 61, 82-83]	[5,8]
4	The user should have the option to have text played back to them. The pace at which the text is played back should be customisable to suit an individual's needs.	[20, 33, 35, 53, 71, 83, 134]	[2-5, 8]

5	The layout of pages must be repeated throughout the application.	[33, 51, 83]	[4, 9-10]
6	Questions presented to the user should be small and straightforward and focus on solitary ideas. All potential options should focus on a single subject.	[48-49, 59, 61]	[1-2, 4]
7	The number of clicks used throughout the application should be reduced to a minimum, to ensure that the patients are able to supply the required data about their conditions.	[83]	[10]
8	A dynamic questionnaire should be implemented. Future questions should be shaped by the information previously supplied by the user.	[112]	[7, 9]
9	The number of potential options displayed on screen should be limited to a maximum of 4.		[3-4, 9-10]
10	The application should port easily across a number of operating systems and screen sizes.		[8, 10]
11	The aesthetics of the application should be made customisable to address the complex and individual needs of stakeholders. The content should remain unchanged.	[12, 53, 134]	[4-5, 8, 10]
12	The symptoms presented to stakeholders should be informed by the specific health	[4]	[1-2, 10]

	needs of adults with learning disabilities, rather than that of the general population.		
13	Questions should be included that aim to extract the medical symptoms experienced by the user.	[17]	[6-7]
14	Questions should be included that aim to extract the duration of specific symptoms experienced by the user.	[17]	[6]
15	Questions should be included that aim to extract the history of specific symptoms.	[17]	[6-7]
16	Questions should be included that aim to extract the overall health of patients, particularly focusing on their mental health.	[4]	[6-7]
17	Questions should be presented to the user one at a time.	[83]	[3-4, 9-10]
18	All feedback provided should not only be simple but also constructive in order to encourage stakeholders to continue using the application.	[68]	[9]
19	A minimum font size of 14 should be used throughout. Text should be made as large as possible.		[3-5, 8-9]
20	Contrasting colours should be used in order to ensure text stands out.		[3, 5, 8, 10]

21	The user should be able to select the colour scheme that addresses their individual needs best.	[53, 83]	[4-5, 8, 10]
22	The application should provide symptoms experienced by patients in advance of consultations.		[2, 4-5, 7]
23	Significant symptoms identified by the application should be stored for future retrieval by GPs		[6-7]
24	Personal details, such as the patients name and date of birth, should be retrieved in order to act as an identifier when storing symptoms within a database.		
25	A set of instructions may be provided that explain how to use the application, as well as the benefits it provides.	[53, 83, 134]	
26	Clickable elements should be large in size and spaced far apart to ensure those who have motor impairments are able to use them successfully.	[33, 51, 58, 134]	

4.5 Conclusion

Throughout this chapter, a variety of requirements for the proposed application were discussed, and a large proportion of these triangulated the requirements identified during the scoping review. Additional features to be included within the application were also presented, due to the semi-structured nature of the interviews conducted. Overall, the experts discussed various requirements relating to the communication modalities to be targeted by the application, the types of questions to be presented to

stakeholders, the language used throughout, the medical conditions included with the application, the features to be used exclusively by GPs, and the aesthetics of the proposed application. However, addressing all of these will not result in the application being accessible to the entire the learning disability population, since many stakeholders will require more individual features to suit their complex needs. The need to include stakeholders in future design decisions was highlighted throughout.

Chapter 5

System Development

The purpose of this chapter is to discuss the decisions made during the development of a technology probe for the proposed application. The author will present user personas for the potential stakeholders involved in the consultation process; the design requirements that emerged during the scoping review and semi-structured interview process (in the form of user stories); how these requirements transformed into the design of the final probe; and the programming techniques used to develop the probe.

5.1 Methodology

As disclosed in chapter 2, two versions of a technology probe were developed to inform the design of the proposed intervention. Technology probes may be considered as a representation of a device that is utilised by target stakeholders to inspire the design process by exposing them to new experiences [118]. The first probe was developed using the requirements extracted during the scoping review and was subsequently presented to the experts at the end of the requirements gathering stage for evaluation. By presenting a concrete version of the probe early in the design phase, the experts were able to significantly shape the intervention's function thus mitigating potential accessibility issues. This feedback, along with any additional requirements identified during the interviews, was used to update the probe to form its second version.

5.2 Personas

To give the reader an idea of the stakeholders that may benefit from the proposed intervention, personas have been developed. Turner et al. [120] state that a persona is a *"detailed data driven description of an imaginary person that focuses on the motivating values, judgment processes, pressures, and trade-offs of an individual."* The goal of a persona is to share an understanding of potential users to support decision making during the design process.

Within a clinical consultation, there are typically 3 stakeholders: the adult patient with mild learning disabilities; the General Practitioner; and a caregiver. The persona for each of these profiles have been developed based on the characteristics that emerged during chapters 2 and 4.

5.2.1 The Patient

Table 8 includes a description of the potential traits and characteristic of a patients with mild learning disabilities.

Table 8: The potential characteristics of a patient with mild LDs.

Persona 1	 **Jane, patient**
Age	18+
Condition	Jane has mild learning disabilities. She may also have an additional disorder such as Autism or Down's Syndrome since LDs are prominent within these conditions.
Intellectual ability	Jane's ability to learn is impeded by her condition and her IQ is between 60 and 70. She may have required support within mainstream educational classes and will generally find it difficult to obtain new skills. Jane may be extremely knowledgeable in subjects she is interested in but her overall intellect is less than that of the general population. Her knowledge of the human is likely to be below average.

Social Skills	Jane's ability to live independently is also affected. For the most part she can conduct everyday tasking such as washing and getting dressed. However, she required support in more complex tasks such managing money and cooking. Jane is able to hold down a conversation with a familiar communication partner providing it is on a subject she is knowledgeable about or comfortable with. However, she may be more hesitant to communication with someone she doesn't know or if it the conversation is on a complex subject such as medical conditions. Jane's receptive skills are generally better than her expressive, although she may struggle with difficult language or when the pace is too quick.
Physical needs	Jane may have additional physical needs such as visual or hearing impairments and poor fine motor skills.
Technological experience	Jane is more likely to come from a household affected by poverty and may therefore have limited experience with technological devices such as tablets. On the other hand, she may have extensive experience in using her own AAC device and could be comfortable with such technologies.

5.2.2 The GP

Table 9 includes a description of the potential traits and characteristic of GP

Table 9: The potential characteristics of the GP.

Persona 2	 **John, GP**

Age	27+
Experience	John's experience as a General Practitioner can differ dramatically from being a new appointed GP to one with over 40 years' experience. The number of patients with learning disabilities who John treats can range from a few a week, to a few a month or even a year. This is entirely dependent on where John's practice is located and is likely to affect his confidence or ability to treat this population.
Education	John is likely to have received little undergraduate or postgraduate training on how to treat people with learning disabilities. Most of his training will occur during his vocational period or out of hours courses. John's motivation to seek out further education is likely to be dependent on the number of patient's attending his practice.
Communication	Depending on his experience John may be unaware of the adjustments required to interact with patients with learning disabilities. The language he uses may be too complex, he may rush his speech, he may fail to give enough time for the patient to deliberate what is being said or use alternative modalities to speech. As such he may rely on a caregiver to facilitate the conversation and these obstacles may be heightened by the time restrictions placed on the consultation. On the other hand, John may be experienced in communicating with patients who have learning disabilities and is able to cater for their individual needs.
Familiarity	John may be the patient's primary GP and sees them regularly. Therefore, he is therefore familiar with the patient's history and their communication needs throughout the consultation. This will help massively when trying to discern what is wrong with the patient.

	Alternatively, John may not see the patient regularly and will be unaware of their health and communication needs. As such he may require support in conducting the consultation.
Technological experience	GPs are required to use computers meaning they should be experience in using such devices. However, this does not ensure that John is proficient in using touch screen devices.

5.2.3 The Caregiver

Table 10 includes a description of the potential traits and characteristic of a caregiver for an adult with mild learning disabilities.

Table 10: The potential characteristics of a caregiver

Persona 3	 **Jillian, Caregiver**
Age	16+
Relationship	Jillian is the patient's caregiver. Jillian's relationship with patient may therefore differ in a variety of way. She may be a familiar member in which case she is likely to have a vast knowledge of the patient's health, habits and communication needs. As such she can have a positive impact throughout the consultation. Jillian may also be a paid caregiver who has worked with the patient for many years and can therefore have a similar impact

	as the family member. Alternatively, Jillian may be a newly employed caregiver and her knowledge of the patient may be limited. As such, her impact on the consultation may be less meaningful.
Communication	Jillian's job is to support the patient during the consultation process. This may begin before the appointment by helping the patient to practice what they are going to say to the GP. Jillian may bridge any communication barriers that occur by translating language into a format understand by both stakeholders. Alternatively, she may pick up on instances where the patient isn't being truthful by relating what is being said to the patient's life experiences. The GP may also ask questions directly to Jillian; however, this is often frowned upon by the patient. There is a possibility that Jillian takes over the consultation and provides views that are not that of the patient's since she is eager to help.
Technological Experience	There is no guarantee that Jillian is technologically proficient with tablet technologies as the home may be affected by poverty or she may have no use for such technologies. Therefore, you cannot assume that Jillian will be able to help the patient to navigate through applications.

5.3 User Stories

A number of requirements for the proposed application were identified throughout the scoping review process and the semi-structured interviews. These were listed in full in section 4.4. The purpose of this subsection is to translate these requirements into user stories and to state when they were first identified i.e. during the development of probe 1 (after the scoping review) or probe 2 (after the expert interviews). User stories may be thought of as a brief narrative that describes a specific action within a specific scenario and usually conforms to the following format: "*As a <type of user>, I want <some goal> so that <some reason>.*" [120] This explicitly highlights how the

identified requirements meet the various stakeholders needs and will be shown in table 11. Please note that the application user is defined as the patient with mild learning disabilities.

Table 11: The user stories identified during the requirements gathering process.

Story ID	Story	First identified
1	As a patient, I want medical conditions to be described using clear and simple language so that I can understand them.	Probe 1
2	As a patient, I want medical information to be communicated using forms other than speech so that I can understand it when the language used is too complex.	Probe 1
3	As a patient or caregiver, I want medical images to depict the condition clearly so that I am not confused by their meaning.	Probe 1
4	As a patient, I want the option to have textual information read back to me so that I can understand if I am unable to read.	Probe 1
5	As a patient, I want text to be large in size so that I am able to read the information clearly.	Probe 1
6	As a patient, I want text to stand out from the page so that I am able to read the information clearly.	Probe 1
7	As a patient, I want to answer one question at a time so that I do not get confused.	Probe 1
8	As an application user, I want the app to run on any device so that I can use my own tablet or one that is provided to me.	Probe 1
9	As an application user, I want objects to be large and spaced apart so that I am able to click on the one I intended.	Probe 1
10	As a patient, I want to answer questions based on my health needs so that I can find out what is wrong with me.	Probe 2
11	As a patient, I want the number of options presented to me to be limited so that I do not get confused.	Probe 2

12	As a doctor, I want symptoms to be brought in advance of the consultation so that I am not rushing to complete the appointment.	Probe 2
13	As a doctor, I want information on the patient's symptoms, the history of these symptoms and their overall health so that I can work out what is wrong with them.	Probe 2
14	As a doctor, I want the symptoms selected by the patient to be stored so that I can use this information during future consultations.	Probe 2
15	As an application user, I want the layout of pages to be the same throughout so that I know how to navigate across page.	Probe 2
16	As an application user, I want to confirm clicks that require fine motor skills so that I know I have clicked on the correct option.	Probe 2
17	As an application user, I want the number of clicks required to be reduced so that I can keep my concentration and complete the questionnaire.	Probe 2
18	As an application user, I want to adjust the look of the app to suit my own needs so that I am able to complete the questionnaire.	Probe 2

5.4 Probe Design

As discussed previously, 2 probes were developed throughout this thesis. The first was created using the requirements that emerged during the scoping review (found in appendix D) and was subsequently presented to the experts involved in the requirements gathering interviews for feedback. The second was an updated version of probe one that incorporated the feedback from the experts as well as the additional requirements identified during the semi-structured interviews (found in tables 7 and 11). Due to the heterogeneous and complex nature of adults with mild learning disabilities, great care must be taken when developing a user interface for these stakeholders. Following this process meant that the final probe was developed using the collective knowledge held by the experts interviewed, as well as the authors of the papers identified throughout the scoping review and should be better suited to the

intricate needs of people with learning disabilities. Target stakeholders may then critique this probe during future studies in order to identify and address further requirements.

5.4.1 Probe 1

The first probe developed was a basic representation of the application and was built to give the experts an idea of the proposed application's goal and the potential impact it may have. As such, the need for paper prototypes was mitigated since the probe was lightweight, quick to develop, and enabled the experts to identify design decisions that they felt were useful and those that needed proving. The probe contained just two separate screens – an image of the body and a page containing specific symptoms relating to pain in a body part. This enabled the experts to comment on the overall layout of the application and the design decisions taken during this process will now be discussed. The author will refer to the user stories in table 11 when justifying the decisions.

Communication Modalities

As discussed in Chapters 2 and 4, adults with mild learning disabilities are heterogeneous in nature and therefore respond differently to various communication modalities. User stories 1-4 suggest that the language used during consultations is often too complex for the patients to understand meaning they would benefit from this information being presented in different formats. As such, all potential options within the probe have been displayed via the use of 3 communication modalities: text, speech and images, as shown in figure 10.

Speech was embedded in the following manner: a passage of text may be played back by selecting the audio button (denoted by a speaker) located nearest to it. Any images used should immediately represent the option it intends to depict (user story 3) to ensure the user is not confused by its meaning; however, both prototypes have utilised placeholders at this moment in time. The author intends to develop an image set in conjunction with the views of stakeholders during future studies. It may also be useful to analyse the medical images used within previous low-tech AAC solutions such as PCS, Widgit and Makaton [127-120]. All text has been written in its simplest form to

ease the cognitive load place on the patients. A function has also been developed to ensure all text fills the entire space assigned to it thus ensuring it is as large as possible. Additionally, the colour of the text contrasts with that of the background and this helps users who are visually impaired to read it clearly (user stories 5-6).

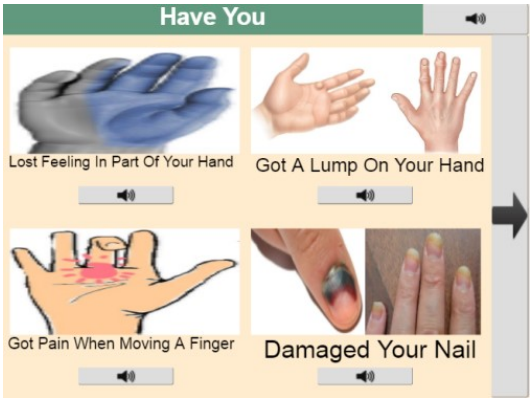


Figure 10: The three modalities used to represent options

Limiting the Number of Options Displayed

Common illnesses and pains experienced by adults with mild learning disabilities may have an abundance of symptoms that the patient could suffer from. Presenting all possible options on the screen at one time would have serious negative connotations for the LD population. The amount of choice available to them would be overburdening and may result in situations where the patient fails to select symptoms crucial to a diagnosis. Additionally, users would be required to use technologically specific actions such as scrolling to navigate through the list of symptoms. As discussed previously, this is not ideal since potential stakeholders may have limited experience with tablet devices.

Consequently, the author decided to limit the number of symptoms displayed to a maximum of 4 (user story 11). This figure was used to ensure that the clickable options were large enough in size and spaced relatively far apart to overcome potential motor impairments that stakeholders may have (user story 9). The experts within the semi-structured interviews also confirmed that the cognitive load placed on the patients

would be significantly reduced, particularly with each option focusing on a solitary concept.

Skipping Questions

Forcing patients to select one of the options displayed on screen would have potentially detrimental effects, since they would be providing GPs with incorrect information that may be used to form a diagnosis. As a result, harmful medication may be prescribed that may have a negative impact on the patients' health. Consequently, a skip button has been implemented (found on the far-right hand side of figure 10) and this has been designed to accommodate for those users who are illiterate and unable to comprehend text. Poulson et al. revealed that such stakeholders respond well to buttons that are large in size and incorporate icons [33]. The participants involved in Prior's study also advocated for the use of symbols to be embedded in clickable elements [134]. Therefore, the button implemented makes use of an arrow, rather than words, to naturally represent that it may be used to move on to the next page. This also enables other objects within the page to be increased in size as using words would have forced the button to be relocated to the bottom of the page. To accommodate for this, the overall height of the images and text used to represent the symptoms would have to be reduced and, as discussed previously, this is not ideal for those users who have from motor or visual impairments. Instead, it made more sense to reduce the width of these containers since the text used throughout has been written in its simplest form, and therefore rarely fills their allocated container without the use of the resize function.

Determining the Body Part Causing Distress

Adults with mild learning disabilities respond particularly well to concrete objects in which they may point to. As such, the author has used an image of the body (shown in figure 11) when discerning which part is causing the patient distress. The user may simply tap on the section of screen that corresponds to the part causing issues, at which point a screen similar to figure 10 will be displayed. For example, if the user taps on the foot then symptoms relating to feet will be presented for selection. The image will scale to suit the size of screen being used meaning patients may run the application on the tablet most suited to their complex needs (user story 8).

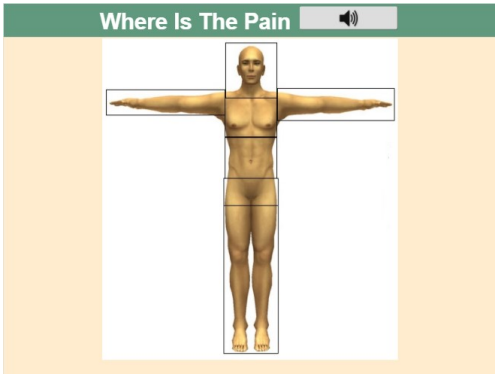


Figure 11: Selecting an area of the body causing pain.

5.4.1 Probe 2

Probe 2 is a more complete version of the application that will look closer to the final artefact. Rather than just displaying a single page of potential options, once the user has selected their primary symptom, the application will display a host of symptoms common to the LD population. These are listed in Appendix H along with an explanation of their inclusion and will give the potential stakeholders an idea of the range of conditions the application may extract during future studies. However, the probe focuses on the needs of the patients and therefore does not contain features aligning to the GPs needs, such as storing the symptoms selected. The updates made during the development of probe 2 will now be discussed.

Communication Modalities

Not all patients possess the cognitive abilities required to read text. As a result, probe 2 also offers ability to playback all passages contained throughout. On completion of page loads, each sentence located on the screen will be read out sequentially and simultaneously highlighted to ensure that it is clear to the user which passage is being played back, as shown in Figure 12. This may also be beneficial to those users who have significant visual impairments and are unable to read text clearly.

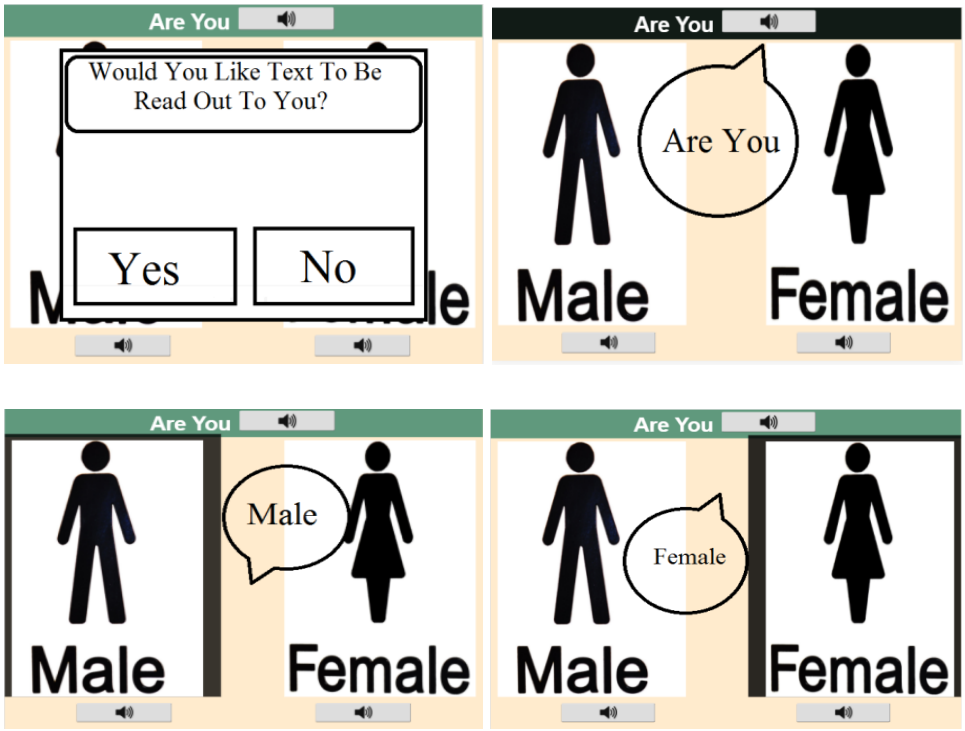


Figure 12: Automatic playback of text.

Determining the Primary Symptom

One of the primary requirements identified during the semi-structured interviews was the need to limit the number of questions presented to the user (user story 17); particularly those that are not directly relevant to the symptoms the patient is currently experiencing. One way to reduce the number of irrelevant questions asked by the application is to determine whether or not the patient is in pain or distress, since many of the conditions described in the previous section may be placed exclusively into one of these categories. For example, poor dental hygiene may cause cavities which tend to cause distress and should therefore be placed into the pain category; whereas, diabetes tends not to cause pain and should therefore be placed into the non-pain category. Some conditions, such as osteoporosis, may be placed into both categories as osteoporosis tends to cause distress in cases where a bone fracture occurs.

An adaptation of the Wong Baker smiley faces pain scale was used to determine whether or not the patient is in distress, as shown in Figure 13. Essentially, the scale consists of images that represent two distinct emotions – a neutral face to represent someone who is not in pain, and an image of someone who is in clear distress. Studies

have shown that similar strategies have been effective in enabling people with learning disabilities to convey the scale of pain they are experiencing [109]. The use of colour was avoided as some patients may only recognise the colours used and not the emotions in which the faces are trying to express, as discussed by the tenth expert interviewed in chapter 4, *"I tried using the kind of emoticons, smiley faces, sad faces for someone, on one occasion and they only saw the colour so they weren't able to recognise the facial expressions."*

If the user selects that they are in pain then they will be forwarded on to the body screen shown in Figure 11; otherwise, a page consisting of primary symptoms relating to non-pain conditions such as chest infection or diabetes will be displayed.

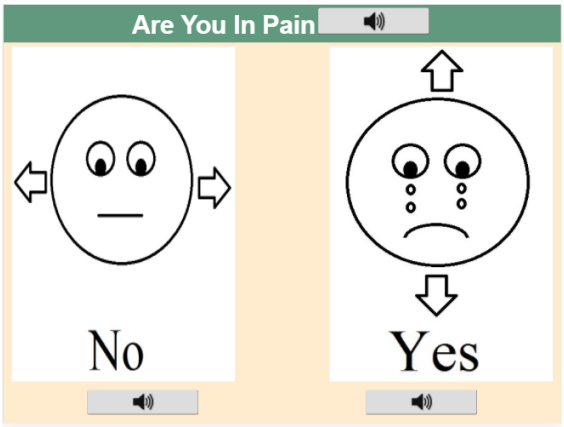


Figure 13: Adaptation of Wong Baker smiley face scale

Confirming Clicks that Require Fine Motor Skills

During the process of identifying the body part causing the patient distress, they may be required to tap on a small area of the screen - for example when tapping on a hand in Figure 11. This requires the user possessing the motor abilities required to carry out such a delicate action; however, many adults with learning disabilities suffer from poor motor coordination. As such, the application requires the user to confirm the specific body part they have selected, as shown in Figure 14. All body parts situated in the proximity of the tap will be presented in order for the user to triangulate their choice. This also enables those that were unavailable for selection in the original image i.e. the back etc. to be presented.

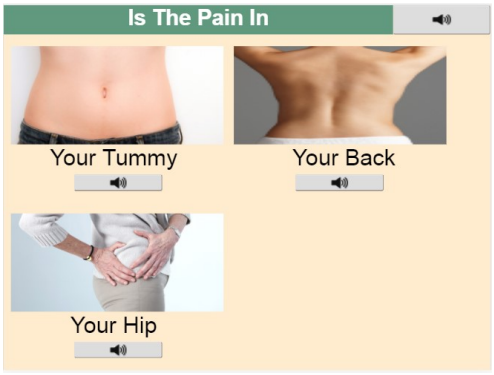


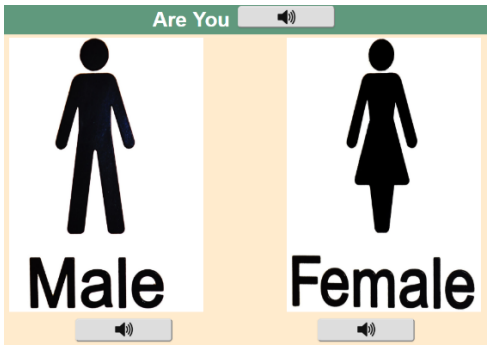
Figure 14: Specifying the body part that is causing pain.

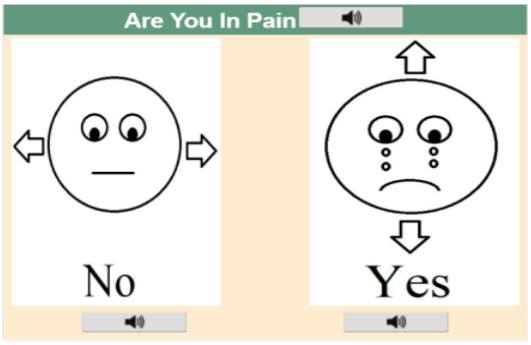
Breaking Down the Consultation

As discussed in Chapters 2 and 4, the success of past AAC technologies relied heavily on their ability to break down complex information into more manageable chunks. Probe 2 also aims to achieve this by breaking what is initially perceived to be an open ended and complex problem i.e. "what is wrong with you?" into a number of smaller, more manageable closed questions, as shown in Figure 15. The patient will first be required to state their sex in an attempt to reduce the number of irrelevant questions being presented to the user, for example asking a male if they are pregnant. They will then select whether they are in pain since many of the conditions embedded within the application can be separate into one of these categories and therefore disregarded based on the users choice. Symptoms relating to potential conditions will then be displayed in sets of 4 to ease the cognitive load placed on users. Each of the options displayed on screen focuses on a solitary symptom to ensure that the patient can fully understand the choice presented to them, as described by participant four, *"But also to think about the kind of construction of your sentences so making sure you don't have lots of different ideas within one kind of sentence."* However, multiple images have been used to represent the range of permutations for a particular symptom. For example, two images have been used to depict the various problems that may cause a damaged or broken nail. This will be discussed in more detail in chapter 6.

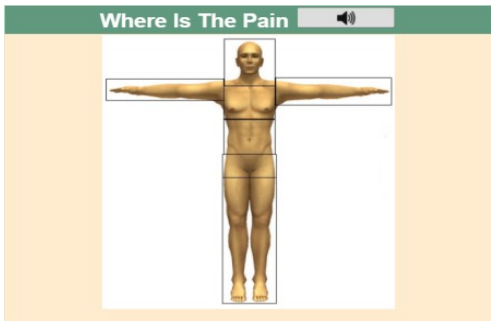
Reducing the number of symptoms displayed on screen may ultimately increase the number of clicks required to complete the process as additional questions will have to be presented to the patient. The tenth expert interviewed revealed that this is not an

ideal scenario as the number of steps required to complete a process should be reduced to a minimum, *"Again it would depend on how easy they were to use but the quicker the better I would say. The, the shorter the better in terms of how much time someone would have to [complete it]. So if it's, so easy to use absolutely, reduce [the] number…. limited…. as few kind of steps in the process, as few clicks in the process as possible."* However, the added benefits for those users who have significant cognitive, motor and visual impairments warrant the need for these additional questions. Limiting the number of options displayed on screen also enables technology related actions such as swiping and scrolling to be avoided, and this has serious benefits for potential users affected by digital exclusion



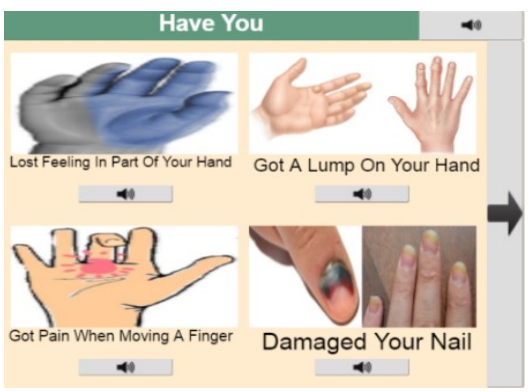


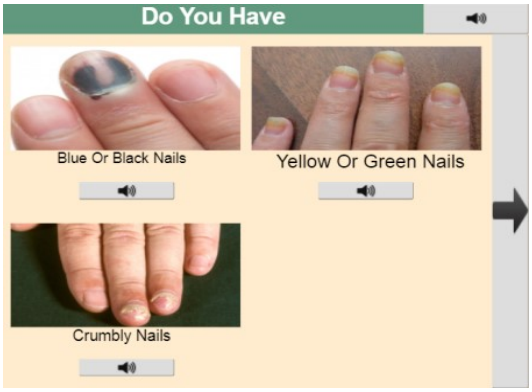
Tap on yes



Tap on hand

Tap on hand





Tap on damaged nail

Tap on black nail

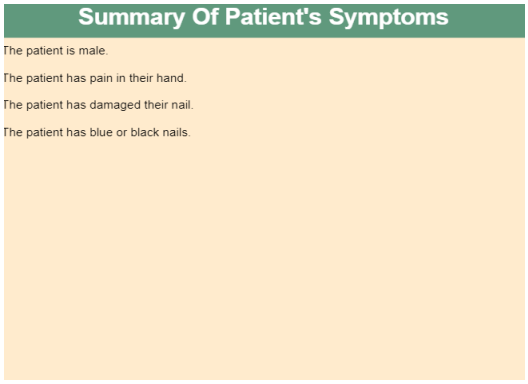


Figure 15: Selecting that you have bruised your nail.

5.5 Implementation

Two key requirements identified during the semi-structured interviews were: the need to limit the number of irrelevant questions being presented to the user by utilising the answers submitted previously to shape future questions; and the need for the application to port across a multitude of operating systems and screen sizes. This section discusses the coding practices used to accommodate for these requirements.

5.5.1 Programming Languages

From the offset, portability has been prioritised as one of the most important features of the application. As discussed in Chapter 4, the application should be able to scale across a variety of tablets and a series of operating systems. This ensures that General Practices are not limited to one device, and may purchase the tablet they deem to be most appropriate. A range of tablets may also be obtained in an attempt to overcome

the heterogeneous nature of adults with mild learning disabilities, since the patient may be presented with the device that is most suited to their complex needs. For example, a larger tablet may be provided to patients who have visual impairments or poor fine motor skills whereas smaller, more lightweight tablets may be offered to those who find it strenuous to operate larger, heavier devices.

To cater for this portability, the decision was made to implement the bulk of the probe using HTML5, CSS3, PHP and JavaScript. As a result, the application can be described as a hybrid mobile application. Rather than targeting a browser, these applications are hosted inside a native container that utilises a mobile platform's WebView [110]. Consequently, they have the ability to access device capabilities such as the accelerometer and camera, amongst others. Each of the aforementioned languages is also cross platform, meaning they port to different operating systems relatively easily [111 in 110]. This is a considerable advantage over native applications since one version of code should essentially run on any device. However, subtle differences across browsers in areas such as styling conventions and API support may result in unexpected behaviour occurring.

To accommodate for these differences, extensive black box testing across a multitude of browsers was carried out. This ensured that a number of major deficiencies across operating systems / browsers were addressed. However, legacy browsers such as Internet Explorer do not provide support for the SpeechSynthesis API used to produce sounds throughout the probe. Therefore, the user is required to run the application on those that do and a list of these may be found in figure 16.

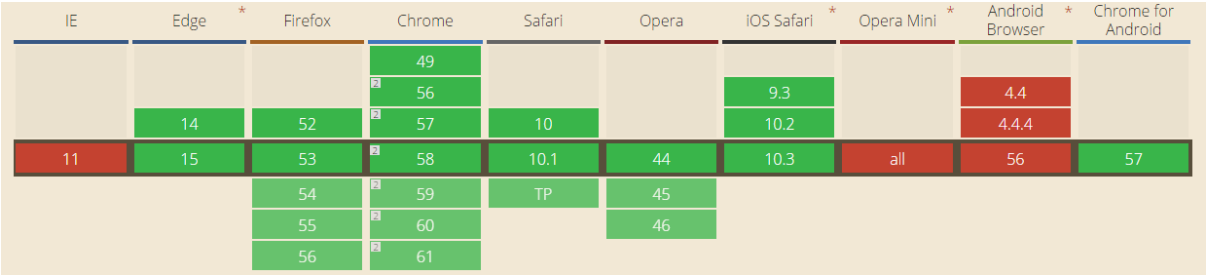


Figure 16: A list of compatible and incompatible browsers

5.5.2 Stack Based Questionnaire

As discussed in Chapter 4, adults with mild learning disabilities tend to have limited attention and memory spans. To accommodate for these stakeholders, the probe must limit the number of questions presented to the user. These questions should directly relate to the potential symptoms the patient may be experiencing, and should adapt to any new information captured from the user. As a result, a static questionnaire would not be appropriate for the application, since the patient would be required to answer a large number of irrelevant questions whilst trying to provide vital information relating to their symptoms.

To address this requirement, the application has been modelled around an adaptive stack based questionnaire similar to that proposed by Bouamrane et al [112]. Essentially, the set of questions presented to the user is formed from a stack of stacks, "where individual stacks correspond to sub-questionnaires within the overall question stack [112]". Questions are comprised of a variety of fields including: the images and text used to convey potential answers; an array of preconditions that must be true for the question to be presented; and potential links to further sub-questionnaires that may be added to the stack depending on the answer selected by the patient. An example of a question may be found in Figure 17.


```
{
    "question": "Do You",
    "answerA": "Hear Ringing Sounds That Aren't There",
    "answerB": "Have To Turn The T.V Up Louder Than Normal",
    "answerC": "Have Fluid Coming Out Of Your Ear",
    "answerD": "Have Dirty Ears",
    "pictureA": "./MedicalImages/ringingEar.jpg",
    "pictureB": "./MedicalImages/tvVolume.jpg",
    "pictureC": "./MedicalImages/earDischarge.jpg",
    "pictureD": "./MedicalImages/waxyEars.jpg",
    "altA": "ringing sounds",
    "altB": "hearing problems",
    "altC": "ear discharge",
    "altD": "ear wax buildup",
    "preconditions": [],
    "subQuestions": {"a": "tinnitus", "b": "glue ear", "c": "ear discharge", "d": ""},
    "answerPrefix": "The Patient"
}
```


Figure 17: An example of the fields used to comprise a question.

The main questionnaire stack will vary depending on the initial symptom selected by the user. For example, if the user selects that they are not in pain and instead their primary symptom is nausea, the corresponding questionnaire will be loaded into the stack. The application then pops and subsequently presents the question at the top of the stack to the user. Once an option has been chosen (including skipping the question), the selected symptom is stored appropriately, before the system checks whether or not a sub-questionnaire must be added to the top of the stack. If so, the questions are pushed to the top of the main questionnaire stack prior to the next relevant question being popped and subsequently presented to the user. This is one where all preconditions have been met by the patient. For example, a question aiming to extract those symptoms experienced by someone who has blepharitis may only be presented to the user if they have previously revealed that they have itchy red eyes. All unsuitable questions up to that point are also popped from the stack and subsequently discarded. If the selected answer results in no additional questions being pushed onto the stack, the application will simply present the next suitable question to the patient. If no suitable questions exist, the questionnaire will be terminated.

Consequently, the adaptive questionnaire has the ability to significantly reduce the number of irrelevant questions being presented to the patient, since many are only added to the stack providing the user upholds certain preconditions. Those questions that are vital to the health of the patient will always be asked, as they will be included within the main questionnaire stack. As a by-product, the application is primarily data driven meaning the number of classes implemented is reduced dramatically (see Appendix F). Therefore, maintainability is increased since the JSON files containing specific questions may be modified rather than fields embedded within classes. Specific classes need only be changed when further functionality is to be added or pre-existing bugs are to be fixed. Developing questions with the use of JSON arrays may also increase the probability of non-programmers being able to comprehend the information they represent, meaning medical professionals can provide essential feedback on the order and types of symptoms being presented to the user.

5.6 Conclusion

The complex needs of adults with mild learning disabilities were taken into consideration throughout the development of a probe of the proposed tablet application. During the semi-structured interviews carried out in Chapter 4, the experts revealed that the conditions explored by the application should be shaped by the specific health needs of adults with learning disabilities, rather than that of the general population, since these two differ dramatically. Therefore, when preparing for consultations, the application aims to identify those conditions that are more prevalent within the learning disability population, along with those that tend to be overlooked by GPs including auditory problems, certain types of cancers, epilepsy and sexual diseases amongst others. This may limit the amount of irrelevant questions being presented to the user since you may assume that the patient is seeking help for one of these conditions. Additionally, presenting symptoms that tend to be overshadowed by GPs may enable the patient to provide information that results in more accurate diagnoses being carried out.

In order to ensure that the patient is able to effectively select the symptoms they are currently suffering from, a number of features have been implemented. The application aims to target a variety of communication modalities in order to overcome the heterogeneous nature of adults with learning disabilities. As a result, potential symptoms are displayed via the use of simplified text, immediately identifiable images, and speech. The patient may then make use of the modality that makes most sense to them. The total number of options presented to the user has been limited to a maximum of four to help ease the cognitive load placed on patients. At stages where the number of options is less than four, the clickable objects embedded within the screen are increased in size, to accommodate for those users who have serious motor impairments. These objects are also placed far away from each other to ensure the user clicks on the object they intended to. As a by-product, those who suffer from visual impairments have an increased chance of being able to read the text displayed.

Patients are presented with an image of the human body to allow them to specify areas that are causing them problems. However, they may not possess the motor abilities required to accurately tap on the correct body part. Furthermore, not all parts are available for the user to select on the original image. Therefore, the application

requires the user to triangulate their selection by displaying body parts close to the proximity of the tap, including those that were not originally available, on another page with the use of larger images.

However, forcing the user to select an option would not be ethical since it may lead to the patient choosing an incorrect symptom that the GP may use to form a diagnosis. As a result, a skip button has been developed that aims to accommodate for all users, including those who struggle to read text. This button makes use of an arrow that naturally represents moving on to the next page, and this has several advantages including being easier to understand than text, and enabling clickable objects within the page to be increased in size.

The order and number of questions presented to the user is particularly crucial. To assist the patient in completing the questionnaire, the number of presented is reduced to a minimum and directly relates to the symptoms experienced by the user. To achieve this, the application makes use of a dynamic stack based questionnaire based on the primary symptom stated by the patient. Crucial questions that stem from this symptom is then added to the stack and presented to the patient sequentially providing they fulfil certain preconditions, such as being female. Further questions may then be added to the top depending on the answers selected by the user. This ensures that questions crucial to the patient's health are always asked but those that are less relevant may not be depending on the users condition.

Chapter 6

Evaluation

The purpose of this chapter is to discuss the feedback received during an evaluation study that aimed to identify the appropriateness of the second probe discussed in chapter 5. 4 experts were involved in the study in order to validate the many requirements identified during chapter 4, and to provide additional feedback on the probe as a whole. This ensures that the probe addresses the basic needs of adults with mild learning disabilities before it is presented to this population. The chapter will begin with a recap of the methods used throughout the study, before a summary of the feedback received is presented.

6.1 Methodology

As discussed in chapter 3, a series of evaluation studies were carried out with learning disability experts to ensure significant usability issues are addressed before the probe is presented to stakeholders. These studies involved 4 experts completing two separate scenarios that were designed to ensure that participants explored all features embedded within the application. A summary of these scenarios may be found in table 12.

Table 12: Symptoms to be selected by participants during user evaluations.

Scenario	Conditions to be selected
1	The participant is suffering from toothache caused by tooth decay.
2	The participant is not in pain. Instead, they are hearing ringing sounds and also feel dizzy and sick. Essentially they are suffering from tinnitus.

Scenario one aims to give the participant a brief introduction to the application. Interviewees were required to make use of the audio features embedded throughout and explore a condition relating to pain. This ensured that the experts utilised the body feature described in chapter 5 and are aware that the application requires the user to triangulate decisions that may be affected by motor impairments. All symptoms to be

selected were immediately presented on screen meaning the skip function was not required within this scenario.

Scenario two aimed to explore those features that were not covered during the first. The participants were required to select symptoms relating to a condition in which pain is not prevalent. This enabled both sections of the application (pain and non-pain) to be scrutinised and for the subsequent language and pictures used to represent various manifestations to be reviewed by the experts. Not all options were immediately available to the participant, thus requiring them to identify and subsequently use the skip button in order to present further symptoms at key stages within the application. No assistance was provided during the completion of these scenarios except at stages where participants were unable to complete a given task, at which point appropriate feedback was given. This ensured that the author did not influence the actions of participants and that key design flaws were identified [100]. Any points of indecision were also observed and noted by the author in order to be explored further at the end of the interview.

On completion of the scenarios, the participants were asked a series of questions that extracted their views on their overall experience with the application, along with whether or not it is appropriate for adults with mild learning disabilities. This enabled features to be identified that may succeed in aiding patients with mild learning disabilities in describing medical symptoms, as well as those that may hinder the process. Subsequently, the probe may be updated in order to address further the complex needs of those who have learning disabilities, before being presented to this population. The questions proposed to the experts may be found in appendix C. The interviews were recorded with participant consent before being transcribed verbatim. The transcriptions were then subjected to a framework analysis that primarily made use of the themes identified throughout the scoping review as codes. The excerpts identified during this analysis will be presented throughout the chapter. A copy of the framework analysis table produced may be found using the following web link: http://dx.doi.org/10.15129/3c176b30-9287-46a0-b3be-a55fcd07843e. The cell rows contained within the framework analysis table are organised in the following manner:

row 2 reflects the views of participant 1 in table 13; row 3 reflects the views of participants 2 and 3; and row four reflects the views of participant 4.

6.2 Expert Feedback

This subsection presents the feedback received from the experts throughout the usability studies. Both the features that the experts believe to be appropriate for adults with mild learning disabilities, as well as those that may be improved upon will be discussed. Once again, the section will be organised to reflect the themes that emerged during the scoping review where appropriate. The professions held by these participants may be found in table 13.

Table 13: Professions of the experts involved in the evaluation studies.

ID	Profession
1	Academic in inclusive education. Previously involved with a special needs school.
2	Governmental advisor – Gathers evidence for the Scottish Government on the health inequalities experienced by those who have learning disabilities. Previous support worker for people with severe and profound learning disabilities.
3	Governmental advisor involved in the coproduction of policies affecting those who have learning disabilities. Previous support worker.
4	Academic in social work and social policy.

6.2.1 Communication Challenges

Consultation Times

Three participants were of the opinion that the main challenge within consultations is the amount of time afforded to each, since many patients with learning disabilities require extended time to present their views and understand the thoughts of others; as summed up by participant four, "*that's a big problem isn't it. It's like one of the kind of things that we know is with people with learning disabilities is they do require longer with these kind of things. And they do, I think a lot of GPs now they have*

extended consultation times with people, for people with learning disabilities but that would mean they could make the most of that time rather than spending the first half of it trying to actually figure out what the person's symptoms were. So yeah I think it's good." Thereby, the application has the potential to alleviate this issue by presenting a list of symptoms preselected by the patient that may then be used to shape further questions throughout the consultation.

Focus

As described in chapter 2, many adults with mild learning disabilities find it challenging to explain their symptoms due to a variety of reasons including: sub-par language skills; a restricted knowledge of the human body; and difficulties in abstract thinking. Participant four was of the opinion that the application may assist with these issues by enabling the patient to focus on the particular issues they wish to discuss, "*I think sometimes if you give someone a blank canvas to start off with their mind just goes blank and they've not, they don't know how to, where to begin. 'Cause I think this is a good way to focus people for the conversation. So I think that's helpful as well and as I said already I just think it would really help someone to clarify what it is the points that they want to convey.*" Stakeholders may struggle to answer general, open ended question such as "how may I help you?" or "what is wrong with you?". Therefore, the application attempts to ease this issue by breaking the problem down into smaller, more manageable chunks that aim to capture relevant information. This information is then used to shape further questions presented in an attempt to centre in on the exact problem the patient is suffering from. This combined with the features described in section 6.2.2 simplifies the process of describing medical symptoms for patients who have mild learning disabilities.

Improvements

Overall, the application has the potential to overcome a number of communication challenges. Firstly, GPs will be presented with an initial list of symptoms thus alleviating the issue of cold starts where they are unable to extract any medical information from the patient. This also reduces the time constraints placed on such consultations since General Practitioners may use this information to ask more

appropriate questions that target the conditions patients are suffering from. The process of describing symptoms is also made easier for the patient due to the inclusion of small, closed questions that aim to extract information relevant to the person's condition. Additionally, using pictures to convey potential manifestations (as described in section 6.2.2) also aids this process.

However, participant four discussed a potential improvement that may further assist adults with mild learning disabilities during clinical consultations, "*I suppose I had just been looking at that [GP summary page] as if well that's the bit that the GP would use as a starting point but actually it would be quite a kind of respectful, kind of empowering thing would be for the patient to have a summary of it as well so that they can then use it when they go in for the consultation. So the GP gets the summary but the person also has a little prompt for themselves in terms of all the things that they were feeling.*" In addition to a summary page for GP's, participant four suggested the need to develop a similar page suitable for the patient. This may enable them to use the summary as a visual prompt in order to discuss the various symptoms selected within the consultation. Such a page must include the pictures used to describe the conditions as well as an option to playback any text embedded as shown in figure 18.

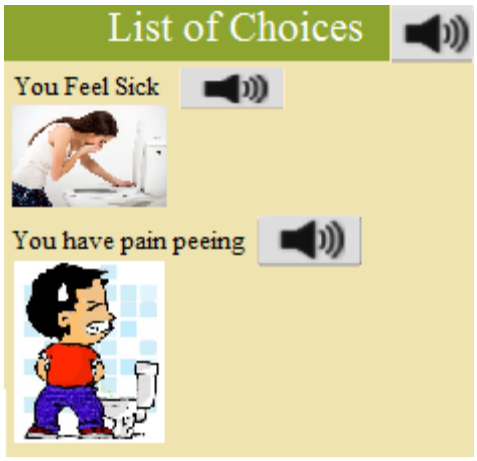


Figure 18: An example of a summary page for patients.

6.2.2 Communication Modalities

Targeting a Range of Modalities

Each of the experts interviewed agreed that the combination of immediately identifiable images, text, and speech presents the user with an increased chance of providing accurate data; as summed up by participant 1, "*Well obviously the pictures are quite detailed quite, they're photographs so they're [helpful]. Being able to have it read to you I think is really important.*" Illustrating symptoms with the use of a number of modalities ensures that the patient has a variety of options to choose from when comprehending the information conveyed, and may simply use the modality that makes most sense to them during each individual case. For example, a patient who has difficulty reading may predominantly make use of the images embedded throughout the application; however, if they do not understand the meaning conveyed by a particular image, then they may fall back on the speech function to ensure the option displayed is understood correctly.

Appropriateness

The images and language used throughout were deemed overall to be appropriate for the target population; however, some areas may be improved upon. For example, participant one believes that patient's may have difficulty understanding some of the symptoms relating to the condition of tinnitus, *"my main concern was as I say some of the symptoms that was actually understood, the symptoms themselves, you know that they actually understand the language of the symptom. So for example the one about tinnitus of the, you know if they had, it said at the end for example do your ears feel stuffed up they might not know quite how to describe it. So, and again I think that's a case of kind of piloting it."* Providing the image used to convey a blocked ear is also unclear, patients with mild learning disabilities may not understand the option presented and therefore not know to select it when required to do so. This highlights the need to involve target stakeholders in the development of the language and imagery used to convey symptoms. Currently, such information embedded within the application may be considered as placeholders, and we intend to develop data that are more appropriate during future studies.

Some of the images used may also be taken too literally by the target population as discussed by participant 2, "*Probably the skin one though [shown in Figure 19] I'd maybe not have necessarily [used] those things cause people might be very literal in*

their interpretation i.e. I don't have any [of] that, so the thing that is wrong with me doesn't look like that, that's wrong to click that so…" Patients who have other skin conditions, such as eczema, may refrain from selecting this image since their condition looks different to those displayed. Therefore, a more appropriate option would be to display an image of skin to encourage those suffering from any skin condition to select the option. This may also hold true for other images including the one used to represent sight, where an image of the eyes may be more appropriate than displaying conditions such as myopia or hypermetropia.

Figure 19: Image used to convey skin problems.

Some of the guidelines presented by Medhi et al. on how to develop text-free user interfaces for those who are illiterate may result in the creation of more appropriate images [113]. Abstract images should be avoided and instead replaced by semi-abstract cartoons or where possible photorealistic graphics. Images that were too abstract were proven to be confusing with many participants taking their meaning literally. The colour schemes used within technologies is also important since users may focus solely on the colours illustrated, and are unable to overcome situations where these are incorrect. This matches the views of the tenth participant interviewed during the requirements gathering stage. One case where Medhi et al. made inappropriate use of colour was when highlighting distinct roads within a map application. They depicted such roads by painting them yellow and many participants felt this was confusing since roads are generally black.

Images that are intended to depict activities such as running should include standard visual cues for indicating motion to ensure their meaning is understood correctly. Situations may also arise frequently where the user is unsure how to progress meaning a help feature must be implemented throughout all pages. This may aid the user in completing the application autonomously and will be discussed in more detail throughout the section. Providing voice feedback for all functional units is also crucial to ensure stakeholders understand the actions that may occur [113]. This further highlights the need to embed the playback of text within the application.

One feature within the application was deemed to be inappropriate for adults with mild learning disabilities. The skip button (shown in Figure 10) was developed with the use of an arrow to ensure that all stakeholders, including those who are unable to read, could profit from its use. However, many of the experts were unsure of its functionality and required an intervention from the author to explain that the questions presented during scenario 2 may be skipped if no appropriate options were available. Consequently, all experts interviewed believed that the button's intention is unclear during its first use, as summed up by participant 4, *"I mean it is, see when you point it out it's like of course it's obvious but I suppose I'm just looking at these options and then thinking oh it's none of them but I didn't automatically register that arrow was there. So I do think that someone with a learning disability might find that tricky. Like there's a, some kind of connection that you have to make so you look at the options and then you have to make a connection between none of them and knowing that you have to press that button to get more options. That might not be, when you tell it's very clear but just to look at that they might just not….like I did, I don't know if I even noticed the arrow."*

A number of options were suggested by the experts as an alternative to the button. Firstly, a help button that produces a pop-up box containing advice on how to navigate through the application was discussed by participant four,*"' Cause a confused face is a sort of common, you know like a, I don't know if I talked, we talked last time about that Makaton system where they have pictures instead of words and I'm sure that's, kind of hmm confused face that one is quite a common one that I think people would know what that meant. So that might be the best idea."* Essentially, the patient would

click on a help button illustrated by a confused face during situations where they were unsure on how to progress i.e. when none of the symptoms represent the condition they are suffering from. In this circumstance, a pop-up box would appear containing a set of easy read instructions that depict how to navigate through the application, including when to use the skip button. This may lead the patient into using the button during similar scenarios in the future and matches the views held by Medhi et al. [113]. Given that many adults with learning disabilities access information through the use of images, there may be some scope to explore the use of a video or avatar to provide help to stakeholders.

A further option involving the use of audio was also proposed by two experts and was summed up aptly by participant four, "*yeah the other option would be if most people ended up doing it by audio you could have a voice saying "or press the arrow for more options*". Currently, the automatic audio function, described in chapter five, highlights and plays back all text displayed on screen. The improvement proposed would ensure that the skip button is also highlighted and verbal feedback is returned denoting its function, and this matches the views held by Medhi et al. [113] who state that "voice feedback should be provided for all functional units". This would ensure that the button stands out from the rest of the page and its function is clear to the user from the offset. However, this feature would only be appropriate for those patients who rely on audio and won't have an effect on those who do not use the automatic audio playback function. These potential improvements will have to be tested thoroughly with the learning disability population in order to evaluate their overall impact. Further options may have to be explored to ensure the button is appropriate for the majority of stakeholders.

Consistency

Two types of images are used throughout the application photographs, and cartoon drawings. Although this may not cause a problem for adults with mild learning disabilities, participant four believes a more consistent approach should be used in the future, *"No I don't think it presents a problem. I think, there's a bit of me that's like just pure for you know, I might like one or the another but I don't think it's problematic at all. I guess that, I suppose that good practice would say you should always take a*

consistent approach to your communication style with people so you know choose one or the other maybe next time round stick to that." Therefore, a set of images should be developed that conform to an individual theme, and should immediately represent the symptoms they wish to convey. A variety of stakeholders should be involved in the creation of these images to ensure they address their needs appropriately.

6.2.3 Barriers to Technology / Accessibility

Sensitivity

Participant one had an issue with the sensitivity of the screen and felt that this may cause serious issues for adults with mild learning disabilities *"I was just wondering there was one when it was, it seemed to be very sensitive 'cause I didn't realise I had clicked on it. So the problem with that is they might click the wrong one by mistake. I don't know if there's, if there's anything you can do with that."* Those stakeholders who have significant motor problems may accidentally brush against the screen without realising it. In the past, tablets failed to afford for adjustment to features such as averaged activation and activation on release [57] meaning accidental activations may be hard to overcome. However, this is currently changing with iOS and Android operating systems enabling adjustments to be made to features such as the amount of time required to hold down a button before its functionality is accessed [72]. Such adaptions should be explored before the application is presented to stakeholders who have motor impairments. An additional feature to aid the user when an accidental click occurs will be discussed in section 6.2.7.

Digital Exclusion

Participant four discussed the possibility of including all symptoms for a particular condition on the one page. This would require the user to scroll up and down the page whilst selecting the options relating to their condition. However, the learning disability population largely experience digital exclusion due to a number of reasons including price and a lack of funding to access such technology [12, 19, 21]. Therefore, they may not be aware of the technological actions required to carry out such actions, hence the decision to limit the number of options to four. Further justifications such as limiting the cognitive load placed on stakeholders were discussed in chapter five. This

digital exclusion also highlights the need for practices to supply such devices to ensure patients can take advantage of the application.

6.2.4 Professionals Attitude

Some GPs may have preconceived opinions of patients with mild learning disabilities due to past negative experiences [28]. As a result, these professionals may subconsciously provide a poorer level of healthcare for this population. They may also fail to provide the patient with a sufficient opportunity to provide their views; however, participant four believes that the application can supply patients with the confidence to overcome such an issue, *"Yeah so I think whoever the carer was like if it was a support worker or parent or something they could sit and go over this together before they went in and it would actually give someone confidence when they went in 'cause I think sometimes people feel quite intimidated. Some GPs don't have the best bed side manner so it gives someone the confidence to actually get their points across. Yeah I think it's really helpful."* By discussing their problem with a caregiver beforehand, the patient may practice exactly what they're going to convey to the GP and as a result have the confidence to make their opinions known. This combined with the visual prompts described in section 6.2.1 may ensure the patient is able to discuss their symptoms in more detail, thus leading to diagnoses that are more accurate. Helmsley and Balandin have advocated for this strategy of preparing patients who have severe communication impairments for their visit to see a medical professional [133].

6.2.5 Individualisation

Three of the participants interviewed believed that the ability to change the background colour is key to ensuring stakeholders are able to read the text embedded in the application, as discussed by participant four, *"That might be a good idea because people do depending on what their particular issue/condition is there are certain colours that work better but the most common one is yellow. But also like a kind of, well I suppose that kind of peachy creamy type colour is quite a common one as well for people so I think that's quite a good idea."* Enabling the aesthetics of application to be altered ensures that the needs of a range of manifestations are accounted for and a larger number of stakeholders have the ability to use the application. For example,

those who have dyslexia generally require a yellow background to assist in the comprehension of text but others with different conditions, such as colour blindness, may require a separate shade.

6.2.6 Co-design

Three of the experts explicitly discussed the need to pilot the probe with a range of stakeholders who have learning disabilities. This will enable the true effectiveness of the application to be extracted and for further user interface issues to be highlighted, as discussed by participant three, "*Yeah I just think it needs to be piloted on people with learning disabilities. I think that's a priority and yeah get as much opinion and insight as you can from individuals with mild learning disabilities 'cause they can sort of share their experiences of how they think it is visually and in terms of hearing and things like that, the audio."* This conforms to the design process discussed in chapter 2 where appropriate stakeholders are involved within the procedure to ensure their complex needs are met before the product is released to the public. Experts were involved within this thesis in order to gather an initial set of requirements that will then be triangulated by adults with mild learning disabilities during future studies.

6.2.7 Further Feedback

Selecting Multiple Options

Whilst completing the scenarios, participant one came across several situations where they wished to select two options displayed on the screen, *"and as I said when I was touching through it there's a couple of ones where you might want to go to two but yeah again I think it was good."* Currently, the application overcomes this issue by displaying symptoms across a number of paths throughout the questionnaire. For example, pain caused by dental cavities may occur when chewing and when brushing your teeth; therefore, the application displays symptoms relating to a cavity no matter what option is selected by the user. However, participant one would like stakeholders to be able to select both symptoms and for future questions to be shaped by the answers provided. This feature should be explored during future studies and be compared with the current method to extract which is most effective.

Distinguishing Pain from Discomfort

The same participant also raised the issue of some patients confusing discomfort with pain in certain cases such as tinnitus, *"they might confuse it with pain though I wonder, discomfort, if they confuse discomfort with pain."* One way to get around this situation would be to use the Wong Baker smiley faces pain scale (described in section 5.4.2) during all stages where the user reveals they are in pain. This would enable the application to assume that the patient is not in pain if they select options gravitating towards the lower end of the scale.

Separating Body Parts Further

Two of the experts suggested that the body image used within the application could be further divided, as summed up by participant one, *"Well if there was a picture like say for example it was a picture of a, you know it was toothache they could actually point to the part of the mouth where it was sore. Do you know what I mean that kind of thing."* Essentially, the probe could zoom in on the appropriate body part i.e. the foot and allow the patient to select the exact area that is causing them problems i.e. their big toe. This will enable the application to hone in on specific questions and thus provide more accurate information to the GP.

Return Function

All participants discussed the need to supply a return/confirm function to ensure any mistakes made by the stakeholders are accommodated for. Two discussed the possibility of embedding a confirm function that enables the user to triangulate their selection, as suggested by participant three, *"I was wondering maybe a box that says did you mean, "Is it your sight, is it correct yes or no" and if no it would go back"*. However, participant four believes that this feature may be distracting for the learning disability population, *"if you weren't making, if you did mean what you pressed, so it's always good to have a back. So if you go oh no I've made a mistake you can press the back button but every time you don't make a mistake you get a pop up saying "are you sure you meant this" that could get quite annoying."* Therefore, a far better option would be to offer the user a choice to return to a previous page providing a mistake has been made. The experts failed to provide advice on how to achieve this and

therefore the return feature should be explored thoroughly during a future study. A solution to the skip button described previously may result in a successful strategy being devised for the return function.

Conditions

Participant four believed that grouping similar conditions was a key feature within the application and may provide opportunities to extract those manifestations that tend to be overshadowed, *"I think the choices are very clear and I also think it's quite helpful that, cause they are sort of, I mean I think they are anyway are they grouped kind of with things that would be commonly associated together? 'Cause everything gets put down to the learning disability and actually there's just some common, you know very common basic health needs that we all have that people just struggle to articulate. I guess ignored because they have a learning disability."* Essentially, the application presents key symptoms from a variety of common conditions in order to try to identify the particular manifestation the patient is suffering from. Without the application there may be a higher chance that these conditions remain undetected.

Autonomy

Finally, participant one believes that the probe has the potential to offer more accurate information to the GP,*"I think some people would use it without a carer and I think obviously the more autonomous people were able to use it the better. I mean what you wouldn't be wanting would be the carer to be telling the doctor what the patient's symptoms are and taking over so the more autonomy that the person has the better. Hopefully you would hope the more accurate it would be as well."* As discussed in Chapter 2, some GPs tend to bypass the views of patients who have learning disabilities and instead interact primarily with the carer present. This may result in incorrect information being provided and the patient becoming frustrated due to their lack of input. Therefore, those users who are able to use the application autonomously have a higher chance of providing the GP with accurate information, thus leading to a correct diagnosis.

6.3 Summary

The experts involved in the evaluation study suggested a number of improvements to the probe described in section 5. Some of these would require further analysis to determine their effectiveness; however, others may have an immediate positive effect on the application. These requirements are listed in table 14.

Table 14. Improvements Listed by the Experts

Improvement ID	Improvement
1	A summary page listing the symptoms selected should also be provided to the patient. The information included should be conveyed via the use of a number of communication modalities.
2	General pictures should be used to represent options that have a range of permutations. For example, a picture of eyes maybe used to represent visual impairments.
3	Audio feedback should be provided for all functional units and not just potential options.
4	A return function should be provided to ensure the user is able to undo potential errors.
5	A scale of pain should be presented where appropriate. The information extracted should be used to shape future questions.

6.4 Conclusion

Overall, the feedback received by the experts was generally positive. The participants were in agreement that the application has the potential to overcome the many communication barriers involved during the consultation process. The various modalities targeted along with the breakdown of information are key features that ease the process of describing medical conditions. Providing the opportunity for the patient to discuss their symptoms beforehand, may enable them to hone in on the information they wish to discuss during the consultation and thus increase their confidence in which do so. Furthermore, providing this information to GPs in advance also enables

them to shape the questions asked and this may potentially ease time constraints placed on such consultations.

However, some improvements must be made before the application is piloted with potential stakeholders. Firstly an alternative to the skip button must be explored since its functionality may not be immediately evident to those who have learning disabilities. On the other hand, an option to return to a previous page must also be provided to ensure those users who have made a mistake may undo their actions. This may be particularly useful to stakeholders who suffer from significant motor issues and select the wrong option by accident. Furthermore, less significant improvements were also discussed by the experts including providing the option to select more than one symptom at a time, and zooming in on particular body parts in order to specify the exact area of pain the user is suffering from.

Chapter 7

Discussion and Future Work

The objective of this chapter is to reflect back on the work conducted throughout the thesis and to highlight areas of success, as well as those that may be improved upon. The chapter will begin with a discussion about the appropriateness of the methods used throughout the research, before the key lessons that emerged are presented. To conclude, future opportunities to build upon the work conducted will be discussed.

7.1 Methods

7.1.1 Appropriateness

Overall, the complex intervention framework is well-suited to the project since it provides crucial guidance on how to develop a successful intervention for vulnerable stakeholders who require a multitude of complex conditions to be met [88]. The framework emphasised the need for the researcher to provide sufficient evidence as to why the proposed intervention is required, and this was achieved through the use of a scoping review that aimed to identify the current technologies used by adults with mild learning disabilities during clinical consultations.

Throughout the review several studies [4, 17, 28, 36, 54] suggested that one of the most common reasons for the ineffective health care provided to this population is the breakdown in communication between patients and staff. However, there are no widely accessible researched based technologies available to overcome this barrier, meaning those devices on offer may not adequately address the complex needs of those who have learning disabilities. As a result, the review enabled the author to focus their attention on a primary factor that negatively affects consultations, thus potentially resulting in the development of an intervention that may have a significant influence on current practice.

As a by-product, the review also identified a number of features to be included / excluded from the potential intervention, by drawing on the conclusions made by previous studies. The framework required this information to be supplemented by new

research and this was achieved by interviewing a purposive selection of learning disability experts. Consequently, further requirements for the application were extracted and these provided evidence as to how the intervention may positively change current practice. This ensured that the probes developed throughout this research is suited to the complex needs of adults with mild learning disabilities, since the knowledge held by a variety of experts were used to design the intervention rather than the sole views held by the author.

Future stages within the framework will focus on producing evidence as to how successful the application is in changing current practice. Firstly, the intervention will be piloted within its intended environment to ensure it is successful in achieving its goal and that any design flaws are identified. Due to the iterative nature of the framework, this may prompt a return to the development stage in order to update the design of application. Once the benefits of the intervention have been made clear, it will be embedded within practice and a long-term evaluation study will be conducted to ensure current practice has been improved.

These stages are out of scope for this project and instead a usability study was carried out with a series of experts to ensure the application is appropriate for the mild learning disability population. This enabled key design flaws to be identified and will be addressed before the application is presented to vulnerable stakeholders for further evaluation. As discussed in chapter 3, similar projects [90-91] are using the Complex Intervention Framework to develop research based resources for adults with mild learning disabilities, thus further highlighting the appropriateness of using the framework in this context.

7.1.2 Improvements

Scoping Review

Some improvements may have been made to the research carried out in this thesis. Firstly, the scoping review excluded those papers that were published in a foreign language. However, Maulik et al. [114] found that the prevalence of intellectual disabilities is significant throughout the world (on average 10.37 cases per 1000 people) with middle and low income countries such as Sri Lanka reporting far higher

figures. Therefore, there is significant scope for similar interventions to be investigated throughout the world meaning successful studies may be excluded due to the language the paper has been published in.

Another limitation was that the review primarily focused on studies that included participants who have mild or moderate learning disabilities. This enabled the author to focus on the complex needs of those who will benefit directly from the intended intervention. However, there may be similar successful technologies that target the needs of those who have severe or profound learning disabilities, and potential features from these technologies could be adapted to suit the requirements of patients with mild learning disabilities.

One final limitation was the number of journal databases accessed throughout the review. In an attempt to extract relevant literature from both the health and computer science domains, a number of searches were conducted across the PubMed and ACM databases respectively. Furthermore, the Google Scholar database was also accessed in order to identify relevant literature that had missed during the previous search requests. However, further databases, such as PsycINFO, may have been scrutinised in an attempt to extract additional papers. This may partially explain the limited number of technologies identified that have been specifically developed for use within the medical setting. The search strategy employed also utilised mesh terms relating to the environment, populations and technologies contained within the research questions proposed. As such further relevant technologies may have been excluded that would have been otherwise identified with the use of further search terms such as person-centred design.

Semi-structured Interviews

In an attempt to extract requirements from all stakeholders involved in the consultation process, a number of GPs were invited to participate in the study. However, due to their hectic work schedules, only two General Practitioners accepted their invite and these GPs had highly conflicting views in various areas. To illustrate, one was adamant that all symptoms extracted by the application should be stored within a database to ensure patient histories are as accurate as possible; whereas, the other

believed that only the most significant symptoms should be stored. As such data extraction did not occur, since the second interview resulted in the development of several new tags throughout the coding process, which had a significant impact on the requirements extracted. This scenario also occurred when interviewing the support workers i.e. participants 1, 2 and 3 in table 6.

This was in stark contrast to the other experts who may be combined into population since the governmental advisors have either been in, or are currently in, an academic role. The final participant interviewed (participant 10) primarily discussed themes that had been raised during the previous interviews. Only one new tag was developed during the coding process that covered the body language used by people with learning disabilities; however, this did not have a significant impact on the requirements extracted for the application. Therefore, the author believes that saturation has almost been achieved for this population, although it may be beneficial to conduct further interviews with GPs and support workers until saturation has been achieved for these sub-groups.

The absence of adults with mild learning disabilities from this study may be considered a limitation. However, Norman believes that stakeholders are ultimately unsure of what they require from a product in the early design stages [95]. As such, the author would argue that collecting initial requirements from a series of experts and using this information to develop several iterations of a technology probe may result in more accurate requirements being extracted from the LD population. The probe may then be utilised by stakeholders within the target environment and its performance can be monitored. People with learning disabilities will then have the opportunity to contribute to the design process through their actions and by suggesting where the probe meets their needs and where it is lacking.

Usability Study

To ensure the developed probe was suitable to be presented to stakeholders, a series of usability tests were carried out. To guarantee these tests were consistent, the participants were required to complete the same two scenarios. As a result, a significant number of conditions remained unexplored, meaning the experts were

unable to evaluate the appropriateness of the language and images used to represent these manifestations. Consequently, further scenarios should be scrutinised during future studies.

In total, 4 experts accepted their invite to participate within the study. The feedback received by these experts was in the large part consistent, with features such as the skip button being identified as a possible hindrance to user experience. This provides an opportunity for the author to address these interface issues before presenting the application to intended stakeholders. As a result, the probe should be better suited to the complex needs of adults with mild learning disabilities. However, some potential improvements were extracted from experts that failed to be triangulated by the others. This subsequently resulted in the development of new tags during the coding process meaning saturation has not occurred. Furthermore, all of the experts who participated were academics meaning it would be beneficial to explore the opinions of the other sub-groups. Consequently, there is an opportunity to conduct further studies in order to discuss these potential improvements until saturation has occurred across each of the sub-groups.

7.2 Key Lessons

This subsection intends to present a discussion of the most significant findings identified throughout the thesis. The section will be organised to reflect the themes identified throughout the scoping review where appropriate.

7.2.1 Communication challenges

As discussed previously, the scoping review identified the breakdown in communication between staff and patients as the primary obstacle to providing effective healthcare to consumers who have learning disabilities [4, 17, 28, 36, 54]. The GPs interviewed subsequently triangulated this view when they revealed that, *"the persons understanding of their condition for instance, their interpretation of symptoms may be different, their ability to communicate symptoms may be different. Our ability on the practitioner's side to elicit those symptoms may be different or more challenging. Our ability to conduct an examination may be more challenging. People, ultimately a consultation is based around communication, two way communication*

and at times aspects of that communication can be difficult whether it be to do with comprehension or to do with abstract thinking or just basic communication."

A variety of reasons contribute to this breakdown was discussed by the literature including: the patient's inability to describe symptoms in a clear manner due to possessing sub-par language skills [29-31], limitations in the patient's abstract thinking and long-term memory skills [7], patient's having trouble understanding information that is presented quickly, via the use of speech, or when complex language such as medical jargon is used [4, 29, 32-35], and staff failing to possess the knowledge required to effectively extract information from those who have learning disabilities [6].

With the amount of challenges prevalent throughout such consultations you may expect a number of technologies to be available that alleviate these issues. This seems not to be the case with 35% of the nurses involved in Helmsley's study specifically requesting AAC resources to be more readily available [132]. The scoping review also revealed that patients tend to utilise AAC devices that have been designed to satisfy general communication needs. These devices may be unsuitable for use within the medical setting since they may fail to provide the features required to describe symptoms accurately. Those limited resources that have been developed specifically for use within medical environments, for example the personal communication passport proposed by Millar et al. [63], have not been implemented on a national scale. This further triangulates the need to develop such an intervention, but also highlights the fact that further research must be conducted into the health and technology needs of the learning disability population. Strategies that are crucial to the success of such technologies will be presented in future sections.

7.2.2 Communication Modalities

Due to their heterogeneous nature, stakeholders may respond to information in different ways [4, 26-27, 29, 53]. For example, some users may have limitations in their literacy skills and fail to grasp the concepts conveyed by passages of text, whereas others may possess the expertise required to read long and complex sentences. To accommodate for a wide range of users, the experts revealed that the application should

target a number of communication modalities. These modalities include simplified text, immediately identifiable images, and the playback of all text embedded within the system. The use of images and clear, concise text to convey information has been a strategy utilised by previous low-tech communication resources such as PCS, Widgit and Makaton [127-129]. However, the experts discussed the dangers of embedding too many images within an aid, thus highlighting the need to take into consideration the cognitive abilities of target users when developing AAC technologies.

The need to triangulate the images and text embedded throughout a system using a variety of stakeholders became evident during the studies discussed in chapter 6. When developing the skip function described in section 5.4.1, the author followed the advice of Poulson et al. [33] and used an image to depict the buttons purpose, rather than relying on text. This could potentially appeal to a larger number of stakeholders, since those who are illiterate may make use of the graphic to identify the buttons functionality. However, many of the experts believed that the image implemented failed to depict the skip function accurately, particularly when the application is used by someone for the first time. As a result, potential stakeholders may believe that they have to select an option displayed on screen, and will not use the skip button when appropriate to do so. This could have a detrimental effect on the user's health, since stakeholders will be providing the GP with incorrect medical information.

One potential way of mitigating this issue was described by participant four who revealed that, "*the other option would be if most people ended up doing it by audio you could have a voice saying "or press the arrow for more options*"". Currently, the automatic audio function, described in chapter five highlights and plays back all text displayed on screen. The improvement proposed would ensure that the skip button is also highlighted with its function being played back. Those stakeholders who make extensive use of the audio features provided may then understand the buttons intention clearly and this matches the views held by Medhi et al. [113]. Further images such as those used to represent the option for skin may also confuse the user. This was also true for some of the language used throughout the application (for example the sentence used to describe a blocked ear) meaning both modalities must be tested extensively with relevant stakeholders to ensure their meaning is understood correctly.

This also follows the approach used by Medhi et al. [113] who tested all graphical objects embedded within their system with a variety of potential users. By doing so, they believe their products are better suited to the needs of their stakeholders.

7.2.3 Communication Aids / Barriers to Technology

Breaking Down Information

Throughout this thesis Talking Mats™ has been identified as one of the most effective communication aids currently used by adults with learning disabilities. The literature states that the success of Talking Mats™ relies heavily on the resources ability to breakdown complex information into manageable chunks [49, 59, 62] and this was subsequently triangulated by the experts interviewed. For example, someone with a learning disability may use Talking Mats™ within an interview that aims to extract their rehabilitation goals [62]. Rather than asking the participants directly what activities they feel are important, or those they would like to perform without assistance in the future, a mat may be presented that focuses solely on a particular environment or action - for example “home” or “mobility”. Options relating to the mat, such as “cooking”, may be presented and the participant can place this option within the category that matches their views, for example “would like to be able to do this”. As a result, the participants are able to focus on smaller concepts and this has the potential to increase the accuracy and depth of the answers extracted from those who have learning disabilities [59]. Further benefits of using this framework stems from the fact that immediately identifiable images are used to represent information. As a result, these images must also be piloted with a number of stakeholders to ensure their meaning is understood correctly.

The author followed this approach when developing the second probe described in chapter 5. Those who have learning disabilities may find it difficult to answer a general, open-ended question such as “what is your problem?” Therefore, the application attempts to present smaller, more manageable questions such as “are you in pain?” in an attempt to ease the cognitive load placed on the users. The information captured is then used to shape future questions asked by the application. For example if the user states that they are in pain, then the probe will attempt to extract the body

part causing this pain. Additional manifestations relating to this pain may then be identified in an attempt to provide the GP with enough information to form a diagnosis. The ninth participant interviewed during the requirements gathering stage revealed that dynamic questionnaires should be embedded within AAC technologies in an attempt to reduce the number of irrelevant questions presented to those users who have short attention spans.

Choice

Many of the experts interviewed throughout this thesis were of the opinion that the amount of choice available to patients should be limited, *"we did a project on choice. We found that when you give people with learning disabilities a choice, they're not used to getting a choice, they're not really sure. So maybe keeping options kind of limited and that, building it out in a kind of, you know, kind of structure so that when you get to the end point you might have to go the long route rather than the shortcut."* Limiting the amount of symptoms displayed on screen eases the cognitive load placed on patients since they are required to consider select from a reduced number of potential symptoms. Additionally, the objects used to represent these symptoms may be increased in size and this has a number of benefits to stakeholders with motor or visual impairments.

Furthermore, the experts discussed the need to limit the number of questions presented to patients, particularly those that are not relevant to their condition. This supports patients with short attention spans in providing relevant information to their practitioner and is in stark contrast to the approach used by Bostrom & Eriksson [83]. They used a 43-question survey to extract the mental health status of children with learning disabilities; however, the experts interviewed in this thesis believe that a questionnaire of such length would present significant challenges for this population to overcome. Instead, a dynamic questionnaire that responds to the information provided by stakeholders would be more appropriate.

Training

Throughout the scoping review there was literature to suggest that the availability of adequate training facilities was crucial in the successful use of interventions. For

example, Broderick et al. [9] introduced a one page patient passport into several practices in England. The resource aimed to provide information about an individual's preference on various aspects such as their communication, support and environmental needs and this information was collected by the hospital staff. The idea of the passport was to ensure all staff interacted with a patient who has learning disabilities in a consistent manner; however, the quality of the initial passports produced was so poor this was not achieved. Various forms of support were then offered, at which point the quality of information extracted by staff improved and the passport had a larger impact on current practice [9]. This suggests that support has to be made available during the initial implementation of an intervention but continue to be offered until all stakeholders are confident in its use.

7.2.4 Professionals Attitude

Studies in the past [4, 28, 36] have revealed that healthcare staff fail to possess the knowledge required to effectively extract information from patients who have learning disabilities. Furthermore, opportunities to increase this knowledge through the use of appropriate training tend to be limited [28, 36], with one survey concluding that all participants contacted had yet to receive any training on communication disabilities [28]. Professionals also recognise the need to access such opportunities but generally feel they lack the time to do so. As a result, they would prefer access to a short handbook on learning disabilities, rather than receiving intensive training [28].

This may suggest that healthcare professionals as a whole may be unwilling to spend the time and effort required to update their knowledge of learning disabilities. This was partially evident during the requirements gathering stage when one GP (participant 6) revealed that they were unwilling to access training resources since the scale of the problem did not require them to do so, *"I would say that it has, that the training resources has to, you know, has to be proportionate to the scale of the problem. It does vary, it is not a scenario you come across very frequently. So I have not particularly looked for any training resources, so I'm not aware how many training resources are available, are out there."*

Consequently, the need to develop an effective communication aid that can be used in the clinical setting is only part of the problem. General Practitioners should actively and regularly seek to update their knowledge on both learning disabilities and AAC technologies to ensure they are aware of various strategies that may enable them to extract information from this population.

The literature also focused on the role in which carers play in aiding the consultation process [15, 36]. However, bypassing the views of someone who has a learning disability may not be an effective strategy since caregivers can provide information that they believe to be correct but in fact are not the opinions held by the patient [36]. Additionally, one of the experts interviewed in this thesis revealed that the funding provided for such carers is being reduced, meaning more adults with learning disabilities will have to attend consultations alone in the future. As a result, patients should be able to use healthcare technologies autonomously and this may ultimately increase the accuracy of the information provided to GPs, as discussed by participant 1 in the evaluation studies, *"I think some people would use it without a carer and I think obviously the more autonomous people were able to use it the better. I mean what you wouldn't be wanting would be the carer to be telling the doctor what the patient's symptoms are and taking over so the more autonomy that the person has the better. Hopefully you would hope the more accurate it would be as well"*

7.2.5 Individualisation

As stated in section 7.2.2, adults with mild learning disabilities are heterogeneous in nature and therefore require a variety of complex needs to be met [4, 26-27, 29, 53]. Many technologies aim to address these needs by offering stakeholders the ability to customise features. For example, Proloquo2go enables the user to pin frequently used options to the home screen or add options of their own to ensure their everyday requirements are met. This feature was prominently discussed by the experts interviewed to ensure a wide range of users are able to use the application effectively. However, the authors believe that the content embedded within medical applications should remain unaltered, due to the nature of the information involved. The conditions included should be based on the available evidence describing the health needs of the target population. Similarly, the imagery and language used to convey symptoms

should be developed in conjunction with target stakeholders, and may therefore be crucial to user comprehension. Instead, the application should enable adjustments to be made to the interface. Features such as background colour, or the pace in which speech is played back to the user be edited to ensure stakeholders understand the information being conveyed.

7.2.6 Co-design

The need to include potential stakeholders within the design of the system has been highlighted throughout this study and by previous literature [18, 22, 70, 78]. Systems that have been developed collaboratively with representative users are far more likely to be easy to use and look 'good' in the eyes of the consumer [18]. Conversely, systems that have not been developed in conjunction with the views of end users are more likely to have major accessibility flaws. This may partially explain why Riemer-reiss & Wacker report AAC device abandonment to be as high as 53%, since they may not contain the required features that allow users to operate the device effectively [119]

However, Norman suggests that stakeholders are initially unsure of what they require from a product in the early design stages and by building and presenting prototypes at this stage, true requirements may be readily identified [95]. This prompted the author into extracting initial requirements from a number of experts. As a result, the probes developed were shaped by the collective views held by these experts and should be better suited to the complex needs of adults who have learning disabilities. Relevant stakeholders may then evaluate this probe in order to triangulate the various requirements extracted from these experts, and to identify additional features that may be implemented.

7.2.7 Summary

The research conducted in this paper supports many of the findings made by Bostrom & Erikkson who attempted to use digital technologies in order to extract the mental health status of children who have learning disabilities [83]. These, in combination with the other requirements identified throughout this paper, lay the foundation for the development of an intervention that assists adults with mild learning disabilities during clinical consultations. Overall, our research may be summarized into the following

design guidelines for the development of medical AAC technologies that target this population:

Table 15. Guidelines for the Development of Medical AAC Technologies that target Adults with Mild Learning Disabilities

Guideline ID	Guideline
1	The overall consultation process should be broken down into manageable chunks by presenting small, closed questions that focus on solitary ideas.
2	Questions should focus on the health needs of target stakeholders rather than that of the general population since these may differ greatly.
3	Questions should aim to extract the symptoms experienced by patients, the duration and history of these symptoms and the overall health of patients.
4	Information provided by stakeholders should be used to shape future questions in an attempt to limit the number of irrelevant questions being presented.
5	Information should be conveyed via the use of a number of communication modalities including simplified text, immediately identifiable imagery and speech.
6	The language and imagery used to convey information should be developed in conjunction with the views of target stakeholders to ensure they are understood as intended. In general, medical jargon should be avoided but this may not be the case for all situations.
7	The number of options available to the user should be limited. We recommend a maximum of 4.

8	Elements should be large in size and spaced far apart in order to accommodate for potential visual and motor impairments.
9	Key navigational and decisions points should not be conveyed solely with the use of text.
10	A consistent layout should be provided including the option to access a help feature at all times
11	The aesthetics of such aids should be customizable; however, the content should remain the same.
12	A record should be kept of all the key activities made within the aid. Both, patients and medical staff should have access to this information, represented in a format suitable to them.
13	The software should be portable to ensure stakeholders are able to use the device most suited to their needs.

7.3 Future Work

The research conducted throughout the thesis lays the groundwork for the development of an intervention that may aid adults with mild learning disabilities during clinical consultations. The scoping review extracted a number of challenges in which this population must overcome to ensure consultations are fruitful, and revealed that there is an opportunity to explore technologies that may be used to solve the most prevalent of these issues i.e. the breakdown in communication between patients and GPs. A number of potential requirements for the intervention were also identified during the review by drawing on the conclusions compiled during previous studies. These were then triangulated throughout a series of interviews conducted with experts in which further requirements were extracted. However, as stated in section 7.1 the views presented by GPs relating to how such technologies may be used to assist consultations involving adults with mild learning disabilities was conflicting. Therefore, there is

scope to conduct further interviews with GPs to ensure that these areas of conflict are addressed and that their needs are met by the intervention.

To further triangulate the requirements extracted throughout this thesis, a series of interviews should be conducted with adults who have mild learning disabilities. This will ensure that the intervention is better suited to the complex needs of this population and that any glaring design flaws overlooked throughout this research are addressed. The recommendations discussed throughout chapter 6 should be implemented and the updated probe should be presented to the stakeholders during these interviews. This provides the opportunity to receive crucial feedback on the design of the probe and to determine whether or not the interface is appropriate for stakeholders.

The questions included within the application aim to extract the most common conditions experienced by those who have learning disabilities. However, the paths in which potential manifestations are displayed should be reviewed by medical professionals to ensure they are suitable and that distinguishing symptoms are correct. A set of images that represent the various symptoms embedded throughout the application should also be developed and subsequently tested with a variety of adults who have learning disabilities. This will ensure that all images adhere to a single theme and this was an issue raised by several experts throughout chapter 6.

Currently, the application aims to collect information from the patient before the consultation begins. This provides the GP with an opportunity to shape the questions presented throughout and thus ease the time constraints placed on consultations involving patients with learning disabilities. However, as discussed in chapter 4, some GPs may be unwilling to use the data collected by such technologies meaning there is ample opportunity to explore similar applications that may be used by GPs during consultations. A concrete evaluation of the developed artefacts should be carried out within the target environment to determine the overall effectiveness of the application and the ways in which it improves clinical consultation with the LD population.

Chapter 8

Conclusion

The research conducted throughout this thesis aims to lay the foundation for the development of an intervention that assists adults with mild learning disabilities during clinical consultations. As per the MRC Complex Intervention Framework, the research began with the completion of a scoping review that intended to answer the first research question presented i.e. what current technologies are used to support adults with mild learning disabilities during clinical consultations?

During the review a plethora of factors that contribute to the ineffective healthcare of those who have learning disabilities were identified; however, the most cited reason was the breakdown in communication between patients and GPs [4, 17, 28, 36, 54] and this was triangulated by the General Practitioners interviewed in chapter 4. The author ultimately found that there is a lack of technologies designed to overcome such a barrier and instead many patients make use of general AAC devices. These devices tended to be grid based systems which enabled users to select from a variety of options in order to playback pre-recorded messages that represented their needs. However, such devices may not contain the features required to accurately describe symptoms and therefore may not be fit for purpose within the clinical environment. Those that did provide such features (for example the AAC applications mentioned in section 2.4.4.3) were not based on evidence and therefore may not address the complex needs of adults with mild learning disabilities.

A number of low-technological interventions were adapted for use within the medical setting. Firstly, a modified version of a Personal Communication Passport was introduced into a number of practices in England [63]. These passports aimed to capture essential information on how best to care for the individual, including the means in which they wish to communicate. This enabled staff to approach the individual with continuity and thus take advantage of the communicative abilities that the patient does possess. However, due a lack of appropriate training facilities, the quality of information being captured by staff was initially poor meaning communication was not promoted between staff and patients from the start.

Talking Mats™ has been used to assist adults with learning disabilities in developing long term rehabilitation goals [62]. Such a resource was proven to be effective in providing a structure for patients to consider their long-term goals and to understand how environmental and personal factors may affect these goals. Talking Mats™ enables intricate ideas to be broken down into more manageable chunks and ensures that those who have issues comprehending complex language are able to understand the information conveyed through the use of immediately identifiable pictures. As a result, fruitious conversations pertaining to the patient's rehabilitation needs were conducted.

Overall, the author was able to provide evidence as to why the proposed intervention is required since similar technologies, such as those mentioned above, have not been implemented on a nation-wide scale. A variety of reasons were identified to contribute to this including inappropriateness, ease of use, the time constraints placed on such consultations, cost, and the lack of opportunities to access appropriate training facilities. This supported some of the conclusions made during the following studies [5-6, 12-13, 18-19, 21, 69]. As a result, the common problems that occur throughout consultations involving adults with mild learning disabilities are still prominent, including those that stem from the breakdown in communication between patients and GPs.

The data collected throughout the scoping review also partially formed an answer to the second research question proposed i.e. what are the requirements for a tablet application that assists adults with mild learning disabilities during clinical consultations? By drawing on the research conducted previously, a number of requirements for the proposed intervention were identified. Furthermore, features that were proven to be detrimental to the user's experience (such as an overly complex interface) were also established and subsequently excluded from the design of the application.

One of the most crucial requirements identified during the review was the need to accommodate for a variety of communication modalities. As described in chapter 2, adults with learning disabilities are heterogeneous in nature and therefore will not respond to information in the same manner [4, 26-27, 29, 53]. Consequently,

symptoms embedded throughout the application had to be displayed with the use of a variety formats to ensure a large percentage of stakeholders understand the meaning conveyed. These formats included the use of immediately identifiable images, simplified text that avoided utilizing medical jargon, and speech by allowing the option to playback all text located within a page.

Due to disparities in the cognitive, linguistic, and motor abilities held by adults with mild learning disabilities, a one size fits all approach to communication models is ineffective [18, 27, 33, 39, 45, 53]. Therefore, AAC technologies are required to be highly adaptable to ensure the requirements of a large range of users are met, and this was triangulated by an abundance of the experts interviewed throughout the thesis. However, both the order of questions presented and the language used to describe conditions may be crucial within technologies that aim to extract medical symptoms. Therefore, the proposed intervention should only enable adjustments to be made to the interface but the content should remain unchanged for all users.

As discussed previously, Talking Mats™ has proven to be an effective tool for enabling people with learning disabilities to express their views in more detail. One of the main reasons stated for this success is the ability to break down complex ideas or questions into more manageable chunks [48-49, 59, 62]. Some of the experts interviewed also supported this concept, thus resulting in a probe that aims to mimic this process by breaking down what is essentially an open and complex question i.e. what is wrong with you? into small, straightforward questions that a cognitively impaired patient may find easier to answer.

Screen size was identified to be a prominent issue for AAC applications throughout the scoping review [56-57]; particular those that operate within more traditional devices such as mobile phones and tablets. As a result, the author developed an interface that ensures clickable elements are placed far apart and are large enough to accommodate for those who have significant motor impairments. The experts also identified the need for the application to port across different operating systems and devices in order to address the needs of individual users. For example, those who have significant visual impairments may require a larger tablet in order to read text, whereas

those who find it strenuous to operate bulky devices may require a small, lightweight device.

To further triangulate the requirements identified during the review, and to extract additional features for the application, the author proceeded to interview a purposive selection of learning disability experts. The most emphasised requirement during these interviews was the need to shape questions based on the health needs of those who have learning disabilities. Therefore, the application focused on extracting manifestations such as GORD, respiratory disease and dental disease since these develop far more frequently in the learning disability population. Many of these conditions are complex and require a great deal of information to ensure a correct diagnosis is made. As a result, GPs would like data pertaining to these conditions to be brought in advance of consultations to enable them to shape further questions throughout. This method also has the potential to identify symptoms that tend to be overshadowed meaning a more accurate diagnosis can be made. A full list of conditions included within the application may be found in chapter 5.

Many of the experts also discussed the need to limit the number of questions being presented to stakeholders, since many adults with learning disabilities have short attention spans and may be unable to complete overly long questionnaires. This is particularly true for when those questions fail to be directly relevant to the patient's conditions. Therefore, the application includes an adaptive questionnaire similar to that proposed by Bouamrane at al. [112] that aims to reduce the amount of irrelevant questions being presented to the user based on the data previously inputted. A more in depth description of the questionnaire may be found in chapter 5. This also reduces the number of clicks required to complete the process - a feature revealed to be desirable by the experts as it has the potential to ease the cognitive load placed on stakeholders.

As discussed previously, the application aims to break down complex questions into smaller more manageable queries. One way to achieve this may be to limit the number of potential options displayed on the screen to a maximum of four. Patients with learning disabilities may find it difficult to select the correct manifestation from an abundance of possible symptoms. Therefore, the application splits potential symptoms

into sets of 4 or less related options to ensure the cognitive load placed on such patients is reduced. This also enables elements on the screen to be increased in size and prevents the need for technology related actions, such as scrolling, to be carried out. However, the number of clicks required to complete the process may increase but this was deemed necessary due to the benefits described above.

Further requirements discussed by the experts interviewed may be found in chapter 4. Overall, the research conducted triangulated the views held by Bostrom and Eriksson [83] who revealed that such applications should aim to present one question at a time, the interface should appear to be basic and remain consistent throughout, immediately identifiable images should be used to represent potential options, and interactions with the application should be kept to a minimum. These, in combination with the other requirements identified throughout, lay the foundation for the design of an intervention that assists adults with mild learning disabilities during clinical consultations. A summary of such development guidelines may be found in chapter 7. The application has the potential to address the communication challenges that exist between patients and GPs by allowing the patient to focus on what they wish to discuss beforehand whilst making use of a variety of modalities to achieve this. As a result, discussion may be promoted throughout consultations in which patients provide more accurate and detailed information to their GP. Practitioners may also make use of the data provided in order to shape the questions they present throughout, thus potentially avoiding situations where they are unable to extract any relevant information from the patient. This may ease the time constraints placed on such consultations – a serious barrier to providing care to patients with sever communication impairments [132-133].

One final research contribution made during the course of this study was discussed during the scoping review. A number of steps were identified for developers to follow to ensure a more appropriate product is created which addresses the needs of stakeholders who have learning disabilities. These steps range from identifying the consumers' communicational needs, to appropriately including stakeholders throughout the lifecycle of the project and concluding with a number of quantitative evaluation studies. A more in depth description may be found in chapter 2.

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Appendix A – Overview of Themes Discovered during Scoping Review

In Depth Overview of Communication Challenges

Overview	Citations
1. People who have learning disabilities are heterogeneous in nature. As a result, physicians are required to have a great deal of knowledge about learning disabilities in order to adapt to the individual needs of each patient.	5 papers discussed the heterogeneous nature of people with learning disabilities and the challenges this creates [4, 26-27, 29, 53]
2. Physicians will be required to know how to interact with the wide range of AAC devices used by people who have learning disabilities. These devices may also require large amounts of time to operate which causes strains on consultation times.	3 papers touched on the wide range of AAC devices used by people with learning disabilities and how the large amount of time required to produce a message is a major barrier [12-13, 21]
3. People with learning disabilities generally struggle when expressing their views. This may result in the inability to describe symptoms accurately thus resulting in a misdiagnosis.	2 papers addressed the problems associated with the poor language skills owned by those who have learning disabilities [29, 31]
4. People with learning disabilities also have trouble in understanding information presented to them. Physicians have to find a way to present information in a manner that the patient can understand.	1 paper detailed the difficulty people with learning disabilities have in understanding information [29]
5. Not all of those people who have learning difficulties understand speech. Therefore, the physician must present information in a variety of forms to accommodate for those who cannot.	5 papers described the need to present information in a variety of forms [19, 32-35]

In Depth Overview of Communication Modalities

Overview	Citations
1. People with learning disabilities have a wide range of verbal communication skills and tend to rely on speech even if they own a limited vocabulary set. However, studies have shown that the use of	8 studies discussed the use of speech and audio by those who have learning disabilities [33, 37-42, 45]

alternative forms of communication can help develop speech.	
2. Gestures can be used in conjunction with or as a substitute to speech. Facial expressions and body language are the most natural forms of communication via the use of gestures. Paying particular attention to a person's body language may provide cues to their needs or overall mood. Pointing is a particularly powerful form of communicating one's needs, especially for those who have communication impairments. People who are not able to share their needs via speech can simply point to an object they desire and the communication partner can respond appropriately The most complex form of communication via the use of gestures is signing which combines the use of gestures, facial expressions, and body language in order to provide a means of communication. Several studies have suggested that the use of manual signing in conjunction with speech results in faster and more complete receptive and/or expressive vocabulary acquisition than using speech alone. However, this is not true for all people with learning disabilities and one factor that appears to be related to how effective manual signing can be is fine motor ability.	5 studies discussed the use of gestures by those who have learning disabilities [20, 46-48, 115]
3. Pictures have been proven particularly effective in aiding communication for those who have learning difficulties. Pictures provide an alternative means of representing language in a fathomable manner, providing the illustrations directly represent the concepts being symbolised. Symbols provide a concrete representation that speech cannot. Participants generally enjoy conversations related to personal photographs [34] and have shown a tendency to provide more complete and accurate answers On the downside, conversations may be limited to the symbols that are available thus potentially restricting	12 papers studied the use of images by those who have learning disabilities [19, 32-33, 40, 48-55]

the answers provided by the person who has a learning disability. Systems that use large amounts of images may become confusing or unmanageable and may result in the user resorting to their traditional form of communication	
4. Eye gazing is a developing form of communication that is primarily used by people who have poor fine motor abilities. The most basic form of eye gazing requires no technology and simply involves the person looking at objects in order to bring attention to them. Forms that are more modern involve using cameras that are attached to a screen in order to track the eyes of the user. Software then determines the area of the screen that the user is looking at in order to select the options related to that area of the screen.	5 papers addressed the need to use eye gazing technology for those who have poor fine motor skills [20-21, 56-58]

In Depth Overview of Communication Aids

Overview	**Citations**
1. The Talking Mats™ framework consists of an inexpensive, textured mat 60 × 30 cm in size and a series of picture symbols with Velcro™ attached to the back. The symbols are moved about the mat in order to express the views of the person who suffers from learning disabilities. On top of this, the Talking Mats™ framework has also been proven to provide its users with a means of expressing views in which they would have had difficulty doing otherwise. The Talking Mats™ framework also aids in the comprehension of a task by dividing the strands of issues into manageable chunks.	7 papers reviewed Talking Mats™ and the components that make up the framework [37, 48-49, 59-62]
2. Personal Communication Passport booklets are made up from a series of symbols and short sentences that disclose essential information about the views and characteristics of a person. Instead of simply listing the owner's likes and dislikes, the short sentences	2 papers reviewed the use of Personal Communication Passports including one that reviewed the use of PCPs in the clinical setting [9, 63]

should contain more powerful information on the person's communication habits. Many people who come from various backgrounds (e.g. nurse, carer, parent or teacher) update PCPs meaning different perspectives on what the most effective means of communication is contained within them. When first introduced into the clinical setting, the quality of the passports were poor leading to the conclusion that without proper training, passports may contain unreliable information that could adversely affect clinical decisions made by healthcare professionals	
3. Illustrations are stored on a Picture Exchange Communication System board with the use of Velcro in a similar fashion to Talking Mats™. The subject is then trained to use their PECS board by selecting various picture cards (e.g. "I want" card plus "biscuits" card) in order to create a sentence, before distributing the cards to a communicative partner as a request for a specific item, rather than resorting to aggression, self-harm or pointing. As with Talking Mats™, PECSs use images extensively and therefore inherit the advantages and disadvantages discussed previously. There are also various studies to support the fact that PECSs can be taught quickly, meaning people can profit from their services almost immediately.	4 papers reviewed and discussed the advantages and disadvantages of using the Picture Exchange Communication System [40-41, 55, 64].
4. Voice Output Communication Aids are typically small, lightweight electronic devices that are used to supplement speech or writing by producing artificial dialogue at the touch of a button. VOCAs come in various forms depending on the needs of the user. These range from complex touch screens that contain an abundance of phrases and symbols spanning numerous pages, to mobile phone applications, and even simple remote controllers that contain only a few buttons and options.	4 papers discussed the advantages and disadvantages of using voice output communication aids[20, 22, 64-65]

As with the Picture Exchange Communication System, none of the papers reviewed discussed using VOCAs in the clinical setting. However, the simplistic nature of VOCAs (entire requests can be made at the touch of a button) combined with the relatively short time period required to become proficient in their use suggests that a VOCA could be developed in order to aid people who have learning disabilities within the clinical environment	
5. Mobile phone and tablet AAC applications are becoming increasingly popular due to a number of reasons including: their low cost in comparison to traditional AAC devices; increased portability; and increased availability. The most popular AAC applications offer much of the services available in the technology previously described. There is a clear gap in the market for AAC applications that are designed specifically for use in the clinical environment. Of the 265 AAC applications listed on appsforaac (http://appsforaac.net/), 3 have been built for the sole intention of being used by people who have communication difficulties in clinical environments. None of these applications are based on research evidence and may not address the needs and skills of individuals with complex communication requirements.	10 studies reviewed the use of mobile technology as a form of AAC [21, 35, 43, 47, 56-59, 67-68]

In Depth Overview of Barriers to Technology/Accessibility

Overview	**Citations**
1. If a device is difficult to use and the interface is overly complex, users may revert to their traditional communication methods such as pointing. This leads to high rates of AAC device abandonment.	5 papers studied the impact operational difficulties have on the use of AAC devices [12-13, 18, 33, 119]
2. The time taken to generate a message is a major barrier. To be effective the device should be able to	3 papers addressed the deficiencies AAC devices have in generating messages [12-13, 21]

'produce' the message in time with the thoughts of the user.	
3. The use of alternative and augmentative devices appears to affect how their users perceive themselves. Many think of AAC devices as uncool and boring and as a result feel uncomfortable when communicating with unfamiliar partners.	2 papers reported on the negative feelings people have towards using AAC devices [18, 21]
4. AAC devices are generally expensive to purchase. On top of this, there is a lack of funding available to purchase such devices. They often require to be tailor made for each user, meaning there may be a lack of cheaper second hand devices available that suits the needs of specific users	5 papers discussed the expensive nature of AAC devices and the problems this creates [12-13, 19, 21, 33]
5. Not all Web Browsers conform to User Agent Accessibility Guidelines meaning users may not be able to take advantage of the accessibility features promised by a Web page that was developed using these guidelines due to the browser or assistive technology device being used.	2 papers discussed the use of legacy browsers and the accessibility problems this creates [45, 70]
6. The tools used to evaluate online resources cannot wholly evaluate accessibility in regards to such aspects as scripting, the suitability of alternative texts that aid in describing graphics for the visually impaired or the accessibility of audio and video files.	A solitary article discussed the deficiencies evaluation tools have in assessing online tools for accessibility [71].
7. Mobile technology and AAC applications alleviate issues of self-image since they are socially valued. Operational requirements of AAC applications are similar to those used in traditional apps, meaning communication partners may have more of an idea in how to use them without a steep learning curve. Mobile technologies are also far cheaper than traditional AAC devices thus making assistive technology more accessible.	2 papers discussed the advantages of using mobile technologies as a form of AAC [21, 56]
8. Some individuals who use appropriate AAC solutions may be advised to switch to the cheaper alternatives since many adhere to the belief that "one size fits all". This can be troublesome since those	3 articles addressed the disadvantages of using mobile technologies as a form of AAC [21, 56-57]

who have learning disabilities may have problems whilst learning new operational skills, and not have access to personnel who can support the learning process. The small screens contained within mobile devices may result in those who have poor fine motor skills being unable to use the device.	

In Depth Overview of Professionals' Attitude

Overview	**Citations**
1. Several papers revealed that professionals have to become more knowledgeable about AAC technology and the ways in which people with learning disabilities interact with such technology. For this to happen, intensive training is required; however, a number of studies revealed that professionals have insufficient access to appropriate training. Time constraints also prevent physicians from taking advantage of such opportunities when they arise.	8 studies revealed the need for professionals to increase their knowledge about learning disabilities and AAC devices [12-13, 19, 28, 36, 38, 47, 66]
2. GP staff are usually unaware of the range of communication disabilities that exist and the various forms of technology on offer that aid these disabilities. As a result, they have a tendency to rely on carers to facilitate conversations between themselves and the person with communication problems. This may result in incorrect answers being provided.	One paper described GPs tendency to rely on carers providing answers rather than speaking directly to the patient [36]
3. General practitioners may experience frustration when consulting with people with learning disabilities, and as a result may subconsciously provide a poorer level of healthcare for all people who have similar conditions.	One paper addressed how negative attitudes held by professionals can affect the health provided to patients with learning disabilities [28].
4. Physicians tend to be reluctant when interacting with new technology due to the perceived negative impact learning how to use such technology has on a physicians' workflow. Therefore they may not possess the skills necessary to interact with people who use AAC devices.	2 papers addressed GPs reluctance to use new technology [74-75]

In Depth Overview of Individualisation

Overview	Citations
1. Communication models are effective for some users but not all will benefit from their use due to disparities in cognitive, linguistic, and motor abilities. Therefore, you should use a wide range of consultation methods to extract the views of those who have learning disabilities.	6 papers recognised the need to use a wide range of consultation methods to extract the views of people who have learning disabilities [18, 33, 39, 45, 53, 76].
2. No AAC device can satisfy the needs of all consumers. Therefore, greater attention to the necessities and characteristics of an individual is required in order to determine the type of AAC device that is most suited to addressing their needs.	2 papers addressed how to select the most appropriate device for AAC consumers [21-22]
3. Websites tend to be designed around generalisation. To avoid this, the principles of accessibility should be introduced as a fundamental system component at the conceptualisation and design stages rather than being left as an afterthought, once the site has been built.	2 papers discussed why generalisation is not a legitimate approach for people who have learning disabilities [53, 77]
4. A set of guidelines that enable a web developer to create an environment that adapts to each user's needs and preferences would be preferable over current Web Accessibility Guidelines	A solitary paper discussed the deficiencies of Web Accessibility Guidelines [45].
5. Three approaches to mass customisation may be followed when developing and updating AAC devices or accessibility compliant websites. Collaborative, Adaptive and Cosmetic customisation may be used when developing AAC devices.	One paper discussed the types of customisation that can be used when developing products [116]

In Depth Overview of Co-Design

Overview	Citations
1. To ensure that the system succeeds in achieving its intention and becomes successful end users must be involved throughout its lifecycle, beginning with design and ending with extensive testing. Systems that have been developed collaboratively with	7 papers discussed the need to include end users in the design of a system [18, 22, 56, 67, 69-70, 78]

representative users are far more likely to be easy to use and look 'good' in the eyes of the consumer [15]. Systems that have not been developed in conjunction with the views of end users are more likely to have major accessibility flaws	
2. There are several reasons as to why developers may not include people with learning disabilities in the design of a system. Firstly, there is a lack of studies available that detail the involvement of those who have cognitive disabilities in research. People with learning disabilities tend to have problems in understanding new or complex information so may not understand what is required of them. They may also experience problems in expressing their own opinions and therefore are not able to convey their needs in a comprehensible manner	4 papers described reasons as to why people with learning disabilities are excluded from studies [22-23, 34, 81]
3. The right to dissent from involvement should be exercised continually whilst people with learning disabilities are involved in the project. A variety of aids (audio, symbols etc.) should be included in the consensual process in order to make the most out of the language and communication skills owned by each individual.	One paper discussed the need to continually exercise subjects right to assent or dissent from involvement [76]

In Depth Overview of Evaluation

Overview	**Citations**
1. Qualitative interviews that made use of communication aids in order to extract information from people with learning disabilities were the main form of evaluation used.	12 studies used qualitative interviews that involved communication aids [17-18, 36-7, 39, 42, 48-49, 54-55, 60-61, 82]
2. Qualitative interviews were also conducted where no explicit communication aid was specified to have been used by those who have learning disabilities.	5 studies used qualitative interviews involving no explicit communication aids [52, 66, 69, 83-84]
3. Professionals and family members who are involved in the lives of people with learning disabilities also participated in qualitative interviews	7 studies carried out qualitative interviews with professionals or family members [17, 28, 36, 58, 60, 66, 85].

4. Qualitative observations were also used as a form of evaluation over a range of studies.	5 studies carried out qualitative observations [47, 64, 83, 85-87]
5. Quantitative analysis techniques were used scarcely in comparison to qualitative techniques. There is a clear need for further use of quantitative analysis in order to determine the true effectiveness of communication aids in areas such as engagement, language development, accuracy of answers provided etc.	7 studies carried out quantitative evaluation in order to determine the true effectiveness of the aids involved [32, 38, 41, 50, 59, 64, 68]

Appendix B – Requirements Gathering Questions

Question Sets Discussed with Learning Disability Experts

Question Set	Summary of Question
1	General background questions on what experience they have in working with people with learning disabilities, and what projects they're currently working on that benefit those who have learning disabilities.
2	Questions based on the stigmas shown towards people with learning disabilities.
3	Questions based on the awareness of the health needs of people with learning disabilities.
4	Questions based on the differences between having a conversation with someone who has a learning disability and someone who has not as well as the challenges involved.
5	Questions relating to the communication modalities used by people with learning disabilities.
6	Questions relating to the communication aids used by people with learning disabilities.
7	Questions relating to touch screen technologies and how proficient people with learning disabilities are in using them.
8	Questions relating to the specific size of tablet that should be used for the application.
9	Questions relating to the amount of answers that should be present per question asked i.e. how many would exceed the cognitive load possessed by people with learning disabilities.
10	Questions relating to the overall look and feel of the application i.e. colour schemes etc.
11	Questions based on the person's expectations of an application that assists people with learning disabilities during the consultation process.

12	General question to allow further issues to be brought up by the participant.

Question Sets Discussed with General Practitioners

Question Set	Summary of Question
1	General background questions on what experience they have in working with people with learning disabilities i.e. how often they consult with those who have learning disabilities.
2	Questions relating to the GPs confidence in consulting with those who have learning disabilities
3	Questions relating to the education that they have received on learning disabilities
4	Questions relating to the differences that occur when consulting with those who have learning disabilities compared to that of the general population
5	Questions relating to the communication aids used during consultations
6	Questions relating to any technologies used when consulting with the general population.
7	Questions relating to the communication modalities used by people with learning disabilities
8	Questions relating to where the application would be best used i.e. waiting room, during the consultation etc.
9	Questions relating to the possibility of storing the results produced by the application.
10	Questions relating to the types of information the application should collect from the user
11	Questions relating to the overall look and feel of the application.
12	General question to allow further issues to be brought up by the participant.

Appendix C – Questions Presented in Usability Studies

No.	Question
1	Do you think the app is appropriate for people with learning disabilities?
2	What features do you think help stakeholders to convey the symptoms they are experiencing?
3	Are there any features that may cause problems for the stakeholders?
4	Are the images and language used throughout appropriate?
5	Do you think the application is visually appealing to those who have learning disabilities?
6	How would you improve the application?
7	Is there anything else you would like to add?

Appendix D – Scoping Review Framework

Summary	Excerpt	Tag
Tablet AAC applications are becoming ever popular due to them being more accessible than traditional AAC devices. **A1**	Mobile phone and tablet AAC applications are becoming increasingly popular due to a number of reasons including: their low cost compared to traditional AAC devices; increased portability since most can fit in your pocket; and increased availability since they are readily obtainable in both the Google Play Store and the Apple App Store **B1**	Accessibility **C1**
Developers tend not to include people with learning disabilities in studies due to a lack of information available in how to include these stakeholders as well the overall difficulty in extracting their views. **A2**	There are several reasons as to why developers may not include people with learning disabilities in the design of a system. The most substantial reason alludes to the fact that there is a lack of studies available that detail the involvement of people who have cognitive disabilities in research. As a result, there is a lack of guidelines on how to involve such users. This appears to be a solvable problem since those who have experience in involving people who have learning disabilities within research, can come together and develop such guidelines. The difficulty in extracting the views of people with learning disabilities is another significant factor. Such people tend to have problems in understanding new or complex information so may not understand what is required of them. They may also experience problems in expressing their own opinions and therefore are not able to convey their needs in a comprehensible manner. **B2**	Barriers to Technology / Co-design **C2**
People with learning disabilities should be included within studies as early as the design stage to ensure their complex needs are met. These stakeholders should continue to be included throughout the entire design process. **A3**	Several studies emphasised the need to include representative users in the design of a system, to ensure that the system succeeds in achieving its intention and becomes successful. Eghdam et al. took this idea a step further and suggested that representative users should be involved in the early design stages and continue to be involved throughout the entire development process and system lifecycle. This is particularly true for a system that is being developed for people with learning disabilities, since the needs of the user may be difficult to extract or even change throughout the development process. Testing the product continuously with representative users will ensure that their complex needs are being met and that they can navigate the user interface with relative ease. **B3**	Co-design **C3**
People with learning disabilities may not be willing to communicate meaning GPs may have difficulty	The willingness of people with learning disabilities to communicate and their abilities to do so can also vary dramatically. For example, people	Communication challenges **C4**

extracting symptoms from these people **A4**	with ASDs tend to be self-absorbent and refrain from initiating conversations, whereas people who have Down's syndrome (DS) are generally highly motivated to communicate with others. This may result in the physician being unable to extract the views of the person who has an ASD, since they may be unwilling to engage in a conversation and share their symptoms. **B4**	
Adults with mild learning disabilities tend to have underdeveloped speech and language skills. Therefore they may not be able to describe their symptoms accurately. **A5**	Most people with learning disabilities tend to develop some speech and language skills but not to an average level of ability. The progress of development is also generally skewed, where the person may build a strong vocabulary in areas of interest but fail to grasp basic concepts in other areas. Due to their sub-par language skills, people with learning disabilities may not possess the vocabulary required to describe their symptoms accurately and this may lead to an erroneous diagnosis of the patient's problems. They may also describe symptoms in an unclear manner, meaning the physician may have difficulty in extracting the key information required to make a diagnosis **B5**	Communication challenges **C5**
Personal communication passports provide essential information on how someone with learning disability prefers to communicate. This ensures that all communication partners act on a consistent basis and get the most out of their person who has a learning disability. **A6**	PCP booklets are made up from a series of symbols and short sentences that disclose essential information about the views and characteristics of a person. Instead of simply listing the owner's likes and dislikes, the short sentences should contain more powerful information on the person's communication habits. For example, a passport could contain information on how the owner shows you what activity they wish to participate in, rather than listing some activities they enjoy. This enables conversation partners to interact with the person who suffers from communication problems in a consistent manner, thus helping the person to comprehend the situation and make the most out of the communication abilities they do possess [55]. This would allow physicians to gather knowledge at a glance about how to communicate best with the patient in order to extract the relevant information required to make a diagnosis. **B6**	Communication challenges / PCPs **C6**
People with learning disabilities are heterogeneous and therefore have a range of manifestations and needs that GPs must adapt to. **A7**	people with learning disabilities are heterogeneous in nature. Disabilities such as Autism Spectrum Disorders (ASDs) have a range of manifestations that may or may not include additional impairments. As a result, these people may share some symptoms, but can differ in terms of when the symptoms start, the severities of the symptoms	Communication challenges / Individualisation **C7**

	present and how many are present. This requires the physician to have a great deal of knowledge about learning disabilities, in order to adapt to the individual needs of these patients. **B7**	
People with learning disabilities use a large range of alternative and augmentative communication devices that the GP must adapt to during consultations **A8**	People with learning disabilities may be entirely non-verbal and take advantage of AAC devices in order to communicate. As a result, GPs will have to accommodate for each individual device and these may require specialised knowledge, which the physician does not possess, in order to operate. Most devices are not built for the sole purpose of being used in a clinical setting and therefore may not contain phrases that accurately describe the problems the user is experiencing. This causes severe problems for the physician since they will have to develop another strategy to extract the relevant information required to make an accurate diagnosis. **B8**	Communication challenges / Individualisation **C8**
People with learning disabilities tend not to pick up on non-verbal communication cues but are proficient in using them. **A9**	Facial expressions and body language are the most natural forms of communication via the use of gestures. Overall, people with learning disabilities are not as proficient in recognising facial expressions of emotions compared to the general population. However, this does not prevent these people from showing their own emotions and desires through the use facial expressions and body language. **B9**	Communication challenges / non-verbal communication **C9**
There are conflicting views on how effective sign language is for people with learning disabilities. Potential barriers include motor problems and poor memory skills **A10**	Several studies have suggested that the use of manual signing in conjunction with speech results in faster and more complete receptive and/or expressive vocabulary acquisition than using speech alone. However, this is not true for all people with learning disabilities and one factor that appears to be related to how effective manual signing can be is fine motor ability. Although the occurrence of learning disabilities does not guarantee the co-occurrence of motor coordination problems, there is evidence to suggest that some individuals may have trouble in this area. On top of this, people with learning disabilities tend to have poor memories and have trouble learning new skills. Therefore, people with serious motor problems are likely to have issues in learning and performing signs successfully **B10**	Communication challenges / Non-verbal communication **C10**
Pictures may result in conversations being limited and an overuse of pictures may result in systems becoming confusing and unmanageable. **A11**	On the downside, conversations may be limited to the symbols that are available thus potentially restricting the answers provided by the person with a learning disability. Systems that use large amounts of images may become confusing or unmanageable and may	Communication challenges / Pictures **C11**

	result in the user resorting to their traditional form of communication **B11**	
People with learning disabilities have trouble understanding complex information or information that is presented to them quickly. They also require more time to deliberate information that is presented to them. GPs must break down consultations into small manageable chunks to overcome this. **A12**	People with learning disabilities also have trouble in understanding information presented to them. They tend to have problems in understanding information that is presented to them quickly or when overly complex language is used. They also require more time to deliberate what was being said to them before constructing an appropriate response. To overcome these problems, physicians must find a way to break the consultation into small manageable chunks and avoid using complex medical terms that may confuse the patient. They must also find the time to allow the patients to consider the information being presented to them and formulate an appropriate response. This may be extremely difficult to achieve considering consultation lengths are so short. **B12**	Communication challenges / Speech **C12**
People with learning disabilities have a wide range of verbal communication skills. **A13**	Due to their heterogeneous nature, people with learning disabilities can have a wide range of verbal communications skills. Some may only be able to use short utterances in order to request attention; however, others may be able to use an extensive vocabulary in order to construct complex sentences. **B13**	Communication challenges / Speech **C13**
Pictures are particularly effective in aiding communication for those who have learning disabilities particularly when used to assist in the comprehension of complex language. Images that are not immediately identifiable may cause problems. **A14**	Pictures have been proven particularly effective in aiding communication for those who have learning difficulties. First of all, pictures assist in processing the concepts that are to be considered [9, 39-43]. People with learning disabilities tend to have complications in reading and processing text and speech, particularly when complex vocabulary is used. However, pictures provide an alternative means of representing this language in a fathomable manner, providing the illustrations directly represent the concepts being symbolised. Illustrations that are not immediately identifiable will result in people with learning disabilities finding their meaning confusing and not profiting from their use. **B14**	Communication challenges / Speech **C14**
AAC devices require large amounts of time to operate and this puts a strain on consultations. **A15**	Generally, AAC devices require large amounts of time to produce the views of the user and this is not ideal considering the short amount of time allocated to consultations. This may result in physicians rushing consultations and not providing the patient with a high level of care. **B15**	Communication challenges / Technology barriers **C15**

Eye-gazing is a developing form of communication that can be used to aid people who have motor impairments **A16**	Eye gazing is a developing form of communication that is primarily used by people who have poor fine motor abilities. Those who have impaired fine motor skills may be unable to use their hands in order to point, swipe, pinch or carry out signs successfully and may become tired relatively quickly when carrying out such actions. **B16**	Eye-gazing **B16**
Not all adults with mild learning disabilities respond to the same communication modalities therefore a wide range of modalities should be included within aids. **A17**	Several studies found that, although certain communication models are effective for some users, not all benefited from their use. People who have the same learning disability may still have disparities in their cognitive, linguistic, and motor abilities. Therefore, you should not assume that the inclusion of alternative forms of communication, such as symbols or photographs, would be sufficient to make the experience beneficial to all participants, since some may have visual processing complications etc. Instead, using a wide range of consultation methods is deemed a more effective approach in extracting the views of those who have learning difficulties. **B17**	Individualisation **C17**
No AAC device will be suitable to all users due to the heterogeneous nature of people with learning disabilities. Great attention to the needs of individuals is required when selecting any devices. **A18**	The AAC market as a whole is small, but the requirements of its consumers are highly diverse. As a result, there is no device available that can conceivably satisfy the needs of all AAC consumers, and no single company is likely to fabricate devices that accommodate for all augmented communicators' needs. Instead, greater attention to the necessities and characteristics of an individual is required in order to determine the type of AAC device that is most suited to addressing their needs. A combination of the views from knowledgeable professionals, family members, and ultimately the end user will result in the most appropriate AAC device being chosen. **B18**	Individualisation **C18**
Voice Output Communication Aids come in various forms depending on the needs of the user. Their main goal is to request the attention of others for example when needing the toilet. The content is also customisable depending on the needs of the user. **A19**	VOCAs come in various forms depending on the needs of the user. These range from complex touch screens that contain an abundance of phrases and symbols spanning numerous pages, to mobile phone applications, and even simple remote controllers that contain only a few buttons and options. The content, organization, and updating of the vocabulary on a VOCA is dependent on the needs of the user, along with the context in which the device is used. For example, the vocabulary required for a VOCA device being used in a clinical setting, would be vastly different from that required by a device being used at home.	Individualisation / Speech **C19**

	B19	
Not all people with learning disabilities respond to speech. Therefore information will have to be presented in a variety of formats to accommodate for all patients. **A20**	Not all people with learning disabilities will respond to information presented to them with the use of speech. In these cases, physicians will be required to present information in other formats such as pictures or text. This may be time consuming especially when no existing resources are available for use. Information presented on prescriptions, packaging etc. should also be presented in a variety of ways in order to ensure the patient can understand what is being conveyed. **B20**	Individualisation / Speech / Pictures **C20**
People with learning disabilities tend to have poor non-verbal communication skill therefore GPs should present all information in a clear and direct manner. **A21**	People with learning disabilities also tend to have poor non-verbal communication skills and may not recognise or understand information presented via body language or facial expressions. Physicians should ensure that all information is shared directly in a clear format and not via the use of secondary cues such as body language. **B21**	Non-verbal communication **C21**
People with learning disabilities may be able to use pointing as an effective means of non-verbal communication. **A22**	Pointing is a particularly powerful form of communicating one's needs, especially for those who have communication impairments. People who are not able to share their needs via speech can simply point to an object they desire and the communication partner can respond appropriately. This requires less physical effort than other communication methods such as signing **B22**	Non-verbal communication **C22**
Personal photographs are a particularly strong form of communication aid. **A23**	Personal photographs are especially fruitful with Cambridge et al. describing them as the most effective resource used to elicit views. Participants generally enjoy conversations related to personal photographs and have shown a tendency to provide more complete and accurate answers. Young et al. were particularly impressed with the answers provided by people with learning disabilities when using personal photographs, and have called for the development of this form of consultation **B23**	Pictures **C23**
Talking mats has been proven to allow users to express their views on topics in which they could not previously do so by breaking tasks into manageable chunks. **A24**	the Talking Mats™ framework has also been proven to provide its users with a means of expressing views in which they would have had difficulty doing otherwise [40, 51, 54]. This is particularly useful during consultations, since people with learning difficulties may encounter problems whilst trying to describe their symptoms. The Talking Mats™ framework also aids in the comprehension of a task by dividing the strands of issues into manageable chunks	Pictures **C24**

	B24	
Picture exchange communication systems use images extensively and therefore inherit their advantages and disadvantages. They require the user to approach a communication partner to begin a conversation and have proven to be taught quickly. **A25**	As with Talking Mats™, PECSs use images extensively and therefore inherit their advantages and disadvantages. However, PECSs are unique in the manner that they depend upon the user approaching a listener in order to begin the communication process. There are also various studies to support the fact that PECSs can be taught quickly, meaning people can profit from their services almost immediately. This could be useful in the clinical setting since patients who have learning difficulties may be trained to use PECSs effectively and, as a result, are able to approach a member of staff with potential problems/symptoms rather than having physicians expend large amounts of valuable time trying to extract these symptoms. **B25**	Pictures **C25**
Professional's knowledge of learning disabilities have to improve however, they are unwilling to exhaust large amounts of their own time improving this education. **A26**	Several papers revealed that professionals have to become more knowledgeable about AAC technology and the ways in which people with learning disabilities interact with such technology. In order to significantly improve a professional's education of AAC technology, intensive training is required. However, a number of studies revealed that professionals have insufficient access to appropriate training. This was particularly true for GP staff as a survey conducted by Murphy found that "none of the staff had received any training on communication disability". On top of this, professionals realise that further education and training would be beneficial, but time constraints prevent them from taking advantage of such opportunities when they arise. **B26**	Professional's attitude **C26**
GPs tend to rely on carers to facilitate consultations however, this may result in inaccurate information being collected. **A27**	they have a tendency to rely on carers to facilitate conversations between themselves and the person with communication problems. However, these carers may provide answers that they believe to be true, but are not the views of the actual patient. Additionally, people with learning disabilities tend to object to the GP bypassing their own views in order to speak to their carer. **B27**	Professional's attitude **C27**
GPs may have preconceptions about patients who have learning disabilities and this may affect the standard of care they're providing to this population. **A28**	Negative attitudes held by medical professionals can affect the standard of health care provided. General practitioners may experience frustration when consulting with people who have learning disabilities, and as a result may subconsciously provide a poorer level of healthcare for all people with similar conditions. **B28**	Professional's attitude **C28**

Physicians tend to shy away from using new technologies in favour of using those they are familiar. **A29**	Physicians also tend to be reluctant when interacting with new technology. The main reason for this is the perceived negative impact learning how to use such technology has on a physicians' workflow. Some believe that learning how to operate new technology or follow new guidelines requires a significant amount of effort that can be directed towards important tasks such as updating health records. This is particularly true when the system has been poorly developed **B29**	Professional's attitude **C29**
Some studies reveal that people with learning disabilities rely on speech even when using AAC devices. **A30**	Several studies revealed that those who have learning difficulties tend to rely on speech (no matter how limited their vocabulary is) even when using alternative forms of communication. These participants may have become frustrated when using the alternative form of communication and reverted back to using whatever speech they possess in order to get across their views. **B30**	Speech **C30**
AAC devices can actually assist in the development of language skills **A31**	the use of alternative forms of communication can actually develop speech. By using the Picture Exchange Communication System (PECS), people with autism spectrum disorders were revealed to increase their use of spontaneous speech dramatically. Others were also shown to increase both the accuracy and length of their answers when provided with aids such as pictures. **B31**	Speech **C31**
Text to speech synthesisers often do not work on the internet as a result of the use of legacy browsers **A32**	Therefore, many Web users require a text-to-speech synthesiser (screen readers) that converts text into audio. The main barrier to the use of text-to-speech synthesisers is the choice of browser. Legacy browsers may not support the use of such technology even though the Web page claims the content is compliable with accessibility guidelines. Therefore, the devices will be unable to convert text into the audio required by the user **B32**	Speech / Web accessibility issues **C32**
Several barriers to AAC devices include: operational difficulties; people's inability to follow complex instructions; and message generation times **A33**	Common barriers to the use of high technological communication models were discussed in an abundance of papers reviewed. Operational difficulties were found to be the most common barrier. People with learning disabilities tend to have problems in learning how to use intricate technology as well as remembering instructions. Therefore, if the device is difficult to use and the interface is overly complex, these people may revert to their traditional communication methods such as pointing. This leads to high rates of AAC device abandonment with Riemer-reiss & Wacker suggesting that	Technology barriers **C33**

	these rates can rise as high as 53.3%. Leading on from this, the time taken to generate a message was also perceived to be a major barrier. The rate of message transmission is quite slow in comparison to normal speech, particularly for those people who use text-based devices **B33**	
AAC devices tend to be too expensive for people with learning disabilities to purchase. Devices also may need to be tailor made meaning the second hand, cheaper devices available are unsuitable for the user's needs **A34**	AAC devices are generally expensive to purchase and a lack of funding to access services or devices is often a primary obstacle. Such devices often require to be tailor made for each user, meaning there may be a lack of cheaper second hand devices available that suits the needs of specific users. There also seems to be a lack of technical support available in the event that something goes wrong. **B34**	Technology barriers **C34**
Mobile AAC applications mitigate some of the challenges presented by more traditional AAC technologies. These include: self-image problems: user interface problems and cost problems. **A35**	Mobile technology and AAC applications mitigate some of the barriers described previously. First of all, the use of tablet or mobile phone applications as a form of AAC may alleviate the issues of self-image. Mobile technologies are socially valued; therefore, people can use AAC applications without the stigma that is often associated with the use of traditional assistive technologies. Unfamiliar communication partners may be less anxious to engage in conversation with an AAC user operating a tablet or mobile phone. Traditional devices tend to contain technical operations that apply menus, layouts and commands that differ considerably from mainstream technologies, thus imposing new learning demands on communication partners. The operational requirements of AAC applications are similar to those used in traditional apps, meaning communication partners may have more of an idea in how to use them without a steep learning curve. The introduction of tablet and mobile phone AAC applications has made assistive technology more accessible. Tablets and mobiles are cheaper and more portable than conventional devices. On top of this, AAC applications are themselves relatively inexpensive making them far more affordable to purchase. **B35**	Technology barriers **C35**
Mobile AAC applications introduce some of their own problems including: devices being prematurely introduced without the needs of the individual being assessed; screen size; and the need to use complex motor actions **A36**	Some individuals who use appropriate AAC solutions may also be advised to switch to the cheaper alternatives since many adhere to the belief that "one size fits all". This can be troublesome since those with learning disabilities may have problems whilst learning new operational skills, and not have access to personnel who can support the learning process. The main downfall of using mobiles as AAC devices is	Technology barriers **C36**

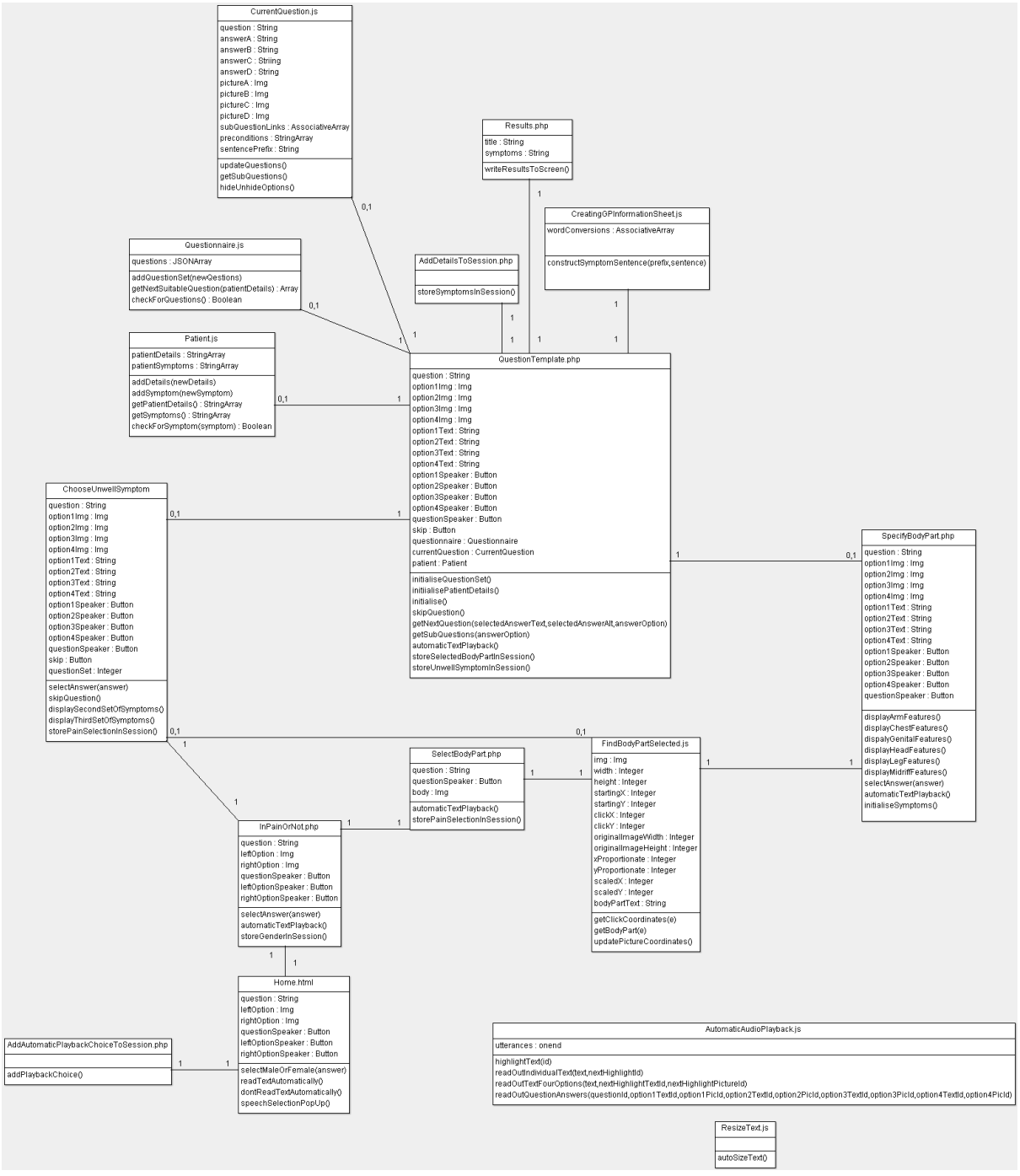
	screen size. The demand for small screens causes problems for those users who have significant motor impairments. Many interactions with a phone require an array of highly coordinated fine-motor movements to carry out such as swiping and pinching. If the screen size is too small then the user may not be able to perform the required movement successfully. Tablets tend to be larger in size, which may allow the user to carry out the required movement successfully. However, along with mobiles, their operating systems do not allow for adjustments to the screens sensitivity, averaged activation, activation-on-release, or any other adjustments to the touch input. These are prevalent features on other devices that enable adjustments for tremors to be made or to reduce accidental activations **B36**	
Differences in browsers may mean certain features promised by websites are unavailable. These features may be crucial in enabling adults with learning disabilities to use the site. **A37**	Web technologies also contain key flaws that limit their use by people who have learning disabilities. Firstly, not all browsers conform to the User Agent Accessibility Guidelines, which is a set of protocols used to improve accessibility to those who have disabilities. This may result in situations where users are not able to take advantage of the accessibility features promised by a Web page that was developed using the Web Content Accessibility Guidelines due to the browser or assistive technology device being used **B37**	Web accessibility barriers **C37**

Appendix E – Requirements Gathering Framework

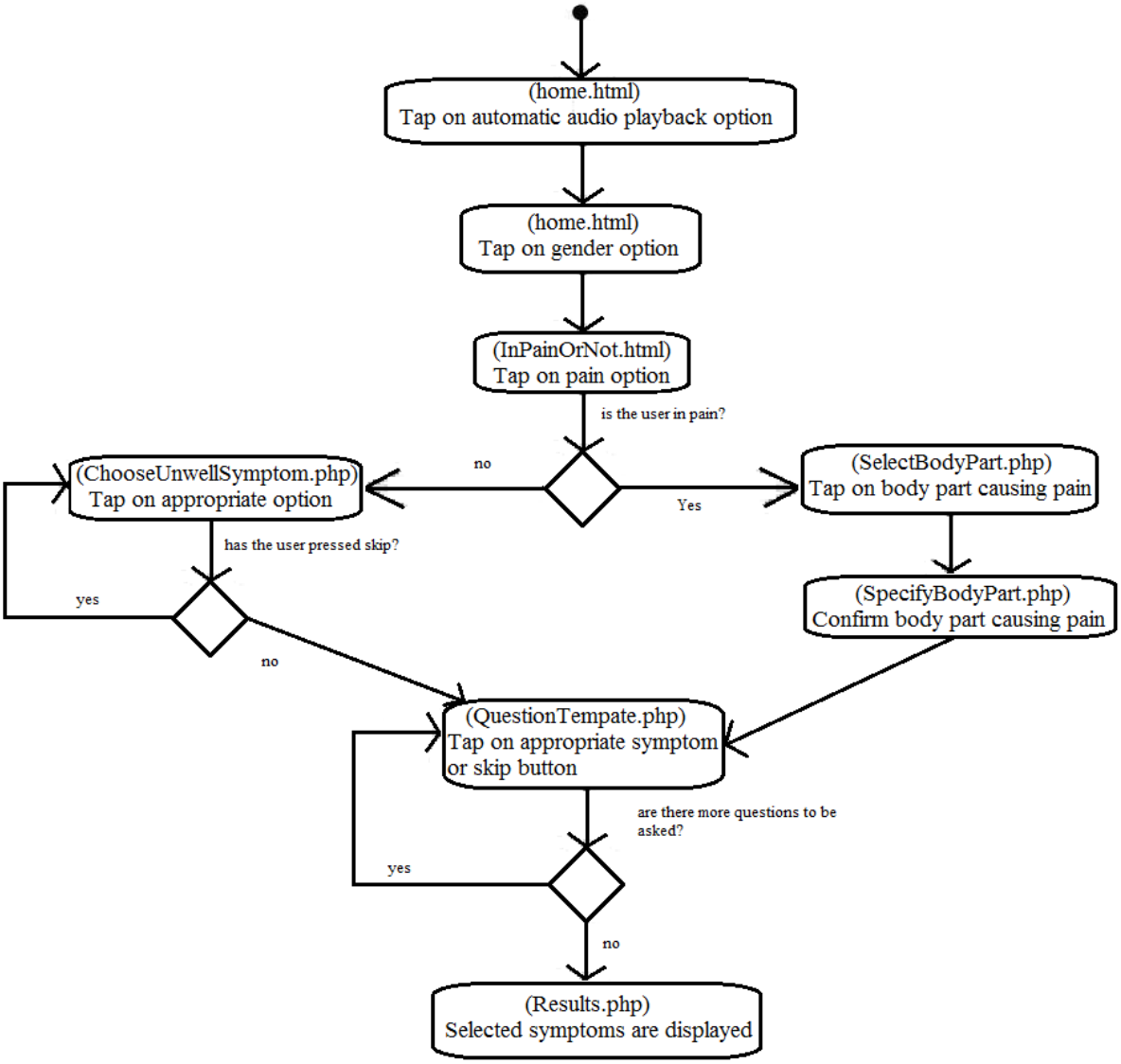
The framework analysis table created during the initial requirements gathering interviews may be found using the following link: http://dx.doi.org/10.15129/7fed3a65-9ac4-4152-953b-b606376b64b5

Appendix F – Design of 2nd Probe

Class Diagram



Interaction Diagram for 2nd Probe



Appendix G – Usability Study Framework

The framework analysis table created during the user evaluation studies may be found using the following link: http://dx.doi.org/10.15129/3c176b30-9287-46a0-b3be-a55fcd07843e

Appendix H – Conditions Embedded Within Probe 2

As described in Chapter 4, the health needs of adults with learning disabilities differ dramatically from that of the general population. Therefore, the conditions included within the application should target these needs in order to reduce the number of irrelevant questions presented to the user. This also ensures that those disorders that are normally overlooked during consultations are brought to the attention of the GP.

An abundance of conditions that are prevalent throughout the learning disability population are explored by the application, to ensure the experts interviewed were aware of the range of symptoms that may be targeted by the intervention, and the potential impact it may have. A number of resources were used to identify these including a NHS guide to the health issues affecting people with learning disabilities [102], literature identifying the general health needs of those who have learning disabilities [103-104], NHS choices [105]; an inquiry into the premature deaths of those who have learning disabilities [106], and primarily Turning Point's learning disability health toolkit [107]. These conditions will be summarised throughout this sub-section, along with a justification for their inclusion.

Head

General Head Pain

Head pain may be a side effect to many of the common conditions experienced by those who have mild learning disabilities [107]. As a result, the application must provide the GP with information relating to the class of headache the user is suffering from, as well as the period of duration. The types of headaches embedded into the application include concussions, cluster and tension headaches, migraines, and those caused by sinusitis or the overuse of painkillers [105]. Distinguishing symptoms range from location of pain to dizziness and confusion, or sensitivity to light.

Eyes

Many adults with learning disabilities suffer from significant sensory impairments [102-104, 107] with around 30% having to cope with an impairment of their sight [102]. A range of impairments must be extracted by the application including long

and short sightedness, double vision and blind spots. Conditions such as posterior vitreous detachment (PVD), retinal detachment, age-related macular degeneration, (AMD), cataracts, and keratoconus [102, 107] may contribute to these impairments.

As well as visual difficulties, the learning disability population tend to suffer from infections or lumps that may painful but are easily treated [107]. Conjunctivitis, sties, blepharitis and iritis are some of the most common conditions and their defining symptoms include sticky red eyes, lumps on the patient's eyelid, and an irregularly shaped iris, amongst others [107]. Corneal abrasions caused by foreign objects are also common along with pain caused by headaches.

Ears

Hearing problems tend to be more common in the learning disability population than visual [102-104, 107], with over 40% of individuals suffering from some sort of hearing impairment [102]. A build-up of ear wax is cited as the most common cause for the hearing loss experienced by this population [102, 107]. Tinnitus (ringing in the ear) and Ménière's Disease may be a by-product of this build up and cause further symptoms such as depression, insomnia and vertigo [105]. Furthermore, glue ear also presents similar manifestations but typically occurs in younger adults and children [105].

Painful ear infections may also induce temporary hearing loss, [107] due to the discharge produced or the swelling of the ear canal [105]. These infections cause flu like side effects; therefore, the application aims to extract a number of additional symptoms including fever, nausea, dizziness and skin problems. Adults with learning disabilities may also insert foreign objects into their ear canal, meaning they are at greater risk of perforating their ear drums [107].

Oral Hygiene / Jaw

A large proportion of adults with learning disabilities suffer from poor oral hygiene [102-103, 107] with some reports suggesting that up to 86% of this population have dental diseases as a result [102]. Therefore, the application aims to extract the various pain related symptoms caused by these diseases including sensitive teeth that may or

may not be a result of receding gums, loose or missing teeth, dental cavities or cracks, dental abscesses, and bleeding or swollen gums. Those diseases that may not cause pain are also explored by the application including leukoplakia, thrush, and oral lichen planus and these conditions are distinguished by both the colour and texture of the rash situated inside the mouth. Significant indicators of oral cancer are also presented since there is data to suggest that poor dental hygiene is a primary risk factor for oral cancer [108].

Toothache is also a primary cause of jaw pain [105]. Other conditions that induce this type of pain include the various ear infections disclosed previously, trigeminal neuralgia that causes a similar sensation to that of an electric shock on one side of the face, and stiff or damaged muscles [105].

Nose

Sinusitis tends to be a common issue experienced by the general population [105]. Consequently, the application extracts the various symptoms relating to this condition including pain across the cheeks, nose and forehead, flu like manifestations such as fever or nausea, and a blocked nose. Adults with mild learning disabilities are more likely to be involved in accidents [103] and as a result have a higher chance of breaking or fracturing their nose. Therefore, the various manifestations of a fractured nose must be identified such as swelling and bruising and persistent nose bleeds.

Neck/Throat

Dysphagia (difficulty swallowing) is also a common problem experienced throughout the learning disability population [102-103, 107]. The application intends to extract the main symptoms of dysphagia, along with other common swallowing conditions including glandular fever, laryngitis, tonsillitis, and the common cold. Symptoms that distinguish these conditions include a lump on your neck, yellow spots inside the mouth, hoarseness, and flu-like symptoms.

As discussed further in section 5.3, the application enables the user to specify the body part that is causing them pain. However, there is no evidence to suggest that certain neck pains are more common in those who have learning disabilities. Therefore, those

neck conditions that are widespread within the general population have been implemented in order to ensure options available to the user are consistent. Whiplash, stress or anxiety, and common strains [105] are just a few of the symptoms explored by this section of the application.

Shoulder / Arm / Hand

Shoulder

Musculoskeletal problems are experienced by an abundance of adults with learning disabilities [103]. As a result, they tend to suffer from muscle, ligament, tendon, and bone pain on a regular basis. However, the exact cause of musculoskeletal pain can vary but typically includes muscle strains and tears through overuse, trauma and dislocations caused by accidents, and osteoporosis [103]. Consequently, the probe aims to extract a number of symptoms relevant to these conditions, such as a stiff shoulder caused by dislocation, tendonitis or infection (septic bursitis), a popping or locking shoulder; and rotator cuff tears [105].

Arm

Septic bursitis and muscle strains are also common throughout the arm, with repetitive strain injuries (RSI) inducing various symptoms such as spasms, muscle weakness, and numbness [105]. One RSI specific to the arm is tennis elbow, where a recurring pain materialises just below the bend of the elbow on the upper forearm [105].

Coronary Heart Disease (CHD) is the second largest cause of premature death amongst adults with learning disabilities [102, 107] and angina is a key manifestation of CHD. Essentially, the blood supply to the muscles of the heart is restricted thus resulting in a pain that spreads from the chest to other areas of the body including the left arm [105]. The application must pick up on the key symptoms of angina as failure to do so may have serious repercussions to the patient's health. Pain that spreads from the neck to the arm may also be a sign of CHD; however, those who suffer from trapped nerves also experience similar symptoms, meaning the application must provide the GP with enough information to predict the correct condition. Those who suffer from

angina, or heart attacks, tend to also experience breathlessness and dizziness and this may not to be the case for those who have a trapped nerve [105].

Hand

Common strains and fractures that may occur within the patient's hand are also explored by the application. Further strains and pains that are exclusive to the hand have also been scrutinised and these include carpal tunnel syndrome, De Quervain's syndrome, and trigger finger [105]. Manifestations of these symptoms involve the loss of feeling across a number of fingers, pain on the thumb side of the wrist, and the stiffness of fingers respectively.

Older adults are prone to developing osteoarthritis in joints throughout their bodies and one of the most common areas in which this condition forms is in the hand [105]. As a result, the application should aim to extract whether the patient's knuckles are red and inflamed or the upper part of their fingers are beginning to bend. The intensity of the pain caused by the osteoarthritis should also be obtained. One further painful lump that commonly forms on the hand are ganglion cysts, which is a smooth lump located under the skin near a tendon [105].

Fingernail problems are also common with adults who have learning disabilities [107]. The application aims to extract four conditions relating to fingernails including bruised, loose or ingrown nails, as well as fungal nail infections.

Chest / Breast

As mentioned previously, CHD is the 2nd leading cause of death for people with learning disabilities, and therefore its manifestations must be explored meticulously by the application. The leading death, however, is respiratory disease [102-104, 107] with over 50% of premature deaths within the population caused by complications arising from this disease [102]. There are a number of manifestations of respiratory disease; however, the probe aims to extract the key symptoms from those conditions that are most common, including flus and colds, pneumonia, asthma, bronchitis, and Chronic Obstructive Pulmonary Disease (COPD) [105]. Information relating to the duration of the infection or chest pain experienced, the intensity of pain experienced,

how breathless the patient is, changes in the person's weight, and whether or not they are suffering from heart palpitations is used to differentiate between these conditions [105]. Gastro-Oesophageal Reflux Disease (GORD) is also prominent throughout adults with mild learning disabilities [102-103, 107] and a main indicator of GORD is chest pain; therefore, the application must aim to extract further symptoms relating to this condition. Common musculoskeletal and osteoporosis problems specific to the chest are also included.

People with learning disabilities are often excluded from screening, [102] and with breast cancer being the most common form of cancer in the UK [107] there is a high probability that this condition may remain undetected for an extended period of time. As a result, the application aims to identify the various symptoms of breast cancer, as well as extracting those lumps on the breast that are non-cancerous.

Abdomen / Anal Problems

Pain inside the abdomen is prevalent throughout an abundance of conditions; however, the inability to go to the toilet effectively is regarded as one of the leading causes of this pain for those who have learning disabilities [102, 105]. Constipation was reported to be the most treatable condition adults with learning disabilities experience before death [106] and is often overlooked by healthcare professionals. Consequently, the various symptoms of constipation are extracted by the application, along with more long term manifestations that may cause this condition, such as Irritable Bowel Syndrome (IBS). On the other hand, diarrhoea is also common, especially for those patients who are suffering from Irritable Bowel Disease (IBD) and IBS; therefore, the probe also explores the various symptoms of diarrhoea including those that may be described as flu like. Dehydration is a particularly dangerous symptom of these conditions, [105] and must be scrutinised thoroughly by the application. Both the location / duration of pain, and the consistency of faeces produced are used to provide the General Practitioner with the information required to decipher the exact condition the patient is suffering from.

Diarrhoea and constipation may cause severe pain within the patient's anus as anal fissures may occur and this can be extremely painful for short periods of time [105].

However, there are a number of other conditions that may be responsible for the pain. Those who suffer from constipation are at greater risk of developing haemorrhoids, meaning the application must also provide options for the user to select from symptoms that relate to this manifestation including swelling or lumps around the anus, and the production of blood or mucus when passing a stool [105]. Coccydynia (pain of the tailbone) is also a common problem throughout the general population, particular for those women who are pregnant [105], thus the symptoms of coccydynia are also explored.

Urinary tract infections are also prevalent throughout adults with mild learning disabilities [102]. As a result, the application aims to discern whether the patient is incontinent, has pain when peeing, or has cloudy/bloody pee [105]. Kidney stones may also contribute to this pain and the application aims to extract the exact area in order to distinguish between the two. Other conditions that cause pain in the abdomen include appendicitis (lower right hand side), cholecystitis (upper right hand side, and diverticulitis (left hand side) [105].

Nausea is also a primary symptom of a number of conditions prevalent throughout the learning disability community. Patients who suffer from the toilet problems and respiratory diseases described previously may also experience severe nausea, as does those who have the skin issues and diabetic problems; therefore these conditions must also be explored within this section.

Leg / Knee / Foot

Osteoporosis and Musculoskeletal problems (such as sprains or tendonitis) are also prominent within these areas of the body [102-103, 107] and the symptoms relating to these are presented to the user throughout the application. However, there are several conditions that are exclusive to both the leg and foot and one of these is sciatica [105]. Sciatica is caused by an irritation of the sciatic nerve and usually consists of severe pain or numbness spreading from the buttocks to the legs and feet. Deep vein thrombosis (DVT) is another one of these conditions and often results in the death of adults with mild learning disabilities before they are able to seek out help [106]. As a

result, the application must identify the common signs of DVT, primarily pain in the calf, redness in the lower leg, and swelling just below the knee.

Septic bursitis presents similar symptoms to DVT except that they are situated around the knee [105]. Due to the infection, patients who have bursitis also tend to develop a fever or suffer from cold shivers. Other prominent conditions that affect the knee include osteoarthritis which causes the knee to become stiff and painful, bleeding joints which causes bruising and swelling, and gout which causes severe pain and extremely limited movement [105]. The intensity of the pain experienced, the presence of lumps and swellings, and the range of movement is used to differentiate between these conditions.

Those conditions affecting fingernails described previously are also explored within this section. Common lumps that appear on the feet are also scrutinised by the application including bunions, calluses, verruca's, and blisters [105]. Gout may also cause serious pain in the foot, as does heel spurs [105]. Along with heel spurs, plantar fasciitis is the most common cause of heel pain and those who suffer from this condition tend to experience more severe symptoms first thing in the morning. Other types of foot pain include Morton's neuroma (pain between your toes), metatarsalgia (pain across the width of the foot), and Achilles injuries which is the primary cause of restricted movement [105]

Genitals

Adults with learning disabilities tend to be excluded from sex related screenings, [106] meaning many sexual diseases remain undetected, since a large majority of health professionals assume that this population do not engage in sexual relations [102]. Consequently, the application aims to extract a number of Sexually Transmitted Infections (STIs) from both males and females. Symptoms relating to: herpes, trichomoniasis, bacterial vaginosis, chlamydia and genital warts are presented to female patients and the colour and consistency of discharge produced, effect on periods, shape and size of lumps formed, and the intensity of pain whilst urinating is used to enable the GP to differentiate between these conditions [105]. Other conditions

that aren't caused by STIs such as irregular bleeding, UTIs, pain during sex, and thrush [105] are also explored.

Symptoms relating to herpes, chlamydia and genital warts are also presented to males. Conditions exclusive to men are also scrutinised including balanitis (swelling on the head of the penis), peyronie's disease (sudden bend in the penis), and penile fractures. Additionally, evidence suggests that fewer men than women visit their GP in order to obtain advice on the conditions they are experiencing [102]. As a result, testicular cancer may largely go undiagnosed. Therefore, the application also aims to distinguish the various types of lumps that may be found including epidymal cysts (smooth, firm lumps on the testicles), varicoceles (worm like lumps above left testicle), hydroceles (swelling of one or more testes), and cancerous lumps [105]. As with females, possible urinary tract infections are also extracted, along with the symptoms of testicular torsion which is a serious condition where the spermatic cord becomes severely twisted and the blood flow to the affected testicle is cut off.

Back / Hip

Osteoporosis and musculoskeletal conditions are also prominent within the back and hip and therefore, common signs such as strains and fractures should be explored. These conditions, along with non-specific back pain (pain that has no obvious cause), account for the majority cases relating to discomfort in a patient's back [105]. However, more serious conditions may be responsible for the pain and these must be identified by the application. As described previously, those who suffer from sciatica tend to experience pain or numbness spreading from their lower back to their legs and feet. Consequently, the application must also present symptoms relating to sciatica when the user reveals they are primarily suffering from back pain. Slipped discs are often a primary cause of sciatica; however, not all slipped discs result in this condition meaning other factors such as the areas and patterns of pain experienced must be obtained in order to distinguish between the two [105]. Spondylolisthesis may also cause sciatica but is often associated with stiffness in the lower back and the curvature of the spine [105].

Tension within the leg, caused by conditions such as hamstring pulls, tends to place extra strain on the hip thus resulting in further injury. Therefore, the application also attempts to extract leg related injuries when the user indicates that they have a pain in their hip. Other, more serious conditions include osteoarthritis, which may cause severe inflammation and pain along with joint stiffness, dysplasia, which may result in the user limping and joint clicking to occur when walking, and a hip labral tear which presents similar symptoms to dysplasia [105].

Skin Conditions

As described throughout the section, lumps on the skin are a common reason as to why many patients visit their GPs. Large proportions of these are non-cancerous and can be easily treated, including skin tags, warts and veruccas, cysts, calluses and corns, and lipomas [105]. Their size, location on the body, colour, and texture are used to differentiate between them. However, some lumps may be an indicator of a more serious underlying condition. Several reveal that the patient is suffering from an infection or cancer including the swelling of the glands below the ear (mumps), swelling on either side of the patient's neck (glandular fever), abscesses (including dental), the swelling of lymph nodes (including in the armpit / neck / behind the ears), and haemorrhoids [105]. Additional symptoms such as fever, pain in the head, and nausea may be used to identify which of these the patient is suffering from. Manifestations that cause rashes are also explored including chicken pox / shingles, scarlet fever, and eczema. Once again the area, texture and colour of the rash, along with additional symptoms such as fever or swollen glands, are used to specify which condition the patient has.

Other Conditions

Further conditions are explored by the application that may not necessarily fit into one of the above categories. Adults with learning disabilities have a higher risk of being overweight and as a result are prone to developing diabetes [102]. Therefore, the application aims to identify the various symptoms of diabetes including, urinating frequently, weight changes, blurred vision, nausea, thrush, dehydration, itchy genitalia, and tiredness [105]. Extreme tiredness may also be a symptom of thyroid

problems, which affects a large percentage of the Downs syndrome population [102]. Overactive and underactive thyroids exhibit a plethora of symptoms and these should be presented to the user at various points throughout the application. Such manifestations may include weight changes, emotional changes, skin conditions, sensitivity to temperature alterations, hair loss, finger and toenail problems, and goitre swellings [105]. The final condition in which the probe aims to extract is epilepsy. Up to 43% of adults with learning disabilities suffer from epilepsy, [106] meaning it is crucial for the application to recognise the symptoms of such a prevalent condition. Confusion, loss of consciousness, loss of limb control, and the appearance of flashing lights in the patient's vision are extracted in an attempt to identify when the user is experiencing epileptic fits.