An Investigation Into How Mobile Apps Can Support Increased Independence for People with Down’s Syndrome

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A thesis submitted for the degree of

Doctor of Philosophy

Glasgow 2023

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Previously Published Work

Research in this thesis has been published as a full paper in ACM transection on Accessible Computing.

1. Al Majed Khan, Dr Mark D. Dunlop, Dr Marilyn Lennon, and Dr Mateusz Dubiel. 2021. “Towards Designing Mobile Apps for Independent Travel: Exploring Current Barriers and Opportunities for Supporting Young Adults with Down's Syndrome.” *ACM Trans. Access. Comput. 14, 3, Article 13 (September 2021), 40 pages*. DOI:https://doi.org/10.1145/3460943

The author was the principal study designer and investigator of the listed articles. He also led the analysis of the results and subsequent write-up. In addition, the author was responsible for the development of the artefacts included in each study, such as the easy-read information sheets and digital prototypes, including content discussed in Chapter 5 (Cycle 1 part 2), Chapter 6 (Cycle 2) and Chapter 7 (Cycle 3) of the main body of this thesis.

Acknowledgements

I would like to thank my supervisor Dr Mark Dunlop who supported me throughout my PhD by encouraging me and empowering me reach my remarkable potential.

I would like to thank my second supervisor Dr Marilyn Lennon, who at very critical stages of my PhD helped me by providing crucial feedback.

I would like to thank all the members of Down's Syndrome Scotland in Scotland, especially Kevin Cummings, Jo Hughes, Brenda Hepburn, who from the very first moment welcomed my project and provided me with all the supports for distributing all the studies to Down's Syndrome community throughout the Scotland.

I would like to thank all the members of the DASSI and DHAWG groups who provided me with feedback and ideas on several stages of my PhD. Especially, Dr Mateusz Dubiel, Dr Ryan Gibson, Ramsay Meiklem.

I would like to thank all the participants (parents, caregivers and individuals with DS) who took part in different stages of this thesis and make this research possible.

I would like to thank the Systems Support team of the department of Computer and Information Sciences (Ian Gordon, Kenneth Forte and Iain McCord) who were always keen on helping me with any technical issue that I had.

Lastly, I would like to thank everyone else who at stages and with different ways helped me during this project.

The present work is devoted entirely to my parents and elder brother, who believed in me and constantly, unequivocally and financially supported me throughout the course of my PhD.

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Abstract

This research aimed to provide a technologically viable solution that can overcome barriers to performing daily independent activities for young adults with Down's Syndrome. The research was conducted through a participatory action research process involving young adults with DS and their parents, family members and caregivers. In total, 53 participants with DS, 61 family members (mostly parents), 3 clinicians, 2 caregivers (from a charity organisation), 1 teacher (from an education centre) and 1 participant from a public health service took part in the different stages of this study and provided their valuable feedback. This research also explored barriers to independent activities for young adults with DS and solutions for overcoming some of those barriers using smartphones and technology through a series of semi-structured interviews, group discussions, co-design sessions, and observations through face-to-face, phone calls and virtual communication settings.

The first outcome of this research was the identification of six key barriers to performing independent activities for young adults with DS. Initially, these six key barriers were recognised from four semi-structured interviews with four mothers of young adults with DS. After that, the survey (39 participants) results also reflected these six key barriers to independent activities. These key barriers are (1) safe use of mobile devices and travel safety concerns, (2) communication difficulties, (3) inability to self-navigate and difficulties with access to public transport (e.g. changing buses), (4) finding suitable technology that can support independent activities, (5) difficulties remembering tasks/activities, (6) lack of knowledge and experiences about the current advancement of smart devices and technology.

The second outcomes were the usage pattern of technologies and smart devices, and barriers to perform daily activities by young adults with DS. iPads/Tablets and smartphones were the most used smart devices to support learning and remote communication for young adults with DS. Lack of suitable

interface and technologies were found as barriers to perform an activity using smart devices through an online survey with 39 participants including parents, caregivers and clinicians, and each represented at least one young adult with DS.

Thirdly, four key barriers to independent travel for young adults with DS were identified. The key barriers are (1) unfamiliarity with route, (2) difficulties accessing public transport, (3) lack of suitable technology and apps to support independent travel, (4) parents' anxiety. This research outcome also revealed sketches/drawings and app requirements to design a prototype for a smartphone app to overcome these barriers to independent travel using smart devices and technology. In total seven group discussions were conducted with seven young adults with DS and thirteen parents (one of them was a family member) in home settings.

A fourth outcome was revealed from the user testing and design validation of the designed prototype for a smartphone app to overcome barriers to independent travel for young adults with DS. This evaluation validated the previous (third outcome) findings such as the four key barriers to independent travel and requirements for an app to prototype. For example, the inclusion of a linear map, a progress bar for the journey to support walking path and ways to deal with unexpected situations during travel were included to reinforce and strengthen the support by the app. This outcome also revealed easy adoption of the main concept of the design by users with DS such as the use of a linear map interface, an interface that displayed the direction arrows as images for navigation support, a progress bar to show the progress from one turn to next, an image of the bus stop for easy recognition, the bus number and image to help identify the correct bus, etc. Also, this evaluation highlighted design gaps and usability issues for young adults with DS through the observation of the designed digital prototype. Later, the use of the paper prototype in the discussion session to identify the design gaps and bridge these issues for young adults with DS revealed the precise issues that also strengthen the support for the app. Such issues included unsuitable use of design alignment, small text size and icons which caused difficulties when reading and touching the screen, use of colours which caused distress (e.g., red) and access to public transport (the bus). A total of seven group discussions were conducted with seven young adults with DS and twelve parents (one of them was a family member).

The fifth outcome reflected on the lessons learned from the user evaluation of the designed prototype app using the process of video walkthrough that inspired by pluralistic and cognitive walkthrough (Nielsen 1994). The designed app was measured against the following usability criteria a) the learnability of the interface, b) the practicality of the designed interfaces (does it serve its purpose) and c) the level of satisfaction by its users on interfaces which adopted methods used by McDonald et al. to uncover usability issues (McDonald et al. 2017). The outcome revealed that the users with DS showed could easily learn and understand navigation methods that appeared on the screens with relevant instructions to follow, for example: following instructions for turn-by-turn direction and walking, as well as processes and actions to recognise and access the bus. However, a few interfaces were had to explain, for example showing the mobile display to the bus driver for the bus ticket. During this walkthrough, most of the users with DS recognised the correct actions and they found relevant actions were available and visible to them. Nevertheless, the overall level of adoption of the navigation app was quite satisfactory, as most of the young adults with DS has showed their positive satisfactions. Furthermore, an alternative approach for the user evaluation was taken due to COVID-19, where participants used a recorded video of travel with the designed application and evaluated it through virtual (Zoom) group discussions with seven young adults with DS, nine parents and six experts (HCI researchers) to assess perceived effectiveness and the appropriateness of performing navigation.

This research has implications for application developers, designers, researchers, parents and caregivers who wish to design and develop an interactive application that can support the performance of independent activities by young adults with DS. This study also reflects on the challenges of designing applications in the context of people with cognitive disabilities and recruiting participants for the study. This study can inform the broader Human-Computer Interaction (HCI) community about holistic co-design process and its principles in the field, and the Down's Syndrome communities about the current advancement of smart devices and technologies to support daily activities for young adults with DS.

Chapter 1

Introduction to Research

1.1 Motivation

People with Down’s Syndrome (DS) perform numerous daily activities during their lifetime that constantly repeat in diverse contexts (Matthews et al. 2018). These activities can be related to cooking, shopping, working tasks, travelling and everyday routines (Katz 1983; Drumm-Boyd 2016). As they grow up, performing these activities independently becomes essential, just as it is for the general population. In order to do so, they need to be able to make the right decisions (Gilmore and Cuskelly 2012; Greer et al. 2013). However, making the right decisions can require substantial cognitive effort in a way that may not be easy for all young adults with DS (Ball et al. 2008; Deb, Hare, and Prior 2007), which can eventually negatively influence their quality of life, social integration and self-esteem (Lee et al. 2021).

Due to a high risk of serious consequences from incorrect decision making, the majority of young adults with DS are supported by their parents and caregivers when making decisions and when planning and performing everyday independent activities, both indoors and outdoors (Lee, Knafl, and Van Riper 2021; Deb, Hare, and Prior 2007; Smith 2001). Therefore, it eventually becomes parents' and caregivers' responsibility to support their young adults with DS throughout their life. It is easy for parents and caregivers to provide support in an indoor activity as parents or other family members are always available to provide support. However, providing support for outdoor activities is often challenging for parents and caregivers (Kramer, Covaci, and Augusto 2015; M Dawe 2006; Al-Holaibah and Al-Saleh 2017; Davies et al. 2010). In order to provide support in outdoor activities either parents or caregivers have to be with their young adult with DS or communicate using phone calls. However, it becomes difficult when no family members or other caregivers are available to provide support. In these cases a young adult with DS's social inclusion can be seriously limited, barriers to independence are created, and their quality of life may be lowered. This is where parents and caregivers take advantage of assistive technology like smart devices (smartphone, iPad, Tablet) and apps for communication, performing tasks and so on (Wennberg and Kjellberg 2010).

Assistive technology like smartphones, smartwatches, iPads, and other tablets has huge potential to support and improve daily life for young adults with DS (Kerkhof et al. 2017; M Dawe 2006; de Joode et al. 2010). However, due to their limited sensory and motor skills, and the complex user interaction design of smart devices, some daily activities are still not easy to perform using assistive technology (Lazar, Kumin, and Feng 2011; Kumin et al. 2012; Hu et al. 2013). Also, most research on technology and apps for people with DS to date focuses on educational and technological accessibility supports with target user groups who are mostly children (aged between 6 to 12 years). A few are focused on support for daily activities with a target user group of young adults. This study looks into opportunities to use technology by designing and developing an accessible application to support daily independent activities that will work shamelessly and enhance the quality of life for young adults with DS.

1.2 Thesis Statement

“Co-designed smartphone apps can assist young adults with Down's Syndrome to overcome some of the barriers to independent activities, improve social inclusion and increase independence.”

1.3 Research Aim and Questions

Aim: the overall aim of this doctoral research is to explore barriers to performing daily independent activities for young adults with DS, and how these young adults can be effectively supported using technologies including smart devices. This research is done through the Participatory Action Research (PAR) process (Kidd and Kral 2005; Macdonald 2012; Mctaggart 1991) with the interest of the target community (i.e. people with DS and their parents and caregivers).

In order to outline the study design and agenda according to the research aim, this thesis seeks to answer the following **Research Questions (RQs):**

RQ1. What are the main barriers to independent activities for young adults with Down's Syndrome?

RQ2. How could smart devices (smartphones, smartwatches or smart-clothing) and apps help young adults with Down's Syndrome to perform independent activities?

RQ3. How can participatory design adopted for application to support people with DS?

1.4 Main Contributions

1. With regards to understanding the current barriers to performing independent activities (RQ1) by young adults with DS with or without using technologies and smart devices this thesis presents an in-depth background analysis of barriers to daily independent activities through conducting a scoping literature review. In addition, conducted a series of enquiries through semi-structured interviews, online survey, and co-design meeting and discussions involving young adults with DS and their parents and caregivers. The results identified the current usage pattern of smart devices and technologies, challenges and difficulties faced by young adults with DS in

order to perform independent activities on daily basis on their own, and also challenges for their parents and caregivers when providing support. The outcome was analysed further to gather design requirements for a smartphone application. See Chapters 4, 5 and 6 for detailed results.

2. With regards to overcoming barriers to independent travel for young adults with DS using smart devices and technologies (RQ2), this thesis presents the design, development and evaluation process of a prototype for a smartphone application by gathering user requirements, sketches and design requirements in order to reduce barriers to independent travel. This resulted in a novel interactive prototype (see Chapter 6 and 7) which effectively provided support with walking navigation and access to public transport for young adults with DS. Moreover, the prototype design had a few novel features including a more inclusive design of the linear bar concept that represented the whole journey (see section 6.5.5), and instructions for the bus driver which aimed to reduce the communication barrier with the bus driver. This prototype has the potential to support similar genetic groups of people i.e., X- Syndrome.
3. With regards to methodology to ensure the effective contribution of the participants in the study, this thesis reflected four complete cycles of participatory action research process (see Chapters 3) to ensure the effective contribution of the participants in the study (RQ3). Changes in methods for group discussions in the home settings and virtual evaluation following the video walkthrough technique also ensured effective outcomes for the participants with DS and their parents. Also, changes in methods allowed researchers toward the correct exploration of participants' daily life challenges and issues, the right solutions for those issues to overcome by reducing challenges and offering interactive designs. Such changes and adoption of the participatory design method throughout the thesis enhanced the process for application design with the precise and effective design requirements to reduce the barriers to perform independent activities for

young adults with DS. (see Chapter 6, 7 and 8). The adoption of the PAR process for people with cognitive disabilities and the video walkthrough process used for the virtual evaluation can have wider implications for the greater HCI community.

1.5 Terms Used in This Thesis

The terms and phrases that are used in this thesis need to be explained, which may be helpful for the reader to understand the context and background better. The term *research* or *thesis* will be used to refer to the thesis, which will be used accordingly to adjust to the context or arguments in this thesis. To explain higher level methodological units the term *phase* will be used. For example, the adopted methodology has five phases (see section 3.4). These five phases together form a *cycle*, and the term *cycle* will be used to refer to the completion of a round of this set of five methodological phases. Each cycle may consist of more than one part that will be referred to as the *study*. For instance, cycle 1 consisted of two studies (see Chapter 4 and 5).

Chapter 2

Research Background

2.1 Introduction

The purpose of this chapter is to give a contextual background to the topics discussed in this thesis to the readers of this thesis, with related studies. This background chapter gives an outline of relevant topics including people with DS and use of assistive technology to support them when performing daily activities, as well as describing Human-Computer Interaction (HCI) and its design processes.

2.2 Impact of Down's Syndrome

2.2.1 Down's Syndrome

Down's Syndrome (DS) is a relatively common genetic condition caused by an extra copy of chromosome 21. The worldwide occurrence of DS is approximately 1 in 1,000 with about 6,000 children born each year with DS (Alfredo et al. 2015). In the UK, it was estimated that there were approximately 41,700 people with DS in 2018 (Stuart 2017). In Scotland, it was estimated that there were about 3,261 people living with DS, and about 1,202 of those were young adults aged between 15 – 39 years in 2016 (Stuart 2017; Lorenz 2020). Later, according to Down's Syndrome Scotland (Down's Syndrome Scotland 2018), it was estimated that there were about 4,500 people with DS in 2019 in Scotland. In 1866, British doctor John Langdon Down first categorised people with Down's Syndrome based on their cognitive impairment and intellectual disabilities with external physical features (Langdon and Down 1966, 1866). In 1959, Lejeune revealed that the main cause of Down's Syndrome is trisomy of chromosome 21 (Lejeune, Gautier, and Turpin 1959). The trisomy disorder occurs when chromosomes fail to separate properly (also known as nondisjunction) or due to chromosomal abnormality. DS affects the development ability of both children and adults (Wiseman et al. 2015; Wu et al. 2010), typically suppressing their cognitive and physical functional ability (R Alesii et al. 2013). The cognitive and physical features of DS can be wide-ranging but often manifest themselves in some form of communication and learning difficulty along with characteristic physical features. Learning difficulties can be caused by the linguistic, cognitive and management effects of DS, and can be compounded by sensory and motor skill effects (Chang, Chen, and Chou 2012).

2.2.2 Down's Syndrome and Cognitive Issues

Cognitive disabilities (Greer et al. 2013) are common among people with DS. In general, a young adult with DS is better at capturing and preserving visual (visuospatial) short-term memory compared to text and verbal (morphosyntax) short-term memory when performing joint/subsequent tasks which require low processing levels (Chang, Chen, and Chou 2012; Covaci et al. 2015; LoPresti, Bodine, and Lewis 2008). However, visual (visuospatial) short-term memory impairments are also prevalent when joint/subsequent tasks are increased among young adults with DS (Visu-Petra et al. 2007; Lanfranchi, Cornoldi, and Vianello 2004). Similarly, people with DS face intellectual development problems that create difficulties in thinking and learning, which results in a lesser capacity for judgment and undesirable behaviour, for example, a tendency to be resistant and unfriendly (Gilmore and Cuskelly 2012); a delay in language learning; as well as a lower capacity for attention and reaction (Bull, MD, and Genetics 2011). Likewise, executive function is an umbrella term which can be described as a set of higher-level cognitive processes responsible for performing tasks, executing skills, and controlling an individual's abilities and behaviours. Working memory, planning, set-shifting, organising, inhibition and emotional regulation are associated with executive functions in the cognitive skills that can all be affected due to DS (Pennington and Ozonoff 1996; Hughes 2011; Carlson 2005). This of executive function deficit is not uncommon for people with DS which can create obstacles with multitasking (Rowe, Lavender, and Turk 2006; Lee et al. 2011; Kogan et al. 2009). These issues often lead to depression, confusion, concern and forgetfulness among people with DS (Ball et al. 2008; Deb, Hare, and Prior 2007). The presence of these symptoms in a person with DS often prevents them from performing daily activities independently. Although there is no cure for DS, given that the condition is caused by a chromosomal abnormality (Arthur Schoenstadt 2017), treatment can be provided by taking special care and providing support. As cognitive disabilities are now better understood and quality of care, support and treatment have improved, as have opportunities for independent living, the life expectancy for people with DS has recently increased to an average of 60 years (Farriols Danés 2012; Stuart 2017). Therefore, people with DS require special care at home and outside as they are likely to have a variety of symptoms including unfamiliar behaviour, less control of cognitive functions and a high percentage of illness (Smith 2001). Consequently, cognitive disorders, intellectual problems and executive function deficits lead an individual with DS to depend on a caregiver for help with completing complex tasks and personal daily activities.

2.3 Down's Syndrome Characteristics

A diverse underlying spectrum of physical properties noticed in people with DS due to overexpression (making too many copies of a protein or other substance) of many genes, which results in facial dysmorphism, short stature, loose joints or muscle tone and intellectual disability. Also, create characteristics difficulties, such as communication, speech, vision, hearing, dexterity and mobility.

2.3.1 Communication and speech issues

Communication is one of the domains in Vineland Adaptive Behavior Scales (VABS) (Del Cole et al. 2017), and people with DS demonstrated difficulties in this communication domain. The average communication IQ for DS was IQ=25.50 on the Wechsler Intelligence Scale (WISC-III) in the study of adaptive behaviour (M. Smith et al. 2020). People with DS show moderate (Crude odds ratio = 2.69, Confidence Interval= 1.63-4.45) communication difficulties about 2.6 times and severe (Crude odds ratio = 1.9, Confidence Intervals = 1.07-3.38) communication difficulties about 1.9 times compared to people with ID (those are not associated with DS) (M. Smith et al. 2020; Hendrix et al. 2020). The oral and written form of communication demonstrated lifelong problems for individuals with DS due to exhibit delays in language development and prelinguistic communication delays (Abbeduto et al. 2020). These delays were observed into the adolescent and young adult years, creating barriers to using complex language for participation and social interaction in day-to-day life (Abbeduto, Warren, and Conners 2007; Hendrix et al. 2020). Also, speech is one of the primary forms of communication; however, people with DS experience reduced speech intelligibility which is common in childhood and adulthood with DS. Some of them have shown speech intelligibility for lifelong due to the results of motor impairments and phonological disorders (Lemons and Fuchs 2010; Hendrix et al. 2020).

2.3.2 Vision issues in DS

The common vision issue in people with DS is called an ocular disorder, which often reduces visual acuity with refractive correction (Hendrix et al. 2020). A few vision issues are known for people with DS, such as refractive errors, strabismus, nystagmus, and corneal abnormalities, all linked to reducing visual acuity found in people with DS (Watt, Robertson, and Jacobs 2015). All these vision problems are observed in people with DS due to irregular visual development, including structural differences in the retina, cornea and optic nerves. Another common vision issue among people with DS is short-sightedness or near-sighted, which causes difficulty in seeing objects at a distance but can see clearly at a closer distance (Pikora et al. 2014). As a result, people with DS can struggle to perform safely related tasks, such as crossing roads or determining distances of objects, including reading books and reading from the phone screen (Pikora et al. 2014;

Satgunam, Datta, and Sumalini 2019), eventually slowing the learning process. Therefore, many people with DS are recommended to wear bifocals but not essential for those who can focus accurately without or with conventional glasses (Woodhouse 2019). Although they concluded that early correction and intervention appear important, Dressler et al. study found that vision problems in adults with DS do not hamper communication (Dressler et al. 2015).

2.3.3 Hearing loss issues in DS

Hearing ability is an essential part of making meaningful spoken communication. Children, young adults and older people with DS are associated with hearing loss which can affect one or both ears with a range from mild to profound. The degree of hearing loss based on the pure-tone average (PTA) defined ≤15 dB HL (decibel hearing level) as normal, 16-25 dB HL as slight, 26-40 dB HL as mild, 41-55 dB HL as moderate and 65-70 dB HL as moderately severe or 90+ dB HL as profound (Kreicher et al. 2018). On average, a reduction of hearing loss was found to be more than 25 dB HL in pure-tone air conduction for people with DS (Austeng et al. 2013). Children and young adults with DS often experience either conductive, sensorineural or mixed causes of hearing loss (Kreicher et al. 2018; Hamberis et al. 2020; De Schrijver et al. 2019; Keiser et al. 1981). The occurrence rate of hearing loss found among children and adolescents between 25% and 85% (Hildmann, and Keßler 2002; Austeng et al. 2013) and adults between 50% and 75% (Keiser et al. 1981; Picciotti et al. 2017). However, most of the studies revealed that people with DS mostly experienced mild hearing loss (Kreicher et al. 2018; Hamberis et al. 2020; De Schrijver et al. 2019; Manickam et al. 2016; Austeng et al. 2013; Tedeschi et al. 2015; Porter and Tharpe 2010). The common reasons for hearing loss were chronic or episodes of acute otitis media with effusion and malformations in the outer, middle, and inner ear (Porter and Tharpe 2010; Kreicher et al. 2018). As a result of hearing loss, a child’s ability to process and develop spoken language can be reduced along with academic and psychosocial development (Keiser et al. 1981; Manickam et al. 2016; Kreicher et al. 2018). Furthermore, individuals with DS can exacerbate spoken expressive and receptive communication difficulties due to hearing loss. Identification of hearing loss is vital for newborns with DS; it is particularly important for young children when they start acquiring spoken language and engaging I in the learning process (Keiser et al. 1981; Austeng et al. 2013; Picciotti et al. 2017). There is a number of conventional hearing aids available such as "*behind-the-ear (BTE) or in-the-ear (ITE) models, and bone-anchored hearing aids (BAHAs)*" in order to support hearing loss and eventually to support effective communication (Keiser et al. 1981).

2.3.4 Dexterity and mobility issues in DS

Several dexterity barriers were recognised by HCI researchers for people with DS while interacting with mobile technology. Such as the size of the mobile screen not being large enough, small graphical elements, tiny movements of the hand and finger on the small screen where graphic details are not large enough and the reduced interactive areas in the screen (Luna-Garcia et al. 2018; Martin-Gutierrez et al. 2021; Nascimento, Zagalo, and Martins 2020). The problem in fine-motor skills found common among users with DS and the potential to be a mobile user might be apparent as limited. Luna-Garcia et al. identified nine most common mobile gestures to be considered when designing and developing mobile apps for DS users: tap, double tap, swipe, drag, hold, hold and drag, spread, pinch and rotate (Luna-Garcia et al. 2018). The most accessible gestures were found to be 'tap' and 'swipe', the gestures like double-tap and pinch require training for some of the users with DS. However, the hardest gestures to perform and learn were 'spread' and 'rotate' for users with DS. A similar result was found by Martin-Gutierrez et al., who evaluated 20 touchscreen gestures for users with DS and revealed that the 'tap' and 'swipe' (slide) was easy to perform by an individual with DS. Gestures like 'rotate', 'pinch', 'stretch' and 'press and drag' were difficult to achieve (Martin-Gutierrez et al. 2021).

Physical mobility refers to being mobile depending upon own body functions and structure for performing different activities by moving, which will influence the ability to participate in life situations (Cleaver, Hunter, and Ouellette-Kuntz 2009). Several reasons affect the physical mobility of people with DS, such as muscle strength in the upper and lower limbs (about 50% less), overweight, obesity, low capacity of aerobic activities (brisk walking, swimming, running, or cycling) (Shields et al. 2013; Pitetti, Baynard, and Agiovlasitis 2013). These conditions resulted in difficulties walking a considerable distance without being tired quickly, participating in an active sport and performing workplace activities that required physical strength (Shields et al. 2013; Pitetti, Baynard, and Agiovlasitis 2013; Cleaver, Hunter, and Ouellette-Kuntz 2009).

2.4 Daily Activities

Living independently refers to living life with own goals, defining own daily activities, and being able to choose where to live, work and how to earn and spend money. Besides, independent living can also be referred to as the ability to perform basic daily activities/tasks that are needed to complete personally and in the community (e.g., social integration) (Matthews et al. 2018; Spector and Fleishman 1998). Based on the nature of the activities/tasks to be performed, the basic daily activities are often categorised into two types, namely Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (see Table 2.4-1). ADLs are activities that need to be performed by all individuals on a daily basis with or without assistance. Young adults with DS were found to be better at performing ADLs than IADLs, such as personal hygiene, dressing, taking showers, self-mobility and feeding independently (Krell et al. 2021). The capability to perform ADL activity mainly depends on their physical abilities and health conditions, for example, fine movement of hands and body, walking speed, muscular strength and body fitness. (see Table 2.4-1). In contrast, IADLs are important activities or actions that can lead an individual to be more independent and require more cognitive effort than physical ability (Delgado-Lobete et al. 2021). Young adults with DS demonstrated poor ability to perform IADL, such as communication, shopping, travelling, taking medicines and managing finances (see Table 2.4-1). However, those activities or actions are not compulsory to perform on a daily basis; instrumental activities often require assistance. ADLs and IADLs categories are listed in Table 2.4-1 below (Katz 1983; Drumm-Boyd 2016).

Table 2.4-1: Type of activities of daily living (Katz 1983; Drumm-Boyd 2016)

Activities of Daily Living (ADLs)	**Instrumental Activities of Daily Living (IADLs)**
Personal hygiene (bathing, grooming and oral care)	Elementary and verbal communication skills (basic ability to communicate via mobile phone, SMS, email and messenger).
Dressing (able to choose appropriate clothes and dressing oneself)	Transportation (ability to drive, order a taxi, or access to public transport).
Eating (able to feed oneself)	Meal preparation (ability to understand and safely use kitchen equipment, ability to plan, cook or store own meal).
Maintaining continence (ability to use bathroom mentally and physically)	Shopping (ability to buy suitable food and ability to make correct purchasing decisions).
Transferring (ability to move f from one place to another) Katz, 1983 and Care, 2016)	Housework (ability to do own work e.g. washing own clothes and doing laundry, keeping own room and house clean, maintaining hygiene).
	Managing medications (able to take medicine on time without hesitation).
	Managing personal finances (manage own money and stay within a budget limit, successfully pay bills) (Katz 1983; Drumm-Boyd 2016)

However, living independently is challenging for young adults with DS, as they require assistance that can be provided by family members, caregivers, assistive technology and devices (Lee, Knafl, and Van Riper 2021). In order to live independently, young adults with DS are required to perform daily activities successfully which often depend on their functional abilities. The functional abilities are connected with quality of life (Lee et al. 2021) and skills at daily activities along with age (Matthews et al. 2018) which creates variance in the performance. Matthews et al. argued about decreasing daily living skills in individuals with DS over the of age 40 (Matthews et al. 2018). On the other hand, according to Lin et al. (Lin et al. 2013) inability to perform daily activities was a multifactorial problem.

The thesis statement given in this research aimed to increase the independence of people with DS by focusing on independent activities e.g., completing a specific task/activity independently, which is similar to IADLs categories; however, the study may contribute to both ADLs and IADSLs depending on the nature of the study.

2.5 Technology to Support Daily Activities

2.5.1 Assistive technologies and devices

Assistive devices and apps can aid people with DS in basic learning and when performing daily activities (Wennberg and Kjellberg 2010). However, implementing such assistive devices and apps according to users' needs can be challenging (Kerkhof et al. 2017; Ok et al. 2016). Dawe (M Dawe 2006) has split assistive technology devices (AT) into the following categories based on purpose: communication; writing; reading; prompting; scheduling and educational. De Joode et al. (de Joode et al. 2010) listed examples of AT devices including Personal Digital Assistants (PDA), smartphones, alarm watches, smartwatches, iPads, tablet, voice recorders and pagers. According to Reis and Almeida (Reis and

Almeida 2016), people with DS often find it difficult to gain good literacy skills, which gives room for technology to aid them with the use of mobile devices such as tablets, laptops, and smartphones to support digital learning through apps for those with DS. Assistive apps can help with the recognition and improvement of skills (Janier et al. 2015) and can guide users through each step of a task suggesting both how to finish the task and how to recover from a mistake or hindrance in a step (Covaci et al. 2015). Currently, most of the AT studies (e.g. mobile phone, tablets and iPads) are used to increase learning ability amongst students with DS by improving cognitive skills. For instance, Disability Credit Canada suggested ten best AT for people with DS, and most of them are used to provide educational support except for the smartphone (Disability Credit Canada 2017). Dibia et al. considered both smartphones and smartwatches to have strong potential (Dibia et al. 2015) to assist people with DS during daily independent activities as they have features including GPS, gyroscopes, accelerometers, magnetometers, proximity sensors and barometer sensors which can be used to monitor health condition and when tracking locations. Therefore, assistive technology like smartphones and smartwatches can help individuals with DS to support their weaknesses and assist them to perform daily activities according to their needs without distress.

2.5.2 Support for activities of daily living

Remembering general activities from graded memory and performing basic daily routines, such as making meals, housekeeping, and grocery shopping (R Alesii et al. 2013), can turn out to be quite complex for people with DS. Furthermore, it is often challenging to improve an individual’s performance solely through technological literacy (Chang, Chen, and Chou 2012). Nevertheless, assistive technology offers a promise to aid individuals with cognitive limitations, and support them with basic common cognitive skills, e.g. daily planning and organising of tasks, managing schedules/tasks, self-supporting, and problemsolving (LoPresti, Bodine, and Lewis 2008). Lazar et al. (Lazar, Kumin, and Feng 2011) stated that the use of computer and smart devices to perform daily activities by people living with DS can be improved through training them to use these skills in their workplace. Authors observed 10 users with DS and found that they were capable of using different types of applications both on the computer and on mobile phones for education, communication and entertainment activities. According to Dawe and LoPresti et al. (LoPresti, Bodine, and Lewis 2008; M Dawe 2006), technology can make a significant difference in the lives of those facing difficulty with organising their daily routines and managing agendas. They suggest that it is possible to make use of external prompting systems to aid people with cognitive limitations. This can take place by helping one to remember the right time to undertake an activity, or through providing prompts regarding the stages of task completion (Engler and Schulze 2017; Chang, Chen, and Chou 2012).

2.5.2.1 Technology for supporting navigation and accessing public transport

Independent travelling when using public transport presents new challenges for users who require support and assistance from smartphones and smartwatches (Al-Holaibah and Al-Saleh 2017; Schlingensiepen et al. 2015). Although several studies support travel on public transport (Kramer, Covaci, and Augusto 2015; Sposaro, Danielson, and Tyson 2010), this issue remains a significant barrier to people with cognitive and intellectual disability (Stock et al. 2013; Davies et al. 2010). Difficulties in wayfinding limit the employability for those with DS, particularly for those who work a considerable distance from home (Gomez, Torrado, and Montoro 2017). Common characteristics of reduced working memory, attention disorders, poor literacy and decision-making skills can considerably hamper tasks such as managing travel timetables, leading to restrictive use of public travel (Haveman et al. 2013; Blais and El-Geneidy 2014). Augusto et al. (Augusto et al. 2018) suggest that it is possible to use sensor-based technology to guide navigation. Davies et al. (Davies et al. 2010) expressed transportation inaccessibility as a barrier that affects employment and all independent activities of an individual with cognitive and intellectual disability, thus isolating them from the community. The results of their experiment with a GPS device revealed that 8 out of 11 participants completed one journey successfully. However, use of generic bus images on the PDA screen to identify the correct bus from the bus colour (green and yellow shuttle bus) might confuse participants when there is more than one bus at a time. Sposaro et al. (Sposaro, Danielson, and Tyson 2010) introduced a navigational app on the Android platform for people with dementia called iWander. Google maps navigation API and GPS sensors were used to provide remote monitoring service to their caregivers. They also used Bayesian network (a probabilistic graphical model) techniques to evaluate collected data and to detect if the patient was wandering before taking appropriate actions e.g., sending alerts, directing them home, calling a caregiver or the emergency services. The authors raised concerns about accuracy issues with GPS and some of the extra features (e.g., calling 911 and alert protocol). Sitbon and Farhin reviewed the literature and assembled the initial design criteria and prototype for a GPS based mobile app for their co-design exploration with several functions e.g. alerting the user about the journey, as well as notifying the user about the arrival of the next bus, remaining stops, time and walking navigation between home/the destination and the bus stop (Sitbon and Farhin 2017). Three participants with intellectual disability were observed during the co-design process. Participants who used both paper and digital prototypes reacted and commented on the features of the developed prototype and even suggested some changes and modifications. Likewise, Kramer et al., introduced a navigational app in their POSEIDON project for people with DS to support independent travel without distress and increase social inclusion. Six individuals with DS travelled a 2 km-long route using a navigation app for the experiment (Kramer, Covaci, and Augusto 2015). Though the overall result was positive, the concerning issues were difficulties to interpret the turning points while using the map for navigation on their phone and too much attention being focused on the mobile screen which led to reduced concentration on the road.

2.5.2.2 Technology for prompting and reminding support

The main basis of the prompting applications were time-based prompting (e.g. Google calendar) (Robertson et al. 2015), location-based prompting (also called context-aware systems) (Marmasse and Schmandt 2000), or pauses between activities (also known as activity-based prompting) (Seelye et al. 2012).

Several studies have shown positive results on both time-based and location-based prompting support to individuals with cognitive difficulties, intellectual disabilities and brain injuries on daily IADL and increased community access and independence (Wilson et al. 1997; Boger and Mihailidis 2011; Marmasse and Schmandt 2000). Location-based applications with reminders linked to a specific location would be very useful for a user with cognitive disabilities that can remind them to do necessary tasks. Lin and Hung (Lin and Hung 2018) developed a location-based reminder application for android cell phone and tablet using GPS sensor and WLAN (Wi-Fi) infrastructure technology. Both technologies were used to define user position both outdoors and indoors, also showing the location on Google Maps. The main function of the development was to prompt reminders while the user passes by specifically defined locations. However, the proposed application delivers prompts based on defined location, and does not define time flexibility e.g., when to remind. It will remind the user even when the user is busy with other activities which may cause a distraction. To provide a flexible more personalised prompting application with learning capability that delivers prompts in the best possible time Fallahzadeh et al. (Fallahzadeh et al. 2016) designed an intelligent personalised intervention prompting application on smartphones based on context and activity awareness. Researchers used the smartphone's location and motion sensors to collect data and real-time activity learning algorithm techniques to detect appropriate moments to deliver prompts. They found users’ response rate to the intervention was 65% on average and at the same time decreased inappropriate prompting on average by 39% which were not satisfactory results. Also, the study was completed with very few participants and a relatively small dataset.

2.5.2.3 Technology for tracking and monitoring health and physical activity

Bieber et al. (Bieber, Haescher, and Vahl 2013) mentioned that the smartwatch enables users to track 24h per day physical movements with the help of an accelerometer. Furthermore, authors introduced an algorithm for an acceleration feature called “activity unit” (AU) to recognise physical activity. AU was also used to detect if the user was wearing the smartwatch and detect sleep. The smartwatch could also be used with gesture controlled applications and mobile assistance in social life. Besides, built-in sensors in smartphones and smartwatches can be used to monitor and detect disability symptoms and can create easier distanced communication between doctor and patient. Sharma et al. (Sharma et al. 2014) developed a framework where a smartwatch had been used along with a smartphone to monitor multidimensional symptoms such as facial tremors, dysfunctional speech, limb dyskinesia, and gait abnormalities in patients with Parkinson’s disease patients. Moreover, the framework allowed doctors to conduct effective interventions through smartphones and smartwatches when patients were at home.

Likewise, modern smartwatches such as the Apple Watch have an organic light-emitting diode (OLED) display to deliver high resolution, high pixel density bitmap graphics and sharp text (Dr. Raymond M. Soneira 2015). However, Ye et al. (Ye et al. 2014) found that visually impaired users preferred to view images and text on monochromic displays rather than OLED. Furthermore, a user with a visual disability can take advantage of the smartwatch camera to detect the faces of people around them. Neto et al. (de Sousa Britto Neto et al. 2015) argued that smartwatches have the potential to become an assistive device for the visually impaired. They proposed a face recognition system to illustrate that it is possible to build a real-time computer vision system in a wearable device with limited resource. A first-generation Samsung Galaxy Gear smartwatch was used to demonstrate facial detection and recognition software that emits audio feedback in order to assist visually impaired users with their surroundings. The authors have done experiments with eight low vision users, which had a 62.50% success rate and the pilot experiment success rate was 83.64% with 13 blindfolded users. Participants shared satisfactory feedback on the designed prototype.

It is impotent for the patients to keep the history of their health and physical Activity. Arsand et al. (Arsand et al. 2015) presented an on smartwatch application that allows diabetes patients to self-monitor. The tool was designed to enter and store records of carbohydrates, insulin, and blood glucose. In addition, the application auto-recorded users' physical activity and gave reminders for physical exercise, as well as providing a dietary data list. Authors tested the implemented application with six patients with type 1 diabetes and gained positive responses. Similarly, most stroke survivors suffered from arm problems. Experts on stroke patients believe it is possible to provide support with technology. Micallef et al. (Micallef, Baillie, and Uzor 2016) designed an aid-memoire stroke app on smartphones, tablets and smartwatches for stroke survivors in order to remind them to exercise using reminder modalities. The resulting reminder application was very useful to all survivors to remember exercise tasks, keep track of exercise history and progress displayed. Furthermore, this study showed that most survivors liked using the smartwatch though some of the users were not happy with the text size on the smartwatch screen.

Technology like Artificial Intelligence (AI) with semi- or fully independent decision-making abilities can have a huge impact on daily life activities for those with cognitive difficulties. Intelligent assistive technology (IAT) can support activities, monitor health or changes to health conditions, and even support wayfinding, all of which increase safety and independent living. Boger and Mihailidis (Boger and Mihailidis 2011) described examples of these, including IATs like Archipel (a cooking IAT), COACH (an IAT for handwashing and tooth-brushing), Brain-Computer Interfaces with Rapid Automated Interfaces for Nonexperts (BRAIN) to assist people who are locked-in, to communicate and access entertainment. They also described the PALMA mobility tool (a robotic vehicle) to overcome severe mobility limitations for children with cerebral palsy. Moreover, they stated that the Opportunity Knocks was the first GPS enabled navigation application with the PDA and listed several host providers e.g. WellAWARE, GrandCare, BeClose, QuietCare, and MedMinder who provide switches and sensors for the home environment, which can track and monitor health remotely or non-remotely.

2.5.2.4 Technology for communication support

Performing daily activities often requires effective communication skills for young adults with DS. Effective communication for young adults with DS is the ability to express and share essential with their parents, caregivers, friends, teachers and other community individuals like pedestrians, shopkeepers and bus drivers (M Dawe 2006; R Alesii et al. 2013). Two main forms of communication exercised by young adults with DS were remote communication (over mediums e.g., direct phone calls or social communication apps) (Lazar, Kumin, and Feng 2011) and face-to-face speaking (verbal communication) (Matthews et al. 2018).

Remote communication: according to Dawe and Kramer et al. (Kramer, Covaci, and Augusto 2015; M Dawe 2006), the need of remote communication are mostly required when individuals with DS are outside the home and alone in the home. Most of the time young adults with DS are required to keep communication with their parents and caregivers to receive support (Melissa Dawe 2007). Two forms of remote communication found to be common are making phone calls and text messaging using mobile devices and apps (SMS, Facebook, email, messengers) (Reis and Almeida 2016; Melissa Dawe 2007). However, most of the time it was making calls by individuals with DS or their parents for remote communication. One primary reason found for calling found was a safety check and other reasons include any unexpected circumstance, such as forgetting pathways home and reminding about activities/events. The text message communication form text messaging requires extensive language skills which are often difficult for young adults with DS, such as writing messages and understanding the received messages (Smith, Næss, and Jarrold 2017). Though the individuals with DS are stronger in visual (images/icons) processing compared to text or audio processing, the phone call was the preferred form for communication for young adults with DS as they found making calls easier than text messaging.

Voice assistants for verbal communication: verbal communication is a form of communication which is mostly required by young adults with DS outside the home to make effective communication with others in order to perform daily activities. For example, face-to-face speaking with shopkeepers and bus drivers. Verbal communication ability is important to perform daily activities for young adults with DS. However, speech difficulties are one of the key factors that affect an individual with DS's ability to make verbal communication with others and eventually impacts performing daily activities in-home, in local settings or around the city (Gomez, Torrado, and Montoro 2017; Carroll et al. 2017). The advancement of voice assistance revealed the possibility of using such technology to support people with cognitive disabilities (Tarakji et al. 2018; Wong et al. 2019; Feng, Fawaz, and Shin 2017). Carroll et al., designed a speech-based prototype of a context-aware assistive application called Robin on Amazon’s Alexa platform to support routing activities by audio prompt for people with dementia (Carroll et al. 2017). The user experiences were positive except for issues with remembering the activation word to continue the conversation with Robin by participants. Similarly, Balasuriya et al., (Balasuriya et al. 2018) observed 18 participants with intellectual disability and understood the user experiences of Voice-Activated Interface. Participants were asked to perform four different activities (search images, voice query, managing calendar and finding direction) using Siri and Google voice assistants. The positive impact of using voice assistance was noticeable – as 55% of users completed all tasks successfully and the rest were able to complete three tasks. Furthermore, voice assistants that run on their own domain can be used on third-party applications by using the provided framework (e.g. Alexa Skills Kit framework). Consequently, voice assistants can eventually be enabled in the assistive app. Tarakji et al. (Tarakji et al. 2018) proposed a prototype of the framework to create Voice User Interfaces (VUIs) on top of existing applications to enable voice assistance with mobile applications such as YouTube, WhatsApp and LinkedIn.

2.6 Human-Computer Interaction (HCI) and Participatory Design

The main purpose of Human-Computer Interaction (HCI) is to understand and improve the usability and accessibility needs of the computer users (Sinha, Shahi, and Shankar 2010). HCI refer to interactions between computer and humans, where interaction refers to the ways humans operate the computers called user interfaces. The concept of the user interface is to create a platform by establishing mutual communication between users and the computer through interactive design that reduces cognitive load and increases the operation abilities of the users (Muller and Druin 2012; Chao 2009; Sinha, Shahi, and Shankar 2010). The user interface creates a layer between computer and human for easy interaction that allows humans to operate the computer through a control panel, which consists of a display with images, audio or physical controller (Chao 2009; Sinha, Shahi, and Shankar 2010). The interaction occurred when the user inputted information to the computer and then the computer processed the information and delivered results to its user. This process is also known as a human-computer interaction process, which can be varied based on the mode of interaction, such as graphical (images and figures), voice, intelligent, and data interaction (Chao 2009). The HCI design process also considers human psychology, functionality, surrounding social and physical environment to ensure the best and easy use of the computer by its users (Muller and Druin 2012). Chao et al. (Chao 2009) stated that the three parts of the design process of the human-computer interface were structure design, interaction design and visual design. Also, these three parts may cross and interact through each other.

HCI supports the participatory design process for vulnerable target groups to be a part of the design team, user test, and user evaluation of a system or application (Bustamante Duarte et al. 2018). Active involvement of the target users in the design process benefits researchers and developers to reveal truthful and refined design requirements, and also benefit from revision in order to gain an optimal design for the application (Sanders, Brandt, and Binder 2010). Participatory design supports brainstorming, storyboarding, paper prototyping, design and co-design workshops methods with the target users (Bustamante Duarte et al. 2018; Sanders, Brandt, and Binder 2010). Nevertheless, paper prototyping allows target users, experts, researchers, and developers to brainstorm, drawing, sketching the user interfaces of the system/application with less budget and time compare to a digital prototype (Osman et al. 2009; Bustamante Duarte et al. 2018).

The majority of these design procedures will persist throughout the research's design process, which includes examining user requirements, determining the task’s purpose, and executing the design. These components are fundamental to structured design (Chao 2009). Also, the research will focus on consistency, operational, easy to communicate, feedback and effective help, as these are the parts of interaction design. Correspondingly, the visual design process will be considered during the design process in this research (Chao 2009).

2.7 Summary

Many studies have been carried out that involved people with cognitive disabilities to increase their independence by providing support in performing daily activities using technology and smart devices. However, few studies have focused on participants with DS and considerable parts of such studies have not been conducted in the context of the independent activities, focusing on the individuals with DS's own goals and needs. In relation to this research, a research question concerns the barriers to performing independent activities for young adults with DS which were not clear and sufficient from the outcome of these background studies. What becomes clear is that the difficulties to perform independent activities existed among individuals with DS due to their cognitive limitation. Also, technologies and smart devices are available which may be used for young adults with DS. However, their capacity to use these devices effectively is in question due to challenges with mobility and dexterity (see section 2.3.4). This raises doubts about the suitability of these technologies for young adults with DS. As a result, it becomes difficult to assess how smart devices like smartphones and smartwatches can provide support to people with DS with achieving their expected goals in real-life settings. Further studies which focus on the use of technology and segregating users into different types of cognitive disabilities (as attempted by Dawe (M Dawe 2006)) would be beneficial especially if they incorporate not only the individual having DS but other stakeholders as well. Although Augusto (Augusto et al. 2018) proposed an advanced environment building system through the User-Centred Software Development Process (UC-SDP), there is still a dearth of research and tools available in the field of software development routines for constructing and employing intelligent conditions (Augusto et al. 2016). There is also a need for further nuanced research that focuses on a specific age group, especially the young adults DS, to assess their abilities in performing independent activities and particular needs of condition, in order to incorporate this information into a system design.

Chapter 3

Research Design Methodology

3.1 Introduction

In this chapter, the methodology was described with each phase that was adopted in order to achieve the goal of this thesis. The description begins with the methodological approach and its clarification of the choice along with the importance. The intention was to provide a brief explanation to the reader of how the methodology served its purposes to achieve this research aim.

3.2 Methodological Approach

This thesis aims to explore barriers to performing daily independent activities for young adults with DS and how effectively they can overcome some of these barriers using technology and smart devices to increase independence. This aim consists of two fundamental elements to achieve: effective understanding of the problems, and the feasibility of technology adoption by the users. Also, both effective understanding and the feasibility of technology adoption link with the context of the users' age and maturity, their surrounding environment, and the use of technologies (performing a motor operation) (Alammary, Al-Haiki, and Al-Muqahwi 2017; Martín-Sabarís 2017). Hence, it is necessary to ensure sufficient understanding of relevant contextual information and users' behaviour in order to bring changes in their lifestyle by design and development of the technological solution (Feng et al. 2010; Abowd et al. 1999).

A methodological approach requires research to be well-defined, standardised and best suited to the demographic of young adults with DS in order to design and develop the most useful, meaningful and successful technological solutions.

Participatory Action Research (PAR) is proven to understand participant needs and problems by providing the facilities of effective design for technological solutions (Kidd and Kral 2005; Baum, MacDougall, and Smith 2006; Kindon, Pain, and Kesby 2009; Macdonald 2012). PAR allows the use of different type of methods that are appropriate based on the research needs and context (Mctaggart 1991; Macdonald 2012). Also, PAR enables researchers to ensure that they are working with the interest of the community (in this context people with DS and their caregivers) (Mctaggart 1991; Macdonald 2012; Kidd and Kral 2005; Baum, MacDougall, and Smith 2006). Hence, PAR was an ideal selection as the core process of this methodology and was adopted throughout the study to meet the requirement for this research.

PAR is where participants are involved in research to share their opinions and convey change, alteration of or solutions to the problem (Kidd and Kral 2005; Macdonald 2012). According to Macdonald (Macdonald 2012) PAR is considered as a dynamic educative process that investigates social problems to mitigate the problem, take sustenance actions. PAR is used in various fields of research e.g. community based research, agriculture, education, social work and health care research (Kindon, Pain, and Kesby 2009). Moreover, Macdonald (Macdonald 2012) named PAR as a philosophical approach to research as this process allows researchers to identify the need and requirements for the persons being studied to take part in all stages of the research. Not only that but also PAR is also used to determine community development, participant empowerment, and increased social inclusion using technology in the research.

3.3 Participatory Action Research Principles in This Research.

In order to fulfil the fundamental elements of the aim of this research, three key principles of the PAR methodology were adopted. These principles are described below.

3.3.1 Community development through defining social problems.

The first principle was to ensure that the research represented the community and their difficulties precisely. That lead the researchers to recognise the problems that are currently being faced by the community. This research focuses on the DS community, particularly difficulties of daily life for people with Down's Syndrome themselves and their parents and caregivers. First, the researcher explored the difficulties of performing daily activities as a current social problem in the DS community. Consequently, the researcher focuses on one of these problems, of performing daily activities. Down's Syndrome Scotland (DSS) has many local branches throughout Scotland. E.g., Ayrshire, Dumfries & Galloway, Oban, Argyll & the Isles Branch, Central, Angus, Edinburgh and the Lothians, Aberdeen – City & Shire, Highland and Islands, Tayside and Fife and West of Scotland. In the first stage, the survey (in cycle 1) was distributed through DSS and requested to spread to all the branches representing Scotland. In all other stages except the survey (in cycle 1), studies were distributed that represent significant geographic areas of Glasgow, Edinburgh, Dundee and Perth in terms of the DS community of the demographic area. Therefore, this research represents most of the geographic areas of Scotland.

3.3.2 Empowering participants

The second principle was to ensure equitable and effective involvement of participants throughout all stages of the research process. Macdonald; Mctaggart; Baum et al. and Kidd et al (Macdonald 2012; Mctaggart 1991; Baum, MacDougall, and Smith 2006; Kidd and Kral 2005) stated that PAR allows emerging democratic procedures that enable equal and active participation of stakeholders with their freedom of opinions in the research. Such democratic process and involvement of participants in every stage of the research assists with gaining more genuine and trustworthy analysis of social reality. One of the main focuses in this research was providing freedom, confidence, and empowerment for participants with DS and their caregivers, and actively involving them in the design and research process by allowing them to articulate their needs, suggestions and solutions. As a result, the outcome of every stage of the research was consistent with existing social issues and the outcome lead forward to further study with a meaningful choice.

3.3.3 Methodological means

The third principle was to make sure of valid and appropriate use of data collection methods to explore social issues, as well as gathering participants' experiences and feedback in each stage of this research. PAR allows different types of method for effective data collection and provides opportunities to pick appropriate methods or make necessary changes in data collection methods based on the circumstances and nature of the study (Macdonald 2012; Mctaggart 1991). There are different types of data collection methods used in this research, including changes in methods to ensure effective and quality data collection (all changes in methods described in the method section of each chapter). Namely, semi-structured interviews, survey questionnaires, field notes, group discussions (face-to-face verbal interaction), participant observation, co-design sessions and application evaluation (a video walkthrough) methods were used throughout the whole research process. The use of dissimilar methods for data collection creates triangulated data generation that guarantees more effective exploration of the social issues, design and solutions to the problems.

3.3.4 Challenges

In the PAR process the researcher should be aware of time, should have knowledge of the community and need to know the sensitivity of the participants, especially when a study represents a community/participants with cognitive disabilities (Macdonald 2012). Conducting research in such a complex context is truly challenging due to time, place, legal and ethical issues. In order to overcome such issues some necessary changes were done to the methods to ensure effective participation e.g. visiting participants' suitable places to run the studies (mostly home), providing extra time for participation, replacing field study methods for evaluation with virtual evaluation through remote participation via Zoom due to COVID-19. Other challenges are described along with each chapter.

3.4 Phases of the PAR Methodology

A PAR cycle consists of five phases. These five phases are problem diagnosis, action planning, action taking, evaluation, and specifying learning (Tetui et al. 2017) (see Figure 3.4-1). In order to complete a research project, the project at least has to complete at least one cycle of the PAR. However, the research project could be completed with more than one cycle (Kidd and Kral 2005; Tetui et al. 2017). In this thesis, a total of four PAR cycles were completed that include a total of five studies. All the studies were conducted with ethics approval from the Department Ethics committee of the University (CIS IDs: 592, 619, 465, 941 and 1361) and a description for each cycle can be found in the designated chapter. This approval ensured that the studies were conducted in an ethical and responsible manner, in accordance with established guidelines and protocols. The five phases of PAR methodology are described below.

3.4.1 Phase 1: Problem diagnosis

The first phase of the PAR methodology was to identify the problem or issue in the community settings that need to be explored and solved (see Figure 3.4-1). As the first cycle was the beginning phase of the research, it was also used for defining scope, understanding context and to develop the conceptual path for the research by undertaking a review of the available literature. As the PAR methodology always leaves new findings to learn at the end of the cycle, this can be analysed further for more understanding (Tetui et al. 2017). This research consists of four completed cycles and each cycle started with a problem diagnosis phase based on the finding of previous cycle except first cycle. The first cycle of this research started with a background literature review to frame the scope of the research and to define the social issues of the Down's Syndrome community as primary problems to address throughout the whole research.

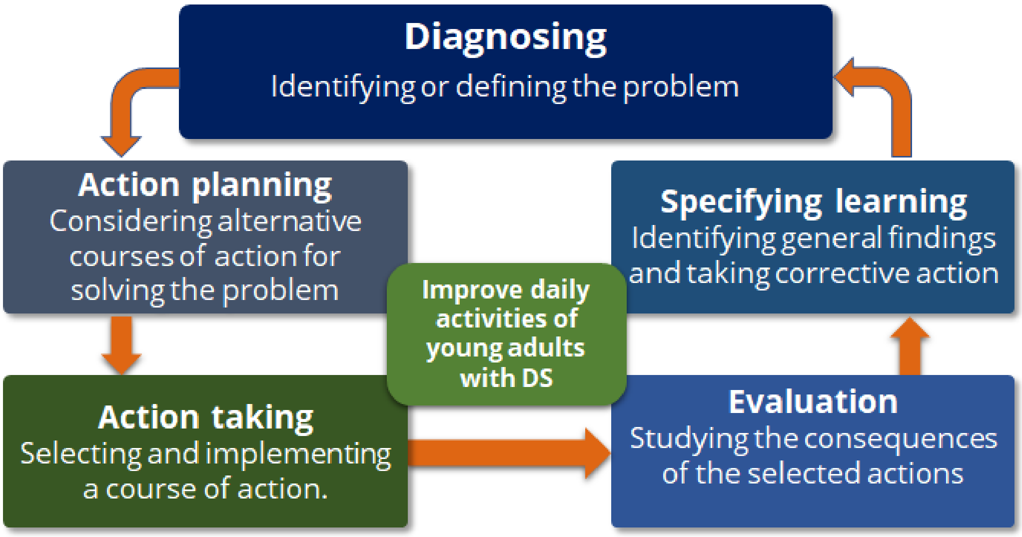


Figure 3.4-1: PAR phases in cycle (adopted from AR cycle (Tetui et al. 2017; Cagney 2015))

3.4.2 Phase 2: Action planning

The second phase of the PAR was action planning to address the specified issue in the diagnosis phase. This phase involves stakeholder participation in the research to consider their consultation through their opinions and feedback in order to build trust and gather a clear indication of their interest in the defined problem (see Figure 3.4-1). As well as this, it aimed to explore deep inside of the specified problem and find possible alternative action to eliminate it. Therefore, this phase begins with the plan for formative study, e.g. review of literature, interviews, questionnaires and surveys with different stakeholders. In the case of this research, the action planning was taken based on the context of the study in each cycle (in all four cycles). For example: semi-structured interviews to enable participants to provide their interest in exploring current problems and to address this problem. Also, the distribution of these planned formative studies to the community members/participants was planned to take place via social media or via charities in this phase. The action planning for all four cycles was described by study methods in designated chapters.

3.4.3 Phase 3: Action taking

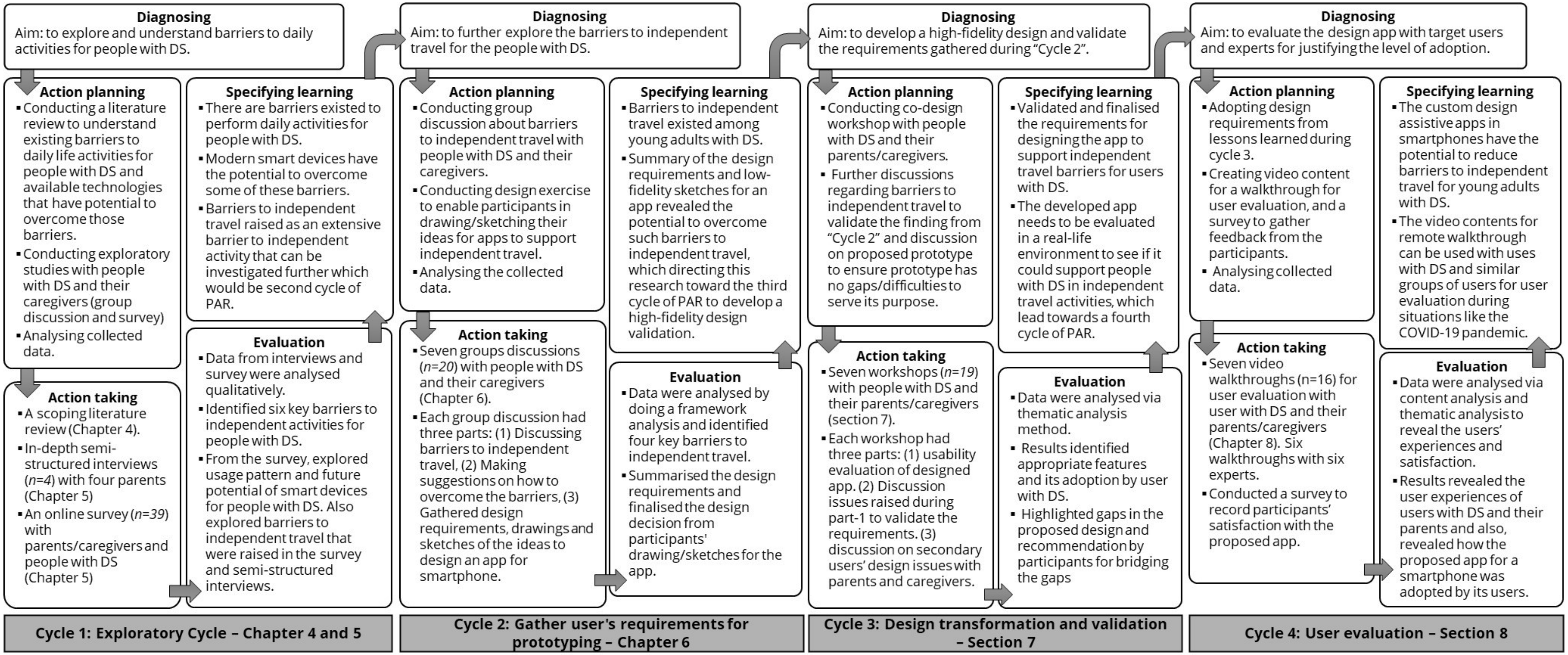
The third phase of the PAR methodology was taking action. This phase comprises the execution and implementation of the specified plans that were defined in the action planning phase (see Figure 3.4-1). The implementation of action can launch a comprehensive in-depth investigation. That can include asking questions, observations or tasks evaluation with one-to-one or group work in the form of a formative study as planned to collect and capture data. Similarly, engagement with key agencies should be confirmed in order to spread the study to the community and participants. In terms of this research, the actions were taken by conducting various formative studies throughout all four cycles of PAR methodology. That included a scoping literature review, semi-structured interviews and an online survey in the cycle 1, group discussions and design sessions in cycle 2, participant observation, prototype evaluation in cycle 3 and a video walkthrough to capture users' interpretations of the designed application for smartphone in cycle 4. All four cycles were conducted with different stakeholders e.g., parents, caregivers, professionals from an education centre and clinicians. All studies were distributed through a charity organisation called Down's Syndrome Scotland (DSS) to ensure that the studies were delivered to the right community and its stakeholders. The actions taken for all four cycles can be found in the procedure section of each designated chapter.

3.4.4 Phase 4: Evaluation

The fourth phase of the PAR methodology was to examine and analyse the collected data to determine the effectiveness of the outcome. This phase comprises various data analysis methods for better utilisation of captured data (see Figure 3.4-1). With regards to this research, a number of qualitative data analysis methods were used based on the nature of the study. Thematic analysis, framework analysis and content analysis etc. were mainly used for the interpretation of collected data from all cycles. The results of the evaluation phase can be found in the findings section of each designated chapter.

3.4.5 Phase 5: Specifying learning

The fifth and final phase of the PAR methodology was to specify the learning outcome at the end of the study. This phase emphasises reporting the results of action by interpreting findings and presenting them to the scientific community (see Figure 3.4-1). The findings will direct the research to a plan for further action which could be the next cycle of the research. In this research, the specified learning is discussed carefully in the discussion session of each cycle which can be found in each designated chapter. All these cycles lead to plans for further action and eventually completed four cycles were completed to gain a satisfactory result (see Figure 3.4-2).



Cycle 1: Exploratory Cycle – Chapter 4 and 5

Diagnosing
Aim: to explore and understand barriers to daily activities for people with DS.

Action planning
- Conducting a literature review to understand existing barriers to daily life activities for people with DS and available technologies that have potential to overcome those barriers.
- Conducting exploratory studies with people with DS and their caregivers (group discussion and survey)
- Analysing collected data.

Action taking
- A scoping literature review (Chapter 4).
- In-depth semi-structured interviews (*n=4*) with four parents (Chapter 5)
- An online survey (*n=39*) with parents/caregivers and people with DS (Chapter 5)

Evaluation
- Data from interviews and survey were analysed qualitatively.
- Identified six key barriers to independent activities for people with DS.
- From the survey, explored usage pattern and future potential of smart devices for people with DS. Also explored barriers to independent travel that were raised in the survey and semi-structured interviews.

Specifying learning
- There are barriers existed to perform daily activities for people with DS.
- Modern smart devices have the potential to overcome some of these barriers.
- Barriers to independent travel raised as an extensive barrier to independent activity that can be investigated further which would be second cycle of PAR.

Cycle 2: Gather user's requirements for prototyping – Chapter 6

Diagnosing
Aim: to further explore the barriers to independent travel for the people with DS.

Action planning
- Conducting group discussion about barriers to independent travel with people with DS and their caregivers.
- Conducting design exercise to enable participants in drawing/sketching their ideas for apps to support independent travel.
- Analysing the collected data.

Action taking
- Seven groups discussions (*n=20*) with people with DS and their caregivers (Chapter 6).
- Each group discussion had three parts: (1) Discussing barriers to independent travel, (2) Making suggestions on how to overcome the barriers, (3) Gathered design requirements, drawings and sketches of the ideas to design an app for smartphone.

Evaluation
- Data were analysed by doing a framework analysis and identified four key barriers to independent travel.
- Summarised the design requirements and finalised the design decision from participants' drawing/sketches for the app.

Specifying learning
- Barriers to independent travel existed among young adults with DS.
- Summary of the design requirements and low-fidelity sketches for an app revealed the potential to overcome such barriers to independent travel, which directing this research toward the third cycle of PAR to develop a high-fidelity design validation.

Cycle 3: Design transformation and validation – Section 7

Diagnosing
Aim: to develop a high-fidelity design and validate the requirements gathered during "Cycle 2".

Action planning
- Conducting co-design workshop with people with DS and their parents/caregivers.
- Further discussions regarding barriers to independent travel to validate the finding from "Cycle 2" and discussion on proposed prototype to ensure prototype has no gaps/difficulties to serve its purpose.

Action taking
- Seven workshops (*n=19*) with people with DS and their parents/caregivers (section 7).
- Each workshop had three parts: (1) usability evaluation of designed app. (2) Discussion issues raised during part-1 to validate the requirements. (3) discussion on secondary users' design issues with parents and caregivers.

Evaluation
- Data were analysed via thematic analysis method.
- Results identified appropriate features and its adoption by user with DS.
- Highlighted gaps in the proposed design and recommendation by participants for bridging the gaps

Specifying learning
- Validated and finalised the requirements for designing the app to support independent travel barriers for users with DS.
- The developed app needs to be evaluated in a real-life environment to see if it could support people with DS in independent travel activities, which lead towards a fourth cycle of PAR.

Cycle 4: User evaluation – Section 8

Diagnosing
Aim: to evaluate the design app with target users and experts for justifying the level of adoption.

Action planning
- Adopting design requirements from lessons learned during cycle 3.
- Creating video content for a walkthrough for user evaluation, and a survey to gather feedback from the participants.
- Analysing collected data.

Action taking
- Seven video walkthroughs (n=16) for user evaluation with user with DS and their parents/caregivers (Chapter 8). Six walkthroughs with six experts.
- Conducted a survey to record participants' satisfaction with the proposed app.

Evaluation
- Data were analysed via content analysis and thematic analysis to reveal the users' experiences and satisfaction.
- Results revealed the user experiences of users with DS and their parents and also, revealed how the proposed app for a smartphone was adopted by its users.

Specifying learning
- The custom design assistive apps in smartphones have the potential to reduce barriers to independent travel for young adults with DS.
- The video contents for remote walkthrough can be used with uses with DS and similar groups of users for user evaluation during situations like the COVID-19 pandemic.

Figure 3.4-2: PAR cycle used to inspire research participation of people with DS and their caregivers. Cycle 1: an initial starting point, explored barriers to independent activities, cycle 2: explored barriers to independent travel, cycle 3: finalised the design needs and validated requirements for the app and cycle 4: remote user evaluation through video walkthrough. The phases of the PAR process were adapted from Gerald Susman (Tetui et al. 2017)*.*

3.5 Alternative Methods: User-Centred Design (UCD)

User Centred Design (Marti and Bannon 2009) approach in the field of HCI involves understanding the users' needs, designing solutions that meet those needs and evaluating the solutions with users to ensure that they are effective, efficient and satisfying to use. User Centred Design framework is an alternative approach that may have been adopted to shape the proposed research design in this thesis. Its main principles are similar to that of the PAR framework for effective interventions, emphasising how a new interactive system/product design and development. Like PAR, User Centred Design methodology focuses on users' needs and satisfaction throughout the design process to create usable and accessible products (Marti and Bannon 2009; Monk 2000).

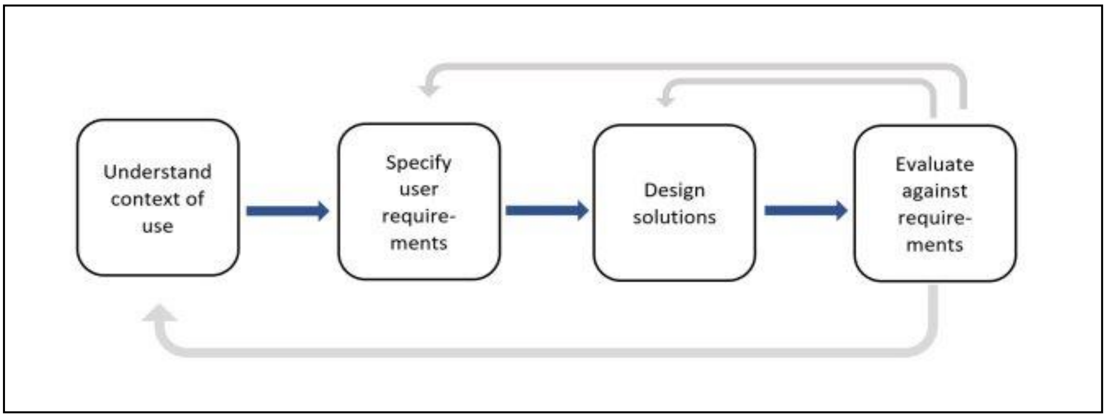


Figure 3.5-1: User-Centred Design Process.

The UCD framework is an iterative design process and consists of four distinct phases in each iteration (Bevan 2003). The first phase, "Understanding the context of use", identifies the users who will use the product, the users' requirements and the environment to use the product and is therefore similar to the first phase (Diagnosing) of the PAR framework for effective interventions. The second phase, "specifying the user and organisational requirements," identifies the users' goals and business requirements to make the product successful. In the third phase, "create design solutions", start an iterative process to design and develop the product based on goals and requirements. Finally, phase four, "evaluating these designs against the requirements", is to prepare useability testing to gather users' feedback on the product and evaluate against the users' context and requirements (Bevan 2003; Chammas, Quaresma, and Mont'Alvão 2015).

The PAR's social design concept, which incorporates the social aspect of product/system development, has an edge over UCD's principles (Ozanne and Saatcioglu 2008; Khanlou and Peter 2005). This thesis aims not only to develop a solution by specifying users' requirements but to explore and understand their problems and then identify users' needs for solutions that can be achieved through both frameworks. However, in terms of the social design concept, PAR is suitable to adopt and can entirely focus on the research aim and its nature.

Chapter 4

Cycle 1, (part 1) Technology to Support Activities of Daily Living for People with Down's Syndrome: A Scoping Review.

4.1 Introduction

This chapter presents a scoping literature review that examines the available literature to provide a deep insight understanding of barriers to daily living activities and opportunities to utilise potential technologies for supporting young adults with DS. This scoping review focuses on those factors that affect everyday activities (RQ1) and potential technologies that are available to provide support in daily activities of living (RQ2). The main purpose of this chapter is to narrow down the areas of the study by identifying the barriers to daily living activities for people living with DS, to determine the potential scope of the study and identify the research gaps.

4.2 Background

Many young adults with DS do not carry out complex daily independent activities on their own (such as cooking or travelling) due to their poorer cognitive capability and intellectual disabilities; instead, they typically receive assistance from carers to complete these complex tasks and activities (M Dawe 2006). The severity range of cognitive capability and intellectual disability may have different impacts on an individual's ability to perform daily activities (Cooper and Prasher

1998; Dykens et al. 2015; Head et al. 2011). While young adults with DS with a mild intellectual disability or mild cognitive impairment (IQ score between 50 and 70) generally have the ability to live independently, they can struggle to complete complex tasks (e.g., travelling or shopping) without receiving support from parents or caregivers (Deb, Hare, and Prior 2007; Smith 2001). In contrast, young adults with DS with a more severe intellectual disability or cognitive impairment tend to require specific support and supervision at all times from their parents and caregivers (Dykens et al. 2015). Most of the articles reviewed in Chapter 2 discussed either intellectual disability or cognitive impairment of participants with DS. The focus on people with DS with mild-ID (IQ score between 50 and 70) aligns with the bulk of the literature in chapter 2 that either considered mild-ID or could be considered a likely focus of their research as strong ID was not reported. This thesis focuses on young adults with DS associated with a mild intellectual disability and mild cognitive impairment under the assumption that such a population is more likely to be in charge of their own in performing daily activities, and they are able to use technology without receiving support from others.

Despite this cognitive incapability, there may have been other factors that may create barriers to carrying out daily independent activities. These barriers may include a lack of support and motivation from the caregivers, a lack of understanding of young adults with DS's needs or how to identify the barriers precisely and how to overcome those barriers with or without using technology and smart devices (Mahy et al. 2010).

Over the last decade technology has been increasingly looked at to support those with disabilities, one of which is the DS. Despite support from parents and caregivers, assistive technology like smart devices and apps have emerged to curb difficulties faced by individuals with DS. Such technology can increase the ability to undertake routine activities accurately and even in some cases, technological supports can reduce dependency on caregivers. For instance, difficulties with remembering, communicating and learning are not uncommon for those with DS due to their poorer cognitive capability, which is where technology can potentially play a role to enable them in performing their daily undertakings. However, there may have been difficulties adopting technologies according to their needs due to such cognitive incapability.

As of September 2018, no high quality scoping literature review was available that particularly focused on barriers to performing independent activities for young adults with DS except barriers to physical activities and healthcare (Mahy et al. 2010). Therefore, there is a real need to explore barriers to independent activities in order to understand their nature and to determine the potential of technologies and smart devices to overcome them. The main purpose of this review was to examine the available literature about challenges to perform daily activities that includes the voice of young adults with DS and to understand the potential of available technology to provide support in daily activities of living. A secondary aim was to determine the potential scope of the study by identifying the research gaps.

4.3 Method

This study review follows Arksey and O'Malley's framework methodologies (Daudt, Van Mossel, and Scott 2013). The framework serves four main goals intended by scoping studies, which are: (i) to scrutinize the degree, range, and nature of research; (ii) to conclude the significance of conducting a complete systematic review; (iii) to summarise and disseminate research results and findings; (iv) to pinpoint gaps in research within prevailing literature. The framework comprises of six steps and the last one is not mandatory; these are: (i) ascertaining the research question(s), that are usually not too narrow; (ii) ascertaining appropriate research to make the selections highly comprehensive (iii) undertaking study selection that takes place by outlining the inclusion and exclusion criteria depending on how familiar the literature is; (iv) laying out the data through phases of filtering, charting, and sorting data in accordance with major themes and concepts; (v) organizing, summarizing and writing the findings, which provides a summary of the findings along with a thematic analysis; (vi) consultation exercise, and additional, analogous step involving key stakeholders to inform and validate study findings (Arksey and O'Malley 2005).

4.4 Identify the Research Questions

The study involves people with Down's syndrome who have cognitive disabilities. The main questions of the review are:

1. "What are the main barriers to independent activities for young adults living with Down's Syndrome?"
2. "How could smart devices (smartphones, smartwatches or smart-clothing) and apps help young adults with Down's Syndrome to perform independent activities?"

The review was focused on young adults with mild cognitive impairment who have Down's syndrome.

4.4.1 Inclusion criteria

Participants: people with DS have specific characteristics as they have a wide range of particular abilities when compared with to people with other cognitive disabilities e.g. dementia, Alzheimer's, schizophrenia, traumatic brain injury, cerebral palsy, autism, Turner syndrome, or older adults (Chapman and Hesketh 2000; HuRuimin and Heidi 2015; Dykens et al. 2015). Also, this study will closely represent people living with DS and their caregivers. Hence, this study will only include those articles that involve at least one participant with DS. Also, the study will include those articles that discuss/involve people with DS's parents and/or caregivers.

Age groups: the age of expectation of performing complex activities independently by individuals with cognitive disabilities is between 12 and 13 years old, particularly when they start attending secondary school. In a number of studies people aged between 13 and 29 years old were considered to be young adults, as this age group emerges with sufficient intellectual ability to take part as the target user population (like young adults) in the study. In relation to this, this study aims to explore barriers to performing independent activities by young adults living with DS and growing understanding of technology use patterns by those with DS. Therefore, this study will consider those articles that involve at least one participant within this age group of young adults (aged between 13 – 35 years) to ensure a similar range of cognitive and intellectual abilities, also design preferences as the target user population for the study.

The study encompassed the following principles:

- Individuals involved have Down's syndrome and mild cognitive disability.
- Articles involved at least one individual with DS who was aged between 13 and 35 years.
- Articles considered were those including assistive technology that is used to support individuals with Down's syndrome in carrying out everyday activities.
- Articles included assistive devices and wearable technology used to support independent activity of people with cognitive issues, e.g., intellectual disability or development disability.
- Articles were written and published in the English language.
- Also, the review included good quality articles discussing assistive technologies for people with cognitive or intellectual disabilities with care.

4.4.2 Exclusion criteria

The scope of the article did not extend to the inclusion of examining:

- Individuals with Down's syndrome with severe cognitive disabilities.
- Article without participants with DS.

- Medical support rather than cognitive and assistive technology support.
- Physical disabilities and telemonitoring.
- Book chapters, dissertation abstracts, non-academic publications and articles of insufficient quality. Such as book chapters or non-academic articles etc., will be removed during the process of the study selection.

4.5 Search Strategy

This study maintained the following search strategies in order to define relevant and quality literature, with a focus on the inclusion and exclusion criteria defined at earlier stages. In order to find articles that were relevant and of the required quality associated with technology, keywords and terms related to {“cognitive disability” OR “dementia” AND “Down’s Syndrome” OR “intellectual disability”} AND {“assistive technology” OR “technology support” OR “smartphone”} were searched for. Searches included terms for Down’s Syndrome combined with search terms for technology and daily activities. Table 4.5-1 shows the terms used as search keywords. The ACM Digital Library (Association for Computing Machinery Digital Library database), PubMed and Google Scholar databases published between 2006 and 2020 were searched and all papers included were published between 2006 and 2020.

Table 4.5-1: Search Terms

Categories	Items
“Cognitive disability”	Down’s Syndrome, dementia, intellectual disability, cognitive impairment.
“Technology”	Assistive technology, assistive technology for cognition, mobile device, iPad, tablet, assistive device,
“Daily activities”	Self-care, independent living, independent activity, support with daily activities, assistive living, independent travelling, ambient assistive living.

4.6 Study Selection

Mendeley bibliography software were used to store the search results and identify possible duplication and deletions from the list. The total hits from the first search result were 1660 articles. During the first stage duplicate papers were removed and 1637 articles remained.

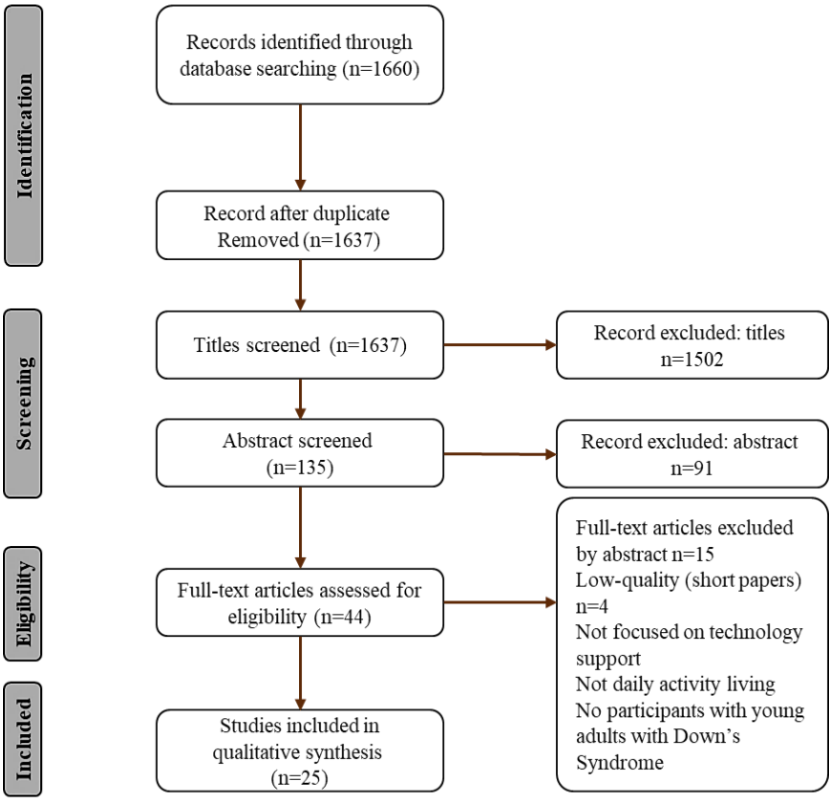


Figure 4.6-1: A PRISMA flow diagram of study selections for the scoping review

Two reviewers (AM and RG) independently screened all titles, and the relevant titles were then moved to the next selection stage, where 135 articles remained. Afterwards, the abstracts of all remaining articles were screened with a more narrow focus by concentrating on smart technology, assistive technology and mobile technology used to support daily activities or independent activities for the people with DS. At this point, 44 articles were left, the full-texts of which were downloaded. Later, the full-texts were compared using the inclusion and exclusion criteria (define on method), meaning that 15 articles, which failed to meet the criteria, were removed. Similarly, 4 articles were removed because of their low-quality (short papers 2-4 pages long and papers with no citations). Therefore, the final selection included 25 published articles (see Appendix A: table of study characteristics and outcome.) appropriate for this scoping review. Figure 4.6-1 contains a diagram with the process of selecting these articles.

4.7 Data Extraction and Synthesis

The data was extracted independently by two reviewers (AM and RG) from selected studies (the final selection of 25 full articles). The extracted data included data related to general information about each study, such as the author's name, publication year, target population, research areas, technologies used and study outcomes. The reviewed articles were categorised into two sections to answer the research questions. Section 1 was based on whether the study examined factors that were related to activities of daily living and if these activities were supported with or without the use of technology. Section 2 was based on study evaluated technologies to facilitate independent living or daily activities of living for those with cognitive disabilities (such as for people with DS).

Later, for section 1, the data was synthesised using qualitative thematic analysis to summarise the key findings from included studies (Braun and Clarke 2006). An index table was created by the first reviewer (AM) which extracted related data for the purpose of answering the research questions. The table was reviewed by the second reviewer (RG) and any disagreements were resolved by joint discussion. For section 2, the main focus was technology used to support daily activities of living and included studies were formed into categories based on technology applied e.g., education, monitoring and tracking health. The initial categories were created by the first reviewer and checked the by second reviewer.

4.8 Findings of Scoping Review

The findings were categorised into two sections based on the research questions. Section 1 summarised the key findings from the selected articles by identifying factors associated with the daily activities of living for people with DS. Section 2 focussed on technologies and devices that have reinforced daily activities for people with DS.

4.8.1 Description of the study

A total of 25 papers were included and listed in a table (see Appendix A: table of study characteristics and outcome. With the name of the authors(s), year of publication and the country where the study was conducted, study areas, the participants' category (e.g. participants with DS, ID, DD, caregivers, experts) with the number of participants involved including age ranges, study methods/designs, the technology/devices stated and the study outcome. The study characteristics are summarised in the list with the details of individual studies.

The studies were conducted in 10 different countries, with 8 of the 23 studies being conducted in the USA. The same number of studies (8) were conducted in mainland European countries (four in Spain, two in France, one Italy and one in Portugal), 3 in the United Kingdom (UK) and one in Australia. The other two studies were conducted in Peru and the Kingdom of Bahrain. All these studies were individual in nature, involved at least one young adult with DS aged between 13 – 35 years old and caregivers/parents. The size of the research samples in individual studies ranged from 1 – 561 participants, including a maximum of 112 individuals with DS (in an online survey, age = 16 – 21 years). The majority were observational or experimental and qualitative studies, and there was no study characterised as a systematic or scoping literature review (for more details see Appendix A: table of study characteristics and outcome.).

Table 4.8-1: Summary of study characteristics with details

Year of publication

Range 2006 – 2020

Country

- UK = 3
- USA = 8
- Spain = 4
- France = 2
- Italy = 1
- Portugal = 1
- Mexico = 1
- Peru = 1
- Australia = 1
- Kingdom of Bahrain =1

Type of study in number

- Focus Group = 5
- Design workshop = 3
- Experimental study/design = 4
- Survey = 2
- Questionnaires = 3
- Case study/Test Case = 4
- User-centred design = 2
- Semi-structured interviews = 2
- Cross-sectional = 1
- Quasi-experimentation = 1
- Ethnographic observation = 1
- Heuristic evaluations = 1
- Performance evaluation = 2

Areas revealed in this study

- Educational and learning = 8
- Technology usage and adoption = 3
- Health = 2
- Independent living and activities support = 10

Participants

- Down's Syndrome = 1478
- Development/Cognitive/Development/ Pervasive Disability = 19
- Attention-Deficit Hyperactivity Disorder (ADHD) = 2
- Autistic Spectrum Disorder (ASD) = 14
- Autism = 6
- Fragile-X syndrome (FXS) = 1
- Cerebral Palsy = 7
- Turner Syndrome = 4
- Encephalopathy without specified aetiology = 4
- Other (disability not specified) = 14
- Parents, teachers, experts and tertiary = 1,149

Age groups of participants with DS

- Range 13 to 35 years= about 775 individuals and roughly 239 individuals excluding survey participants.

The characteristics of the participants did not differ considerably from one to another. The majority of these studies involved participants with DS and also included other categories of participants such as autism, DD, cognitive disabilities, cerebral palsy, neurotypical children, Turner syndrome, cerebral paralysis, teachers, experts, specialists, computer scientists, medical doctors, geneticists, neuropsychologists, and parents. The types of technology used are not similar between studies, such as assistive technology, mobile and web apps, AAC, speech-recognition techniques, video remote integrator, assistive listening devices, educational software, computer applications, smartphone GPS, virtual environment, virtual reality, Google map and OpenTripPlanner. Clearly, there is a wide range in terms of the type of technology and the number of participants involved.

4.8.2 Section 1: factors that are associated with daily activities of living of an individual with DS to answer this question "*What are the main barriers to independent activities for young adults living with Down's Syndrome*?"

This section focused on those factors that affect daily activities of living and eventually create barriers to performing independent activities for young adults with DS. Based on the evidence, three themes were emerged after conducting the thematic analysis of the selected papers. The study focused on difficulties, inabilities, and barriers, that affect capability to perform, handle or understand daily independent activities by an individual with DS during thematic analysis.

4.8.2.1 Remembering activities:

The inability to remember activities emerged as one of the key barriers to independent activities. Remembering general activities from graded memory and performing basic daily routines, like making meals, taking care of the house, and shopping for daily food items (Alesii et al. 2013), can turn out to be quite complex for those with DS. A total of fifteen studies reported involving challenges to perform daily activities that were linked to remembering like learning difficulties and use of technology by gaining the literacy helpful to understand the technology that would aid and assist the people concerned (Alonso-Virgós et al. 2018; Lourdes et al. 2016; Reis and Almeida 2016; González-González et al. 2018; Fernández-López et al. 2013; Villasante et al. 2019; Alammary, Al-Haiki, and Al-Muqahwi 2017; Felix et al. 2017; J. Feng et al. 2008; J. H. Feng et al. 2010; Lazar, Kumin, and Feng 2011; Hu et al. 2013; Kumin et al. 2012; Bathgate et al. 2017; Lazar et al. 2018).

4.8.2.1.1 Difficulties in independent learning

A student's learning potential and opportunities often depend on the educational environment, support, and encouragement. Also, to strengthen learning abilities it is required to create suitable settings that enable people with DS to achieve satisfactory success. According to Lourdes et al. learning disabilities can exist for all ages of people with developmental disabilities if they do not practice any task for a long time or do not practice repeatedly (Lourdes et al. 2016). Lack of basic skills like the inability to recognise and remember numbers, letters, money, shapes, and colour could delay the learning process. Reis et al. and Felix et al. argued that there is a lack of suitable learning environments and encouragement for people with DS (Reis and Almeida 2016; Felix et al. 2017). Furthermore, tasks or activities that are not broken down into smaller steps with no facilities to repeat it tend to be difficult for them to learn and keep remembering. Also, the inability to recognise their own learning style could slow the strengths of learning, and as a result individual with DS cannot concentrate on some activities and quickly get bored. There are always issues of teaching strategies and social environments for people with DS who are trying to improve their learning and basic skills. González-González et al. tried KIBO robotic kits to reinforce the learning process by involving them with teaching-learning programming and computational thinking (González-González et al. 2018).

Fernández-López et al. and Reis et al. discussed the lack of customisable and adaptable applications that focus on non-factional requirements and individualization to enhance the learning process for a student with special educational needs (Fernández-López et al. 2013; Reis and Almeida 2016). This lack of customisable techniques and methods that help to adopt learning style and sharpen their intellectual abilities was also discussed and described by Villasante et al. (Villasante et al. 2019). Accordingly, Alammary et al. described barriers to use and adopt AT by teachers and caregivers may limit the opportunities to supporting people with DS in their learning process (Alammary, Al-Haiki, and Al-Muqahwi 2017). Although, many AT devices are available in the market, adopting an AT that will serve the actual purpose correctly is still challenging for young adults with DS and other people with development disabilities. Adopting the correct AT has massive potential to enhance learning abilities (Alammary, Al-Haiki, and Al-Muqahwi 2017).

4.8.2.1.2 Technology use and adoption

A total of eight studies reported involved technology usage by an individual with DS (Alonso-Virgós, Baena, et al. 2018; Jinjuan Feng et al. 2008; Feng et al. 2010; Hu et al. 2013; Lazar, Kumin, and Feng 2011; Kumin et al. 2012; Lazar et al. 2018; Bathgate et al. 2017). These studies indicated a number of skills that were required to use technologies and mobile devices by the user with DS, specifically sensory and motor skills, visual memory skills, visual and audio processing skills, reading and literacy skills along with the ability to remember.

Text entry: text entry difficulties using keyboards were found to be as a common barrier for people with DS as a result of limited fine motor skills. The recent survey results from Lucía Alonso-Virgós et al. found 51.8% of users with DS had difficulty using a keyboard out of 112 participants (Alonso-Virgós et al.

2018). Jinjuan Feng et al. and J Feng et al. defined lack of typing skill as an obstacle to interact with the computer and use communication tools by people with DS (Jinjuan Feng et al. 2008; Feng et al. 2010). And according to them typing skill requires a combination of literacy skills (language, spelling and writing) along with fine motor skills and memory abilities for users with DS (Jinjuan Feng et al. 2008; Feng et al. 2010). Improvement of these areas is surely challenging due to developmental delays and may eventually create great difficulty in typing among users with DS. To mitigate this difficulty Ruimin Hu et al. further investigated keyboard and mouse, speech input technology and word prediction software (Hu et al. 2013). The study results indicated some individuals with DS achieved the required level of keyboard and mouse skills to enter text at an acceptable level. However, much higher rates of an error on speech recognition software indicated that people with DS's speech was not clearly recognisable due to substantial speech intelligibility problems. On the other hand, use of the word prediction software was not clear due to the additional browsing time and cognitive overhead. Though the result indicated no improvement or reduction of word entry rate, it achieved comparable results with the keyboard and mouse solution. However, according to authors, it helped to correct spelling for users with DS where J Feng et al. found spelling difficulty as a big challenge for individuals with DS (Feng et al. 2010).

Training and practice: it was found that the lack of training facilities limits the potential of computer and technology usage for individuals with DS. Lazar, Kumin, and Feng; Kumin; and Ruimin Hu et al. argued about the absence of formal training and continuous practice to use input devices (e.g., keyboard, mouse) and different type of computer application (e.g., email, word processing, presentation software). As a result, a boundary to computer and technology-related employment opportunities is created (Lazar, Kumin, and Feng 2011; Kumin et al. 2012; Hu et al. 2013). Similarly, J Feng et al. mentioned a lack of well-trained teachers or computer applications to provide computer knowledge and skills to both caregivers and people with DS (Feng et al. 2010). Ruimin Hu et al.

also argued about the necessity of formal training as their study results showed typing skills for text entry were at a productive level in some participants because the participants had received the training (Hu et al. 2013). According to Jinjuan Feng et al. typing and security features were an issue (J. Feng et al. 2008), however, Lazar, Kumin, and Feng et al. found these were no longer an issue once users with DS received training and became expert users (Lazar, Kumin, and Feng 2011). Libby Kumin et al. recommended formal computer training and to make sure to continue practicing trained tasks or activities that help them keep remembering (Kumin et al. 2012). The survey conducted on 112 participants with DS by Alonso-Virgós et al. found 74.1% of participants said that they make mistakes while performing tasks using a computer (Alonso-Virgós et al. 2018), which indicated that people with DS need to receive sufficient training and continue to practice their desired tasks or activities using a computer. Nevertheless, Bathgate et al. study findings suggested that video instructions should be preloaded onto mobile devices for initial training to enhance practice desire tasks and activities by users with DS (Bathgate et al. 2017).

Usability and accessibility issues: lack of user-friendly interface designs of applications creates complexity to operate applications by users living with DS. Also, applications that were designed without consideration of the user's special needs are less feasible or often inaccessible to users with DS. Feng et al. argued about the importance of interface designs for accessibility and particularly focused on the special needs of users living with DS (Jinjuan Feng et al. 2008; Feng et al. 2010). Feng et al. uncovered difficulties using different types of applications due to lack of accessible designs and these create frustration among users with DS (Feng et al. 2010). They reported that navigating applications (e.g., operating Windows systems) or browsing the website (searching keywords) were real challenges. They also, reported that the design flaws are a big issue, such as information presented which is too overwhelming to handle during the use of applications by an individual with DS. Furthermore, Lazar et al. explored a shortage of cognitive impairment friendly versions of applications that have the possibility to learn the use of application spending less time and ability to achieve higher performance (Lazar, Kumin, and Feng 2011). Libby Kumin et al. stated that the use of inappropriate interface designs (colour, visual, and size of the icon/button) and less controllability limit the accessibility to touch-screen smart devices by an individual with DS (Kumin et al. 2012). Authors also specified that it caused frustration among individuals to use or perform the desired tasks on touch-screen devices. The recent survey results from the study by Alonso-Virgós et al. revealed that the need for internet access on daily basis by young-adults (aged between 15 – 35 years old) was more than 50% out of 112 participants with DS (Alonso-Virgós et al. 2018). Also, the results revealed that 17% of users had navigation problems. Learning the use of technology tools due to job requirements e.g., from PDA and other technological tools found that 23.2% of users faced difficulty when learning the use of these technological tools on a daily basis. This indicates that there is a need for a simpler or cognitive impairment friendly version to enable users with DS to learn the use of different types of tools. The result also indicated a lack of accessible designs as 48.2% reported needing support from someone to find buttons, 9% had issues with colours of the website (e.g., text, button, background colours) and 20% of respondents with DS found the website difficult to read. Nonetheless, Lazar et al. also suggested some principles for interface designs that have huge potential to overcome design flaws and suit people living with DS's needs (Lazar et al. 2018). As such, the written content should have to be easy to read, short and understandable. Navigation menus should have a limited number of menu options to reduce the overwhelming need to make sure users are not jumping between apps. Personalisation by using images of family members, friends, and recorded videos to keep continue interest in the use of applications is a good idea.

4.8.2.2 Independent living and self-navigation

The second area of concern was independent living and self-navigation. Independent living requires reduced dependence on parents/caregivers, and self-navigation to ensure unrestricted and anonymous movement for young adults with DS. A total of ten studies reported concern about these issues (R Alesii et al. 2013; Roberto Alesii et al. 2015; Augusto et al. 2018; Lazar et al. 2018; Bathgate et al. 2017; García De Marina, Carro, and Haya 2012; Courbois et al. 2013; Covaci et al. 2015; N Kaoua, Landuran, and Sauzéon 2019; Kramer, Covaci, and Augusto 2015).

4.8.2.2.1 Independent living

Roberto and R Alesii et al. pointed out the necessity of reducing dependency of adults with DS on parents and caregivers, due to natural circumstances like an earthquake or the death of parents (Roberto Alesii et al. 2015; R Alesii et al. 2013). In these regards, the authors introduced the CASA+ project to assists with independent living and analysed problems and needs that were required by users with DS. The problems faced by people with DS are time management: difficulty in organising and scheduling daily activities. Daily actions that need assistance may include food preparation, grocery shopping, keeping the house clean, and providing outdoor mobility support. Similarly, Augusto et al. pointed out the lack of prompts and encouragement of independent living, and decision-making through information and guidance that resulted less improvement in usual daily life situations and prevents social inclusion for people living with DS (Augusto et al. 2018). Their study revealed challenges faced by people living with DS, mostly when undertaking outdoor activities such as using public transport, handling shopping lists and money, understanding food consumption and scheduling activity reminders based on context. Also, independent living leads to healthy foods choices and consumption. An individual with DS is less likely to be able to express themselves about their health conditions and issues. They often have difficulties with making healthy food choices and diet control. As a result, people with DS are more likely to be overweight or obese. Individuals with DS demonstrated a scarce understanding of information related to healthy food selection e.g. nutritional content, calorie content, when to eat meals, and an inability to process these pieces of information due to their difficulties in mathematical, reading, and reasoning skills (Lazar et al. 2018), resulting in increased dependence on caregivers to make healthy food choices which eventually creates barriers to independent living and social inclusion. Bathgate et al. stated the need for a feasible method to assess and control eating habits for young-adults with DS and used an image-based mobile foods recording application (Bathgate et al. 2017). The study result showed a positive impact in dietary assessment when recording food and beverages consumption with detailed visual information over written food records.

4.8.2.2.2 Self-navigation

Difficulties in self-navigation are a common problem among young adults living with DS. A reduced working memory ability, attention disorder, poor literacy, and poor decision-making skills can considerably hamper tasks such as managing travel timetables, finding desirable locations, and using public transport. An inability to self-navigate limits employability, ability to maintain social networks, well-being, autonomous travel, and ability to interpret public information (bus timetables) for those with DS (Lazar et al. 2018; García De Marina, Carro, and Haya 2012).

Yannick Courbois et al. discussed a lack of processing ability to understand the spatial location of an object and its surrounding in term of distance and directions, as such difficulty may create complexity when processing spatial navigation and eventually affect a person’s navigation skills (Courbois et al. 2013). However, their study findings in VE shown that the people with DS have the ability to learn routes. Alexandra Covaci et al. also raised similar issues of deficiency in spatial knowledge that caused obstacles to actively exploring an environment actively and learning self-initiated navigation (Covaci et al. 2015). Authors argued that recognition of appropriate landmarks has the potential to improve spatial knowledge resulting in enhanced route learning. Their study results in VE indicated that identifying and recognizing desired places using landmarks may not be easy in different weather conditions/ at night-time and only four out of thirteen participants identified route sequences correctly. Such findings were not satisfactory in terms of landmark use to enhance special knowledge to identify places and route learning for people living with DS.

Consequently, Bernard N'Kaoua et al. argued about the wayfinding difficulties for unfamiliar routes, even often with the familiar routes by individuals with DS (N Kaoua, Landuran, and Sauzéon 2019). Their study particularly discussed the difficulty in processing the dynamic construction of spatial representation: landmark level (landmark free-recall task), route level (wayfinding, direction estimation, and landmark ordering tasks), and configurational level (starting point direction estimation task). They mainly focused on elucidating the spatial deficit associated with DS and evaluated the effectiveness of the landmark-route-survey model in wayfinding with VE. Findings suggested that by providing appropriate supports and aids (the authors provided brightly coloured landmarks) based on the need of spatial knowledge to improve performance on tasks associated with landmark and route level. Such findings made it clear that the digital aids with technology have the potential to deliver navigation support for unfamiliar routes. However, the findings also suggested no improvement of spatial knowledge on a configurational level with the level of aids provided among participants with DS.

García De Marina et al. stressed a lack of understating each user's ability, strengths, and needs that create difficulties to help them in the best possible way according to their specific needs in different situations (García De Marina, Carro, and Haya 2012). Also, they mentioned the necessity of well designed computer-based systems or interfaces that potentially assist with practicing and improving certain routines e.g. outdoors navigation, dealing with unforeseen situations, and assistance with decision making. The results of their proposed mobile application called "Where Should I Go?" (WSI-Go) to support navigation showed positive impacts of visual and audio mode, except for a few difficulties faced by two out of twenty participants when it comes to understanding the overall tour goal, and five of them not able to use the device correctly. Apart from these the poor-quality GPS signal also affected users' performance. Likewise, Kramer et al. (Kramer, Covaci, and Augusto 2015) introduced a navigational app in part of the POSEIDON project for people living with DS to support independent travel without distress and increase social inclusion. Six individuals with DS travelled a 2 km-long route using a navigation app for the experiment. Though the overall result was positive, the concerning issues were difficulties interpreting the turning points while participants used the map for navigation on their phone and too much attention being focused on the mobile screen which led to reduced concentration on the road.

4.8.2.3 Communication challenges

Communication needs were raised mostly in outdoor conditions to exchange information about locations, safety check-in, notify users about upcoming events, and help to perform activities (Melissa Dawe 2007). Difficulties in remote communication using phone call were found to be a common problem for people living with DS. Study in (Melissa Dawe 2007) specified a numbers of causes of communication issues are: lack of motivation to use cell phones due to unwanted service charges (internet bills) from network providers while parents have limited budgets, a lack of simplified design of phone menus to operate, and a lack of extensive training to make calls, or leave/access voicemail messages. Similarly, speech intelligibility difficulty was one of the key factors that affected some individuals with DS's ability to communicate with others, especially someone new whom they did not talk to before and interactions with speech recognition technologies (Hu et al. 2013). Furthermore, a lack of typing skills and ability to operate different types of communication tools (e.g. online chat, text messaging and email) create boundaries to effective communication for individuals living with DS (Feng et al. 2010). However, such difficulties in communication ability fail to ensure independence and safety which eventually creates barriers to active community participation by people with DS.

4.8.3 Section 2: Technologies to support people with Down's syndrome, to answer the question of "*How could smart devices (smartphones, smartwatches or smart-clothing) and apps help young adults with Down's Syndrome to perform independent activities?*'

Several advancements in technology have emerged in recent years e.g., smart devices' sensors (GPS, motions, gyroscope, vibration, microphone, camera etc.), speech-recognition techniques, and artificial neural networks. These act as assistive systems or devices to aid and assist in completing daily activities/routine by reminding and prompting users with step-by-step guidance, voice and visual instructions and visual representations of tasks.

4.8.3.1 Technology for memory support

A total of eleven studies, in particular, were focused on prompting and reminding users to do activities and tasks to support prospect memory for those who have cognitive disabilities, including people with DS (Reis and Almeida 2016; Lourdes et al. 2016; N Kaoua, Landuran, and Sauzéon 2019; Kramer, Covaci, and Augusto 2015; Covaci et al. 2015; Kumin et al. 2012; Augusto et al. 2018; Roberto Alesii et al. 2015; R Alesii et al. 2013; Bathgate et al. 2017; Lazar et al. 2018). Findings suggested that technology offers a promise to aid individuals with DS by providing reminder facilities on various occasions (Covaci et al. 2015). According to Dawe technology can make a significant difference in the lives of those facing difficulty in organising their daily routines and managing agendas (M Dawe 2006).

They suggest that it is possible to make use of external prompting systems to aid people with cognitive limitations. This can take place by helping one to remember the right time to undertake an activity, or through providing prompters regarding the stages of the task requiring completion.

4.8.3.1.1 Prompter and scheduler

Lourdes et al. and Sofia Reis et al. discussed computer-based prompting system technology. Such technology is included with image schedules and a video-based prompting system that represents activities or tasks with pictorial instructions and step-by-step video guidance to perform properly (Lourdes et al. 2016; Reis and Almeida 2016). Dean Kramer et al. and Bernard N'Kaoua et al. (N Kaoua, Landuran, and Sauzéon 2019; Kramer, Covaci, and Augusto 2015) mentioned prompt instructions with texts, audio, and images of route directions and Alexandra Covaci et al. adopted an approach that synchronised Google Calendar that synchronised with the system to support navigation by prompting notifications (Covaci et al. 2015). Similarly, Sofia Reis et al. proposed note-taking using a calendar feature and to set event reminders that synchronised with parents' mobile devices (Reis and Almeida 2016). Also, musical notifications that remind users to get off the bus at the correct stop were suggested.

4.8.3.1.2 Reminder and notification

There are also context-aware guidance systems that remind users about tasks or assist in navigation and support in decision making. Kumin et al. and Augusto et al. (Augusto et al. 2018; Kumin et al. 2012) have finding that suggested contextualised reminders that helped users to prepare and plan for activities accordingly, for example, a reminder that helps to choose appropriate clothing based on weather conditions, or a reminder to take necessary belongings before leaving home. R Alesii et al. 2015 and 2013 proposed "*a service to broadcast* *preloaded audio messages"* to play based on context e.g. messages related to an incorrect situation and messages to manage timetable e.g. wake-up, shopping, dish washing (Roberto Alesii et al. 2015; R Alesii et al. 2013). Also, the use of reminders found in the study conducted by Bathgate et al. in which they developed an image-based mobile food record application with reminder features to notify users to take pictures after having the meal in order to assess their daily food consumption (Bathgate et al. 2017). Furthermore, Lazar et al. findings suggested the need for the use of alert and reward features to support and encourage healthy food choices that have the potential to changes users' behaviour for healthy food consumption (Lazar et al. 2018).

4.8.3.2 Technology to support employability

Five studies reported the use of technology to aid and assist individuals with DS in workplaces (J. Feng et al. 2008; Hu et al. 2013; Lazar, Kumin, and Feng 2011; Kumin et al. 2012; Alonso-Virgós et al. 2018). The study results from Jinjuan Feng et al. in the survey indicated that 72% of individuals with DS (out of 561 responses) started using computers by the early age of five were and by the age of six this figure had increased to 80% (J. Feng et al. 2008). The study findings also revealed the frequent (very often or often) usage of educational software by 65% of respondents and the use of websites for education-related purposes by 25% of respondents. Also, 33% were cell phone users, digital watches were used by 18.2% of respondents, and iPods were used by 45.3%. Generally, the results indicated that people with DS are familiar with technology and different type of smart devices, but the result did not reveal whether there are any challenges to using these technologies or devices. The authors emphasized the effective usage of email, IM, and office automation applications with the skill of using a keyboard (for text entry) that could bring employment opportunities for those living with DS.

Ruimin Hu et al. demonstrated the use of speech recognition technology for text entry as an alternative to keyboard and mouse (Hu et al. 2013). However, their findings revealed that some users with DS are better at using a keyboard compared to speech recognition technology for text entry. Similarly, a study was done by Lazar et al. on workplace-related computer skills that revealed the use of applications and devices by participants (*n*=10) living with DS (Lazar, Kumin, and Feng 2011). Participants have demonstrated the ability to use their skills on different types of operating systems (Windows 7, Windows XP, Mac) and devices (desktop, laptop, MacBook, mobile/cell phones, iTunes/iTouch). Also, the use of computer applications was observed such as word processing (ten out of ten participants were successfully able to use), Excel (five), PowerPoint (five), Database (four), calendar (five), email (ten), instant messaging (four), Facebook (six) and security applications including a password (was easy to all) and CAPTCHAs (100% done by eight participants) was observed. Text entry with the keyboard (ten out of ten participants were successfully used), mouse (ten), phone keypad (six), touchscreen/touchpad (five) and speech input (one) were also tested. The use of mobile applications on mobile devices was observed, such as email (three out of ten participants completed mail tasks successfully), text messaging (seven) and entertainment (five were able to use iTunes/iTouch). Furthermore, participants showed their ability to search for information using Google (ten out of ten), YouTube (seven) and weather/map (six participants). Likewise, a study done by Kumin et al. found nine out of ten participants indicated easy use of a touch-screen virtual keyboard (Kumin et al. 2012). Also, this study confirmed participants' ability to use the smart devices such as iPads and applications such as the Safari web browser, Facebook, Mail accounts (Gmail, Yahoo mail or AOL), calendar, and Amazon by individuals with DS. Furthermore, in order to make sure of easy accessibility to websites Alonso-Virgós et al. proposed a set of recommendations guidelines for web developers to consider when designing websites. These apply to multimedia, audio, text, form design, contrast (colour) and link contents (Alonso-Virgós et al. 2018).

4.8.3.3 Technology for education

Nine studies were mainly focused on educational technology to mitigate learning difficulties (discussed in Section 4.8.2.1.1) for people living with DS (Reis and Almeida 2016; Fernández-López et al. 2013; Lourdes et al. 2016; R Alesii et al. 2013; Roberto Alesii et al. 2015; Felix et al. 2017; Villasante et al. 2019; González-González et al. 2018; M Dawe 2006). A variety of assistive applications were designed and developed that support people with DS in the educational processes of writing, reading, recognising characteristics, numbers and mathematics (counting) which increases higher engagement in education and reduces learning difficulties. Desktops, laptops, computer applications, and smart devices like smartphones, iPad, tablets (touchscreen devices) with assistive applications and access to websites were commonly used to improve the learning process with a better approach.

Álvaro Fernández-López et al. developed a mobile learning application on iPad and iPod called Picaa with customisable content and user interface level to enhance learning and reduce learning difficulties (Fernández-López et al. 2013). This study was focused on four educational activities: exploration, association, puzzle, and sorting which are related to five basic skills: language, maths, environment, autonomy, and social. The study findings of the evaluation of five basic skills revealed positive results with an increase in scores in each skill. Similarly, Lourdes et al. introduced a web application for iPad to improve recognition of numbers, letters, money, shapes, and colours (Lourdes et al. 2016). Authors used high-quality images of money and coins, different types of shapes and lower- and upper-case letters, as well as yellow for highlighting and white on black for the background. The study results indicated mostly positive reactions (80.4% on average) from participants (*n*=10) on all basic skill reinforcement activities using the web app on iPad.

Moreover, difficulties with effectively handling of money were also raised by Sofia Reis et al. and the authors focused on developing numeracy and financial skills using a smartphone to recognise the correct value of the money, counting, making payments and receiving the correct change after purchasing items (Reis and Almeida 2016). As a proof of concept to handle the money appropriately, they mentioned a set of mobile apps with similar features e.g. “Aurasma” app for instructional videos about performing tasks, “Cha-Ching Pocket Money Manager” and “Eurok@s” to check the budget and help to calculate it. Similarly, R Alesii et al. used images of money and coins after selected items to purchase using a mobile app in the CASA+ project (R Alesii et al. 2013; Roberto Alesii et al. 2015). Likewise, Felix et al. introduced a mobile application called HATLE on Android Tablet and used an artificial neural network for speech recognition and handwriting to enhance reading and writing (on a touch-screen) support (Felix et al. 2017), as well as involved visual and audio information with the motive of a play and learning environment that incorporates education, exercise, assessment, practicing correct pronunciation, and character/sign recognition. Consistently, Josué Villasante et al. designed two prototypes on a Huawei P9 smartphone and an iPad to improve language and maths skills (Villasante et al. 2019). Authors used visuals (sets of images) and sound techniques for cognitive support with counting and pronouncing of words. Also, an NFC card was used to display images of the corresponding items. However, apart from smart devices, AlphaSmart is among one of the electronic devices that support writing by word predicting, processing, and spelling. Conversely, the discussion felt that the web-based educational game and computer-aided educational software may encourage the learning process and limit the barriers to education. Additionally, the use of special keyboards, switches, and calculators with large-button, KIBO robotic techniques were found to be useful apps and devices for supporting education and reinforcing learning (M Dawe 2006; González-González et al. 2018).

4.8.3.4 Technology for tracking, monitoring and way-finding

A total of ten studies, in particular, reported using of technologies like VE, VR, smartphone's GPS, Google Maps, OpenTripPlanner, MyMap for teaching and training routes, tracking and monitoring movement, and wayfinding for people living with DS (Courbois et al. 2013; Covaci et al. 2015; N Kaoua, Landuran, and Sauzéon 2019; Kramer, Covaci, and Augusto 2015; Reis and Almeida 2016; R Alesii et al. 2013; Roberto Alesii et al. 2015; Vukovic et al. 2016; García De Marina, Carro, and Haya 2012; Augusto et al. 2018).

4.8.3.4.1 Virtual Environment (VE) and Virtual Reality (VR) to teach and practice navigation

VE was used to assist an individual with DS to receive training and practice tasks/activities safely until satisfactory results were achieved. The wayfinding activity required to practice multiple times by individuals with DS, and their caregivers have to make sure a safe environment while practicing route finding. In this case, wayfinding practice in VE turns out to be suitable and safe for those who required assistance for travelling in the real-life environment.

Yannick Courbois et al. and Alexandra Covaci et al. conducted experiments to assess learning through the ability of wayfinding activity with fundamental assessment phases including learning, route learning and finding shortcuts in VE (Covaci et al. 2015; Courbois et al. 2013). The experimental results revealed the expected outcome that the individuals with DS were able to learn route navigation, but several practices were required to memorise the order sequence of landmarks. Also, it was suggested that individuals with DS have a lack of ability to use the configuration knowledge as they were not able to find shortcuts (Courbois et al. 2013). Nonetheless, the ability to recognise landmarks found was significantly lower in the VE by individuals with DS. However, a study done by Bernard N'Kaoua et al. through VE found that it was easy to recognise landmarks when the landmark was highlighted with bright colours (N Kaoua, Landuran, and

Sauzéon 2019). Both studies (N Kaoua, Landuran, and Sauzéon 2019; Courbois et al. 2013) used Virtools software to create VE, and also used a personal computer and projector for VR room. Keyboard, mouse and joystick were used to control movement in the environment. Alexandra Covaci et al. developed a VR system using Google Street View API with 360-degree images, and Google Maps to build realistic routes in VE and all the routes characteristics shored in cloud topological in a JSON object (Covaci et al. 2015). The VR system was interconnected with tablet/mobile phone, Kinect sensor, mouse and interactive table to provide training for navigation and control movement in the VE. They also developed an AR position-based app to improve the real-world experience using GPS and Global Navigation Satellite System compass.

4.8.3.4.2 Mobile navigation using smartphones, GPS, Google Maps, OpenTripPlanner, MyMap

The use of mobile applications combined with different types of sensors e.g. GPS, wireless network, maps are becoming common ways to provide support with way-finding and helping to use public transport by GPS collaboration with the local transport system and informing users of the correct bus or route to be taken (Reis and Almeida 2016; Kramer, Covaci, and Augusto 2015). Alesii et al. introduced a smart home project to aid independent living called CASA+ for those living with DS (Roberto Alesii et al. 2015; R Alesii et al. 2013). The study attempts to explore the ability of technology to assess the capabilities of users with DS through analysing data produced by remote monitoring. Also, wrist watches were used as mobile nodules within a wireless sensor network (WSN) zone which was made to receive indoor location details of guests/users including web and mobile phone technologies. As a part of this project authors also introduced the potentiality of mobile navigation technology for both indoor and outdoor environments. A radiofrequency beacon with sensor-based applications was used indoors to assist users for navigation, while global positioning systems (GPS) were used outdoors. Also, wearable technology in the form of smart wristwatches with GPS has been advanced as an assistive technology with location-tracking facilities. These can alert guardians or caregivers if the user exits a predefined safety-area (Vukovic et al. 2016). These sensors can detect an individual's location and customizes the information accordingly to suit the location, which enables navigation to different points safely that included the geo-fencing and direction facilities with the point of interest (POI). Also, caregivers were notified about circumstances of the route during travel e.g. GPS signal lost, delays reaching the destination (Roberto Alesii et al. 2015). The application developed by García De Marina et al. called WSI-Go was used to provide guidance in way-finding using mobile devices that also include GPS sensors to receive users' current location details, 15 audio files for auditory direction and 150 street view images (images were edited and direction arrows were inserted) to indicate directions for navigation (García De Marina, Carro, and Haya 2012). Furthermore, the authors developed a Java application with the Google Earth API combined with GPS data to record users' movements in order to provide monitoring support.

However, the technology mentioned does not only involve hardware, but sophisticated software is also required to develop an intelligent environment (IE) in which assistance can be facilitated. In developing these conditions, inputs were taken from those with DS through the POSEIDON (PersOnalized Smart Environments to increase Inclusion) project to enhance the solution's effectiveness to make it better suited to both the user with DS and their caregivers (Augusto et al. 2016). Thus, Augusto et al. developed the UC-SDP model to assist software developers to develop more robust and user-appropriate Ies (Augusto et al. 2018). Dean Kramer et al. described the development of navigational service which was a part of the POSEIDON project (Kramer, Covaci, and Augusto 2015). The technologies used were: OpenTripPlanner to create and display route data with the map, GPS to extract location coordinates, photographs of decision (turning) points with voice commands to help with direction and cloud service to store contextual data including GPS coordinates that help the caregiver to locate users with DS and keep records of daily events.

4.8.3.5 Technology for communication support

A total of seven studies reported that assistive technologies have the potential to overcome communication difficulties as discussed in section 4.8.2.3 (Kumin et al. 2012; M Dawe 2006; Melissa Dawe 2007; J. Feng et al. 2008; Lazar, Kumin, and Feng 2011; Hu et al. 2013; Alammary, Al-Haiki, and Al-Muqahwi 2017).

Dawe's 2007 and 2006 findings revealed the need for remote communication in which mobile phone devices were found to be commonly used to maintain remote communication between users with DS and their parents through phone calls (Melissa Dawe 2007; M Dawe 2006). Also, Dawe found that some users were capable of leaving a voicemail on landline phones which can be checked by parents. Some had adapted to use AT devices such as memo recorders and augmentative communication devices (such as Alpha Talker or Blackhawk) to mitigate verbal communication with others (M Dawe 2006; J. Feng et al. 2008). Studies conducted by feng et al. and Kumin et al. also listed various communication tools such as email, IM, and Facebook used on both desktop and mobile for professional and unprofessional communication purposes (J. Feng et al. 2008; Kumin et al. 2012; Lazar, Kumin, and Feng 2011). Ruimin Hu et al. and Alammary et al. suggested speech recognition technologies (authors used ViaVoice tool in the study) for those with intelligibility speech (Alammary, Al-Haiki, and Al-Muqahwi 2017; Hu et al. 2013). Nevertheless, Alammary et al. pointed to several difficulties for individuals with DS like hearing, vision, cognitive and motor impairment, which can influence communication problems in one way or other (Alammary, Al-Haiki, and Al-Muqahwi 2017). Authors listed different types of AT for hearing, vision, cognitive and motor impairment to aid individuals with DS e.g. Digital pens, iCommunicators, audio loop systems, voice to text/sign, video remote integrator, assistive listening devices, automated alarms for time-linked tasks, smart boards, different magnification modes, basic readers, braille keyboard stickers, iPing, calendar, paging system, wristwatches, pocket computers, electronic notebooks, touch screens, ergonomic wireless keyboards, portable carts, and automatic page turners.

4.9 Discussion of Scoping Review Findings

This study aims to give insight into barriers to performing daily activities and the effects of technology in reducing those barriers for individuals with DS by critically evaluating the literature on the topic. Though this is a relatively new research area, a total of 25 studies were found with a focus on both difficulties performing daily activities and potential support with technologies. The diverse research methods from all selected studies reflects the novelty of this research field.

In reviewing the factors related to performing daily activities (in Section 4.8.2) a key finding was the growing understanding of the method of receiving support and complications of using technologies by individuals with DS. The study findings indicated that the difficulties performing daily independent activities existed due to their cognitive limitations such as a lack of memory, independent living and self-navigation, difficulty communicating with others and an inappropriate surrounding environment for appropriate technology use. In reviewing technologies for performing activities (section 2), a key finding was acquiring knowledge on available technologies that were used by individuals living with DS. This finding revealed several types of technologies and assistive applications in existence that have the potential to aid most of these activities revealed in section 1 (see section 4.8.2).

Likewise, the technological advancements can play a significant role in supporting both the day-to-day lives of and specialised activities for those living with DS. Such advancements are viewed as assistive technology since they assist those with disabilities. However, such technology was not necessarily developed for serving those with disabilities. For example, the smartwatches as a wearable technology were not particularly designed to serve those with DS. On the other hand, there are several custom-built applications developed to serve such needs. A common trend has been to investigate ways in which technology could be used to benefit those with disabilities. Furthermore, such needs do not substitute the need for caregivers or family support entirely. Nonetheless, assistive technology makes their lives substantially easier by providing them with reliable care for the subject, such as allowing them to keep a track of those they care for and obtaining accurate and precise data for medical purposes.

Additionally, at present, the accessibility and usability of different technologies can make them a reliable form of assistance for such purposes, particularly when the technology comes with the benefit of being able to be customized to suit the need of the users (Reis and Almeida 2016). However, it is not entirely possible to guarantee that such technology functions smoothly, and systems failing or devices breaking could impact users with cognitive disabilities. Also, especially in the case of technology used for medical purposes, there are multiple prototypes available, with not all of them having the same levels of reliability. Further issues can arise if pilot-testing has also only been done on a limited population, which can lead to the technology being overly generalized (Felix et al. 2017; Kumin et al. 2012).

Thus, on one hand, technology offers extensive benefits to the users and their support groups, but at the same time, it is crucial to be aware of the technology’s limitations and that it should not entirely be depended upon (Hu et al. 2013; Courbois et al. 2013). Nonetheless, advancements in these areas are rapid and there is scope for technology to contribute even more in the future. Now, with the help of information from caregivers and family members, it is possible to design and develop assistive apps specifically around the user’s needs, making their experience more personal and user-appropriate.

Nevertheless, a tendency revealed for receiving support through technology based on the age of individuals with DS. Age between 4-12 years mostly received education-related support using technology like computers, iPads/Tablets with assistive applications (Reis and Almeida 2016; Fernández-López et al. 2013; Lourdes et al. 2016; R Alesii et al. 2013; Roberto Alesii et al. 2015; Felix et al. 2017; Villasante et al. 2019; González-González et al. 2018; M Dawe 2006). On the other hand, ages between 12-35 years usually received support that was related to independent living, navigation and communication using technology like GPS, WSN, IE, digital maps, AT and mobile devices (Reis and Almeida 2016; Kramer, Covaci, and Augusto 2015).

The study's results indicate that interventions using mobile devices and technology are effective in supporting individuals with Down Syndrome, particularly when taking into account their age-specific needs. The use of multimedia (audio, visual, animated objects, video) instructional design with the repeated learning process, personalised tasks and understanding of individual learning profiles can help individuals with attention deficit, working memory limitations, and abstract thinking. The intervention also showed improvements in auditory-verbal and visual-spatial working memory.

4.9.1 Methodological quality of the studies and knowledge gap

4.9.1.1 Methodological quality

Methodological quality involves critically analysing the methodological rigour of the ways that findings of studies are arrived at. Studies have been conducted on assistive technology, which particularly takes into consideration those with DS. Hence, the ones providing the most useful insights are those that specifically focus on the kinds of assistance or the area of specialisation of technologies like assistance with navigation, promoting, tracking, education, and monitoring etc. However, since the number of these studies is relatively limited, it is rather challenging to find adequate academic work that offers a comprehensive picture of how such technology supports the concerned group's wellbeing. As Table 4.8-1 notes, there is a dearth of studies that focus specifically on those with DS; rather, conclusions have to be drawn from the insights offered on other or general cognitive disabilities like autism, dementia, schizophrenia, or cognitive impairment. The heterogeneity in types of patients limits the ability to draw concrete conclusions. Furthermore, the studies conducted are also rather new, taking place over the last decade. This means there is not a great amount of depth in this area of study, as most studies are still in their pilot stage. Not enough time has elapsed to evaluate the after-effects or the long-term consequences of the projects, neither has there been substantial time allotted to conducting these projects to allow for concrete conclusions to be drawn from them.

Additionally, there is significant variation in the data collection methods of these studies, which can be a major determinant in how research findings are shaped. A range of methods have been used, including literature reviews, observations, interviews, and focus groups. The overall research design was also not homogenous, as it varied from case studies to literature reviews. This constrains generalisability since the findings may not be replicated if different research used different methodologies.

Furthermore, a range of different technological software and devices were used as tools for the studies. This shows promise about the range of technology that can be applied to assist those with cognitive impairment. While this again makes the interventions quite dissimilar, there was a high coherence in the usage of some applications or tools; for example, a large number of those used GPS (6 studies) and smartphones or mobile phones (15 studies), while some were very specific needs-based tools developed for the programme only, such as WSI-GO, HATLE, MANGO, an image-based mobile food record application (mFR), and a mobile app for shopping list in CASA + system.

4.9.1.2 Knowledge gap

Several studies have been conducted on individuals with impaired cognitive abilities and the ways in which their independence could be enhanced through several support provisions in areas like navigation, communication, prompters for everyday functions, and medical monitoring and tracking. However, there is a lack of studies which focus specifically on individuals with DS, and on the context of performing daily activities independently and meeting their personal needs. Hence, it becomes difficult to conclude the extent to which assistive technologies effectively aid in the lives of these individuals. Hence, there is further room to explore and add to the knowledge regarding which specific areas of everyday life for those with DS can be aided by making use of assistive technology, and how technology can offer such support. There is also room to investigate the implications of the use of technology for different age groups with DS. Obtaining further knowledge about how technological dependence impacts the lives of those with DS will help in the further development of such technology and improve the living conditions of not only those with DS but also their caregivers and family.

Further studies would be beneficial which focus on the use of technology segregating different types of cognitive disabilities (as attempted by Dawe (M Dawe 2006)), that incorporate not only the individual having DS but other stakeholders as well. Although, Augusto et al. proposed an advanced environment building system through the User-Centred Software Development Process (UC-SDP), there is still a dearth of research and tools available in the field of software development routines for constructing and employing intelligent conditions (Augusto et al. 2016, 2018). Further nuanced research is also desirable that focuses on a specific age group, especially the young adults, to assess their employability and condition needs further, in order to incorporate this information into a system design.

4.9.2 Strengths and limitations

Research has shown how individuals with DS experience a range of barriers due to their disabilities related to cognition and intellect, and that these can get worse with time. These conditions make it difficult for such people to undertake everyday chores and routine activities and can affect their ability to socialise with other people in their communities. In this regard, their independence would be enhanced if technology like smartphones or smartwatches, GPS, sensor-based systems, or automated monitoring systems can provide technological assistance in performing day to day functions.

4.10 Conclusion of Scoping Literature Review (Cycle 1)

This study attempted to explore which areas in the everyday life of someone with DS require technological assistance and what kinds of existing technological assistance are available. In exploring these areas, the study formulated two questions related to how to find out the common issues present in everyday lives of those living with DS: firstly, where technology can support them, and secondly, the type of technologies available for such support. The study adopted a scoping review methodology, which conducts an extensive literature review by establishing a set of inclusion and exclusion criteria, a search strategy, and study selection, data extraction and synthesis, in order to reach the major themes. The findings of this study have revealed those areas where young adults with DS have been supported with technologies, which include prompting and reminders for daily routine activities, in navigating and communicating, and with monitoring and tracking health conditions. To serve these purposes, several technological advancements have been developed, including the following: automated prompters to provide prompts for daily activities; wearable technology and mobile devices to aid with navigation and communication both in and outdoors; and computerised systems to track and monitor health conditions along with sensors to provide alerts, that simultaneously produce essential data needed for health analysis. Through this, the study concludes there are several aspects in the everyday life of someone with DS where technology can play an essential assistive role and improve the living conditions of both the subject and the caregivers/parents in the context of the independent activities. Though this study revealed several areas that affect daily activities of living where modern technologies can be used to provide support, it still remains unknown which areas currently need the most support, what technologies should be used for and by people with DS in everyday life and the overall impact of technology. There is a need for further investigation through field study involving people with DS. However, at the same time, it is important to remain aware of the limitations of technology and not be overly reliant on the devices and software, as these can be prone to errors or failures. Nonetheless, rapid technological advancements will mean further ways in which technology can play a role in the lives of individuals with disabilities.

Chapter 5

Cycle 1, (part 2) Identifying Current Barriers of Independent Activities and the Potential of Smart Devices for People with Down's Syndrome: An Exploratory Cycle.

5.1 Introduction

This chapter represents the first cycle of PAR methodology in two parts aimed to explore the contextual understanding of the research. In order to demonstrate contextual understanding, it is required and important to recognise the current barriers to performing daily living activities for young adults with DS. Also, it is required to reveal the current usage pattern of technologies and smart devices by young adults with DS on a daily basis. An initial exploration of current barriers to performing daily activities for young adults with DS is represented in the first part of this cycle through semi-structured interviews (see section 5.2). In the second part of this cycle current technology usage by young adults with DS for supporting barriers to performing daily activities of living and other purposes is explored through an online survey (see section 5.3). Also, the technology used by parents and caregivers to support their young adults with DS is represented.

The exploration for both parts of the cycle revealed deep insights of difficulties performing daily living activities for young adults with DS, and difficulties providing support by their parents and caregivers. Also, it revealed use of technology and smart devices, plus their potential and limitation for delivering support.

5.2 Exploring Current Barriers to Performing Daily Activities of Living for People with Down’s Syndrome.

In this exploratory study, the primary purpose was to understand the current challenges and impediments to performing daily life activities for people with DS. Additionally, this study was interested in how people with DS and their caregivers perceive mobile and wearable technologies and how technologies could help with performing those activities. In the participatory design process, caregivers are one of the main sources of information (Johnson and Lamontagne 1993) as they regularly provide support to people with cognitive disability when performing daily life activities (Lee, Knafl, and Van Riper 2021). Participants with DS were involved during subsequent cycles of the research to ensure their voices were heard as recommended by the participatory design approach.

5.2.1 Interview method

In this initial stage of this research, the plan was to conduct focus group discussions with parents and caregivers of young adults with DS. Parents and caregivers are closely attached to people with DS’s daily life, supporting them in making the most crucial decisions in everyday life activities (Krell et al. 2021). Parents and caregivers always prioritise the health and well-being of people with DS. Such as providing support for language learning, delivering speech therapy, helping to gain new skills etc. Parents and caregivers often make decisions for medical treatment, such as hearing tests, eye tests, blood tests or heart tests (Delgado-Lobete et al. 2021; Krell et al. 2021). In this initial stage, understanding parents’ and caregivers’ experiences would be comprehensive for this research rather than directly approaching people with DS. Therefore, focus group discussions with the parents and caregivers in this initial stage can ensure achieving significant outcomes in understanding current challenges and barriers to performing daily activities by young adults with DS. The focus group study was designed and then distributed through Down's Syndrome Scotland (DSS, a charity organisation).

Although, the target was to conduct at least 4-5 focus groups. Unfortunately, we only received five responses, leaving us no choice but to conduct one focus group. Three days before the focus group discussion was supposed to be conducted, three participants informed us not to be able to join due to personal circumstances, and they were asking for an alternative date. Therefore, only two participants were left for the group discussion, which led to conducting semi-structured interviews by making necessary modifications to the focus group format. No changes were made to the discussion topics/questions. Later, those three participants who could not join the focus group were invited for semi-structured interviews, and one did not join the interview. PAR allows semi-structured interviews, a research method widely used in social science. The semi-structured interview method is open and supports new ideas to be brought up and explored during the interview (Gratton 2020).

The results of this chapter are based on one group discussion with two parents and two semi-structured interviews with a further two parents of young adults with DS (see Table 5.2-1). Participants were recruited through Down's Syndrome Scotland[1]. Initially, we attempted to capture requirements through focus groups with parents and caregivers. However, it was difficult to arrange a suitable time for all participants to attend the focus group at the same time as parents and caregivers were simply too busy with their daily commitments, therefore, making individual appointments instead was more convenient.

5.2.1.1 Interview ethics

First, a department ethics approval (University of Strathclyde, CIS ethics approval ID: 592) was obtained for the group discussion and later modified, the group

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[1] https://www.dsscotland.org.uk

discussion format into semi-structured interviews. A consent form was made to get the participants' approval for the interview, the gathering of anonymous data, and the audio recording of the interview.

A summary of the investigation, including the purpose and aims of the study, what participants will be required to do, how participants will be involved, and the possible benefits and risks of taking part, were explained in the participants' information sheet. The process of the interviews and tasks with timetables to be followed during the interview were mentioned in the participants' information sheet. A description of how the collected data will be stored, such as using the university's cloud database with password protection. Personal identity anonymisation process, for example, removing participants' names (if any) and words that indicate personal identity from the transcription of audio-recorded interviews. The collected data will be used in the publication, and the thesis was mentioned in the participants' information sheet.

An interview guideline was submitted with the ethics application, which includes the interview process, questions for participants, who will be the interviewer and who will be taking notes (by the author) during the interview. The departmental ethics form included discussions of the data analysis techniques (qualitative data analysis) and possible results.

5.2.1.2 Procedure

One group discussion with two mothers took place in a city-centre university office and two via telephone at the participants' request. A participant information form about the interview questions and procedures were given to parents before the interviews took place. The author and first supervisor conducted the first joint interview with two participants (see Table 5.2-1, parents ID C1 and C2) at a university office and took 55 minutes. The reason for taking a joint interview was that they were invited to the focus group discussion at the beginning. We did not change the date and time for the group discussion but changed the discussion format to semi-structured interviews. However, no dominant voice or voice is overlapping noticed. The other two interviews (parents ID: C3 and C4) were conducted via telephone and took 25-30 minutes each. All interviews contained the same questions and a short presentation of smart technologies (for phone interviews the presentation and an online video link were given to participants prior to the interviews). Two main questions were asked, Q1. *What are the main barriers to independent activities in <city> for a young adult with Down's syndrome?* Q2. *How could smart devices (smartphones, smartwatches or smart clothing) and apps help people with DS to perform independent activities*?

Table 5.2-1: Caregivers Demographics (C=Caregiver, M=male and F=Female).

Interview IDs	Parents IDs	Parents Gender	DS's Gender
1	C1, C2	F, F	M, M
2	C3	F	M
3	C4	F	F

5.2.1.3 Participants

Participants were aged between 51-54 years and were all mothers of individuals with DS who have provided full-time care support to people with DS for more than 15 years. The average age of young adults with DS was 22.5 years with mild cognitive disabilities.

5.2.1.4 Data analysis

The thematic analysis method considers explorative studies and supports inductive studies without having an explicit knowledge of the patterns to be discovered. Therefore, adopting the thematic analysis method would benefit this exploratory study's data analysis. All interviews were audio-recorded, transcribed verbatim by a third party then qualitatively analysed using thematic analysis (Braun and Clarke 2006). This process involved familiarising myself with the interview data, coding and searching the text to identify themes within the data, and then reviewing and confirming the final themes following the process of Braun and Clarke.

Familiarisation with the interview data: in the beginning, the audio recording of the interview has listened, and then the interview transcript was carefully read and re-read until I became intimately familiar with the data. ***Coding the interview data***: the data coding started by highlighting relevant words, sentences or paragraphs using different colours and labelling them using the comment tool in a word document. The purpose was to generate a set of pithy labels of relevant and important concepts or interests within the data focused on the research question. After then, the codes were collated into groups and relevant data extracts to gain a brief overview of the main points and common meaning. The coding was conducted inductively without using a predefined set of codes. ***Searching for themes:*** once the coding was completed, all related codes were condensed into single categories by reassembling and recognising these categories to form tentative themes based on their properties and dimensions. At this stage, some codes were discarded that were too vague and irrelevant according to the research question. ***Reviewing themes***: these tentative themes were then reviewed and ordered appropriately to confirm the final themes. At this stage, final themes were compared against interview data to ensure relation to both extracted codes and the full data set. Also, ensured that the themes reflect true representations of the data.

Furthermore, an additional researcher (Dr Mateusz Dubiel, a researcher in conversation agents and speech synthesis from the same department as the second coder) reviewed the interview transcripts, independently coded them to identify themes and then met with the author to agree on the final themes. The differences between the two coders were in the first two themes. The first coder resolved this by creating one theme called “care supports”, which then split into two separate themes of “personal security and safety” and “communication” (see Figure 5.2-1) after discussions with the second coder Dr Mateusz Dubiel. ***Defining***

and naming themes: later, these themes were discussed with Dr Mark Dunlop (1st supervisor) and Dr Marilyn Lennon (2nd supervisor) and confirmed how the final themes and names of the themes fit into the overall story and easy understanding of the data. ***Writing up:*** all themes were described in the finding section, including how often the themes were repeated, their meaning with participants' quotations from the data as evidence, and how the research questions were answered.

5.2.2 Interview results – six key barriers to independent activities (themes)

The interviews resulted in the identification of six key barriers to independent living activities (Figure 5.2-1 Figure 5.2-1); each of these barriers are discussed briefly here along with supporting quotes from caregivers listed in Table 5.2-1. Parents/Caregivers are referred as "C" with their ID when quoted.

5.2.2.1 Theme 1: Security and safety

Security and safety in both indoor and outdoor conditions were one of the main barriers for people with DS. All parents expressed their desire that their sons/daughters be able to go outdoors on their own. However, parents raised the issues of lack of security and safety. C1 stated concern about the vulnerability of her son that caused fear about the safety of outdoor conditions as she always has to be with her son when her son meets his friends in the town centre. Similarly, C3 expressed her desire that as a mother she wants her son to be independent, and to be able to travel alone to the town centre for shopping. However, she also raised concerns about the vulnerability of her son that led her to worry about his security and safety outdoors. Furthermore, people with DS are often not considered safe to do certain activities at home without supervision from parents, as they sometimes have difficulties understanding the unsafe activities and are unable to recognize hazardous situations. For example, C2 raised concern about a lack of understanding of hazardous activities in the kitchen.

> C3: "*Because as a parent, I very much want him to be out and about. I want him to be as independent as possible. I certainly want him to be safe and secure, but there are situations in… City Centre that I would be concerned about.*"

> C2: "*There was one time I had jumped in the shower, I came out and Bob had the frying pan on full, so although he can do things he thought he would do something different but would have no understanding of how hot, how high or how dangerous… I think with his little sandwich making and toast making, that's absolutely fine. But, there wouldn't be the ability to understand danger and understand heat, just anything that hadn't been taught, he wouldn't get.*"

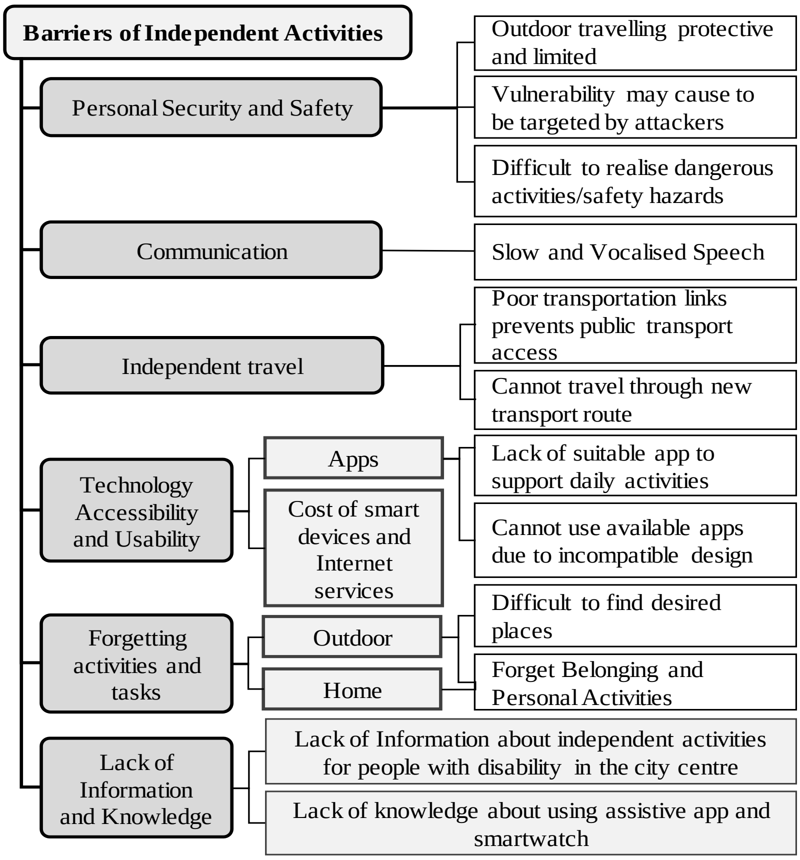


Figure 5.2-1: Categorisation of barriers to independent activities.

5.2.2.2 Theme 2: Communication

All parents specified that poor communication ability when outdoors was also a barrier to performing independent activity for people with DS. C1, C2, and C3 stated that their sons/daughters have speech difficulties and are unable to communicate successfully with someone new. Similarly, all parents stated that phone calls and text messages were the main ways to keep contact with each other when the individual with DS was outside or alone at home. The main purpose of communication was to ensure safety and check their location when going to school or on their way back home.

> C3: "*He speaks. Sometimes not fully clearly, so it would maybe take you a bit of time to tune into him. But, he is verbal and he vocalizes.*"
>
> C4: "*I always call her [my daughter] or she will call me, you know, just to make sure she arrived at school safely.*"

Likewise, failure of communication can cause serious concern to both caregivers and people with DS when neither of them are able to communicate with each other. Due to concern about communication failure parents stated that this leads to limits on independent activities.

5.2.2.3 Theme 3: Independent travel

All participants expressed the desire that their sons/daughters become an independent traveller and that they believe that increased independent travel would make significant changes to their son'/daughters' daily life. However, participants raised concerns about vulnerability in remembering and decision-making, which were perceived barriers to independent travel for their sons/daughters. A strong concern raised by all participants was that their sons/daughters are only able to travel through known and established routes. C4 stated her daughter was not able to follow unknown routes except between home and school.

> C4: "*She can't travel independently, no. She can't find a new route, even incredibly easy. She can't do that on her own. She's very reluctant …*"

> C3: "*Follow transport road is a real difficulty. There is somebody needs to help to get into the correct bus and on the way coming home he does one independent journey at the moment, it's only one journey and way coming home, because we have to cross a very busy main road we actually have somebody meet him on there he gets off to help him in crossing the road and gets into correct bus*."

Consequently, self-travelling was reported to be quite challenging through new routes with public transport. All participants showed high concern when more than one form of transit is required while travelling by bus or train. C3 stated that travelling by bus with many transits was challenging for her son.

5.2.2.4 Theme 4: Technology accessibility and usability

The parents specified that lack of suitable apps and cost of both smart devices and internet/mobile-data service restricts potential mobile support for daily independent activities. C4 expressed her concern that there were no suitable apps she found that specifically designed to aid her daughter's in daily activities. C4 also used a tracking app to know her daughter's location but even after practice, her daughter had difficulties due to the poor design quality of the app. Similarly, C1 tried a GPS location tracking app for her son, but faced many technical hitches e.g. updating location information was not quick enough and drained the smartphone's battery while using GPS the service. C1 had also tried an AAC app to teach communication but found that it was difficult to use for her son due to low sound quality and poor interface design.

> C4: "*That's where mobile technology appears. We've got Life360 [tracking app], which means that she takes her phone and we're able to follow progress on the iPhone, so we can see where she is at. But, from her [her daughter] point of view, she got problems to use it, as it appears with lots of information together*."

Parents also reported that motor skills could be a barrier for accessing smart devices. C3 stated her concern that the screen size of devices were too small as were the size of the buttons/tabs of any app. Parents sometimes restricted access to smart devices because of the high cost of the devices, apps and internet services. C3 and C4 stated the cost of devices and internet services as barriers to technology access.

> C3: "*The only thing I would say is manual dexterity. Particularly for people with Down's Syndrome, their fingers tend to be a bit podgier. Manual dexterity, particularly fine motor control, can be an issue. So, if it's very, very small taps on the smartwatch, that can actually be a barrier to them successfully managing to use the technology*."
>
> C4: "*We are quite wary of expanding too much of her use of a phone because then she's going to use a lot of data. In that respect, we've not allowed her to search the internet on her phone because we don't want her not realizing she's not in a Wi-Fi area and then starting using data left, right and center and therefore costing an awful lot of money*" (most young people in this study were using pay-as-you-go packages with limited included data and high costs for extra data).

5.2.2.5 Theme 5: Remembering activities or tasks

Participants reported forgetting activities and managing particular tasks as key barriers to independent activity. C3 stated that forgetting about belongings was not uncommon for her son. Furthermore, doing something that involved multiple steps was not possible for her son on his own. Likewise, C2 reported that her son has the issue of remembering to perform any particular activity with multiple tasks e.g. in baking or cooking something with multiple steps.

> C3: “*Probably the big issue is personal belongings. Remembering to take the right things, not leaving things. He regularly loses his wallet and leaves things on buses”. “Yes. … that’s something we very much encourage in him in terms of his independent living. To be able to put on his own washing, … to be able to cook his dinner. But there is usually somebody there to support him as he is doing that. May need to remind him of the steps that he following”*
>
> C2: “*But, in the kitchen, that’s probably as much as he’d do, make a sandwich, he would just do it from beginning to end. Whether that’s because it’s quite a short spell, and because each step is quite short, I’m not sure, but he would stay focused on that. But cooking or baking something like a cake, he cannot stay focused on*”

5.2.2.6 Theme 6: Lack of information and knowledge

Gaps in knowledge and information were found to be a barrier to independent activity as all participants reported a lack of knowledge using modern smart devices/apps that are available on the market. All of them stated that they do not know much about assistive apps and smartwatch usage, and they were not sure how such devices could support a person with DS. All participants except C4 mentioned that they cannot find information about any independent activities that are available in <anonymous> city centre for people with disabilities. C2 expressed her lack of knowledge about activities in <city> that are accessible for her son. Similarly, C3 mentioned that there is a lack of resources for her son in <city>.

> C3: *"I would say, are lack of resources. Whether those resources are physical space, or places to go where people would be supported, or even financial resources, or clubs. There is particularly a distinct lack of social clubs for people with disabilities*."

> C2: "*At the moment we don't know of any activities in <city> that he would go to. A lack of knowledge of activities that are in <city>, I suppose, would be something because we don't know or have any support to take him to some. Him being able to access what's available to see if it's something we'd like to… To know what's out there. I think it's lack of knowledge and how to access*."

5.2.3 Individual comments

A few individual comments were not formed into themes but were still significant to this research. These individual comments are described below.

5.2.3.1 Parents' Fear and Desire

All participants were mothers of young adults with DS and most of them started revolving their whole lives around their sons'/daughters' needs since birth. Also, parents stated that it is a burden for them to assist and monitor 24 hours a day, as their sons/daughters are young enough to take care of themselves. Though there are family members available to help them, most of the time they need to care for their sons/daughters by themselves.

C1 stated that her 22 years old son depends on her support to travel the city or visit friends and do most daily activities unlike other young adults, and she does not feel that is fair for her either for her son. C2 said that her greatest desire would be for her son to be able to look after himself properly without anyone's help. Unlike other children who grow normally, she stated that her son would need continuous inspiration, both physical and emotional, to ensure he reached his potential and more importantly being as independent of his parents as possible. C3 was very concerned about her son’s vulnerability and learning disability. As a mother, she likes her son to be independent and autonomous at outdoor with safety and security. Noted:

> C3 “*Is there anything you can do to minimise the vulnerability of the person of learning disability. Because, as a parent I wanted him to be as independent as possible.*

All of them are expressed their greatest hope that their sons/daughters could be capable of living very independently.

5.2.3.2 Money Handling

Cash handling is a challenging issue for a person with DS elevated by C1 and C4 as a barrier to independent activity. C1 stated her worries about handling money as her son is able to buy things from shops but cannot work out with changes (money) and at the same time easily can become a target. Similarly, C4 contributor revealed her views about money handling applications to the as her daughter cannot handle money herself especially change and counting.

5.2.4 Continued exploration.

The outcomes of this exploratory study were substantial in terms of understanding barriers to independent activities. However, a few limitations of this study create boundaries to deciding the correct route for further investigations. First, the number of participants in this study and their opinion was insufficient to determine which barriers should be investigated further. Second, one of the purposes of this study was to reveal current devices and apps used in order to support daily independent activities for young adults with DS. Unfortunately, the outcome revealed only a few devices and apps, which were insufficient to conclude the overall usage routine and how to reduce barriers to independent activities for young adults with DS. Therefore, a follow-up study (see section 5.3) was conducted to determine which barrier needs to be investigated further and to reveal suitable technology/devices for overcoming the barriers with sufficient numbers of participants involved. The detailed discussion for this part of the cycle discussion in section 5.4.

5.3 Survey Into Improving Support for People with DS Using Smartphone and Smart-watch Technology.

Previous studies (see sections 4.8 and 5.2) have provided valuable insights into the barriers that prevent individuals with DS from engaging in independent activities, including limited access to technology. First, the findings from the scoping review (see section 4.8) revealed factors that prevent or limit the performance of daily activities, including access to technology and its usage by individuals with DS. The scoping review provided a noteworthy understanding of the existence of barriers to performing daily activities and the technology used to deliver support. Second, the results of the interview (an initial stage of this thesis) revealed six key barriers to independent activities that impede the ability of individuals with DS to engage in independent activities (see section 5.2). The interview results aided in gaining an understanding of the current barriers to independent activities by individuals with DS. However, neither study fully assisted in considering a further study on a particular barrier to independent activities, and participant numbers were limited due to practical constraints. Nor did it provide an understanding of the current usage patterns of smart devices and apps to support daily activities for young adults with DS. Nevertheless. Some participants replied via mail that they could not travel to Glasgow as it was not close to their location. To address these gaps, the author designed and distributed an online survey to parents/caregivers and individuals with Down Syndrome, which enabled greater participation and allowed for the involvement of young adults with DS. This survey aimed to explore the usage of smart devices and apps for daily activities and to gain a more comprehensive understanding of the difficulties faced by young adults with DS.

Implementation of survey questionaries: the survey questionnaires were developed meticulously by taking into account the results of interviews and the examination of relevant literature, with a specific emphasis on addressing the research questions. It is worth noting that this study extends the scope of a previous study. The survey questionaries mainly focused on the usage of devices and apps to perform activities along the barriers. For example, questions in section 5.3.2.2, statements in the response alternatives for the use of smart devices (e.g. smartphone, iPad/Tablets, Smartwatch and AAC technologies) considered from both interviews (see section 5.2.2.4, theme 4) and literature review results (see section 4.8.3). Statements in the response alternatives in section 5.3.2.3 for the usage purposes of the smart devices are considered mostly from interview results such as “tracking and monitoring location”, “helping in communication while outside” (talking with people, phone calls and texts) and “reminding tasks or activities” (see section 5.2.2, theme 2 – 5). Although, these usage purposes of the smart devices were revealed in the literature review (see section 4.8.2). Questions in sections 5.3.2.4 and 5.3.2.5 were developed by considering the literature review (see section 4.8.3) for the purpose of revealing apps, features and devices used by young adults with DS. These questions were not restricted with response alternatives in order to provide complete freedom in the responses. To design the statement of response alternative for the question in section 5.3.2.6 was considered the result of interviews. For example, “High cost for device or app”, “cannot find appropriate apps/devices”, and “unsure if the apps are suitable” these response alternatives considered from interview results (see section 5.2.2.4, Theme 4). Similarly, the interview results that were related to lack of information and knowledge (see section 5.2.2.6, Theme 6) for performing activities considered in developing the response alternatives of question to usage barriers. Such as “lack of knowledge about assistive apps and devices”, “require training to use apps”, and “apps do not have features according to user’s needs”. Although, these issues were revealed in the literature review results (see section 4.8.2). The question in section 5.3.2.7 was developed by considering all themes of the interview results, particularly theme 3 and this question was supported by the literature review results (see section 4.8.2). The statement for response alternatives in this question was not considered in order to provide complete freedom to collect opinions from participants. Also, the question in section 5.3.2.8 was developed by giving complete freedom to respond without the option for response alternatives and based on the literature review results (see section 4.8.3). Also, this question was supported by overall interview results, including parents’ fear and desire (see section 5.2.3.1). Question 5.3.2.9 was developed from both interviews and the literature review results. Also, the response alternative, such as “learning independently” was considered from the literature reviews’ results (see section 4.8.2.1). The statement of response alternatives “living/doing daily activities independently” (see section 4.8.2.2) and “travelling independently” (see section 4.8.2.2) were considered from both interview and literature review results.

5.3.1 Survey method

In order to involve young adults with Down’s Syndrome in the survey, a meeting was arranged with the manager of Down’s Syndrome Scotland (DSS). During the meeting, it was discovered that DSS does not have a comprehensive direct contact list for young adults with DS, but they do have access to contact lists of parents and caregivers. Therefore, a single survey was designed with two parts: one for young adults with DS (with assistance from their parents or guardians if necessary), and one for parents and caregivers to complete. Additionally, sending the survey directly to parents and caregivers' contact lists ensures that the maximum number of young adults with DS can participate.

5.3.1.1 Survey accessibility and its implementation

Accessibilities: the survey was designed using the Qualtrics tool and ensured to meet accessibility standards towards WCAG 2.0 AA (Patch, Spellman, and Wahlbin 2015; Caldwell et al. 2008; Whiting 2019). Qualtrics provides a range of features for adjusting contrast, color schemes, font and text size, and screen size, including a responsive interface that makes it easy to read. The tool also includes large box-style buttons, highlighting of content with colors, and the separation of content using blocks to ensure easy accessibility, page navigation, and understanding of the survey content for participants with disabilities. In addition, Qualtrics has data protection policy and implemented measures to ensure that its users' data is secure and protected. For example: encryption techniques, access control, compliance (GDPR), backup and recovery, data deletion and privacy policy.

The author took the necessary measures to ensure that participants with DS and their caregivers could easily access the survey. First, the survey was separated into two sections, one for participants with DS and the other for parents and caregivers. The questions were presented in a clear block format, with a font size of 18px and bold to ensure visibility. A Qualtries theme was used, which included a progress bar at the top of the screen to help users track their progress. Second, box-style buttons were used for all response options in multiple-choice questions, with a clear separation between each statement. The Qualtries theme allowed statements to be highlighted with different colors when selected, which helped users with low visibility and dexterity. Third, an email was sent to parents and caregivers during survey distribution, requesting their assistance in completing the survey and understanding the questionnaires. This provided support to address any potential accessibility issues for young adults with DS. It was deemed practical and fair to ask parents and caregivers to help participants with DS in completing the survey, given that it was distributed through their contact list.

Overall, these measures helped ensure that the survey was accessible and user-friendly for participants with DS and their caregivers.

Implementation: to begin the survey, a page with an introduction and a consent form was included. Participants were not required to answer all questions and were free to skip any questions they wished. The email sent during the distribution and the participant's information form provided details on any restrictions or requirements for participation.

The survey questions were created based on the results of the literature review (see section 4.8) and interviews (see section 5.2). The questions were divided into two subsections. The first subsection consisted of two primary questions for young adults with DS. Q1 asked about the devices and apps they use, and Q2 asked about the purposes for which they use those devices and apps. Both questions were close-ended multiple choice questions with a list of items in the statement of response alternative. However, since people with DS may use other devices and apps not listed in the above questions, a third open-ended question was included where participants could list any other apps, features, devices and their usage.

The second subsection was for parents and caregivers, who were asked about their views on the potential of smart devices and technology to support independent activities for people with DS. The survey was created using Qualtrics tool (J. Feng et al. 2008) and included a combination of multiple-choice questions (with only one/many options to be checked), Likert scales, close-ended questions (each multiple-choice question included a text box as an 'other' option) and open-ended questions (see Appendix B: survey data.). Respondents were not asked for their origin (neither collected in Qualtrics) to maintain anonymity. The survey was limited to those who do not support individuals with DS with mild intellectual disability.

5.3.1.2 Survey ethics

A department ethics approval (University of Strathclyde, CIS ethics approval ID: 619) was obtained for this survey before the distribution. The design of the survey, its questionaries (provided the survey distribute link), anonymous participation (never asked for any identity, name or address) and anonymous data collection (ensured by disabling the IP tracing feature in Qualtrics tool) were maintained accordingly. Safe data management of the collected data (Qualtrics database with secure access), how the collected data will be analysed and used for the publication and in the thesis, all these were discussed in the ethics application.

5.3.1.3 Survey distribution

One of the aims was to ensure a sufficient number of participants involved in this survey. Therefore, the DSS distributed the survey throughout Scotland to ensure maximum participation. At first, young adults with DS were the main target participants for the survey and the survey questions were designed accordingly. However, after an initial discussion with Down's Syndrome Scotland (DSS), the survey questions had to change and considered both people with DS and their parents as the target participants. According to DSS, they do not have a sufficient direct contact list of people with DS, but they have their parents and caregivers, as most parents do not allow their sons/daughters to be contacted directly due to safety. Thus, the survey was distributed throughout the contact list of parents and caregivers to ensure a maximum number of participants with DS involved. DSS used two channels for distributing the survey, the email contact list of parents and caregivers and the DSS website.

5.3.1.4 Data analysis

The data analysis of this survey data was conducted using the Qualtrics tool and Excel spreadsheet. Statistical analysis was conducted for the descriptive results and visualisation of the study data, e.g. population, activities, and devices using the Qualtrics tool. Cross-tabulations were reported to illustrate the number of responses for each item used and visualised them using the Qualtrics tool. Also, data from the ‘other’ option (each multiple-choice question included a text box as an ‘other’ option) and data from open-ended questions were collected as words and phrases in an Excel spreadsheet and analysed by conducting a content analysis. In step 1, words and phrases were read several times to increase familiarity and labelled with keywords (code) according to the context of the words or phrases. In step 2, all keywords were grouped accordingly in a column and created a list. Each key words labelled with a key letter (e.g. “C” for communication) for easy categorisation and frequency analysis. Step 3, all similar/related keywords were categorised using key letters and eventually formed into themes based on their relationship. Step 4 conducted a frequency analysis of each theme (used Excel functions) using key letters (labelled in step 2). In step 5, themes from all questions, along with counted frequency then visualised in column charts using the Excel tool (Johnson and Lamontagne 1993). Consequently, a numerical analysis was conducted (for example see Figure 5.3-6) for descriptive results.

5.3.2 Survey results

5.3.2.1 Participants

The survey consisted of a total of 39 respondents who participated in both subsections. The first subsection was designed for young adults with Down’s Syndrome, and all 39 respondents who participated fell within this category. The second subsection consisted of 39 parents and caregivers who provided support to individuals with DS. Of these, 32 were family members (mostly parents), 3 were clinicians, 2 were caregivers from charity organizations, 1 was from an education centre, and 1 was from public health service. All caregivers were from Scotland and provided support to at least one individual with DS. 28 caregivers had provided support in a home setting for over 15 years, while the remaining caregivers had provided support for between 0 and 2 years. The majority of the caregivers (27, mainly parents) supported a single individual, while two professional caregivers supported fewer than 10 individuals, and one clinician supported more than 10 individuals annually. Approximately 44% of responders supported individuals with DS aged between 21-30 years, 24% between 31-40 years, 24% between 10-20 years, 4% between 41-50 years, and 4% less than 9 years old.

5.3.2.2 Usage patterns of smart devices by people with Down's Syndrome

It is important to understand usage patterns and current levels of technological support in order to know what types of smart technologies and devices are currently being used by people with DS in their daily life activities.

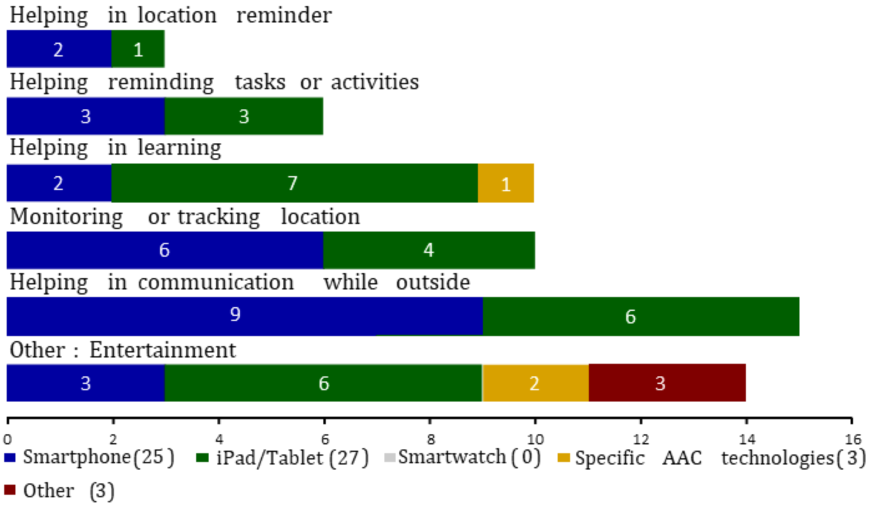


Figure 5.3-1: Usage of smart devices and supported activities with smart devices by young adults with DS. Note: Some of the participants reported using multiple devices; hence, the 'total responses count' was 56 despite a total of 39 young adults being counted.

Figure 5.3-1 illustrates the result of the survey in which young adults with DS were asked about their regular use of smart devices that are currently being used to support daily living activities. The findings from the survey unveiled iPads/tablets as the most frequently used smart device followed by smartphones. Three responses included other devices (radio and camera). Additionally, only three responses (out of fifty-eight) counted on the usage of Augmentative and Alternative Communication (AAC) technologies to reduce verbal communication difficulties.

Since iPads/tablets and smartphones are the most popular smart devices, and it can be observed that the vast majority of young adults with DS used some kind of smart device to support their daily life activities, enabling their use to support daily life activities of people with DS.

5.3.2.3 Tasks and Activities Supported with Smart Devices for users with DS

To better understand device usage, young adults with DS were asked about what purposes these devices were used for. Figure 5.3-1 also shows the activities supported using those smart devices by young adults with DS. The result indicated that to 'retain communication with parents, caregivers and family members' was one of the main essential activities for people with DS while in outdoor conditions (15 responses), a topic also raised in the earlier study (Section 5.2.2.2). The activity of 'location reminder' (3 responses) and 'tasks/activity reminder' (6 responses) were quite the opposite with low responses, despite these activities being identified as relatively important to live independently according to literature. Subsequently, 'activities of learning' (10 responses) and 'monitoring/tracking location' (10 responses) were both found to be equally needed as the need for communication with users with DS was assisted by smart devices. Nevertheless, other activities (e.g. listening to music, watching films, looking for information through the internet and use of apps to motivate communication) that are not directly linked with independent activities were also raised (14 responses). It confirmed that the users with DS operate many different types of applications (e.g. Cbeebies, YouTube, Hangout, Keep Safe Scotland app, Spotify, Picture Exchange Communication System etc.) and smart devices. Overall, this finding indicates that the main context of smart device usage was supported in outdoor activities.

5.3.2.4 List of apps, features and devices used for providing support individuals with DS

An open-ended question asked respondents to list particular apps or services that either used by people with DS or their caregivers to support them. A total 27 responses were counted and listed in Table 5.3-1 below.

Table 5.3-1: Apps, features and devices are currently used by people with DS

Categories	**Name**	**Description**
Application	'Find my iPhone' (used by parents to locate their daughters' location using GPS tracker).	A cloud based service for iPhone users to find the phone location if the user lost the phone.
	Keep Safe Scotland.	An app for vulnerable people that list safe places across Scotland on maps and can help people plan routes.
	Life 360°.	An app for regular users for location sharing and tracking.
	Pictello App.	An iOS app for children with special needs. Create and share visual stories by adding your own pictures, videos and recordings.
	Proloquo2Go	An AAC app to support daily communication for adults, teens, and children.

	Special stories	App for children and older adults for an active learning experience by creating engaging social stories.
	Sibelius software (Used by a young adult with DS with the help of his parents and teacher).	Sibelius is a scorewriter software or music notation program used with a computer to create, edit, and print sheet music.
	Google Maps	A mapping service app that comes with some smartphones.
	WhatsApp, Facebook and Messenger and Google Hangout App.	Social communication apps used to connect with friends and family members.
	Audiobooks.	Audio recording of a textbook
	YouTube	A video-sharing and watching platform available as an app for smart devices.
	Music and Video app in smartphone.	These apps come with smartphones to play recorded audio and video.
Features	Phone call, SMS, Camera Alarm Clock for reminder	These are basic features in a smartphone.
Devices	Smartphones, iMac, iPad and iPod. Hearing aids over ear headphones. Doro phone. Interactive whiteboard. Desktop Personal Computer, Laptop	These are smart devices and other electronic devices.

The result revealed a number of different applications, phone features and different types of devices used by users with DS (some with the support from parents e.g., Sibelius software). The usage of most of these applications indicated to support for remote communication, location identification and entertainment. Some quotes are noted for instance.

> *“We use ‘Find my iPhone’ for tracking our son’s location when he is doing ‘independent travel’ (walking home from college or sports or catching a bus). We used to use a dedicated GPS tracker but the iPhone app is easier to use.”*
>
> *“Life 360 enables us to follow where Linda is at when she walks back from school and when she goes to some of her activities. I would like to investigate other apps that could help her.”*
>
> *“Our son is keen on music and we and his teachers use Sibelius software to make his printed music more readable for him (standard notation but large size and with coloured coded notes). His teachers use this for other pupils at the local special needs school as well (Down’s and other conditions).”*

Similarly, most of these devices and the usage of its features indicated support for education and activities. Quotes for instance:

> *“Doro phone, iPad and interactive whiteboard for learning games and activities”, “Clock for alarms for catching buses/getting ready to go out”.*

However, two devices (hearing aids and Doro Phone) listed in the survey results require further discussion as those are not commonly used devices and are not mentioned by many participants in this survey.

The responder stated the use of “hearing aids over-ear headphones”, but the participant did not mention any other reason to use such a device for the person with DS. It is an assumption that the person may have hearing difficulties along with DS. However, it was very substantial to know the use of such technology in this study, because similar technology may be considered in this study if it is required. Other valuable responses recorded were the use of Doro Phone, audiobooks, and an interactive whiteboard for learning and performing activities.

Doro phone is compatible with hearing aids and has loud and clear sound, large and separated keys with adjustable font size and a contact list with images and large display. Similarly, interactive whiteboard has a large touchscreen display. Audiobooks have recorded texts with high-quality sound. These technologies are suitable and useful for a person with reading and visual impairment along with DS. It is important to recognise these technologies for this study so that those technologies can be considered when designing an application for users with DS.

All other responses about usage of personal computers and laptops, iPads, and smartphones which lead this study one more step ahead as it leaves the evidence about how some users with DS can use apps on smart devices.

5.3.2.5 Additional apps and devices for individuals with DS

An open-ended question was asked to determine what other technologies are used by people with DS to support their daily life. This question was answered by participants and caregivers and a total of sixteen (*n*=16) responses to this question were counted. The result revealed individuals with DS desire technology and devices. There are smartphones, smartwatches, talking mats apps, robotic buddy, voice to text messaging with speech recognition technology, location tracking assistance with a robotic buddy, and smart home technology mentioned. It is truly substantial to know about participants' desire for technology and devices.

Talking mats apps use symbolic language instead of text to overcome communication barriers. Using speech recognition technology could reduce the typing difficulties and saving time but it might be challenging to recognise the voice of a person with DS. One of the participants talked about using a robotic buddy for location tracking and daily assistance. Also, smartphones or smartwatches can be used to perform different tasks and to track user location. Similarly, a participant talked about smart home technology though did not mention particular devices used. All these findings lead this study to step forward in its potential of using smart devices and technology.

5.3.2.6 Barriers to obtaining and using of smartphones and apps

Barriers to obtainment: in this close-ended question, a total of 40 responses (*n*=40) were counted from parents and caregivers describing barriers to obtaining smartphones and suitable apps (see Figure 5.3-2).

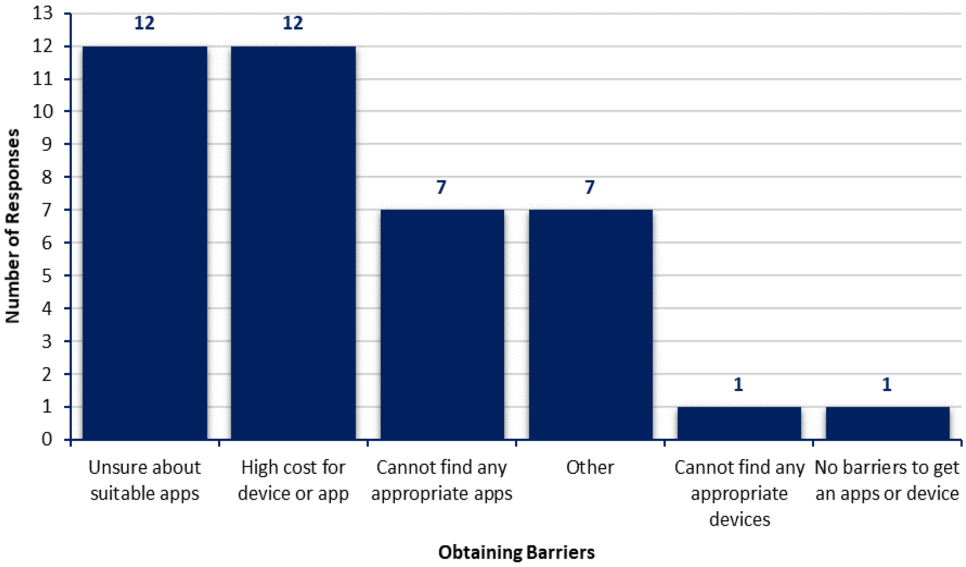


Figure 5.3-2: Barriers to obtain smartphone and apps

Two noteworthy key barriers recognised from the outcome for this question were a lack of knowledge and awareness among parents and caregivers about suitable apps for individuals with DS, and a shortage of apps in the market that could mitigate the needs of individuals with DS. As such, the result indicated that a large number of parents and caregivers (*n*=12) were not sure about the suitability of the apps for providing support to individuals with DS (see Figure 5.3-2). A few of them (*n*=7) stated that they did not find apps that are suitable for individuals with DS. On the other hand, this outcome indicates the availability of suitable devices in the market for supporting individuals with DS as only one respondent (*n*=1) described a lack of suitable devices. Moreover, the cost for devices and apps is truly high in the current market, which was reflected in 12 responses which also recognised cost as one of the key barriers to obtaining smart devices and apps for parents and caregivers.

Participants mentioned the lack of guidance about available apps to use, parents' concern about phones being lost and a lack of awareness also reflected from the "Other" text field, which was included in this question to allow respondents to record their opinions. A total of seven (*n*=7) responses were counted in the "Other" text field, and some of these quotes are noted below:

> "*Supporting appropriate use. Previous experience of contacting people inappropriately and continuously*"
> "*No one to recommend apps or to show you how to use them*"
> "*Would be huge help if bus companies had live tracking of busses so he would know when the next bus was due*"
> "*Their ability to use 'normal' apps. I haven't researched to see if there are any apps specifically for people with special needs.*"

Nevertheless, only one participant (*n*=1) stated that no problem obtaining devices and apps to support individuals with DS.

Usage barriers: Figure 5.3-3 illustrates the responses to participants being asked about barriers to using assistive devices (smartphone) and apps by an individual with DS in the view of parents and caregivers (*n*=45). According to parents and caregivers, two key barriers to using assistive devices (e.g. smartphone) and apps were lack of knowledge (*n*=14) and lack of training (*n*=14). Also, as frustration is common in individuals with DS, the second-highest number of responses (*n*=9) indicated that apps must be user friendly and easy to use which might help to reduce frustration. Similarly, eight responses (*n*=8) indicated experiences of using a device or an app that did not have suitable features for the user's needs. Some of these usage barriers e.g. "*Lack of knowledge about assistive apps and devices*", "*apps do not have features according to users need*" are similar to obtained barriers illustrated in Figure 5.3-2.

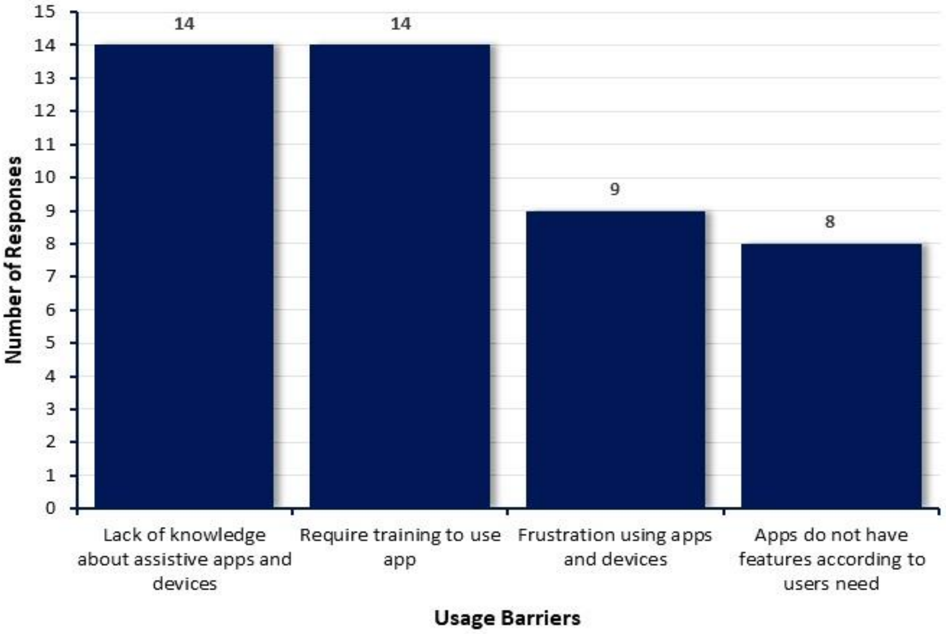


Figure 5.3-3: A close-ended question was asked to parents and caregivers to reveal barriers to the use of apps and smartphones by individuals with DS

5.3.2.7 Barriers to performing independent activities

Parents and caregivers were asked to mention possible barriers that could be faced by individuals with DS when going to school, vising friends in a town centre or performing an activity independently in a city like Glasgow using a smartphone app (see Figure 5.3-4).

Training, practice and support: the results indicated that individuals with DS require intensive training in order to use smartphones apps, as 12 responses (*n*=12) talked about training, practices and support needed before starting to use an app (this could be any app suitable to provide support for performing activities) in a real-life environment. According to parents and caregivers, users with DS require training for understanding, as well as practicing as many times as possible to acquire knowledge and gain confidence before using a particular app.

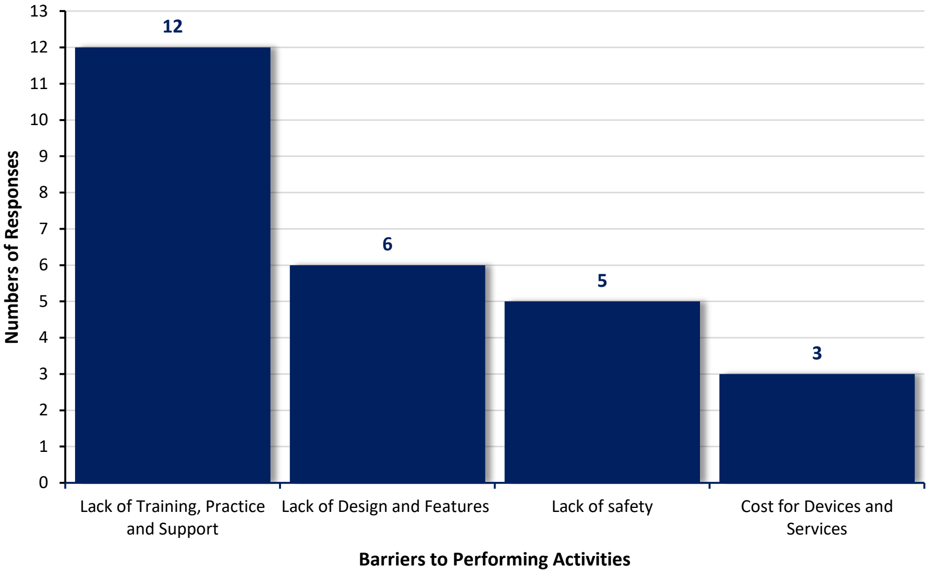


Figure 5.3-4: This was an open-ended question for parents and caregivers regarding barriers to performing independent activities for individuals with DS. All responses (n=26) were analysed by coding and categorized into themes.

Also, due to their (users with DS) disabilities they may require additional support when performing tasks. Respondents noted:

> *"Lots of intensive training and opportunity to practice", "Understanding of the app" "Difficulty understanding the App",*

Designs and features: this finding revealed that accessibility issues due to lack of suitable design and features in apps used to support people with DS were recognised as a key barrier to performing activities. The second highest number of responses (*n*=6) were obtained about app accessibility issues due to dexterity, motor control, visual difficulty, and cognitive limitation for users with DS. A few quotes are noted:

> *"Dexterity and fine movements, visual acuity, screen size, mental ability to understand them" "visual processing difficulties."*
> *"Their capability to read", "Often the user has a severe learning difficulty. So apps have to be easy to use and 100% reliable. Symbol not language based, control by simple choices, structured ordered input and output."*

Safety concern: the third-highest number of responses (*n*=5) revealed in safety issues for users with DS, namely that parents and caregivers were concerned about smartphones being stolen or targeted due to their hight cost. According to parents and caregivers, the safe use of smartphones was mentioned as a major concern while users with DS were outside the home. Also, according to their views, losing mobile signal, an inability to communicate or running out of credit while performing activities outside the home may put users with DS at risk. Quotes are noted:

> *"I suspect that a person with Down's Syndrome would be more vulnerable to phone thieves.", "running out of credit", "Not sure. Could be at risk of device being stolen if it's the latest model.", "inability to communicate."*
> *"We are worried that someone might try and steal [her] smartphone so we are reticent to let her take it with her everywhere."*

Cost: besides all this, the cost of the internet services and device was also pointed out by some of the participants as a key issue for performing activities using a smartphone (*n*=3). Also, a similar issue of high device cost was found in the previous section (see Figure 5.3-2). As such some quotes are noted:

> *"Lack of Wi-Fi in supported accommodation, high cost of devices."*
> *"We are also worried she will use online data and in the long run this could cost a lot."*

5.3.2.8 Parents' and caregivers' opinions on how technology could support individuals with DS to perform activities

The purpose was to know about parents' and caregivers' opinions on the use of technology that could support individuals with DS when performing independent activities in outdoor conditions. The total responses counted were *n*=27 out of 20 respondents (see Figure 5.3-5).

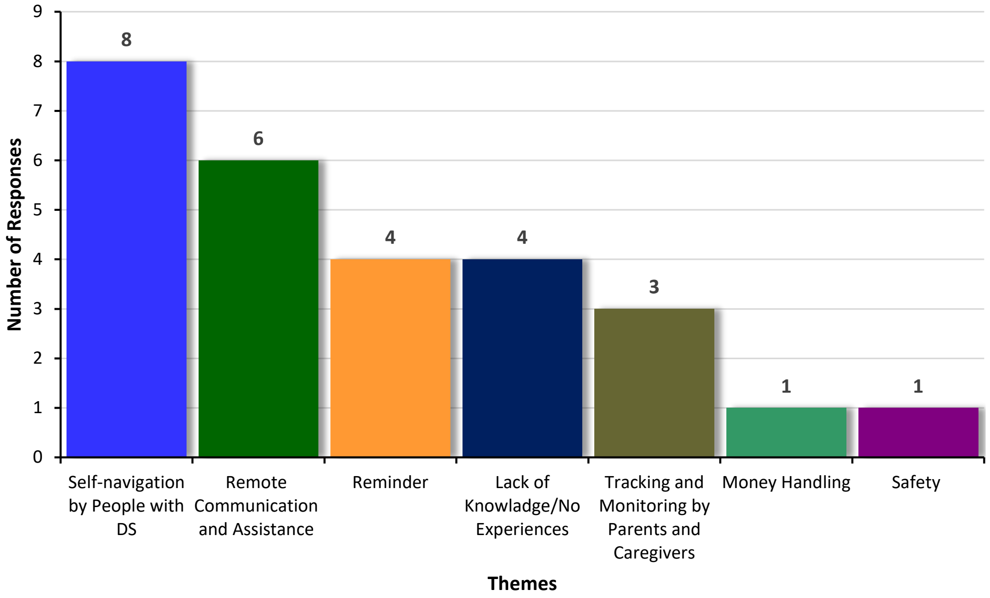


Figure 5.3-5: A graph of identified themes from responses to an open-ended question answered by parents and caregivers about how mobile and wearable technology like smartphones and smartwatches could help people with DS to perform independent activities around the city. All responses were analysed by coding and categorized into themes.

There are few themes that have been recognised based on responses from the participants. First, a maximal number of parents and caregivers (highest responses repeated 8 times) thought that smartphones and smartwatches could help individuals with DS to navigate using GPS sensors. Secondly, some of them (the second highest response, repeated 6 times) gave their opinion that the technology can provide support for remote communication and to deliver assistance by parents to individuals with DS when required. Thirdly, some of them (repeated 4 times) pointed out reminder facilities based on specific moment/tasks for individual with DS to assist in performing independent activities. Similarly, some of them mentioned that they do not have enough knowledge or experiences to recommend technology support. Also, the result indicated that the intention of the parents and caregivers was location tracking and monitoring (repeated 3 times) using these technologies for their sons/daughters with DS. Furthermore, only one response counted for each "*money handling*" and "*safety*" issues from the parents and caregivers. Some quotes listed below:

> "*Support them to do this safely as can be monitored from a distance. Can provide guidance if person gets lost*", "*Useful for location (GPS) and task reminders*", "*Independent travel; handling money; telling the time".*
> *"I think they would be really useful for those people who are competent to be out alone in the same respects as other people i.e. communication with family/carer, checking bus times, reminders and alerts for meals, time to go home, appointments.*"

5.3.2.9 Parents' and caregivers' views on three important independent activities

In this study, I intended to learn the perspectives of parents, caregivers and family members regarding three key independent activities where smart devices and apps could potentially provide assistive support to individuals with Down Syndrome. These activities were "Learning independently", "Living/Doing daily activities independently", and "Travelling/Shopping independently". The data presented in Figure 5.3-6, demonstrates that the median scores for these three activities were similar, with "Living/Doing daily activities independently" and "Travelling/Shopping independently" both receiving a median score of 6 (with an IQR of 2 and 1.5, respectively) and "Learning independently" receiving a median score of 5 (with an IQR of 2). The scores for all three activities fell within the same range, indicating that they were equally important to the participants. The majority of participants indicated a good degree of agreement by selecting "Agree" as their response. These findings suggest that these three activities are all significant areas where smart devices and apps could offer beneficial assistive support to individuals with Down Syndrome.

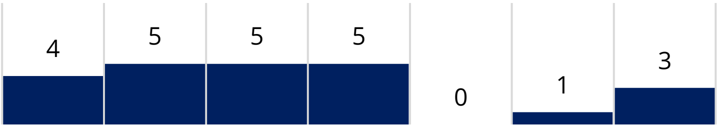
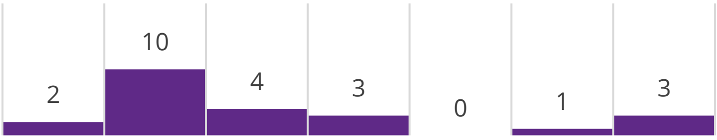
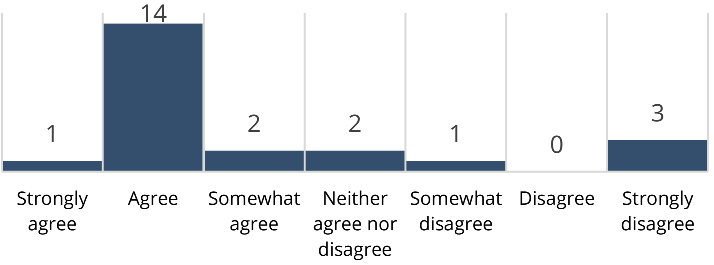
Activities	**Median**	**IQR**	**Parents'/caregivers' agreement of independent activities**
Learning independently	5	IQR=2	
Living/Doing daily activities independently	6	IQR=2	
Travelling/ Shopping independently	6	IQR=1.5	

Figure 5.3-6: parents'/caregivers' agreement of independent activities could be supported by apps and/or smartwatches. Responses were listed on a 7-point Likert scale. A total of 23 participants were counted. Activities included were learning independently (self-prompting studies and communication studies); living/doing daily activities independently (cooking/baking and washing up own clothes); travelling/shopping independently (self-navigating with or without using public transport).

5.4 Discussion: Cycle 1 – Interviews and Survey

The purpose of this exploratory cycle was to explore current challenges to performing daily activities and identify opportunities to support overcoming such challenges through the use of technology for young adults with DS. The outcome of cycle 1 is summarised and represented in a conceptual diagram (see Figure 5.4-1) below:

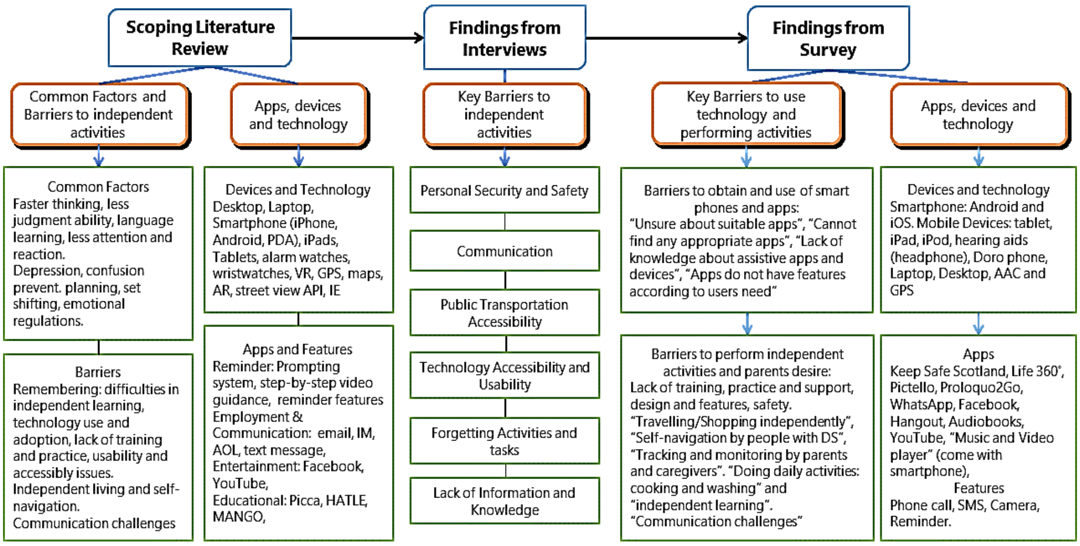


Figure 5.4-1: A conceptual diagram based on outcome of cycle 1

The findings from the interviews (section 5.2) pointed toward six key barriers that were common and affect the daily life of individuals with DS: (1) safe use of mobile devices and travel safety concerns, (2) communication difficulties, (3) inability for self-navigation and access to public transport (e.g. changing buses), (4) finding suitable technology that can support independent activities (5) difficulties remembering tasks/activities, (6) lacking knowledge and experiences about the current advancement of smart devices and technology. Such outcomes clearly indicated that there are challenges that exist when to performing daily activities for young adults with DS. Some of these findings were new and some were discussed in the literature. As such, the findings indicate that participants felt insecure about performing activities in outdoor conditions by people with DS that were not discussed in the related study of literature. Similarly, a failure to recognise hazards by people with DS was not directly discussed in the literature. Likewise, a lack of knowledge from parents and people with DS about new smart devices (smartwatches) and assistive apps (e.g., tracking and monitoring, activity supporting apps) was also not discussed directly in the literature.

Furthermore, a number of issues revealed from interviews (Section 5.2) and survey results (section 5.3) were discussed in the literature. The issue of safe use of mobile devices and concerns about travel safety were identified in previous research by Dawe and Vukovic et al. (Vukovic et al. 2016; M Dawe 2006). Similarly, communication difficulties due to speech intelligibility problems were identified in previous literature, i.e. (Balasuriya et al. 2018; Carroll et al. 2017; Chang, Chen, and Chou 2012; Tarakji et al. 2018). Likewise, the need to stay in touch with caregivers via phone calls was described by Carroll et al. Dawe; Lazar et al. and Carroll et al. (Lazar et al. 2018; Lazar, Kumin, and Feng 2011; Carroll et al. 2017; M Dawe 2006). Additionally, barriers to independent travel arising from difficulties in accessing public transport, an inability to take multiple type of transport and being unable to travel through a new route were other problems discussed by Davies et al., Kramer et al., Sitbon et al. and Sposaro et al. (Kramer, Covaci, and Augusto 2015; Sposaro, Danielson, and Tyson 2010; Davies et al. 2010; Sitbon and Farhin 2017). Finally, the obstacle of finding suitable technology to assist the needs of people with cognitive and intellectual deficits is not new, as similar issues were previously identified by LoPresti et al. and Dawe (LoPresti, Bodine, and Lewis 2008; M Dawe 2006). Such findings provide in-depth insights in relation to barriers to performing activities for young adults with DS and their implications on daily life. However, the findings from the interviews highlighted a few types of technology (smart devices and apps) along with barriers. It was not clear what other technologies are currently being used by people with DS and for what purpose. Therefore, a further study was required to gain deeper insights into technology use and how challenges of activities of daily living can be supported with suitable technology.

The survey results provided an initial usage pattern of smart devices (see Figure 5.3-1) for the daily routines of people with DS. The findings of the survey confirmed the expectations, as most of these smart devices were already identified in previous research (e.g. Dawe (M Dawe 2006) and Kramer et al. (Kramer, Covaci, and Augusto 2015)) and have the potential to support people with learning disabilities. Additionally, several activities that were also observed in previous research were revealed, e.g. reminder tasks/activity (Vukovic et al. 2016), learning (Janier et al. 2015), communication and entertainment (Lazar, Kumin, and Feng 2011). However, new aspects identified by the results include the usage of smart devices in outdoor conditions e.g. location tracking/reminder and communication were noteworthy in relation to performing independent activities along with parents' agreements (see Figure 5.3-5, Figure 5.3-6 and Figure 5.4-2).

A noteworthy result revealed in Table 5.3-1 is that the use of different types of apps for supporting individuals with DS strengthens the potential of using technology to provide support. Also, it indicated that some individuals with DS were familiar with smartphones' features like phone call, SMS, and camera, as well as being familiar with devices like computers, laptops, and Doro phones. It is worth considering the desired technology and devices listed in sections 5.3.2.2, 5.3.2.3 and 5.3.2.4. All those desired technologies and devices mentioned by the participants with DS lead towards one common smart device in terms of technological facilities, namely the smartphone (e.g. use of symbolic language, speech recognition, location tracking and calling feature), and a smartwatch could be a second potential device. However, the robotic buddy might not be feasible at this stage to provide assistance to a human with cognitive disabilities (such as an individual with DS) due to ethical issues and may cost a lot of money, which not everyone can afford.

Figure 5.4-2 illustrates the reflection, link and relation between interviews and survey results. The results of the survey highlighted some of the barriers to obtaining and using (see Figure 5.3-2, Figure 5.3-3 and Figure 5.3-4) the smart devices and apps for young adults with DS. These results reflected the findings from the interviews, such as: "*Unsure about suitable apps*", "*Cannot find any appropriate apps*" (see Figure 5.3-2), "*Lack of knowledge about assistive apps and devices*", and "*Apps do not have features according to users need*" (see Figure 5.3-3). "*Lack of design and features*" (see Figure 5.3-4) reflected two of the themes identified from the interviews, namely "Theme 4: Technology accessibility and usability" and "Theme 6: Lack of information and knowledge" (see section 5.2.2.4 and 5.2.2.6).

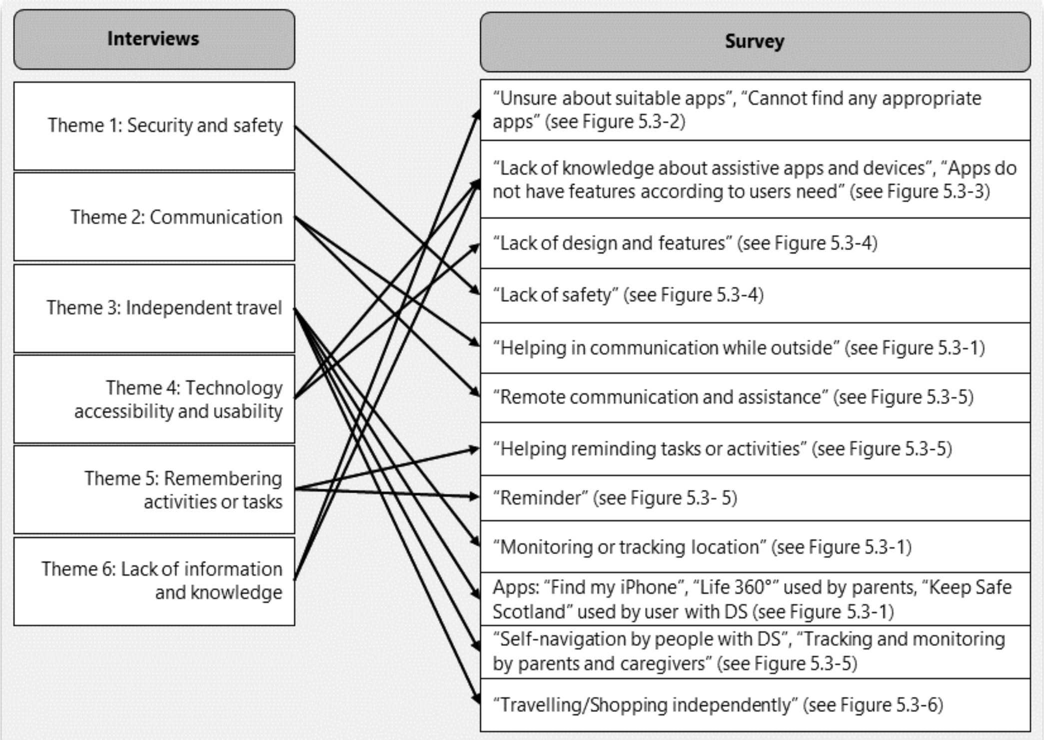


Figure 5.4-2: Reflection, link and relation between interviews and survey results.

Similarly, "*Lack of safety*" (see Figure 5.3-4) revealed in the survey can be linked with "Theme1: Security and safety" from the interviews (see section 5.2.2.1). Furthermore, the "Theme 2: Communication" can be linked to activities such as "*Helping in communication while outside*" (see Figure 5.3-1) and "*Remote Communication and assistance*" (see Figure 5.3-5) highlighted in the survey though the activity "*Helping in communication while outside*" was revealed as a purpose of using smart devices and the activity “*Remote Communication and Assistance*” was revealed from parents’ and caregivers’ opinions on technology usage when performing activities by young adults with DS, and not recognised as barriers to using devices/technology or performing activities. Also, “Theme 5: Remembering activities” (see section 5.2.2.5) from the interview results can be linked with one of the activities “*Helping reminding tasks or activities*” (see Figure 5.3-1) and the “*Reminder*” (see Figure 5.3-5) theme found in the survey, though this theme was not revealed to be a barrier to performing activities in the survey.

The activities revealed in the survey such as “Monitoring or tracking location” (see Figure 5.3-1) were the purpose of apps such as “Find my iPhone” and “Life 360°” used by parents, and “Keep Safe Scotland” used by people with DS (see Figure 5.3-1 and Table 5.3-1). Parents suggested that smart devices could possibly be used for “*Self-navigation by people with DS*”, “*Tracking and monitoring by parents and caregivers*” (see Figure 5.3-5) and “*Travelling/Shopping independently*” (see Figure 5.3-6) which are very much intended for outdoor activities performing by young adults with DS, which may not directly point toward barriers to travel but are close enough to link with “Theme 3: Independent travel” (see section 5.2.2.3).

Nevertheless, these reflections, links, relations and repetition (some of barriers and activities) between interviews and survey results disclosed the validity of findings from studies with a sufficient number of participants involving parents, caregivers and young adults with DS.

Furthermore, the survey outcome revealed that young adults with DS had some knowledge and user experience of operating smart devices like iPads/tablets and smartphones (see Figure 5.3-1 and Table 5.3-1). This was taken as a positive indication to do further research to overcome the barriers identified in this exploratory cycle to eventually enhance independence and quality of life for people with DS. Overall, the findings revealed a link to outdoor activities, such as safety, and security concerns when performing outdoor activities, verbal communication problems, and difficulties in finding desired places were related to outdoor activities among six barriers explored from the interview outcomes.

Similarly, the outcomes from the survey included "*Helping in communication while outside*" and "*monitoring/tracking location*" (see Figure 5.3-1), as well as parents' and caregivers' opinions in "*Self-navigation by people with DS*", "*Remote communication and assistance*" and "*Tracking and monitoring by parents and caregivers*" (see Figure 5.3-5). "*Travelling/shopping independently*" (see Figure 5.3-6) was also related to outdoor activities. Findings revealed that smart devices were recognised to have a strong potential to overcome barriers to independent travel by young adults with DS and their caregivers. Furthermore, the usage of smart devices (smartphones) to provide support in outdoor conditions by parents (see section 5.2.2.4) and the second-highest smartphone usage by people with DS revealed in the survey (see Figure 5.3-1), indicated that young adults with DS and their parents have positive experiences of smartphone usage.

5.5 Considering Independent Travel as a Gap.

Cycle 1 (part 1 and part 2) of the study produced significant findings that expanded the scope of the research on barriers to independent travel. The outcome of the interviews conducted in part 1 identified six key barriers to performing independent activities, all of which were linked to both indoor and outdoor environments. While parents and family members may find it easy to provide support for indoor activities, they may not be available or able to support outdoor activities. For instance, parents found it challenging to provide walking navigation support to their young adults while they travelled to college. Therefore, it may be beneficial to focus on activities related to independent outdoor activities to benefit both parents and young adults with DS. In this regard, independent travel could be a viable option to consider.

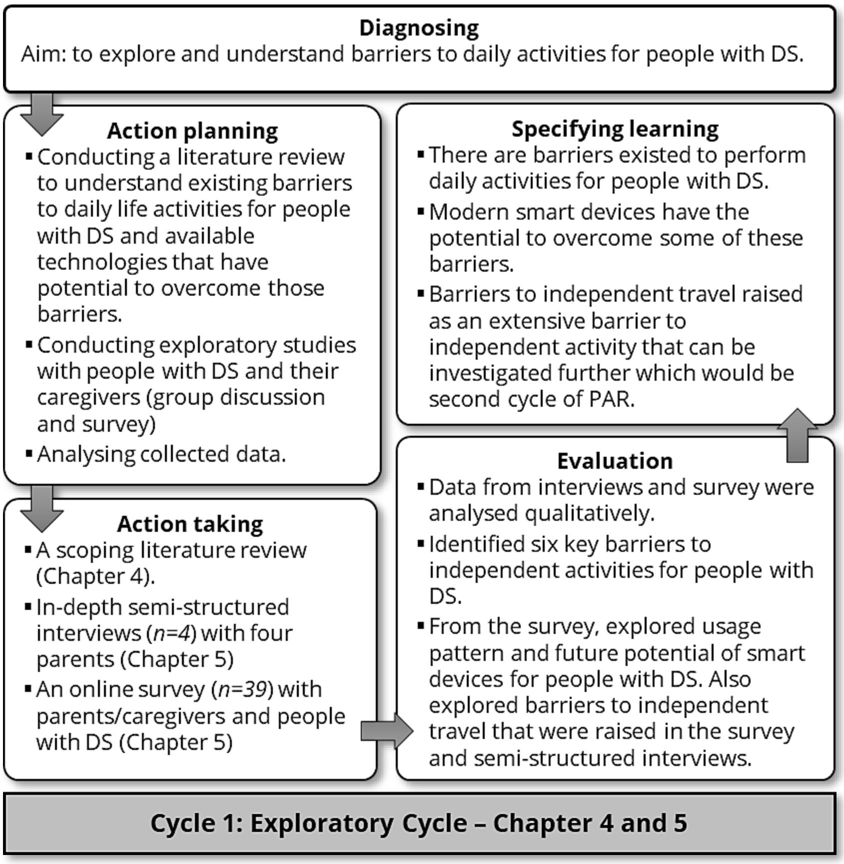
The second main outcome of the study, which was based on the survey (part 2), showed that outdoor activities like travelling/shopping independently, using navigation and monitoring apps, and outdoor communication support were crucial to young adults with DS and their parents. These findings were in line with the outcomes of the interviews, which also highlighted the importance of outdoor activities. As a result, the survey results provide strong support for the study's continued investigation into the barriers to independent travel.

Thirdly, the choice of further study on barriers to independent travel is supported by the available literature (see sections 4.8.2.2 and 4.8.2.3). Such as independent living, self-navigation and communication challenges were revealed as existing barriers to independent activities from the scoping literature review, which usually relate to barriers to performing independent travel (Augusto et al. 2018; Lazar et al. 2018; Kramer, Covaci, and Augusto 2015; Covaci et al. 2015; Melissa Dawe 2007; J. H. Feng et al. 2010). Fourth, I believe that by considering barriers to independent travel for further study, it is possible to eliminate certain levels of communication, remembering tasks, usability and accessibility challenges associated with travel (outdoor) for young adults with DS. Therefore, these triangulated outcomes of literature reviews, interviews and survey results, and the personal desire can be considered a sensible and realistic decision to study further barriers to independent travel.

5.6 Conclusion of Exploratory Cycle 1

This first cycle of the process was about understanding the context and exploring initial barriers to performing daily activities through three stages of enquiry process and initial analysis of them. The previous chapter (Chapter 4) presented the initial exploratory enquiry through examining existing literature by targeting the general specificities of the context. This chapter described a more focused investigation targeting current barriers to performing daily activities for young adults with DS in order to gain in-depth understanding and inside exploration of the context. According to the findings, young adults with DS were confident when performing independent activities, though barriers existed to performing an independent activity on their own. Smart devices and currently available technologies were found to have potential for overcoming such barriers.

Consequently, such findings partially answered RQ1 and RQ2. Also, this research completed the first cycle of PAR methodology, and the overall process with the findings of this first cycle was presented in the figure below (see Figure 5.6-1).



Diagnosing

Aim: to explore and understand barriers to daily activities for people with DS.

Action planning

- Conducting a literature review to understand existing barriers to daily life activities for people with DS and available technologies that have potential to overcome those barriers.
- Conducting exploratory studies with people with DS and their caregivers (group discussion and survey)
- Analysing collected data.

Action taking

- A scoping literature review (Chapter 4).
- In-depth semi-structured interviews (*n=4*) with four parents (Chapter 5)
- An online survey (*n=39*) with parents/caregivers and people with DS (Chapter 5)

Evaluation

- Data from interviews and survey were analysed qualitatively.
- Identified six key barriers to independent activities for people with DS.
- From the survey, explored usage pattern and future potential of smart devices for people with DS. Also explored barriers to independent travel that were raised in the survey and semi-structured interviews.

Specifying learning

- There are barriers existed to perform daily activities for people with DS.
- Modern smart devices have the potential to overcome some of these barriers.
- Barriers to independent travel raised as an extensive barrier to independent activity that can be investigated further which would be second cycle of PAR.

Cycle 1: Exploratory Cycle – Chapter 4 and 5

Figure 5.6-1: PAR Cycle 1, an initial exploration of barriers to independent activities and the potential of smart devices and technology.

The next chapter (Chapter 6) presents an in-depth exploration of barriers to independent travel and prototype generation to reduce this barrier to independent travel based on the outcome of this cycle (as shown in Chapter 4 and 5).

Chapter 6

Cycle 2, Co-Design and Prototype Generation to Support Barriers to Independent Travel: A Design-Based Home Exercise.

6.1 Introduction

This chapter presents the implementation of the second cycle of the PAR methodology, which aimed to investigate one of the barriers to independent activities – specifically, the obstacles faced by young adults with DS when travelling independently – and develop a solution to overcome them. The previous cycle (cycle 1), which investigated the barriers to independent activities in general, proved to be a convenient and successful approach for participants. The findings from cycle 1 revealed travelling difficulties as one of the common barriers to independent activities, which are linked to communication barriers for young adults with DS. Hence, it is crucial to investigate these travel barriers further and explore the possibility of overcoming them using smart devices and intelligent technologies. Nonetheless, the co-design sessions conducted during this cycle allowed for the exploration of barriers to independent travel, the identification of design requirements, and the creation of low-fidelity sketches or prototypes based on the participants’ inputs.

6.2 Impacts of Independent Travel for Young Adults with DS.

Normalisation principles (LaGrow, Wiener, and LaDuke 1990) and social inclusion (Abbott and McConkey 2016) demand independence and self-determination for people with disability. People with DS should be facilitated to be able to take part in the general economic system, be able to be part of the social setting and be able to live independently. All these abilities to facilitate could not be realised without achieving a satisfactory level of independence in travel. Numerous benefits are associated with independent travel for young adults with DS. Such as gaining access to school, work, medical, leisure or recreational centres and other destinations (LaGrow, Wiener, and LaDuke 1990; Abbott and McConkey 2016). The absence of independent travel skills among young adults with DS must rely on their parents or caregivers. But the achievement of minimum levels of independence in travel may ensure standard living in a community setting and can contribute to the world of work and attain economic benefits. The range of travel skills can be defined simply as walking from one place to another and returning using or without using one of the media, such as public transport (Slevin et al. 1998). But a complex set of skills may be required to obtain the use of public transportation. Therefore, independent travel skill is an essential independent activity for young adults with DS that can reinforce being more socially included, achieving employment and being more independent in life.

6.3 An Investigation into Barriers to Independent Travel and Develop Low-fidelity Sketching.

This study aimed to investigate barriers to independent travel for young adults with DS. The investigation intended to explore difficulties to navigate alone around the home, visiting friends or travelling to the town centre and access to public transport for a young adult with DS. Also, it aimed to build an understanding of how such difficulties can be overcome through discussions with participants with DS and their parents and caregivers. Additionally, the investigation focused on the current usage of smart devices and technologies by individuals with DS to support navigation in order to understand their potential of smart devices and technologies. This investigation involved the participant sketching their own design ideas along with requirements for an app to support the removal of barriers to independent travel through an additional drawing session.

6.3.1 Co-design method

Seven group discussions were held in the homes of young adults with DS, accompanied by their parents and caregivers. Participants were contacted through Down's Syndrome Scotland (DSS) mailing list and previous studies' contact lists. However, recruiting participants was challenging in the previous cycle, and traditional co-design workshops proved difficult to conduct. Hence, for this study, participants were recruited for home-based group discussions with parents and young adults with DS. Anonymity was maintained throughout the study, with substitute names used where necessary.

6.3.1.1 Procedure

At least one person with DS and both parents/caregivers were present during each group discussion, except for one interview with one person with DS and one caregiver. Full information about the group discussion and procedure was given to parents and family members beforehand and they were asked to explain the procedure to the young adult (see Appendix C: participant's consent form and information sheet). During the discussion with group 1 and group 7, parents and caregivers were requested to repeat some of the words or sentences that were not understood by the interviewer due to occasional problems with understanding the voice of some young people with DS.

Each discussion group was split into three sub-sessions (see Figure 6.3-1):

1. In the first sub-session, participants were asked to discuss current barriers and experiences to independent travelling with or without using public transport and the current usage of smart devices and apps to support independent travelling. Two questions were asked during this session, Q1: *"what are the main barriers to independent travel using public transport for a young adult with Down's Syndrome?"* and Q2: "*what are the main benefits and usability issues to use technology (smart devices and apps) for independent travelling?*" These questions were discussed separately with participants with DS, and their parents and caregivers. First, the questions were discussed with young adults with DS and after that these same questions were discussed with their parents and caregivers.

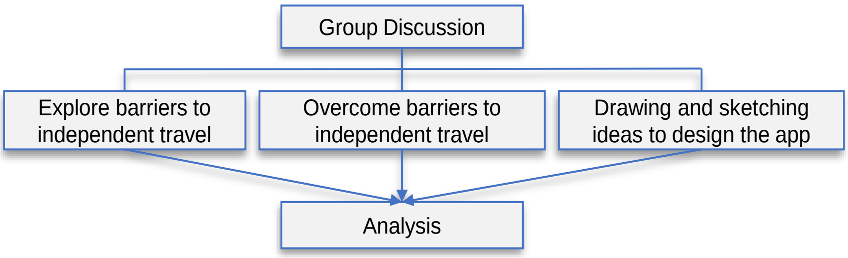


Figure 6.3-1: The study design process.

2. In the second sub-session, participants were asked to provide suggestions on how those barriers (discussed in the first sub-session) could be overcome with or without the use of smart devices and technology. One question was asked, Q3: "*how could the identified barriers from above (discussed in the first sub-session) could be overcome with or without using technology (e.g. smartwatches and smartphone apps)?*" This session was a joint discussion together with parents, caregivers, and their son/daughter with DS.
3. In the third sub-session, the interviewer briefly introduced routing and navigating technologies, apps and features. Participants were then engaged jointly in a short design session to sketch an interface of their

own ideas for an app to prototype. All sketches were drawn collaboratively by parents, caregivers, and their son/daughter with DS. Participants with DS were asked and confirmed by their parents/caregivers about the features that they want to include in the app or if they did not understand any feature drawn by parents/caregivers. All drawings and sketches were described by parents/caregivers at the end of the session.

Each session took about 90 – 110 minutes, and each sub-session took 30 – 35 minutes on average.

6.3.1.2 Ethics for co-design meetings

To ensure the safety and comfort of participants during co-design sessions, it was deemed ideal to conduct the sessions at their own homes or a location of their choice. In order to fulfil this requirement, the author underwent a criminal records check through Disclosure Scotland, which resulted in obtaining a basic disclosure report. This report was submitted to the first supervisor before commencing the co-design sessions. Additionally, departmental ethics approval (University of Strathclyde, CIS ethics approval ID: 465) was obtained to ensure the safety and participation of all involved.

To maintain the safety of young adults with DS according to the principles of co-design, parents were instructed not to leave them alone with the interviewer during the discussion. Furthermore, the confidentiality of participants was protected as outlined in their information sheet, which detailed secure data storage, data analysis processes, and the co-design process (see Appendix C: participant's consent form and information sheet.).

Before starting the session, the purpose of the research and co-design process were explained to ensure that the participants understood their involvement in the study. Consent forms were given to participants to read and sign, and they were introduced to smartphone and smartwatch technology through slide presentations, video clips, and graphs. To empower participants and provide equal opportunities, young adults with DS were given the chance to discuss their ideas at the beginning and afterwards with their parents. During the sketching session, participants were provided with A4 size blank papers, multi-colour brush pens, and a ruler to create their sketches.

6.3.1.3 Data analysis

Stage1, Transcription: all co-design discussions were audio-recorded with the consent of the participants. The audio recordings were transcribed verbatim by professional transcribers from a third-party company, and these transcripts were used for the framework analysis (Gale et al. 2013). ***Stage2, Familiarisation with the data:*** first, the author read the transcriptions several times and listened to the audio recordings at least once until he became intimately familiar with the data. During this process, I created notes of key ideas. I also highlighted (yellow colour) phrases in the transcripts that were deemed relevant to the research questions and appropriate for assisting with coding in the next stage. ***Stage3, Identifying thematic framework (Coding):*** an initial coding started with a line-by-line reading of the transcripts, highlighting relevant and appropriate words, sentences, and paragraphs using green colour. Labelled them by assigning appropriate code under the following format "[code]" in Microsoft word. Notes created in stage 2 were applied in this initial coding. The coding process was conducted inductively without using a predefined set of codes but focused on research questions. Also, a code file was created in a Microsoft spreadsheet, and all codes were transferred to the code file. After the initial coding, this process was repeated and added new codes to the code file, including comments to explain certain codes. This process was repeated until the interpretation of the data was achieved by the author. Furthermore, a second researcher (Dr Mateusz Dubiel) reviewed the transcripts and noted any codes that needed to be updated in the code file (Gale et al. 2013; Iliffe et al. 2015). ***Stage4, Developing and applying analytical framework (indexing):*** at this stage, the author and second

researcher resolved their discrepancies by comparing labels (codes) and updating the code file (in Microsoft spreadsheet). Both researchers then agreed on a set of codes and similar codes grouped into categories to form tentative themes that shared commonalities or consistencies. These tentative themes were then reviewed by both researchers, rearranged appropriately, and confirmed as final themes. ***Stage5, Charting data into the framework matrix:*** at this point, I used a spreadsheet to create a matrix table. The final themes, which included a structured summary of the obstacles faced by young adults with DS when traveling independently, as well as the preliminary requirements for developing an application, were charted into the matrix. To ensure an accurate representation of the relationship between the final themes and the interview data, the final themes were compared against the interview data. ***Stage6, Interpreting the data:*** all themes were represented graphically to show their relation to each other based on their priority, repetition and significance to the context. Also, it described all themes, how often they were repeated and their meaning with participants' quotations from the data as evidence in the finding section (Gale et al. 2013). I included a summary of only two groups in a table due to the large file (see Appendix H: the matrix table of framework analysis), and the full matrix table can be accessed/downloaded through this link:
"https://strathcloud.sharefile.eu/d-s80adb120d2534e14825c7177ccc633ee"

6.3.1.4 Participants

In total 20 people took part in the study, including seven individuals with DS across seven sessions. Thirteen parents and family members aged between 22-57 years (average age 49 years) were full-time caregivers who had provided support for more than 18 years except for one caregiver (who providing support for 4 years). For people with DS, the level of cognitive capabilities varied widely, and as such this thesis only considered individuals with mild cognitive disabilities. All individuals with DS (seven) were young adults (four females and three males), aged between 18-28 years, the average (mean) age of the group was 22.1 years. Participant demographics were listed in Table 6.3-1. One of the female participants (C6*) took part in Cycle 1.

*Table 6.3-1: Participants with DS' and caregivers'/parents' demographics (P=Young adults with DS, C=Caregivers and * = number of participation).*

Group IDs	DS's IDs	DS's Gender	Caregivers' IDs	Caregivers Gender
1	P1	F	C5, C6*	F, M
2	P2	M	C7, C8	M, F
3	P3	F	C9, C10	F, M
4	P4	F	C11, C12	F, M
5	P5	F	C13, C14	M, F
6	P6	M	C15, C16	M, F
7	P7	M	C17	M

6.4 Findings 1: Barriers to Independent Travel for Young Adults with DS

This section briefly describes the theme of key barriers to independent travel and the outcome from the group discussion on how to overcome these barriers. Figure 6.4-1 presents a summary of the themes and Table 6.5-1 presents the identified requirement's to design an app. Figure 6.5-1 and Figure 6.5-2 present representative sketches for designing an app that were drawn by parents and individuals with DS during the design session. The outcomes as described with participants' quotes listed in Table 6.3-1. "P" referred to young adults with DS and "C" referred to parents/caregivers/family members.

6.4.1 Unfamiliarity with route

One of the difficult activities for people with DS was navigating by foot when they were not familiar with the route e.g., finding new places after getting off a bus, walking to a shopping centre or transit and crossing the main road.

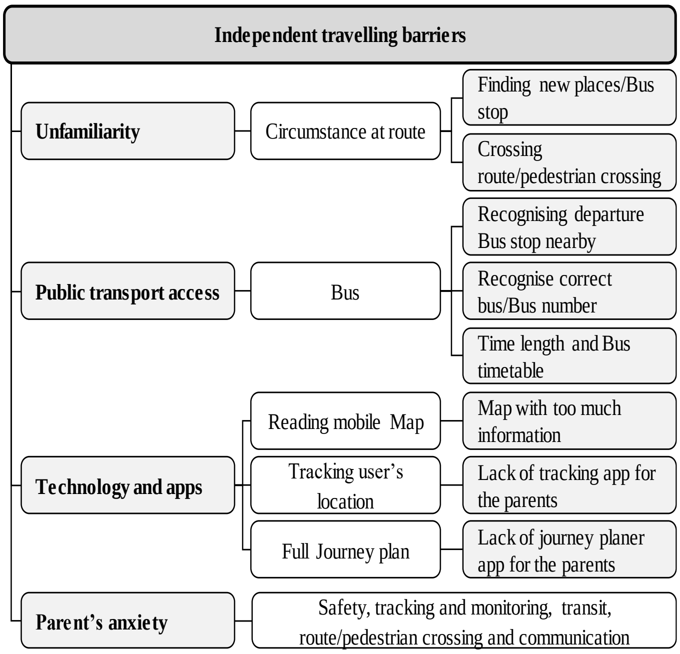


Figure 6.4-1: Barriers to independent travelling for people with DS.

All parents of participants expressed unfamiliarity with the route as a barrier to independent travel and that circumstances on the route could create an obstacle to independent moving. Consequently, a similar view was obtained from the discussion with group 4 that the unfamiliarity creates navigation complications for people with DS.

> P1 (Individual with DS): *"Well, when I went the bus to school, I got a bit lost because and I phoned mum and dad. They didn't answer me, so my dad phoned me back. He told me where am I, and then I told my dad, "I'm a bit lost,""*

> C9: “*It is very scripted, you know: ‘Goes to this bus stop. Gets this bus until this stop. Gets off.’ It is very scripted. And if one of those things is knocked off, like say, her walk. If that road is shut…she might not know just to go one street down… she would struggle with that unfamiliarity*.”

A concerning issue raised by group 5 was that unfamiliarity could cause a loss of confidence to travel alone by people with DS. Subsequently, crossing busy streets often required support while taking transit, walking home or to a bus stop and executing these tasks on an unfamiliar route become difficult for people with DS.

> P5 (individual with DS): “*When I first found out that my mum told me I had to do independent travel to college it made me feel scared*.”
> C14: “*Yes. You’ve then got to worry about the hazards on that road. If you’re doing one straight line and it crosses four other streets, you need to know that that’s a crossing so that you don’t just keep walking. Because I look at a map and it’s got four roads, I understand there’s a crossing there and there’s a crossing there and there’s a river there*.”

6.4.2 Public transport access

Public transport access was confirmed as one of the main barriers to independent moving for people with DS by all groups. Finding the nearest bus stop and recognising the correct location in urban or suburban areas were barriers to access public transport with repeated practice required to find the correct bus stop. Five participants of this study have been trained for one independent journey and had the ability to find the bus stop but raised concerns such as the bus stop moving due to roadworks.

> C9: “*Just the one thing, in town, there was loads of temporary bus stops which were not exactly where the closed bus stop was, they were maybe like 100 yards*

> *further down. That kind of thing can throw her off as well. .... Because she might just see the bus stop go past in the window and then be like, 'Oh, where...?'*"

Furthermore, C14 stated that her daughter required someone with her to recognize the bus stop. Recognizing the correct bus is also considered as a barrier to move independently for people with DS. Though, five participants with DS of this study practised recognizing the correct bus except for P4 and P7. However, according to them (those who were trained to recognise the bus stop), it is not always easy for a young adult with DS to easily identify the correct bus.

> C5: "*We regularly have people stopping at the bus stops to give you [individual with DS] lifts. People say, "I stopped and gave her a lift [helped to access the bus]." [but] she's trying to use the bus!*".

In addition, concerns were raised over understanding bus timetables, journey times and impact of weather for those living with DS. Group 3 described the difficulties of understanding time duration and group 2 described impacts due to weather conditions. Likewise, getting off the bus was identified as an issue for people with DS during the discussion. All groups discussed the issue of getting off the bus.

> C10: "*When she finishes early from college, she will walk to the bus stop and then I think she immediately phones me and says, "Where is the bus? The bus is not here." So, usually, I have to say, "It's okay. How long have you been there?" And she is not good with [time]... "Half an hour." Everything is half an hour".*
> P2 (Individual with DS): "*Last time when I was in a bus, I fell asleep by accident and I missed my stop.*"
> P2's parent C8: *"...I know how difficult it would be for John to get off the bus and explain to somebody what he was doing .... So that was a big issue, but fortunately the driver was able to get him back."*

6.4.3 Technology and apps

Lack of suitable technology and apps to support travelling was again raised as a barrier. Only one participant (P1) with DS used a mobile app called ‘Bus & Tram’ to recognise the bus number while travelling by bus. Although the app comes with the general map, the user cannot interpret it because too much information was displayed. Also, the app does not have the tracking feature for the parents, C5 stated that identifying locations using a map would be a useful feature as he often used the ‘Find My iPhone’ app to see his daughter’s location. He also mentioned an unexpected experience when his daughter lost the way back to home where he (C1.1) used the app (Find My iPhone) to identify her location.

> C5: “*I think if I didn’t know from the map [using Find My iPhone feature], I wouldn’t have known where she was*”.
> And C6: *“It’s quite easy to read, isn’t it? Because all that just says is a big bus number, which you know, and then it tells you whether it’s due [commented on ‘Bus& Tram’ app].”*

Due to reduced distance judgment and sense of direction, people with DS often struggle to identify their current location or identify how far they are from home (Covaci et al. 2015). C14 specified that technology should provide progress for every stage of the journey, which eventually will increase the confidence of parents to encourage self-travelling. Interpretation of mobile maps was found to be difficult for people with DS due to excessive information causing confusion and preventing navigation. Similarly, P3 claimed not to be a map user. Parents and caregivers had tried a number of apps with GPS sensor to support travelling by bus and to know the current location of the traveller, but none of them found any suitable app that actually met their needs. ‘Find My iPhone’, ‘Find My Friend’ and other bus apps were mentioned by participants.

> C13: "*Any technology, any additional information to know that she's got on the bus, arrived, got off, these would make a huge difference to our comfort and reduce the nervousness*".
>
> P1: "*No, I don't know how to use map".*
>
> P3: *"I don't use maps, not really".*
>
> P7: *"For me, it is too difficult. It didn't always pick the best journey."*
>
> And C11: *"Google Maps is probably a little bit too dense" "A bit more simplified, but the same basic thing might work for her."*

6.4.4 Parent's anxiety

All parents in the groups revealed that their fear was one of the main barriers to independent travel for people with DS. This fear intensified when any unwanted circumstance occurred during travel. As in the exploratory study (cycle 1), safety was a concern in public places raised by all participants and caregivers. People with DS can easily be targeted if, for example, they carried expensive phones, hence group 5 felt that wearable devices could improve safety on a journey.

> C8: "*I worry about him and his phone. I worry about people using a daily trip, recognizing that he's on his own, he's a bit vulnerable… Another time, he lost his wallet. There was some money in it, but also travel card, cinema card, lots of things to replace*."
>
> C13: "*Yes, continually, which is where the watch would be an advantage because you can wear it [smartwatch]. You've lost it, so there's that. Yes, absolutely, stolen because they are expensive, and they are a target."*

Likewise, parents and caregivers have expressed their views about losing an expensive smart device that can be caused that limit independent travel. Further, any unexpected circumstance on the route can create anxiety for parents. Also, those parents were concerned about the reliability of transport and transit.

> C14: "*We're just nervous of new circumstances." "As far as Bob concerned, I think the biggest problems will come when something goes wrong. When the bus doesn't turn up or when the bus breaks down halfway into town or something like that*."

6.5 Findings 2: Developing Low-Fidelity Sketching and Design Requirements to Overcome Barriers to Independent Travel.

Group discussions started with a discussion of the barriers to independent travel. This was followed up with a discussion of how these barriers could be overcome and identified several solutions to overcome such barriers from participants with DS and their parents/caregivers.

6.5.1 Notification and alert

All participants and their parents/caregivers talked about the importance of reminders and notifications before getting on and off buses, or any changes (e.g. due to road works) in the planned route of the journey (Sposaro, Danielson, and Tyson 2010; Ramos et al. 2014; Sitbon and Farhin 2017). It was revealed from the discussion with all groups that the notification and alert with vibrations to get the user's attention would be more convenient.

> C14: "*Sometimes they move the bus stops… so that's really useful if that information could be available, 'Your bus stop is not here today, it has moved.' 'Yes, get on the bus,' notification so that whoever is in charge of that day they know Amy's on the bus. Absolutely. Notification."*

6.5.2 Dealing with unforeseen circumstances

A key finding revealed was that dealing with unforeseen circumstances that can occur during the journey is often challenging for people with DS. Caregivers are required to intervene to deal with some circumstances that are impossible to navigate for young adults with DS. All young adults with DS (P1–P7) emphasised the importance of keeping contact with parents/caregivers when individuals with DS are unable to deal with a particular situation (Sposaro, Danielson, and Tyson 2010; Ramos et al. 2014; Kramer, Covaci, and Augusto 2015). Consequently, parents/caregivers and young adults with DS suggested a help button for emergency contact with instructions if something unusual occurs.

> P2 (Individual with DS): *"I always turn my iPhone, so then someone can contact me, maybe a carer or my parents or someone. If I get lost, I will probably call someone."*
>
> P4 (Individual with DS): *(I don't know, a quick dial to phone Mum or somebody to get help. So maybe if there was a shortcut button or something that she could just press, that phoned Mum straightaway. Again, if Mum's not answering, a back up, so that if it doesn't get you, it will go and try somebody else, kind of thing."*
>
> C9: *"Well, even maybe the option of if something could flash up to say, phone, … 'If you don't know what to do, phone Mum'." Or "Phone Alex", "Go into shop", "Go back to college," you know, just to remind her…"*

6.5.3 Smart map with voice assistance

All groups insisted that the information or instruction to support navigation should be easy and simple for users with DS. A simple journey plan that could be customisable from parents'/caregivers' phones was suggested by parents/caregivers.

> C16: "*You have every journey to pick up from. But if you were on another app that just showed her journey that she needs to get to college. So, for instance, if she could click "To college" or "From college to home" and then it loads a pre… like, That would be a pretty good way…".*

Parents and caregivers from all groups except group 2, suggested a voice navigator and assistance with a simplified version of the map. Group 5 (C13) discussed walking directions with voice instruction to support navigation (Kramer, Covaci, and Augusto 2015; Carroll et al. 2017; Balasuriya et al. 2018). Likewise, group 4 (C11) discussed text instructions with images together which could provide precise navigational support. Similarly, group 3 (C10) discussed voice output to assist the user to notify the current location.

> C13: "*Yes, talking instructions, "Walk forward, turn right, turn left," would certainly help or even just a larger display with an arrow, turn left, turn right*".
> C11: "*Yes, she can do directions no bother. If there was a voice or a visual, like a text thing came up on the screen the same way Google Maps has. Google Maps is probably a little bit too dense*".
> C10: "*If the smart technology knows where John is and is supposed to be, could the technology tell her where she is? You know, could it actually have voice output?"*

6.5.4 Summary of functions and features as design requirements to design and develop an app to support independent travelling

The requirement of function and features were summarised (see Table 6.5-1) from the group discussions and design sessions to design an app for smartphones. Most of these requirements were discussed in the literature, however, a few requirements were new in the context to support the travel barrier for people with DS. One novel requirement was a pop-up message that displayed the destination name (requirements ID: 5) which can be shown to the bus driver to get the right ticket for the journey. This will reduce the verbal communication barrier with the driver and who can confirm by reading the message that the person with DS got the right bus. Another requirement was to notify parents/caregivers about each step of the progress of the journey e.g. when he/she reached the bus stop, when he/she got on the bus, when he/she got off the bus and arrived at the arrival stop, and when he/she reached the final destination.

Table 6.5-1: The app features and requirements identified from group discussions to be included in travel support app for people with DS and their caregivers.

GROUP IDS	REQUIREMENTS	REFERENCES	IDS
1 – 7	The app should have two types of users: primary and secondary.	(Engler and Schulze 2017)	1
1 – 7	Full route plan should include walking directions.	(Covaci et al. 2015; Engler and Schulze 2017)	2
1, 3, 5, 6, 7	Route plan should be editable by parents, with the option to add pictures of landmarks.	(Covaci et al. 2015; Engler and Schulze 2017)	3
1, 2, 3, 4,	Show the bus stop’s picture when user is near the bus stop.	(Stock et al. 2013)	4
1 – 7	Notify user when the bus is near the departure stop and display a pop-up message with the destination name to show the driver to get the ticket.	(Stock et al. 2013)	5
1 – 7	Notify parent or caregiver when the user gets on the bus.	(Reis and Almeida 2016)	6
1 – 7	Notify a parent or a caregiver about user’s journey progress with details (location information).		7
1, 5	Notify user to get off at correct bus stop before arriving at destination stop.	(Stock et al. 2013; Davies et al. 2010)	8
1 – 7	Notification must be triggered to both user with DS and caregiver if a user with DS took wrong turn or missed a bus stop. Also, a help interface must display		9

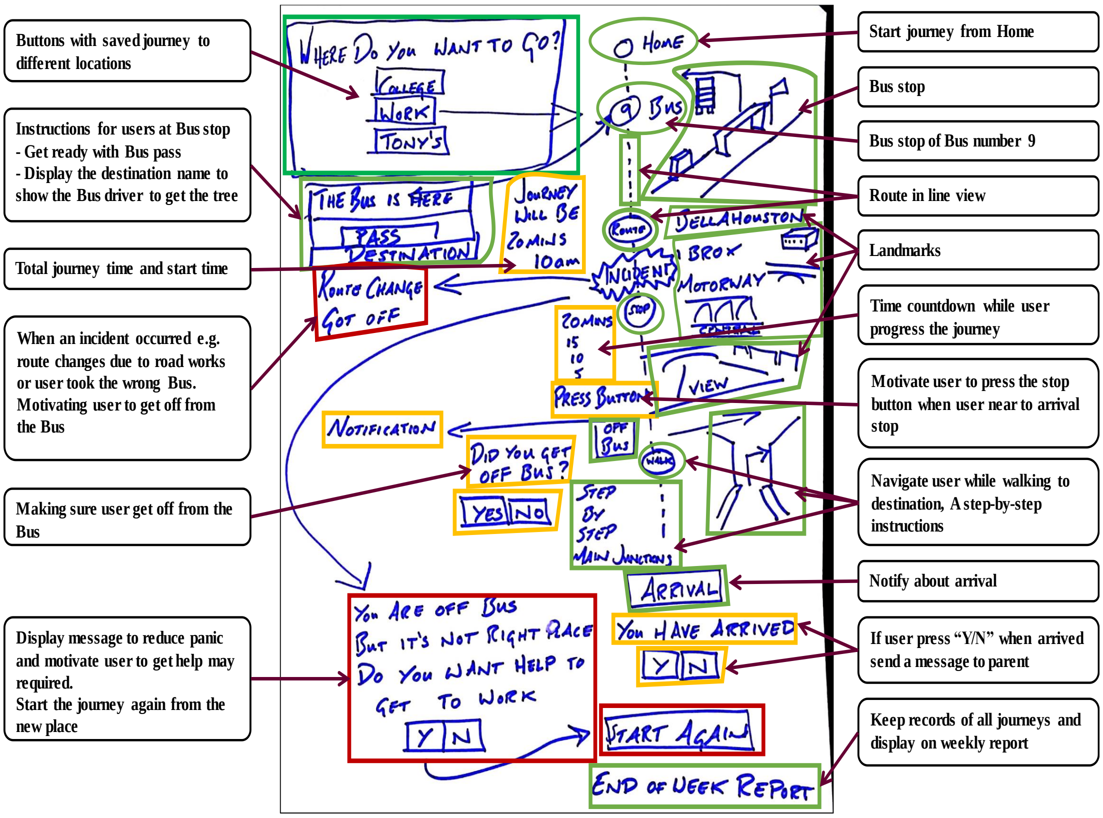
	simple instructions and a phone call option to communicate with the caregiver.		
1, 4, 5, 7	The progress bar should contain the full journey outline with the name of bus/train stops and progress of the journey.		10
1, 4, 5, 7	Icons/images of any superstore or landmark while the user is travelling by bus or train to increase the familiarity with the route	(Stock et al. 2013; Kramer, Covaci, and Augusto 2015; Farran et al. 2012; Lingwood et al. 2015)	11
1, 3, 4, 5, 6, 7	Textual navigation [20] with voice output to support the user to navigate while walking	(Carroll et al. 2017; Davies et al. 2010)	12
1, 6, 7	Save all journey plans in a list with appropriate names	(Engler and Schulze 2017)	13
1 – 7	Parents should be able to identify user's locations from their device when user with DS does not go in the right direction or gets lost on the way to the destination.	(Sposaro, Danielson, and Tyson 2010)	14

A continuous notification to parents/caregivers about each step of the journey progress (requirements ID: 7) could be included to reduce parents' anxiety and help to increase confidence in independent travel by public transport for people with DS. Notification triggering (part of requirement ID: 9) has been developed in many commercial navigation apps e.g. alerts when user is not in the right direction (Davies et al. 2010; Sposaro, Danielson, and Tyson 2010). However, dealing with any unforeseen circumstance during travel was a new requirement that requires a simple instruction to support such situations and an option for calling parents/caregivers immediately. The requirement ID:10 (linear bar) was not new, and these have been used in many commercial navigation apps, however, it is new for supporting people with DS. Also, the requirement ID:10 (linear bar) appears as a substitute to the traditional mobile map and may open a new door to support barrier to independent travel.

6.5.5 App prototype drawings

Sketches of front-end design requirements were collected from all groups. Parents, caregivers and participants with DS used drawing to demonstrate how to overcome the identified barriers and appropriate use of these features identified above (Table 6.5-1). All participants were given a minimum of five minutes to describe their sketch, and later these sketches were analysed along with recorded audio (Sturdee and Lindley 2019). Two representative sketches are described below. For the first sketch, P7 and his parents sketched together a linear map (Figure 6.5-1) of the full journey that included walking points and travel by public transport. This drawing illustrated all the steps of the journey, the messages displayed for the user when unexpected circumstances happen on the road and how to deal with them, as well as reminders of landmarks for increased familiarity and trigger notifications (e.g., get on and off the bus) to ensure a smooth journey. For the second sketch (Figure 6.5-2), P1 and her parents created a sketch of the full journey plan in a linear bar with GPS tracking ability for users with DS. Parents or caregivers must authorise any journey planned by users with DS before performing the journey. Every place name or name of bus stop and landmark would be highlighted with a circle in the bar. The progress of the journey is shown by changing the bar colour and notifying parents about the progress. A reminder should be triggered when the user is near any landmark or about to get off the bus to ensure a comfortable journey. A motivational message is also displayed for users after every completed journey.

Other sketches included suggested a home screen button and related information for users with DS. All sketches are available at Appendix D: sketches and drawings from participants.



Buttons with saved journey to different locations

Instructions for users at Bus stop
- Get ready with Bus pass
- Display the destination name to show the Bus driver to get the tree

Total journey time and start time

When an incident occurred e.g. route changes due to road works or user took the wrong Bus. Motivating user to get off from the Bus

Making sure user get off from the Bus

Display message to reduce panic and motivate user to get help may required.
Start the journey again from the new place

Start journey from Home

Bus stop

Bus stop of Bus number 9

Route in line view

Landmarks

Time countdown while user progress the journey

Motivate user to press the stop button when user near to arrival stop

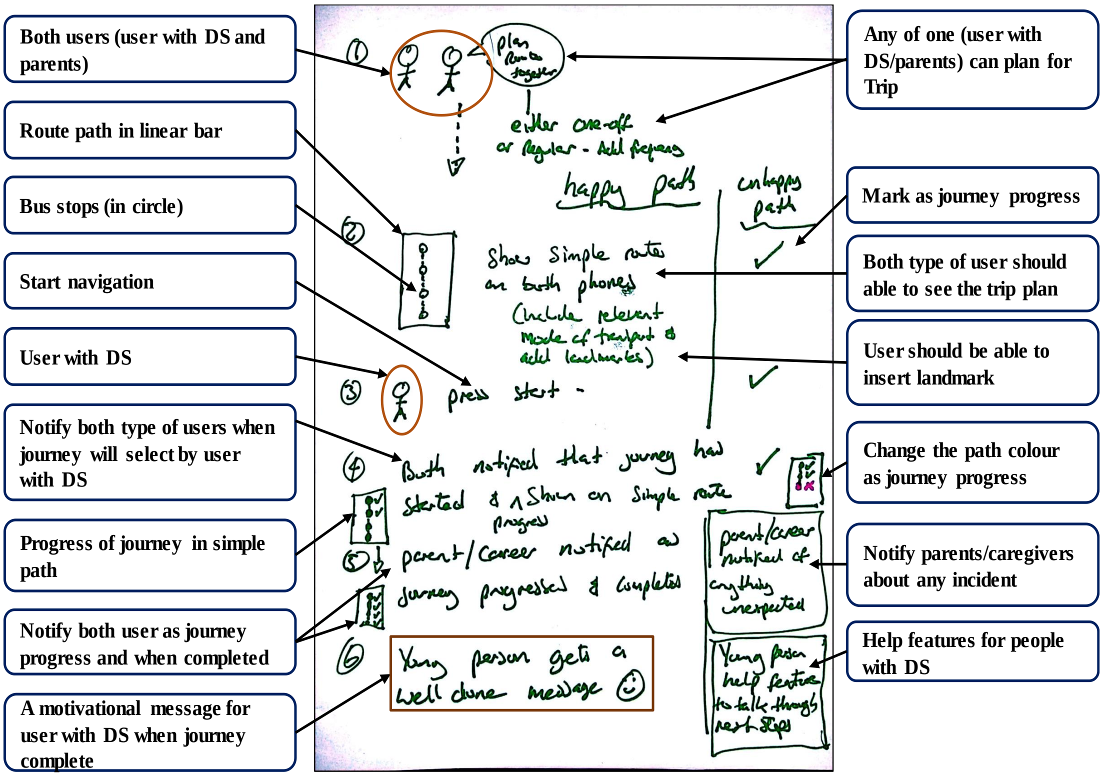
Navigate user while walking to destination, A step-by-step instructions

Notify about arrival

If user press “Y/N” when arrived send a message to parent

Keep records of all journeys and display on weekly report

Figure 6.5-1: Drawing of a linear map (P7 and parents)



Both users (user with DS and parents)

Route path in linear bar

Bus stops (in circle)

Start navigation

User with DS

Notify both type of users when journey will select by user with DS

Progress of journey in simple path

Notify both user as journey progress and when completed

A motivational message for user with DS when journey complete

Any of one (user with DS/parents) can plan for Trip

Mark as journey progress

Both type of user should able to see the trip plan

User should be able to insert landmark

Change the path colour as journey progress

Notify parents/caregivers about any incident

Help features for people with DS

Figure 6.5-2: Progress of journey as Linear bar (P1 and parent)

6.6 Discussion of Cycle 2 – Discussion Groups

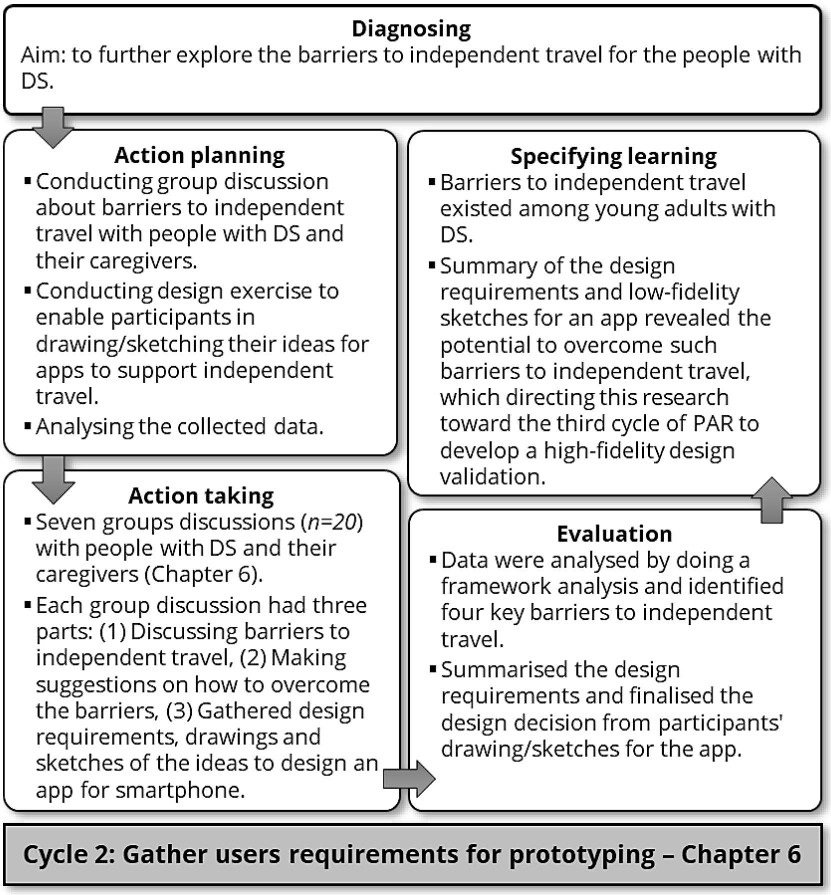
The findings indicated to four key barriers (Figure 6.4-1) that can prevent an individual with DS from travelling independently. The first one of these barriers is unfamiliarity with routes, which affects all other barriers. In order to address this problem, travelling with a “travel trainer” can increase DS individual’s familiarity with a new route. However, it cannot alleviate a parent’s anxiety. Alternatively, smart devices e.g. smartphone with a smart app could be used as a substitute for a “travel trainer” and shadow an individual with DS while travelling (c.f. tracking users’ activities (Kramer, Covaci, and Augusto 2015)). The next difficulty was finding the correct arrival bus stop, recognising the correct bus and basic routing with the regular map. These were often mentioned as persistent problems (as reported in Davies et al. (2010)). Also, this study revealed the importance of notifications for parents and caregivers, providing updates about circumstances on the route, and proving support in unusual situations.

Furthermore, the findings confirmed that the “pedestrian crossings” and reading “regular maps” to navigate at a short walking distance were difficult for young adults with DS. These barriers have been observed in an earlier study of Sposaro et al. and Kramer et al. but remain unsolved (Sposaro, Danielson, and Tyson 2010; Kramer, Covaci, and Augusto 2015). The complexity of standard smartphone maps was raised as a common problem by the participants. Participants suggested that the difficulties in navigating to a new route or walking home to the bus stop could be overcome by simplifying the maps, which include combining the textual and voice navigation. Participants’ drawings also revealed a new way to visualize the full journey by using a linear bar map and voice assistance (see Figure 6.5-1 and Figure 6.5-2). Correspondingly, one of the key barriers was parents’ anxiety, which may possibly be reduced by overcoming the identified barriers (see section 6.4.4Figure 6.4-1), except for safe use of a smartphone in public places without being it targeted, lost or stolen. Nonetheless, a smartwatch (four participants with DS in the study of supporting independent travel were smartwatch users) is the only device that can be used safely in public places and is less prone to be targeted.

6.7 Conclusion of Cycle 2

This cycle described an in-depth understanding of barriers to independent travel and the analytical process of requirements gathering to overcome such barriers. Initially, this cycle explored deep insights of the barriers to perform independent travel for young adults with DS (partly answered to RQ1). Afterwards, the detailed needs and requirements were formulated in order to overcome the barriers to independent travel (partly answered to RQ2). Lastly, based on these needs and requirements developed low-fidelity sketches and drawings from parents, caregivers, and young adults with DS to prototype an app on the smartphone (partly answered to RQ2). Also, to ensure safety and comfort for participants with DS, the study (Cycle 2) was conducted by adopting the co-design style workshop with necessary changes. Such as home-based group discussion and each discussion group was split into three sub-sessions (see section 6.3.1), which facilitated face-to-face conversation with participants with DS and ensured the quality data collection for the study (partly answered to RQ3). The findings of this cycle will be used in the next cycle to guide the design and development of a prototype app to overcome such barriers. Consequently, this research completed cycle 2 (see Figure 6.7-1).

The next chapter describes the design implementation and design validation cycle (cycle 3) where the requirements and low-fidelity sketches guided the design and the development of the app.



Diagnosing

Aim: to further explore the barriers to independent travel for the people with DS.

Action planning

- Conducting group discussion about barriers to independent travel with people with DS and their caregivers.
- Conducting design exercise to enable participants in drawing/sketching their ideas for apps to support independent travel.
- Analysing the collected data.

Action taking

- Seven groups discussions (*n=20*) with people with DS and their caregivers (Chapter 6).
- Each group discussion had three parts: (1) Discussing barriers to independent travel, (2) Making suggestions on how to overcome the barriers, (3) Gathered design requirements, drawings and sketches of the ideas to design an app for smartphone.

Evaluation

- Data were analysed by doing a framework analysis and identified four key barriers to independent travel.
- Summarised the design requirements and finalised the design decision from participants' drawing/sketches for the app.

Specifying learning

- Barriers to independent travel existed among young adults with DS.
- Summary of the design requirements and low-fidelity sketches for an app revealed the potential to overcome such barriers to independent travel, which directing this research toward the third cycle of PAR to develop a high-fidelity design validation.

Cycle 2: Gather users requirements for prototyping – Chapter 6

Figure 6.7-1: PAR Cycle 2, exploration of barriers to independent travel and specifying design requirements with low-fidelity drawings/sketches for a smartphone app.

Chapter 7

Cycle 3, High-Fidelity Design Validation Workshops and Bridging the Gaps in Design: The Transformation of Digital Prototype from Low-Fidelity Design.

7.1 Introduction

A high-fidelity prototype in the suitable device allows researchers, designers, and users to perform usability testing and help to gather usage information regarding tested applications such as log activities, answers to questionnaires and experiences by the end-users (Lim et al. 2006; Chávez et al. 2019). Furthermore, end-users benefited to act and behave naturally during the testing sessions as the high-fidelity prototype delivers the appearance and functions as similar as possible to the actual application (De Sá et al. 2008; Lim, Stolterman, and Tenenberg 2008). Also, with a high-fidelity prototype, it is possible to test graphical, audio and text elements in specific UI or interactions (De Sá et al. 2008; Rukzio et al. 2006). The purpose of transforming low-fidelity sketches and drawings into a digital prototype for smartphones was to gather meaningful feedback and gain a solid understanding through usability testing with its users.

This chapter describes the third cycle of the PAR methodology, which was about developing the solution based on the requirements and needs to overcome the barriers to independent travel. Also, it describes the process of design validation for the proposed solution. Initially, as of the solution for barriers to independent travel, a digital (with high-fidelity design) prototype for smartphone was designed based on the requirements and low-fidelity sketches which were revealed in cycle 2 (see Chapter 6.5). Afterward, the designed high-fidelity prototype was evaluated with individuals with DS and their parents and caregivers for validation checks through a series of co-design session in order to bridge the design gaps.

7.2 Prototype Design

The initial design requirements and sketches for a smartphone app were produced in paper from the participants during cycle 2 (see section 6.5). These requirements and sketches were transformed into a digital prototype for a smartphone app. One of the PAR principles is to ensure the active involvement of the participants in the research, which is then required to focus on accessibility for young adults with DS. Therefore, the prototype interfaces were designed under the accessibility standards towards WCAG 2.0 guidelines (Patch, Spellman, and Wahlbin 2015; Caldwell et al. 2008; Ribera et al. 2009). Such as font style (Arial and Tahoma), text size (14px, 16px, 18px, 20px to 30px), button size (medium and large) and forecolour for the panels and boxes.

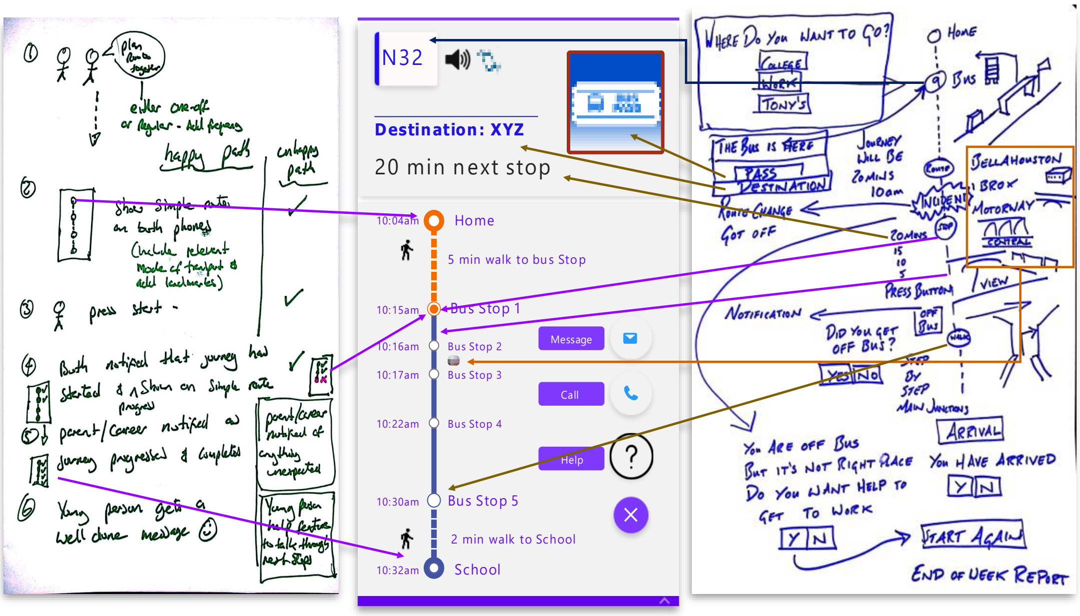


Figure 7.2-1: Transforming sketches into a digital prototype.

The digital prototype: the prototype consists of two types of users— people with DS as primary users and their parents/caregivers as secondary users. The prototype was designed in Adobe XD and used Google material design concepts (Chowdhury 2019) (e.g. cards, buttons, navigation panels, etc.) for smartphone users. For the primary users (people living with DS), the interfaces were designed to support overcoming travel barriers. These design requirements and sketches were strictly followed and transformed into a digital prototype. Figure 7.2-1 represents how whole design concepts were transformed from sketches into a digital prototype.

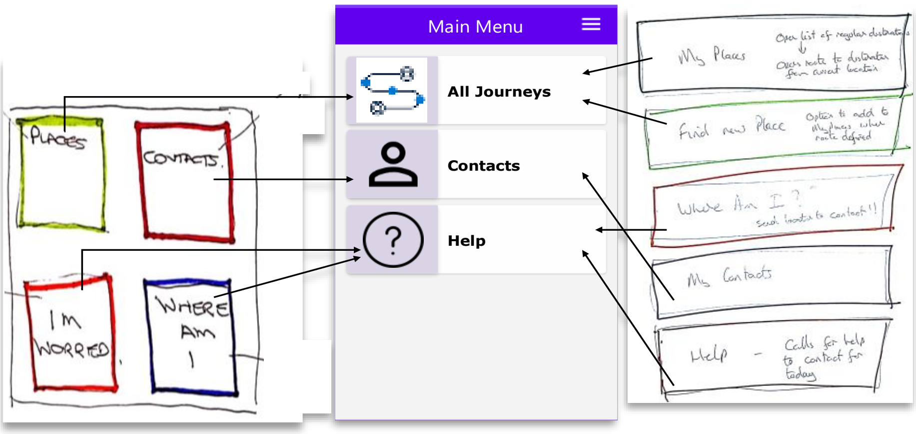


Figure 7.2-2: Transforming main menu into high-fidelity design.

Figure 7.2-2 shows how the main menu was transformed from low-fidelity into high-fidelity design for the smartphone app. Similarly, Figure 7.2-3 shows how buttons were transformed for the digital prototype.

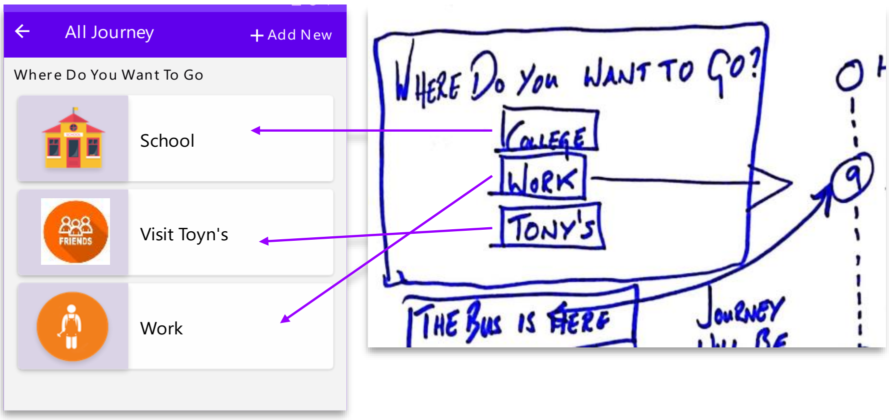


Figure 7.2-3: Transforming buttons from sketch.

Also, the design consisted of a directional panel, instructional messages and a linear map to aid easy walking navigation and to recognise the correct bus or train easily, which were transformed into a digital prototype (see Figure 7.2-4).

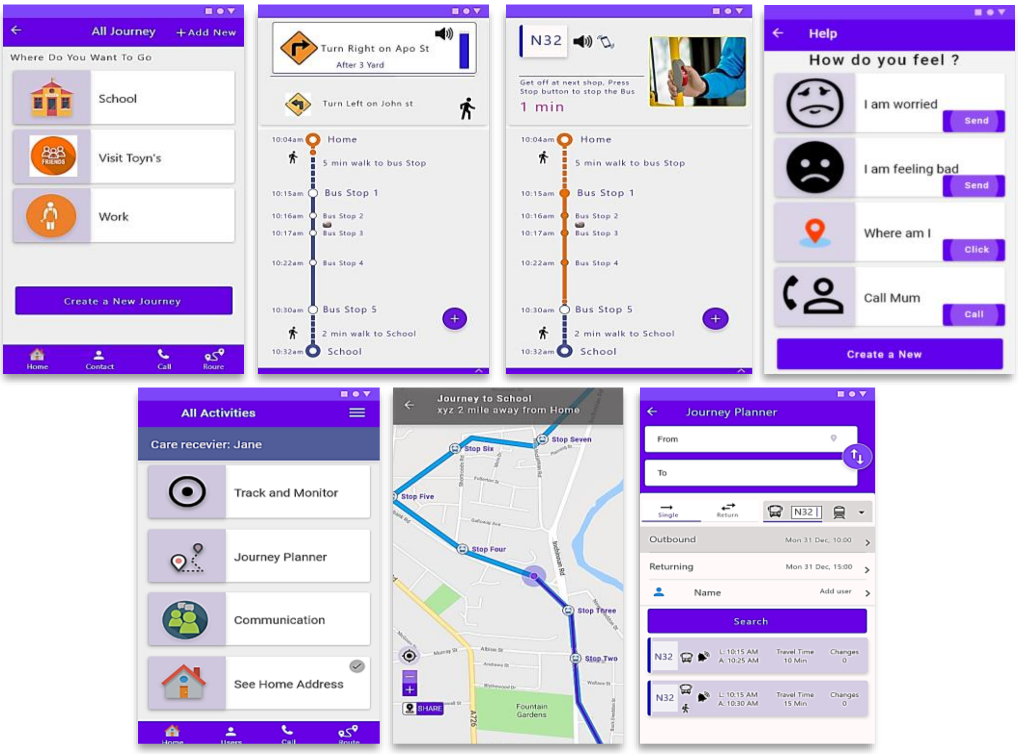


Figure 7.2-4: Digital prototype designed for smartphone (top four images for the primary users and the next three for secondary users). The help page (top right) features a short-written message to be sent to caregivers. Messages can be customised by the user with DS or caregivers, and there is an option to share user location and make a phone call to caregivers.

A total of 26 screens were created to represent a journey from home to school. For the secondary user (parents and caregivers) the interface was designed to enable parents/caregivers to shadow users with DS. Parents/caregivers were given access to admin controls, e.g., planning for the journey, tracking locations, monitoring journey progress, checking journey history, receiving updates or monitoring any unexpected circumstances that occurred while the individual with DS was performing the journey (see Figure 7.2-4, bottom three images).

7.3 Method for Prototype Review meetings

Participants were recruited via email and social media posts (through mailing list and Facebook page of Down's Syndrome Scotland, see Appendix F: social media post by Down's Syndrome Scotland.) and from the contact list of earlier studies. As the researcher experienced difficulty recruiting for the previous study, again the researcher decided to give more flexibility to participants by visiting them at a place (usually their home) of their convenience.

7.3.1 Procedure

An easy to read participant information form (Issues 2017) about the group discussion and procedure was given to parents and caregivers in advance, and then they were asked to explain the procedure of the group discussion to their young adults (Appendix E: easy to read consent form and participant's information sheet.). Before started the group discussion, the digital prototype was presented in a web browser using a laptop and projector and all features for both types of users were explained to the participants. All the screens of the designed prototype (see Figure 7.2-4) were printed on A4 paper (Kaltenrieder, Papageorgiou, and Portmann 2016; Bailey et al. 2008; Bell and Davis 2016) with narrow margin layout and landscape orientation, and were used to gather feedback from both types of users (first set for primary users with DS and second set for secondary users parents/caregivers).

In total, seven group discussions were conducted, three at the university campus (*n=7*, three participants with DS, one married couple, one mother, one brother) and four in participants' homes (*n=12*, four participants with DS, three married couples, one mother and one brother). The group discussion was divided into three sub-sessions. The first sub-session was to understand and observe usability issues with the designed digital prototype for users with DS (primary users). Participants with DS were given the digital prototype to use on a smartphone (Samsung Note 3, screen size 5.7-inch). The task was to navigate through the whole prototype (this task represents a journey from home to school). Participants were allowed to ask questions and discuss with their parents/caregivers if they did not understand any interface or had difficulty navigating. The purpose was to observe the usability issues and take notes to discuss these issues using the paper prototype in the second sub-session. The second sub-session was a detailed discussion of how to overcome those usability issues that were raised in the first sub-session and used a printed version of the digital prototype to record their feedback. This sub-session was a joint discussion with parents, caregivers and participants with DS. A third sub-session was a short discussion with parents and caregivers on the user requirements for and usability issues with the designed prototype for secondary users.

Though the discussion started by mentioning to participants the findings (four barriers to independent travel) from the earlier studies (cycle 1 and cycle 2) and asked for their feedback on this, it was also stated that they were not restricted in discussing any other barriers that were not found in cycle 2 findings (see section 6.4). Each group discussion lasted around 90 min (Range = 70 – 100 min) and was audio-recorded. The main discussion comprised of three elements: 1) Comments and feedback on the designed prototype, what do participants like/do not like and what features should be included/removed from the prototype? 2) *What are the accessibility issues with the designed application for a young adult with DS?* 3) *What aspects of the app overall are useful to support overcoming travel barriers and why?* These questions were formulated based on the literature review and findings from the previous studies (Chang, Chen, and Chou 2012; Covaci et al. 2015; Kaltenrieder, Papageorgiou, and Portmann 2016; Lindsay et al. 2012; Engler and Schulze 2017).

7.3.2 Ethics for group discussion

Due to difficulties in recruiting participants during the cycle 1, the author decided to visit participants at their homes or other convenient locations nearby during cycle 2. This led to a sufficient number of participants being involved in the study. As a result, the author plans to follow the same process in cycle 3. The author will use the previous disclosure report that was submitted to the first supervisor as a basis for conducting this study with young adults with DS in home settings. Additionally, a departmental ethics approval (University of Strathclyde, CIS ethics approval ID: 941) was obtained for this study.

To ensure the safety of participants with DS, parents/caregivers were instructed not to leave them alone with the interviewer during the discussion. Participants' identity and confidentiality will be protected that stated in the easy-read participant's information sheet (see Appendix E: easy to read consent form and participant's information sheet.) including secure data storage, data analysis processes, and a detailed process of conducting workshop sessions.

A guideline was created for conducting this workshop and submitted with the ethics application approval. A workshop guideline was created, which included a detailed description of the study's process, main questions, sub-questions, and related materials and instruments. Participants will be asked to provide feedback using printed interfaces in A4 size paper of the designed prototype, multi-colour brush pens, and a ruler. The designed prototype was installed in a smartphone (Samsung Galaxy Note 2) for participants with DS to use and provide feedback. At the beginning of the session, the study's objectives, prototype features, and navigation were explained to ensure effective participant involvement and quality feedback. The PAR methodology's principle of empowering participants was maintained by giving young adults with DS an opportunity to discuss at the beginning of the session and afterwards their parents.

7.3.3 Participants

The criteria stated during the recruiting process were that participants with DS should be aged 16 years and above, able to move physically, keen to learn independent travel by public transport, and have no worse than mild cognitive disability (i.e., excluding those with a moderate or severe level of cognitive disability). Seven young adults with DS (Alroobaea and Mayhew 2014) took part in the study (three male and four female), four participants were new and three took part in an earlier study (see Table 7.3-1). The average age of participants with DS was 21 years (age between 17 – 28 years). Also, twelve parents/caregivers (five male and seven female) took part with an average age of 52 years. All participants with DS were smartphone users. All parents/caregivers were full-time carers of a young adult with DS, except for one who was a part-time carer.

*Table 7.3-1: Young adults with DS and caregivers' demographics (P=Young adults with DS, C=Caregivers and * = number of participation)*

Group IDs	DS's IDs	DS's Gender	Caregivers' IDs	Caregivers Gender
1	P8	M	C18	F
2	P9	F	C19	F
3	P10	F	C20, C21	M, F
4	P11*	M	C22*	F
5	P12*	F	C23*, C24**	M, F
6	P13*	M	C25*, C26*	F, M
7	P14	F	C27, C28, C29	F, M, M

7.3.4 Data analysis

The author opted to utilise the thematic analysis method introduced by Braun and Clarke to conduct the qualitative data analysis for this study (Braun and Clarke 2006). This method involves a systematic approach to identifying, analysing, and reporting themes or patterns within qualitative data. Braun and Clarke's qualitative data analysis process comprises six stages, which the author carefully followed in this study.

Familiarisation with the data: first, the audio recordings of the workshop discussion were transcribed verbatim by a third party. The transcripts were carefully read several times until the author became intimately familiar with the data. During this process, the keynotes of initial thoughts were recorded in Microsoft word to support the initial coding in the next stage. The first sub-session was then subjected to largely inductive thematic analysis (Braun and Clarke 2006). Also, the feedback recorded in the paper prototype during the second and third sub-sessions was scanned and formed into digital copies and carefully examined to increase the familiarity for analysis. ***Coding the workshop data:*** the data coding started by highlighting relevant words, sentences, or paragraphs using different colours and labelling them using the comment tool of the word document for the first sub-session. At this stage, these initial codes are recognised as tentative codes after being compared with the keynotes that were created during the familiarisation stage. Consequently, a set of codes were listed from the digital copies of the paper prototype (for the second sub-session) and transferred to a separate Microsoft word file. After that, the codes of the first sub-session (group discussions) and second sub-session (feedback on the paper prototype) were collated into groups and relevant data extracts to gain a brief overview of the main points and common meaning. A similar process was also applied for coding the data from the third sub-session (discussion and feedback in the prototype for secondary users). The purpose was to generate a set of pithy labels of relevant and important concepts or interests within the data focused on the research question. Another researcher (Dr Mateusz Dubiel) reviewed transcripts, feedback gathered on the paper prototype, and keynotes (created during the familiarisation stage) and coded them independently. After then met with the author to discuss their discrepancies and updated the code file to reflect their conclusions. ***Searching for themes:*** once the coding was completed, similar codes were then condensed into single categories by reassembling according to the prototype's interface. These categories were then recognised to form tentative themes based on their properties and dimensions. Later, some of the codes discarded were too vague and irrelevant according to the reviewed prototype or the research questions. ***Reviewing themes:*** these tentative themes were then reviewed and arranged appropriately to confirm the final themes. At this stage, final themes were compared against interview data to ensure relation to both extracted codes and the entire data set. Also, it confirmed that the themes reflect true representations of the data. ***Defining and naming themes:*** later, these themes were discussed with Dr Mark Dunlop (1st supervisor) and confirmed how the final themes and names of the themes fit into the overall story and easy understanding of the data. ***Writing up:*** all themes were described in the finding section, including how often they were repeated, their meaning with participants' quotations and figures (scanned copy of paper prototype) as evidence and how the research questions were answered, and the proposed prototype was reviewed.

7.4 Findings of Design Validation and Evaluation

Outcomes of users with DS (primary user): this section presents the design gaps of the proposed prototype for people with DS and describes them briefly with participants' quotes. Again, "P" refers to young adults with DS and "C" refers for caregivers/parents. Through the group discussions, the participants discussed and identified several gaps in the proposed prototype. The description of the results includes the most relevant designs and its gaps that were appreciated and criticized by the participants. For instance, linear map, help UI, features e.g. notification instructions, information presentation and correct alignments of the elements.

7.4.1 Most appropriate design features.

Linear map: the linear map was one of the key features developed based on the participants' suggestions (discussed in section 5.2.2.3). Findings revealed positive views from both participants with DS and their parents/caregivers. Parents and caregivers from all groups described it as a novel feature to reduce travel barriers. Nevertheless, the participants with DS felt familiar with the linear map quickly as revealed while observing use of the digital prototype in the smartphone. The only issue was the displaying of the names of bus stops in between departure and arrival stops, as these stops are not their stops to get off and lead to confusion because of the unfamiliarity. On the other hand, P11* and P13* had no objection to the inclusion of these stops and argued that the inclusion of the names of these bus stops will help them to increase familiarity with the route. Additionally, parents of P12 recommended including instructions for getting on and off the bus alongside with departure and arrival stops name in the linear map as noted.

> C20: *"Like the linear map".* And C19: *"Emma*[2] *will not know the names of the stops so noting them here will not be helpful"*
> C24**: "*Bus stop 1 – add text → "Get on bus here". Bus stop 2 – add text → "Exit bus here or get off bus here.""*.

Help interface: the designed prototype consists of a help feature (see Figure 7.2-4) for users with DS to send a message instantly to their caregivers while outside. Both people with DS and their caregivers from all groups stated the importance of this feature and described that the capability of sending this message will increase confidence among users with DS while travelling and decrease loneliness.

7.4.2 Features with design gaps.

Instruction features: the instruction features were one of the key features of the designed prototype discussed by all participants and their caregivers. Based on the findings the instructions were categorised into three sub-sections: turn-

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[2] All participant names were changed to preserve anonymity

by-turn instructions for direction (e.g. turn left, turn right); prompt instructions to take action (for example, “did you get the right bus, action = YES/NO”, “press the stop button to stop the bus”); and alert messages to notify the user or provide important information (landmark notification e.g. “you are passing by Tesco now”).

Ordering the box design: turn-by-turn direction instructions for the navigational instructions contained two instructions at a time, the first instruction was to follow for direction with the next instruction to inform users about the upcoming turn in advance (see Figure 7.4-1). However, it found that this created confusion to participants except for P12* while observing participants using the prototype on the smartphone. P8, P9 and their parents suggested one instruction at a time to make sure that they were easy to read and could be understood by people with DS.

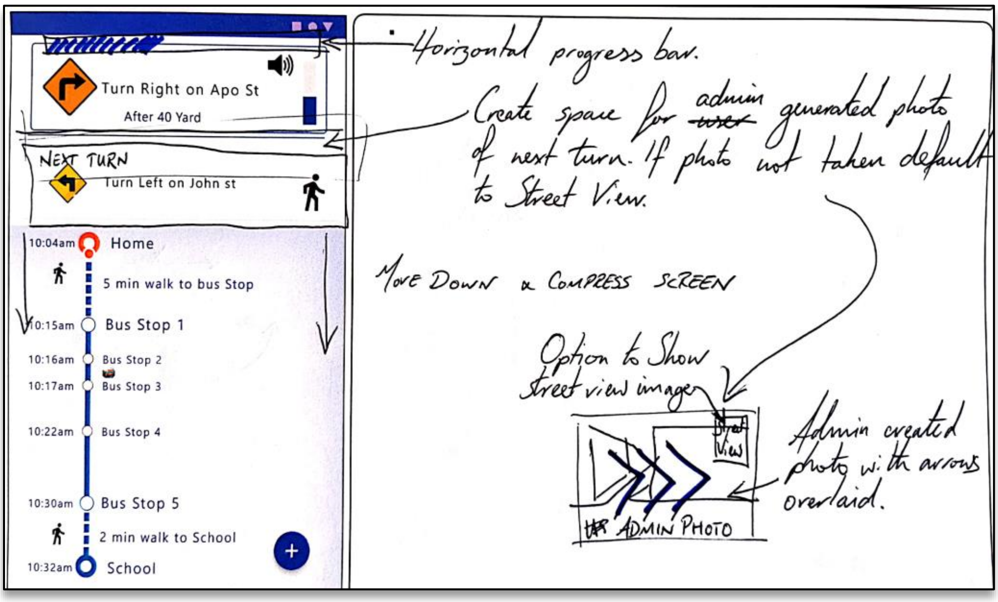


Figure 7.4-1: Showing changes made by participants in turn-by-turn direction (P11 and parents).*

> C19: *“I think one instruction box at a time would be less confusing.” “I don’t think the distance [in yards] notification is helpful.”*

> C22*: *"create space for admin generated photo of next turn. If photo not taken default to street view."*

The parents of P11* suggested keeping both instructions together but that upcoming instructions should be in a smaller box (see Figure 7.4-1). The instructions were presented with text and images but unfortunately none of the participants with DS understood the distance when presented in "yards" (e.g., turn right after 20 yards). Consequently, parents suggested that the distance text should be in metres. Although all participants and caregivers were happy with the instructional images, C22* (the parents of P11*) suggested customisable images and direction arrow on the images for the navigation instruction. The panel also contained a progress bar that fills up while the user is moving towards the next turn. The parents of P8, P11* and P12* suggested a horizontal progress bar (see Figure 7.4-1) rather than a vertical one on top of the direction instructions box.

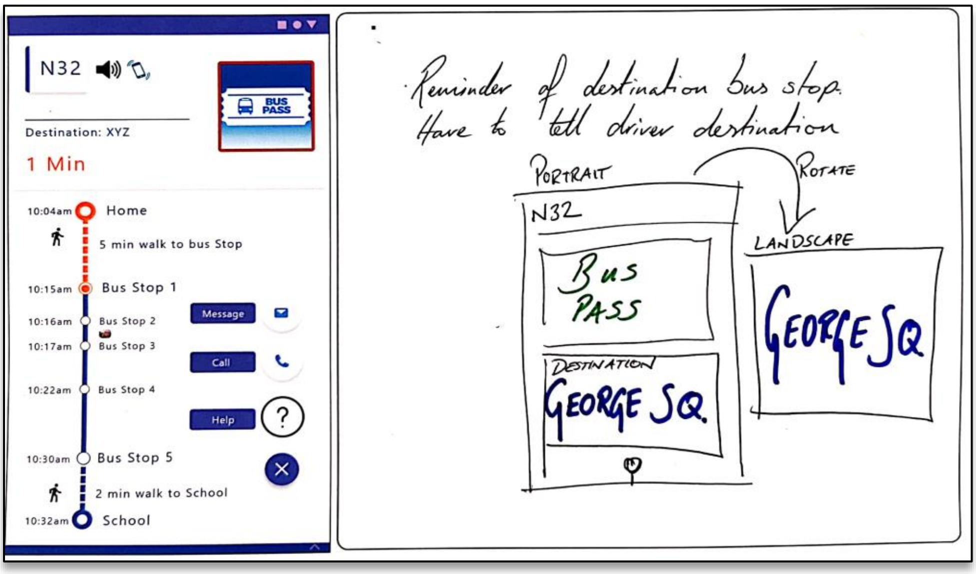

Reminder of destination bus stop.
Have to tell driver destination

Figure 7.4-2: Showing changes in action instructions by participants (P11 and caregiver).*

Design the interface with correct alignment: action instructions were presented with text and images. While the user is waiting for the bus at the bus stop, the bus pass image will appear on the right side of the panel and that tells the user to get ready with their bus pass when the bus is nearby. The text instructions with destination name as well as the remaining time until the bus arrival is also displayed here. P11* and his caregiver suggested that it would be better for the image to appear under the bus number rather than on the right-hand side (see Figure 7.4-2) and the destination name with a separate box below for the bus pass image, by taking up more space on the screen. The same change should be implemented for other action instructions e.g. instructions for crossing the road. To reduce verbal communication with the bus driver this instruction box should also include the destination name. P8, P11*, P12* and their caregivers recommended that the destination name should be the arrival stop name instead of their final destination as the final destination (user with DS's destination) might be away from the arrival bus stop and the bus driver may not be able to recognise the name of the users' final destination.

Contents adjusting and ordering: findings indicated positive views of the alert messages by all participants and their caregivers except for the colour and text size. Parents have suggested that a message to be sent to caregivers when the user with DS presses "NO" when alerting message display on the screen to confirm that the user got the right bus. Similarly, sending messages to parents about incidents in route was found to be crucial as discussed by group 12*.

> C18: *"If he gets on a bus which doesn't go in the direction the app expects – it would send me a message to alert me."*

For the designed instruction page on how to deal with such situations (see Figure 7.4-3) when users with DS get on the wrong bus, all participants and their caregivers provided constructive views and opinions on how to deal with such situations. Observations with the digital prototype on the smartphone indicated that all participants with DS took time to understand this instruction page. All participants and their caregivers also indicated the significance of the call button for help (discussed in an earlier study in section 6.4.2). The parents of P12* also advocated for text instructions and rearranging the current instructions (see Figure 7.4-3).

> P13* (Individual with DS): *"I was a bit hesitant about this page". And* C25*: "when pressing YES [in response to: did you get off the Bus?], this takes you to new journey but takes away the ability to call Mum for help".*
> C23* and C24***: "Wrong bus", "Don't panic", "press stop button, get off at next stop".*

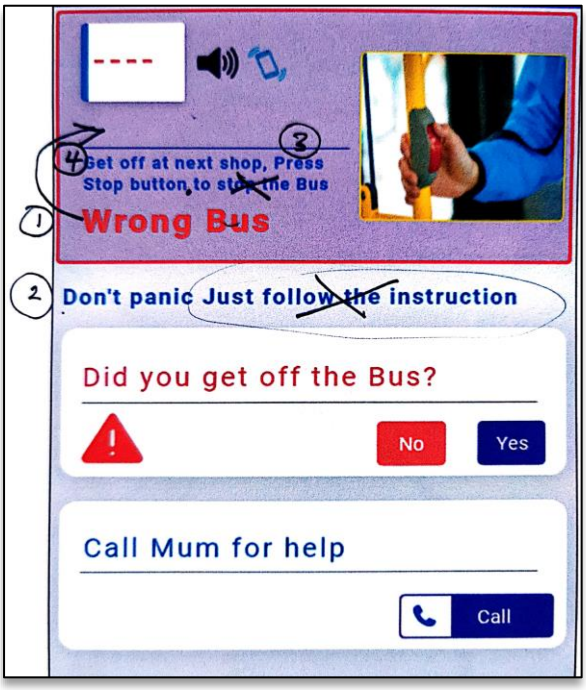
Nonetheless, all participants and their caregivers assured that the button to send the message to notify caregivers about journey progress will reduce the anxiety of parents and increase the level of confidence of participants with DS to perform independent travel. Parents of P10 (C20) recommended an option to customise the message by participants with DS.

7.4.3 Other features (Text size, font style and colour)

Problems designing a suitable interface using appropriate text size, colour and images are not uncommon for people with DS due to their vision issues. Observations with the digital prototype on the smartphone revealed that all participants with DS struggled to read the text instructions when written in font size 14.

> C24**: "*I would use 'comic sans' font for hounded 'a'*". And C26*: "*visual marker was what Bob picked up on first*". And C22*: "*the red colour may be a little too alarming*".

But the instructions written in text size 20 were adequate to read without stress. The caregivers recommended a minimum text size of 18 and bold with a suitable font style e.g. Arial or Tahoma. The font style and the font size changed accordingly before testing with the last participant P14, where observations indicated no difficulties in reading instructions. Also, findings revealed that the use of graphical icons and text together for the instructions and buttons were accurate and suitable for the participants with DS. However, the use of inappropriate colour (e.g., red) in the text, icon or alert messages possibly caused anxiety to people with DS. The parents of P11* proposed using the colour yellow instead of red in the alert message (see Figure 7.4-3).



④ Get off at next shop, Press ③
Stop button, to ~~stop the~~ Bus

① Wrong Bus

② Don't panic Just follow ~~the~~ instruction

Did you get off the Bus?

Call Mum for help

Figure 7.4-3: showing changes in an alert message by participants (P12 and parents).*

7.4.4 Additional features

Two additional features were revealed from group discussions. The parents of P11*, P12* and P13* raised the issues of battery drain due to the use of GPS data that could seriously affect the journey and lead to anxiety for caregivers. To overcome this issue parents of P12* suggested a remote view of battery level on the caregivers' app that makes them aware of them to mark the last location when users with DS's phones are about to switch off due to low battery.

> C23*: "*add battery indicator to carer app so that I will know her last location*". And C25*: "*a mute button will give them an option to turn off the voice instruction when needed*".

Also, parents of P13* suggested an alert message to turn off GPS before closing the app to save the battery energy. Parents of P8, P11*, P12*, P13* and P14 revealed that the voice alerts/instructions may distract others while participants with DS are inside the bus and they recommended a mute button to turn off the voice alerts or instruction.

Outcomes of parents and caregivers (secondary users): in this section, the key features present that were important for the designed prototype for parents/caregivers are described briefly with parents'/caregivers' quotes.

7.4.5 Remote tracking and monitoring feature

These features were presented to help parents and caregivers to know their sons'/daughters' (user with DS's) real-time location. Findings revealed an optimistic outcome from all parents and caregivers during the group discussions that the ability to track location, monitor the progress of the journey and receive live feeds (notification and text) about the journey increased the self-confidence of parents and caregivers. The significance of remote tracking and monitoring was suggested in the previous literature (Sposaro, Danielson, and Tyson 2010; Ramos et al. 2014). All these features were marked as excellent features by parents/caregivers, who stated that these features will help them to balance their level of anxiety by shadowing their sons/daughters.

> C21: *"useful if Emma gets lost".* And C22*: *"tracking facility is an excellent idea, that will make me worry less…"*

7.4.6 Landmark feature

The designed prototype included a ‘landmark feature’ which allowed parents/caregivers to add multiple landmarks with images when creating a trip plan. Previous literature has shown the importance of effective use of landmarks for people with cognitive deficit (Stock et al. 2013; Kramer, Covaci, and Augusto 2015; Farran et al. 2012; Lingwood et al. 2015). Findings revealed that all parents and caregivers were explicit with their views that this was an important feature, and that the landmark feature will help to increase the level of confidence and familiarity with road for people with DS. For instance, group C14 expressed their views on the importance of using familiar landmark images.

> C27: “*it would be good to add Tesco’s image for Nikki, she sees Tesco when travels to school*”.

Journey history: the journey history interface was designed for the parents/caregivers to see the individual with DS’s travel history. However, findings revealed that the feature was not deemed to be important and it seems that the parents were not interested in checking the history of previous journeys. Indeed, parents and caregivers from groups P8, P9, 11*, and 12* recommended not including such a function and group 13* made no comment.

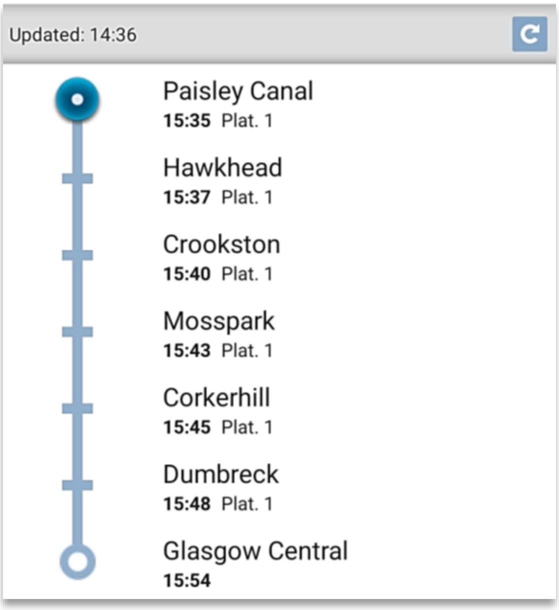
> C22*: “*I don’t like to see her all travels history, I want to help her if any incidence on the road*”.

All other features were verified by parents and caregivers throughout all groups that were not deemed important e.g., plan for the trip, edit/delete and save with name and icon. Two screens that were common to both types of users were loading and login screens. All participants recommended that they liked seeing their name (primary user’s name) on the loading screen with the bus image and a colourful background. Consequently, parents and caregivers suggested highlighting the login button in bigger font size for users with DS. The login text (not a button) for the caregivers should be called “admin” and the size should be smaller than the primary users’ login button.

7.5 Discussion Cycle 3

A few user interfaces (UI) were listed that were appreciated by individuals with DS and their parents (the list was arranged based on the quality and significance of meaningful quotes that were used to rank interfaces. The highest-ranked interfaces were placed first in the list followed by subsequent interfaces). The listed UIs include: (1) the linear map interface (see Figure 7.2-4 and Figure 7.5-1); (2) a progress bar to support walking path (see Figure 7.4-1); (3) an interface to get the ticket from the bus driver (see Figure 7.4-2); (4) an interface to deal with unexpected situations during travel that has a calling option to call a parent/caregiver; (5) a help interface to share feelings with parents during travel (see Figure 7.2-4); and (6) a landmark feature to increase familiarity with the route. These identified six UIs with features that were found to be relevant and important for both types of users (users with DS and their parents/caregivers). Findings indicated that there were gaps (see section 7.4.2) in the designed prototype and that it was crucial to revisit participants (under the PAR process) to ensure that the result meets their needs and serves the actual purposes.

Several features have been discussed in the literature to support the walking path. For example, designed text instructions on the screen which was also used by Kramer et al. (Kramer, Covaci, and Augusto 2015) along with images of the turning points but did not use any arrows to indicate the direction on the image as recommended by parents of P11* (C22*) which was discussed in section 7.4.2. The designed turn by turn navigation with an image of the arrow to support direction was an approach that was also discussed by Sposaro et al. (Sposaro, Danielson, and Tyson 2010). However, a few features and concepts were introduced in the designed prototype that were not mentioned in the literature. A novel feature that used a `progress bar' to support the walking path for users with DS was much appreciated by participants in the previous study (see Figure 7.4-1). The bar gets filled up while the user moves toward the next turn and repeats that process on each turn. An interface designed to overcome verbal communication (see Figure 7.4-2) with the bus driver includes the bus number and destination name for the bus driver to read and make sure that the passenger with DS got the right bus and appropriate ticket for the journey. The interface creates a safeguard that substantially reduces the risk of boarding the wrong bus.


Updated: 14:36

Paisley Canal	**15:35** Plat. 1
Hawkhead	**15:37** Plat. 1
Crookston	**15:40** Plat. 1
Mosspark	**15:43** Plat. 1
Corkerhill	**15:45** Plat. 1
Dumbreck	**15:48** Plat. 1
Glasgow Central	**15:54**

Figure 7.5-1: the ScotRail app with linear map showing all stops between the departure and arrival stops in a linear vertical bar with time and platform number.

The linear map concept (see Figure 6.5-1 and Figure 6.5-2) sketched by participants in a previous study (section 6.5.5) was presented as an alternative to traditional maps. This concept has been implemented in many commercial apps (e.g. in the National Train app for ScotRail, see Figure 7.5-1) for regular users but had not been applied to users with DS. A different concept that involves dealing with unforeseen circumstances (see Figure 7.4-2) is yet to be evaluated through an empirical study. Likewise, the concept of a help page (see Figure 7.2-4) with written messages to increase the comfort of the journey for people with DS has not yet been addressed in the literature. Nevertheless, as discussed in section 7.4.3 the difficulties reading instructions from the mobile phone screen by users with DS due to font size and colour lead the researchers to stick to the standard WCAG 2.0 accessibility guidelines of web/mobile designs for people with learning disabilities. Consequently, this study completed another cycle of the PAR process (see Figure 7.6-1).

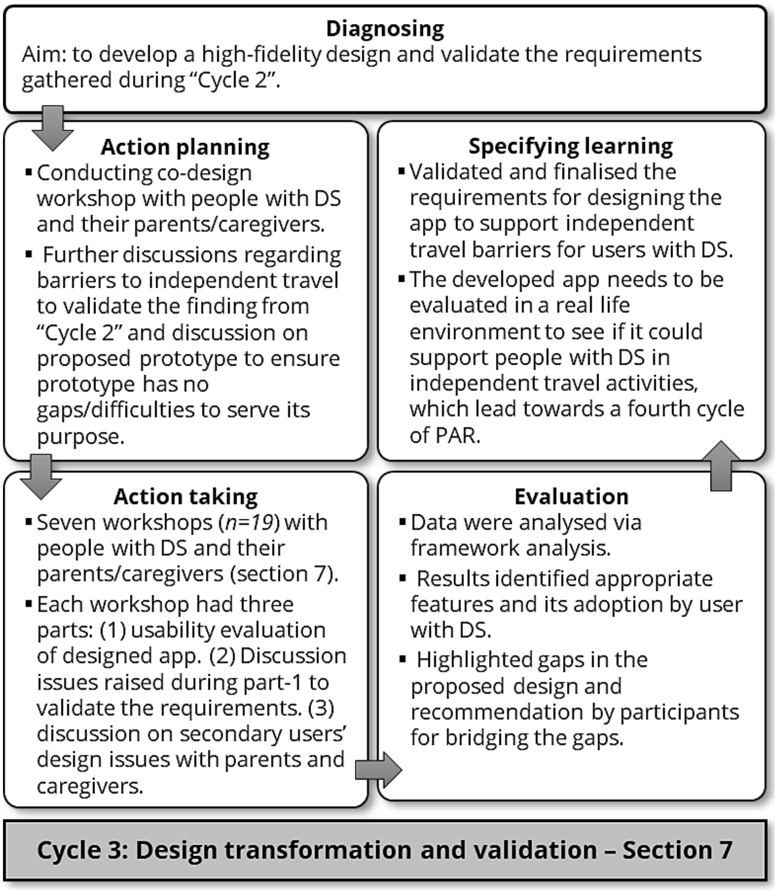
User diversity: is an important issue to address in terms of design and research for young adults with DS. Although many studies reported wide individual variation in cognitive, physical and learning abilities among people with DS, the findings in cycle 3 indicated less wide individual variation in skills when using smart devices, as most of the participants were capable of using smart devices and applications for education and entertainment purposes (from survey results). It is believed that this was because cycle 3 only considered young adults with DS (aged between 16–35 years) with mild cognitive disabilities. On the other hand, a few participants reported an inability to use applications in smart devices to support navigation and tracking (see section 5.3.2.2 and section 6.4.3). However, two aspects can be considered to provide a broader context of usage. First, the participants had to use traditional digital maps that come with smart devices, for example, Google Maps, tracking apps (Life360), and bus scheduler apps because participants were not aware of available navigation systems designed particularly for them. Second, even though there are some applications available that were designed particularly for people with DS to support navigation, these applications come with digital maps which are difficult to interpret by this user group (e.g. POSEIDON navigation application for users with DS). If an application with accommodations were available that mitigates their cognitive needs, it is possible that the users with DS might be able to learn the independent travelling quickly and their parents can let them travel confidently.

The observations resulted in easy adoption of the linear bar map concept with the progress bar by participants with DS (see section 7.4.1), which indicates opportunities to be able to learn the route using custom designed apps for users with DS. While these studies worked with young adults with DS who have mild cognitive disabilities, the outcome of this thesis could have lessons for other users with similar genetic syndromes of sub-groups e.g., young adults with Fragile X syndrome and people with dementia with mild cognitive disabilities that need further investigation.

7.6 Conclusion of Design Validation

This chapter described the transformation process of low-fidelity design for a smartphone app and design validation through participatory design (partly answered to RQ3). Also, described gaps in design and how to bridge these gaps. At first, the initial requirements and sketches were used to develop the design for the smartphone app. Later, this created design was tested against the requirements for design validation through a series of group discussions with young adults with DS and their parents and caregivers. The designed app was transferred to a smartphone for usability testing and given to participants during the testing session, which helped to highlight a few accessibility and usability issues, and identified gaps in the designed app (partly answered to RQ2). The qualitatively analysed result also showed that the designed app is effective and feasible for adoption to perform independent travel for young adults with DS. Also, the result showed the potential to reduce parents' anxiety (partly answered to RQ2). The findings of this cycle will be used in the next cycle to guide the design and make the necessary adjustments to the prototype app before formal user evaluation of the prototype. Consequently, this research completed cycle 3 (see Figure 7.6-1).

The next chapter (cycle 4) discusses the user experiences through a video walk-through for a formal evaluation of the designed prototype along with the answers to research questions.



Diagnosing

Aim: to develop a high-fidelity design and validate the requirements gathered during "Cycle 2".

Action planning

- Conducting co-design workshop with people with DS and their parents/caregivers.
- Further discussions regarding barriers to independent travel to validate the finding from "Cycle 2" and discussion on proposed prototype to ensure prototype has no gaps/difficulties to serve its purpose.

Action taking

- Seven workshops (*n=19*) with people with DS and their parents/caregivers (section 7).
- Each workshop had three parts: (1) usability evaluation of designed app. (2) Discussion issues raised during part-1 to validate the requirements. (3) discussion on secondary users' design issues with parents and caregivers.

Evaluation

- Data were analysed via framework analysis.
- Results identified appropriate features and its adoption by user with DS.
- Highlighted gaps in the proposed design and recommendation by participants for bridging the gaps.

Specifying learning

- Validated and finalised the requirements for designing the app to support independent travel barriers for users with DS.
- The developed app needs to be evaluated in a real life environment to see if it could support people with DS in independent travel activities, which lead towards a fourth cycle of PAR.

Cycle 3: Design transformation and validation – Section 7

Figure 7.6-1: Development of high-fidelity design, usability testing and design validation.

Chapter 8

Cycle 4, A Smartphone Application to Support Barriers to Independent Travel: A Usability Evaluation.

8.1 Introduction

This chapter presents the final cycle (cycle 4) of PAR methodology which was about usability evaluation of the developed app in terms of user experience. The usability evaluation was conducted to see how well participants can learn and understand the use of the proposed app in order to reduce the barriers to independent travel (identified in cycle 2, see section 6.4), alternatively to answer the RQ2. Moreover, this cycle was conducted using a remote evaluation method via video walkthrough to ensure participant's safety and not to overdue the study because of the COVID-19 pandemic. Also, the cycle comprised of a satisfaction survey to generate and report the user satisfaction of the proposed app. The chapter starts by adopting design gaps that were revealed in cycle 3.

8.2 Inclusive design

Several issues of accessibility and usability for smartphones used by young adults with DS and their physical and cognitive capabilities were revealed through the literature review (see sections 2.3 and 4.8.2). The principal concern was to mitigate accessibility issues by focusing on physical and cognitive capabilities in terms of the design approach. Therefore, a design methodology needs to be adopted that can guide in reducing accessibility issues with a focus on the users' disabilities. Several approaches were available for designing more inclusive products and services, one of which is Inclusive Design, among others, such as Universal Design, Extra-Ordinary Human Centered Design and Ability-based Design.

Inclusive design is often referred to as design philosophy than a process of the end product being designed. Its supports as many diverse users as possible with their requirements. One of the principles of this philosophy is to enable different users in the design process rather than exclude them. Inclusive design does not frequently focus on achieving a 'universal' solution; instead, it forms generic design solutions that consider different users' specific needs and accessibility issues (Pattison and Stedmon 2006). The target population for inclusive design approaches is mostly users with impairments and elderly users, such as people with cognitive disabilities.

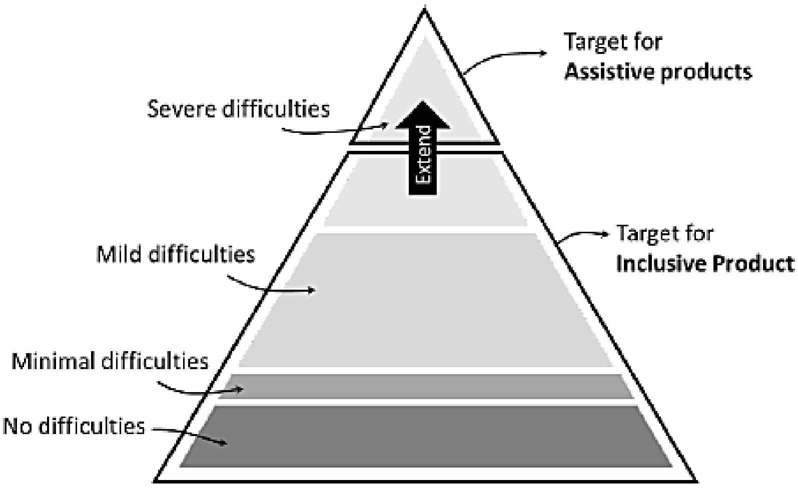


Figure 8.2-1: the users' pyramid approach adapted from Clarkson et al. (Hosking, Waller, and Clarkson 2010)

The user pyramid approach represents different capability levels based on the level of impairment of target users, called principal levels of capability that are severely impaired, moderately impaired and unimpaired (see Figure 8.2-1).

The design process varies depending on the impairment level of the target users. Technologies with complex functions and features are suitable for users with unimpaired capability, whereas severely impaired individuals require specially designed products such as assistive technology. For those with mild impairments, the design process falls between the severely impaired and unimpaired capability levels, making them suitable for inclusive design. As a result, young adults with DS with mild ID are best suited to the middle level of the user pyramid and should be the target of inclusive design/products (S Keates et al. 2000; Simeon Keates and Clarkson 1999).

The "*user-pyramid design approach*" is a model that connects user capabilities to design approaches (S Keates et al. 2000; Simeon Keates and Clarkson 1999). It uses "The Inclusive Design Cube" model, which offers three design approaches: user-aware design, special purpose design, and modular/customizable design (Simeon Keates and Clarkson 1999; John Clarkson and Coleman 2015; S Keates et al. 2000). The modular/customizable design approach is best suited for young adults with mild ID. Furthermore, the Inclusive Design Cube model represents three dimensions of user experience: perceptual, cognitive, and motor actions. The perceptual dimension refers to how the user perceives and interprets information, the cognitive dimension refers to how the user processes and understands that information, and the motor dimension refers to how the user physically interacts with the product or system.

The 5-level methodology (Simeon Keates, John Clarkson, and Robinson 2002) is best suited for the design approach that provides a complete structure of the design phases, which can be compared with PAR Cycles in this thesis. Level 1 defines the user needs and understands their problems, which was the focus of Cycle 1 and Cycle 2. Levels 2 to 4 focus on the user's perception of the application, user cognition of the designed application, and the user's motor function to the application, which was the focus of Cycles 3. These Levels (2 to 4) are also called stages of interaction where techniques for reducing accessibility and usability issues were applied. Such as visual symbolic feedback and audio feedback-typically shapes, colours and icons, sign language, spoken text, touch-screens, buttons or switches. Also, Level 5 focuses on user evaluation and result validation which can fit with Cycle 4. The 5-Level methodology was mainly divided into three main stages: stage 1 to identify the problem, stage 2 to develop an appropriate solution, and stage 3 to evaluate the proposed solution (See Figure 8.2-2).

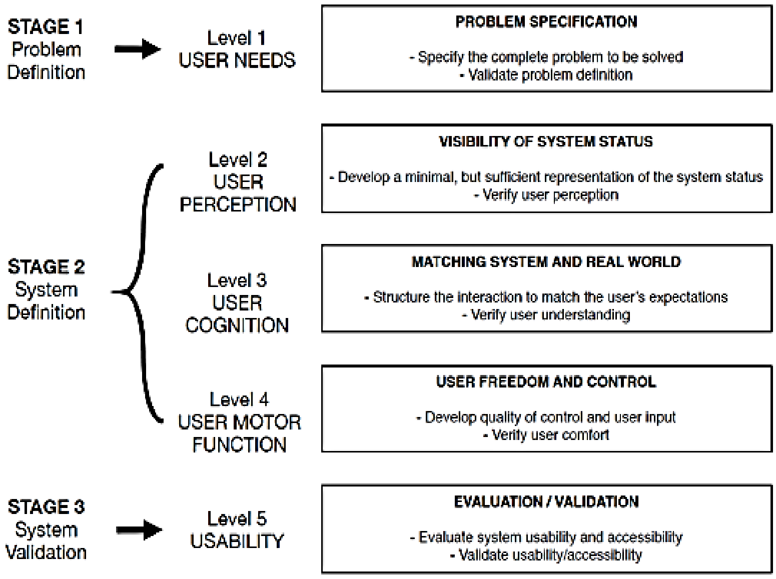


Figure 8.2-2: the "5-level design approach with design stages (S Keates et al. 2000; Simeon Keates, John Clarkson, and Robinson 2002)

Therefore, both the "Inclusive Design Cube" and the "5-level methodology" share a similar emphasis on the design process that takes into account the user's perceptual, cognitive, and motor actions.

To create a usable and accessible application that can help young adults with DS overcome independent travel barriers, a reliable design method was needed. The method should allow for iterative modifications and refinements of the interfaces, incorporating both design steps and usability evaluations to measure against users' known performance criteria. Due to the nature of the study and its participants, a cognitive walkthrough was deemed suitable for the usability evaluation, as it can well address the user's perceptual, cognitive, and motor actions with an emphasis on the design and evaluation processes.

8.3 Design Adoption from the Findings of Cycle 3

The result of cycle 3 listed several accessibility issues in the designed prototype, which were discussed in Chapter 7, cycle 3. The necessary changes were adopted in the designed digital prototype based on the outcome of cycle 3 in order to remove accessibility barriers. Figure 8.3-1 illustrates an updated version of the designed smartphone app called "*MyIndependentTravel*".

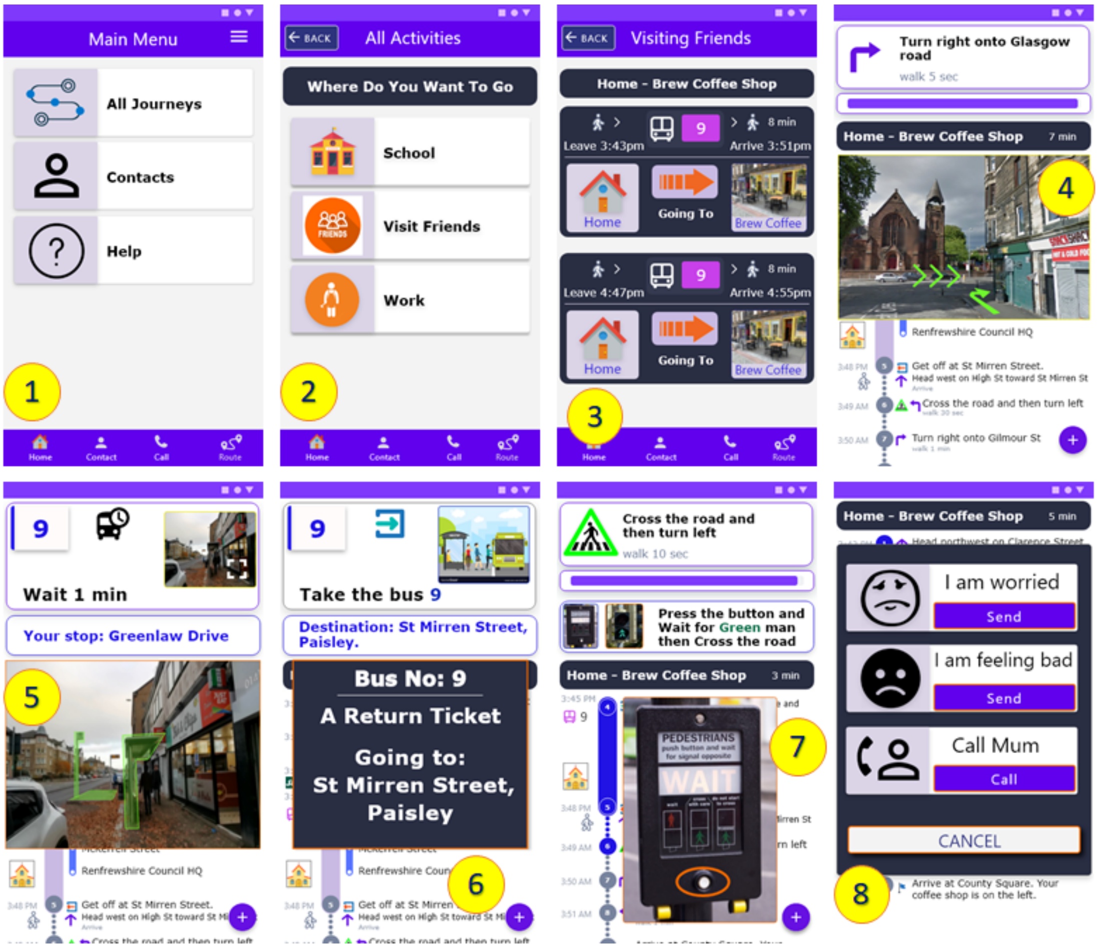


Figure 8.3-1: An updated version of the digital prototype with adopted design for the users with DS.

8.4 The Usability Review Method for "*MyIndependentTravel*"

Although, at first the plan was to let users with DS performing a journey using the designed app in a smartphone for usability evaluation. However, involving users directly in the field study was restricted due to the COVID-19 pandemic. There are several approaches for usability evaluation practised in HCI research. Such as heuristic evaluation, cognitive walkthrough, and user satisfaction questionnaires or focus groups (Cáliz, Gomez, et al. 2016; Jadhav and Mehta 2013; Spencer 2000; Mahatody, Sagar, and Kolski 2010). I have used the cognitive walkthrough method including user satisfaction questionnaires as an alternative approach because of the COVID-19 pandemic.

Cognitive walkthrough widely used method in the HCI research community for usability evaluation of mobile devices and applications (Jadhav and Mehta 2013; Spencer 2000; Mahatody, Sagar, and Kolski 2010). This evaluation method focuses on basic usability principles, cognitive activities, goals, and knowledge of users when performing a particular task (Mahatody, Sagar, and Kolski 2010). Rick Spencer (Spencer 2000) described well the adoption of the cognitive walkthrough process from Wharton et al, I adopted most of this process for this usability evaluation by making necessary changes. In addition, some of the processes were adopted from (Mahatody, Sagar, and Kolski 2010; Jadhav and Mehta 2013; Cáliz, Gomez, et al. 2016; Gabrielli et al. 2005). One major change was made worth mentioning was the creation of video footage of performing travel to avoid direct involvement of the users due to the COVID-19 and used this video footage during remote evaluation in order to avoid direct contact with participants.

Guideline for cognitive walkthrough process using video content involving users with DS, their parents/caregivers and HCI experts.

1. Recruit participants (Cáliz, Gomez, et al. 2016)
    a. Recruit a minimum number of participants.
    b. Consider mental age for participants with DS.
    c. Involve users with DS's parents/caregiver/tutors, usability experts.

2. Define/establish inputs to the walkthrough (Spencer 2000)
    a. Define tasks (the creation of video footage that includes tasks to be evaluated according to the need for this study).
    b. Sample tasks for evaluation (edit the video footage and split tasks).
    c. Action sequence for completing the tasks (rearrange split tasks accordingly for evaluation purposes if needed).
    d. Description of the video footage that includes interfaces to be evaluated (description can be done verbally or using audio clips by playing full video footage before starting the walkthrough session)

3. Convene the walkthrough (Spencer 2000)
    a. Describe the goals of the walkthrough, what will be done and how (can be mentioned in the participants' information form and when creating awareness to recruit participants through ads).
    b. Write instructions for what will be done and what will not be done during the walkthrough including any assigned roles (can be done by preparing an oral presentation before starting the walkthrough session).

4. Walkthrough the action sequence for each task (Spencer 2000)
    a. Make sure all split tasks are arranged in sequence order in single footage and ready to use.
    b. Asking relevant questions to participants regarding the user interface.
    - Asking a maximum of two questions to users with DS would be fair regarding each task/interface to be evaluated. (I chose to ask two questions to users with DS for each task due to their cognitive limitation. And three questions to parents/caregivers and experts for each task).
    c. Maintain control of the walkthrough session by enforcing the ground roles (such as no debating cognitive theory, no defending a design etc.).

5. Run pilot tests and refine the plan (Cáliz, Gomez, et al. 2016)
    a. Arrange a meeting with users with DS (including their parent/caregiver) and run the test.
    b. Make necessary updates if needed after the pilot test.

6. Run the cognitive walkthrough.

    a. At the beginning of the session play the video footage and make sure the audio is on.
    b. Again, play the video footage step by step according to tasks to be evaluated. Also, pause the video when needed (for asking questions and discuss). Because of the remote evaluation process, make sure to use a large monitor (minimum 22" or 24" inch) and set the screen side by side to play the demonstrated video footage and at the same time to see the facial expression of the participants.
    c. Record video of the walkthrough session: it is recommended not to record participants' faces during the session if it is not needed (Cáliz, Gomez, et al. 2016). But, for the data analysis purpose if the walkthrough session needed to be recorded make sure to take consent from the participant before recording the participants' faces. It is highly recommended not to share the recorded video with anyone else, but only for the principal researcher for the purpose of data analysis.

7. Record satisfactory and critical information (Spencer 2000; Jadhav and Mehta 2013)
    a. Report the findings including satisfactory or possible learnability problems for each defined task.
    b. Design ideas (include new interfaces if demanded by participants).
    c. Design gaps (update any usability issues or the interface accordingly based on the feedback of the participants).
    d. Problems in the task adoption (report any difficulty to perform/understand the task).
    e. Report all participants' views including parents/caregivers/family members and experts by referring them (Cáliz, Gomez, et al. 2016).

8. Revise the interface to fix the problem (Spencer 2000)
    - Use the opportunity to revise and fix the problem/designed interface from lessons learned during the walkthrough.

8.4.1 Define/establish inputs to the walkthrough

The core element of cycle 4 was to evaluate the user experience of young adults with DS on the developed smartphone app (*MyIndependentTravel*) and to determine the adaptation efficacy in learning navigation. However, due to the

COVID-19 pandemic, it was not possible to involve participants with DS and their parents directly in the study due to a need to strictly maintain social distancing, especially with regards to public transport (as the study involve access to public transport). Therefore, a video record of performing tasks that include interfaces was created as an alternative to executing the evaluation process. The process was divided into two parts: part 1, creation of video: to capture video of performing journey and part 2, video walkthrough: to execute a video walkthrough using captured video for usability evaluation with young adults living with DS and their caregivers and experts through virtual video conferencing.

8.4.1.1 Creation of videos (Part 1):

COVID-19 safety details: capturing video of performing an independent journey in an outdoor environment involved walking and access to public transport (bus). Two individuals (the author and his flatmate) were involved in performing the journey and capturing the video. Because of health and safety issues due to the COVID-19 pandemic, the governments' guidelines[3] of phase-3 restriction were strictly followed and own safety was maintained during this process. The video capturing was executed in phase-3, as public transport was available to access. However, travel guidelines were needed to follow strictly while accessing public transport (bus), such as:

- maintaining 2 metres of physical distancing.
- use a face mask to cover the face in enclosed public spaces including public transport.
- use hand gloves.
- Carry an anti-bacterial hand hygiene gel to use on hand when needed.

All other rules were followed to ensure safe travel by public transport[4].

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[3] www.gov.scot/collections/coronavirus-covid-19-guidance/

[4] www.transport.gov.scot/coronavirus-covid-19/transport-transition-plan/advice-on-how-to-travel-safely/#section-63885

Capturing video of primary users by performing an independent journey: The author performed a journey as a primary user of "*MyIndependentTravel*" app using a smartphone (Samsung Note 3) that demonstrated performing the journey from A to B. This performance of the journey was capture by a cameraman (the authors' household were asked to do the recording) using his smartphone's camera (Huawei P30 pro).

Capturing video of entering and leaving the bus: while access to the bus, the only footage captured was a) getting a ticket from the driver, b) pressing the stop button to get off the bus (did not capture passenger's face). Before starting to record the process of gaining access to the bus, the lead researcher talked to the bus driver to gain permission to record and confirm not to record the faces of any passengers on the bus. However, some passenger's faces were captured mistakenly during record the video, the face of the passenger captured mistakenly were blurred by using video editing tools.

The test route for the journey: it was a one-mile onward journey from A to B including walking and access to public transport.

Video script: the "*MyIndependentTravel*" app was designed to deliver some instructions (e.g., navigation support instructions, alert messages and how to access public transport) while participants use the app to perform a journey. For easy execution of the evaluation process, these instructions were further divided into three types:

1) Directional instructions: these instructions mainly support users with walking navigation e.g., "Turn right onto Gauze Street, and go for 106 m".
2) Action instructions: these instructions alert users to take appropriate action/decision e.g., "Get your Bus Pass ready" 30 seconds before getting on the bus. "Press stop button" to get off the bus - an alert will be triggered 20 seconds before getting off the bus at the arrival stop.
3) Communication instructions: these instructions are for the bus driver to be shown by users aiming to get the right ticket and confirm the right bus.

The instructions will include the destination name and the bus number so that the bus driver will provide the right ticket and make sure the user is on the right bus.

Tasks: the script consisted of four core tasks to be performed using "*MYINDEPENDENTTRAVEL*". These tasks were allocated according to findings on barriers to independent travel and design requirements during cycle 2 (see section 6.5). The core tasks are:

Table 8.4-1: Tasks to create video of performing journey.

Tasks	Description of tasks
Task-1	**Navigate to the bus stop and recognise the bus stop:** direction instructions (turn-by-turn) assigned to support walking navigation and action instructions to identify the correct bus stop e.g. "Go to the Smithhills Street Bus Stop".
Task-2	**Access public transport and get the trip ticket:** action and communication instructions assigned to recognise and access the bus (public transport), get the right ticket for the trip and get off the bus at the right stop. For example: a) "Take bus '9' toward to Paisley" (followed by direction instructions) b) Get a travel ticket from the bus driver (followed by communication instructions). c) Press the stop button to off the bus (followed by action instructions)
Task-3	**Crossing road:** perform pedestrian crossing by following direction instruction same as Task-1.

Task-4	**Dealing with unexpected circumstances (DUC):** these interfaces were designed to deal with unexpected circumstances during navigation and divided into two sub-tasks. DUC 1. Press the help button to get assistance during the journey if required. DUC 2. Dealing with unexpected circumstances in the route during the journey (e.g. walking in the wrong direction).

Screen capture of primary users using the app: also, a screen capture video was recorded of the use of the app ("*MyIndependentTravel*") via the smartphone (Samsung Galaxy Note 3) during the journey using AZ screen recorder for Android[5], in order to contrast with the captured video of the performing journey.

Capturing video of secondary users: Ryan Gibson is a fellow PhD student, who agreed to perform the role of a secondary user of the "*MyIndependentTravel*" app, was seated at home and monitored the journey progress using a smartphone. The use of secondary users' part of "*MyIndependentTravel*" was captured as a video using AZ screen recorder in order to be used during evaluation.

Data adjustment by editing: the recorded videos (performing journey and screen captures) were edited and put together using video editing software. Also, each task was marked and prepared for the video review process (part 2, video walkthrough).

8.4.2 Convene the walkthrough

The walkthrough sessions were conducted virtually through Zoom to ensure participants safety due to COVID-19. Participants were recruited through Down's Syndrome Scotland (mailing list, Facebook page and news portal) and Facebook business ads. The participants' information forms send via email and also

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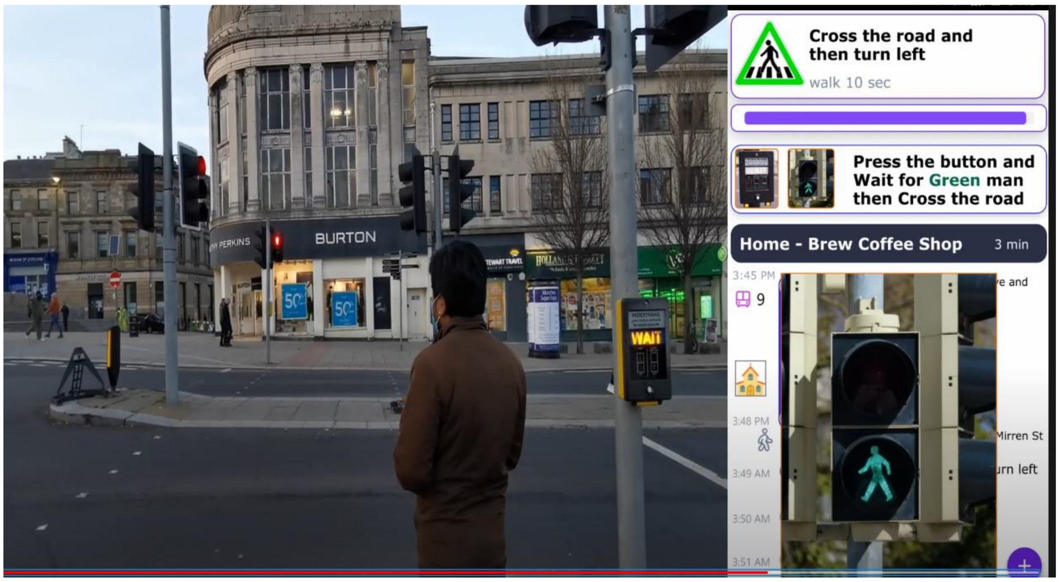
[5] https://play.google.com/store/apps/details?id=com.hecorat.screenrecorder.free&hl=en_GB&gl=US

attached with the ads (an easy read participant information form for participants with DS and participants information form for parents/caregivers and experts, see Appendix E: easy to read consent form and participant's information sheet.). Both participants information forms have a description of the goal for the walkthrough session. Such as what will be done, how, and how participants can take part in the walkthrough study. With regards to detailed instructions of the walkthrough session, a detailed description of the session was explained verbally before starting the session. For example, what video content will be played and how the participants will interact/answer explained by playing a short video clip. The questions were sent via Zoom chat. A guideline was written on how to conduct the session to ensure quality data collection.

8.4.3 Walkthrough the action sequence for each task

The study was conducted by adopting the process of video walkthrough (inspired by cognitive walkthrough) (Cáliz, Gomez, et al. 2016; Mahatody, Sagar, and Kolski 2010; Jadhav and Mehta 2013) to evaluate the "*MYINDEPENDENTTRAVEL*" app and used edited video footage (recorded video captured in part 1, see Table 8.4-1) during this evaluation process. The main purpose was to involve users with DS and their caregivers in the evaluation process. As for the field study, contacting participants directly was restricted due to the COVID-19 pandemic. Therefore, the virtual video conference via Zoom was arranged and invitations were sent to participants for remote participation with the following objectives:

a) Gather comments and opinions of experts, people with DS and their caregivers on usability and accessibility issues of "*MYINDEPENDENTTRAVEL*" for reducing barriers to independent travel including access to public transport.
b) Identify potential features that support users' navigation in term of new aspects of design to overcome barriers to independent travel.



Cross the road and then turn left

walk 10 sec

Press the button and Wait for Green man then Cross the road

Home - Brew Coffee Shop 3 min

Figure 8.4-1: A screenshot of the edited video demonstrates road crossing.

Video footages used for the video walkthrough: the captured video (in part 1) for the user with DS was 5 minutes and 45 seconds long after being edited (see Figure 8.4-1) with "full HD" resolution (1920 x 1080 pixels), which was divided into four tasks (see Table 8.4-2) according to the tasks defined during the video capture in order to facilitate easy discussion with participants. The video footage represents the main tasks for the purpose of evaluation through video review. In addition, one short video was edited for the secondary users (parents/caregivers).

Table 8.4-2:The video footages with tasks to be evaluated after being edited.

Footage-1 for the primary users: this video footage split into four core tasks.	
Core task 1	Footage showing navigating to the bus stop and recognising the correct bus stop. The video clips include the sub-tasks are: - Turn-by-turn direction instructions for walking to the bus stop ("Turn left after 20 mitres" etc.). - Progress bar to indicate - Identifying the correct bus stop using instructions from "*MYINDEPENDENTTRAVEL*".

Core task 2	Footage showing the user recognising the correct bus, accessing the right bus, and getting a trip ticket from the bus driver. This video clip includes these sub-tasks: - “Take bus ‘9’ towards Paisley” by following the instructions from “*MyIndependentTravel*” - Get a travel ticket from the bus driver by following the instructions from “*MyIndependentTravel*”
Core task 3	Footage showing how to get off the bus, crossing the road carefully and finding the destination. The sub-tasks are: - Press the stop button to get off the bus by following the instructions from “*MyIndependentTravel*”. - Carefully crossing the road by following the instructions from “*MyIndependentTravel*”. - Navigating to the destination by following the instructions from “*MyIndependentTravel*”.
Core task 4	Footage showing how to deal with unexpected circumstances, e.g., user turning in the wrong direction off the route while navigating to the bus stop from home. This video clip includes these sub-tasks: - Press the help button in the app to get assistance during the journey if required. - Dealing with circumstances like walking in the wrong direction during the journey.
Footage-2 for secondary users (parents and caregivers)	
Core task 5	Showing a caregiver tracking and monitoring the primary user’s (individual with DS) location using a smartphone and receiving notifications of the journey progress. The sub-tasks are: - Receiving notifications of the progress of the journey. - Tracking/Monitoring the current location of the primary user using “*MyIndependentTravel*”. - Creating/editing a trip plan using “*MyIndependentTravel*” for users with DS.

8.4.4 Execution process of video walkthrough and the survey.

8.4.4.1 Video walkthrough procedure

Participants were given Zoom details (the link to join and password) after scheduling the meeting with the guideline how to use Zoom. The video walkthrough started by playing video footage-1 (see Table 8.4-2) for the primary user (young adults with DS) (Gabrielli et al. 2005). First, at the beginning of the review session, the full video footage was played for the participants. After that the footage was played step-by-step and participants discussed each core tasks through group discussion with young adults with DS and their parents/caregivers. The video footage-2 (see Table 8.4-2), discussed with parents/caregivers, maintained a similar process during the walkthrough. Also, a similar process was maintained during the discussion with experts. The process of this video walkthrough was inspired by the cognitive walkthrough method (Jadhav and Mehta 2013; Mahatody, Sagar, and Kolski 2010; Cáliz, Gomez, et al. 2016)

Questions: participants were asked questions during step-by-step playing of each video and each core task of footage comprised two questions for young adults with DS and their parents, and three questions for the experts. These two questions were asked to participants with DS during the evaluation process:

Q1. Is that what you expected to happen?
Q2. Do you know what to do/what action is need now/after?

These three questions were asked to parents/caregivers and experts during the evaluation process:

Q1. Is the effect of the current action the same as the user’s goal at that point?
Q2. Is the action available/visible to users?
Q3. Will users understand the feedback they get after the action is taken?

8.4.4.2 Walkthrough data collection and analysis

Seven group discussions with young adults with DS and their parents, and six expert consultations were conducted through Zoom. These discussions were recorded using the Zoom built-in recording tool. The data from the video walkthrough was analysed qualitatively by adopting the process of thematic analysis (Braun and Clarke 2006; Johnson and Lamontagne 1993).

Prepare the data for analysis: first, the author collected transcribed verbatim copies of all group discussions of young adults with DS, their parents and all experts from the Zoom cloud. Second, the author added the core tasks' names (Core Task 1, Core Task 2..., see Table 8.4-2) into each transcript to separate the content according to the Tasks discussed during the walkthrough. Therefore, all transcripts now have task names that make data analysis easy. ***Become familiar with the data:*** all transcripts were read several times, and the recorded videos of the walkthrough were watched at least once until the author became acquainted with the data. The author took notes of ideas and recorded them in a separate Microsoft word file during this stage, which has the potential to support analysis in the later stage. ***Coding:*** at this stage, the words, sentences and paragraphs were highlighted using colour and labelled by applying the appropriate name. The coding process included those relevant concepts and interests within the data that focus on the research and walkthrough questions. The coding process was conducted inductively without using a pre-defined set code (Braun and Clarke 2006). Later, all codes were copied to a spreadsheet and collated into groups based on relevance. ***Assigning themes:*** at this stage, all codes were condensed into categories and allocated to appropriate tasks that were discussed during the walkthrough; more specifically, categories were set accordingly with the UIs discussed during the walkthrough. ***Reviewing and defining themes:*** the categories recognised as tentative themes were set with the UIs reviewed during the walkthrough and ensured that the themes reflected accurate data representations. An additional researcher was invited to involve in the analysis and then discussed all the themes against UIs before reaching a final consensus. At that point, the notes file was updated to reflect their conclusions. Eventually, the final themes alongside UIs described in the finding section include suitable UIs, barriers for young adults with DS and solutions.

8.4.4.3 Survey procedure

The young adults with DS and their parents were asked to fill out an online survey at the end of the discussion. The survey for the users with DS and their parents was categorised into two sections, one for the user with DS (primary user) and other for the parents/caregivers (secondary users). Parents were requested to help individuals with DS to fill out the survey but not to intervene. Similarly, the experts were also asked to fill out the online survey. The survey statements were related to UIs and features of the app that were discussed during the walkthrough (Cáliz, Martínez, and Cáliz 2017; Cáliz, Martinez, et al. 2016; Gomez, Torrado, and Montoro 2017). The survey contained with 7 point Likert scales (Heiberger and Robbins 2014), close-ended and open-ended questions in order to record the level of adoption and satisfaction of the proposed travel app. See “Appendix G: a survey to record users’ satisfaction” for the survey statements and questions. Participants were given 10 hours to fill out the survey after the evaluation study took place. All the participants filled out the survey within the time provided and the origin of the respondents was not collected to maintain anonymous participation.

8.4.4.4 Survey design:

To implement the survey design, including response statements were adopted the HCI survey design guideline (Ozok 2012). In order to overcome the technology accessibility barrier for young adults with DS revealed through scoping review, the survey was designed in the Qualtrics tool that meets the accessibility standard of WCAG 2.0 (Caldwell et al. 2008; Ribera et al. 2009; Whiting 2019). The tool allows users to adjust colour, text size, font style and large buttons according to their needs. Most of the survey designs were the same as the survey designed in cycle 1. Such as text size (18px, bold) and large buttons with text inside, including the statement of response alternatives to ensure easy access and support vision issues. Also, I used blocks to create sections and separate the survey contents. The emoji emotion faces were used in all Likert-type questionnaires that were asked to answer by young adults with DS, and the emoji faces were used to reduce their cognitive load (see Appendix G: a survey to record users' satisfaction). The survey procedures were described, and explained how to answer the survey questions at the end of the walkthrough. Therefore, it was ensured that the young adults with DS understood the purpose of the survey. Also, parents and caregivers were requested to provide support to complete the survey and assist them in understanding the questionnaires.

8.4.4.5 Survey data analysis

First, the data were transferred into a spreadsheet from the Qualtrics server. Then the data were assembled according to participants' responses and the questionaries. Most survey questionaries were Likert-type, which were analysed using the descriptive analysis method to reveal modes, median and frequencies (Allen and Seaman 2007; Boone and Boone 2012). After then, the data were presented using a diverging stacked bar chart (Heiberger and Robbins 2014).

8.4.4.6 Ethics

Due to the nature of the walkthrough process, the ethics were divided into two parts. First part was to create a short video of performing the journey instead of letting participants with DS perform due to their safety because of COVID-19. The crated video than to be used during the evaluation process through Zoom in the second part.

A departmental ethics approval (University of Strathclyde, CIS ethics approval ID: 1361) was obtained for both parts. A details description of personal safety and COVID-19 rules were maintained for the performer and the cameraman described in detail in the ethics application. Also, a detailed procedure of walkthrough via Zoom for young adults with DS and their parents/caregivers were stated in the "Easy read participants information form" (see Appendix H: Easy Read Participants Information Form for User with DS (Walkthrough)) and in the invitation mail. Also, a video tutorial link on how to use the Zoom tool was provided to participants in advance. All Zoom sessions were created with the access code required, and the access coder was mailed to participants one day before conducting the session to ensure secure involvement.

In order to ensure easy accessibility and usability, parents and caregivers were requested to use a device with a large screen, such as a laptop or personal desktop with a large monitor (14" - 15" screen size) to support a clear view for young adults with DS. Also, Zoom's video and voice quality were tested before the session to ensure that the young adults with DS had no issues watching. Similarly, parents and caregivers were requested to put Zoom in full-screen mode to give a clear view to young adults with DS. The consent to record the entire session was obtained from both young adults with DS and their parents/caregivers. They requested to turn off their cameras if they were uncomfortable being recorded on their faces.

8.4.5 Recruit participants

The participatory design allows involving domain experts in assistive technology research for reducing communication challenges or ensure participation of the target users with disabilities in the study by modifying the process participatory design (M. Allen et al. 2008). Also, the involvement of experts in usability evaluation techniques is common in the HCI research under the participatory design process e.g. heuristic evaluation and cognitive walkthrough (Mahatody, Sagar, and Kolski 2010).

This usability evaluation involved HCI researchers as domain experts for a video walkthrough. Also involved target users of the designed app such as young adults with DS and their parents. It is often difficult to reveal the overall judgment of the proposed design/application from its target users due to their lack of knowledge on realistic development and excessively focus on problems discussion rather than focus on its functions and realistic design (M. Allen et al. 2008; Mahatody, Sagar, and Kolski 2010). In addition, involving experts in the usability evaluation may reveal novel outcomes as they have relevant knowledge and experiences in assistive technology research compared to target users.

*Table 8.4-3: Participants with DS's and parents' demographics (P=Young adults with DS, C=Caregivers and * = number of participation).*

Group IDs	DS's IDs	DS's Gender	Caregivers' IDs	Caregivers Gender
1	P15**	F	C30***, C31**	F, M
2	P16*	F	C32*	F
3	P17	M	C33	F
4	P18**	F	C34**	F
5	P19**	F	C35**	F
6	P20*	F	C36*	F
7	P21	M	C37, C38	F, M

Young adults with DS, their parents, and HCI experts were involved in the user evaluation of the designed app on smartphones. Young adults with DS aged 16 and above with mild cognitive disabilities were allowed to take part. Seven young adults aged between 18 to 28 years, three male and four female, nine parents (seven mothers and two fathers) age between 45 to 55 years. Five groups took part in previous cycles (in cycle 2 and cycle 3), referred them with "*" along with ID and two were new (see Table 8.4-3). Six HCI expert researchers aged between 30 – 36 years took part in the walkthrough. Also, for the experts at least one year of experience in the HCI research field was required. All experts had a computer science background knowledge, experienced at doctoral level with usability evaluation techniques, co-design workshop, cognitive walkthrough and were further instructed on how to correctly apply cognitive walkthrough before starting their evaluation session. See Table 8.4-4 for expert participants' demographics.

Table 8.4-4: Expert participants' demographics

Experts' IDs	Profession	Gender
E1	HCI researcher in the health and wellbeing of people with ID.	M
E2	HCI researcher in the health and wellbeing of people with ID.	M
E3	HCI researcher in the health and wellbeing of people with diabetics.	F
E4	HCI researcher in human conversational agents.	M
E5	HCI researcher in health and wellbeing.	M
E6	HCI researcher in the health and wellbeing of people with ID.	F

8.5 Findings of Video Walkthrough and Survey – Users' Experiences

The findings of the user evaluation cycle were described in two parts. First, the findings from the video walkthrough and then the findings from the survey were presented. Also, all these findings were described according to the tasks (see Table 8.4-2 video footage used for the video walkthrough) evaluated during the video walkthrough with participants' quotes where 'P' referred for users with DS, 'C' for caregivers/parents and 'E' for expert users listed in Table 8.4-3 and Table 8.4-4.

8.5.1 Primary users' experiences of the walkthrough (young adults with DS)

Young adults with DS were the primary user of the evaluated prototype. This section presents the findings of primary users' experiences of the proposed prototype for a smartphone. First presented the findings from the walkthrough and then findings from the survey. Also, the findings were described along with quotes from participants with DS, parents/caregivers, and experts.

8.5.1.1 Core task-1: footage showing navigating to the bus stop and recognising the correct bus stop.

UI for turn-by-turn direction instruction (including step-by-step progress bar): the users with DS showed the understanding of turning points during walking. They successfully recognised the walking path were and able to identify the correct direction to take turns. They were able to answer the questions asked about directions by raising their hand to indicate the correct direction. Two features that mainly helped them to recognise this are direction images with direction arrows and auditory voice output. Quotes from young adults with DS and their parents are listed below.

> P15* (Individual with DS): "*the arrow says to turn this way.*"
> P16*: *"I will follow the arrow.",* P17: "*it said to turn right [raising hand]*"
> P18*: "*I will go this way as it tells me to do so.",* P19*: "*I think this way [raising hand]*", P21: "*yes, this is the way to turn right*."
> C30***: "*one instruction at a time. That's great you know any picture, which is which matches what you're looking at in front of you yeah. I think it was good that there was the voice and visuals.*"
> C32*: "*But I think the arrow for the right turn on the screen is the stronger clues and the word turns right.*"
> C37: "*Both the audio and the words.*"

Also, both these features were appreciated by the parents and experts. However, parents and experts suggested not using direction instructions like "*head north-west*" or "*head south-east*", which were not suitable for users with DS due to the complexity of processing spatial navigation (Courbois et al. 2013). They instead suggested using direction images with arrows instead, which were used for other turn-by-turn direction instruction. E3 suggested animated direction arrows (>>>) on top of images would be more attentive for the users with DS. In order to support users with DS in walking navigation a progress bar was introduce that gets filled up while the user walks toward an upcoming turning point. Although, users with DS and their parents felt that this feature can provide a sense of walking progress, it was required to explain the purpose of this feature during walkthrough as always (also required to explain about this feature in the previous cycle). According to expert, as this feature was completely new to users with DS, they recommended practice around the home or a video tutorial to increase their familiarity. With that, E2 also recommended increasing the visual of the progress bar, such as increasing the size and bright colour.

> E4 (Expert): "*You may want to just give them a quick overview for the first-time users, anyway, normally walkthrough. Give them a quick heads up that this going to happen*."

UI to identify the correct bus stop: user with DS were successfully able to recognise the correct bus stop from the image provided in the proposed app. According to the users with DS, the bus stop image was large enough and highlighting it with colour with and auditory voice output helped them easily recognise the bus stop. Similarly, parents and experts showed their optimistic views on the interface for supporting walking navigation that the highlighted colour of the bus stop in the image was a huge help for users with DS (see Figure 8.3-1, image 5).

> P15*: "*Yes, I can see the bus stop [pointing to the bus stop in the video clips]; yes this stop.*"
> P16*: "*I will wait here for the bus*".
> C33: "*In an ideal world, the bus stops have some very clear unique names. And, you would be able to check yours at the right one.*"

8.5.1.2 Core task-2: footage showing recognising the correct bus, accessing the bus, and getting a trip ticket from the bus driver.

Recognising the right bus: the users with DS were able to understand and identify the correct number from information provided in the proposed app e.g., icon with the bus number, the image of the bus and voice over. The recorded video demonstrated three buses at a time approaching the bus stop (see Figure 8.5-1). The users with DS were asked questions "e.g., *which bus will you take?*" after pausing the video. They were able to answer correctly saying the bus number ('9') and pointing to the correct bus on the laptop screen. Also, they understood getting ready with their bus pass while the video demonstrated how to prepare for the bus with the bus pass. E3 suggested a flashing gif image to be highlighted for the image of getting into the bus (see Figure 8.5-2, image 1).

> P17: "*No, it's not number 9 [while other buses were arriving at the stop].*"
> P18**: "*yes, it says number 9 here [pointing on the app screen]*."
> E3: "*maybe you want to emphasize more so, a gif could work well there or flushing images stuff, other one stays away from clashing images in case…*"

Getting a trip ticket from the bus driver: the task of getting a trip ticket from the bus driver requires verbal communication. The designed UI (see Figure 8.3-1, image 6) was used to overcome verbal communication with the bus driver. Users with DS showed the understanding to perform the task. They need to show the smartphone screen to the bus driver for the correct trip ticket. They were able to read the instructions for the bus driver from the smartphone screen and explain them. The UI for the trip ticket contained the instructions of the journey destination with the type of trip ticket (return/single ticket) they need and their bus number. Parents and experts described it as a novel interface to reduce communication barriers between the bus driver and individuals with DS.

Figure 8.5-1: the video demonstrates three different buses approaching the bus stop.

> P19**: *"it says bus no 9. A return ticket. Going to……, Paisley. [reading instructions from the screen]",*
>
> P15**: *"yes, a return ticket. "*
>
> C34**: "*That on the screen [instructions for the bus driver] is the best thing for me".*
>
> C30***: *"so that comes on your show you the driver yeah I tell you what's good about this, you get on the wrong bus the driver is a way, he should say, is it not number nine [bus number], you have to wait for the next bus yeah. The screen that's really good, because that will allow the driver and he's on the wrong path."*

According to them, the bus driver can ensure the right bus for the user with DS by reading the instructions on the smartphone screen. (Note: during video recording, the bus driver gave the right ticket only by reading instruction from the smartphone screen). Although no issue was raised from the bus driver to read the message from the smartphone screen, all experts suggested the UI (the message for the bus driver) could be made more visible for the bus driver by removing the text layer in the background. Later, the UIs was updated based on the suggestion given by the experts (see Figure 8.5-2, image 1). E4 noted:

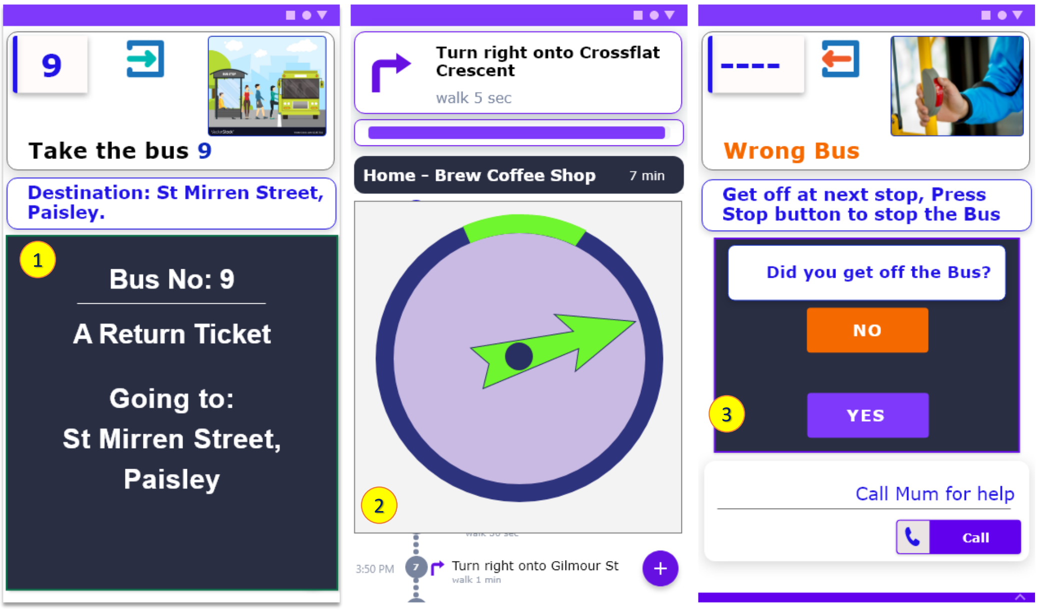


Figure 8.5-2: the updated UI to get the trip ticket from the bus driver (image 1), UI for dealing with directions while walking (image 2) and UI for supporting when the user gets on the wrong bus (image 3).

> E4: *"You could probably bring more attention to start by clean out the background. That may be a bit easy to read for the driver if you clear the background* [Figure 8.3-1, *image 6] then know what they're looking at."*

8.5.1.3 Core task-3: footage showing how to get off from the bus, crossing the road carefully and finding the destination. The sub-tasks are:

Get off from the bus: findings proved that the users with DS showed an easy understanding of stopping the bus by pressing the stop button. According to the users with DS, the use of the image in the UI (see Figure 8.5-3) helped them to understand this task compared to voice instructions. Also, both parents and experts expressed their views toward easy adoption of stopping the bus for the user with DS.

P16*: *"I will press the red button, yes…".*

C35**: *"What do I think it's good, it's clear for you to press the button there yeah, you get off the bus."*

C37: *"The tech know you're [user with DS] going to arrive at the stop, what do you [user with DS] need to do is looking at the presented picture."*

Figure 8.5-3: UI demonstrates to take off the bus.

Road/Street Crossing: the task that demonstrated road crossing was not easy to understand for the users with DS, because this task involved a few steps to follow, which forced them to take extra time to adapt quickly. The steps are pressing the stop button at the road crossing, waiting for the green light and crossing the road when the green light appeared. The designed UI contained all these steps in sequential order and the video was demonstrated accordingly. The video was paused on each step during the video walkthrough and they were asked related questions (e.g. *do you know what to do if you see this screen?*). In regard to answering the questions, the user with DS was looking at the screen and looking for instructions from the UI, which took a few moments to answer correctly. Eventually, the confidence and excitement in their facial expression showed that they successfully understood the whole purpose of the UI.

Parents and expert described this UI as useful for users with DS when crossing the road. They particularly mentioned the crossing highlighted with the bright colour, use of images in each step with text instructions (see Figure 8.3-1, image 7 and Figure 8.4-1) and described it as a good reminder for the users with DS.

> P17: *"I will for the green man, then cross."*
> P18**: *"I will wait, see both sides, then cross…."*
> C36*: "*One good at that I think again it's a good reminder if he [user with DS] saw a friend at the other side of the road, might get excited to cross the read."*

8.5.1.4 Core task-4: footage showing how to deal with unexpected circumstances, e.g. user turning in the wrong direction off the route while navigating to the bus stop from home.

Help UIs to support during the journey: one interface for sharing feelings or requests for support (see Figure 8.3-1, image 8) and two interfaces were designed to deal with unexpected circumstances during travel (see Figure 8.5-2, image 2 and see Figure 8.5-2,image 3).

a) **UI for help to get assistance and share feelings with parents/caregivers**: the use of the first UI was recorded in the video when the user was inside the bus and the scenario was to send a message or make a phone call to contact or share their feelings with their parents. The demonstrated video showed the use of UI by pressing the floating help button on the bottom right side of the screen and sending a message to parents (see Figure 8.3-1, image 8). The findings revealed that the users with DS find it difficult to understand the use of the UI for help during the video walkthrough. Also, parents had to provide a detailed explanation about the use of the UI to users with DS, which helped them to understand the purpose and circumstance of using this UI. Parents and caregivers suggested practicing in the real-life environment.

> C33: *I think once they know that's what happens after practice a few times that would be fine with him [user with DS]. Because he [user with DS] will be a user you know.*
> P15** and P16*: *"I will call my mum. "*, P18**: *"I don't know [confused face]."*

b) UI to deal with unexpected circumstances during travel - walking in the wrong direction: the outcome revealed that the users with DS have understood the use of the UI with the compass to deal with circumstances like walking in the wrong direction during walking navigation (see Figure 8.5-2, image 2). The adoption of the use of this UI was quick enough by the user with DS after being explained during the walkthrough. However, parents and experts recommended practicing and training both UIs for help and dealing with unexpected circumstances. However, C30*** stated the concern about the compass usage by the user with DS.

> C30***: *"yeah the difficulty with the compass, I imagine, is it depends, which way you're holding your phone, so if you turn the phone a different way it will take you that way."*

c) UI to deal with unexpected circumstances during travel - getting on the wrong bus: this UI represented how to deal with the user taking the wrong bus or the bus going in the wrong direction (see Figure 8.5-2,image 3). The users with DS showed difficulties in interacting with this UI during the walkthrough. In regard to answering the question "*do you know what to do if you see this screen?*", they were only able to answer with the use of the calling button e.g. "*Call mum for help*". They were not able to answer that they have to get off the bus at the next stop as the UI instructed them to do so.

> P15**: *"I will phone mum; I know mum's number."*
> P18**: *"I don't know. I can call my dad."*

However, the users with DS understood the instructions for getting off the bus after they were explained. Although, according to parents the UI was useful for users with DS and it carried useful features for interaction and overcoming such circumstance. Regarding the safety issue, a few contradictory views were revealed between parents and experts in order to get off the bus when the user with DS realised that he/she was on the wrong bus. Parents recommended motivating the user with DS to get off the bus, as soon as the app will detect the wrong bus from the bus direction and GPS location. C30*** and C37 noted:

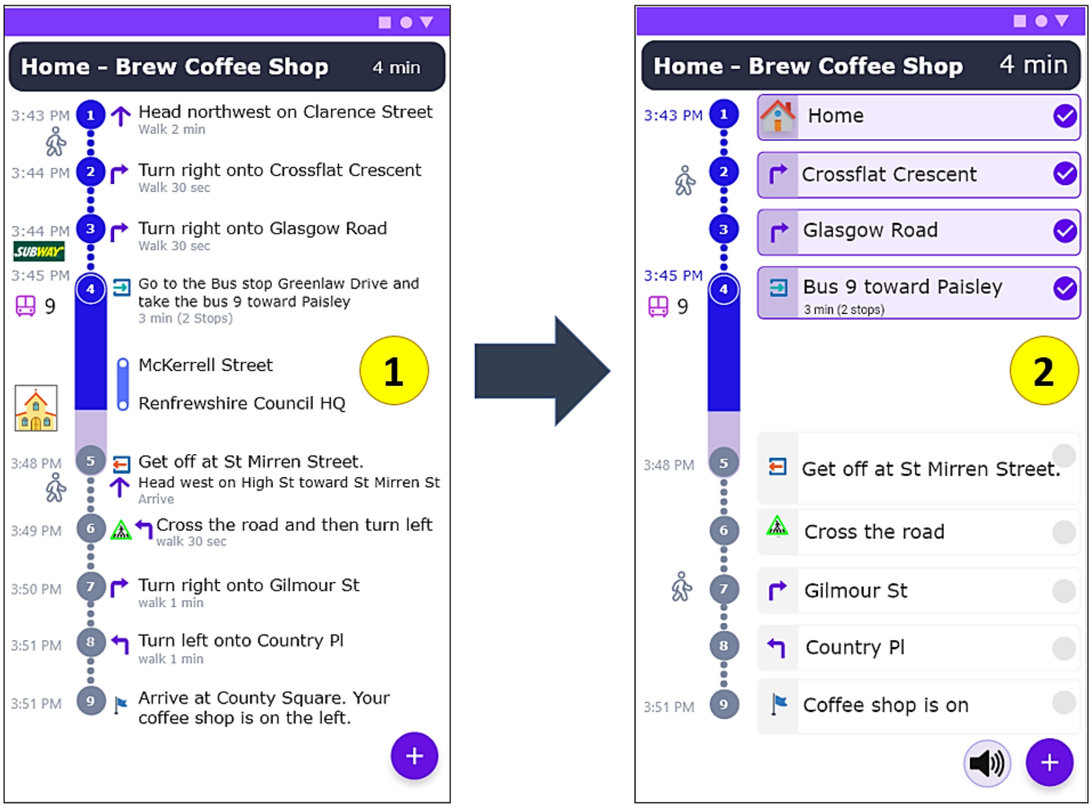
> C30***: *"It's a tricky one; I think the most important thing is probably for them to get off the bus."*
> C37: *"I think it was bus been funny that he [user with DS] was going in the wrong direction completely so most important thing is for him to get off the bus, and I think that's quite good yeah."*

According to C36*, getting on the wrong bus can be prevented from happening if the UI of 'getting a trip ticket from the bus driver' is used correctly.

> C36*: "*Because if you've done, the first step of showing [mobile screen] the bus driver when you buy the ticket this shouldn't happen anyway.*"
> E1: *"getting off at a stop that they are not familiar with would really make them more vulnerable"*

On the other hand, experts (E1 noted) raised the issues of safety concern that the instructed bus stop may not be safe for the user with DS to get off the bus (it is needed to mention that the instruction to get off from the bus was a requirement that was gathered during the requirement gathering cycle in cycle 3). However, parents and experts agreed to provide training and help practicing until the user with DS adopted the UI.

Linear map to represent the whole journey: the linear map represented the whole journey with all steps from start to end in chronological order (see Figure 8.5-4, image 1).



Home - Brew Coffee Shop 4 min

3:43 PM 1 Head northwest on Clarence Street
Walk 2 min

3:44 PM 2 Turn right onto Crossflat Crescent
Walk 30 sec

3:44 PM 3 Turn right onto Glasgow Road
Walk 30 sec

3:45 PM 4 Go to the Bus stop Greenlaw Drive and take the bus 9 toward Paisley
3 min (2 Stops)

McKerrell Street

Renfrewshire Council HQ

3:48 PM 5 Get off at St Mirren Street.
Head west on High St toward St Mirren St
Arrive

3:49 PM 6 Cross the road and then turn left
walk 30 sec

3:50 PM 7 Turn right onto Gilmour St
walk 1 min

3:51 PM 8 Turn left onto Country Pl
walk 1 min

3:51 PM 9 Arrive at County Square. Your coffee shop is on the left.

Home - Brew Coffee Shop 4 min

3:43 PM 1 Home ☑

2 Crossflat Crescent ☑

3 Glasgow Road ☑

3:45 PM 4 Bus 9 toward Paisley ☑
3 min (2 stops)

3:48 PM 5 Get off at St Mirren Street. ○

6 Cross the road ○

7 Gilmour St ○

8 Country Pl ○

3:51 PM 9 Coffee shop is on ○

Figure 8.5-4: the design adoption of the linear bar from the previous interface (left image 1) and shown each completed step with check-marked (right image 2).

Findings revealed a neutral outcome of the linear bar adoption by young adults with DS. The purpose of the linear bar use was able to be understood quickly by the users with DS after a short explanation. The UI was tested with users with DS to justify the adoption. First, young adults with DS were asked to identify the start and end points of the journey. Second, to determine their current location on the linear bar. They pointed out their current position and start and end point on the linear bar by pointing it out on the laptop screen during the walkthrough.

> P15** and P21: *"Here is me [pointing to the location on the mobile screen in the linear map]*."
> P17: "*I am on '2' here [step 2 in the linear map].*"
> P19**: "*my current location here [pointing to the location on the mobile screen in the linear map]*".

Third, they were asked to read instructions based on their journey progress and location. Only three answered correctly, but all of them showed their confusing faces. It turns out that the direction instructions were listed without highlighting, which confused users with DS. Also, the instructions that were in long sentences demotivated them to read. According to parents, the linear bar was useful to provide a sense of journey progress and to represent the whole journey with live GPS location. However, C30*** recommended highlighting the bar along with the direction instructions around it with colour while the journey progressed, not only the bar colour. Also, they recommended using the checkbox along each step, highlighting with colour, and marking when the step progressed. These requirements were also captured during requirement gathering in cycle 2 (see section 6.5.5, Figure 6.5-2). Similarly, C32* suggested removing the bus stop name between departure and arrival stops. According to her, it does not help users with DS. The participants in cycle 3 raised a similar issue.

> C30***: *"And I think we need some kind of very strong visual clue as to which steps you've done, which step you're on and which steps you haven't got to yet, at the moment I look at that I didn't know where I haven't. We are just have that one [highlighted bar with colour] shining out with something that's good.*

Adoption: it became clear that the design for the linear bar needs to be updated in order to ensure effective interaction by the users with DS, therefore the design was adopted according to parents' suggestion (see Figure 8.5-4, image 2). Several implementations in the design make adoption easy for them. Such as the linear bar representing the journey route and circles in numeric order to represent steps that helped them follow the instruction to make the right move. The journey progress represented in the liner bar with blue colour enabled them to recognise the current location. However, the textual instructions in each step were a bit confusing for them. Because all steps instructions were listed together, some of the instructions were in a long sentence. Also, the textual instructions contained walking time length between steps (see Figure 8.5-4, image 1). Young adults with DS did not show interest in the times on each step and landmark icons with the bar during the walkthrough. Eventually, this UI contained some needless navigation support information, resulting from the interface being incompatible with reading information. Therefore, the repeated textual information removed, such as "turn right/left onto", only kept the steps name with turning arrows and increased the font size. Also, removed walking times length between turns from the textual instruction, times in each step and landmark icons. However, removing all this information will not affect their navigation performance, as it is available in other interfaces. Such as textual information for navigation support is available in the top instruction panel and appears on the screen when needed (see Figure 8.3-1, image 4).

Likewise, the landmark image is also available and will appear on the screen when needed. The changes also included the checkmarks that tie in with the journey progress of each step. All these changes will ensure easy adoption by young adults with DS. On the other hand, experts recommended practice and training a few times to increase familiarity for adoption, as this feature was completely new for the users with DS.

Voiced instructions: parents and experts appreciated the use of auditory instructions which provided huge support for users with DS to adopt the app. According to parents' opinions, an upgrade in voice instructions was urged. The voice triggers and speech playback used in the "*MYINDEPENDENTTRAVEL*" app were more like a robotic voice (used speech playback voice from Adobe XD) than a human voice with a foreign accent. Parents recommended a voice like a human for speech playbacks such as Siri and Alexa with a local language accent. Furthermore, according to experts, playback speech and language accents can be adopted easily in the proposed app, which will help users with DS to interact with the app without having an excessive cognitive load.

C33: *"The voice is very [country] not familiar."*

Additionally, users with DS and parents both suggested a mute button on the screen to mute instructions when needed, which was made available on the screen see Figure 8.5-4 (image 2). The need for an on-screen mute button also raised during cycle 3 (see section 7.4.4).

8.5.2 Primary Users' Satisfaction - Findings from the Survey

A total of eleven statements were asked to users with DS to provide their level of understanding about the designed UIs of the "*MYINDEPENDENTTRAVEL*" app on a seven-point Likert scale from 1 (= strongly disagree) to 7 (= strongly agree) (Heiberger and Robbins 2014). The statements referred to the UIs and features with users' role for using the "*MYINDEPENDENTTRAVEL*" during travel. Also, similar statements were asked to expert users for their feedback after the walkthrough. Figure 8.5-5 illustrates the summarised views of users with DS and expert users. Overall, affirmative scores were revealed in the majority of the statements. According to both users with DS and experts, the agreement was particularly strong on four statements "*current location update in real-time*" (users with DS's score = 7 and experts' score = 6-7), "*UI for communication with bus driver*" (scores=

6-7), *UI for help to get assistance (help button) during travel”* (users with DS’s score = 7 and experts score = 5-7), “*turn-by-turn direction instructions to support walking path*” (score= 6-7 for both users with DS and experts). On the other hand, similar agreement was revealed from both types of users on “*use of auditory instructions*” (score= 4-7). Although, users with DS found easy understanding (score = 5-7) of “*step-by-step progress bar to support walking path*” but the experts' score (score = 4-7) were not as similar as users with DS, which means experts did not think that the task will be easy for users with DS to understand.

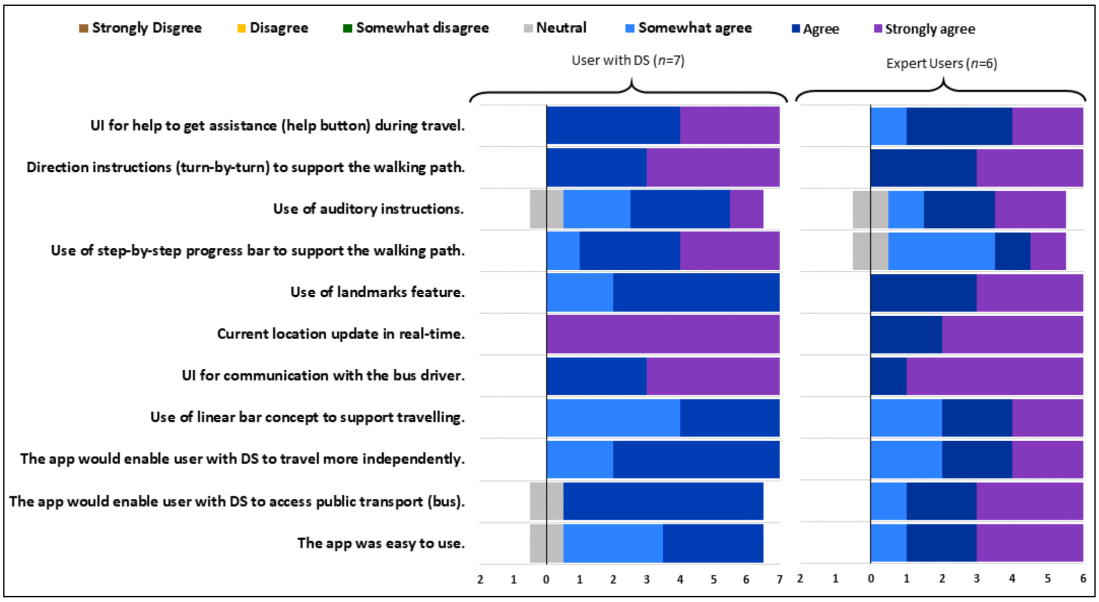


Figure 8.5-5: users with DS (n=7) and expert (n=6) views on UIs and features of the “MyIndependentTravel”. Diverging stacked bar chart demonstrating the frequency of different levels of agreement on 11 statements. Score from 1 (strongly disagree) to 7 (strongly agree)

However, agreement on UI for “*use of linear bar concept to support travelling*” (both types of users’ scores= 5-7) was revealed as strong from both users with DS and experts. On the other hand, more diverse viewpoints were revealed between users with DS (score= 4-7) and experts (score= 5-7) on the statement of “*the app* *was easy to use*". Similarly, for the statement of "*The app would enable users with DS to access public transport (bus)*".

8.5.3 Secondary users' experiences of the walkthrough (parents and caregivers)

Parents and caregivers were the secondary users of the evaluated prototype. This section presents the finding of secondary users' experiences of the evaluated prototype for a smartphone. First presented the findings from the walkthrough and then findings from the survey. Also, the findings were described with parents'/caregivers' and experts' views together.

8.5.3.1 Core task-5: showing caregiver tracking and monitoring the primary user's (individual with DS) location using a smartphone and receiving notification of the journey progress.

Notification and alert message for the journey progress: the aim of the UI for notifications was to provide updates about the journey progress of the user with DS to parents' smartphone. According to parents and experts' views, the UI for notifications about the journey progress was satisfactory in term of parents' expectations. All parents and experts have expressed their constructive views and explained this as one of the foremost UI to maintain their peace of mind by receiving the journey progress. However, parents requested limiting the amount of notifications by categorising important events instead of receiving notifications for all events. For instance, notifications for when a user with DS reaches the bus stop, gets on and off the bus, reaches the final destination etc. Also, they requested an option/button to turn off the notifications, which will help them when they are busy at work. In addition, besides notifications parents requested an alert message about any serious incident, e.g. when the user with DS gets on the wrong bus. Such requirements were also revealed in cycle 2 (see section 6.5.1).

Tracking and monitoring location: findings revealed an acceptable level of satisfaction among parents during the walkthrough with tracking and monitoring UI. With regards to parents' worries and tensions, when users with DS are outside the home, it seems like it has reduced their anxiety already after the walkthrough. Both parents and experts greatly appreciated the UI that gave the live location tracking facilities. Similarly, the UI for receiving/sending messages and calling options for communication was appreciated by all parents.

Moreover, findings did not reveal any difficulties or disagreements on other features or UI such as creating/editing journey plans for the user with DS, adding landmark and bus stop images etc.

8.5.4 Secondary users' satisfactions – Finding from the survey.

Parents' and experts' views on the secondary user of the "*MYINDEPENDENTTRAVEL*" app were evaluated based on seven statements that the participants were asked to rate on a seven-point Likert scale from 1 (= strongly disagree) to 7 (= strongly agree). The statement referred to the UIs and features with the secondary users' role for using the "*MYINDEPENDENTTRAVEL*" app to deliver support to an individual with DS.

Figure 8.5-6 summarised the views of parents and experts as secondary users of the "*MYINDEPENDENTTRAVEL*". The findings recorded affirmative scores in all seven statements. The statement for "*UI for tracking and monitoring feature*" was revealed as a strong statement with the highest agreement scores (6-7) from both parents and experts. The statements "*Receiving notification regarding the progress of the journey*" (parents' score=5-7, *n*=7 and experts' score=6-7, *n*=6) and "*UI to deal with unexpected circumstance for users with DS during travel e.g. get into the wrong bus*" (parents' score=5-7, *n*=7 and experts' score=6-7, *n*=6) were found dissimilar agreements between parents and experts. Also, diverse views from both parents and caregivers were revealed on the statements "*the app would enable users with DS to travel more independently*" (parents' score=6-7, *n*=7 and experts' score=5-7, *n*=6), "*the app would enable users with DS to access public transport*" (parents' score=5-7, *n*=7 and experts' score=5-7, *n*=6) and "*the app was easy for you to use as parents/caregivers*" (parents' score=5-7, *n*=7 and experts' score=6-7, *n*=6). Accordingly, diverse user agreements were recorded on the statement of "the app helped to reduce your anxiety as a parent/caregiver" (parents' score=6-7, *n*=7 and experts' score=5-7, *n*=6), the levels of agreement ('agree/strongly agree') with this statement indicated that parents were confident enough that the "*MyIndependentTravel*" app could reduce their level of anxiety.

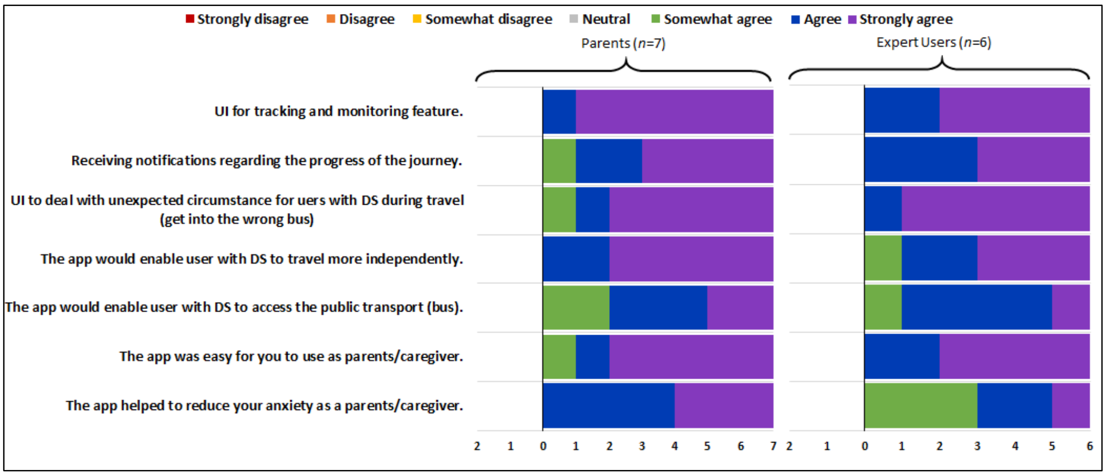


Figure 8.5-6: parents' (n=7) and experts' (n=6) views on UIs and features for secondary users of the "MyIndependentTravel" app. Diverging stacked bar chart demonstrating the frequency of different levels of agreement on seven statements. Score from 1 (strongly disagree) to7 (strongly agree).

8.6 Discussion Cycle 4

The outcome from both discussion and survey make it clear that the usability interaction of the designed app through video walkthrough was satisfactory for young adults with DS and their parents.

8.6.1 Eradicating identified barriers to independent travel for young adults with DS.

Six important and necessary UIs under four core tasks were evaluated and discussed for the users with DS. These were 1) UI for help to get assistance (help button) during travel, 2) turn-by-turn instructions UI (including step-by-step progress bar) to support the walking route, 3) UI to identifying the desired places (bus stops, landmarks), 4) UI of the linear bar with the live GPS location and travel instructions, 5) UI to support communication with the bus driver and 6) UI to support crossing the road. The findings from the walkthrough and survey results indicated that most of these UIs' usability purposes have been understood by the users with DS. Also, most of these interfaces appreciated by the parents and experts. In addition, parents and experts recommended and suggested alternatives to those UIs/tasks that were found to be difficult to understand by the users with DS. Given that, the findings revealed that most of the barriers to independent travel identified in cycle 2 could be overcome successfully (see section 6.4).

8.6.2 As for the barrier to unfamiliarity with the new route

The outcome of Core task-1 (see section 8.5.1) and the survey agreement score for “*turn-by-turn direction instructions to support walking path*” (score = 6-7 for both users with DS and experts), also positive agreement score for “*step-by-step progress bar to support walking path*” (users with DS score= 5-7 and experts score = 4-7) indicated that the use of direction images, text, landmark, and the step-by-step progress bar with auditory instructions in the “*MYINDEPENDENTTRAVEL*” app can effectively increase familiarity with the new route for navigation (García De Marina, Carro, and Haya 2012; Bathgate et al. 2017). Also, can efficiently remove the difficulties to recognise the desired places (e.g., bus stop) by the young adults with DS. Similarly, the outcome of Core task-3 (see section 8.5.1.3) revealed that the use of simple instructions with images (e.g. images of pedestrian crossing light) and auditory instructions for the pedestrian crossing in the app can successfully remove the difficulty of using pedestrian crossings for the users with DS (N Kaoua, Landuran, and Sauzéon 2019; Lazar et al. 2018).

8.6.3 For the barrier to public transport access

The outcome of Core task-2 and the survey results (see section 8.5.1.2) with the optimistic agreement of "*UI for communication with Bus driver*" (both types of users scores= 6-7) suggested that the young adults with DS can efficiently access public transport from the UIs' instructions and used images in the app. Participants were able to recognise the correct bus stop and the bus from the UIs' instruction and images (actual bus stop and the bus images were used in the UI). Difficulties like communicating with the bus driver were easily overcome by using the designed UI (see Figure 8.5-2, image 1) that helps users with DS to receive a trip ticket without communicating verbally (Stock et al. 2013; Davies et al. 2010).

8.6.4 Reducing the barrier to suitable technologies and apps for navigation

It was clear from the outcome of Core-task-4 (see section 8.5.1.4) and from the survey results on the agreement of the statement of "*use of linear bar concept to support travelling*" (both types of users scores= 5-7). Also scored for the statements of "*the app was easy to use"* and "*The app would enable users with DS to access public transport (bus)*" (users with DS's score= 4-7 and experts score= 5-7) indicated that the linear bar as an alternative to Google Map and full planed journey with the live location tracking abilities were found useful to be for users with DS.

8.6.5 With regards to parents' anxiety

Removing all these barriers (discussed above) for the users with DS seriously reduced parents' anxiety which was found to be a key barrier to travel for young adults with DS. Furthermore, the ability to receive and monitor the progress of the journey by parents through notifications and GPS tracking brought tranquillity among parents which also was a sign of reducing anxiety for the parents. As such calmness among parents was revealed from the outcome of Core task 5 (see section 8.5.3.1) and all positive agreement on all statements in the survey results, especially the positive agreement on the statement of "*the app helped to reduce your anxiety as a parent/caregiver*" (see Figure 8.5-6) indicated that the proposed solution was not only suitable for young adults with DS, it was also appropriate for their parents.

8.6.6 The ability to perform tasks/activities by young adults with DS

The most appreciated UI was "*UI for communication with the bus driver*" which supports the user with DS to receive a trip ticket from the bus driver (see section 8.5.1.2, Figure 8.3-1, image 6). According to parents and experts, a user with DS can use this interface without spending a heavy cognitive load (Reis and Almeida 2016; Lourdes et al. 2016; N Kaoua, Landuran, and Sauzéon 2019; Kramer, Covaci, and Augusto 2015). Similarly, most of these interfaces included with auditory speech playback such as "*turn-by-turn direction instruction*", "*step-by-step progress bar*", "*recognising right bus stop*", "*identifying correct bus*" and the interface for "*road crossing*" were found to be effective and these interfaces did not require a heavy cognitive load to interact with for users with DS (Roberto Alesii et al. 2015; R Alesii et al. 2013; Bathgate et al. 2017; Lazar et al. 2018). Furthermore, the satisfactory understanding of the UIs by the users with DS falls in line with the previous findings in the literature that the use of images, signs, graphics, landmark and audio help them to increase their capability for performing tasks/activities with lower cognitive load (Visu-Petra et al. 2007; Lanfranchi, Cornoldi, and Vianello 2004; Villasante et al. 2019). However, one interface "*UI to deal with unexpected circumstance during travel (get into the wrong bus)*" was found to be difficult and required a heavy cognitive load to translate by the user with DS.

It was noteworthy that the users with DS easily understood/adopted those interfaces that required one or two subsequent steps to follow/process. However, the interfaces that required more than two steps to follow/process were found difficult to understand/adapt by the users with DS. To explain in detail, interfaces that were understood and adopted well by the user with DS only required one/two steps to perform or remember (or process cognitively) such as the interface for "*turn-by-turn direction instruction*", which only required the user to follow one instruction (one-step process) at a time which was the instruction for direction, they did not need to remember the road name or how many turns until the bus stop. In addition, they have many forms of instruction for direction such as text, images with direction arrow and auditory instructions. Similarly, the interface for "*identifying correct bus*" only required matching the bus number displayed on the smartphone screens' to the bus that came to the bus stop. In addition, they did not require thinking about when the bus is approaching as they received an alert, so then the user with DS required only a step to understand and adopt these UIs.

On the other hand, the interface to deal with when the user took the wrong bus included more than two steps that the user was required to adapt to and understand. First, the user was prompted with an alert screen with written instruction and audio playback speech which the user wad required to read/listen to the alert messages carefully. Second, the user was prompted to press the stop button to get off the bus, which may not require a heavy cognitive load, but it was a subsequent step that needed to be followed. Third, after getting off the bus, the user was automatically redirected to home by being directed to the nearest bus stop for the bus to home. Therefore, it proved previous findings of the literature review about difficulties to interact/translate/understand/process those tasks/activities that involved two or more subsequent steps and required a heavy cognitive load to process for people with DS (Rowe, Lavender, and Turk 2006; Lee et al. 2011; Kogan et al. 2009). In addition, such evidence proved that young adults with DS may not be able to perform certain complex tasks/activities that involve multiple steps. However, such tasks/activities that involved multiple steps (more than one step process) can only be performed by individuals with DS by presenting those tasks/activities as a step-by-step process (Lourdes et al. 2016; Reis and Almeida 2016; Covaci et al. 2015).

The findings of the inability to understand the complex direction instructions ("head north-west") by users with DS evidenced the previous findings in the literature that they have deficiencies to process spatial knowledge for navigation and explore their own location surrounding in an environment (Courbois et al. 2013; Covaci et al. 2015).

8.6.7 Human factors

Human factors that affect the performance of young adults with DS were revealed throughout the literature review (see section 2.3) and findings from the previous cycles (cycle 2, cycle 3 and cycle 4). These factors were summarised with design solutions in Table 8.6-1. These factors were highlighted as design barriers and can be established as boundaries to the "Inclusive Design Cube" as each cube axis represents the inherent interaction of perceptual, cognitive and motor actions (Pattison and Stedmon 2006; Simeon Keates, John Clarkson, and Robinson 2002; S Keates et al. 2000).

Therefore, the designed prototype can be more inclusive by considering these factors and potentially including more users. Most of these human factors were encountered by following the principle of WCAG 2.0 (including WCAG 2.0 Techniques that Apply to Mobile) (Patch, Spellman, and Wahlbin 2015; Caldwell et al. 2008)

Vision: the button and text size were increased due to the vision difficulty, and used speech playback to support direction information for navigation. Although none of the participants was associated with severe vision difficulty in this research, some had reading difficulty (reading from the mobile screen).

Hearing: although no participant showed hearing difficulties in this research. However, recommended using headphones while on public transport, such as the environment inside the bus may be noisy during busy hours, which may affect the hearing of young adults with DS (with mild ID) or similar groups of users

(Kreicher et al. 2018; Hamberis et al. 2020; De Schrijver et al. 2019; Keiser et al. 1981).

Table 8.6-1: Factors that affect young adults with DS and taken actions to support

Factors	General effect on young adults with DS	Potential design solution	Taken actions according to WCAG 2.0
Vision	▪ Bifocals may require ▪ Standard light required	▪ Large and separated keys with adjustable font size ▪ Texts with high-quality sound.	▪ Increased font and button size ▪ Used speech playback
Hearing	▪ Mild hearing loss	▪ Hearing aids, "hearing aids over-ear headphones", loud and clear sound,	▪ Recommended using "headphones."
Finger function	▪ Dexterity often impaired ▪ Gesture difficulties	▪ Increased size of the touch button, ▪ Use the most accessible gestures, such as 'tap' and 'swipe.'	▪ Used medium extra-large buttons with icons. ▪ 'Tab' for gesture was used.
Communication	▪ Limited remote communication via phone call ▪ Oral communication due to speech intelligibility	▪ Direct phone calls ▪ Augmentative communication devices, audio loop systems, voice-to-text/sign. ▪ Contact list with images and large display. ▪ Symbolic language	▪ Image along with text ▪ Help button (phone call) ▪ Pre-written massages
Cognitive processes	▪ Lack of time management/scheduling ▪ Poor remembering ability (activities/tasks) ▪ Poor decision-making ability ▪ Poor understanding of geolocation	▪ Video-based prompting system, prompt instructions, Google Calendar. ▪ Context-aware guidance systems. ▪ "Aurasma" and "Cha-Ching Pocket Money Manager" for money handling. ▪ Virtual Environment (VE) practice navigation and landmarks. ▪ Direction arrows on photographs.	▪ Places images with direction arrows for walking navigation ▪ Prompt notification, voice alerts and vibrations. ▪ Used places images for the landmark, ▪ Horizontal and vertical linear progress bar to represent the journey

Dexterity: touching small buttons were difficult for the DS user revealed from the outcome of this research, and gesture difficulties, including keyboard, were found in the literature. Therefore, the author focused on implementing those touching features that will reduce dexterity issues, such as pre-written messages, which will help users avoid using the keyboard. Buttons were designed with large/extra-large and text sizes and used only "Tab" to support effortless dexterity for users with DS.

Communication: a help button was created to support direct phone calls during emergencies and pre-written text messages to save time and avoid typing difficulties. Also, used buttons, panels and alert messages by combining text and images. Such as the "home button" with a home image and bus image for alert notifications while the bus is about to approach.

Cognitive progress: experts recommended practices tasks/activities until they (users with DS) become familiar with them. Alert messages and prompt notifications (with vibration) were designed in order to support timetables and schedules. A horizontal progress bar to help turn-by-turn directions along with directional arrows on the image and a vertical linear progress bar to represent the whole journey, tracking the journey's progress and landmark with the place's images, eventually decreasing cognitive pressure.

8.6.8 Methodological strength and weakness

The remote usability evaluation through video walkthrough for mobile app review was found to be effective for parents, experts and young adults with DS. Such remote usability evaluation approach was especially found to be essential and useful for overcoming situations like COVID-19. However, the inability to understand the scenarios related to tasks/activities by the users with DS during the walkthrough revealed a drawback for such remote evaluation. For instance, UI for help (see Figure 8.3-1, image 8) presented during walkthrough that surprised and confused users with DS, because there was no real need for help during remote evaluation. Similarly, how to overcome such a barrier when the user gets on the wrong bus was found to be difficult to understand by the users with DS, which could have been easy to understand for them through the field study.

8.6.9 Experts' assessments

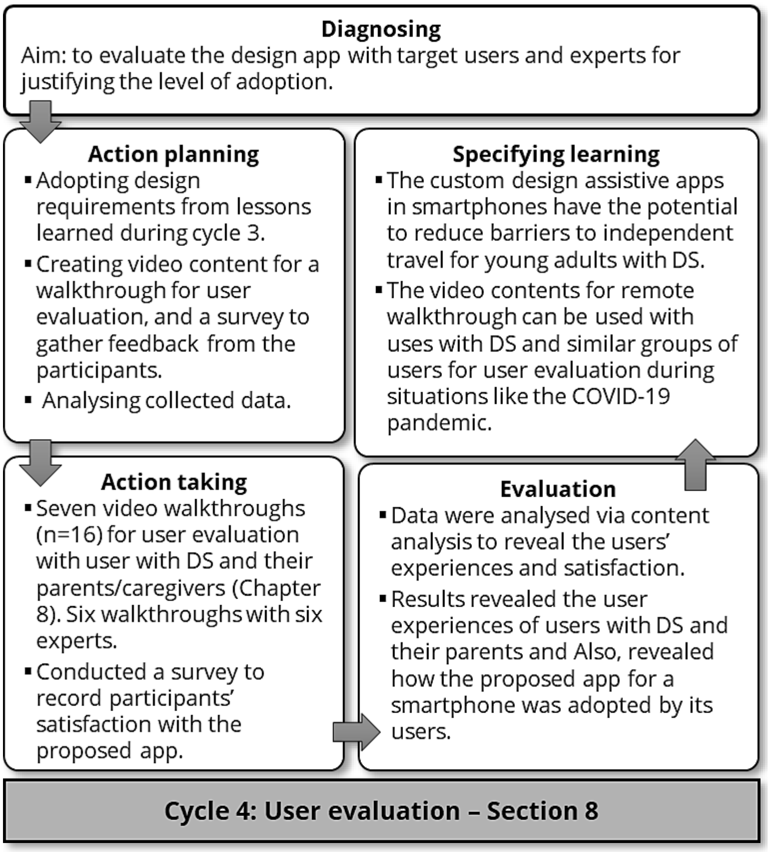
Experts suggested training and practice on those tasks/activities that might be difficult or those features that are new to understand/perform by the users with DS. They mainly suggested two forms of training/practice e.g. video training (Lourdes et al. 2016; Reis and Almeida 2016) and learning by doing.

> E6: *"you need to make that clearer to users then, especially first-time users, have icons in it to help or give a tutorial when start to show them the main functions."*

Such training and practice recommendations by parents and experts were not new, as previous findings through the literature review (see section 4.8.2.1 and 4.8.3.4) revealed the necessity of practice and training on particular tasks to achieve a satisfactory outcome (Lazar, Kumin, and Feng 2011; Kumin et al. 2012; Hu et al. 2013).

8.7 Conclusion of User Evaluation

This chapter described the groundwork for remote usability evaluation and then presented the process of the remote usability evaluation through the video walkthrough with young adults with DS, their parents and expert users in the field of HCI. At first, the design gaps were adopted accordingly from the outcome of cycle 3 and created an updated version for the remote evaluation. Later, the updated version of the app was used to create a video of performing an independent journey to be used during the evaluation. Afterwards, the result of the user evaluation was presented in two parts, one was users experience for young adults with DS and the other was users' experience of parents.



Diagnosing

Aim: to evaluate the design app with target users and experts for justifying the level of adoption.

Action planning

- Adopting design requirements from lessons learned during cycle 3.
- Creating video content for a walkthrough for user evaluation, and a survey to gather feedback from the participants.
- Analysing collected data.

Specifying learning

- The custom design assistive apps in smartphones have the potential to reduce barriers to independent travel for young adults with DS.
- The video contents for remote walkthrough can be used with uses with DS and similar groups of users for user evaluation during situations like the COVID-19 pandemic.

Action taking

- Seven video walkthroughs (n=16) for user evaluation with user with DS and their parents/caregivers (Chapter 8). Six walkthroughs with six experts.
- Conducted a survey to record participants' satisfaction with the proposed app.

Evaluation

- Data were analysed via content analysis to reveal the users' experiences and satisfaction.
- Results revealed the user experiences of users with DS and their parents and Also, revealed how the proposed app for a smartphone was adopted by its users.

Cycle 4: User evaluation – Section 8

Figure 8.7-1: Remote user evaluation through a video walkthrough to capture user experiences.

The qualitative analysis and the survey outcome revealed a well understanding of the user interfaces (UIs) of the designed app for overcoming most of the barriers to independent travel (identified in cycle 2) by the users with DS. These outcomes strongly supported the thesis statement and the RQ2 that the use of technologies and smart devices through the co-design process (also, partially answered the RQ3) can overcome some of the barriers to performing independent activities for young adults with DS. Given that, by reducing barriers to daily life independent activities this research can open a new door of opportunities to social inclusion and increase independence for young adults with DS. Thus, this research completed the final cycle 4 (see Figure 8.7-1).

The next chapter synthesises the results of the evaluation for answering the research questions along with implications, limitations and conclusions.

Chapter 9

Main Discussion and Conclusion

This chapter provides an overall discussion based on the main findings throughout the whole research of this thesis. This thesis reported four design cycles in five chapters (Chapter 4, 5, 6, 7 and 8) using Participatory Action Research (PAR) methodology. In cycle 1 (Part-1), I conducted a scoping literature review and explored the scope and potential of the study with research gaps (see Chapter 4). In cycle 2 (Part 2), conducted an exploratory study and identified barriers to independent living (see Chapter 5, section 5.2.2). Also, in cycle 1 (Part 2), conducted an online survey and explored popular and frequently used smart devices, technologies, apps, and barriers to use smart devices and technologies by young adults with DS (see Chapter 5, section 5.3.2). In cycle 2, reported key barriers specific to independent travelling and design requirements, sketches and drawings to design an app to support travel barriers for young adults with DS (see Chapter 6). Cycle 3 was developing a prototype by transforming the Low-Fidelity design to Hi-Fidelity and the design validation of the prototype through user testing (see Chapter 7). In cycle 4, conducted a user evaluation of the designed prototype to justify the effectiveness and level of adoption by users with DS to perform independent travel (see Chapter 8).

This chapter starts by responding to the research questions of this thesis according to the results of each cycle of the participatory action research process. Second, a wide discussion on the findings and its implications, limitation, challenges and future work. Lastly, the findings are summarised and conclusions drawn.

9.1 Answer to Research Questions

In order to produce an answer to the research questions the PAR process was adopted throughout the thesis. This process entails all the steps for an in-depth understanding of the problem and produces a solution based on its needs and requirements. The PAR process produces a solution from both existing literatures and field studies. The answers were categorised according to the nature of findings.

9.1.1 Answer to RQ1

RQ1: *What are the main barriers to independent activities for young adults with Down's Syndrome*?

An initial investigation was conducted in the form of a scoping literature review (see section 4.8.2), which revealed three primary barriers to performing independent activities for young adults with DS. These barriers are listed below:

1. Remembering: inability to remember general activities or the process of performing an activity caused difficulties with independent learning, use of instruments/smart devices and to adopt technology (Alonso-Virgós et al. 2018; Lourdes et al. 2016; Reis and Almeida 2016; González-González et al. 2018; Fernández-López et al. 2013; Villasante et al. 2019; Alammary, Al-Haiki, and Al-Muqahwi 2017; Felix et al. 2017; J. Feng et al. 2008; J. H. Feng et al. 2010; Lazar, Kumin, and Feng 2011; Hu et al. 2013; Kumin et al. 2012; Bathgate et al. 2017; Lazar et al. 2018).

2. Independent living and self-navigation: caused dependence on caregivers and eventually reduces the freedom of self-movement for young adults with DS (R Alesii et al. 2013; Roberto Alesii et al. 2015; Augusto et al. 2018; Lazar et al. 2018; Bathgate et al. 2017; García De Marina, Carro, and Haya

2012; Courbois et al. 2013; Covaci et al. 2015; N Kaoua, Landuran, and Sauzéon 2019; Kramer, Covaci, and Augusto 2015).

3. Communication: limits the freedom of expression and social interaction, and correspondingly leads young adults with DS to become dependent on caregivers (Feng et al. 2010; Melissa Dawe 2007; Hu et al. 2013).

Secondly, the exploratory cycle 1 (see section 5.2.2) revealed six key barriers that were also seen as general key barriers to performing independent activities for young adults with DS. Afterwards, in cycle 2, one of these barriers to independent activities was investigated further and it revealed four key barriers to independent travel (see section 6.4). Overall, findings revealed a few barriers to independent activities for young adults with DS. However, barriers to remembering, communication, independent living (including self-navigation) and access and use of technologies and smart devices were repeated several times throughout this thesis, which can be seen as main barriers to independent activities for young adults with DS.

9.1.2 Answer to RQ2

RQ2: *How could smart devices (smartphones, smartwatches or smart-clothing) and apps help young adults with Down's Syndrome to perform independent activities*?

First, an initial investigation into the existing literature (scoping literature review cycle 1, see section 4.8.3) was conducted to understand the possibilities of smart devices to support independent activities. This scoping literature review revealed such smart devices, technologies, and assistive app (co-designed) that showed strong potential to support remembering, employing, education, navigation and communication for young adults with DS. For example a scheduler, a reminder app with audio and video content, Google Calendar for reminders, speech recognition technology, AlphaSmart (an assistive app to support writing), GPS, Wi-Fi, Google Maps, OpenTripPlanner, WSN, VE, VR for navigation support, text, email, social communication app and messenger for work and communication support (Reis and Almeida 2016). Most of these technologies and assistive apps were built to be used by smartphones, iPads/tablets, desktop and laptop computers. For more please see section 4.8.3.

The exploratory field studies in cycle 1 revealed that the custom-designed and co-designed apps in smartphones, iPads/tablets and computers as regular apps that individuals with DS and their caregivers currently use to support remote and face-to-face communication, walking navigation, reminder, education, entertainment and to ensure safety (see section 5.2.2 and 5.3.2).

Consequently, cycle 2, cycle 3 and cycle 4 resulted in the use of a smartphone with a co-designed app as an exclusive smart device to overcome barriers to independent travel and increase independence for young adults with DS. The process started with an initial inquiry (see cycle 1, Chapter 5) in order to understand current difficulties performing independent activities for people living with DS. The result of this initial inquiry was analysed methodologically which led to further inquiries into barriers to independent travel. Afterwards, the results from cycle 2 revealed in-depth details of the barriers to independent travel (see section 6.4), and requirements and sketches (see section 6.5) for designing an assistive app for smartphone by adopting the co-design process. Although participants were introduced to and asked about smart-cloth technology during interviews (cycle 1) and reminded in group discussions (cycle 2), unfortunately, participants were not shown their interest in such technology as smart-cloth. Therefore, it revealed that participants, particularly parents and caregivers, are not ready to adopt technology like smart-cloth due to the nature of the needs and requirements of their son/daughter with DS. Later in cycle 3, these design requirements and sketches were analysed and transformed into a digital prototype for a smartphone (see section 7.2). Also, the designed prototype was presented and discussed with participants with DS and their caregivers in the form of a co-design process in order to evaluate the requirements and validate the design (see section 7.4). Finally, in cycle 4, based on the result of cycle 3 necessary changes were resolved in the designed app and recorded a video of performing an independent journey for usability evaluation was recorded. The result of this usability evaluation with the final designed app for smartphone revealed its capacity to fulfil the participants' requirements (see section 8.5) and as a result, meet the research aim and statement.

With the result of the usability evaluation, it becomes clear that a co-designed assistive app for smartphone poses an appropriate medium for overcoming barriers to independent travel for young adults with DS. Also, it can help parents and caregivers to reduce their anxiety by allowing them to receive updates during the journey through notifications and tracking/monitoring facilities. It also can report to parents and caregivers if the user with DS has not followed the direction correctly. All these facts combined together brought a positive answer to the research questions.

9.1.3 Answer to RQ3

RQ3: *How can participatory design adopted for application to support people with DS?*

Participatory design was an excellent approach for this research to understand users' problems, explore user requirements, and apply the proposed solution. The users' and stakeholders' participation were ensured in the design process across all stages in this thesis resulted in great benefits of understanding their needs and empowering them. In order to ensure the involvement of participants with DS throughout research, it was required to gain knowledge about them and their problems, which were acquired by conducted a scoping literature review (see cycle 1, section 4.8) and semi-structured interviews with parents (see cycle 1, section 5.2.1).

The participatory design processes were adopted efficiently throughout this research by making necessary changes in the data collection methods. Such as, a separate section was created in the online survey (see section 5.3.1) for young adults with DS to gather relevant inputs regarding daily life activities, usages for technology, and its usages barriers. Furthermore, equivalent engagement of participants was ensured by facilitated separate discussions with young adults with DS and their parents during co-design sessions and video walkthrough. At the same time, they were engaged jointly for groups discussion and design sessions on the same topics (see cycle 2 section 6.3.1, cycle 3, section 7.3, and cycle 4, section 8.5). It helps participants to create a particular form of interaction that assisted participants to raise their issues of difficulties and to discuss how to remove/reduce those difficulties. The remote usability evaluation due to the COVID-19 pandemic assisted the researcher (author) to continue with the research and enabled participants to provide valuable feedback (see cycle 4, section 8.5). Furthermore, creating video content of performing tasks due to the COVID-19 pandemic as an alternative to performing tasks by the user themself in real life was a novel approach. Such changes in the methods may benefit other researchers and participants to overcome situations like pandemics by following the guideline (see section 8.4) adopted for the usability evaluation through cognitive walkthrough.

The result shows that the participatory design approach was well adopted in this research and determined users with DS with their cognitive limitations can deal with performing daily activities, custom design assistive apps, and mobile devices.

Overall findings confirmed the existence of barriers to performing independent activities for young adults living with DS. Also, it was demonstrated that the use of advanced technology in smart devices with the co-designed app can overcome such barriers and increase independence by providing facility to contribute to social events for young adults with DS (Kramer, Covaci, and Augusto 2015).

9.2 A Constructive View of Findings

9.2.1 Scoping literature review, cycle 1 (Part 1).

The opportunity to conduct this research was formed through a scoping literature review. The scoping review helped to narrow the research areas in term of context, in order to understand the existing barriers to performing daily activities and the technologies that were previously used in supporting such activities for young adults with DS. Also technology used by parents and caregivers to provide support to individuals with DS was discussed (Arksey and O'Malley 2005; Daudt, Van Mossel, and Scott 2013; A. Lee, Knafl, and Van Riper 2021). The findings provided evidence of difficulties performing daily activities particularly for young adults with DS. For example, lack of remembering activities or how to perform them, independent living (including self-navigation), communication with others in the workplace or contact via mailing/messaging and a lack of knowledge of how to use technology and smart devices (see section 4.8.2). In order to support such barriers, the scoping literature review also revealed some of the advanced technologies such as GPS, Wi-Fi, motions, gyroscopes, vibration, microphone, camera, touch screen, WSN, IE, digital maps etc. and smart devices such as iTunes, iPad, tabled, laptop, smartphone (iOS and Android), etc. with custom and co-designed assistive apps that have been used by young adults with DS (see section 4.8.3). Eventually, the pick one from the scoping literature review strengthens the opportunity and possibilities to continue the research to deliver support in performing daily activities using the technologies and smart devices for young adults with DS (Daudt, Van Mossel, and Scott 2013). A detailed discussion of cycle 1 can be found in section 4.9.

9.2.2 Exploratory cycle, cycle 1 (part 2).

Findings revealed the evidence of current barriers to independent activities, as well as the usage pattern of smart devices and technologies for young adults with

DS through semi-structured interviews (*n*=4) and an online survey (*n*=39). First, the evidence highlighted six key barriers to independent activities for young adults with DS through semi-structured interviews with parents, these key barriers were (1) lack of safety, (2) verbal communication problems, (3) barriers to independent travel, (4) inability to use/access technology, (5) forgetting tasks/activities, and (6) lack of accessible interfaces and information (see section 5.2.2). Later, these six key barriers were cross examined with survey findings (see section 5.4). The online survey of young adults with DS and their parents and caregivers also delivered the evidence of smart devices and technologies used by young adults with DS and their parents (see sections 5.3.2.3, 5.3.2.4 and 5.3.2.5). Eventually, the results revealed that the barriers to performing independent activities still existed for young adults with DS, and the usage pattern of technologies and smart devices opened the door to provide potential support to overcome such barriers for young adults with DS. Also, the findings helped to build a strong understanding of the context of this research in term of RQs. Ultimately, the findings of cycle 1 showed the light towards the thesis aim and answered part of RQ1 and RQ2 by revealing such barriers to performing daily activities and the potential for overcoming some of these barriers using technology. Eventually, the desire of young adults with DS and their parents to overcome barriers to independent travel lead toward further investigation into such barriers and the potential assistive use of technology and smart devices. A detailed discussion can be found in section 5.4, which compared the outcomes of exploratory cycle 1 with previous literature.

9.2.3 Prototype generation through co-design (a design-based home Exercise), Cycle 2.

As the desire of individuals with DS and their parents and caregivers was to overcome barriers to independent travel, cycle 2 was an initial investigation through a total of seven group discussions including seven young adults with DS and thirteen parents (*n*=20, one participant was family member) in the form of a co-design process to understand and explore barriers to independent travel and how such barriers can be overcome using technology and smart devices for young adults with DS. Findings show the existence of four key barriers as (1) unfamiliarity with routes, (2) barrier to public transport access, (3) lack of suitable technology and apps for travelling and (4) parents' anxiety that prevent young adults with DS from travelling (see section 6.4). Some of these key barriers were crucial findings, such as inabilities to interpret the digital map, difficulties recognising the correct bus stop, and verbal communication with the bus driver when buying the right bus ticket Also, there was a lack of tracking, monitoring and communication facilities with their son/daughter (individual with DS) for the parents and caregivers. Based on the group discussion on overcoming such barriers, smartphones were found to be a useful and relevant device with huge potential to deliver support for travelling. Findings revealed low-fidelity sketches and requirements to design an app for smartphone (see section 6.5). Most of these requirements were found to be important in order to overcome such barriers to independent travel. For example, dealing with unusual circumstances during travel, linear bar with full journey outline, turn-by-turn navigation with a progress bar, navigational instructions with arrows of images and text (see section 6.5.5). Clearly, there are barriers to travelling that exist among young adults with DS and findings suggested how to overcome some of these barriers using technology and smart devices. Ultimately, findings from cycle 2 revealed the scope toward social inclusion for young adults with DS by uncovering the potential of contributing to social activities. For instance, meeting friends, going to work, college and the leisure centre. Thus, the findings moderately supported the thesis aim and answered part of RQ1 and RQ2. A detailed discussion of cycle 2 can be found in section 6.6, which compared the outcomes of cycle 2 with previous literature.

9.2.4 High-Fidelity design validation workshops (the Transformation of digital prototype, Cycle 3.

The low-fidelity design sketches were transformed into a high-fidelity app for the smartphone as a prototype and returned to the participants to ensure that the prototype contained the correct design with their expectation and to bridge the gap in design. Also, the Hi-Fi prototype introduced features that were brand-new as these features had never been applied before for people living with DS e.g. progress bar, visual representation of the linear map, overcoming communication barrier to communicate with the bus driver, emergency call button and help page. The validation study of the designed prototype was conducted by allowing users with DS and their parents to use the designed prototype in a smartphone. The usage of the prototype was closely observed to identify accessibility issues and discussed the issues raised by them were discussed in order to understand any problems with the design. This investigation was conducted through seven group discussions with seven young adults with DS and twelve parents (*n*=19, one participant was family member). A co-design process was adopted and the data collected data was analysed qualitatively. First, findings confirmed the four key barriers to independent travel that were revealed in cycle 2 through group discussions. Second, findings established the design validation of the prototype by comparing it against the requirements to see if the designed prototype for the smartphone met the users' needs. For example, participants with DS have understood the purpose of the use of icons, signs, symbols, direction instructions, notifications and alert messages, progress bar and linear bar in the designed prototype. Third, findings delivered evidence of the necessity of the validation study with the end-users, for example, gaps between low-fidelity and high-fidelity designs (see section 7.4), mostly accessibility issues in designed UI e.g., alignment of the contents, text size, colour of the text and button. Eventually, findings lead toward a satisfactory outcome of the co-designed prototype for the smartphone to overcome travel barriers for young adults with DS with the necessary changes to be made (a detailed discussion can be found in section 7.5). Ultimately, the findings of cycle 3 brought the light study towards social inclusions and independence for young adults with DS by extending the opportunities for overcoming barriers to independent travel. Consequently, the findings partially supported the research aim, statement and answered part of RQ1 and RQ2. A detailed discussion of cycle 3 findings compared with past research can be found in section 7.5.

9.2.5 Usability Evaluation, Cycle 4:

The usability evaluation was conducted virtually using Zoom by adopting a video walkthrough process with seven young adults with DS, nine parents and six experts in order to address usability issues in the final Hi-Fi prototype for overcoming travel barriers. Findings suggest potential adoptability of the designed app ("*MyIndependentTravel*") for young adults with DS such as the recognition of turning points, turn-by-turn instructions represented with direction arrows. The level of successful adoption of these tasks by young adults with DS showed effective usability skills which proved that the "*MyIndependentTravel*" app contained correct design elements with appropriate UI interfaces, though some UI interfaces needed to be modified according to their feedback. Eventually, the findings of cycle 4 confirmed that young adults with DS can perform travel using "*MyIndependentTravel*" and at the same time it can reduce dependency on parents and caregivers. Therefore, the designed app can contribute to improved social inclusion by providing facilities for independent travel and increased independence. Thus, the findings completed the thesis aim with the thesis statement and also completed the answers of RQ1 and RQ2. A detailed discussion of cycle 4 findings compared with past research can be found in section 6.6.

9.2.6 Relationship between independent travel and social inclusion for young adults with DS.

It is to be believed that the effective removal of travel barriers can improve the social inclusion of and increase independence for young adults with DS. Several previous studies also focused on achieving social inclusion and reducing dependency on parents and caregivers (Roberto Alesii et al. 2015; Kramer, Covaci, and Augusto 2015; Lazar et al. 2018). The final findings of cycle 4 revealed a satisfactory level of adoption of the proposed app for young adults with DS, given that young adults with DS are assumed to be able to make short journeys using "*MyIndependentTravel*" without having parents or caregivers with them. With the support of the "*MyIndependentTravel*" app a young adult with DS can navigate by following walking directions, being able to identify the bus stop and the correct bus number, being able to get a travel ticket from the bus driver and being able to cross the road carefully. The findings also showed that the ability to track and monitor the journey from home by using a smart device brought comfort to parents and caregivers. The live update of the journey's progress received in the form of notifications helps to reduce parents' anxiety and that can build the confidence to allow their son/daughter to perform more independent journeys. Thus, this proved that removing barriers to independent travel by introducing ("*MyIndependentTravel*") a co-design app can deliver support to young adults with DS to contribute to social activities and increase their independence.

9.2.7 Relationship between privacy, tracking, and monitoring for parents, caregivers and young adults with DS.

Based on the findings the privacy did not appear to be a concerning issue in this thesis. However, one young person with DS raised the issue of privacy as he does not like to be tracked or monitored while visiting his friends or girlfriend. A similar issue may exist for other young adults with DS, which was carefully considered during the design of the Hi-Fi prototype by creating a button in the main menu of the app for primary users. The button has a checkbox that contained a list of individuals’ names (parents/caregivers), and a tick mark beside the name will ensure who is tracking him/her. The user with DS (primary user) can uncheck the box if he/she does not like to be tracked and it will disconnect the device that pairs with the parents’ or caregivers’ device. The use with DS can regain the paired connection with their parents’ devices by marking the checkbox when needed. Alternatively, parents can send a request from their devices to the user device to regain the paired connection, which needs to be accepted by the user with DS.

9.2.8 Cognitive capabilities of young adults with DS to participate in research.

Abstract thinking capabilities: young adults with DS participated actively in all studies of this thesis except cycle 1, such as in cycle 2, cycle 3 and cycle 4. As it has been discussed in the previous session (see section 2.2.2 and 4.8.2), the limited cognitive abilities of young adults with DS often show difficulties expressing themselves. Gathering feedback from them during the group discussions and interviews was challenging. However, all methods (interviews and group discussion procedures) were designed following HCI design guidelines so that the young adults with DS did not require a vast amount of cognitive load to participate in the studies. For example, in cycle 2, the chosen method was the group discussion in three sub-sessions. The first sub-session was a separate discussion between young adults with DS and their parents or caregivers. The discussion started with young adults with DS with ice-breaking questions such as how are you? How do you go to school or college, or what type of smart devices do you use on a daily basis etc. after then, move on to actual questions and break the question, e.g., do you like travelling, where do you travel, do you find any problems while you travel to school/college etc.? The young adults with DS were not appeared with difficulties continuing the discussion as they did not require a lot of abstract thinking to continue the conversation. The second sub-session discussed how to overcome such barriers (discussed in the first sub-session) to independent travel, which may require substantial thinking capabilities for a young adult with DS. However, keeping in mind the cognitive abilities of young adults with DS, the second session was designed as a joint discussion with their parents and caregivers so that they could discuss the asking questions jointly and provide the correct feedback. Such a design in the method may facilitate easy participation for young adults with DS without putting a vast cognitive load during discussion.

Similarly, the third sub-session was a joint drawing session with a young adult DS and parents/caregivers. Although the parents were drawn sketches, they discussed with their son/daughter with DS, confirmed what they like to include, see or keep, and then moved on to the next part of the sketch. Such design in a method not only ensures less cognitive load for young adults with DS but also ensures quality data gathering and equal contribution to the study.

In cycle 3, a similar process was used to support the abstract thinking of young adults with DS. This process involved dividing the session into three sub-sessions and allowing joint discussions with parents or caregivers. During the first sub-session, the young adults were given a designed prototype in a smartphone and were given enough time to navigate through it. Any issues or difficulties that were encountered were noted by the author. In the second sub-session, a printed version of the designed prototype in A4 size paper was made available to the young adults with DS. This was done to ensure easy and quality feedback and to reduce cognitive load. The young adults were also allowed to discuss the prototype with their parents or caregivers during this sub-session.

During Cycle 4, the full video footage was played at the beginning of the session to eliminate confusion and provide a clear view of the video for young adults with DS. Subsequently, the footage was played step-by-step, with the option to replay it if necessary. Joint discussions were allowed with parents or caregivers to build confidence and reduce cognitive load for young adults with DS.

Overall, this process aimed to provide young adults with DS with a more accessible and supportive environment for abstract thinking and ensure that the young adults could fully engage with the material presented.

Use of Likert-type scales: the use of Likert-type scales was reported to be a useful method that supports capturing a wide range of response variance in self-reported attributes and behaviour among people with ID (Hartley and Maclean 2006). The use of Likert-type scales is increasing, and young adults with mild ID have shown better responses in terms of reliability and validity of Likert-type scales (Hartley and Maclean 2006). Also, evidence suggested that the pictorial representation of response alternatives, along with questions clarification, rephrasing, pretests, and response descriptions (in a single set of one or two words), can increase the response rate of the Likert-type scale's reliability and validity (Hartley and Maclean 2006; Leutner et al. 2017). However, the response bias in the Likert-type scale was also noticeable. The tendency to choose the most positive response alternative and the use of yes/no and either/or as response alternatives may increase the rate of response bias among young adults with mild ID (Hartley and Maclean 2006; Leutner et al. 2017). On the other hand, the low response rates and response bias were documented, particularly among young adults with moderate to profound ID, even after applying the pictorial representation of response alternatives (Leutner et al. 2017; Sigan L. Hartley and MacLean 2005).

In cycle 4, all young adults with DS were associated with mild ID. The survey questionaries for the Likert scale were carefully designed to capture better responses and maintain reliability and validity. First, all survey questions were explained to the parents and young adults with DS at the end of the walkthrough session. For example, questions were read and explained and reminded by showing the related video clips for clarifying the questions and providing a clear view of the associated questions, which also ensured that the participants with DS understood the questions. Second, the response alternatives were carefully explained how to provide their responses in the Likert scale by explaining and showing the survey scale. All these response alternatives were attached with pictorial representation (face emojis) in order to support better and easy responses from young adults with DS. Also, a single set of one or two words were used, such as: “Strongly agree” and “Neutral”. Third, parents were requested to help them (participants with DS) understand the questions and answers but not put their own opinions. Therefore, considering these principles in designing a Likert-type scale in the survey can ensure the easy interpretation of the Likert-type scale by young adults with DS and their parents.

9.2.9 Author positions

Author position as a researcher under PAR methodology: the principles of PAR stated in section 3.3, such as active involvement of the participant throughout all stages and representing the social problem. Similarly, the author was responsible for conducting a series of studies, collecting data and data analysis, including the interpretations, and implementing the prototyping. Therefore, all studies in this thesis were conducted by the author except the first pair interviews that were conducted jointly with first supervisor. Also, the author used different tools for data collection, such as an audio recorder, paper prototype, online survey and Zoom tool. Furthermore, the author actively represented the collected data and published it to share with the DS community. The author faced challenges in the recruitment of participants and conducting research. However, the author exhibited creativity and ingenuity in adapting research methods to overcome these challenges. For instance, the author conducted group discussions at participants' own locations, which facilitated a comfortable environment and promoted open communication. Additionally, the author utilised remote study methods (video walkthrough) via Zoom to comply with COVID-19 restrictions, which allowed the research to continue without interruption. As the research came to an end, the author's knowledge and understanding of young adults with Down Syndrome increased notably, particularly their abilities, which could potentially inform future research and interventions aimed at improving their quality of life.

Cultural differences: I am the author coming from Bangladesh and lived in England for seven years before moving to Scotland helped me to gain an adequate understanding of the UK culture. However, I realised some cultural differences between England and Scotland after moving to Scotland, especially the local accent in the language in Scotland. Though it did not take long to adopt the accent in Scotland, working in a local shop helped me overcome such difficulty in pronunciation, although English is my second language. I had to visit participants in their homes to conduct a series of studies, and I received a warm welcome invitation from the parents. Most participants were very excited to meet me, and it was probably for two things. First, because of the university, the University of Strathclyde is well-recognised internationally, which excited participants to know about the research and contribute. Secondly, maybe I am not local, which may also excite participants. I found all the parents and caregivers were friendly, helped me understand their son/daughter with DS and allowed me to talk before even running the study. The general conversation at the beginning of the discussion with young adults with DS helped me understand their voices as they have speech difficulties. Furthermore, I was slightly worried about understanding the language with the local accent, but thanks to all the parents and caregivers for not using it, which was truly helpful for me to understand them. However, I was used to with local accent. Also, I was welcomed by Down's Syndrome Scotland (DSS) to conduct the study throughout Scotland. DSS worked as a primary source to enter the Down's Syndrome community, supporting me in gaining the participants' trust. Also, it was successful marketing of the research and distributing all studies through the DSS. Therefore, such charity organisation plays a vital role as a bridge of contact between participants, researcher, and the university.

Own thought on the potential outcome: my initial thought at the beginning of the research was that the study might lead me to a lab study instead of conducting a field study. Also, the initial idea was that there would be a scope to design an application using Artificial Intelligent technology for smart homes that can support performing daily activities of users with DS. Furthermore, interest in smart clothes technology was not shown by the participants. However, my views regarding the research completely reformed after conducting the first cycle 1, which led me to research independent travel support activity and design an app for navigation support. Each cycle in this thesis has a similar pattern; the outcomes were not entirely predictable until complete. Also, cycles were iterative, which led to a further investigation at the end of each cycle, which eventually represented the spiral model of the PAR methodology. Therefore, achieving such outcomes under the PAR approach was beyond my expectation at the beginning year of my PhD.

9.2.10 Conducting fieldwork with young adults with DS, the author consideration of the potential risks and difficulties involved.

Firstly, it is important to acknowledge that conducting fieldwork with any vulnerable population, including individuals with DS, carries inherent risks. Researchers must ensure that they are taking steps to protect the safety, privacy, and dignity of their participants. For young adults with DS, in particular, there may be additional risks related to communication difficulties, cognitive impairments, and social vulnerability. It is crucial that researchers approach this population with sensitivity and respect, and take steps to ensure that participants are fully informed about the research process and have the option to withdraw at any time. The author provided the participant’s’ information sheet before conducting each study that informed participants regarding the study process including the safety and privacy.

In addition to the ethical considerations, there may also be practical challenges associated with conducting fieldwork with young adults with DS. For example, researchers may need to adapt their methods to accommodate the unique communication styles and cognitive abilities of this population. It may also be necessary to involve parents or caregivers in the research process to provide additional support and ensure that participants are comfortable and engaged. In that case, author requested parents and caregivers to be available and provide support during the study was conducted.

Despite these challenges, there are many potential benefits to conducting fieldwork with young adults with DS as a researcher. For example, this population may have unique insights and perspectives that can enrich the understanding of important social and psychological phenomena. By working collaboratively with individuals with DS and their families, researchers can help to empower and amplify the voices of this often marginalised group. Therefore, author conducted joint sessions with young adults with DS and their parents and caregivers in each study.

In conclusion, conducting fieldwork with young adults with DS as a researcher was challenging but important endeavour. While there are inherent risks and challenges associated with this population, author mitigate these risks and promote the safety and wellbeing of participants by taking a collaborative approach. With careful planning, sensitivity, and respect, fieldwork with young adults with DS has the potential to make important contributions to my understanding of this population and to promote greater social inclusion and empowerment.

9.3 Implications of this Research

9.3.1 Implications for designers

This research revealed several potential design implications for the development of smartphone applications to support navigation for young adults with DS.

a) First, it appears as a new finding that there is a need for an alternative to traditional digital maps (e.g., Google Maps) to support navigation as indicated by the findings. An inclusive design of the linear bar map concept (see Figure 8.5-4, image 2) to support navigation without the use of digital maps found as strong potential for adoption by users with DS. The linear bar map should contain a list of all the steps between the start and the end of the journey, presented in order with corresponding step numbers and instructions at each step (see Figure 8.5-4, image 2). The steps should be provided in a single vertical line, with a current location indicator displayed on the vertical line which moves while users move towards their goal. The goal of the location indicator with an order list of each step is to assist the users in understanding and identifying their current location in the linear bar map.

b) Second, it is important to understand the concept of the progress bar that gets filled up while the user moves from one turning point to a subsequent point (see Figure 8.4-1, image 4). The concept of this progress bar provides cognitive support to the user by creating a sense of the journey's progress and serves as an alternative to following a path in the digital map. Also, the user is not required to remember the upcoming road names and the turning points as it provides notifications for turning points based on the user's GPS location, and indicates the user's proximity to the upcoming turning point based on how much it gets filled.

c) Third, it is suggested that the use of images and icons should be clear and relevant within the context of the journey. For instance, it is not recommended to use the bus stop and landmark images from Google Street View as sometimes it does not appear with a correct angle from the user's walking path position. Instead, it is recommended that caregivers take the bus stop and landmark images at the correct angle that helps users with DS to recognise the bus stop without imposing a heavy cognitive load (see Figure 8.3-1, image 5). That fits in the common practice of pre-walking in a road by the parents.

d) Fourth, design for accessibility should provide more flexibility to the user by making the interaction with the system easier for those with fine motor control inability. Due to the lack of motor control ability in users with DS, the designer should design systems that require less screen touching of smart devices. For instance, the designed system does not require a lot of touching on the smartphone's screen, with the exception of requesting help from caregivers, when the user needs to touch the help icon and send a written message. Furthermore, users are not required to write messages as they can choose from ones already written and saved in the message list (see Figure 8.3-1, image 8).

9.3.2 Implications for developers

A few important implications for developers can be derived from the findings. Due to the visibility issues of users with DS the size of buttons, text, box panels and borders should be sufficiently large. It is recommended to use at least 18px or 1.125em due to visibility issues for the users with DS. Similarly, the use of appropriate colours for background, buttons, and box panels are suggested for the user with DS. The findings are in line with Alonso-Virgós, Rodríguez Baena, et al (Alonso-Virgós et al. 2018) for the usage of colours, but it suggests avoiding using the colour red as some of the users with DS in this research found the red colour used in the alert message annoying. One of the important recommendations is to use icons together with text. For instance, the "back" button should include an icon of the back arrow (←) together with text saying "BACK" and a distinctively bright coloured border to make sure that the size of the buttons is big enough to help users with DS to tap on the button precisely on a smartphones screen.

9.3.3 Implications for researchers

It has been noticed that some of the young individuals with DS felt nervous to start talking at the beginning of their interviews. The recommendation for the researchers is to start the session by asking participants about general questions, for instance, asking their name, about their studies, asking about their day and then slowly moving to the study questions. It is highly recommended not to start with technological questions at the beginning because doing so may lead to participants feeling uncomfortable and stressed. Also, researchers should consider involving all those individuals into research who have an influence on the daily life of the participants. For instance, findings on barriers to independent travel suggested that the bus driver and train staff are involved in individuals with DS's lives for a successful journey to be completed, not only their parents/caregivers.

9.3.4 Implications for parents/caregivers and charities

Parents' motivations play an important role for individuals with DS to perform independent activities using smart devices. On the other hand, parents' fear creates barriers to performing independent activities due to safety concerns during journeys outside the home and the use of additional internet data in smart devices.

a) First, it is recommended for parents to practice a short journey by bus together with their son/daughter with DS at least 2-3 times and to help them understand most of the steps of performing a journey e.g. finding the bus stop, getting on and off the bus, buying a ticket. Also, these practice journeys will provide a clear overview to the parents on how difficult or easy it is for their son/daughter to perform a journey by bus. Such practice of journeys will help to increase confidence among parents and remove some of their fears regarding the safety of their children.

b) Second, parents and caregivers can use the data usage feature under the network settings on smart devices to limit the monthly data plan in order to prevent the use of extra data that will also notify the user when the data limit is about to be reached.

c) Third, it brings huge satisfaction and builds up confidence when a parent knows how other parents are helping their son/daughter with DS in performing daily activities. Creating social groups on Facebook and Twitter with other local parents and caregivers would be the best way to involve themselves in social networks and share each other's experiences.

d) **Charities**: recommendations for charities involved in supporting individuals with DS include providing regular updates to parents/caregivers on emerging technological advancements that may aid in facilitating daily activities. Such information may be disseminated through local or international Down syndrome organisations, such as the Down's Syndrome Research Foundation UK[6], Down's Syndrome Association[7], Down's Syndrome Scotland[8], Down Syndrome International[9], National Down Syndrome Society[10] and the National Down Syndrome Congress[11], among others. For optimal accessibility and convenience, parents are advised to follow the organisations' Facebook and Twitter pages to stay abreast of current developments.

9.3.5 Implications of co-design in the PAR process

The process of participatory action research methodology was well-documented in this research involving young adults with DS and their caregivers, and potentially persuasive technology.

a) First, due to intellectual disabilities and indistinct speaking voices among people with DS, it is recommended for the researchers to involve their parents and caregivers in the study process in order to get a deep insight into their abilities and understand problems. This felt the most natural and

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[6] https://www.dsrf-uk.org/

[7] https://www.downs-syndrome.org.uk/

[8] https://www.dsscotland.org.uk/

[9] https://www.ds-int.org/

[10] https://www.ndss.org/

[11] https://www.ndsccenter.org/

safe way to conduct studies and it does not appear that it resulted in to excessive leading by parents/caregivers.

b) Second, designing methods: an important recommendation is to take separate interviews/discussions with individuals with DS at the beginning of the session (instead of joint interviews/discussions with parents/caregivers) that help to set the focus on them and reveal their actual views/problems on discussed topics. After that the same topics should be discussed with parents/caregivers to get their views.

c) Third, designing methods: due to the cognitive disabilities of users with DS, findings suggested that it is effective to involve both parents, caregivers and individuals with DS together in such a co-design session for designing and drawing ideas. It is believed that such implications will support researchers to disclose the users' needs and understand their individual problems precisely, and eventually ensure the success of the study.

9.4 Challenges and Limitations of this Research

This thesis reports in-depth four cycles (five studies) with a relatively small number (DS *n*=21, parents and caregivers *n*=34, and experts *n*=6, excluding survey participants *n*=39 in cycle 1, part 2) of participants and a broad age range (age between 16 to 35 years) amongst young adults living with DS and their caregivers as participants. One of the challenging issues encountered during research was participant recruitment, as parents were busy with their daily life commitments and people living with DS were not safe to attend the workshops alone. The methodology was adjusted in the in order to overcome recruitment problems for co-design workshops by conducting individual, detailed home studies that proved a valuable tool for getting input from parents/caregivers and young people living with DS in a safe environment. Also, recruiting participants for the final usability evaluation cycle 4 was delayed by about a year due to

COVID-19 and eventually the study was conducted virtually using Zoom[12] by making an adjustment in the methodology again. This research provides some crucial insights into barriers to independent travel and potential ways to overcome them. Believe that the findings to overcoming barriers to independent travel will have wider implications for individuals with DS and their caregivers. Another limitation was the survey accessibility by people with DS. The researchers designed the survey by creating separate sub-sections for both people with DS and their caregivers, and the survey was distributed via the parents' contact list. Parents and caregivers were requested to help their children with DS to understand and answer the survey questions. However, we cannot guarantee that all surveys were completed with the presence of an individual with DS (as caregivers could have filled out the survey themselves without asking opinions of their dependants). Therefore, it cannot be guaranteed that the survey sample (the sub-section of the survey designed for people with DS) is representative of all people with DS.

9.5 Recommendation for Future Research

A set of barriers to independent activities (see cycle 1 section 5.2.2 and section 5.3.2.7, cycle 2 section 6.4) and design requirements for the prosed smartphone application to support independent travel (see cycle 2 section 6.5, cycle 3 section 7.4 and cycle 4 section 8.6) was established through participatory action research methodology. Nevertheless, future research can focus on support travel barriers by developing an app using Augmented Reality (AR) in the smartphone collaborate with wearable smart glass (Aiordachioae, Schipor, and Vatavu 2020). AR technology could help users with DS to identify the correct bus/train and the bus stop or train platform as the proposed application used static images to recognise the bus stop or the bus. Furthermore, the proposed app required

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[12] https://zoom.us/

parents/caregivers to take photos of the bus stop and the bus and upload them to the app. The AR app can easily highlight the bus stop among multiple stops and the right bus if there is more than one bus (Kumar, Kumar Singh, and Peddiny 2018; Aiordachioae, Schipor, and Vatavu 2020). As an extension, the AR technology can be used for supporting walking navigation by highlighting the turning points with voice instructions for direction (Kumar, Kumar Singh, and Peddiny 2018; Aiordachioae, Schipor, and Vatavu 2020; Zhao et al. 2015), for instance Google AR. It would be interesting to see how young adults with DS interact with wearable glass including AR navigation and voice instructions.

As a result of COVID-19, journeys by public transport have been seriously affected. Therefore, another option for future research as an extension of the current app is to develop an app that can help young adults with DS and Fragile X-Syndrome to call a taxi from home with a payment option for the taxi service. Such an extension could help individuals with DS to avoid crowded areas like busy bus stops/buss/trains due to COVID-19 or similar regulations in the future or in the case of strike action and in any area where public transport services are rare.

9.6 Conclusion

This thesis reported five research studies in four cycles of PAR methodology, which offer several contributions to the HCI and Down’s Syndrome literature regarding the barriers to performing daily activities, technology, and smart devices for young adults with DS. Also, contributions to co-design, development and investigation of the navigation app for young adults with DS and their parents and caregivers. The outcomes have important implications for the use of technological support in independent travel practice, access to public transport and the design and development of navigation support apps. The area of smart devices and technology to overcome barriers to independent activities will benefit parents, caregivers and researchers who aim to improve the lives of people with DS through effective interventions. Also, researchers, UI designers and developers will be benefited who aim to understand and improve the usability, accessibility and user experience of smartphones and its technologies. Lastly, this thesis will hugely benefit young adults with DS and people who have similar conditions such as Fragile X-Syndrome to overcome barriers to independent activities and especially to overcome barriers to travel with the use of smart devices and technologies and to improve their social inclusion and increase independence.

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Appendix A: table of study characteristics and outcome.

ID	Authors Name and Year of Publication	Research Areas	Target Population and ages	Study Method/Design	Technology and Devices	Study Outcomes/Aim
	Educational and learning.					
1	Felix, V.G. et al. (Felix et al. 2017) Mexico	Computer-aided learning (reading and writing) therapies.	DS =12. Ages between 6 - 15 years.	Treatment group and control group assessment through a pilot study.	HATLE, mobile computing (Android tablet), multimedia design and speech-recognition techniques (artificial neural network)	To measure the efficiency of a computer-assisted learning tool (HATLE) for writing and reading ability by children with DS.
2	Álvaro Fernández-López et al. 2012 (Fernández-López et al. 2013) Spain	Support special education needs through mobile learning technology.	DS= 3, Autistic Spectrum Disorder (ASD) = 13, Pervasive Developmental Disorder (PDD)= 1, Fragile-X syndrome (FXS) = 1, Attention-Deficit Hyperactivity Disorder (ADHD)=2, Other= 9. total 39	A pre-experimental study to evaluate the use of developed app (Picca) based on pre/post-testing	iPad, iPhone/iPod, GPS and digital compass, Bluetooth or Wi-Fi network, graphic	To improve the learning process to support students with special need using mobile learning technology.

			students with special education need and age ranged from 4 – 20 year.			
3	Josué Villasante et al. 2019 (Villasante et al. 2019) Peru	Adopt learning styles through a mobile application.	Children and teenagers with DS. 15 participants ages between 6 – 12 years and 4 participants ages between 13 – 16 years. Total = 19	Quasi-experimentation to test. Test group and control group	Huawei P9 smartphone and iPad Air 2, NFC, sound. Two literature-based mobile tools.	To improve the learning style of mathematics and linguistic skills through mobile application among people with DS.
4	Lourdes M. Morales-Villaverde et al. 2016 (Lourdes et al. 2016) California (USA)	Online learning for people with developmental disabilities through web app in iPad.	DS = 2, Autism = 2, Inverted X Syndrome =1, cognitive/intellectual disability = 4, cerebral palsy = 1. Ages between 23-35 years. Participants were with DS, one age was 36 years and other was 30 years old.	Requirements gather: Focus group sessions with caregivers. Evaluation: Heuristic evaluations and usage scenarios.	HTML5 web app, iPad and iPhone	To support and improve basic skills such as recognizing numbers, letters, money, shapes, and colors.
5	Carina González-González et al. 2018 (González-González et al. 2018)	Use of robot to promotes learning.	7 participants with DS, age between 7 – 19 years.	Case study.	KIBO robotic	To motivate learning and increase programming thinking by using of KIBO robotic.

	Spain					
6	Jaflah ALAMMARY et al. 2017 (Alammary, Al-Haiki, and Al-Muqahwi 2017) Kingdom of Bahrain	AT adoption in teaching and learning.	700 teachers, experts, specialists and parents of DS	Questionnaires	AT: Digital pen, iCommunicator, audio loop systems, video remote integrator, assistive listening devices, automated alarms for time-linked tasks.	To investigate the level of AT adoption in the teaching and learning process for the student with DS.
7	Sofia Reis et al. 2016 (Reis and Almeida 2016) Portugal	Support daily routines	One participant with DS, age 16 years	Comprise preliminary and comparative studies, Case study	Mobile devices: Tablet, laptop and smartphone.	To presents ongoing research on the use of mobile devices to support daily routines and promote digital literacy of a Down syndrome teen.
	Technology usage					
8	Jinjuan Feng et al 2008 (J. Feng et al. 2008) USA	The use of various computer application and electronic devices by people with DS	449 participants with DS between the ages of 4 – 15 years. 112 participants age between 16 – 21 years. Total of 561 participants.	Web-based survey with 56 questions in four sections on the use of computers by children and young adults with DS.	Word processing, presentation, E-mail, IM, Web, Educational Software, Video, computer game, online chatting and augmented communication device (such as Alpha Talker or Blackhawk).	To explore the use of computer applications and devices by people living with DS and potential of these applications and devices to use in workplaces

9	JINJUAN FENG et al 2010 (J. H. Feng et al. 2010)	Computer usage and design challenges	449 participants with DS between the ages of 4 – 15 years. 112 participants age between 16 – 21 years. Total of 561 participants.	Web-based survey. This article discussed the responses to Questions 29 and 30 out of 56.	Computer, computer application (MS Word), web browser, voice-activated word processing, Mouse,	To explore difficulties of using the computer application by users with DS and potential solutions to those difficulties.
10	Ruimin Hu et al. 2011 (Hu et al. 2013) USA	Three input techniques (keyboard and mouse, word prediction, and speech recognition) of computer technology as assistive technology.	8 participants with DS, ages between **10 to 28** years. 5 neurotypical participants, ages between 10 – 13 years.	Performance evaluation on give tasks and compared between groups (groups a: children and young adults with DS, and group b: neurotypical children)	Laptop, Spector Pro, touchpad on the keyboard or an external mouse, or both. Word prediction software WordQ^{TM}, MS Word^{TM} and ViaVoice.	To better understand the use of three input techniques (keyboard and mouse, word prediction, and speech recognition) by children and young adults with DS.
11	Libby et al. 2012 (Kumin et al. 2012) USA	Use of multi-touch devices to perform workplace-related tasks	10 young adults with DS. Ages between 19 – 29 years.	An experimental design that focused on usability testing of five categories tasks and pilot sessions.	iPad. Safari web browser, Facebook, Mail accounts (Gmail, Yahoo mail or AOL), calendar, Amazon.	To evaluate the usability of multi-touch devices by people young adults with DS for workplace-related tasks
12	Jonathan Lazar et al. 2011 (Lazar,	Workplace-related computer usage	10 participants with DS, age between 20 - 38 years	Ethnographic observation	Computer application: specialized	To explore and examine the workplace-related computer skill of young-adults with DS.

	Kumin, and Feng 2011) USA	skills of users with DS.			applications (including word processing, Excel, PowerPoint, Database, and calendar), communication tools (including email, instant messaging, Facebook), and security-related applications (including password and CAPTCHAs). Mobile app: email, text message, iTunes, iTouch.	
13	Dawe 2006 (M Dawe 2006) USA	Technology adoption	DS=5, Autism = 4 and DD = 12. All participants age ranged from 13 to 23 years, with the majority between 18 – 23 years old	Semi-structured interviews	AAC, AlphaSmart, Watches, Timers, Learning Software, Web Game and Cell phone.	To understand and explore the usability of technology with people with cognitive disabilities.
14	Lucía Alonso-Virgós et al. 2018 (Alonso-	Web content accessibility and usability.	112 voluntary users with DS in the survey, age between <14 – 55	Quantitative and qualitative data analysis including	Paper survey. Two designed websites, one	To improve the accessibility and usability of web content for people with DS. And propose

	Virgós et al. 2018) Spain		years. And age between 15 - 35 years 78.57%. = 88 individual with DS	users' reactions, comments and impressions from the test survey (paper), Test: Web test, Eye-tracking test, Multimedia Elements test, Sound test, Textual content text. Content Design text. Form evaluation. Color contrast evaluation. Temporal elements evaluation.	accessible and other inaccessible with similar tasks. Laptop, eye-tracking software and glasses. Video, audio, texts, color graphs (level, icons) and images content.	web content design recommendations for web developers.
	Health					
15	Jonathan Lazar et al. 2018 (Lazar et al. 2018) USA	Manage nutritional habits for healthy living.	10 participants with DS age between 13-35 years and their caregiver. Computer scientists, medical doctors, geneticists, neuropsychologists.	User-centred design. Two focus groups and three design workshops.	Smartphones app.	To manage the nutritional habits for people with DS a smartphone app

16	Katherine E. Bathgate et al. 2017 (Bathgate et al. 2017) Australia	Foods and beverages consumption record for the diet	51 adolescents and young adults with DS	cross-sectional analysis of food and beverage intake captured using the mobile food record from two studies—the Physical Activity, Nutrition and Down syndrome (PANDs) stud and the Connecting Health and Technology (CHAT) study	Mobile food record application (a mobile app) called image-based mobile food record application (mFR)	To assess the feasibility of assessing diet with an image-based mobile food record application
	Independent living and activities support					
17 and 18	R Alesii et al. 2013 and 2015 (R Alesii et al. 2013; Roberto Alesii et al. 2015) Italy	Independent living, location tracking and activities support.	4 experts from DS association.	Performance evaluation on the test case, White-box and Black-box Test	WSN, GPS, web, mobile phone, Smart house (Ambient Assisted Living)	To improve the physical, cognitive support and assistive living for the people with DS introduced project Casa+ a smart home architecture
19	Melissa Dawe 2007 (Melissa Dawe 2007) Colorado (USA)	Remote communication using a mobile phone.	DS = 1, Cerebral palsy =1, DD= 2, autistic =1. Total = 5, ages between 19-25 years.	Nine semi-structured interviews	Mobile phone, recorded memos, hand-written notes, set kitchen timers for schedule	To understand and explore the current usages of remote communication among young adult with cognitive disabilities and their caregivers.

					activities, alarm clocks.	
20	Yannick Courbois et al. 2013 (Courbois et al. 2013) France	Wayfinding in VE	10 participants with DS, age between 14 – 29 years and mean age 22.22	Three experimental phases on VE (Virtual Environment)	VE using the 3D VIDIA VIRTOOLS software	To assess the ability to learn routes and wayfinding trough a VE
21	Bernard N’Kaoua et al. 2019 (N Kaoua, Landuran, and Sauzéon 2019) France	Wayfinding in VE	12 participants with DS, age between 21 – 44 years.	Experimented with the condition and observed participants movement with three phases of procedures are training phase, learning phase and wayfinding task.	VR-based application, VIRTOOLS software, joystick to control movements in the VE, VR room with a Dell personal computer.	To use virtual reality technology to (a) elucidate the spatial deficits associated with ID in reference to the Siegel and White framework and (b) to evaluate the effectiveness of 3 wayfinding assistive procedures (signified landmarks, arrows, and elevated views).
22	Alberto et al. 2012 (García De Marina, Carro, and Haya 2012) Spain	Tracking and way-finding	20 participants with DS, Turner syndrome, cerebral paralysis and encefalophaties without specified aetiology. Age between 18 – 23 years.	Case study, Observing self-care tasks, Participants' questionnaires for qualitative analysis.	WSI-GO, mobile, GPS, Visual, Audio and Mscape.	To provide outdoor travelling and assisting in way-finding using a mobile device, by developing a tool called WSI-GO,

23	Augusto et al. 2018 (Augusto et al. 2018) UK	Daily activities, navigation and decision supports.	Young adults with DS =67 as primary users, 439 caregivers as secondary users and 6 tertiary users (teachers, bus driver, local authorities etc.)	U-C IEDP, Co-design methodology. Including questionnaires, face-to-face interviews, project pilots, workshops and observation.	Smartphone, GPS, Google MyMaps, large smart table, with Wii control, mouse/keyboard and ambient intelligence	POSEIDON project to provide support daily activities, work, mobility and socialization using static services. Also offers information and guidance to support decision-making and independence
24	Dean Kramer et al. 2015 (Kramer, Covaci, and Augusto 2015) UK	Navigational services	DS=6, mean age of the group was 24.6 years average	Focus groups, interviews, and questionnaires. Usability study was a task to travel 2km route using navigate as a guide.	Mobile navigation application on Android OS, OpenTripPlanner, Google map and GPS.	To explore how context-aware, and assistive technology can enable users with Down's Syndrome to be more independent.
25	Alexandra Covaci et al. 2015 (Covaci et al. 2015) UK	Train and support navigation skills	DS = 13, mean age = 26.4 years.	Preliminary study on a focus group with people with DS based on a navigation task.	Street View images, virtual environment (VE) composed of Street View Images, a route with six steps in VE, GPS and Global Navigation Satellite System (GNSS). Database, Tablet/Mobile camera	To evaluate the visual and spatial perception of people with DS when interacting with different elements of developed navigation system.

Appendix B: survey data.

Survey into improving support for people with DS using smartphone and smart-watch technology

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Start of Block: Section 0 of 4 - Consent form

Thank you for your interest in completing this survey. This survey is part of the doctoral thesis research project conducted by Majed Al Khan at The University of Strathclyde's Computer & Information Science department. The purpose of the research is to explore technology for supporting people with Down's syndrome, with a focus on wearable and mobile technologies such as smartphones and smartwatches

We are interested in your responses if you use, have used, or would like to use technologies to support people who have Down's Syndrome - either in your family, in a professional role or in another support/care role. Your response on this survey will help to better understand how assistive applications and devices are currently used by people with Down's Syndrome and to explore future possibilities.

Data Protection Consent

We take your privacy seriously and will protect your anonymity. Before taking the survey though, it's important that you understand that: Anonymous summaries quotes and analysis from your submission may be used in academic publications and in other materials concerning the research project. The only personal information we ask for is your email if you wish to take part in further studies - we will not share this. We will also check that no identifying information is contained in forms by accident. You are free to withdraw at any time during the study without the need to give any explanation and can ask within a reasonable period to have your data removed. If you have any questions or concerns, please contact the research student Majed Al Khan (majed.khan@strath.ac.uk) or the project supervisor Dr. Mark Dunlop (mark.dunlop@strath.ac.uk). This investigation was granted ethical approval by the Department of Computer and Information Sciences Ethics Committee, University of Strathclyde.

If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the Departmental Ethics Committee
Dept. Computer and Information Sciences
University of Strathclyde
Livingstone Tower
Richmond Street, Glasgow
G1 1XH
Telephone: 0141 548 3189

Email: enquiries@cis.strath.ac.uk

Q1. I understand and agree to the terms above?

○ Yes, I agree

○ No

End of Block: Section 0 of 4 - Consent form

Start of Block: Section 1 of 4 – About you

Section 1 of 4 – About you: This section is about you and your roles.

Q2. What is your relationship to the person, or people, with Down's Syndrome (please select all that apply)?

☐ I am a family member

☐ I am an educator

☐ I am a clinician

☐ I am a caregiver

☐ I am a service provider

☐ Other (Please specify): ________________________

Q3. Which answer best describes your main involvement with people with Down's Syndrome?

☐ Carer for most of the day most days

☐ Carer for sometimes per day most days

☐ Carer for sometimes per week most weeks

☐ Carer on "As Needed" Basis

☐ Full Time job

☐ Part Time job

☐ Support/charity Volunteer with no direct care responsibilities

☐ None of above (Please briefly describe your role): ________

Q4. Where do you live?

○ Scotland

○ England

○ Wales

○ Northern Ireland

○ Other (Please Specify): ______________________________

Q5. In which setting do you support people with Down's Syndrome? (Select all that apply).

☐ Home

☐ Public Service (NHS, HSE ...)

☐ Private Practice

☐ Charity

☐ Nursery

☐ Schools and Primary Education Centres

☐ University/Academic Research

☐ Others (Please Specify) __________________

Q6. How long have you been supporting people with Down's syndrome?

○ 0 - 2 years

○ 3 - 7 years

○ 7 - 15 years

○ 15 + years

Q7. How many people do/did you support with Down's syndrome in a year?

○ 1

○ 2-3

○ 4-9

○ 10-19

○ 20-29

○ 30+

End of Block: Section 1 of 4 – About you

Start of Block: Section 2 of 4 – About support technologies

Section 2 of 4 – About support technologies.

This section is about technology used by Down's Syndrome users. Please answer all questions thinking about the person or people that you support.

Q8. Please select all devices that (they) use regularly

- ☐ Smartphone
- ☐ iPad/Tablet
- ☐ Smart-watch
- ☐ Specific AAC technologies (Please Specify): ________
- ☐ Other (Please Specify): ________

Q9. Please list any particular apps or services that either you or the person/people you support use (Name all applications)

____

Q10. Please indicate what the main purposes are using these devices and apps (Select all apply)

- ☐ Helping in learning
- ☐ Helping in reminding tasks or activities
- ☐ Helping in doing daily activities
- ☐ Helping in monitoring or tracking location while they are outside home
- ☐ Helping in location reminder
- ☐ Helping in communication while they are outside
- ☐ Other (Please specify): ________________________________

Q11. Please list any other technologies you use for supporting people with Down's Syndrome? (Name all technology)

____

Q12. Are there any technologies you do not use but would like to?

____

End of Block: Section 2 of 4 – About support technologies

Start of Block: Section 3 of 4 – Attitudes to support technologies

Section 3 of 4 – Attitudes to support technologies.

This section is about technology used by you as a carer/caregiver. Please answer all questions thinking about the person or people that you support.

Q13. How old is the person or the people you support? (Select all that apply)

☐ 9 years of age or younger
☐ 10-20 years of age
☐ 21-30 years of age
☐ 31-40 years of age
☐ 41-50 years of age
☐ 51-60 year of age
☐ 61 years of age or older+

Q14. How comfortable do you feel assisting a person with Down's syndrome using smartphone?

- ○ Extremely comfortable
- ○ Moderately comfortable
- ○ Slightly comfortable
- ○ Neither comfortable nor uncomfortable
- ○ Slightly uncomfortable
- ○ Moderately uncomfortable
- ○ Extremely uncomfortable

Q15. To what extent do you agree that smartphones and apps contribute to support independence of a person with Down's Syndrome?

	Strongly agree	Agree	Somewh at agree	Neither agree nor disagree	Somewh at disagree	Disagree	Strongly disagree
Learning independently	○	○	○	○	○	○	○
Living/Doing daily activities independently	○	○	○	○	○	○	○
Travelling/Shopping independently	○	○	○	○	○	○	○

Q16. What are the biggest barriers of obtaining smartphone devices and apps to support someone with Down's syndrome? (Select all apply)

- ☐ High cost for device or app
- ☐ Can't find any appropriate apps
- ☐ Can't find any appropriate devices
- ☐ Unsure if they apps are suitable
- ☐ No barriers to get an apps or device
- ☐ Other (Please specify): ___________

Q17. What are the barriers of using smartphone and apps for a person with Down's Syndrome? (Select all that apply)

☐ Frustration using apps and devices
☐ Lack of knowledge about assistive apps and devices
☐ Apps doesn't have features according to their needs
☐ Require training to use app
☐ Other (Please specify): ________________________

Q18. What are the barriers do you think might be faced by someone with Down's Syndrome using smartphone and apps to support travelling around home, going to school or going for shopping independently in city like Glasgow, Scotland?

____

____

Q19. How do you think mobile and wearable like smartphone and smart-watch technology could help people with Down's Syndrome with independent activities around the city?

____

____

End of Block: Section 3 of 4 – Attitudes to support technologies

---

Start of Block: Section 4 of 4

Section 4 of 4 - Comments and Feedback

Q20. Would you be willing to join a workshop to share more about your thoughts and experiences working with people Down's Syndrome and helping us to understand more about barriers of smartphone and smart-watch use for

reminding, tracking, monitoring, guiding and assisting people with Down’s Syndrome?

- ○ Yes, I would like to join in Workshop
- ○ No - Thank you

Q21. You have reached the end of the survey. Please feel free to write any comments, feedback or thoughts in use of smartphone and apps to support independent activities of a person with Down's Syndrome. Please click 'Next' to finish the survey.

____

____

End of Block: Section 4 of 4

Appendix C: participant's consent form and information sheet.

Consent Form for home interviews

An Investigation into mobile and smartwatch apps to support city mobility for people with Down's Syndrome

Please read and sign:

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time.
- I understand that the data collected in these workshops and meetings will be used in the design of applications and in research publications as outlined on the information sheet. I understand that anonymous versions of the data may be made available in full through the University of Strathclyde Open Access policies and excerpts used in academic publication and related promotional material – but that all data will be carefully vetted so that I cannot be identified from published data.
- I understand that I can later ask to have data related to my contribution withdrawn from the study (within 28 days to be removed from anonymous versions).
- I understand that meetings will be audio recorded and transcribed by third parties but that these recordings will not be made public nor will I be identified to the transcription company.
- By signing this form, I consent to being a participant in the project.

(PRINT NAME)	
Signature of Participant:	Date:

Participant Information Sheet for Home Interviews

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it will involve. Please read the following information carefully and ask questions if anything you read is not clear or would like more information.

Title of the study:
An Investigating into mobile and smartwatch apps to support independent city mobility for people with Down's Syndrome

Introduction and aim of this study:
I am "Al Majed Khan" a doctoral student at University of Strathclyde, conducting research on how smartphones and smart watches can support daily activities of young adults with Down's Syndrome. Based on my early research, the aim of this study is to investigate the use of smartphones and smartwatches to provide support for city mobility. This is a part of a series of interviews in which we will explore potential designs for apps that could help support independent activities and travel with public transport. This study will focus on your experiences and suggestions to design the front-end through available supported technologies.

Do you have to take part?
No, this is voluntary and you can withdraw at any point (with or without giving a reason). This study is interested in the views and experiences of people who support young adults with Down's Syndrome. As a participant, you can help us by sharing your experiences and providing your suggestions, which is why I am asking you to be a participant in this study. In this part of the study, I am particularly interested in experiences of supporting young adults with DS with transport and independent mobility around cities or towns. I am also interested in your experience of smartphone apps both to support young people with DS and in how young people with DS use apps.
Participation is totally up to you, if you wish to take part in this study and you are free to withdraw at any time without giving a reason.

What will you do in the part of the project?

For this part of the project, I am conducting a number of semi-structured interviews in home environments. If you are interested in taking part in the study, you asked to reply to the invitation mail with suitable times for you. We'll then agree a time and location (either your home or somewhere else nearby).

The interview will last no longer than 90 minutes.

The plan for the interview is as follows:

1. Confirm audio recording
2. Q1: Discussion around the question of "what are the main barriers to independent travelling with public transport for a young adult with Down's Syndrome?" We will summarise this in a handwriting page summarising and recording the main barriers.
3. Q2. Following the same format: "what are the main benefits and usability issues for young people with DS using smartphone apps".
4. Brief introduction to smartphone and smartwatch technologies with examples of usage
5. *Short break if needed*
6. Q3. Following the same format: "how the identified barriers from above could be overcome with smartwatches and smartphone apps?"
7. A sketching session in which we will jointly draw some rough outline interface designs for smartwatch and smartphone apps.
8. A short final discussion of any points that you wish to raise.

What will happen after the interview?

We will take the sketches, notes and audio recordings from all interviews and write them up for academic publication and inclusion in my PhD thesis. We will then prototype some of your ideas and hope to come back to you later in the year to get feedback on developed apps. At that stage, we may also be interested in sessions directly with young adults with Down's Syndrome as well as your feedback.

Why have you been invited to take part?

You have invited because you have experience with a young person with Down's syndrome.

What are the potential risks to you in taking part?

There are no direct risks to take a part in this study and you can leave at any point if you feel uncomfortable.

What happens to the information in the project?

The session will be recorded as audio along with notes and our final design drawings. Audio recordings will be kept securely and shared only with the transcription companies, transcripts will be anonymous. Signed paper consent forms will be kept in secure locked cabinets. All consent forms and recordings will be destroyed at the end of the PhD.

Anonymous quotations, summary data and photographs sketches may be used in academic publication and research group promotional material (potentially including the group website), but your identity will be protected and no personal/contact information will be shared with third parties.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998 and General Data Protection Regulations 2016. All personal data on participants will be processed in accordance with the provisions of the acts.

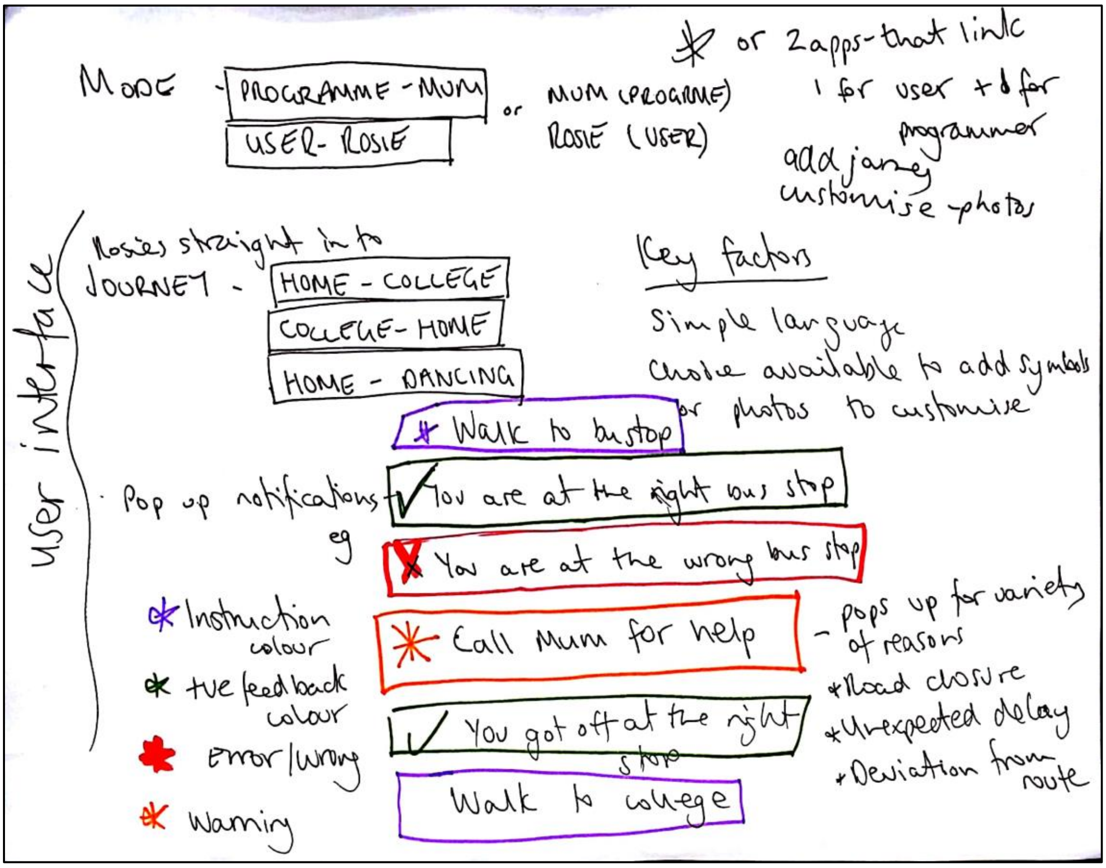
Researchers contact details:
If you have any future questions or concerns about this study, please feel free contact:

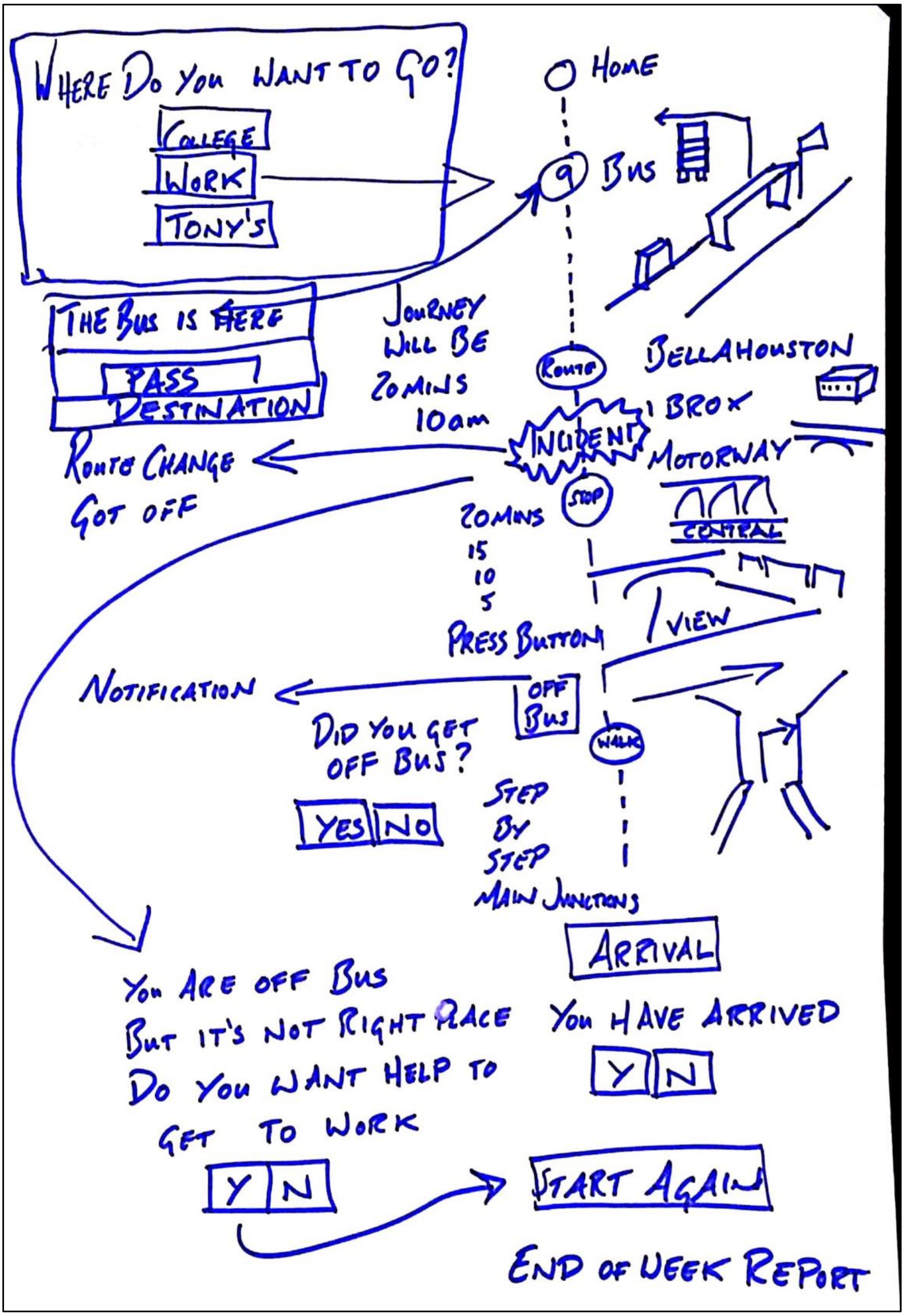
Principal Investigator and PhD Student:	**Senior Lecturer and Project Supervisor:**
Al Majed Khan	Dr Mark Dunlop
University of Strathclyde	University of Strathclyde
Computer & Information Sciences	Computer & Information Sciences
26 Richmond Street	26 Richmond Street
Glasgow, G1 1XH	Glasgow, G1 1XH
majed.khan@strath.ac.uk	mark.dunlop@strath.ac.uk

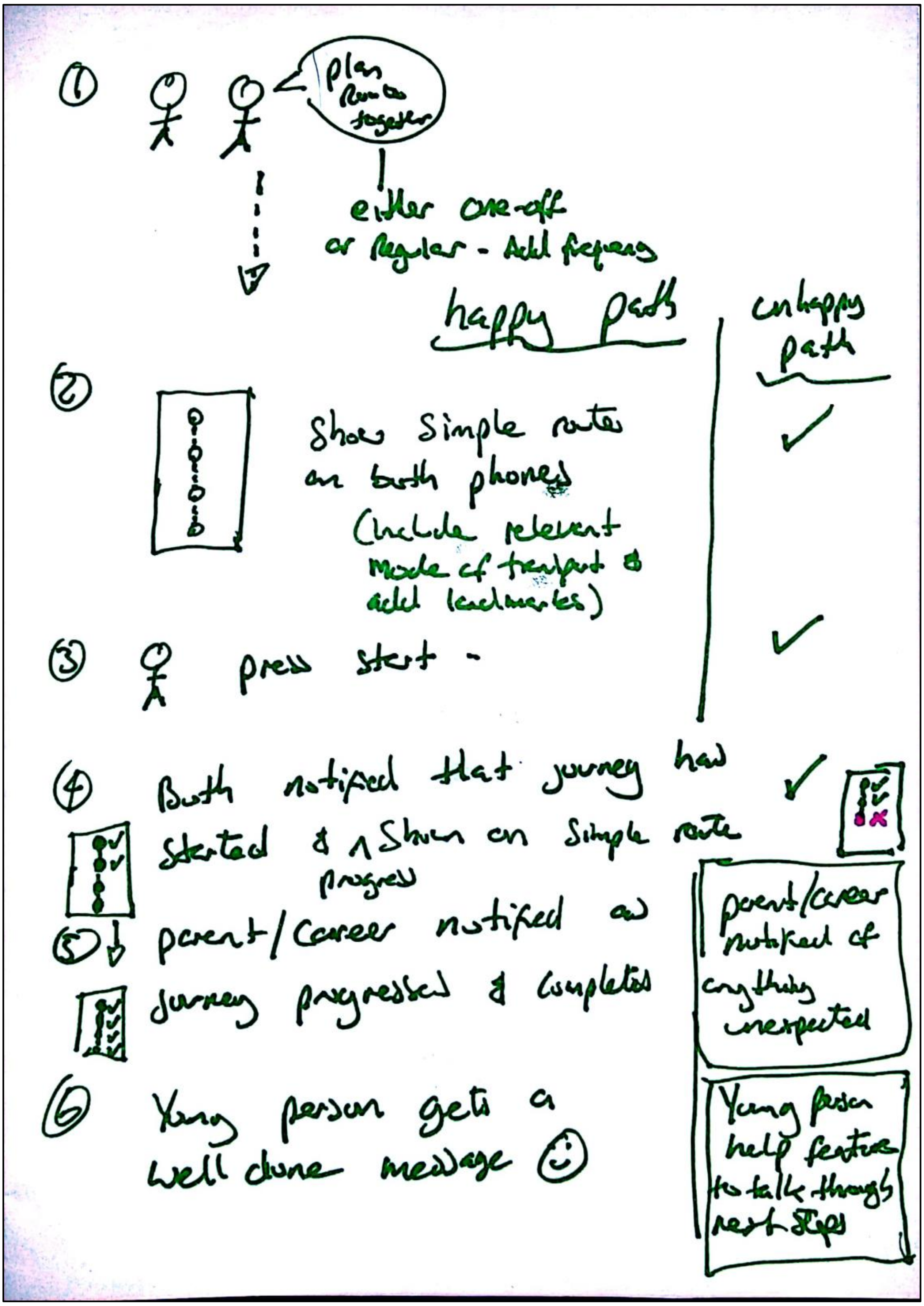
This investigation is conducted under ethical approval of Computer and Information Sciences Ethics Committee. Ethical approval ID: 765. If you have any questions/concerns, please contact: Departmental Ethics Committee, Computer Information Science, University of Strathclyde, 26 Richmond Street, Glasgow G1 1XH. enquiries@cis.strath.ac.uk

Thank you for reading this information – please ask any questions if you are unsure about what is written here. If you do not wish to take a part in the study, thank you for your time and consideration.

Appendix D: sketches and drawings from participants.




WHERE DO YOU WANT TO GO?
COLLEGE
WORK
TONY'S
HOME
9
BUS
THE BUS IS HERE
PASS
DESTINATION
JOURNEY WILL BE
20MINS
10am
ROUTE
BELLAHOUSTON
IBROX
INCIDENT
MOTORWAY
ROUTE CHANGE
GOT OFF
STOP
CENTRAL
20MINS
15
10
5
PRESS BUTTON
VIEW
NOTIFICATION
OFF BUS
DID YOU GET OFF BUS?
YES
NO
WALK
STEP BY STEP
MAIN JUNCTIONS
ARRIVAL
YOU ARE OFF BUS
BUT IT'S NOT RIGHT PLACE
DO YOU WANT HELP TO GET TO WORK
Y
N
YOU HAVE ARRIVED
Y
N
START AGAIN
END OF WEEK REPORT



① plan Routes together

either one-off or Regular - Add frequency

happy path

unhappy path

② Show simple route on both phones (include relevant mode of transport & add landmarks) ✓

③ press start - ✓

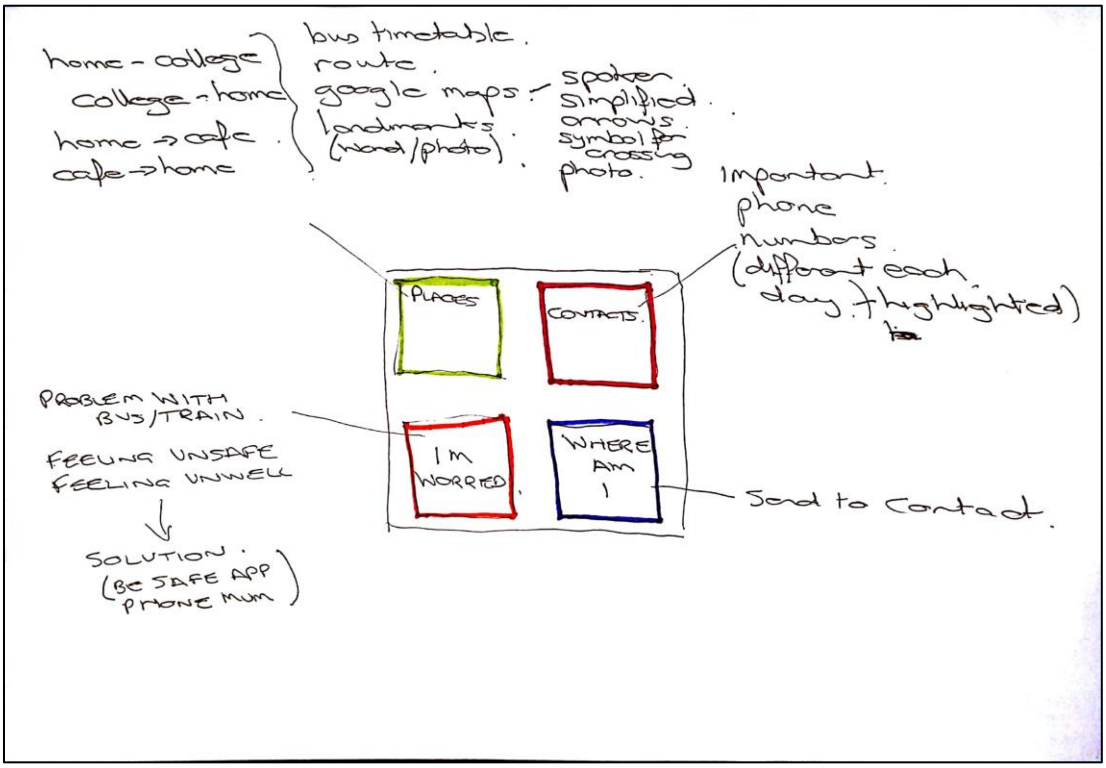
④ Both notified that journey has started & progress shown on simple route ✓

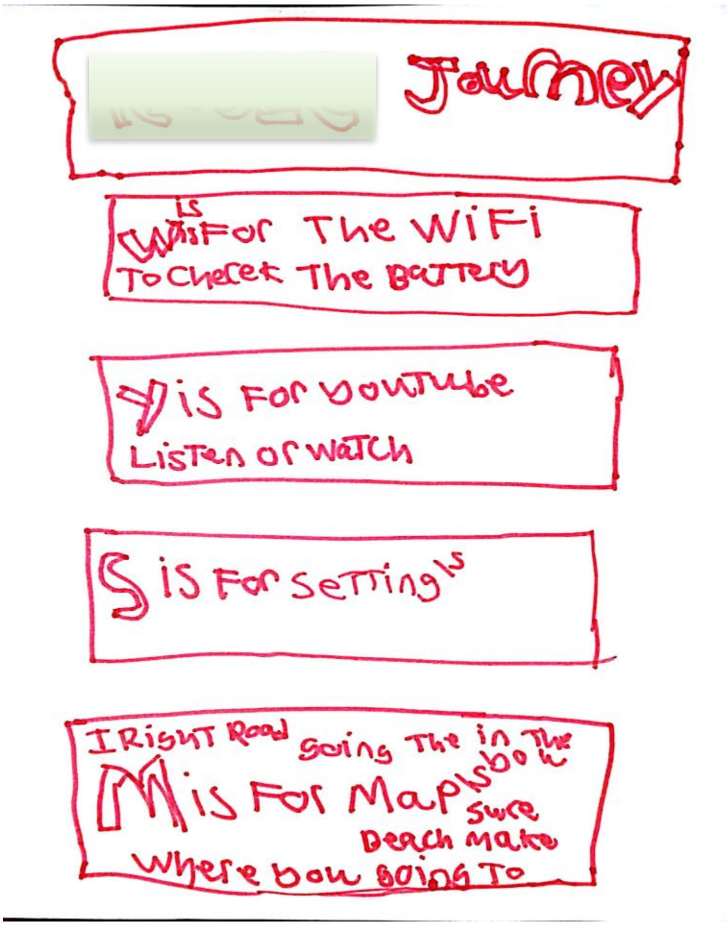
⑤ parent/career notified as journey progresses & completes

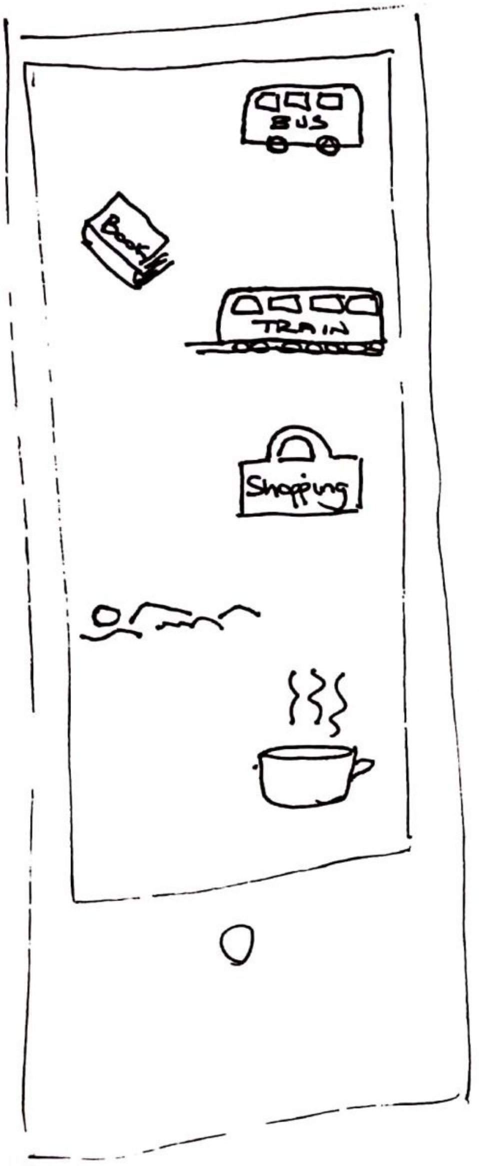
parent/career notified of anything unexpected

⑥ Young person gets a well done message ☺

Young person help feature to talk through next steps

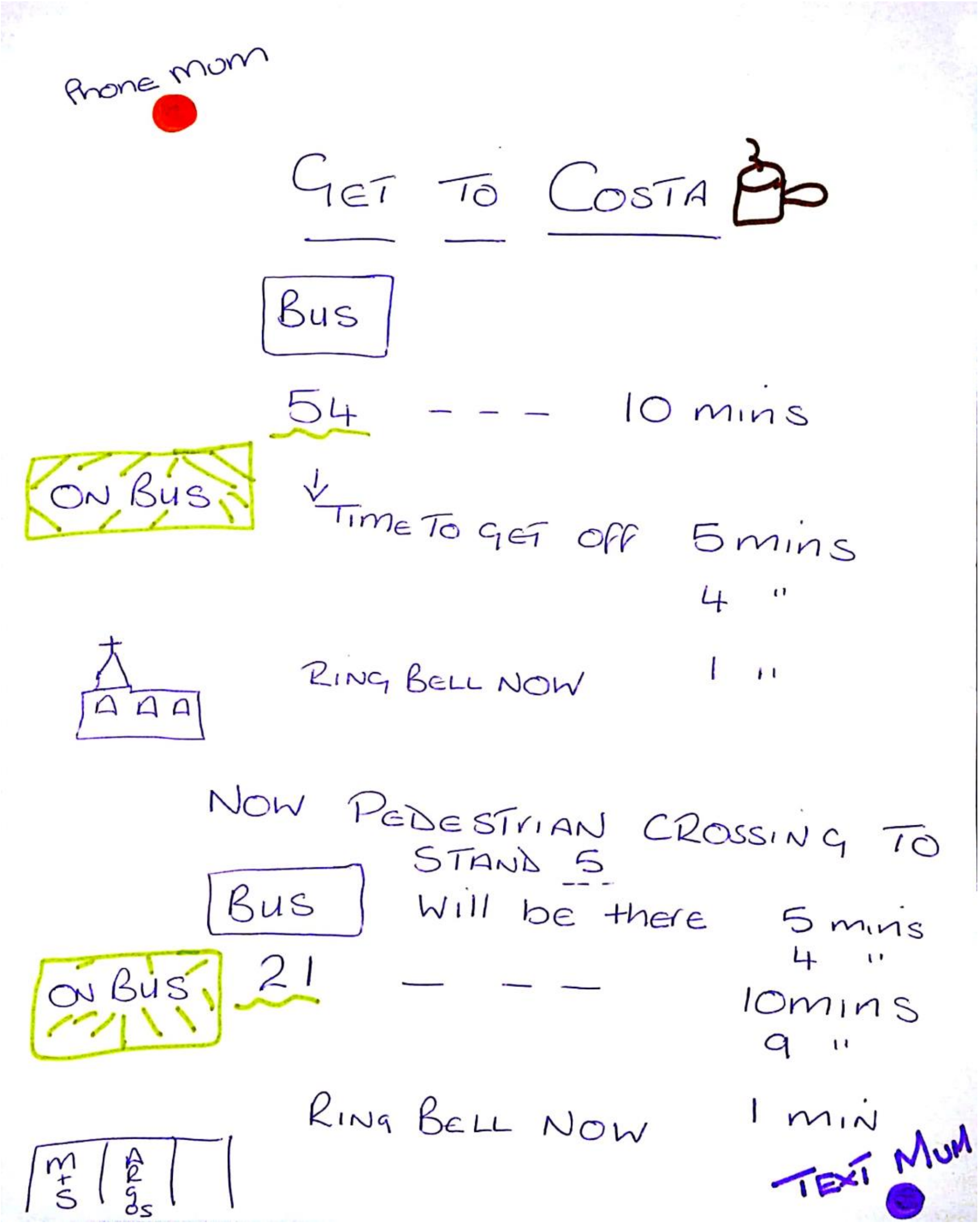

home - college
college - home
home → cafe.
cafe → home
bus timetable.
route.
google maps -
landmarks.
(word/photo).
spoken.
simplified.
arrows.
symbol for crossing
photo.
Important.
phone
numbers.
(different each
day.+highlighted)
PLACES
CONTACTS.
I'm WORRIED.
WHERE AM I
PROBLEM WITH
BUS/TRAIN.
FEELING UNSAFE
FEELING UNWELL
SOLUTION.
(BE SAFE APP
PHONE MUM)
Send to Contact.


Journey
W is For The WiFi
To Cherck The Battery
Y is For youtube
Listen or watch
S is For settings
I Right Road going the in the
M is For Maps bow
sure
beach make
where bow going to



Theatre
Swimming
Cinema
Shops.
Churchhalls
(for activities)
Cafe
Hotels
Bank
local address
for family & friends

Bus Numbers
Bus Stands
Stations



Phone mom

GET TO COSTA

Bus

54 - - - 10 mins

ON BUS

TIME TO GET OFF 5 mins

4 "

RING BELL NOW 1 "

NOW PEDESTRIAN CROSSING TO STAND 5

Bus

Will be there 5 mins

4 "

ON BUS

21 — — — 10mins

9 "

RING BELL NOW 1 min

M + S

ARgos

TEXT MUM

User

Voice notification would be useful.
– Perhaps a personalised voice – Mum? Alexa?,

On-screen 'help' character, dog, cat etc.

Notifications
eg How long it will take to get to the bus stop.
Directions to bus stop. 'Walk down the road'. 'Press for crossing' and cross when 'Green man' shows.

Seeing 'me' on the screen.

Seeing which stop is next.

Notification 'Get off the bus' at the next stop'.

'Well done' when user has alighted from the bus.

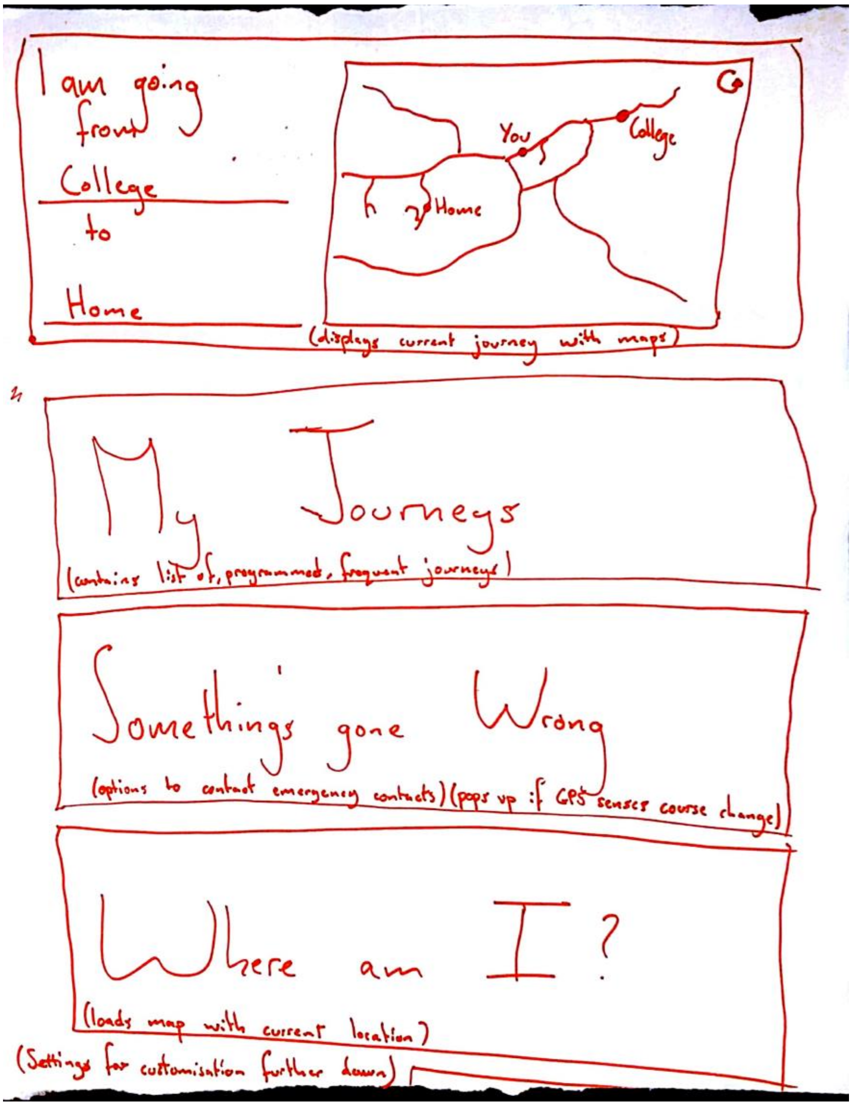
Routes stored.

User arrives at the bus stop and
Parents notified when he ~~child~~ gets on ~~the bus~~ or off the bus or arrives at destination.

When something goes wrong, a '~~Would you~~' 'I can help' button.

Different levels for different abilities.


My Places
Open list of regular destinations
↓
Opens route to destination from current location
Find new Place
Option to add to MyPlaces when route defined
Where Am I?
Send location to contact!!
My Contacts
Help -
Calls for help to contact for today



I am going from

College

to

Home

(displays current journey with maps)

My Journeys

(contains list of programmed, frequent journeys)

Something's gone Wrong

(options to contact emergency contacts) (pops up if GPS senses course change)

Where am I?

(loads map with current location)

(Settings for customisation further down)

Appendix E: easy to read consent form and participant’s information sheet.

Consent Form for home interviews

Study Title: An Investigation into mobile and smartwatch apps to support independent travel with public transport for people with Down's Syndrome.

Please tick the box after each statement if you agree.

I have read and understood the information sheet for the above project.

I have been able to ask the researcher questions.

The researcher has answered any queries to my satisfaction.

☐ ✓

I want to take part.

☐ ✓

I know that my participation is voluntary, and I can leave at any time.

I know that I do not need to finish all tasks.

☐ ✓

I agree to sound recordings in all tasks.

I agree that the data collected in these workshops will be used in the design of applications and in research publications.

☐ ✓

Participant Name:

Participant Signature:

Caregiver Name:

Caregiver Signature:

Date:

Interviewer Name:

Date:

Participant Information Sheet for Home Interviews

University of Strathclyde
Computing and Information Science
16 Richmond St, Glasgow G1 1XQ

Study Title: An Investigation into mobile and smartwatch apps to support independent travel for people with Down's Syndrome with public transport.

Introduction

You are invited to take part in a research study.

This study is about how people with Down's Syndrome easily navigate around and access public transport.

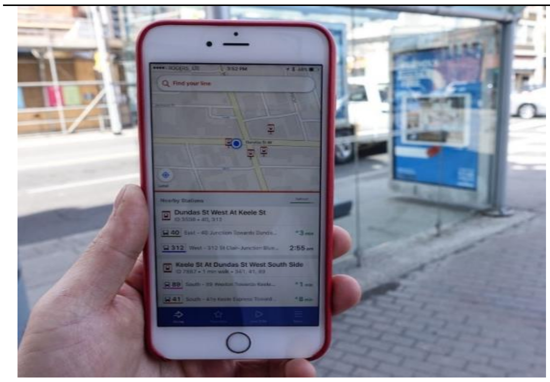
Taking part in the research study may help to improve support for people with Down's Syndrome to become more independent.

Before you decide if you would like to take part, we would like you to get more information about the research study and what we are asking you to do

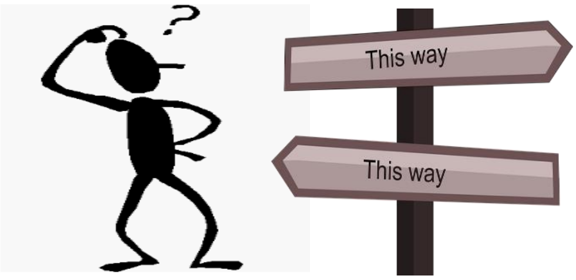
What is the research study about?

Exploring potential designs for mobile and smartwatch apps to support independent travel with public transport.

Discussing the difficulties of finding a bus stop and getting the correct bus when travelling independently.



Current bus app with too much information, difficult to use by people with Down's Syndrome.



If lack of appropriate apps leads to confusion and limits independent travel.

N32

Wait 5 min

10:04am Home
5 min walk to bus Stop
10:15am Bus Stop 1
10:16am Bus Stop 2
10:17am Bus Stop 3
10:22am Bus Stop 4
10:30am Bus Stop 5
2 min walk to School
10:32am School

Get feedback on our prototype app to support independent travel with Bus and navigation to support short walking distance.

We would like to discuss what you do/don’t like, anything you like to improve or include something new.

Who will be involved?

2-5 People

You and your parents/caregiver will be invited to take part in the design of the app.

You can invite any family members along to help you.

There will one person visit your home and running the study: Majed Khan

Majed is a PhD student at the University of Strathclyde under the supervision of Dr Mark Dunlop.

What will I need to do?

2 Tasks (60 Minutes)

You will take part in 2 tasks

Task 1 (30 Minutes)

A demonstration on designed prototype

You will be asked to give your opinions on designed prototype.

Task 2 (30 Minutes)

A demonstration on current development of Smartwatches

We will be asked on potential solutions to overcome those barriers using smartwatch.

Do I have to take part?

No, this is voluntary, and you can leave at any time you want.

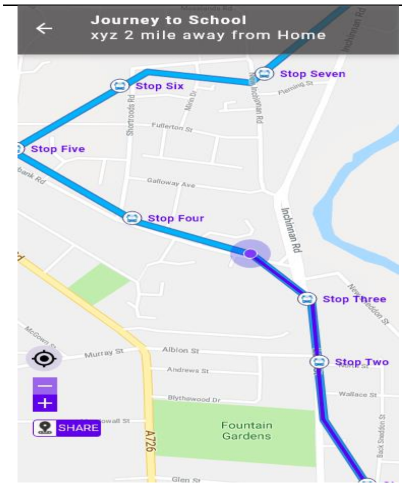
What information will be kept?

Our conversation will be recorded using a voice recorder. The recordings will be kept confidential and store in the university server. Only the Principal Investigator will be able to access the stored recordings.

Signed paper consent forms will be kept in secure locked cabinets.

Final design drawings will be kept and may be used in publications. Your name will never be used us.

Where will the information be used?



Collected drawings will be used to implement the mobile and smartwatch app.

The developed apps, drawings, and quotes may be presented at conferences and included in research papers.

Also, all related information will be included in Majed’s PhD thesis.

All consent forms and recordings will be destroyed at the end of the PhD.

Who to contact?

If you have any question about this study, please contact

Principal Investigator and PhD Student

Al Majed Khan.

Email: majed.khan@strath.ac.uk

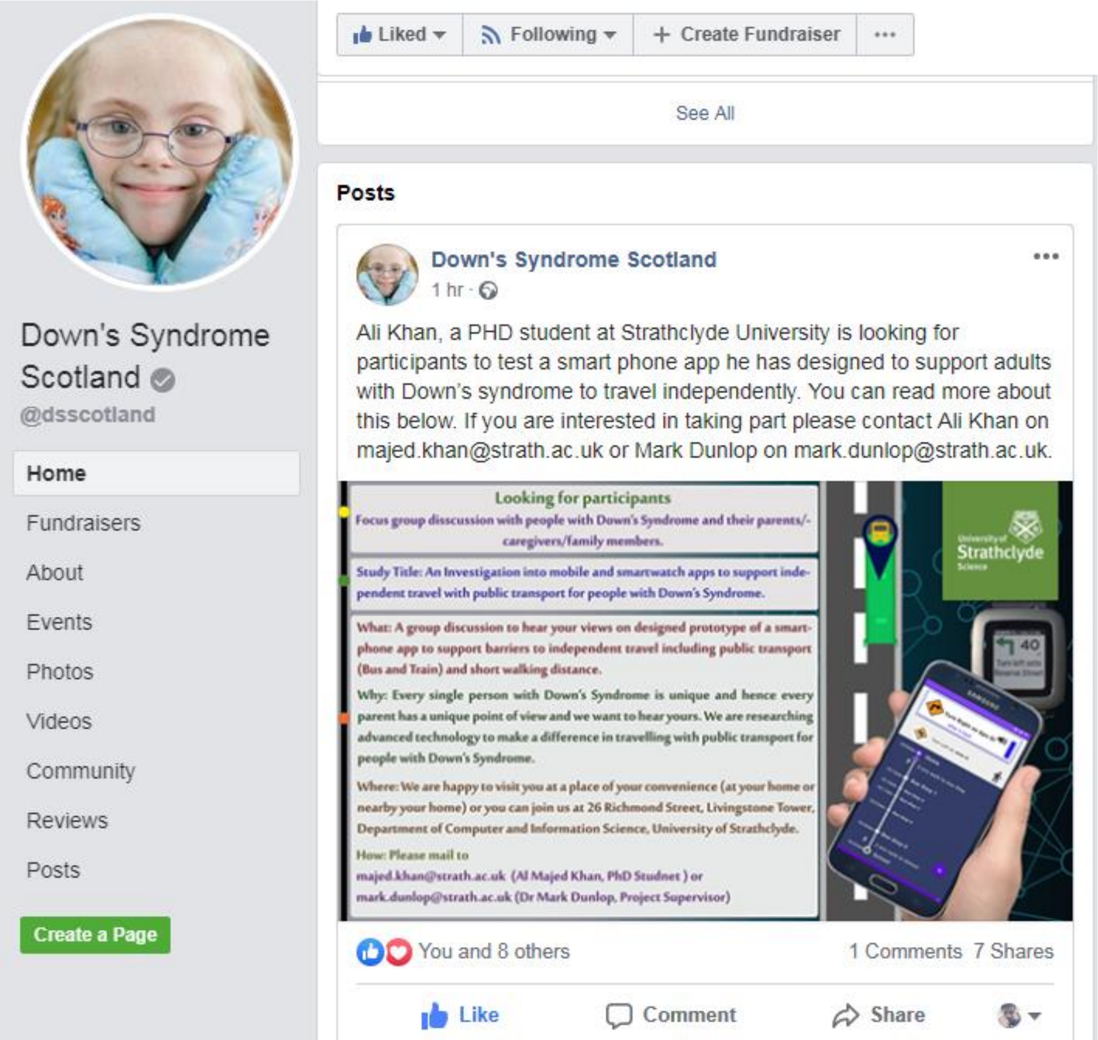
Senior Lecturer and Project Supervisor

Dr Mark Dunlop.

Email: mark.dunlop@strath.ac.uk

Departmental Ethics Committee
ethics@cis.strath.ac.uk
University of Strathclyde
Computer & Information Sciences
26 Richmond Street, Glasgow, G1 1XH
Ethical approval ID: 941.

Appendix F: social media post by Down's Syndrome Scotland.



Ali Khan, a PHD student at Strathclyde University is looking for participants to test a smart phone app he has designed to support adults with Down's syndrome to travel independently. You can read more about this below. If you are interested in taking part please contact Ali Khan on majed.khan@strath.ac.uk or Mark Dunlop on mark.dunlop@strath.ac.uk.

Looking for participants

Focus group disscussion with people with Down's Syndrome and their parents/-caregivers/family members.

Study Title: An Investigation into mobile and smartwatch apps to support independent travel with public transport for people with Down's Syndrome.

What: A group discussion to hear your views on designed prototype of a smartphone app to support barriers to independent travel including public transport (Bus and Train) and short walking distance.

Why: Every single person with Down's Syndrome is unique and hence every parent has a unique point of view and we want to hear yours. We are researching advanced technology to make a difference in travelling with public transport for people with Down's Syndrome.

Where: We are happy to visit you at a place of your convenience (at your home or nearby your home) or you can join us at 26 Richmond Street, Livingstone Tower, Department of Computer and Information Science, University of Strathclyde.

How: Please mail to
majed.khan@strath.ac.uk (Al Majed Khan, PhD Studnet) or
mark.dunlop@strath.ac.uk (Dr Mark Dunlop, Project Supervisor)

Looking for participants

Focus group disscussion with people with Down's Syndrome and their parents/-caregivers/family members.

Study Title: An Investigation into mobile and smartwatch apps to support independent travel with public transport for people with Down's Syndrome.

What: A group discussion to hear your views on designed prototype of a smatphone app to support barrires to independent travel including public transport (Bus and Train) and short walking distance.

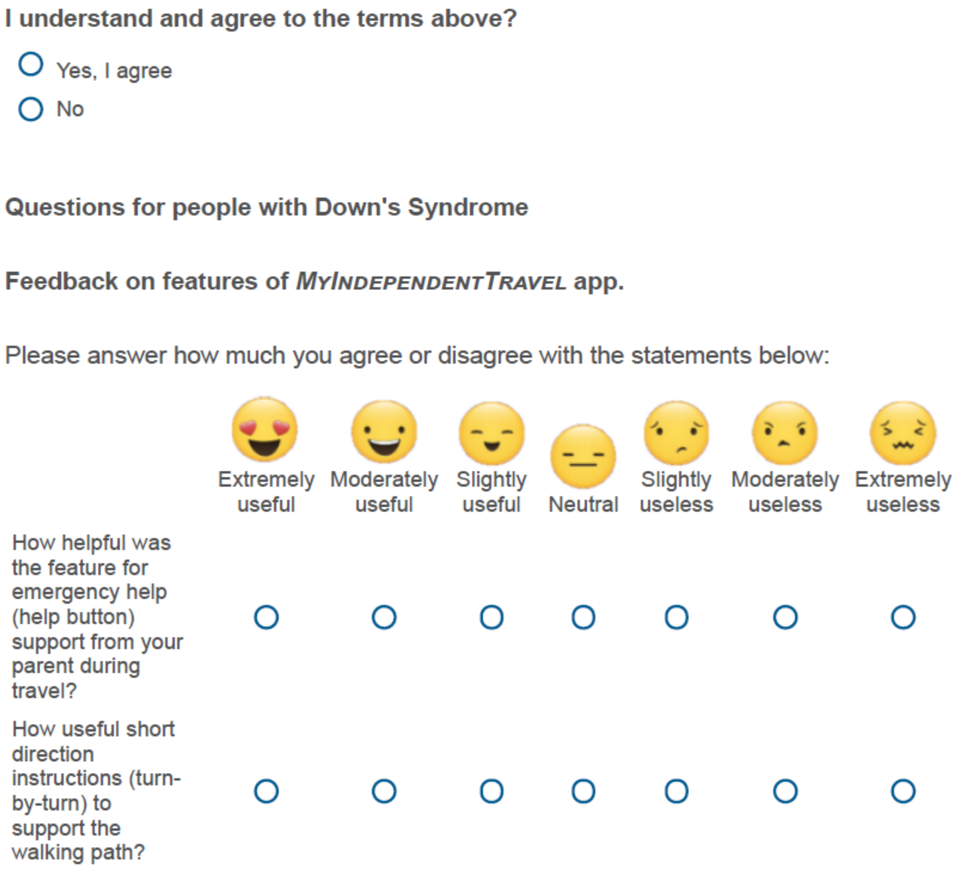
Why: Every single person with Down's Syndrome is unique and hence every parent has a unique point of view and we want to hear yours. We are researching advanced technology to make a difference in travelling with public transport for people with Down's Syndrome.

Where: We are happy to visit you at a place of your convenience (at your home or nearby your home) or you can join us at 26 Richmond Street, Livingstone Tower, Department of Computer and Information Science, University of Strathclyde.

How: Please mail to
majed.khan@strath.ac.uk (Al Majed Khan, PhD Student) or
mark.dunlop@strath.ac.uk (Dr Mark Dunlop, Project Supervisor)

Appendix G: a survey to record users' satisfaction

An investigation into the navigation app to support people with DS



I understand and agree to the terms above?

○ Yes, I agree
○ No

Questions for people with Down's Syndrome

Feedback on features of *MyIndependentTravel* app.

Please answer how much you agree or disagree with the statements below:

	Extremely useful	Moderately useful	Slightly useful	Neutral	Slightly useless	Moderately useless	Extremely useless
How helpful was the feature for emergency help (help button) support from your parent during travel?	○	○	○	○	○	○	○
How useful short direction instructions (turn-by-turn) to support the walking path?	○	○	○	○	○	○	○

	Extremely useful	Moderately useful	Slightly useful	Neutral	Slightly useless	Moderately useless	Extremely useless
How useful do you think auditory and vibrating notification usage?	○	○	○	○	○	○	○
How useful in preparing upcoming decision points?	○	○	○	○	○	○	○
How useful personalised landmark feature?	○	○	○	○	○	○	○
How useful current location update in real-time?	○	○	○	○	○	○	○
How helpful the communication feature to communicate with the bus driver?	○	○	○	○	○	○	○

General feedback on *MyIndependentTravel* app

How appropriate the linear bar (to represent the planned route summary) concept to support travelling?

Extremely appropriate	Moderately appropriate	Slightly appropriate	Neutral	Slightly inappropriate	Moderately inappropriate	Extremely inappropriate
○	○	○	○	○	○	○

To what extent do you agree that *MyIndependentTrave* app would enable you to travel more independently?

Strongly agree	Agree	Somewhat agree	Neutral	Somewhat disagree	Disagree	Strongly disagree
○	○	○	○	○	○	○

How comfortable would make your ride on public transport (bus) using *MyIndependentTravel* app?

Extremely comfortable	Moderately comfortable	Slightly comfortable	Neutral	Slightly uncomfortable	Moderately uncomfortable	Extremely uncomfortable
○	○	○	○	○	○	○

How easy to use the *MyIndependentTravel* app?

Extremely easy	Moderately easy	Slightly easy	Neutral	Slightly difficult	Moderately difficult	Extremely difficult
○	○	○	○	○	○	○

What are three good and bad points of the app

	Good points	Bad points
Point 1		
Point 2		
Point 3		

Block 1

Questions for parents/caregivers.

Feedback on features of *MyIndependentTravel* app that implemented for parents/caregiver

Please answer how much you agree or disagree with the statements below:

	Extremely useful	Moderately useful	Slightly useful	Neutral	Slightly useless	Moderately useless	Extremely useless
How helpful the tracking and monitoring feature?	○	○	○	○	○	○	○

Appendix H: Easy Read Participants Information Form for User with DS (Walkthrough)

Participant Information Sheet for Evaluation of *MYINDEPENDENTTRAVEL* App

University of Strathclyde Science

University of Strathclyde
Computing and Information Science
16 Richmond St, Glasgow G1 1XQ

Study Title: An investigation into a navigation app to support independent travel with public transport for people with Down's Syndrome.

Introduction

You are invited to take part in a research study.

This study is about how people with Down's Syndrome easily navigate around and access public transport.

Taking part in the research study may help to improve support for people with Down's Syndrome to become more independent.

Before you decide if you would like to take part, we would like you to get more information about the research study and what we are asking you to do.

What is the research study about?

Turn left onto Glasgow Road. Go for 51.1 m.

Wait for Green light then Cross the road

Evaluating navigation app called "*MYINDEPENDENTTRAVEL*" to support independent travel with public transport for people with Down's Syndrome.
This process involves the following:

To assess directional instructions that support walking navigation. E.g. "Turn right", "Turn left"

To assess finding correct of Bus stop and recognising correct Bus number.


N32

1 min to arrived stop

Get off at next shop, Press Stop button to stop the Bus

Home - School

To assess other instructions that alert user about a particular situation during travel, e.g. "Press stop button" to get off the Bus".

To assess communication instruction with the Bus driver.

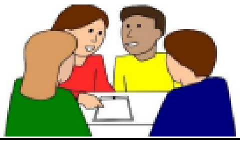
ZOOM/Skype MEETING

Get feedback on developed app through online semi-structured interview.

We would like to know what you do/do not like, anything you want to improve or include something new.

Who will be involved?

2 - 4 People



You and your parents/caregiver will be invited to take part in this evaluation process of the app.

You can invite any family members along to help you.

What will I need to do? (2 Tasks 60 minutes)

We recorded a video that demonstrated travel from A to B using "*MYINDEPENDENTTRAVEL*" app. You can watch the video by visiting this link https://abc

Task 1: A brief introduction with about demonstrated video.

Task 2: We will watch together the demonstrated video step-by-step and you will be asked related questions during this process.

Do I have to take part?

No, this is voluntary, and you can leave at any time you want (with or without giving a reason).

What information will be kept?

All the demographic information that we collect about you and all digital data will be kept secure storage environments.

Our meeting will be recorded as video and audio, you can keep turn off the camera if you do not want your face to be recorded.
Agreement of digital consent and data will be kept securely in the university's StrathCloud server.

All consent forms and recordings will be destroyed at the end of the PhD (est April 2021).

Where will the information be used?

The interview data will be analysed to validate the developed app "***MyIndependentTravel***".

Collected data may use in publication but your identity will be obscured from the data.

Who to contact?

If you have any question about this study, please contact
Principal Investigator and PhD Student
Al Majed Khan.
Email: majed.khan@strath.ac.uk
Senior Lecturer and Project Supervisor
Dr Mark Dunlop.
Email: mark.dunlop@strath.ac.uk
Departmental Ethics Committee
ethics@cis.strath.ac.uk
University of Strathclyde
Computer & Information Sciences, 26 Richmond Street, Glasgow, G1 1XH, Ethical approval ID: 1361.

Appendix H: the matrix table of framework analysis

Framework analysis for co-designed discussion with young adults with DS and their parents/caregivers											
Themes	**Unfamiliarity**		**Public transport access**			**Technology and apps**			**Parent's anxiety**		**App requirements**
Sub-thems/ Group ID	Finding new places/Bus stops/road change	Road Crossing/Pedestrian Crossing	Recognising departure Bus stop nearby/ destination	Recognise the correct bus/Bus number	Time length and Bus timetable	Reading mobile Map/using apps	Tracking user's location	Full Journey plan/ lack of suitable apps	Safety	Tracking and monitoring/transit, route/pedestrian crossing and communication	Help
Group 1 (DS_H_Inter_230718_13)	Male: he was identified as a potential candidate to receive some training to catch a bus, which involved several months of working with a support worker and going on the same route at the same time of day. It was broken down into stages. Where to catch the bus or how to	Male: It was broken down into stages. Where to catch the bus or how to cross a road to get to the bus stop. How to catch a bus. The stop he goes to, there are three different services that come past, so he had to catch the	Male: Yes. When [DS's name] first started catching the bus, I remember thinking that it would be brilliant, something to tell when it was time to get off. And even if he had fallen asleep or just nodded off, it would vibrate and possibly end up waking him. Because falling asleep is a common issue. Male: One of the issues he had	Individual with DS: Thirty-four is my bus. Male: There are two buses, aren't there, you can get them. Individual with DS: Thirty-four or a thirty-four-a. Interviewer: And you're able to see and get the bus number? Individual with DS: Yes.	Male: Timetable could be how long it's got to be before the bus comes, not necessarily time of day, which doesn't mean very much to [DS's name], how long he's got to wait. Also a list	Male: Yes. Well, they wouldn't use phones. Did Threshold show you how to use Google Maps? Individual with DS: No, I don't think so. Male: Did they show you that? You've never	Male: When he first started, I used- I have an iPhone as well, so I used 'Find my iPhone' and I used it to track him. I think if there was someth		Male: I would see that he'd got off the bus, and it actually became more of a worry because sometimes he	Male: Yes, I would, yes, if not track, if it was a known route and then it was some indication that something was different. Because if he goes to college every day, I wouldn't probably follow it every single day. But say there was an app that knew what he was supposed to be doing, like catching the bus here and going to college and getting off at a certain stop. Male: I just try and track him sometimes to find out where- Male: No, I just know what days the college, and then sometimes I send him a	Individual with DS: I always turn my iPhone so then someone can contact me, maybe a carer or my parents or someone.

	cross a road to get to the bus stop. How to catch a bus. The stop he goes to, there are three different services that come past, so he had to catch the right bus.	right bus. But I am concerned about the crossing, that he is able to cross on his own.	was missing the stop.	I got trained by someone at school. But it was a lady called XX from a company from Glasgow Green. Threshold.	of favourite activities. He always goes to the same cinema. Just now people take him, but if he was able to, say, from here go to the cinema, go in town, there would be a number 75 bus, but he's never done it independently. Do you think you could do it yourself? Male: The next thing on his list was the bus to	used it, have you? Individual with DS: No, I didn't use it. No, I saw Google Maps in college.	ing that drew on live sources, you know, Google Maps, bus timetables, live bus positioning and there was something that was a simple interface that could draw information with these things		would be at the bus stop when he's actually on the bus, and it's maybe five minutes out of date and I would worry that he'd dropped his phone or something had happened. But	message when I know he should be on the bus. I'll say, "How are you doing [DS's Name]?" to give him the opportunity to say, "I'm fine. I'm on the," tracking to see the bus	Male: he phoned us, "I caught the bus." So he uses his phone, but it's for a WhatsApp group because he can send a message on WhatsApp and either his sister or his mum or dad will

					come, but he didn’t realise the snow might prevent the bus from coming because the road was slippery.				then I think he worked out how to switch it off, the ‘Find my iPhone’ thing, so now I don’t track him. I just let him- and just think, well, he can- Male: Yes. Yes, although he’s		pick it up. Individual with DS: If I get lost, I would probably call someone. Individual with DS: I do talk to the driver sometimes, I’d probably try to ask the driver how to get to food shops

									never lost a phone. Male: I worry about him and his phone. I worry about people using a daily trip, recognising that he’s on his own, he’s a bit vulnerable, and you wouldn’t		or supermarket or something.

									even need to mug him for it. You would just take it, but he’s been doing it for two years now with no incident, and probably the concern about it is actually greater than the realit		

									y. Male: Well, the twice he’s fallen asleep on the bus, I know how difficult it would be for [DS's name] to get off the bus and explain to somebody what he was doing for them to		

									understand what he was doing. So that was a big issue, but fortunately, the driver was able to get him back.		
Group 2 (DS_H_Inter_310718_04)	Female: Yes. I think barriers- well, at the moment she wouldn't be able to do it independently. She would need to have someone with her, or she would need to have someone go and practice it		Male: Just the one thing, in town, there were loads of temporary bus stops which were not exactly where the closed bus stop was, they were maybe like 100 yards further down.	Female: if multiple buses are coming at a time she would struggle to recognize the bus. If some reason bus service is cancelled she will not know, she	Male: you would go to the bus station and get the bus, or you would go to the train station and get the train, and where is it	Male: she can't use Google Maps and that, do you know what I mean? It's a bit beyond her. Again, you've got to actually key in the location		Male: I mean, I would say, if you were making an app for it, it would need to have some way of being able to track [DS's name] location when she's out. If	Female: Okay, well, I think at the moment for me it's personal safety. So		Female: It's difficult, because if something went wrong on that, that's where she

	with her for quite a few times before she was able to go on her own. She goes to college, but she actually gets picked up by mini bus. So there isn't really anywhere that [DS's name] travels on her own at the moment. There was somebody who came from Visibility Scotland that worked with her for a number of weeks to let her walk to college, but that didn't work out. If I had suggested to [name] walking, she would then not have been			will wait for the bus.	and what time is it?	you want to go to there, and she doesn't necessarily know a postcode or, like, full address and that. She just knows what she thinks about that. Male: I don't think she's ever used it. Male: Yes, she can do directions no bother. If there was a voice or a visual, like a text thing came up on the		[name] got in some kind of trouble, there'd need to be a way for her to either signal to her mum or someone else, and then there would also need to be some way, if she doesn't quite know what she's asking for, like a bus ticket or whatever, a rail ticket.	to have something which you can do on the phone or something, so it picks up that she's in danger or she's not sure of something going on. So something that she can quickly		would need to be able- I don't know, a quick dial to phone Mum, or phone somebody to get help. So maybe if there was, like, a shortcut button or something that she could just press that phoned

	able to get the bus. I had thought initially, well, maybe she could walk on the days that the weather was good and get the bus other days, but they said, “No.” So it’s ended up that she’s really not very independent at all. we went to go for a bus and I couldn’t see, because I went to the stand that we usually went to. [DS's Name] was actually directing me to go somewhere else, so I don’t know whether it had changed. Again, things like that that					screen the same way Google Maps has. Google Maps is probably a little bit too dense.			flick to ask for help from someone at the- Male: some way to tell someone if she gets in trouble Male: That is a parental concern more than an actual issue. Female: at		Mum straightaway. Again, if Mum’s not answering, a back up, so that if it doesn’t get you, it will go and try somebody else, kind of thing. Male: suppose she was wanting to get on a bus from this

	happened, she would need to be able to get help with to know where to go to get the bus. Female: there were a few times when she was younger where she just let herself out for a bit, but she always seemed to find her way home. So she has got a good sense of direction locally, because she’s familiar with the area from walking about. She’s familiar with the area from walking about just with them. Male: I think if it’s a place								the moment, [DS's name] doesn’t use public transport, and it’s partly for all of these reasons because I can’t allow her, from a personal safety point of view and also		part of town up to, like, the opposite side. She wouldn't know to say, "I need a single to West Station," or whatever it is, right? So if you were making an app or something like that, it

	she’s familiar with, she can usually navigate back just the same way anyone else would. I think it’s more when it’s an unfamiliar place she’s really going to struggle. I don’t know whether she has the, sort of, on-her-feet decision making as well. If something was to happen that changed what she’d rehearsed, I don’t think she’d be able to make it up as she goes along either.								because if it all goes wrong. If you rehearsed it with her and she knew where she was going, then that’s fair enough and I think she would learn it. If somebody approached her		would need to actually tell her what she needed to ask for to get to her destination. So it would need to be like, “Where is it you're going? Okay, that’s at the bus station. Are you coming back? Right, you

									or something like that, that's		need a return," etc. It wouldn't occur to her to say, "I need a return to this place." Needs to be spelled out, really. Male: if she wanted to get a rail ticket to Glasgow Central, say, she

											would need some way to be told what she needs to say to the ticket man, do you know what I’m saying ?

The end.