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CO-DESIGNING WITH ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: A PARTICIPATORY ACTION RESEARCH APPROACH

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Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

School of Information Technology College of Science and Engineering James Cook University 2020

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Statement on the Contributions of Others

Nature of Assistance	Contribution	Names and Affiliations of Co-Contributors
Intellectual Support	Editorial assistance	Dr. Dianna Hardy Professor Trina Myers
	Workshop design	Dr. Dianna Hardy Professor Trina Myers
Use of infrastructure	Access to North Queensland Autism Support Group members	Lynne Derry Gwenyth Cutler Mark Eggert
	Access to NQ Employment Building for workshops	Lynne Derry Gwenyth Cutler Mark Eggert
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v

List of Publications

Publication	Nature and extent of the intellectual
	input of each author
Building Applications that Matter: Co-	Zhu, Hardy and Myers
designing with Adolescents with Autism	
Spectrum Disorder	I conducted participation observation on
	the support group and the design
International Conference on Health	workshops. In addition, I performed the
Information Science	analysis, and wrote the manuscript.
	Dr. Dianna Hardy and Professor Trina
Presented in October 2018	Myers assisted in designing the study,
	interpreting the results and editing.
	interpreting the results and curring.
Co-designing with Adolescents with	Zhu, Hardy and Myers
Autism Spectrum Disorder: From	
Ideation to Implementation	I facilitated and conducted the design
	workshops. In addition, I performed the
31st Australian Conference on Human-	analysis, and wrote the manuscript.
Computer-Interaction	Dr. Dianna Hardy and Professor Trina
I	Myers assisted in designing the study,
Presented in December 2019	interpreting the results and editing.
Community-led Approach to Co-design	Zhu, Hardy and Myers
a Social Networking Platform with	
Adolescents with Autism Spectrum	I facilitated and conducted the design
Disorder	workshops. In addition, I performed the
	analysis, and wrote the manuscript.
Journal of Autism and Development	Dr. Dianna Hardy and Professor Trina
Disorders	Myers assisted in interpreting the results
	and editing.
Under review	
	<u> </u>

Keywords

Co-design; Participatory Action Research; Participatory design; Autism; Social networking

Abstract

Technology-based applications for people with special needs are on the rise as mobile devices and wearable technology become more pervasive in society. However, developing applications for people with special needs can be an intricate process due to the physical or mental challenges of the prospective users. People with Autism Spectrum Disorder (ASD) process the world differently and often encounter poor User Experience (UX) with applications that are not designed with them in mind.

Co-design in software design offers both software designers and users a means to collaborate and contribute to the design and development of an application. The codesign method has been adopted in previous Autism Spectrum Disorder (ASD) research, specifically in developing educational or intervention software due to its empathetic focus and collaborative nature. Most co-design based ASD research is conducted with participants in early childhood and adopts the participation via proxy approach where the parents, carers or psychologists are involved in the design process instead of the users themselves. Using Participatory Action Research (PAR) as an overarching methodology, this research provides an in-depth investigation of the culture and the social challenges faced by a local autism community regarding the use of technology.

Support groups within the local community provide adolescents with ASD a social life outside school, and the opportunity to connect people who share similar experiences and values. However, the social interaction among the support group members seldom extends outside of organised group activities. Social networking applications can be used as a platform to facilitate social engagement and maintain relationships with family and friends. Studies have also shown that the frequency with which adolescents with ASD used social networking application can have a positive effect on their social self-esteem and well-being. Nonetheless, adolescents with ASD are avoiding the use of open social networking applications due to fear of being cyberbullied.

This research had three phases. Phase One involved contextual investigations of different stakeholders such as people with ASD, their parents/carers, and a local ASD support group through a community immersion approach. Phase Two involved a co-

design study to explore ways to engage adolescents with ASD as co-designers in early the phases of the software design process. Two co-design workshops were conducted with six adolescents with ASD over a month. Finally, Phase Three involved an extended co-design study to investigate design and community implications when engaging adolescents with ASD as co-designers in an iterative software design process Seven co-design workshops were conducted with six adolescents with ASD over eight months. Phase Two and Phase Three used the same engagement methods and thematic analysis to identify key themes. Participants' attitudes towards co-design, the potential benefits of the design process, and the implication of a co-designed social network platform were explored.

The findings provided insights on self-esteem and well-being of adolescents with ASD during a participatory process, the roles of the participants and parents, and the interaction and communication among them. The research main findings suggest that: 1) participants experience poor UX due to their unique perspective; 2) participants expect to make design decisions for applications built for them; 3) parents, community group and fellow participants are able to make better design decision over an iterative software design process; 5) participants demonstrated an increase in self-advocacy skills through a co-design process; 6) participants perceived to have gained self-esteem and increased well-being through participatory process; 7) parents, community group and fellow participants play a pivotal role in engaging adolescents with ASD on social networks; and 8) closed group social networking applications may provide adolescents with ASD a safe environment to participate in social engagement. These findings should be considered when engaging adolescents with ASD as co-designers in an iterative software design process.

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List of Abbreviations

HCI: Human-Computer Interaction PAR: Participatory Action Research UX: User Experience

1.1 CHAPTER OVERVIEW

This chapter sets out the thesis outline and research questions. Section 1.2 outlines the background of the research, highlighting the gaps and related studies from the existing literature. Section 1.3 describes the context of the research, and outlines the motivation and research aims. Section 1.4 highlights the research questions and research objectives for this research. Section 1.5 outlines the contributions of the research. Finally, section 1.6 provides an outline of the remaining chapters of the thesis.

1.2 BACKGROUND

Technology-based solutions for people with special needs are on the rise as mobile devices and wearable technology become more pervasive in society. People with special needs require assistance in education or recreation services due their disabilities (Greenspan, Wieder, & Simons, 1998). The wide proliferation of such devices has resulted in the reduction of barriers to entry such as affordable hardware and unified software development tool kits. These conditions have propelled the creation of technology-based application development for people with special needs. However, not all applications are well received by the intended users. Products and services that are centred to people's unique needs and abilities allow them to manage their lives more easily (Hsieh, Munson, Kaptein, Oinas-Kukkonen, & Nov, 2014; Johnson, Bianchi-Berthouze, Rogers, & van der Linden, 2013). Conversely, the lack of understanding between users' needs and functionality, device availability, poor device performance, and change in user needs or priorities can lead to user frustration that can potentially result in software abandonment (Nganji & Nggada, 2011; Phillips & Zhao, 1993). The development of applications for special needs can be an intricate process due to the physical or mental challenges of prospective users. This process is more convoluted for people with Autism Spectrum Disorder (ASD) who have a unique perspective in engaging with technology due to their ASD traits as compared to their neurotypical peers.

Autism Spectrum Disorder (ASD) is a range of neurodevelopmental disorders characterised by impaired social and communication development, repetitive behaviours, and restricted interest (American Psychiatric Association, 2013; Asperger, 1944; Kanner, 1943). The number of Australians estimated to have the condition has increased to 205,200 in 2018 as compared to 164,400 in 2015 (Australian Bureau of Statistics, 2019). That is a 25.1% increase over three years and the number of individuals diagnosed with ASD in Australia is expected to continue to increase due to an elevated awareness of the condition, and improved diagnostic processes (Parner et al., 2011; Ward, Sullivan, & Gilmore, 2016; Williams, MacDermott, Ridley, Glasson, & Wray, 2008). Currently, there is no cure for ASD, however, customized interventions such as speech correction and cognitive, physical, and motor skills therapies can lessen the deficits (Duncan & Bishop, 2015). Social deficits include: evasive eye contact, difficulty in interpreting verbal and nonverbal social cues, delayed or poor response towards social stimulus, inappropriate emotional response, and lack of empathy to others' distress (American Psychiatric Association, 2013; Asperger, 1944; Kanner, 1943). Early intervention for children diagnosed with ASD may result in an improvement in both their social and non-social challenges over time (Duncan & Bishop, 2015).

Nonetheless, ASD is a lifelong condition and the strong research focus on early childhood leaves a gap in the study of social and emotional interventions with adolescents and adults with ASD. Adolescents with ASD often face challenges with social interaction and have fewer friends than their peers without ASD (Rowley et al. 2012). In addition, adolescents with ASD are also more likely to face rejection and be bullied by peers as a result of their social awkwardness (Attwood, 1997; Cappadocia, Weiss, & Pepler, 2012). The lack of social skills may also lead to the development of anxiety and depression (White and Roberson-Nay 2009). Attwood (1997) suggests that improving social skills can have a direct effect, involving less peer rejection and more friendships. ASD support groups within the local community can provide the opportunity for adolescents with ASD to have a social life outside of school. Parents involved in these support groups also have the opportunity to meet others with similar experiences and to exchange information (Weidle, Bolme, & Hoeyland, 2006). For some adolescents with ASD, the support groups may be the only social activity involving peers on a regular basis apart from school. As such, adolescents with ASD

view the group meetings as a positive activity and attend regularly however, the social interaction among the support group members seldom extends outside of organised activities.

Despite these challenges, research has found that children diagnosed with ASD are able to better express themselves using technology such as assistive devices and applications. In addition, they have a higher tendency to interact with other people with ASD when both are interested in the specific technology (Hourcade, Bullock-Rest, & Hansen, 2012). The current generation of adolescents have had access to computers and technology as a part of their daily lives since early childhood. A study by Kuo et al. (2014) examined the use of media by adolescents with ASD and reported that 98% of the 92 participants used computers approximately five hours per day to watch cartoons and play games. In addition, many adolescents with ASD find technology to be engaging and prefer to access or use technology over other leisure and social activities. Prior studies have also described positive outcomes such as increased social interaction and improved communication skills of using digital technology in ASD social research (Alarcon-Licona, Loke, & Ahmadpour, 2018; Soysa & Mahmud, 2018).

Like the rest of healthcare, the digital revolution has impacted the ASD community as mobile device-based software and smartphone/tablet apps are constantly being developed and made commercially available for people with ASD and their families (Shic & Goodwin, 2015). A quick search of the term "autism" into the Apple or Google apps stores returns innumerable related apps. Though the use of technology-based interventions or applications built for people with ASD is on the rise, not all applications are well received (Odom et al., 2015). Failing to consider the unique perspectives of users with ASD can lead to a lack of uptake of technology. In addition, prior research shows that the relationship between the user, technology, and the environment should be considered in designing technology for marginalised groups like the ASD community where individuals face challenges in full social participation in their social life (Laurin & Pleasant, 2008, pp. 129-142). Gabriels and Hill (2010) suggest that applications designed for people diagnosed with ASD should allow the user to operate the device independently and that the attitude of all stakeholders involved plays a role in the success of application uptake. Applications built for a marginalised group such as people with ASD should no longer focus solely

on the delivery of the technology. Instead, the design approach should be inclusive of the group and partner with users and communities to increase the acceptance and adoption of newly developed technology (Scherer, 2002). The community will also benefit from forming new partnerships between patients, families, clinicians, and app makers with the goal of bringing as many stakeholders as possible together and work as a team to find ways to ensure that apps are effective and safe (Pulier & Daviss, 2016).

Co-design is a methodological approach that includes stakeholders, such as potential users and the community in the design process (Fuad-Luke, 2013). The iterative process in the co-design approach allows the developer and participants to make fine-grained adjustments to the application functionalities and interface design as the project progresses with the aim of improving User Experience (UX) (Steen, 2013). Co-design in software design has been adopted in previous ASD research, specifically in developing software used for education or therapy-based intervention that aims to improve the ASD deficits. Due to co-design's emphasis on balancing power inequities, participants reported feeling valued, safe and able to contribute meaningfully to the design process. This involvement can increase user "buy-in" and support the likelihood of an end product that is useful, usable, and desirable (Frauenberger, Good, & Keay-Bright, 2011).

Participatory Action Research (PAR) is a pragmatic community-based research methodology that focuses on producing an emancipatory change for community members (Freire, 1982). PAR encourages the active participation of the researcher with the research community, and involves the collaboration of researchers with a population of interest to solve a problem and/or develop a program (Kemmis, McTaggart, & Nixon, 2013). This approach is built on the concept that the ideas and perceptions of those directly affected by the problem are critical in the development of the solution (Löfman, Pelkonen, & Pietilä, 2004). The researcher gains community and cultural insights through active participation in the research community which can then direct changes to the research design during implementation (Kemmis et al., 2013). PAR has been adopted in previous ASD research with positive outcomes. Wright et al. (2014) suggest that PAR creates a "community-engaged" notion with people diagnosed with ASD, along with their families and the environment. This "community-engaged" mindset creates sustainable actions that improve the lives of

stakeholders. Due to its emancipatory approach, PAR is often used as an overarching research principle with co-design methods in research with marginalised group research (Sanoff, 2008).

Social networking sites provide a platform to support communication and relationship building with family and friends. Many adults with ASD use some form of social networking sites (Mazurek, 2013). Nonetheless, a study by Carrington et al. (2017) suggests the number of adolescents with ASD on online social networking sites is decreasing due to the risk of being cyberbullied. Parents/carers are also generally cautious with social networking sites due to potential problems with cyberbullying and inappropriate content (O'Keeffe & Clarke-Pearson, 2011). Nonetheless, previous studies have described positive outcomes of using digital technology and the importance of user involvement in ASD research (Alarcon-Licona et al., 2018; Soysa & Mahmud, 2018).

A community-led social networking platform for adolescents with ASD could encourage the healthy use of social networking in a safe space. As well, userinvolvement during design and development can lead to an increase in uptake of the final product (Francis, Balbo, & Firth, 2009). People with ASD expect to be included in making design decisions that affect them (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012; Bossavit & Parsons, 2016; Makhaeva, Frauenberger, & Spiel, 2016; Millen, Cobb, Patel, & Glover, 2014). Nevertheless, people with ASD may find participation in standard co-design methods such as the use of personas or usability questionnaires difficult due to their particular communication needs and preferences (Neale, Cobb, & Kerr, 2003). Prior studies have adapted co-design methods to support the potential difficulties for participants with ASD by using visual and concrete examples to initiate and prompt ideas rather than relying on abstract concepts for discussions (Benton et al., 2012; Bossavit & Parsons, 2016; Nastasi, Varjas, Sarkar, & Jayasena, 1998).

Technology is an enabler to improve our ways of life when it works in line with the user's workflow or routine. Different people have different needs and ways of engaging the same technological solutions. A one size fits all solution generally does not work most of the time especially for marginalised groups of people such as those with special needs. Moreover, the traditional software development process waterfall method (Balaji & Murugaiyan, 2012) does not include end users as part of the design process. In a traditional software development process, development tasks are divided into phases such as design, implementation, and testing. However, only the software designers have access and control to make design decisions while users have little or no opportunity to provide feedback on the design decisions. This often results in a mismatch of product expectations between the designers and the users. It is only until the early 2000s where research and industry have put a stronger focus on involving users in the design process such as agile methodology (Shore, 2007) and design thinking process (Plattner, Meinel, & Leifer, 2010).

1.3 CONTEXT

Adolescents with ASD have a unique perspective in using technology-based solutions and so off-the-shelf solutions may result in poor UX. Previous ASD codesign research has shown promising results in engaging adolescents with ASD as codesigners and improving the UX of the developed product. Such as, prior studies only involved people with ASD in the early phase of software development and over a short period of time. The software design process requires an extended period and through multiple iterations. By iterating the software design process, software designers can make incremental changes to improve product UX and functionality. The motivation for this research arises from the need for exploring ways to involve adolescents with ASD in an extended iterative software design process to include their unique perceptions and input. This research focuses on the need to engage with an ASD support group to understand cultural insights and establish positive relationships with stakeholders. Stakeholders including parents and members of the local ASD support group and the adaption of co-design methods play a vital role in engaging adolescents with ASD in an extended co-design study. This research explores how adolescents with ASD can be engaged as co-designers in an extended iterative software process. In addition, this research also examines how longitudinal co-design study can be used to understand the lived experience of adolescents with ASD.

1.4 PURPOSE

This research follows the participatory action research approach to explore ways of sustaining collaborative design with adolescents with ASD with the support of the parents and the local ASD community. In so doing, this research firstly aims to understand the culture of the local ASD community through an ASD Support group and the role the community can play in an extended co-design process. Relationships and trust among the collaborators are explored through community immersion and workshop activities. A co-design approach was employed with adolescents with ASD to define the nature of the software and, subsequently developed through an iterative software design process.

1.4.1 Research Questions

Q1. How can adolescents with ASD be engaged as co-designers in an iterative software design process?

Q2. How can a longitudinal co-design study be used to understand the lived experience of adolescents with ASD?

1.4.2 Research Objectives

The following objectives were defined to answer the research question.

O1. Understand the diverse motivations, challenges and qualities of a local ASD community through in-depth interactions and observations.

O2. Understand the challenges adolescents with ASD face in using technologybased solutions through conducting collaborative discussions.

O3. Explore challenges and ways to engage adolescents with ASD in existing co-design methods.

O4. Understand the unique roles of various stakeholders when engaging adolescents with ASD as co-designers in an iterative software design process.

O5. Explore and co-design software to facilitate social engagement and communications with the local ASD community.

1.5 CONTRIBUTION

This thesis explores the concepts and approaches related to designing with people with ASD as described in the academic literature (detailed in Chapter 2). Design approaches and methods are investigated for their value in engaging with people with ASD and adaption to suit ASD participants' traits.

An ethnographic and phenomenological contextual inquiry was conducted to understand the culture and group practices of a local ASD support group which includes members with ASD and their parents/carers (detailed in Chapter 3). This study consisted of a community immersion over ten months. Results from this study provided insights on the diverse motivations, challenges and qualities of a local ASD community and highlight the role of a support group in a co-design study.

A co-design pilot study was conducted to investigate how adolescents with ASD use technology and explore how they could participate as co-designers in the early

phases of application development (detailed in Chapter 4). This study consisted of two co-design workshops with six adolescents with ASD over two months. Results from this study assess the design gap faced by participants in existing technological solutions and the viability of involving participants as co-designers in a software design process.

Following the pilot study, a longitudinal study was conducted to investigate how adolescents with ASD can participate as co-designers in an iterative software design process (reported in Chapter 4). This study consisted of seven co-design workshops with six adolescents with ASD over eight months. Results from this study highlight the role of stakeholders in a longitudinal ASD co-design software design process and contribute to existing co-design and ASD literature. In addition, the longitudinal study demonstrated how adolescents with ASD can be engaged as co-designers and contribute to an iterative software design process.

Reflecting on the longitudinal study, I examined the lived experience of adolescents with ASD, their challenges with existing social networking sites, and the potential benefits of a community-led social networking platform. The participants' attitudes towards co-design, the potential benefits of the design process, and the implications of a co-designed social network platform were investigated. Results from this study highlight the concerns of the social wellbeing of adolescents with ASD in cyberspace and the potential social benefits of involving adolescents with ASD in a co-design study (Chapter 5). The framework and methods used in this study provide a structured approach for researchers to engage adolescents with ASD for research through a support group.

Finally, the study is concluded by evaluating the outcomes of the research in the context of its objectives and research questions, followed by a discussion of the implications and possible directions for research in the future (in Chapter 5).

In addition to the contribution to existing co-design and ASD literature, this study has also created sustainable actions that can improve the lives of stakeholders through the computer club and the development of the closed-group social networking platform for the Autism Support Group. This outcome is a tangible emancipatory benefit of the PAR process. The computer club continues to provide NQASG members with a platform to interact and socialise with each other through the common interest in technology. The computer club continues to function and is now an integral NQASG

activity. NQASG has also since adopted the social networking platform and is in the process of extending the platform to all its members.

1.5.1 Research Papers

An overview and the objectives of each publication from the thesis are listed in Table 1-1 below. A preamble is provided for each paper, connecting one publication to the next.

Table 1-1 - Overview of the	research publications
-----------------------------	-----------------------

Paper and Overview	Objectives
Zhu, R., Hardy, D., & Myers, T. (2018, October). Building	01, 02
Applications that Matter: Co-designing with Adolescents with	
Autism Spectrum Disorder. In International Conference on Health	
Information Science (pp. 167-174). Springer, Cham.	
This paper discusses how adolescents with ASD in a local community	
use technology and explore how they could participate as co-designers	
in the early phases of application development. Interviews and	
observations found that participants (1) are technology savvy users;	
(2) experience poor UX due to their unique perspective; and (3) expect	
to make design decisions for applications built for them	
Zhu, R., Hardy, D., & Myers, T. (2019, December). Co-designing	02, 03
with Adolescents with Autism Spectrum Disorder: From Ideation	
to Implementation. In Proceedings of the 31st Australian Conference	
on Human-Computer-Interaction (pp. 106-116).	
This paper highlights the role of stakeholders in a longitudinal ASD	
co-design software design process. Design artefacts generated from	
the co-design workshops and observations suggest that: (1) parents,	
community group and fellow participants play a pivotal role in	
supporting a longitudinal ASD co-design study and (2) adolescents	
with ASD are also able to make better design decision over an iterative	
software design process.	

Zhu, R., Hardy, D., & Myers, T. Community-led Approach to Co-	04, 05
design a Social Networking Platform with Adolescents with	
Autism Spectrum Disorder. Under review at Journal of Autism and	
Development Disorders	
This paper highlights the challenges adolescents with ASD faced with	
existing social networking sites and how a community-led approach	
can alleviate these challenges. Group discussions and observations	
found that: 1) adolescents with ASD demonstrated self-advocacy skills	
through an iterative co-design process; 2) a safe and familiar	
environment encourages active participation from adolescents with	
ASD as co-designers; and 3) parents, community group and fellow	
participants play a pivotal role in engaging adolescents with ASD on	
a social-network.	

1.6 THESIS OUTLINE

The next chapter of the thesis will include a critical discussion on related work to highlight the gaps in knowledge. Theoretical frameworks that inspired the selection of methods and the overall design of the research are detailed in Chapter 3. The implementation and results of the research are discussed in Chapter 4. The final chapter discusses the significance of these research findings and their practical implications, limitations of the research, and future directions.

2.1 CHAPTER OVERVIEW

The central purpose of this chapter is to explores previous research regarding codesign with ASD adolescents and identify any gaps in knowledge and to guide the research methods surrounding software design approaches that suit the requirements, needs, and capabilities of adolescents with Autism Spectrum Disorder (ASD). Past literature relating to the research questions will be discussed to give context for the research and this study and determine where it lies regarding previous work.

Section 2.2 discusses the importance of customising designs to suit individual requirements, needs, and capabilities. Principles of accessibility, usability, and universal design will be discussed to provide an overview of the ways in which disability is understood and framed. This section will also discuss the usefulness of codesign in engaging with people with a disability and how people have adopted known design methods to enhance self-expression. Besides, implications and considerations of using Participatory Action Research with marginalised groups will be discussed in this section. Section 2.3 highlights past research in the area of disabilities and ASD such as medical contextualisation, including ASD traits and the nature of social impairment for people with ASD. Section 2.4 reviews past literature on the topic of designing tools for people with a disability. Past research of technological solutions involving modern design process for people with ASD will be discussed in this section. Finally, section 2.5 provides a summary of this chapter.

Research Questions

This study sought to answer the following research questions:

Q1. How can adolescents with ASD be engaged as co-designers in an iterative software design process?

Q2. How can a longitudinal co-design study be used to understand the lived experience of adolescents with ASD?

2.2 DESIGNING FOR THE INDIVIDUAL

The involvement and importance of user participation in the design process were first addressed in an international conference entitled 'Design Participation' in 1971. The conference was sponsored and organized by the Design Research Society (DRS) with the aim is to discuss the importance of user participation in the design process (Banham 1972). Since then, two main design approaches with contrasting views of user participation in the design process emerged from the practice. The user-centred design approach led by the United States adopts the view of the user as a subject. Users provide their expertise and participate in design activities in the early design phases. The participatory approach led by Northern Europeans adopts the view of the user as a partner. Users are treated as an equal stakeholder and participate throughout the entire design phase (Sanders & Stappers, 2008). This approach is echoed in the Scandinavian participatory design movement and the ensuing participatory action research method. Figure 2-1 gives an overview of the current state of the humancentred design research landscape.



Figure 2-1 - Design landscapes adapted from Sanders and Stappers (2008, p. 6)

Human Centred Design (HCD), User Centred Design (UCD), and Participatory Design (PD) gained popularity as the design of technologies shifted from a designercentred approach towards a more human-centred approach (Norman & Draper, 1986). Designer-centred approaches often treated people as passive users, locked out of the design process, and often forced to adopt and use designs that others had created for them (Simonsen & Robertson, 2012). This shift in design approach became prominent as more technologies were introduced to workplace, home, and schools. Practitioners started to believe that people are experts at arranging their own lives and end users should be put the centre of the design process (Abras, Maloney-Krichmar, & Preece, 2004; Sanders & Stappers, 2008). Human-centred Design (HCD) emphasises the importance of integrating multiple stakeholders including the community in the design process (Gummesson et al., 2010). Methods in HCD usually involve immersion, observing, and contextual framing with the community to gain a holistic understanding of the design problem. Maguire (2001, p. 589) presented the principal activities in the HCD process as depicted in Figure 2-2 below.



Figure 2-2 - The human-centred design cycle adapted from Maguire (2001, p. 589)

2.2.1 User as Partner

User as partner approaches aim to involve the users in the design process, through ideating, designing, and experiencing together. While there is an increased focus on including users as partners in the design process, people who have physical and intellectual disabilities are often excluded due to their unique physical, cognitive and sensory needs (Hook, Verbaan, Durrant, Olivier, & Wright, 2014). Participation design has a root in HCD, and user involvement is the core value of HCD.

Two notions, co-design and co-creation emerged within the field of participation design. Sanders and Stappers (2008) defined co-creation as the collective effort with two or more people in a process and co-design as the design development process with the collective creative inputs from both designers and non-designers. The terms co-

design and co-creation are often confused and in some instances, used synonymously with one another. However, by this definition, co-creation is an overarching term that encompasses co-design where the design development process is a collective effort with multiple stakeholders. Co-design encourages participation from stakeholders who design and then use the artefact and aims to create a balance of power equities between designers and non-designers. Fuad-Luke (2013) claims that co-design improves the usability of the designed artefacts and in the process, supports mutual learning between all participants. He suggests that participants in a co-design process go through a recursive phase of problematising, experiencing and solutioning to achieve the desired outcomes of the co-design (Figure 2-3 below). Involving end users in design has now become an essential part in design research (Ivey & Sanders, 2006).



Figure 2-3 - Co-design cycle adapted from Fuad-Luke (2013)

Co-design has its limitations, however. Design capital such as methods and philosophy are mainly upheld by the practitioners (designs and non-designers) and can be lost once the team dissolves at the end of the project or individuals are transferred to other work. Despite the promise of producing relevant and usable solutions, codesign approaches tend to stretch for a longer period and require more resources, thus teams have to confront trade-off decisions on cost, features, and delivery (Bruce & Bessant, 2002; Holmlid, 2008). In addition, the implementation of co-design approaches largely depends on the practitioners' proficiency and the profile of the users. Different backgrounds, interests, and perspectives of the users in creating the 'shared understanding' can influence the quality of the final product as well. A critique of allowing non-designers to design is that they sometimes make novice mistakes that result in poor design (Spinuzzi, 2005).

The use of co-design can lead to solutions that are more acceptable and relevant to the needs of an individual with a particular disability. Co-design takes into consideration all stakeholders who will be affected by the artefact, including caregivers as well as people with disabilities (Cole, Dehdashti, Petti, & Angert, 1994). Stakeholders go through a recursive phase of problematising, experiencing and solutioning via workshops. Co-design workshops can adopt qualitative methods that can suit an individual with a particular disability. This pragmatic approach allows the researcher and research participants to learn and adjust the requirements of the solution through each cycle (De Couvreur & Goossens, 2011). The recursive workshops also aim to incorporate human-centred design and activity-centred design (Norman, 2005), creating solutions that are applicable in their daily activities. Co-design has also been adopted in many ASD research studies, specifically in developing technology-based solutions used for education or intervention. The use of co-design addresses the specific needs of marginalised groups such as those with ASD (Madsen et al., 2009). Frauenberger, Good, and Keay-Bright (2011) suggest that due to the balance of power being more equal in co-design, marginalised communities can feel valued, safe, and able to contribute meaningfully to the design process. This can in turn increase the likelihood of designing an end product that is useful, usable, and desirable. The balance of power in the design process is closely associated with the concepts of accessibility, usability, and universal design which are explored in the next section.

2.2.2 Accessibility, Usability and Universal Design

Disability is often viewed as a biological phenomenon where someone is considered as disabled only when they have bodily impairments (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). However, this view is often criticised as it neglects the cognitive and the social aspects that often contribute towards the ease or difficulty of functioning in life (Shakespeare, 2006). The International Classification of Functioning, Disability and Health (ICF) defines disability as any difficulty in one or many areas of human functioning. These areas include impairments of proper body function, ability to execute activities, and engaging in social activities.

Accessibility is the ability of a person to partake in a desirable activity that depends on physical mobility and geographic proximity (Iwarsson & Ståhl, 2003;

Petrie & Bevan, 2009). Accessibility is a relative concept as it depends on the relationship between the person and the environment. For example, an event hosted at James Cook University in North Queensland is more accessible for people living in Townsville than people living in Sydney due to geographic proximity. Accessibility often takes an objective viewpoint to ensure inclusions of all people - with and without disabilities (Iwarsson & Ståhl, 2003). As such, accessibility is a key aspect to be considered when designing physical environments, providing information and social services both at home and within community spaces.

Usability is a concept that looks into the fulfillment of functional requirements and relates to whether a product or service is fit for purpose, i.e. fit to be used (Frauenberger et al., 2011). Though often associated with the term accessibility, usability looks at how well a person can use a product to perform an intended task and this is largely dependent on the aptitude of an individual instead of generalised norms or standards. For example, computer laboratories can be designed to accommodate people with a disability (by ensuring accessibility) however usability is limited if the computers cannot be adequately used by them. Furthermore, the ability to use the computer adequately differs between individuals even if they have the same disability. Usability is commonly associated with UX (User Experience) since UX reflects a person's overall experience in using a product or service.

Universal design views the entire population as a composite of individuals who have equal rights but with a spectrum of human abilities. These individuals have different needs, wants, abilities and universal design aim to design products and environments that are usable by the majority of the population (Bringolf, 2008; Iwarsson & Ståhl, 2003). This notion is in contrast with accessible design, which assumes two different populations: abled and disabled. Iwarsson and Ståhl (2003) viewed universal design as the best approach of a design that aims to meet the needs of the maximum possible number of users. While the universal design approach can accommodate a heterogeneous population, it is often criticised as an unrealistic goal and more of a "Utopian ideal" due to the impracticality to address the unique needs, wants, and capabilities of all those who have physical and cognitive disability (Bringolf, 2008; Crabtree et al., 2003; Godden & Hys, 2016). In such situations, accessible design may produce better results since it caters directly to the needs and capabilities of people with disabilities.

2.2.3 Personalisation of Design Process

Each person has their own ways of accomplishing design tasks, depending on their capabilities and characteristics. It is necessary and important to understand these elements to design solutions with them. Personalisation of design methods can be easily attained if the requirements and preferences of people can be unveiled and communicated clearly. Nonetheless, this exchange of requirements and preferences can be challenging for people with disabilities or from other marginalised groups due to their ability to express themselves and due to power inequality between the designer and the users. In addition to the design process, the requirements elicitation process also needs to be personalised to suit the abilities and characteristics of people with disabilities. For example, one person may prefer to use verbal communication methods as the mode of expression while another may prefer to use non-verbal communication methods such as drawings. Involving people with disabilities in the design process can be challenging when they have different cognitive and sensory abilities than those of the research team. This disparity in an individual's capabilities and characteristics is well documented for people with Autism Spectrum Disorder (ASD) (Kientz, Goodwin, Hayes, & Abowd, 2013). For instance, Benton et al (2011) propose the IDEAS (Interface Design Experience for the Autistic Spectrum) method that attempts to adapt co-design methods to support the potential difficulties for participants with ASD. Their study suggests that children with ASD do have the potential to be involved in these design activities, but often require additional appropriate support.

Personalisation of the design process for people with a disability is an emerging area for exploration. While there is an emerging movement to tailor technologies for people with disability, many people with a disability were not consulted or involved in a design process that would suit them (Nganji & Brayshaw, 2017; Papavasiliou, Saridaki, Mourlas, & Van Isacker, 2014). Often the technologies are developed based on the inputs through a proxy like subject matter experts or those with intimate knowledge of the user population, such as parents and teachers.

2.2.4 Participatory Action Research

Action research focuses on the active involvement of both the researcher and the research participants in a recursive process of planning, knowledge generation, action, observation, and reflection that leads to further inquiry and action for change. Lewin (1946) is often referred to as the originator of action research. He argues that traditional
social science research methods are incapable of understanding and solving complex human problems and developed the action research methodology. Avison, Lau, Myers, and Nielsen (1999) suggest that action research is a recursive process where we learn to make an action by acting on it. Since then, many adaptations of action research has been practiced in many diverse fields.

Participatory Action Research (PAR) is a pragmatic community-based research methodology that extends from action research. PAR focuses on the active participation of the researcher with the research community and involves creating a shared vested interest with the research group (Kemmis et al., 2013). A researcher with no shared vested interest with the research community is isolated from the real-world consequences of the research outcome (Kemmis et al., 2013). As such, PAR adopts a critical stance in which the researcher becomes an agent of social change by empowering or creating the space for the community to empower themselves through a collaborative process (Donovan, 2016).

PAR has three distinct tenets that are used to understand and improve the research community (Baum, MacDougall, & Smith, 2006). Firstly, PAR focuses on action and it inherits the framework of action research where the researcher and the research participants go through an iterative cycle of planning, understanding, executing, observing, and reflecting. The reflection at the end of each cycle leads to further inquiry and action for change in the subsequent cycle. This pragmatic approach seeks to apply new found knowledge into practice in the real world (Kemmis et al., 2013). Secondly, PAR focuses on balancing power structures. Action research's emphasis is on the involvement of the researcher and research participants, however, it does not specifically address the balance of the power structure between the researcher and research participants throughout the process. The researcher tends to dominate in a research project and, while research participants are involved in the action research process, they are not empowered to make decisions that may improve their situation throughout the research. PAR aims to breaks down the power structures between the researcher and the research participants through collaboration and developing solutions for community issues (Kemmis and McTaggart 1988; Davis 2008). This emancipatory change allows research participants to gain ownership of research progress and preserves the pragmatic nature of the research. Lastly, PAR focuses on having a shared vested interest in both the researcher and the research community. Through immersion in the research community, the PAR researcher will be able to understand the culture and challenges faced by the research community. Eventually, the PAR researcher can be part of the community and share the common goal of improving the lives of those in the community. This participatory approach also supports the breaking down of power structures between researcher and participants as participants can be seen as "co-researchers" with a shared vested interest in the research (Clark, 2010). Figure 5 below illustrates participatory action research as adapted from Chevalier and Buckles (2019).



Figure 2-4 - Participatory Action Research adapted from Chevalier and Buckles (2019)

PAR as a research approach is widely adopted in multiple fields such as education and information technology through it is primarily associated in the field of social science (Sanoff, 2008). The widespread use of PAR across multiple fields can be attributed to the pragmatic approach that leads to practical improvements or transformations to the environment of the research community (Zuber-Skerritt, 1992). In education, Flaherty Weist, and Warner (1996) found that many school-based health and mental health programs fail because they are planned, conceived, and implemented by researchers without the inputs of stakeholders. These programs failed to get acceptance from stakeholders (parents and teachers) and also lacked the potential for sustainability (i.e. continuance after the researcher departs). PAR addresses this concern with a strong focus on stakeholders' involvements, making it a suitable methodology for developing research in educational programs that are both effective and acceptable at the system level (Ho, 2002).

In information technology, Wood-Harper, Antill, and Avison (1985) introduced action research to the information systems (IS) community purely as a research methodology. IS researchers then noticed the relevance of systems theory and PAR where the researcher recognises that human activities are systematic and they are involved in the social systems (Baskerville, 1999). PAR compliments systems theory with the focus on balancing power structures and IS researchers soon began to see the value in implementing PAR in IS research (Lau, 1999). Avison et al. (1999) suggested that the use of action research in IS development practice empowers the users and improves the developers' skills, and IS projects developed with action research have clear goals and the potential for sustainability. PAR shares many similarities with co-design and is also often used as an overarching research framework with co-design (Sanoff, 2008).

The pragmatic and emancipatory nature of PAR makes it a suitable research methodology for marginalised communities. Marginalised communities including people diagnosed with a disability often find themselves with a lower status in a research project. Conrad and Campbell (2008) found that in PAR, participants gain more control of the project outcome and this provides a sense of ownership to the research groups, leading to better outcomes. PAR has also been used in ASD research; Wright et al. (2014) claim that PAR creates a "community-engaged" notion with people diagnosed with autism, along with their families and the environment. This "community-engaged" notion creates sustainable actions that improve the lives of stakeholders.

PAR is recognised and valued for the transformative outcome, however, there are considerations and implications when implementing PAR as a research methodology. The most commonly used methods in PAR are qualitative methods such as interviews, discussion-based workshops, and participant observation although quantitative methods such as surveys may be used at times (Kindon, Pain, & Kesby, 2007). The choice of methods is based upon their suitability with the participants, though they all emphasise shared learning, shared knowledge, and collaboration

(Kindon et al., 2007). Qualitative and interpretive methods form the foundations of PAR research and each implementation is tied to a unique community and context. As such, researchers find it difficult to have an agreed upon criterion for evaluating PAR. The participatory nature of PAR allows researchers to gain insights into deep-seated cultures and challenges faced by the research community, however, in the process, the researchers may become too embroiled in the problem set, and lose contact with their obligations to develop general knowledge about related theories (Baskerville, 1999). PAR research often requires time-intensive methods and strong commitment from both the researcher and researchers and the community over a longer period of time (Wright et al., 2014). The balance of power structures provides research participants with more controls however this may also diminish the researchers' ability to control the process and outcomes of the research. The relinquishment of the researcher's perceived control of the project enables PAR to offer the participants agency to solve their own problems.

2.3 AUTISM SPECTRUM DISORDER

Autism is a lifelong developmental disability characterised by impaired social and communication development, repetitive behaviours, and restricted interest (American Psychiatric Association, 2013). The disorder was described almost at the same time by Kanner (1943) and Asperger (1944). Their research described children with typical cognitive capability but with severe social deficits and unusual behaviours. Kanner coined it as "early infantile autism" while Asperger coined it as "autism psychopathy". Since then, autism is primarily investigated in various levels in psychology research such as cognitive, perceptual, developmental, social, linguistic and others (Warren et al., 2011). Autism is conceptualised as a spectrum condition covering a vast range of abilities (including IQs below 70 and above 130) and challenges (i.e. from organising one's daily life to misinterpreting implicit meaning). Symptoms of social skills deficits include: evasive eye contact, difficulty in interpreting verbal and nonverbal social cues, delayed or poor response towards social stimulus, inappropriate emotional response, and lack of empathy to others' distress (Weiss & Harris, 2001). Sinzig, Morsch, Bruning, Schmidt, and Lehmkuhl (2008) associated ASD with cognitive difficulties in perspective-taking (such as the ability to infer mental states in others), weak central coherence (detailed-focussed processing)

and executive functioning (i.e. difficulties in planning, inhibition, and flexible thinking).

Several terminologies used in neurological conditions such as neurodiversity, neurodivergence and neurotypical are commonly associated with autism. Nick Walker has produced a freely accessible glossary which examines and clarifies these terminologies (Walker, 2014). Neurodiversity, according to Walker, states that the diversity of human brains and minds including deficits, disorders, and impairments, is a trait possessed by a group and cannot be possessed by any one individual. A neurodivergent person is one that diverges from the socio-cultural norm. Several recognised types of neurodivergence, include ASD, dyslexia, dyscalculia, epilepsy, hyperlexia, dyspraxia, attention deficit hyperactivity disorder, obsessive-compulsive disorder, and Tourette syndrome. In contrast, the term neurotypical in the ASD community, is used to describe a person whose neurological development and state conform to what most people would perceive as normal.

2.3.1 Diagnostic and Statistical Manual of Mental Disorders (DSM)

The American Psychiatric Association (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) is a globally recognised tool used in categorising types of mental disorder. The DSM listed "infantile autism" as a new condition in 1980. Since its inception, new subcategories of autism such as Asperger's Syndrome, Childhood Disintegrative Disorder and Pervasive Development Disorder-not otherwise specified (PDD-NOS) have been added into DSM over the years. Each condition had a set of clear characteristics that are distinct from other subcategories of autism. However, in 2013, the DSM fifth edition (DSM-V) merged all the subcategories of autism under one umbrella diagnosis of Autism Spectrum Disorder (ASD) (American Psychiatric Association, 2013). With DSM-V, a non-axial system was introduced to replace the multi-axial classification system in DSM-IV. Instead of using axis to describe the level of functioning, DSM-V uses the specification of symptoms experienced by an individual (Shujah & Mulligan, 2017). The specification of symptoms are categorised under two main criteria; impaired social and communication development and repetitive behaviours and restricted interest. Each criterion can be associated with three levels of severity based on the level of support required for the individual. Severity levels are shown in Table 2-1 along with the measures of support required. People diagnosed with ASD can be associated with intellectual disability (American

Psychiatric Association, 2013) but Baio (2014) suggests that around 50 % or more of people with ASD have an IQ in the normal range.

Table 2-1 - Severity levels for ASD (DSM-5)

Severity Level	Social communication	Restricted, repetitive behaviour	
Requiring very	Severe deficit in verbal and	Inflexibility of behaviour,	
substantial	non-verbal communication	extreme difficulty in coping	
support (Level 3)	skills causing severe	with change or repetitive	
	impairment in functioning,	behaviours markedly interfere	
	very limited initiation of	with functioning in all spheres	
	social interactions and		
	minimal response to social		
	overtures from others		
Requiring	Marked deficits in verbal and	Inflexibility of behaviour,	
substantial	non-verbal communication	difficulty in coping with	
support (Level 2)	skills; social impairments	change or other restricted and	
	apparent even with supports	repetitive behaviour frequently	
	in place; limited initiation of	enough to be obvious to casual	
	social interactions and	observer and interfere with	
	reduced or abnormal	functioning in a variety of	
	responses to social overture	contexts	
	from others		
Requiring support	Without support in place,	Inflexibility of behaviour	
(Level 1)	deficits in social	causes significant interference	
	communication cause	with functioning in one or	
	noticeable impairments.	more contexts	
	Difficulty initiating social		
	interactions and clear		
	examples of atypical response		
	to social overtures		

2.3.2 ASD in Australia

The Australian Bureau of Statistics SDAC 2018 estimated that there were 205,200 Australians with ASD in 2018 and this was a 25.1% increase from the 164,400 people with the condition in 2015 (Australian Bureau of Statistics, 2019). This increasing prevalence of people diagnosed with ASD has been reported across multiple research studies in other countries since the 1990s. Wing and Potter (2002) suggest that the increasing prevalence of ASD is primarily due to changes in diagnostic criteria and the increased awareness and recognition of ASD. This notion is supported by a recent study conducted in Australia by May et al. (2017) who suggest that the prevalence of ASD in Australia is not increasing in childhood but is an increase in diagnosed cases due to the improved administrative process in accessing an ASD diagnosis and the increased awareness and recognition of ASD. Recent studies have suggested that at least 1% of children and adults have an ASD (Baio, 2014). The number of people diagnosed with ASD in Australia is expected to increase with elevated awareness and improved diagnostic processes (Bent, Dissanayake, & Barbaro, 2015; Williams et al., 2008).

2.3.3 ASD in Human Development

ASD is a lifelong condition. There is no cure for the condition, however, intervention through customised therapies such as speech correction, cognitive, physical, and motor skills therapies can lessen the deficits (Duncan & Bishop, 2015). People diagnosed with ASD can have the same cognitive capacity as their peers, and as such, they are often conscious of the dissociation bought upon them due to their social deficits. Since ASD is a lifelong condition, adolescents diagnosed with ASD may also have difficulty sharing their retrospective experience or understanding the perspective of others, both skills that are key components to social reciprocity and the development of friendships (Gutstein & Whitney, 2002). The lack of social skills in adolescents diagnosed with ASD can often lead to bullying and rejection by their peer group (Church, Alisanski, & Amanullah, 2000). ASD deficits can persist into adulthood where they continue to influence social and occupational functioning (Seltzer et al., 2003). As such, adults diagnosed with ASD are less likely to have satisfying social relationships and they are also at a higher risk of being unemployed or underemployed (Hendricks, 2010; Tobin, Drager, & Richardson, 2014; Venter, Lord, & Schopler, 1992).

Little research directly examines the social needs of adolescents diagnosed with ASD (Gerhardt & Lainer, 2011; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Strunk, Pickler, McCain, Ameringer, & Myers, 2014). Bauminger & Kasari (2000) found that children diagnosed with ASD find it hard to make friends and engage socially. Although early intervention for children diagnosed with ASD results in an improvement in both their social and non-social deficits over time, these deficits remain over the span of their lifetime (Duncan & Bishop, 2015). The quality of their friendship is also poorer in terms of companionship and security. A study conducted by Gerhardt and Lainer (2011) indicates that adolescents diagnosed with ASD showed increased interest in social relationships along with continued development of social skills. Adolescents with ASD do value positive peer relationships as a key to social inclusion, however, they can miss opportunities to develop these relationships due to the lack of social skills in social gatherings (Pinheiro Mota & Matos, 2013). In a recent study, over half of the tertiary Australian students diagnosed with ASD lived at home as they faced comorbid anxiety, depression, and executive function difficulties (Cai & Richdale, 2016). Orsmond, Krauss, and Seltzer (2004) were among the first to investigate the social lives of people diagnosed with ASD beyond childhood. Their study suggested that the social world of adolescents with ASD is important for future research as there is an increasing interest from families, researchers, and providers. In recent years, tools and technology have been developed as interventions for people with ASD to improve their social deficits. A study conducted by Mirenda (2001) suggests that low-technology learning and education tools have a significant value in enhancing learning and social skills of people with ASD. In her study, she also recommends investigating the impact of these tools with high-technology equivalents such as computers or portable devices.

2.3.4 Support Groups and Social Support

Support groups play a vital role in the community especially for marginalised groups. Support groups in health-related contexts are usually led by people living with the condition, family members, volunteers, or trained professionals and usually involve little or no cost. Unlike licensed professional-led therapy groups that incur a fee, support groups are more accessible and affordable to most people living with the condition and their family. In addition to providing support and practical advice, support groups can offer friendship and encouragement to the people who participate

in the group (Hermann & Colón, 2005). Through the interaction in the support group, people with similar experiences can provide social support by encouraging each other (King & Moreggi, 2007). Social support takes place when there is an exchange of resources between at least two individuals perceived by the provider or recipient to be intended to enhance the well-being of the recipient (Shumaker & Brownell, 1984). Notably, social support can also be viewed as a multifaceted construct since the value of the resource is subject to the perception of the recipient (Cutrona & Russell, 1990). Nonetheless, social support has been well-reported to be an important element of mental health and promotes health and well-being (Uchino, Bowen, de Grey, Mikel, & Fisher, 2018). Though there is no universal consensus on the classifications of social support, Cutrona and Russell (1990) provided a guide to classify social support under five categories (Table 2-2).

Category	Description
Emotional	The ability to receive comfort and security from others during times of stress, leading a person to feel that he or she is cared for
Network	The feeling of belonging to a group that shares common interests and concerns
Esteem	Others' bolstering of a person's sense of competence or self- esteem
Tangible	Instrumental assistance where necessary resources are offered for one to cope
Informational	Providing one with advice or guidance concerning possible solutions to a problem

Table 2-2 - Five categories of social support	adapted from Cutrona and Russell (1990)
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Parents with a child with ASD have long been using support groups since 1990s to share their experiences with other group members, seek new information, or get emotional support (Banach, Iudice, Conway, & Couse, 2010; Cutrona & Russell, 1990; Mandell & Salzer, 2007). These parents typically have high levels of stress, social isolation, and poor health (Benson & Karlof, 2009). Though these challenges might be a common trait in families of a child with different kinds of disabilities, families of a

child with ASD may experience it to a greater extent (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Thus, support groups could be a powerful resource for these families as sources of instrumental, informational, and emotional support which are critical to well-being (Mandell & Salzer, 2007). ASD support groups provide the opportunity for children and adolescents with ASD to have a social life outside of school. For some adolescents with ASD, the support groups may be the only social activity involving peers on a regular basis apart from school. As such, adolescents with ASD view the group meetings as a positive activity and attend regularly (Weidle et al., 2006). Researchers can conduct contextual inquiry on the support group to gain an understanding of the culture and practices of the community. In addition, support groups can be a great avenue to access and recruit research participants. However, support groups often face frustrations with research and intervention approaches that are not relevant to the community's needs and provide no action for change to improve the lives of those in the community (Minkler, 2005). On the other hand, communitybased approaches that emphasise the active involvement of both the researcher and community in contextual inquiry that leads to action for change may be the preferred approach when partnering with support groups.

2.4 TOOLS FOR PEOPLE WITH DISABILITY

Technical tools have been used to support, replace, and enhance the body functions of individuals with disabilities throughout the history of healthcare. Two distinct design concepts for such tools emerged in the twentieth century; universal design and rehabilitation engineering. Universal Design (mentioned in section 2.2 above) was defined by architect Mace (1991) who suggested that the designer takes into consideration individuals with disabilities when designing products, architecture and habitable spaces that are meant for everyone. He claimed that this inclusive design approach to accommodate individuals with disabilities benefits everyone including those without disabilities. Eventually, the universal design evolved into a general approach in which designers take into consideration that their products should meet the needs of people of all ages and abilities (Story, Mueller, & Mace, 1998). This approach resulted in a set of guidelines and accessibility standards based on different fields, allowing designers to adopt and adapt them to their traditional design process (Story, 2001). The second design concept emerged during World War II where rehabilitation was needed for disabled veterans. The rehabilitation notion was a joint effort with surgeons and professionals in multiple scientific and engineering fields (Pope & Brandt Jr, 1997). Their purpose was to improve prosthetics and orthotics with scientific principles and engineering methodologies. This joint effort eventually led to the conception of the second design method known as rehabilitation engineering and the development of assistive technology. Unlike universal design where products and services are meant to be inclusive and usable for everyone, rehabilitation engineering and assistive technology consist of products and services developed specifically for people with a particular disability. Though both design approaches have different directions and focus, they share the common goals to increasing personal independence and to improving the quality of life for people with disabilities.

2.4.1 Assistive Technology

Assistive Technology (AT) is a broad term describing a range of devices that enhance or improve how a person can function (Mace, 1998). The range of devices includes both low-technology (low-tech) devices through adapted equipment such as spoons with built-up handles to high-technology (high-tech) devices such as microswitches, electronic communication devices, powered mobility, environmental controls, and software solutions. These devices and software solutions can help improve daily functioning ability and increase the independence of a person with disabilities (Phillips & Zhao, 1993). Table 2-3 shows the differences between low-tech AT and high-tech AT.

Low-tech AT	High-tech AT
No electronic components	Contain electronic components and
	usually based on computer technology
Usually inexpensive. Fixed hardware	Cost can be considerably high. Includes
cost	hardware and software cost
Ease of use. Usually require less training	Usually require more training

Table 2-3 - Differences between low-tech AT and high-tech AT

A well-designed AT must match the individual's specific needs and do the job for which it is intended. It is also critical that individuals view the device positively and be amenable to incorporate it into their daily activities (Lewis & Lewis, 1998). These factors can lead to a positive adoption of an AT which is associated with the reduction of personal assistance hours required by the people with disabilities (Hoenig, Donald H. Taylor, & Sloan, 2003). While there are several frameworks such SETT and USERfit used in assessing the appropriate AT for an individual, they focus on the relationships between the person, technology, and the environment (Laurin & Pleasant, 2008; Poulson & Richardson, 1998; Zabala, 1995).

2.4.2 Technology-Based Solutions for People With ASD

Technology-based solutions have been in use for the treatment and intervention of people with ASD since the 1970s (Ploog, Scharf, Nelson, & Brooks, 2013). However, technology-based solutions only gained traction recently after computers have become widely and inexpensively available to individuals and researchers (Ploog, 2010). Furthermore, approaches and ways to interact with a computer have changed significantly with the introduction of programmable, portable, and connected devices such as smartphones, smart watches, and other light, portable, and often wearable devices. People diagnosed with ASD may have difficulty expressing their thoughts and emotions, however, Hourcade et al. (2012) found that some children diagnosed with ASD were able to better express themselves through the use of technology. Their study also suggested that children diagnosed with ASD have a higher tendency to interact with each other in the context of using technology in which they are both interested. Orsmond et al. (2013) suggest that due to their social deficits, people diagnosed with ASD often have a small social circle of friends and acquaintances and that adolescents with ASD have a further decrease in interaction and social meetings with peers when they transition to adulthood. Wainer and Ingersoll (2011) suggested that the use of innovative technology-based solutions focusing on receptive social-communication skills is a promising strategy for intervention. Though there are studies on using technology-based solutions with people diagnosed with ASD to improve their expressive skills, their results are promising but not conclusive. These studies were conducted over a short period and typically focused on the adoption of the technology instead of the design. Valencia, Rusu, Quiñones, and Jamet (2019) conducted a systematic literature review on 94 ASD studies related to technologybased solutions and found that few studies provided details about usability, user experience, and accessibility. Their study also highlights the importance of user experience in ASD studies and suugested future studies to consider accessibility and usability tests to ensure positive experiences and comfort with the use of their solutions.

Technology-based solutions have the potential to enhance motivation and improve communication skills for the community members with ASD. As such, it is likely to play a very prominent role in the treatment of people with ASD in the near future (Khan et al., 2019; Parsons, Cordier, Lee, Falkmer, & Vaz, 2019; Ploog et al., 2013).

2.4.3 Designing Technology-Based Solutions for People With ASD

A well-designed technology-based solution can assist people with ASD to attain skills for increased adaptive functioning. Research has shown that technological solutions have produced better results when paired with existing treatment methods such as reading programs and social skills interventions (Williams, Wright, Callaghan, & Coughlan, 2002). Nonetheless, there can be exceptions. A well-designed technology-based solution can assist children with ASD to attain skills for increased adaptive functioning. Equally, a poorly designed solution can create the opposite effect of socially isolating a child (i.e., only interacting with a machine and not with other people) (Ploog et al., 2013). Technological solutions can be complex and specific training may be required to educate the users on its functionality (Kagohara, 2011). The relationship between the person, technology, and the environment should be considered in designing a technology-based solution (Laurin & Pleasant, 2008). Poorly designed technology-based solutions can result in user frustration and can lead to an abandonment of the technology. Issues around the lack of understanding between users' needs and functionality, device availability, poor device performance, and change in user needs or priorities are significantly related to abandonment (Phillips & Zhao, 1993). Gabriels and Hill (2010) suggest that technology-based solutions designed for people diagnosed with ASD should allow the user to operate the device independently and the attitude of all stakeholders involved plays a role in the implementation of the technology-based solution. As such, the development of a technology-based solution can no longer merely focus on the delivery of the

technology. Instead, the design approach should be inclusive and partner with users and communities to increase acceptance and adoption (Scherer, 2002).

Studies show that people with ASD expect to be included in design decisions that affect them (Benton et al., 2012; Francis et al., 2009; Frauenberger, Good, & Pares, 2016). User-involvement during the design and development phases can lead to an increase in uptake of the final product (Francis et al., 2009). Benton et al. (2012) conducted a short study involving children with ASD as co-designers and suggested that children with ASD have the potential to participate as full co-designers. Nonetheless, their study also calls for future studies to include people with ASD in a full co-design process to verify the results. Frauenberger et al. (2016) conducted a co-design study to co-create smart objects with four children with ASD and their study suggests that children with ASD can explore design spaces that are unique and unimaginable even for the adult designers.

Most co-design based ASD research has been conducted with participants in early childhood and has adopted the participation via proxy approach. The proxy approach involves parents, carers or psychologists in the design process but not with the children themselves. This approach is preferred with young children with ASD, as they can have considerable challenges in communication, as well as cognitive and behavioral difficulties (Francis et al., 2009). However, the participation via proxy approach does not allow the actual end-users of the software, i.e. people with ASD, to directly influence design decisions. A study to develop a facial expression recognition software with adolescents with ASD found the use of co-design improves the UX of the software and was critical to the uptake of the technology (Madsen et al., 2009). The study also highlights the importance of gaining cultural insights from the ASD community such as parents and carers in the design process. The practice of co-design methods in software design can lead to applications that have higher acceptance metrics than non-co-design projects and have the potential to be more relevant to the needs of an individual with a particular disability.

2.5 SUMMARY

Designing applications for people with special needs offers a challenge in terms of application usability and usefulness. An empathetic and inclusive design approach should be taken to ensure equal power relationships between designers and users with special needs. While successful design approaches with people with ASD have often been discussed, the key focus seemed to be placed on children with ASD. Furthermore, participants are only involved in either the early stages of a co-design process or over a single co-design cycle (Benton, Johnson, Brosnan, Ashwin, & Grawemeyer, 2011; Frauenberger, Makhaeva, & Spiel, 2016; Makhaeva et al., 2016). An iterative codesign process is required for the researcher and participants to critically examine the impacts of the incremental redesigns in progress. Previous studies have revealed the potential and feasibility of involving people with ASD in a co-design study. However, more work is required to investigate ways to engage adolescents with ASD as codesigners in a longitudinal software design process (Benton et al., 2012). Engaging the ASD community through a Support Group could act as a lens to foster and integrate co-design as a design process that amalgamates different stakeholders to achieve a common goal.

A novel approach may be required to capture the complexities involved in a longitudinal co-design study, in particular, the relationship, and role played by the different stakeholders. Traditional views and methods of co-design may not be sufficient to capture such complexities as much of their focus is usually placed on the design process and artefacts. This is further exacerbated when the users are from a marginalised group like people with ASD who are often viewed as research subjects without a "voice" in the research design and progress. A community-based approach such as PAR should be adopted to ensure that participants gain more control of the project outcome and a sense of ownership over the research goals and outcomes. In addition, PAR is often used as an overarching research principle with co-design methods in marginalised group research and has produced positive outcomes (Sanoff, 2008).

This chapter highlighted the gaps in the relevant literature and introduced the concept of participatory action research as an overarching methodology and of codesign as a method to use with people with ASD. Chapter 3 describes the design adopted by this research to achieve the study aims and objectives.

3.1 CHAPTER OVERVIEW

The previous chapters introduced the concept of participatory action research as an overarching methodology and co-design as a method to use with people with ASD and highlighted the gaps in the relevant literature. This chapter describes the design adopted by this research to achieve the aims and objectives stated in section 1.4 of Chapter 1. Section 3.2 discusses the underlying theoretical stances and applicability of a constructivist approach for this study; section 3.3 details the stages by which the methodologies were implemented, and the research design; section 3.4 describes the participants in the study; section 3.5 lists all the methods used in the study and justifies their use; section 3.6 outlines the timeline for completion of each phase of the study; section 3.7 discusses how the audio data was captured; section 3.8 discusses how the data was analysed; section 3.9 discusses the trustworthiness (quality criteria) for this research; section 3.9 discusses the ethical considerations of the research and its problems and limitations; finally, section 3.10 provides a summary of this chapter.

This research had three phases. Phase One involved contextual investigations of different stakeholders such as people with ASD, their parents/carers, and a local ASD support group. In Phase Two, a co-design pilot study was conducted to explore ways to engage adolescents with ASD as co-designers in the early phases of the software design process. In Phase Three, an extended co-design study was conducted to investigate design and community implications when engaging adolescents with ASD as co-designers in an iterative software design process. The methodology and methods chosen enabled participants to express themselves openly and without constraint. This approach provided a way to develop theory from the data to understand how adolescents with ASD can be engaged as co-designers in an extended iterative software design process and how this process can be used to understand their lived experience.

3.2 RESEARCH PARADIGM AND METHODOLOGY

A research paradigm influences how research is designed and conducted. The term "paradigm" refers to a set of ideas or general philosophical assumptions about the nature of the world (ontology) and how the researcher understands it (epistemology), and how the researcher interprets and acts within that world. The research paradigm chosen then determines the lens through which the researcher examines the methodological aspects of their research project to choose the research methods that will be used and how the data will be analysed (Kivunja & Kuyini, 2017).

The philosophical stance of this research lies in constructivism which seeks to understand the subjective world of human experience (Crotty, 1998). In contrast to positivism where there is only one reality, constructivism is concerned with an individual's subjective reality that is socially constructed. Using this lens, one's reality is constructed from one's perspectives, perceptions, and experiences (Bogdan & Biklen, 1997). Constructivism seeks to understand the viewpoint of the person being observed, rather than the viewpoint of the observer. Value is placed on understanding the individual and their interpretation of the world around them. Furthermore, constructivists believe that to understand the world, researchers must engage with and participate in it, and they must actively interpret it. In this paradigm, theory follows the research based on the data generated by the research act. As such, data are gathered and analysed in a manner consistent with grounded theory (Strauss & Corbin, 1990) and other qualitative inquiry.

From a constructivist view, qualitative research methods investigate social phenomena by focusing more on the depth of data than its quantity (Corbin & Strauss, 2014). The richness and complexity of long term exposure to the individual experiences of participants provide a great amount of data not available by other means. Qualitative research is heavily used not only in the social sciences, but also in information system and design research for its capability to provide detailed accounts based on experiences and emotions (Myers & Avison, 2002; Ritchie, Lewis, Nicholls, & Ormston, 2013). In addition, qualitative research involving people with a disability can be used to shed light on the complex interrelationships among physical impairment and societal barriers which are difficult to obtain using quantitative methods (O'Day & Killeen, 2002). In The Semantic Turn (2006), Krippendorff presents a comprehensive interpretation of constructivism for design and describes co-design as

one of the suggested design practices. Bredies et al. (2010) acknowledged the merits of co-design in a follow-up study but also highlighted the issue of how designers interpret other people's professional practice without prior experience in the same practice. My research follows a qualitative approach to understand a local ASD community and adolescents with ASD mainly through contextual inquiry (using participatory action research and co-design) and subsequently, engaging adolescents with ASD as co-designers through an iterative software design process to answer the research questions re-stated below.

Research Questions

Q1. How can adolescents with ASD be engaged as co-designers in an iterative software design process?

Q2. How can a longitudinal co-design study be used to understand the lived experience of adolescents with ASD?

3.3 RESEARCH METHODOLOGY

The overall research project was split into three phases with key principles of shared outcomes and community immersion from PAR adopted as overarching principles in a co-design framework and methods. Phase One involved an ethnographic contextual investigation of different stakeholders such as people with ASD, their parents/carers, and a local ASD support group. In Phase Two, a co-design study was conducted to explore ways to engage adolescents with ASD as co-designers in the early phases of the software design process. In the final phase, Phase Three, a co-design study was conducted to investigate design and community implications when engaging adolescents with ASD as co-designers in an iterative software design process. Figure 3.1 shows an overview of the research framework.



Figure 3-1 - Research framework

3.3.1 Phase One – Community Immersion

O1. Understand the diverse motivations, challenges and qualities of a local ASD community through in-depth interactions and observations.

Phase One was conducted to meet the first research objective O1 listed above. An ethnographic and phenomenological approach was adopted to explore the functions, values, and beliefs of a local ASD support group from their perspectives. Ethnographic inquiry is a qualitative method that prioritises participant observation, interviews and group discussion to understand the cultural interactions of members in a group (Janesick, 1991). Phenomenology seeks to understand the individual experiences of a phenomenon, in this case being an adolescent with an ASD diagnosis (Turner-Brown, Lam, Holtzclaw, Dichter, & Bodfish, 2011). The combination of these two methods was used in this phase to explore individual characteristics and practices of the community and the support group. Ethnography provided the philosophical inspiration to explore the culture and practices of the support group while phenomenology compliments the study in exploring the characteristics of individuals. Observations were made on collaborating parties and stakeholders over the group activities. Ethnography and phenomenology are described in more detail in section 3.3.4.

To facilitate observations, the researcher actively participated in group activities to interact with the collaborating parties and stakeholders. This phase also began to establish the positive rapport and relationships with the participants, parents/carers and committee members of the support group necessary to complete the study successfully and to put participants at ease in sharing opinions and contributing towards design decisions. Positive rapport and relationships were crucial in this research as the influence, working practices, and support of the stakeholders on the remaining phases were considered and investigated. Figure 3.2 depicts Phase One in the overall research framework, showing that immersion was the key aspect of the co-design process that was undertaken using ethnographic and phenomenological contextual inquiry.



Figure 3-2 - Phase One

3.3.2 Phase Two – Pilot Study

O2. Understand the challenges adolescents with ASD faced in using technology-based solutions through conducting collaborative discussions.

O3. Explore challenges and ways to engage adolescents with ASD in existing co-design methods.

Phase Two was conducted to meet research objectives O2 and O3 listed above. Through designing a computer game, this phase explored the challenges adolescents with ASD faced in using technology and as co-designers in the early phases of the software design process.

A traditional software design process consists of five stages: Plan, Design, Build, Test and Review (Davis, Bersoff, & Comer, 1988). A full participation co-design approach was used to design a game with adolescents with ASD, however, the pilot study was limited to the 'Plan' and 'Design' stage of the software design process. Fuad-Luke's (2013) approach to co-design provided the principles and guidelines for the design activities while the level of co-design participation was based on guidelines in Frauenberger et al. (2012). The research in Phases Two and Three are representative of the "Full Participation" approach in co-design. These guidelines are listed in Table 3.1 below.

Approach	Description
Non-participatory	Design is informed by best practice or prior experience. Users have no direct involvement in the design process
Participation via proxy	Design is informed by subject matter expert or those with intimate knowledge of the user population, such as parents and teachers. Users have no direct involvement in the design process
Full participation	Users are directly involved in the design process

Table 3-1 - Co-design approaches with people with disability (Frauenberger et al. 2012)

Co-design activities such as group discussion and sketching were employed to engage participants, support their expression of wants, needs and design ideas, and to enhance design contribution. Chapter 5 will describe the workshop implementation and findings from the pilot study. Findings from the pilot study were used to inform Phase Three of this study. Figure 3.3 depicts Phase Two in the overall research framework.



Figure 3-3 - Phase Two

3.3.3 Phase Three – Main study

O4. Understand the unique role of various stakeholders when engaging adolescents with ASD as co-designers in an iterative software design process.

O5. Explore and co-design software to facilitate social engagement and communications with the local ASD community.

Phase Three was conducted to meet the last two objectives (O4 and 5). The aims of these objectives were related to understanding the relationships and implications of stakeholders in supporting adolescents with ASD as co-designers in an iterative software design process and to empower participants in co-designing software that can have a positive impact on their current lives.

The main study adopted the same co-design approach and participation level as the pilot study. However, the main study is extended to three software iterations (V1-V3) where a software iteration is a single software design cycle. Co-design activities such as group discussion, sketching, dot voting, reflections, and mind maps were employed to engage participants, enhance design contribution, and to reflect on design implications. Observations were also made on collaborating parties and stakeholders over the main study. This phase also investigated the influence and relationship with the participants, parents/carers, and committee members of the support group on a codesign study. Figure 3.4 depicts Phase Three in the overall research framework.



Figure 3-4 - Phase Three

3.3.4 Ethnography and Phenomenology

Ethnography is an approach where the researcher aims to understand the ways in which participants express their real-life values, beliefs, and actions within and through culture, by having extensive and prolonged interactions with them (Liamputtong, 2010). Ethnography derives from the efforts by anthropologists to record the culture of people of a group to whom they do not belong. While anthropology focuses on the behaviour of people in culture, ethnography seeks meanings for such behaviour (Ingold, 2008). The ability to draw a detailed and holistic picture of a culture makes ethnography a popular research tool across multiple disciplines. Ethnography gained popularity in the field of human-computer interaction (HCI) design when Computer-Supported Cooperative Work (CSCW) emerged as an area of inquiry as researchers sought to better understand the social environment in which activities take place (Beckman & Barry, 2007). In design and participatory action research, ethnography is often used in conjunction with phenomenology by researchers to learn about their potential users and as a research tool for understanding the context of design applications (Anderson, 1994; Suchman, 2002).

Phenomenology aims to explore the lived experience of a person or group of people who have shared the same experience about a concept or a phenomenon of interest (Zahavi, 2003). This approach differs from ethnography which focuses on a group that shares the same culture instead of the same experience. Phenomenology plays a vital role in social science, information systems, and design research. Research

using phenomenology seeks to allow researchers to understand people's interpretations of their experiences and as a way of establishing ongoing relationships while exploring their cultures when used in conjunction with ethnography. As both ethnography and phenomenology requires active participation and involvement of the researcher in the process, Kidd and Kral (2005) argue that the approach and mindset of the researcher are key in the development of a successful and genuine participatory process. On the same note, Benton et al. (2012) suggest that such approaches need to value engagement, mutual learning, and reciprocity between the researcher and the community.

3.3.5 Participatory Action Research and Co-design

Key PAR principles of community immersion and shared outcomes from PAR were adopted into the co-design framework. Through immersion in the research community (Phase One), the researcher gained key insights on the culture and challenges faced by the local ASD community that were valuable in designing the research study. In addition, community immersion provided opportunities for the participants to become familiar with the researcher and the research study prior to the study commencement. People with ASD may have social skills deficits and lower self-esteem (Cooper, Smith, & Russell, 2017). This approach allowed the researcher to establish a positive rapport with the parents/carers and participants with ASD and aid in the balancing of power equities between the researcher and participants. Stakeholders in the research study, which include the Autism Support Group, participants, parents/carers and the researcher, were able to establish and understand the shared goals and potential outcomes of the research study. This approach also aligned the research outcomes with the community needs and provided a sense of ownership to all stakeholders.

Co-design activities that use visual and concrete examples to initiate and prompt ideas were used over the series of workshops (Phase Two and Phase Three). Using information gathered from the group discussion and drawings, the design team create low-fidelity prototypes such as sketches and paper storyboards to frame requirements, generate ideas, and test solutions. This pragmatic approach allowed the research team to learn and adjust the requirements of the software through each cycle. The iterative cycle aims to incorporate human-centred design and activity-centred design, creating software that is applicable in their daily activities (Norman, 2005). In addition, reflection conducted at the end of every workshop provided insights for the researchers to adjust the co-design activities to suit the needs and preferences of the participants.

3.4 PARTICIPANTS

Participants were all members of the North Queensland Autism Support Group (NQASG) between the ages of fourteen to sixteen years and were studying in Townsville, Queensland state high schools upon recruitment. A total of nine participants contributed to the pilot study and the main study. Parents were requested to share their child ASD diagnosis with the researcher before the research and all participants were diagnosed with Asperger's (DSM-IV). Both the pilot study and the main study had six participants. Three participants from the pilot study did not continue with the main study while another three new participants joined the main study. Studies suggest that ASD is more prevalent in males than females with a ratio of 4:1 (Gillberg, 2010; Nygren et al., 2012) and the researcher observed the same higher ratio and attendance of male members than female members across NQASG activities. In addition, NQASG committee revealed that their member database shows a higher count of male members as compared to female members. Table 3-2 summarises the details of the nine participants including their age, gender, technology background, ASD diagnosis, and workshop attendance.

Table 3-2 -	Participants	demographics
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No.	Age	Gender	Technology	ASD Diagnosis	Pilot	Main
			Background		Study	Study
1	15	Male	Nil	Asperger's (DSM-IV)	✓	
2	16	Male	Nil	Asperger's (DSM-IV)	✓	
3	14	Male	Nil	Asperger's (DSM-IV)	~	
4	16	Male	Nil	Asperger's (DSM-IV)	✓	✓
5	14	Male	Game Design	Asperger's (DSM-IV)	~	✓
6	14	Male	Nil	Asperger's (DSM-IV)	✓	✓
7	15	Female	Nil	Asperger's (DSM-IV)		✓
8	14	Male	Nil	Asperger's (DSM-IV)		✓
9	16	Male	Nil	Asperger's (DSM-IV)		✓

3.4.1 Sampling

Homogenous purposive sampling was used in this research as the sampling criteria were specific and concise. Below are the three main sampling criteria and their rationale in using homogenous purposive sampling.

Adolescent members of NQASG

Adolescent participants who identified themselves with the local ASD support group (NQASG) were chosen for the study. NQASG had the largest member database in Townville and all members were either individuals diagnosed with ASD or parents/carers whose child was diagnosed with ASD. As adolescents members of NQASG met the inclusion criteria, the researcher spent 10 months conducting an ethnographic study and immersion programme (Phase One). The immersion programme with NQASG and its members provided insights for the researcher in understanding the diverse motivations, challenges, and qualities of a local ASD community.

Be able to engage in group activities and verbal communications without major challenges

A further criterion for recruitment was that the participant was not diagnosed with cognitive impairment or extreme social communication deficits. Co-design activities such as design charette and discussions require group interactions and communications. As such, to be eligible to take part in this study, participants were required to have been diagnosed with Asperger's (DSM-IV) or ASD without language or intellectual impairment (DSM-V) classifications based on the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). Furthermore, participants had to be attending state high schools upon recruitment to demonstrate their capacity in engaging group activities and establish verbal communications without major challenges.

Be willing to engage in monthly face-to-face group activities and run field trials over nine months

A total of nine workshops (pilot study and main study) were conducted over nine months in Phases One and Two of this research. Parents/carers though not participating in the monthly workshops, committed to the logistics and transport support for the participants to access the workshop venues. In addition, parents/carers were located near the workshop vicinity to provide support if their child was to experience any anxiety or distress during the workshop. Parents/carers term this as "meltdown" and this term will be used subsequently in this thesis. Participants committed to the monthly face-to-face activities in the workshop and ran field trials (testing the software) throughout the study. These commitments were high and over a long period of time for both parents/carers and the participants. NQASG members were chosen as the NQASG were already running monthly group activities for their members and the workshops were planned to run at the same time and venue as NQASG activities. This arrangement facilitated the NQASG members to participate in the workshops without any disruption to their current routine.

3.4.2 Recruitment

Based on the initial sampling criteria, a recruitment advertisement was put up on the NQASG Facebook page and was sent directly to members via the monthly newsletter. The NQASG manages its own Facebook page and members database. The NQASG committee members actively use Facebook to share the latest development in ASD research/intervention and as a channel to inform members of the latest group events. Thus, the recruitment ad was posted on NQASG Facebook in addition to the monthly newsletter emailer in order to reach out to more members. As the researcher was an executive member of NQASG and the organiser of the NQASG computer club, the recruitment ad was put up by a neutral committee member to prevent any perceived coercion. Furthermore, the recruitment ad included a neutral NQASG member's contact details where interested participants might also seek clarification before committing to the research project. An information sheet was made available to the potential participants after they had responded to the recruitment ad. The information sheet and informed consent forms are listed in Appendix A.

Participants were encouraged to attend all the workshops because the research focus was on the user experience in the co-design process. Participants and parents/carers were briefed that in the case that less than 50% of the participants were able to turn up for a scheduled workshop then the researcher would have to arrange for a make-up workshop. In addition, new recruitment ads would put up via NQASG channels if more than 50% of the signed-up participants had withdraw from the research. Newly joined participants might have missed out on the previous session, would still be involved in the remaining co-design process which contributes to the research goals. In summary, all participants met the sampling criteria and the number of participants was modest. No make-up workshop was scheduled as every workshop had more than 50% of the overall participants. However, it is important to note that at no point in this study was sampling intended to be representative of the entire population of NQASG.

3.5 METHODS

3.5.1 Participant Observation

Participant observation is a method in ethnography where the researcher spends an extended period in a social group to collect data. Participant observation comprises a collection of ways to elicit and collect data, including the observation of individuals and groups of individuals, unstructured interviews, documentary analysis, and the use of a researcher's field notes (Morgan-Trimmer & Wood, 2016). In addition, engagement with a particular social or cultural group is also a key feature of ethnography. To observe the 'true' practices and experiences, researchers actively participate and engage in the daily life of its members (Tedlock, 2005). Through these engagements, researchers would be able to gain a deeper understanding of the practices of communities and their day-to-day functioning activities (Aktinson & Hammersley, 1998; Gans, 1999; Schensul, Schensul, & LeCompte, 1999). Information obtained through participant observation reflected the viewpoint from the investigated person or persons.

Participant observation is commonly used in ASD research to observe and understand the meaning of participants' behaviour from their perspectives. Parents/carers can be interviewed to provide second-hand interpretations of their child's activities however, not all people with ASD are receptive or capable to engage in verbal interviews. Participant observation provides a non-linguistic alternative to studying people with ASD (Spitzer, 2003). In addition, participant observation can be used to complement a range of alternative techniques that still rely on shared linguistic and perceptual knowledge between the participant and the researcher such as drawing pictures or interviewing in groups (Cesaroni & Garber, 1991; Solomon, 2008).

3.5.2 Group Discussion

Group discussion is a qualitative research method where a small group of participants gathers to discuss a specified topic to generate data. Data generated from group discussion include contextual knowledge, perspectives, and attitudes of people, and explanations for behaviours in a way that would be less easily accessible in responses to direct questions, such as in one-to-one interviews. Group discussion can provide content-rich and qualitative information that is difficult or expensive to capture with other methods. As such, group discussion is a common data gathering method in social, health, medical, and human-computer interaction research (Kontio, Lehtola, & Bragge, 2004; Parker & Tritter, 2006).

Group discussion also captures the interaction between the researcher or moderator and the group, as well as the interaction between group members. Such interactions can provide non-verbal cues on the attitudes and interests of the participants on the discussed topic in co-design and ASD research. These non-verbal cues are important data as people with ASD may not be able to express themselves well verbally (Cridland, Jones, Caputi, & Magee, 2015). Co-design's emphasis is on the balance of power between the researcher and among fellow participants to exchange ideas/thoughts/feelings freely. These interactions can be observed and analysed to reveal insights on the balance of power within the design team.

3.5.3 Sketching

Sketching is the production of paper drawings that allow designers to explore the forms and functions of things. Buxton (2010) uses the term sketch to describe any visual representation of an idea or concept that can be used to get new ideas, develop old ones or think about well-known issues. Sketching is a common method used in codesign research as it can be performed by both professional designers and amateurs. Sketching can also be a means to drive discussion and thinking together with participants in co-design workshops. Participants and the researcher can use sketches to share an idea, inspire thinking, and engage in conversation.

Sketching is a common method to produce low-fidelity prototypes of the actual solution in a software design process. A low-fidelity prototype made up of drawings of software designs and interfaces is an efficient way to explore the design space, enhance user participation in the design process, enable visualisation of possible design solutions, provoke innovation, and drive discussion (Moggridge, 1993; Muller, 1991; Wulff, Evenson, & Rheinfrank, 1990). Low-fidelity prototyping is also an effective method to engage people with ASD in the design space (Cibrian, Pena, Vazquez, Cardenas, & Tentori, 2016; Wilson, Brereton, Ploderer, & Sitbon, 2019).

3.5.4 Dot Voting

Dot voting is an activity used to prioritise items or make decisions in a group setting. Participants placed coloured dots on paper drawings or lists of items to vote on the importance of design ideas and features in the workshops. In addition to prioritising items, dot voting also allows the design team to gather collective consensus, engage, and obtain an opinion from every participant (Dalton, 2019). A collective consensus and a 'voice' in making design decisions is important to ensure the balance of power within the design team. Dot voting is a method common in decision making and design processes and proved to be valuable as an entry point in promoting discussions towards issues (Katterfeldt, Zeising, & Schelhowe, 2012).

In practice, dot voting is a common approach used in incremental software design process for its simplicity and ability to gain group consensus on prioritising software changes (Dalton, 2019). Dot voting is also frequently used in co-design research for its ability to balance power within the design team.

3.5.5 Reflection

Reflection is a method where participants consciously review and think about their experiences, actions, feelings, and responses, and then interpreting or analysing them to learn from them (Getliffe, 1996). Reflection can be performed through a combination of techniques such as think-aloud, observation of practice, and reflective recall process (Osmond & Darlington, 2005). Thinking aloud is a process where participants express their thoughts verbally while reviewing an issue and analysing the resulting verbal protocols (Van Someren, Barnard, & Sandberg, 1994). The observation process involves the researcher in taking observation notes through their interactions with the participants and serve as discussion points following a design event. Reflective recall involves using the recorded observations as a stimulus for discussion.

Reflection activity is encouraged to take place shortly after a design activity so that participants have no introspection of the details and provide true accounts of their experience and thought process. The researcher would be able to identify the design making process by analysing the reflection data. Retrospective meetings are a type of reflection commonly used in incremental software design process to evaluate the previous work cycle and determine areas of improvement in the design process (Sutherland & Schwaber, 2013). Reflection has also gained popularity as a co-design method to ensure rigour and accountability in the design process and outcomes (Bødker & Iversen, 2002; Frauenberger, Good, Fitzpatrick, & Iversen, 2015).

3.5.6 Mind Mapping

Mind maps are hierarchical diagrams that use visuospatial orientation to organise and relate themes or objectives (Buzan & Buzan, 2006). Mind mapping techniques are associated with modern constructivist approaches to learning, emphasising the active involvement of the researcher who utilises existing knowledge structures to construct new knowledge (Dhindsa, Makarimi, & Roger Anderson, 2011). In addition, the use of mind maps in learning and teaching is often associated with critical thinking (D'Antoni, Zipp, Olson, & Cahill, 2010). Mind maps often start with a single concept, drawn or written in the centre of a page, to which associated representations of ideas such as images, words, and parts of words are added.

Most people with ASD are visual thinkers and as such, mind maps are methods used in ASD research to facilitate and present information visually (Millen, Cobb, & Patel, 2011). Mind maps can also be used as a knowledge map for reflection (Osmond & Darlington, 2005). Observation notes can be constructed into a mind map and serve as discussion points following a design event.

3.6 TIMELINE

This research was completed in nineteen months. Phase One of the community immersion ran for ten months where the researcher engaged the local ASD support group and conducted the ethnographic contextual inquiry. Phase Two of the pilot study ran for two months with two co-design workshops conducted. Finally, Phase Three of the main study ran for seven months with seven co-design workshops conducted. Though contingency plans were made for make-up workshops if the majority of the participants were not able to turn up for a scheduled workshop, all workshops from both the pilot study and main study were conducted on schedule with more than 50% attendance. Figure 3.5 presents an overview of the research timeline.

3.7 AUDIO RECORDING AND TRANSCRIPTION

All workshop conversations were audio recorded and transcribed for data analysis. Conversations were recorded with the participants' consent. Two audio recorders (smartphone and tablet) were used in every workshop to minimise the risk of losing recorded content due to technical failure. This set up is necessary as it is not possible to replicate the same workshop twice. The audio recordings were of reasonable quality. Each participant's voice can be clearly distinguished from one another. A few words were indecipherable, because of participants having their small conversations in the background.

All workshops recordings were manually transcribed verbatim by the researcher into typed transcripts. The act of transcribing prompted further reflection about the workshop process and content. Although time consuming, this promoted intimacy with the data.



Figure 3-5 - Research timeline overview

3.8 DATA ANALYSIS

Data in this research were qualitative in nature and the data collection techniques included group discussions, observations, and design engagement activities with the participants. The design artefacts created through the design engagement activities were photographed while group discussions were audio recorded. At no time were participants themselves photographed while engaging in research activities.

Data in this research was analysed using thematic data analysis guidelines defined by Braun and Clarke (2006). Thematic analysis is an approach for identifying, analysing and organising key issues in data and grouping data under themes. This allows the researcher to identify emerging themes and to understand participants' concerns, in particular, those that were not predicted or prompted by planned questions (Tanaka, Parkinson, Settel, & Tahiroglu, 2012). As such, thematic analysis is also widely adopted in co-design research (Halskov & Hansen, 2015). One of the benefits of thematic analysis is its flexibility. However, this flexibility also creates different manifestations of the method within the broad theoretical framework. Furthermore, methods are essentially independent of theory and can be applied across multiple disciplines, as such, different disciplines may have a different approach in performing thematic analysis. Antaki et al (2003) suggested that qualitative research without clear and concise guidelines around thematic analysis suggests that the 'anything goes' in some instances. As this study deals with unstructured data from multiple input sources, it is important to ensure data is managed across the various stages of thematic analysis.

Braun and Clarke (2006) proposed a guideline for performing thematic analysis that retains the flexibility of thematic analysis but also with a clear and detailed approach in managing data. Figure 3.6 provides an overview of the adopted data analysis in this research.



Figure 3-6 - Data analysis approach adapted from Braun and Clarke (2006)

3.8.1 Becoming Familiar with the Data

The results of the thematic analysis depend largely on how familiar the researcher is with the depth and breadth of the data. This is achieved usually by 'repeated reading' of the data and reading the data in an active way - searching for meanings, patterns. It is vital to read through the entire data set at least once prior to any coding, as ideas and identification of possible patterns will be shaped as the reading proceeds. This iterative reading of data is time-consuming, as such, qualitative research tends to have a smaller sample size.

All data in this research was collected by the researcher. This allows the researcher to have some prior knowledge of the data and initial analytic interests or thoughts. Audio recordings were also transcribed manually by the researcher into written form as inputs for the thematic analysis at the end of every workshop. Although the process of transcription is time-consuming, frustrating, and at times seen as counterproductive, is a recommended approach for researchers to be familiar with the data (Riessman, 1993). Transcriptions were conducted through a rigorous and thorough 'orthographic' style – verbatim account of all verbal and nonverbal articulation. This included the tone of the utterances to reflect the true original meaning of the data.

3.8.2 Generating Initial Codes

Coding is common in qualitative research and was fundamental to data analysis in this study. Codes identify a feature of the data (semantic content or hidden) that appears interesting to the researcher, and refer to 'the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon' (Boyatzis, 1998; Charmaz, 2014). Data are being analysed and organised into meaningful groups through the process of coding. Coded data differ from the units of analysis (themes). Themes are the interpretative analysis of the coded data and in relation to which arguments about the phenomenon being examined are made. Coding can be 'data-driven' or 'theory-driven'. Data-driven coding seeks to identify themes only with dataset while theory-driven coding seeks to identify themes in relation to specific questions that the researcher has in mind (Braun, Clarke, Hayfield, & Terry, 2019).

Data in this research was coded using a hybrid approach where the data was inductively analysed for open themes and deductively analysed with the workshop goals (software design changes). A set of goals, aims and discussion points were planned for each workshop (Workshop Guide). This allowed the researcher to direct and facilitate team discussion through the software design process. Transcription was coded using Microsoft Excel as it was easily accessible and available for the researcher. The transcript was labelled in relation to the aims and discussion pointers for the specific workshop. Labelled utterances were then copied into a new Excel tab for sorting purpose as shown in Figure 3-7 - Coding.
	R		Hi everyone, in this research, we are looking at how we
1	к	3	design and determine what the application can do. How be audio recording this session but no pictures will be $t\epsilon$
261	S	YouTube	I want to make YouTube videos.
265	R	YouTube	OK, do you want to create a video? If you want to create
269	М	YouTube	My channel barely have anything
270	S	YouTube	I want to take a video of my face playing game
285	R	YouTube	OK, sorry. We can discuss about your YouTube videos afte
358	М	YouTube	Look at mine. A PC phone so that you can watch YouTube
398	М	YouTube	I use my iPad.
428	M & D	YouTube	It is a YouTube channel. They draw
561	S	YouTube	You know what video he is saying?
562	R	YouTube	Nope, I need to go watch that video.
<mark>56</mark> 3	М	YouTube	Yes, go watch that video.
565	М	YouTube	Ask your watch to watch the video.
566	R	YouTube	Will it be cool if your watch can show you YouTube video
568	М	YouTube	It is like someone is talking to you about a video and you
569	S	YouTube	What it could amaze me the most if you can watch any $Y_{\rm C}$
572			
573			
574			
575			
576			
577 578			
5/8		Raw Emoji	igital Tech 🕞

Figure 3-7 - Coding on Microsoft Excel

3.8.3 Searching for Themes

Codes are analysed to form themes in this phase. Codes related to the goals, aims and discussion points are sorted and collated into potential themes, while unrelated codes are discarded. Identified themes can be combined into overarching themes and form sub-themes. The use of visual representation would help to sort the different codes into themes.

Codes in this research were sorted and collated into themes based on their relationships. Identified themes were mapped on a mind mapping software (Coogle.it). Coogle is an online visual mind mapping tool and the researcher used it to produce mind maps that explore relationships among the identified themes. Identified themes were arranged or combined when necessary. Figure 3-8 - Workshop 4 mind map shows a snapshot of workshop 4 mind map.



Figure 3-8 - Workshop 4 mind map

3.8.4 Reviewing Themes

Identified themes were reviewed under two phases. Phase One reviews the identified themes at the level of the coded data. All collated extracts (codes) for each theme are reviewed and considered whether they form a coherent pattern. Phase Two reviews the identified themes in relation to the entire data set. Themes are reviewed if the validity of individual themes accurately reflects the meanings evident in the data set as a whole. Themes were reviewed based on the theoretical (software design process) and analytic (data-driven) approach. Additional data within themes missed in earlier coding stages can be captured in this phase. The need for re-coding from the data set is to be expected as coding is an ongoing organic process.

Themes identified in this research were cross referenced with the codes developed in the earlier stage. Using the identified themes, the researcher cross referenced the information with codes in Microsoft Excel. Next, the researcher reviewed the identified themes in relation to the aims and goals for each workshop. This process allowed the researcher to review whether identified themes accurately reflect the direction of the respective workshop's aims and goals. Themes and outlying cases were shared and discussed with the participants at the start of every workshop.

3.9 TRUSTWORTHINESS

A constructivist study is deemed credible when the research results were derived from the perspective of the participant in the research. Credibility is established in the study through the triangulation of data sources and the use of member checking. Data from multiple sources such as transcriptions, drawings, and observation notes were triangulated to ensure consistency of the data as part of the thematic analysis process. In addition, identified themes were shared with the participants at the start of every workshop. Using member checking, participants were encouraged to correct any misinterpretations of the researcher analysis. These two approaches ensure the credibility of the data and help to counterbalance the researcher's personal bias in analysing the data.

Transferability in research refers to the degree to which the results of the research can be generalised or transferred to other contexts or settings. Transferability is established in the study with clear descriptive data, such as the environment in which the research was carried out, its setting, sample size, sample strategy, and demographic of the participants. In addition, all workshop guides (Appendix D) and the changes in software design through the iterative research process are documented in this study.

Dependability in research refers to the level of confidence in replication and repeatability. Since the philosophical stance of this research lies in constructivism, this research is concerned with a subjective reality that is socially constructed by the researcher and participant. It is therefore not indicative if the research can be replicated with the same results. Nonetheless, if the changes that occurred in the research and how these changes affected the research were well documented, other researchers may take inspiration from the study and replicate a similar study to suit their context.

Confirmability in research refers to the degree to which the results could be confirmed or corroborated by others. Though the design decisions in this study were made collectively through co-design methods like group discussion and voting, there is no formalised method to determine the reliability of the qualitative data and methods other than taking the participants at their word. The longevity of the study and the consistency of the answers reported gives a higher level of reliability than a once-off workshop. However, the methods and results of this study have been published in peerreviewed conferences, indicating a degree of recognition in the methods used and results obtained.

3.10 ETHICS AND LIMITATIONS

Ethical clearance was obtained for this study from the James Cook University Human Research Ethics Committee (JCU HREC Approval Number H7366). In conformity with the approval, participants and their parents/carers were informed that they could withdraw from the study at any time without explanation or prejudice and to withdraw any unprocessed data they have provided. This research followed standard procedures to ensure that participants' rights were protected during the research study. Participants and their parents/carers were presented with the study Information Sheet (see Appendix A) before the commencement of their first workshop. To participate in the workshops, participants and parents/carers had to sign the Informed Consent Form (see Appendix B) as an acknowledgment that they were informed about the research and agreed to participate in this study.

Considerations to reduce any unnecessary stress were taken in workshop design due to the participants' age and ASD condition. No video recording or photography was undertaken to protect the identity of the participants. Parents/carers had to provide their contact number and be nearby during the workshop to pick up their child if they began to show signs of distress or meltdown; for example, if a child displayed an agitated behaviour or uncontrollable behaviour.

This study also aimed to create sustainable actions that can improve the lives of stakeholders through the computer club. This outcome is a tangible emancipatory benefit of the PAR process. The establishment of a computer club can continue to provide NQASG members with a platform to interact and socialise with each other through the common interest in technology. Other NQASG members were involved in running the computer club. Though the study has been completed, the computer club continues to function and is now an integral NQASG activity.

The chosen methodology has several limitations and thus, replicating the same research design in other conditions may yield different results. First, this study uses a constructivist approach to explain a phenomenon by relying on the perception of the participant's experience. No two people have the same experience and understand the world in the same way. Second, this study only investigated and involved one ASD support group. Other similar ASD support groups may have different set-ups and support for their members. Finally, this study had a limited number of participants and they are all diagnosed with Asperger's (DSM-IV).

3.11 SUMMARY

The goal of this chapter was to outline the research method used to answer the research questions. A discussion of the methodology, study participants, data collection, and methods outlined the specifics of how the study was conducted and who participated in the study. A constructivist theory methodology was used to develop theory on how adolescents with ASD can be engaged as co-designers in an extended iterative software design process. All study participants contributed to this theory by sharing their experiences in the co-design workshops and their perspectives of being a co-designer in a software design process. The goal of Chapter 4 is to provide the study results and demonstrate that the methodology described in Chapter 3 was followed.

The contents of chapter 4 have been published in:

- Phase Two Zhu, R., Hardy, D., & Myers, T. (2018). Building Applications that Matter: Co-designing with Adolescents with Autism Spectrum Disorder. In International Conference on Health Information Science (pp. 167-174). Springer, Cham.
- Phase Three Zhu, R., Hardy, D., & Myers, T. (2019). Co-designing with Adolescents with Autism Spectrum Disorder: From Ideation to Implementation. In Proceedings of the 31st Australian Conference on Human-Computer-Interaction (pp. 106-116). and

Community-led Approach to Co-design a Social Networking Platform with Adolescents with Autism Spectrum Disorder. Under review with The Journal of Autism and Developmental Disorders

4.1 CHAPTER OVERVIEW

The previous chapter outlined the methodology, methods and phases that this study followed to answer the research question and objectives. The purpose of this study is to understand how adolescents with ASD can be engaged as co-designers in an extended iterative software design process and how this process can be used to understand their lived experience. This chapter describes the implementation of the three phases of research. Section 4.2 describes the ethnographic study conducted to explore the functions, values, and beliefs of members of an ASD support group from their perspectives in Phase One. The researcher participated in the support group activities and committee meetings as part of the ethnographic study. Observation field notes were taken and analysed with thematic analysis to understand individual characteristics and the practices of the support group. Section 4.3 describes the pilot study comprised of two co-design workshops conducted in Phase Two to explore the challenges adolescents with ASD faced in using technology and identify ways to involve adolescents with ASD as co-designers in the planning and design stage of a software design process. Design artefacts generated from the workshops were analysed with thematic analysis to identify the challenges faced by the participants in using technology and investigate their roles as co-designer in the pilot study. Section 4.4 describes the extended study comprised of seven co-design workshops conducted in Phase Three to investigate design and community implications when engaging adolescents with ASD as co-designers in an iterative software design process. Design

artefacts generated from the workshops were analysed with thematic analysis to investigate how adolescents with ASD can be involved as co-designer in an iterative software design process over an extended period and how other stakeholders, such as support groups and/or parents, play a pivotal role in supporting the co-design process. Finally, section 4.5 provides a summary of this chapter.

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4.2 PHASE ONE - COMMUNITY IMMERSION



Figure 4-1 - Phase One timeline

In Phase One, an ethnographic approach (Liamputtong, 2013) was adopted to get a preliminary understanding of the culture and group practices of a local ASD support group which includes members with ASD and their parents/carers. The researcher joined the North Queensland Autism Support Group (NQASG) committee as an executive member ten months prior to the commencement of Phase Two - pilot study. As an executive member, the researcher participated in committee meetings and activities organised by the NQASG. Activities included a Christmas party, members meet-ups and fundraising events. Participants of the NQASG activities include individuals with ASD and their parents/carers. In addition, the researcher set up a computer club for the Autism Support Group with the support of the executive committee.

The researcher started a computer club to provide a platform for members with ASD who are interested in technology to socialise and exchange ideas through monthly "meetings". The researcher planned and organised the monthly computer club meetings which included liaising with parents on registrations and providing mentorship for the club members. The computer club ran for eight months before commencement of Phase Two - pilot study. Figure 4-2 shows the setup of a regular computer club meeting.



Figure 4-2 - Computer club set up (author's archive)

Casual discussions and participant observation were conducted during the engagement activities with the NQASG. The discussion topics were based mainly on motivations, challenges, and success factors in engaging individuals with ASD. Table 4-1 below shows a breakdown of all the engagement activities in this phase. Field notes and observational data were then thematically analysed. The identified themes reveal

a diversity of assumptions, motivations, culture practices and challenges. These themes provided the researcher with key insights that were valuable in designing the remaining research study. Apart from gaining valuable insights on the functions, values, and culture practices of Autism Support Group, these engagement activities also provided a platform for the participants to become familiar with the researcher and the remaining research study. Stakeholders in the research study, which include the Autism Support Group, participants, parents/carers and the researcher, were able to establish and understand the shared goals and potential outcomes of the research study. Three main themes emerged from the investigations: integration to current practices, motivations to develop technologies and the need to engage stakeholders.

Activity	Participants	Period	Duration	
Committee	Committee members	July 2017 – April	20 hours	
meetings		2018		
Fundraising	Committee members	September 2017	10 hours	
activities	Members with ASD Parents/carers	May 2018		
Members meet-up	Committee members	July 2017 – April	8 hours	
	Members with ASD	2018		
	Parents/carers			
Christmas party	Committee members	December 2017	2 hours	
	Members with ASD			
	Parents/carers			
Computer club	Committee members	July 2017 – April	16 hours	
	Members with ASD	2018		
	Parents/carers			

Table 4-1 - Participant observation engagement activities with NQASG in Phase One

4.2.1 Integration to Current Routines

The importance of catering programs or workshops to accommodate people with ASD was highlighted by many stakeholders. One of the ASD traits as outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) is that the individual shows restricted, repetitive patterns of behaviour, interests, or activities. As such, people with ASD tend to prefer a predictable routine to follow. Many parents/carers maintain a daily routine for their child and reported that having a daily routine can help to reduce their child's anxiety and meltdown occurrences. NQASG activities were also scheduled at a regular date and time (Table 4-2) to facilitate parents in integrating NQASG activities into their child's routine.

Activity	Date	Time	Venue	
Adults Group	First Saturday of the month	6рт – 8рт	Not fixed	
Computer club	Second Sunday of	2pm – 4pm	NQ Employment	
	the month		Building	
Siblings Group	Third Sunday of	2pm – 4pm	NQ Employment	
	the month		Building	
Adolescents Group	Last Sunday of the	2pm – 4pm	NQ Employment	
	month		Building	

Table 4-2 - Regular NQASG activities

Activities involving children were conducted at a regular venue noted in the table above. One of the NQASG committee members mentioned that this practice allows parents/carers and their children to be familiar and comfortable with the venue as participant P4 noted "*I am familiar and comfortable in this place because I am here a few times a month*.". The NQ Employment building also has several rooms available for the activity facilitator to create a quiet space when children are feeling stressed to help lower levels of anxiety.

A designated NQASG facilitator did the planning, organising, communicating and conducted each activity. Having a single point of contact for parents/carers and members with ASD for each activity facilitated the communications between the facilitator and other members. The facilitator sent out emails and put up Facebook posts to inform and remind parents/carers and members with ASD of the next activity. Parents/carers are all familiar with this practice. The computer club adopted the same practice and has had regular attendance since its inception.

4.2.2 Motivations to Develop Technologies

All stakeholders highlighted the importance of developing or integrating technologies for people with ASD within the community. As an example, participant P4's mother mentioned that P4 is interested in game design and character animation, however, there was no one in the family that could work with him on developing such projects. Parents/carers also reported that their child would attempt to engage in conversation that relates to technology, games or YouTube videos with them, however, they were unable to take the conversation further due to their lack of familiarity with the technical topics. People with ASD have limited social skills and often do not participate or engage in conversation actively, and many parents felt that this is a missed opportunity for social engagement with them and fellow peers (Wilson et al., 2019). The NQASG committee acknowledged this gap and mentioned that many parents faced similar issues especially those with adolescent children. However, the committee did not have the resources and expertise to engage members on technology related projects/activity. The computer club provided an opportunity for members with ASD who were interested in technology to socialise and exchange ideas through the monthly meetings. Members with ASD who attended the computer club commented that they enjoyed the sessions and were able to share their design ideas with fellow peers.

Many members with ASD reported on the lack of design input from people with ASD in applications that target them as users. In addition to common social applications like Facebook and Pinterest, they also face difficulties using applications that are built specifically for them such as intervention or education applications. They commented that the design of the application does not consider their preferred interaction style and abilities.

4.2.3 The Need to Engage Stakeholders

Members of the NQASG with ASD were observed to have close bonds with their parents/carers and it was noted that parents/carers play a vital role in providing support, encouragement, and advice for their child. For example, participant P9 stated that his parents encouraged him to join the activities as they believed it would help him to make friends. Parents/carers were also observed to converse with other parents/carers about their experiences and to exchange information. Some parents/carers shared that their child does not attend any group activities other than school and the support group. However, all parents/carers agreed that the social interaction among the support group members often does not extend outside of organised activities at the NQASG.

The computer club provided the researcher with a platform to establish a positive rapport with the parents/carers and members with ASD. Some participants shared that they felt safe and comfortable with the researcher, fellow participants, and the activities conducted in the computer club. Through the computer club, the researcher had the opportunity to share the research objectives and goals with parents/carers. The common goal identified by all stakeholders in this study was to provide a platform where adolescents with ASD can interact and socialise.

4.2.4 Implications for Phase Two pilot study

Phase One findings corroborate with reports in prior studies in the literature regarding the challenges faced by people with ASD and ways to engage them through qualitative methods. Participants commented that they were keen to make friends through the computer club or workshops which corroborates with a study conducted by Gerhardt and Lainer (2011) that suggested adolescents with ASD showed increased interest in social relationships along with continued development of social skills. Weidle et al. (2006) suggested that some adolescents with ASD only attend peer support groups as the only group activity outside school. In this study, P3's parents mentioned that P3 only attends the computer club outside school activities and therefore, does not have many opportunities to develop friendships. Participants P2 and P3 commented that they may face difficulties expressing themselves verbally and the use of group discussions allowed them to build on top other's view or correct themselves if other's misunderstood their words. Participants also commented they felt comfortable to share ideas and exchange ideas or thoughts through the use of drawings. These findings corroborate with prior studies that the use of group discussion and

drawing is an effective method to engage people with ASD in the design space (Cibrian et al., 2016; Wilson et al., 2019),

In addition, Cridland et al. (2015) suggest a list of recommendations for using qualitative methods with people with ASD and Phase Two has adopted recommendations suited for this study (Table 4-3).

No.	Recommendation	Implementation	Rationale
1	Schedule	Group	The engagement of
	interviews at a	discussions/workshops	participants with ASD
	preferred time for	were conducted on a	may be particularly
	participants.	regular time and day	influenced by the timing.
		(every second Sunday of	Avoid interviews shortly
		the month from 2pm-	after school or work when
		4pm).	the participant may be
			stressed or tired.
2	Conduct	Workshops were	A private space may
	interviews in an	conducted in a private	facilitate discussion of
	appropriate	room. Nonetheless,	challenging issues.
	private space.	participants were free to	
		move around throughout	
		the workshop (see Figure	
		4-3).	
3	Include	Group discussion began	An introductory statement
	introductory	with an introductory	may be particularly
	statement	statement to remind	relevant for people with
		participants about the	ASD given their general
		content of the discussion,	preference for
		the expected length and	preparedness.
		update on the research	
		process.	

Table 4-3 - Reommendations from Cridland et al. (2015) adopted in Phase Two



Figure 4-3 - Workshop layout

4.3 PHASE TWO - PILOT STUDY



Figure 4-4 - Phase Two timeline

Six boys aged fourteen to sixteen years old inclusive participated in the pilot study. All participants had been previously diagnosed with Asperger's syndrome and only one participant had prior software design experience in game design. P5 had prior experience in designing his first 2D game using GameMaker Studio and considers himself a novice (beginner) in game design. Table 4-4 summarises the details of the six participants including their age, gender, technology background, ASD diagnosis and workshop attendance

	P1	P2	P3	P4	Р5	P6
Age	15	16	14	16	14	14
Gender	М	М	М	М	М	М
Software design experience	Nil	Nil	Nil	Nil	Game design	Nil
ASD diagnosis		Asperg	ger's synd	rome (DS	M-IV)	
WSP1	\checkmark					
WSP2	\checkmark					

Table 4-4 - Pilot study participants demographics

Two co-design workshops were conducted in the pilot study. Each workshop lasts for two hours. The pilot study investigated how adolescents with ASD can be involved as co-designers in the planning and design stage of the software development process, in this case a computer game. Participants were engaged in all three co-design roles 1) Learner; 2) Mentee; and 3) Partner over the two workshops. Table 4-5 shows the co-design stages and activities for the workshops.

Table 4-5 - Summary of co-design activities in the pilot study

Co-design Stage	Activities	Aims
WSP1 (Plan)	Group discussion	Familiarise participants with co- design activities
		Co-design nature of the game

WSP2 (Design)	Group discussion	Familiarise participants with co-
	Sketching	design activities
	Reflection	Produce low-fidelity prototypes of a
		game

Workshop P1 had two main goals: (1) familiarise the participants with co-design methods and (2) determine the nature of the game to be designed. Participants were seated around a table to facilitate discussion.

The first workshop engaged the participants as "Learner" and "Mentee" roles. Participants were introduced to the research topic and their role in the study at the start of the workshop. A group discussion was then conducted with the researcher leading the group through a series of semi-structured group discussions relating to their experience in using technological devices and software. Participants were prompted with follow-up questions for them to elaborate on their thoughts and opinions. Subsequently, the researcher taught the participants (Learner) basic skills around game design (i.e. the use of drawings to illustrate ideas and levels) and encouraged the participants to design their individual computer games. Finally, the workshop ended with researcher providing the participants (Mentee) one-to-one guidance to refine their game design techniques. Figure 4.5 shows the notes taken by participant P5 on game mechanics.

Rivid body = Altowing Physics avard/ Bick word! Orgin ray = Paue PA = Fast Force Priment: Alighting that happens to the X-Y or Z of rotation scale V (ubec Position the child copies happens to the X.Y or Z as relation liscally Child : when Of the parent, that happens to the Child as Void Stort: The code will Only hopen when the object is In play

Figure 4-5 - Participants notes on game mechanics

Workshop P2 focused on the Partner role. The researcher instructed the group to act as a design team at the start of the second workshop. The team was tasked to design a game and produce a low-fidelity prototype (drawings) for the game. The research team expressed their ideas through group discussion and used drawings to illustrate ideas and game level design with one level for each section of the game. P3 had the idea of a road safety game where people with ASD can learn how to handle different road situations. Figure 4-6 below depicts a prototype drawing by participant P3.



Figure 4-6 - Phase Two prototype

Participants reflected on their experiences as co-designers at the end of the workshop. The discussions from both workshops were transcribed and analysed using thematic analysis. Three main themes emerged from the pilot study: strong interest in gadgets and technology, unique perspective in UX and the need to make design decisions.

4.3.1 Strong Interest in Gadgets and Technology

All of the design team participants are savvy technology users. Most of them use computers and mobile devices daily for education or leisure purposes. Participants also commented that they are familiar with navigating and downloading content from Google Play Store and Apple App Store and use social media and YouTube to stay informed of the latest gadgets and games. Despite their ASD challenges, participants were able to engage and communicate with peers and the researcher about technology where they shared a common interest.

4.3.2 Unique Perspective in UX

Participants highlighted frustrations with poor UX design. For example, the interface for applications such as YouTube (to upload videos) and educational software or games used at home or school seem difficult for them. Participants

indicated a strong preference in terms of user interface options such as font type, colour and interface layout. One participant commented that he prefers text to be in blue even if the background is blue though having the same foreground and background colour tends to make the text less readable and is generally avoided in user interface design. Key statements from the participants are listed in Table 4-6 below.

Table 4-6 - Themes related to poor UX

Participant	Comment
P1	"I don't understand why some software took long to load up. I can't wait."
P2	"I find it difficult to use some applications, like those in schools and even for my therapy"
Р3	"I like to upload my own YouTube videos but I just cannot remember the steps to do upload. Every time."
P4	"I find it annoying to use an application with different fonts and colours."
P6	"I don't like to follow instructions on a computer, I just want it to show me what I like to do."

Participants also indicated that they sometimes find the wordings used in the software interfaces to be unhelpful. P1 mentioned that he has difficulties understanding wordings like "Please wait" or "loading" as he doesn't understand what the application is doing. Participants commented they were confused and often misunderstood the meaning behind the software instructions. P6 mentioned that he tried to upload videos onto his YouTube channel but he was confused with the terms and instructions from YouTube. They reported that it is common for them to misread instructions because of their ASD traits. Participants also commented that they do not understand the meaning behind certain icons used in applications and they were bothered by their appearance in the interface.

4.3.3 The Need to Make Design Decisions

Participants commented that they face difficulties using applications that are built specifically for them such as intervention or education applications. They identify the following challenges when using these applications: too many steps required to complete a task; instructions not written to their level of understanding and user interfaces not designed to their individual preferences. Participants further commented that these challenges probably exist due to the lack of design input from people with ASD when developing these applications. For example, participant P2 said, "*I was told to use this app in my speech therapy which I have no idea how it works, they could have just ask me how I want to use it.*"

Participants found using applications to be difficult when the design did not consider their preferred interaction style and abilities. Despite communication difficulties in other areas, participants actively engaged in the design discussion and were able to provide in-depth details of their preferences and experiences in terms of collaborating in a group. Key statements from the participants are listed in Table 4-7 below.

Participant	Quote
P1	"Now that I know how to design a game, I want my game in my way."
P3	"My favourite colour is blue. I want the font colour to be this."
P5	"I only like to use the applications where I have interest in."
P6	"If I can change the layout, it will look very different and I think I will like it more."

Table 4-7 - Themes related to making design decisions for applications built for them

Participants were also observed to be more motivated to contribute design input towards the end of the pilot study. They commented they felt more confident and interested to design their game after knowing the design process. Participants also expressed interest to make layout changes to their frequently used applications.

4.3.4 Implications for Phase Three

Phase Two findings corroborate with prior reports in the literature that participants with ASD when given the opportunity and equal balance of power, can engage actively in group discussion and contribute to the software design process (Benton et al., 2012; Millen et al., 2014; Wilson et al., 2019). Participants commented that they enjoyed the workshops and found them interesting. Observations showed that participants showed little sign of awkwardness despite their ASD condition in both workshops. Participants were also able to engage in small talk with each other during and after the workshops. Participants also commented that they enjoyed the workshops and found their design if given more time. Nonetheless, some participants initially did not actively engage in the group discussion and took a while to "warm up" to the environment. On reflection, the study could have considered that though the participants were in a familiar environment, there were still variances in terms of engagement methods and type of information exchanged between the computer club and the research workshop. Several participants also preferred to use drawings to illustrate their ideas and message as compared to verbal communication.

Table 4-8 highlights the adaptions made in the design of Phase Three activities based on participant feedback and researcher observation.

No.	Adaptation	Rationale
1	Include break time for small talk	To "warm up" participant and build rapport
2	Use more visual cues and aids in workshops	Participants respond better with visual cues and aids
3	Regular reflection session at the end of every workshop	Help participants better remember the experience for the next workshop

Table 4-8 - Adaptations made to Phase Three

4.4 PHASE THREE - MAIN STUDY



Figure 4-7 - Phase Three timeline

Seven co-design workshops were conducted for over eight months. Six participants – five boys and one girl, participated in the study. Three participants were from the pilot study while the remaining three participants were new to the study. Five participants were recruited at the beginning of the study while the last participant joined from Workshop 3 onwards. Only one participant had prior experience in game design and all participants were diagnosed with Asperger's syndrome (Table 4-9). P5 had prior experience in designing his first 2D game using GameMaker Studio and considers himself a novice (beginner) in game design. Participants were regularly reminded that attendance at workshops was voluntary and they could withdraw at any time if they felt uncomfortable (Table 4-10).

	P4	P5	P6	P7	P8	Р9
Age	16	14	14	15	14	16
Gender	М	М	М	F	М	М
Software design experience	Nil	Game design	Nil	Nil	Nil	Nil
ASD diagnosis		Asperg	ger's synd	rome (DS	M-IV)	

Table 4-9 - Main study participants information

Table 4-10 - Participants attendance for each workshop

	P4	Р5	P6	P7	P8	P9
WS1		\checkmark	\checkmark	\checkmark	\checkmark	
WS2	\checkmark	\checkmark	\checkmark			
WS3	\checkmark	\checkmark	\checkmark			\checkmark
WS4	\checkmark	\checkmark	\checkmark			\checkmark
WS5	\checkmark	\checkmark	\checkmark			\checkmark
WS6	\checkmark	\checkmark	\checkmark			\checkmark
WS7	\checkmark	\checkmark	\checkmark			\checkmark

After the first workshop, the design team determined that there is a need for a safe online platform for participants to communicate and socialise. The researcher and participants used the remaining workshops to co-design the UX of a closed group social platform. Table 4-11 shows the co-design stages and activities for the main study.

Co-design Stage	Activities	Aims
Iteration One		
WS1	Group discussion Sketching Dot voting Reflection	Familiarise with co-design activities Co-design nature of software
Break (1 month)		Researcher develops software
WS2	Group discussion Mind Mapping Sketching Dot voting Reflection	Install software Introduce user testing process
Break (1 month)		Participants test software (field trial)
Iteration two		1
WS3	Group discussion Mind Mapping Sketching Dot voting Reflection	Review key software features Improve UX through interface design
Break (1 month)		Researcher continues to develop software Participants test software (field trial)
WS4	Group discussion Mind Mapping Sketching Dot voting Reflection	Receive software updates
Break (1 month)		Participants test software (field trial)
Iteration Three		
WS5	Group discussion Mind Mapping Sketching Dot voting Reflection	Prepare for software release Review UX through interface design
Break (1 month)		Researcher continues to develop software Participants test software (field trial)
WS6	Group discussion Mind Mapping Sketching Dot voting Reflection	Receive software updates Prepare for software release
Break (1 month)		Participants test software (field trial)
WS7	Group discussion Mind Mapping Reflection	Review co-designers' experiences

Table 4-11 - Summary of co-design activities in the main study

4.4.1 Iteration One

Iteration One had two main goals: (1) determine the nature of the software to be designed and (2) familiarise the participants with co-design methods. Participants were seated at a round table to facilitate discussion. The workshop opened with an ice-breaking session at the start of the workshop. Participants were asked to share two facts about themselves during the ice-breaking session. After this, the participants were introduced to the research topic and their role in the study. From this point onwards, the researcher addressed the group as the design team. Participants were then introduced to the concept of using emotion tags (paper-based emoticons) and drawings to convey ideas and messages during group discussion as shown in Figure 4-8. This approach (include more visual aids and cues) was adopted based on the Phase Two findings and to facilitate sharing emotions non-verbally.



Figure 4-8 - Emotion tags and drawing board

The researcher then conducted a semi-structured group discussion relating to technology and social challenges. Participants were prompted with follow-up questions for them to elaborate on their thoughts and opinions. Table 4-12 shows a list of the questions for Workshop 1.

Theme	Questions
Technology reference	What is a smartphone? Try drawing your current phone. What applications do you have on your devices? Why do you use these applications?
Social challenges	What social challenges do you face in school and at home? Why do you think you have these challenges?

The researcher consolidated the list of challenges and participants were asked to vote for their top three challenges. During Workshop 1, the team decided to design software that could be used on both mobile and wearable (smartwatch) devices. The researcher provided participants with mobile and smartwatch outlines where they drew low-fidelity prototypes and shared their opinions on what they could expect from the software. Workshop 1 ended with a team reflection. Figure 4-9 shows the low-fidelity prototype drawings from the participants. Participants were trying to draw how they expect the menu interface to look like for the mobile and smartwatch applications.



Figure 4-9 - Low-fidelity prototyping

The discussions from workshop 1 were transcribed and analysed using thematic analysis. Patterns and themes were identified as shown in Figure 4-10. The analysed results of Workshop 1 determined the nature of the software and the features required for the first iteration. A collaborative mind map was constructed based on the thematic analysis results while low-fidelity drawings from the participants were used as design references in coding the software. The researcher took a month to develop the first version of the software.



Figure 4-10 - Identifying key themes (Mind map)

The researcher shared key findings from Workshop 1 with the participants using the mind map (visual aid) at the start of Workshop 2. Participants were introduced to the first version of the social communication software (named InterestMe). The software name InterestMe was chosen after a group discussion, participants felt that the name reflects the goal of the software to allow people with the same interest to communicate and share information. The software was then installed onto the participants' mobile devices and smartwatches provided by the researcher. The smartwatch used in this study is a TicWatch E2 running on WearOS platform. Figure 4-11 and 4-12 shows the user interface of InterestMe V1.



Figure 4-11 - InterestMe V1 Smartwatch design



Figure 4-12 - InterestMe V1 Mobile design

Participants were then introduced to the note-taking method for tracking UX issues during software testing (Shore, 2007). In this approach, participants were asked to note down details such as date, time, location, and the task they were performing when they faced any issues with the software. These notes served as a memory aid for

the participants in subsequent workshops. Finally, Workshop 2 ended with a reflection session with the design team. Participants were given a month to perform a field trial on the software and were instructed to use the software at least once a week during the field trial. Table 4-13 shows the software features available on mobile and wearable in InterestMe V1. On average, participants used the software three times a week.

Feature	Mobile	Wearable
Post messages	\checkmark	\checkmark
View posting	\checkmark	\checkmark
Search posting		
Private chat	\checkmark	\checkmark
Manage Groups	\checkmark	
Manage Profile	\checkmark	

Table 4-13 - Iteration One feature list

4.4.2 Iteration Two

Iteration two had two main goals: 1) review key software features and 2) improve UX through interface design. One participant (P9) was new to the study and the Autism Support Group. In workshop 3, the design team used a likes/dislikes comparison table as shown in Figure 4-13 to consolidate their software testing results. Participants were then prompted with follow-up questions for them to elaborate on each point.

Like	
Menu	
proFiel	
chat	

Dislike the white scren GLiching exses APPs

Figure 4-13 - Likes/Dislikes Table

A whiteboard was used by the design team as a common space to discuss UX, interface design, and software changes. Dot-voting was conducted to shortlist and

prioritise five software changes for the next iteration. Table 4-14 shows the list of software changes for this iteration.

Table 4-14 - Iteration two software changes

Features	Mobile	Wearable
Send pictures	\checkmark	
Send voice clip		
View user's status	\checkmark	\checkmark
Add animations	\checkmark	\checkmark
Add tutorials	\checkmark	

Participants were then asked to create low-fidelity prototypes for the requested software changes as shown in Figure 4-14. Workshop 3 ended with a reflection session with the design team.

3G Intere POPYF: (rondi. ub is isout clyb # sa Ad Merrio Sevel

Figure 4-14 - InterestMe V2 low-fi prototype

Participants were introduced to InterestMe V2 in Workshop 4 and the concept of remote software updates. The researcher used remote software updates to push critical software changes to the participants' devices, allowing the participants to test the latest features and changes during the field trial. Similarly, the participants were given a month to perform a field trial on the software. Workshop 4 ended with a reflection session with the design team.

4.4.3 Iteration Three

Iteration Three had two main goals: 1) prepare for software release and 2) review co-designers' experiences. Iteration Three used the same methods as Iteration Two. The design team discussed and reviewed the result of the software testing. Table 4-15 shows the software changes for InterestMe V3.

Features	Mobile	Wearable
Customisation of App interface	\checkmark	
Change menu scroll interface		\checkmark
Change recent stories interface	\checkmark	
Credit co-designers in splash screen	\checkmark	\checkmark
Add sound effect	\checkmark	\checkmark

Table 4-15 - Iteration Three software changes

Participants were introduced to InterestMe V3 in Workshop 6 and discussed the implementation plan to have other adolescents of the Autism Support Group on-board the platform. Figure 4-15 and 4-16 shows the user interface of InterestMe V3.



Figure 4-15 - InterestMe V3 Smartwatch design



Figure 4-16 - InterestMe V3 mobile design

Participants shared and reflected on their experiences as co-designers in the last workshop. Four participants attended Workshop Seven and they were prompted with follow-up questions for them to elaborate on their thoughts and opinions. Participants were also prompted to reflect on the design decisions they made throughout the study.

The findings from Phase Three of the research study are listed in the following sections and describe the co-designers experience in an iterative software design process focusing on community development, software design and UX, social
interaction and social networking, and co-designer experience. Findings were based on the results of the thematic analysis across all the workshops and observations made by the researcher.

4.4.4 Developing Community

In Phase Three, the design team identified three major themes that relate to developing a community: (1) parental support, (2) team membership, and (3) safety. Parental support for the research was evident in this study. Parents/carers were supportive of the study and encouraged their child to participate actively in the workshops. Several of the participants made statements regarding this point (participants P4, P5, P6 and P9). The design team commented during the workshops that their parents reminded them to test the software. The researcher also received positive feedback from participants P4, P5, P9's parents through email exchange and P6's parents through face-to-face communication.

Team membership was displayed throughout the workshops. Participants were excited to see their design ideas adopted in the software. P5 had prior experience in game design and was able to better express himself on technology-related discussion however, the other participants were able to express themselves equally well after Workshop 3. They also acknowledged each other's contributions and were observed to be more proactive and engaged in the study over time. From researcher observations, participants seemed more motivated to complete the software and eager to deploy the software for use by other Autism Support Group members.

Participants shared that they felt safe and comfortable with the researcher, fellow participants, and the activities conducted in the workshops. Observations showed that participants showed no sign of awkwardness despite their ASD condition even in the first workshop. Participants were able to engage in small talk with each other during the workshops. One participant even brought homemade snacks to share with the design team. Based on observations, the computer club facilitated the creation of a safe and familiar environment for the co-design workshops. Participants were familiar with the venue and people through the computer club. Key statements from the participants are listed in Table 4-16 below.

Table 4-16 -	Themes	related	to community	development
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Theme	Participant	Quote
Parental support	P4 P5 P9	"Yeah. My mum sometimes will ask me if I have used the watch today as well." "My dad will sometimes ask me and hey, you should go check if you have any messages on the watch."
		"My mum thinks the workshop will inspire me in my interest in technology."
Toom momborship	P4 P5	"Hey look! My ideas were put in."
Team membership	F.5	"Yeah. We definitely should fix this up, get more users like a community-based."
Safety	P4	"I know you, I know you! I feel safe to say whatever I want here."
	Рб	"I feel comfortable to talk in this group."

4.4.5 User Interface Design and User Experience

Based on the workshops, three major themes were identified that relate to user interface design: (1) interface personalisation, (2) visual attention and (3) software platform. The ability to personalise the software interface was important for the participants. Participants changed their profile picture and status immediately after receiving the software. Participants also suggested having more options to personalise the user interface. Personalisation of the user interface was voted as a software change to be included in Iteration Three.

Participants appeared to be quite sensitive to visual changes in the interface. Participants reported that they experienced better UX after animations were added to the software interface. Rather than moving just once and then stopping as is typical with most designs, the animation would spin repeatedly until the screen was changed. The participants were also observed to be delighted with the repetitive nature of animated graphics in the software. One of the participants commented that he enjoys watching the animated graphics. Figure 4-17 shows the animated icons.



Figure 4-17 - Use of animation

Participants preferred to use the mobile app as opposed to the smartwatch option. Participants reported that they experienced poor UX with the smartwatch. None of the participants owned a smartwatch; however, they had a basic understanding of how a smartwatch functions and were excited to use a smartwatch for the study. Nonetheless, the process of pairing the smartwatch with the mobile device is complicated and many of the participants faced difficulty in navigating around the smartwatch interface. Despite the novelty of having a smartwatch, participants still preferred to use the software on the mobile most of the time. Key statements from the participants are listed in Table 4-17 below.

Theme	Participant	Quote
Customisation	P4	<i>"I still think adding wallpaper should be in the app."</i>
	Р5	"What I mean is that, what we could do is that we change these colours and if we can't read the text then we can go in the settings and change the text colour."
Software platform	P4	"Yes, it is actually easier for me to use the mobile."
	Р5	"I don't like all the excess apps."
	Р9	"I get lost in all these menus. I don't get connection sometimes and I am not sure why."

Table 4-17 - User interface design and user experience

4.4.6 Social Interaction, Media and Networking Sites

Three major themes emerged from the research that relate to the use of social interaction, media and networking sites: 1) social interaction challenges; 2) impression of social networking sites; and 3) content censorship were identified in this study. Participants agreed that they faced challenges in socialising with people and came up with a list of social challenges. The group did a vote in Workshop 1 to determine the top three social challenges. The results show that finding people with a common interest (5 votes) and talking to people (4 votes) were the key challenges faced by the participants. A group discussion was then conducted for participants to brainstorm solutions that may improve or solve the two challenges. Participants identified that they wanted to stay connected with fellow group members and needed a safe platform for social communication. A social communication platform for the support group was developed in this study to assist participants to improve on these two areas. The results of the voting is shown in Table 4-18.

	0		DC	D7	DO
Theme	P4	P5	P6	Ρ/	P8
Find people with a common interest	\checkmark	\checkmark	\checkmark		\checkmark
Talking to people	\checkmark	\checkmark		\checkmark	\checkmark
Forming groups	\checkmark				\checkmark
Ability to watch videos on any devices		\checkmark	\checkmark		
Being interrupted			\checkmark		
Prevent Misunderstanding				\checkmark	

Table 4-18 - Voting of challenges

Participants did not report any challenges in face-to-face interaction with fellow participants during the workshops. Despite their ASD condition, participants were able to create and share design artefacts as well as participate in group discussions with the other members of the team.

Participants expressed scepticism about social networking sites and had a negative impression of popular social networking sites like Facebook. Participants reported that comments on Facebook are "rude" and "mean" and expressed that social networking sites should be more regulated. Content censorship was also suggested as one of the software requirements for the InterestMe app. Interestingly, all participants used social media platforms to obtain information but rarely participated in content creation. Key statements from the participants are listed in Table 4-19.

Theme	Participant	Quote
Impressions of social networking sites	P4	"Facebook is mean. I don't really have much privacy. I don't do much social media in the sense like Facebook."
	Р5	<i>"Facebook is less regulated and has rude people at the moment."</i>
Regulating social content	P4	"Yeah. Build an AI that takes out bad words. Recognise the F word and censor it to a dotsomething. Then we can be in a safe place."
	Р5	"Maybe we can have sort of censorship. Maybe with dots or hashtag. I think that is an important to add before we go on a wider scale."
Social media	P4	"I like watching videos. I watch more YouTube stuff than TV stuffs. When I see something interesting on Pinterest. I will save it."
	Рб	<i>"I learned most of the things from YouTube."</i>

Table 4-19 - Themes related to social media and networking sites

4.4.7 Co-designers: Making Better Design Decisions

Two major themes that relate to the co-designer experience: 1) technology reference; and 2) software design experience were identified in this study. Participants became more aware of the impact of their design decisions after each iteration. The participants framed requirements and made design artefacts in the first iteration based on their technology reference. Their technology reference was mostly based on prior knowledge obtained through existing applications on their devices. In the first iteration, participants suggested the feature to share video, particularly YouTube videos through the software. Participants also suggested features like "Likes" and "Followers" which are features found on Pinterest. The design team voted and

implemented these features, however, some of these features have low to zero usage as the software moved into Iteration Three. This is consistent with design literature that suggests that people make design decisions based on their prior experience with software and technology (Bossavit & Parsons, 2016; Halskov & Hansen, 2015; Steen, 2013).

Most participants did not have prior software design experience. Participants 4, 5 and 9 commented that they learned how software is designed and distributed over content stores like Google Play Store through the study. They also commented that they enjoyed the experience and felt that they would be able to contribute more to the co-design activities through the self-reflection process in each iteration. Participants also commented that they felt more confident to participate in the co-design activities after Iteration One. A sample of feedback from the participants is listed in Table 4-20.

Theme	Participant	Quote
Technology	P4	"I have drawing app, I have Minecraft, I
reference		have YouTube. I got Pinterest."
	P5	I guess I prefer to share pictures more than
	10	YouTube videos"
	P8	"What it could amaze me the most if you can watch any YouTube video on your watch."
Software design	P4	"I am sure if we do this again, I have a
experience		better idea of what I am doing"
	P5	"I learned how mobile and smartwatch software are made"
		software are made

Table 4-20 - Software design inputs

4.5 CONCLUDING REMARKS

The goal of this chapter was to describe the implementation and findings of the study following the methodology described in chapter 3. In addition, this chapter also provides a summary of findings from the respective phases. Three main themes emerged from Phase One investigation: integration to current practices, motivations to develop technologies and the need to engage stakeholders. Three main themes emerged from Phase Two investigation: strong interest in gadgets and technology,

unique perspective in UX and the need to make design decisions. Finally, four main themes emerged from Phase Three investigation: developing community, user interface design and UX, social interaction, media and networking sites and making better design decisions as co-designers. The goal of Chapter 5 is to discuss the study results with the identified themes and their implications for co-design with people with ASD.

The contents of chapter 5 have been published in:

- Phase Two Zhu, R., Hardy, D., & Myers, T. (2018). Building Applications that Matter: Co-designing with Adolescents with Autism Spectrum Disorder. In International Conference on Health Information Science (pp. 167-174). Springer, Cham.
- Phase Three Zhu, R., Hardy, D., & Myers, T. (2019). Co-designing with Adolescents with Autism Spectrum Disorder: From Ideation to Implementation. In Proceedings of the 31st Australian Conference on Human-Computer-Interaction (pp. 106-116). and Community-led Approach to Co-design a Social Networking Platform with Adolescents with Autism Spectrum Disorder. Under review with

The Journal of Autism and Developmental Disorders

5.1 CHAPTER OVERVIEW

The findings from chapter 4 demonstrated that adolescents with ASD can act as co-designers and provide valuable contributions in an iterative software design process. This final chapter discusses the significance of these research findings and their practical implications. The prototype design and software developed as part of the thesis project are discussed and presented as the major contributions of this research. Section 5.2 provides a research overview that outlines the study's objective and research questions; sections 5.3 to 5.6 discuss the four main facets identified from the categories in relation to the research objectives; section 5.7 outlines the contribution of this study to existing knowledge and practice; section 5.8 outlines the limitations and possible directions of future study; section 5.9 describes a reflection on the researcher's experience with the research; section 5.10 describes the implications of the study and provide recommendations to existing practices, finally section 5.11 concludes the thesis regarding co-designing software with people with ASD.

5.2 OVERVIEW OF RESEARCH OBJECTIVES AND QUESTIONS

Adolescents with ASD have a unique perspective in using technology-based solutions and off-the-shelf solutions may result in poor UX. Previous ASD co-design research has shown promising results in engaging adolescents with ASD as co-designers and improving the UX of the developed product. However, prior studies only involved people with ASD in the early phase of software development and over a short

period. The software design process requires an extended period of time and design goes through multiple iterations. By iterating the software design process, software designers would be able to make incremental changes to improve product UX and functionality. The motivation for this research arises from the need for exploring ways to involve adolescents with ASD in an extended iterative software design process to derive software that is better suited to their individual preferences and interaction style. The design considerations and interaction style derived from this project may suit other people with ASD who share similar traits and concerns with the co-designers. In addition, the research also investigates the use of co-design to understand the lived experience of adolescents with ASD. The questions posed at the beginning of this research were:

Q1. How can adolescents with ASD be engaged as co-designers in an iterative software design process?

Q2. How can a longitudinal co-design study be used to understand the lived experience of adolescents with ASD?

The following objectives were defined to answer these questions.

O1. Understand the diverse motivations, challenges and qualities of a local ASD community through in-depth interactions and observations.

O2. Understand the challenges adolescents with ASD faced in using technologybased solutions through conducting collaborative discussions.

O3. Explore challenges and ways to engage adolescents with ASD in existing co-design methods.

O4. Understand the unique role of various stakeholders when engaging adolescents with ASD as co-designers in an iterative software design process.

O5. Explore and co-design software to facilitate social engagement and communications with the local ASD community.

The overall research methodology was split into three phases with key principles of shared outcomes and community immersion from PAR adopted as overarching principles in a co-design framework. Phase One involved an ethnographic contextual investigation of different stakeholders such as people with ASD, their parents/carers, and a local ASD support group. In Phase Two, a co-design study was conducted to explore ways to engage adolescents with ASD as co-designers in the early phases of the software design process. In the final phase, a co-design study was conducted to investigate design and community implications when engaging adolescents with ASD as co-designers in an iterative software design process. This approach allowed for: a deeper understanding of the experiences of adolescents with ASD as co-designers, provided a way to develop theory from the data to understand how adolescents with ASD can be engaged as co-designers in an extended iterative software design process, and how this process can be used to understand their lived experience.

Based on Chapter 4 results, four main facets in relation to the research objectives were identified: 1) integrating into the community; 2) exploring technological usability challenges; 3) co-designing with adolescents with ASD; and 4) social networking for the community. The following sections discuss each facet in detail, relating the findings to existing literature and how these findings corroborate and extend existing works.

5.3 INTEGRATING INTO THE COMMUNITY

O1. Understand the diverse motivations, challenges and qualities of a local ASD community through in-depth interactions and observations.

In this study, the researcher immersed himself into the ASD community by joining the North Queensland Autism Support Group (NQASG). This approach allowed the researcher to observe cultural insights and group practices of the Autism Support Group. This activity also established positive rapport and relationships with the participants, parents/carers and committee members of the support group.

Findings from this study corroborate prior findings that researcher integration into the community plays a vital role in successful community-based research. Direct involvement between the researcher and the community can align shared goals and outcomes between the researcher and the community (Shamrova & Cummings, 2017). A study on school-based social skills program with children with ASD suggests that this process helps to promote stakeholder buy-in as the process directly addresses their goals and needs (Ostmeyer & Scarpa, 2012). One ASD trait is the lack of social skills and parents/carers offer support and encouragement for their child to engage in social interaction. The common goal established with all stakeholders in this study was to provide a platform where adolescents with ASD can interact and socialise. Initiatives and support from the parents/carers and the Autism Support Group were evident in this study. The Autism Support Group provided support in participant recruitment and provided a familiar venue for the co-design workshops while parents/carers encouraged their child to partake in the workshops and motivated them throughout the study.

This study also found that a familiar venue allows adolescents with ASD to feel safe and comfortable while participating in the study. The establishment of the computer club provided the opportunity for potential participants to interact and exchange ideas. A similar study conducted by Rizzo et al. (2012) suggests that social connections can be forged among people with ASD through common technological interests. They set up "The Lab" which is a standalone technology-enabled 'learning community' for young people with ASD. However, Rizzo et al. (2012) adopted a slightly different approach than the research reported in this thesis. The computer club is an activity of the North Queensland Autism Support Group instead of a standalone project. The setup of the computer club such as duration, venue, and timing were considered with the insights acquired through participant observation and advice from the Autism Support Group.

Participant observation in the community immersion also revealed that parents/carers maintain a routine for their children, as adolescents with ASD often prefer activities with a fixed venue and timing. Many parents/carers commented that having a daily routine can help to alleviate their child's anxiety and reduce meltdown occurrences. This finding corroborates with current literature that people with ASD prefer fixed routines and routines are commonly adopted in teaching and learning ASD strategy (Kashinath, Woods, & Goldstein, 2006; Larson, 2006). Both the computer club sessions and the co-design workshops were conducted at a regular date, time and venue. This setup allowed parents/carers to include these activities into their child's routine and aid in keeping regular attendance. This study suggests that the practice of keeping a regular activity venue can lower the participants' anxiety levels. Participants were observed to be comfortable with the activity venue and commented in their workshop reflection that the familiar venue helps with keeping their anxiety level low. Participants were able to engage in the co-design activities at the start of the workshop as they were comfortable with the venue.

Integrating into the community provided the researcher insights into the diverse motivations, challenges, and qualities of a local ASD community. In addition, this approach is commonly adopted in PAR with a focus to situate power within the research process with those who are most affected by a program (Chevalier & Buckles, 2019). With the common outcomes and goals established with all stakeholders, this study was driven by the community which includes the NQASG, parents/carers, participants, and the researcher.

5.4 EXPLORING TECHNOLOGICAL USABILITY CHALLENGES

O2. Understand the challenges adolescents with ASD faced in using technology-based solutions through conducting collaborative discussions.

Designing applications for people with special needs has presented a challenge in terms of application usability and usefulness (Frauenberger et al., 2011). Nonetheless, there is an increased interest in the use of technology for people with ASD with the increase in ASD diagnosis in the general population and the recognition of people with ASD users may have an affinity with computers (Brown & Murray, 2001; Grynszpan, Weiss, Perez-Diaz, & Gal, 2014). The findings from this study corroborate with existing literature that adolescents with ASD are technology savvy users and in most cases and they prefer to use technology in their daily lives. Due to their ASD challenges, people experience an application differently from their peers, and in some cases, the inability to perform a task on an application could lead to user frustration and technology abandonment (Corlu, Tasel, Turan, Gatos, & Yantaç, 2017). A study conducted by Benssassi et al. (2018) suggests that there has been an increase in the development of touch-based applications designed for ASD users. The study also highlighted that the use of touch-based applications is attractive and easy for most ASD users. However, some ASD users may have motor skills and cognitive limitations that make touch-based applications less usable (for example mouse movements).

People with ASD may not have the means or ability to explicitly describe or give feedback on their user experience to the designers of applications, even when they are required to use them in everyday life. This group of users are often locked out of the software design process by the lack of involvement in the design decisions and are often forced to accept applications that do not consider their challenges (Malinverni et al., 2014). Participants in this study commented on the lack of input from people with ASD in applications that target them as users and their desire to be included in the design process. As such, they found using applications to be difficult when the design does not consider their preferred interaction style and abilities. They faced further frustration in using applications that are built specifically for them such as intervention or education applications. Participant's comments suggest that these applications which target them as users were designed for a general ASD population but not for particular user preferences.

People with ASD have a unique perspective that may differ from the assumptions of software designers. As such, an inclusive approach in designing technology for people with ASDs can improve the usability of the solution (Porayska-Pomsta et al., 2012). Adapted co-design methods can be used to support the potential difficulties for participants with ASD by using visual and concrete examples to initiate and prompt ideas rather than relying on abstract concepts for discussions (Benton et al., 2012; Bossavit & Parsons, 2016; Nastasi et al., 1998).

This study further demonstrates that participants with ASD can engage actively in group discussions and contribute to the software design process when given the opportunity and an equal balance of power. Evidence from the pilot and main studies suggests that the use of co-design in software design is an approach with great potential for people with ASD. Furthermore, the findings from this study also corroborate with prior studies that there is a need for customisable solutions. Researchers and software designers should focus on the importance of developing applications for the real world and not only for controlled environments (Koumpouros & Kafazis, 2019).

The findings from this study provide insights regarding the challenges faced by adolescents with ASD in using technology. These findings corroborate with prior studies which suggest that people with ASD continue to face usability challenges with the software even when it is designed with them in mind. For example, participants reported that they were unable to fully understand how to use or react to some of the software used in their intervention therapies. The usability challenges faced by people with ASD may have a greater impact with the rise of technology-based intervention and education tools. Participants in this study reported that they wished to be included in the design process for application made for them and an inclusive approach may address or improve on the usability of the solution.

5.5 CO-DESIGNING WITH ADOLESCENTS WITH ASD

O3. Explore challenges and ways to engage adolescents with ASD in existing co-design methods.

O4. Understand the unique role of various stakeholders when engaging adolescents with ASD as co-designers in an iterative software design process.

5.5.1 Designers as Learners

Co-design methods support the gaining of new knowledge in each cycle. The design team gained new insights from every workshop and interaction. While typical co-design studies start with a specified topic and goal for design (i.e. build a game for learning activities), this study adopted an open-ended approach where participants explored their needs which then determined the goal of the software. In this approach, the researcher provided an opportunity for the participants to scope the software themselves that aimed to solve or improve one of their existing challenges.

Participants became more aware of the effects of their design decisions after each iteration. The iterative process in the co-design approach allowed the researcher and participants to make fine-grained adjustments to the application functionalities and interface design (Steen, 2013). Participants framed requirements and made design artefacts in the first iteration based on their technology reference, mostly based on prior knowledge obtained through existing applications on their devices. As inexperienced software designers, some of the participants' design choices were not technologically feasible in the long-run, but they were able to learn and understand the impact of their design decisions through the self-reflection process in each iteration. The iterative process allowed the participants to learn and understand their needs and interests while the co-design methods provided a platform for them to express their views about design changes. This learning process goes some way to counter a critique of novice designer involvement in software design, as a primary contribution made by the design team in this study was the insight into the lived experiences and motivations of youth with ASD. Bell and Davis (2016) conducted a similar co-design study with adolescents to design a digital badge system. Their study highlighted the learning opportunities for the participants through scaffolded reflection. The study reported in this thesis extends the notion that adolescents with ASD can experience the same learning opportunities through an iterative process.

This study also found that participants prefer to use the software on the mobile as compared to on a smartwatch for intricate tasks. People with ASD may have motor skills limitations and may face difficulties in using touch-based devices (Benssassi et al., 2018). Participants in this study displayed strong enthusiasm in designing and using smartwatch software; however, they prefer to use the software on mobile after the software is developed. A smartwatch may provide a less intrusive approach in performing a software task as compared to mobile devices however participants faced difficulty in navigating the small screen. The current set up for smartwatches was also too complex for the participants. Participants were observed to use mobile software most of the time due to a perceived better UX.

In terms of UX, we also found that participants were sensitive to visual changes and experienced better UX with the introduction of animated graphics in the software interface. One ASD trait is restricted interest and behaviours, and so the ability to customise the software font size, font colour, and wallpaper provided an opportunity for the adolescents with ASD to change the software interface to their liking.

5.5.2 Conducive Co-design Environment

A safe and familiar environment encourages adolescents with ASD to continue participation in a co-design study. The study findings corroborate with prior findings in the literature that the research environment plays a vital role in conducting research with participants with an ASD diagnosis (Carrington et al., 2017; Cridland et al., 2015; Odom et al., 2015; Xin & Leonard, 2015). Benton et al. (2012) proposed the Interface Design Experience for the Autistic Spectrum (IDEAS) method that attempts to adapt co-design methods to support the potential difficulties for participants with ASD. In that study, the author highlighted the importance of having an 'ideal' co-design environment to suit children with ASD. This ideal "environment" included support from the: 1) community group; 2) parents/carers; and 3) design team (Benton et al. (2012). In the research reported in this thesis, the researcher was immersed in the ASD community by joining the North Queensland Autism Support Group, which gave access to community, cultural insights, and shared goals. The Autism Support Group provided the workshop venue and access to the local autism community. Having a familiar venue allowed adolescents with ASD to feel safe and comfortable while participating in the study. Though the Autism Support Group was not directly involved

in the co-design workshops, the researcher provided regular updates to the group in committee meetings.

Parents/carers also played an important role in this study through support, encouragement and advice for the participants. Through the computer club, parents/carers had the opportunity to interact with the researcher and were able to establish a positive relationship with the researcher prior to and throughout the study via regular email updates. Findings from this study show that parents/carers were very supportive of the study and constantly reminded participants to attend the workshops or review the software during field trials of the designed software and device.

The establishment of the computer club provided the opportunity for potential participants to interact and exchange ideas before the study. Most of the participants have attended the computer club before the first workshop. These regular meetings created a team membership between the participants. They showed no sign of awkwardness and were able to engage in casual talk during the workshops. Participants enjoyed attending the workshop because of the companionship of fellow participants. This sense of belonging was also displayed when one of the participants initiated and brought snacks to share with fellow participants.

Notably, however, having a conducive co-design environment does not guarantee participants' attendance. Two participants who had participated in previous computer club meetups did not continue with the study after the first workshop. Their parents informed the researcher that their child wanted to stay out of all group activities other than NQASG activities for a period. The researcher understands from the parents that self-initiated social isolation is common with people with ASD.

5.5.3 Self-advocacy

Co-design methods allow the researcher and participants to unearth tacit knowledge and examine the impact of their design decisions. Study findings corroborate with prior findings that adolescents with ASD can collaborate and contribute as co-designers in a software design implementation. In addition, study findings suggest that participants demonstrate an increase in self-advocacy skills in an iterative software design process.

Self-advocacy is the ability to understand one's own needs and effectively communicate those needs to others (Brinckerhoff, 1994). Though participants showed

no sign of awkwardness despite their ASD condition in the first workshop and were able to engage in small talk with each other, they seldom commented or expressed their views on other participant's input during the first iteration. Participants reported in their reflection of Workshop 1 that they were unsure of their own needs despite the use of visual and concrete examples in the co-design activities. However, they also reported that they felt more aware of their roles and needs after the first field trial as they were able to experience the software as a user.

Participants were observed to be less engaged in the co-design activities in the first iteration as these activities were mostly guided by the researcher and were unfamiliar to the adolescents. Participants reported in the Workshop 2 reflection that they were not familiar with co-design activities and were unsure of how to express their views and opinions. However, participants subsequently reported in workshop 4 reflections that they were now familiar with the co-design activities and the design team members and felt comfortable and confident in leading some of the activities or making a debate with fellow team members. The researcher also observed more active discussion and debate among the participants in Iteration Two and Iteration Three.

5.6 SOCIAL NETWORKING FOR THE COMMUNITY

O5. Explore and co-design software to facilitate social engagement and communications with the local ASD community.

This study's findings corroborate prior findings that adolescents with ASD continue to face social challenges in their daily lives (Cooper et al., 2017; Laugeson & Ellingsen, 2014; Mazurek, 2013; Orsmond et al., 2013). Due to their ASD condition, adolescents with ASD face difficulty in finding friends with similar interests. Though our participants are active consumers of social media sites like YouTube and Pinterest, they do not participate or engage in online interaction.

The findings also suggest that participants avoid popular social networking sites such as Facebook. Participants reported that postings and comments on Facebook were "rude" and lacked social etiquette. Participants in this study reported not feeling safe to communicate, share and socialise under this perceived harsh environment. A study by Carrington et al. (2017) suggests the number of adolescents with ASD on online social networking sites are decreasing due to the risk of being cyberbullied. In addition, parents/carers are also generally cautious with social networking sites due to potential problems with cyberbullying and inappropriate content (O'Keeffe & Clarke-Pearson, 2011).

Social networking sites provide a platform for people to support communication and maintain relationships with family and friends. Most adults with ASD uses some form of social networking sites (Mazurek, 2013). However, findings from this study suggest adolescents with ASD do not actively participate in social networking sites. This difference in findings is worth investigating in future studies. A safe localised social networking platform may provide an opportunity for adolescents with ASD to gain confidence and encourage healthy use of social networking. In this study, a localised closed group platform ensured that the participants were safe to express themselves freely over the platform and with familiar people. Stakeholders play a key role in supporting the participants to socialise and interact on social networking platforms. Parents/carers are generally cautious with social networking sites due to potential problems with cyberbullying and inappropriate content (O'Keeffe & Clarke-Pearson, 2011). In this study, parents encouraged their child to make use of the project's social communication platform because they were familiar with all the members on the platform and understood that the content on the platform was regulated and closed to outsiders. An inclusive approach to include parents/carers in the design or implementation process of a closed group social networking platform may alleviate their concerns.

5.7 OUTCOMES AND CONTRIBUTIONS

This study contributes to existing co-design and ASD literature and demonstrated how adolescents with ASD can be engaged as co-designers and contribute to an iterative software design process. The framework and methods used in this study provide a structured approach for researchers to engage adolescents with ASD for research through a support group. The ethnographic study provided insights into the implications of group culture and practices have on the co-design process. In addition, this study presents a novel approach to understand the lived experience of adolescents with ASD through the co-design process. Through the co-design project, adolescents with ASD provided detailed accounts of their lived experiences and the challenges they faced.

This study has also created sustainable actions that can improve the lives of stakeholders through the computer club and the development of the closed-group social networking platform for the Autism Support Group. This outcome is a tangible emancipatory benefit of the PAR process. The computer club continues to provide NQASG members with a platform to interact and socialise with each other through the common interest in technology. Parents have commented that their child enjoyed the computer club sessions and established positive friendships with fellow participants. Though the study has been completed in March 2019, the computer club continues to function and is now an integral NQASG activity. NQASG has since adopted the social networking platform and is in the process of extending the platform to all its members. All the digital assets of the developed prototype have been made publicly available through GitHub.

5.8 LIMITATIONS OF STUDY

Results from this study add to the limited but growing body of evidence supporting co-designing software with adolescents with ASD. However, the philosophical stance of this research lies in constructivism where the results and findings are a subjective reality that is socially constructed by the researcher and participant. However, the changes that occurred in the research and how these changes affected the research were well documented in this thesis. Due to the subjective constructionist nature of the research exact results might not be replicated with a different group since no two people have the same experience and understand the world in the same way. The presence of an Autism Support Group has been long established and played a pivotal role in this study, nonetheless, the other adolescents with ASD may not have similar experience under a support group. In addition, this study is limited due to the number of participants in the study and with only participants diagnosed with Asperger's (DSM-IV).

The approach of this study was designed to integrate and conduct a longitudinal co-design software process through an existing support platform such as an Autism Support Group. In other words, the presence of the Autism Support Group is crucial to this study.

5.9 REFLEXIVITY

Reflexivity is a vital element in qualitative research as the researcher addresses his/her subjectivity in relation to the people and events that they encounter throughout the process as the actions occur (Primeau, 2003). In addition, reflexivity extends the understanding that the position and interest of the researcher play in role in driving the research process and influencing the results. This action can be contrasted with reflection that occurs after actions have taken place.

Prior to the research, I acknowledged that I had limited knowledge and experience with people with ASD. Though I was trained to manage students with special needs, including those with ASD, the training was targeted specifically for tertiary students and focused on academic and classroom management. Moreover, I was new to Townville and the people here. I had my doubts and reservations before starting the research however, I do believe that technology is an enabler and can be used to enhance a person's life. This research had three phases. Phase One involved contextual investigations of different stakeholders such as people with ASD, their parents/carers, and a local ASD support group. I started Phase One with the aim to learn from the community through volunteering and observations. I thought it would be challenging to assimilate into the community however, the community welcomed my presence and was extremely willing to share their experiences and practices. The NQASG committee shared that there was little research collaboration effort with the group and this was the first time a researcher was willing to engage and partake in support group activities. They also commented that they valued my contributions through the research and community services to the group multiple times throughout the research. On reflection, Phase One played a critical role in setting up the subsequent phases. I gained practical experience and built positive relationships with the support group and group members with ASD. I was confident in running the remaining two phases and I felt that the community was with me in driving the research instead of a one-sided affair.

In Phase Two, a co-design study was conducted to explore ways to engage adolescents with ASD as co-designers in early the phases of the software design process. Phase Two involved having the participants to co-design a game. I assumed that participants would be designing games that were of high fidelity; games that were in high graphics or require complex controls similar to console-like experience. However, this thought was quickly diminished after a group discussion where participants suggested more cartoonish or simple game design. On reflection, the research direction would have taken another direction with my personal biases if I had predetermined the genre of game instead ideating the nature of the game with the participants.

In the final phase, an extended co-design study was conducted to investigate design and community implications when engaging adolescents with ASD as co-designers in an iterative software design process. Participants from Phase Two commented that they enjoyed the session and I assumed that all participants from Phase Two would continue with Phase Three. However, three participants from Phase Two decided not to continue with Phase Three. Though three more new participants were recruited at the start of Phase Three, two of the new participants decided not to continue after workshop 1. I assumed that there could be a trigger in the workshop set up that prompted the participants to drop out of the study and attempted to adjust the workshop set up. However, parents explained that self-initiated social isolation is common with people with ASD and there may not be any reasons. Furthermore, all remaining participants reported that they were comfortable and enjoyed the workshops. On reflection, I may have overreacted to the situation due to my lack of experience with ASD participants. Fortunately, parents and remaining participants assured me that the workshop set up was not of concern.

Participants were observed to be more interested in improving UX of other applications or products in their daily lives as they progressed into the study. The transfer of knowledge could have shifted the participants thinking and thus, they gained a greater awareness of the design decision made by others. Participants were also observed to have more social interaction in the workshops over the course of the study. Participants would engage in small talks about the latest movie or share what they did over the week. The use of co-design methods could have promoted and encouraged participants to engage with one another. Participants may also have developed positive friendships with each other over the study.

5.10 RECOMMENDATIONS

This study has demonstrated that adolescents with ASD can interact and engage as co-designers in an extended software design process. With the rise in technologybased solutions, this approach to improve users UX through co-design has scope for other domains of the health and disability sectors. In addition, co-design process provides an opportunity to understand the lived experience of adolescents with ASD. A co-design approach with PAR' overarching principles enabled exposure of the rich lived experiences of ASD participants, parent/carers, and the community, the meanings assigned to the interactions, and the interpretations of those meanings by the researcher. Additionally, PAR combined with co-design may promote self-advocacy skills and serve as a platform for social engagement.

5.10.1 Policy

The National Disability Insurance Scheme (NDIS) is a social policy implemented to provide support for Australians with a disability, their families, and carers. The purpose of the scheme is to enable people with disabilities to: access mainstream services and supports, access community services and supports, maintain informal support arrangements, and receive reasonable and necessary funded supports (National Disability Insurance Scheme, 2020). NDIS provides people with ASD support for therapies and interventions based on their ASD deficits however, people with ASD do not receive support or information about support groups in their community. The impact and importance of the role that a support group can play in the ASD community should be highlighted by ASD researchers and policymakers. As identified by the researcher and parents/carers in the study, support groups could be a valuable resource for people with ASD and their families as sources of informational and emotional support which were critical to well-being. In addition, a contextual inquiry through an ASD support group may provide a snapshot of the lived experience and challenges that the ASD community faces. NDIS's goal is to provide support to people with disabilities to strengthen their health and wellbeing and to develop their capacity to actively take part in the community. Collaborating with support groups may improve the general wellbeing of the people with ASD and their families.

5.10.2 Practice

The findings of the study indicate that adolescents with ASD can act as codesigners and engaging them as co-designers in software design can increase an application's usefulness and usability. Organisations developing therapies, intervention, or education software for people with ASD could explore the approach of engaging people with ASD as co-designers in the design process. This approach has the potential to design software that would suit their needs, capacities, and unique perspective. Community immersion can allow software designers to understand the challenges faced by the target population. Furthermore, community immersion can build trust and positive relationships with potential participants which could improve engagement in the co-design process.

Though there is an increasing call to adopt User-Centred Design approach in software design, many software designers face challenges in adopting these approaches when designing for groups with special needs. Both community immersion and co-design approaches require significant time investment and proficiency of researcher/designer to carry out the activities. Organisations may not have the resources to invest in long hours of community immersion prior to the design phase. In addition, organisations may not have trained designers that could adapt co-design methods to suit the capabilities and needs of people with ASD. Organisations developing software for people with ASD can consider partnering with existing community groups such as support groups or schools in co-designing the software. Codesign methods and principles can be shared with personnel from the community groups and they will conduct the co-design workshops with the target users. Extensive community immersion would not be required in this approach since personnel from the community group would be familiar with the culture and design practices of the group and with potential participants. This approach could shorten the development time and is more scalable as multiple personnel from different groups can be trained with the co-design methods and principles at the same time.

5.10.3 Future Work

Future work of a similar study on a larger scale to investigate a wider depth of opinions is needed to further support the geralisability of these findings. Besides, this study can be extended to investigate the UX and adoption of the co-designed social platform on the sider population of adolescents with ASD. A possible direction for future research would be to investigate if a similar approach can be conducted with Disability Service Organizations (DSO). Expanding the research in this manner would be useful to determine if DSO could fill in the role of an Autism Support Group in providing the 'ideal' co-design environment.

A future collaboration that involves people with different cognitive and sensory abilities may find the insights from this research useful. Such a project could propose new viewpoints and methods. For example, a person with Attention Deficit Hyperactivity Disorder (ADHD) may have different needs and wants regarding technologies and his/ her circumstances may inspire a different genre of designs. New co-design engagement methods could surface from such a collaboration.

5.11 CONCLUSIONS

Wearables, mobile technologies and enhanced communication and computing capabilities have led to the upsurge of innovative mobile applications. Many research efforts have taken place recently in the domain of ASD. However, without an inclusive approach to design these applications, people with ASD can struggle with UX due to their unique perspective. Custom application design approaches should partner with users and communities to increase application acceptance, improve useable features, and create enjoyable interfaces. This thesis has shown that adolescents with ASD can be engaged as co-designers in a software design process. Furthermore, participants expect to be included in the software design process, especially in applications that were made specifically for them as an individual. Researchers or software designers will not only need to consider what technologies can do but what users need or prefer and how technologies can better serve that purpose.

Methods like community immersion can complement a co-design study and an iterative process allows knowledge transfer within the design team to make better design decisions. Co-design participants learned through experience and became more aware of the effects of their design decision after each iteration. The setup of a safe and comfortable environment can promote an interesting, enjoyable, and engaging co-design experience. Moreover, these factors may also promote participants' self-advocacy skills over the course of an iterative software design process. Co-design methods such as group discussion and reflection allow adolescents with ASD to share their lived experiences. Participants with ASD often prefer a routine, predictable timetable, and as such, workshops are set up at a time and place where the participants have their usual group activities.

Finally, social networking sites provide a platform for people with ASD to communicate and socialise with family and friends. However, many people with ASD and their parents/carers are avoiding social networking sites due to the potential risk of cyberbullying and inappropriate content. A local community such as an Autism

Support Group may provide a familiar and regulated social networking site for people with ASD. The development of a community-led social networking platform for adolescents with ASD may encourage the healthy use of social networking in a safe space.

References

- Abras, C., Maloney-Krichmar, D., & Preece, J. (2004). User-centered design. Bainbridge, W. Encyclopedia of Human-Computer Interaction. Thousand Oaks: Sage Publications, 37(4), 445-456.
- Alarcon-Licona, S., Loke, L., & Ahmadpour, N. (2018). From autism educators to game designers: integrating teaching strategies into game design for autism education support. Paper presented at the Proceedings of the 30th Australian Conference on Computer-Human Interaction.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (DSM-5®). In *Book Diagnostic and statistical manual of mental disorders (DSM-5*®): American Psychiatric Pub.
- Anderson, R. J. (1994). Representations and requirements: the value of ethnography in system design. *Human-computer interaction*, 9(2), 151-182.
- Antaki, C., Billig, M., Edwards, D., & Potter, J. (2003). Discourse analysis means doing analysis: A critique of six analytic shortcomings.
- Asperger, H. (1944). Die "Autistischen Psychopathen" im Kindesalter. Archiv für Psychiatrie und Nervenkrankheiten, 117(1), 76-136. doi:10.1007/bf01837709
- Attwood, T. (1997). Asperger's syndrome: A guide for parents and professionals. In *Book Asperger's syndrome: A guide for parents and professionals*: Jessica Kingsley Publishers.
- Australian Bureau of Statistics. (2019). Australian Bureau of Statistics. Disability, Ageing and Carers, Australia: Summary of Findings, 2019 (catalogue no. 443.0), Canberra: Commonwealth of Australia.
- Avison, D. E., Lau, F., Myers, M. D., & Nielsen, P. A. (1999). Action research. *Communications of the ACM*, 42(1), 94-97.
- Baio, J. (2014). Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators; Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. MMWR Surveill Summ, 63(2), 1-21.
- Balaji, S., & Murugaiyan, M. S. (2012). Waterfall vs. V-Model vs. Agile: A comparative study on SDLC. *International Journal of Information Technology* and Business Management, 2(1), 26-30.
- Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups*, 33(1), 69-83.
- Baskerville, R. L. (1999). Investigating information systems with action research. *Communications of the AIS*, 2(3es), 4.
- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal* of Epidemiology & Community Health, 60(10), 854-857.
- Bauminger, N., & Kasari, C. (2000). Loneliness and Friendship in High-Functioning Children with Autism. *Child Development*, 71(2), 447-456. doi:10.1111/1467-8624.00156
- Beckman, S. L., & Barry, M. (2007). Innovation as a learning process: Embedding design thinking. *California management review*, 50(1), 25-56.

- Bell, A., & Davis, K. (2016). *Learning through participatory design: designing digital badges for and with teens.* Paper presented at the Proceedings of the The 15th International Conference on Interaction Design and Children.
- Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39(2), 350-362.
- Benssassi, E. M., Gomez, J.-C., Boyd, L. E., Hayes, G. R., & Ye, J. (2018). Wearable assistive technologies for autism: opportunities and challenges. *IEEE Pervasive Computing*, 17(2), 11-21.
- Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *Medical Journal of Australia, 202*(6), 317-320.
- Benton, L., Johnson, H., Ashwin, E., Brosnan, M., & Grawemeyer, B. (2012). *Developing IDEAS: supporting children with autism within a participatory design team.* Paper presented at the Proceedings of the SIGCHI conference on Human factors in computing systems.
- Benton, L., Johnson, H., Brosnan, M., Ashwin, E., & Grawemeyer, B. (2011). *IDEAS: an interface design experience for the autistic spectrum.* Paper presented at the CHI'11 Extended Abstracts on Human Factors in Computing Systems.
- Berghs, M. J., Atkin, K. M., Graham, H. M., Hatton, C., & Thomas, C. (2016). Implications for public health research of models and theories of disability: a scoping study and evidence synthesis.
- Bødker, S., & Iversen, O. S. (2002). *Staging a professional participatory design practice: moving PD beyond the initial fascination of user involvement.* Paper presented at the Proceedings of the second Nordic conference on Human-computer interaction.
- Bogdan, R., & Biklen, S. K. (1997). Qualitative research for education. In *Book Qualitative research for education*: Allyn & Bacon Boston, MA.
- Bossavit, B., & Parsons, S. (2016). *This is how I want to learn: High functioning autistic teens co-designing a serious game.* Paper presented at the Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems.
- Boyatzis, R. E. (1998). Transforming qualitative information: Thematic analysis and code development. In *Book Transforming qualitative information: Thematic analysis and code development* (pp. 63): sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. *Handbook* of Research Methods in Health Social Sciences, 843-860.
- Bredies, K., Chow, R., & Joost, G. (2010). Addressing use as design: a comparison of constructivist design approaches. *The Design Journal*, *13*(2), 156-179.
- Brinckerhoff, L. C. (1994). Developing effective self-advocacy skills in college-bound students with learning disabilities. *Intervention in School and Clinic*, 29(4), 229-237.
- Bringolf, J. (2008). Universal design: is it accessible? *Multi: The Journal of Plurality and Diversity in Design*, 1(2).
- Brown, J., & Murray, D. (2001). Strategies for enhancing play skills for children with autism spectrum disorder. *Education and Training in Mental Retardation and Developmental Disabilities*, 312-317.
- Bruce, M., & Bessant, J. (2002). Managing design as a process. *Design in business: Strategic innovation through design*, 36-58.

- Buxton, B. (2010). Sketching user experiences: getting the design right and the right design. In *Book Sketching user experiences: getting the design right and the right design* (pp. 135): Morgan kaufmann.
- Buzan, T., & Buzan, B. (2006). The mind map book. In *Book The mind map book*: Pearson Education.
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(1), 31-41.
- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(2), 266-277.
- Carrington, S., Campbell, M., Saggers, B., Ashburner, J., Vicig, F., Dillon-Wallace, J., & Hwang, Y.-S. (2017). Recommendations of school students with autism spectrum disorder and their parents in regard to bullying and cyberbullying prevention and intervention. *International Journal of Inclusive Education*, 21(10), 1045-1064.
- Cesaroni, L., & Garber, M. (1991). Exploring the experience of autism through firsthand accounts. *Journal of Autism and Developmental Disorders*, 21(3), 303-313.
- Charmaz, K. (2014). Constructing grounded theory. In *Book Constructing grounded theory* (pp. 111): sage.
- Chevalier, J. M., & Buckles, D. J. (2019). Participatory action research: Theory and methods for engaged inquiry. In *Book Participatory action research: Theory and methods for engaged inquiry*: Routledge.
- Church, C., Alisanski, S., & Amanullah, S. (2000). The social, behavioral, and academic experiences of children with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, 15(1), 12-20.
- Cibrian, F. L., Pena, O., Vazquez, V., Cardenas, C., & Tentori, M. (2016). *Designing a deformable musical surface for children with autism*. Paper presented at the Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct.
- Clark, A. (2010). Young children as protagonists and the role of participatory, visual methods in engaging multiple perspectives. *American Journal of Community Psychology*, *46*(1-2), 115-123.
- Cole, E., Dehdashti, P., Petti, L., & Angert, M. (1994). Design and outcomes of computer-based cognitive prosthetics for brain injury: A field study of three subjects. *NeuroRehabilitation*, 4(3), 174-186.
- Conrad, D., & Campbell, G. (2008). Participatory research–An empowering methodology with marginalized populations. *Knowing differently: Artsbased and collaborative research methods*, 247-263.
- Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, 47(7), 844-854.
- Corbin, J., & Strauss, A. (2014). Basics of qualitative research: Techniques and procedures for developing grounded theory. In *Book Basics of qualitative research: Techniques and procedures for developing grounded theory*: Sage publications.
- Çorlu, D., Taşel, Ş., Turan, S. G., Gatos, A., & Yantaç, A. E. (2017). *Involving autistics in user experience studies: A critical review*. Paper presented at the Proceedings of the 2017 Conference on Designing Interactive Systems.

- Crabtree, A., Hemmings, T., Rodden, T., Cheverst, K., Clarke, K., Dewsbury, G., . . . Rouncefield, M. (2003). *Designing with care: Adapting cultural probes to inform design in sensitive settings*. Paper presented at the Proceedings of the 2004 Australasian Conference on Computer-Human Interaction (OZCHI2004).
- Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2015). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews. *Journal of Intellectual and Developmental Disability*, 40(1), 78-91.
- Crotty, M. (1998). The foundations of social research: Meaning and perspective in the research process. In *Book The foundations of social research: Meaning and perspective in the research process*: Sage.
- Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching.
- D'Antoni, A. V., Zipp, G. P., Olson, V. G., & Cahill, T. F. (2010). Does the mind map learning strategy facilitate information retrieval and critical thinking in medical students? *BMC medical education*, *10*(1), 61.
- Dalton, J. (2019). Dot Voting. In Great Big Agile (pp. 165-166): Springer.
- Davis, A. M., Bersoff, E. H., & Comer, E. R. (1988). A strategy for comparing alternative software development life cycle models. *IEEE Transactions on software Engineering*, 14(10), 1453-1461.
- De Couvreur, L., & Goossens, R. (2011). Design for (every) one: co-creation as a bridge between universal design and rehabilitation engineering. *CoDesign*, 7(2), 107-121.
- Dhindsa, H. S., Makarimi, K., & Roger Anderson, O. (2011). Constructivist-Visual Mind Map Teaching Approach and the Quality of Students' Cognitive Structures. *Journal of Science Education and Technology*, 20(2), 186-200. doi:10.1007/s10956-010-9245-4
- Donovan, D. (2016). How children represent sustainable consumption through participatory action research and co-design of visual narratives. *International Journal of Consumer Studies*, 40(5), 562-574.
- Duncan, A. W., & Bishop, S. L. (2015). Understanding the gap between cognitive abilities and daily living skills in adolescents with autism spectrum disorders with average intelligence. *Autism*, 19(1), 64-72. doi:doi:10.1177/1362361313510068
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.
- Flaherty, L. T., Weist, M. D., & Warner, B. S. (1996). School-based mental health services in the united states: History, current models and needs. *Community Mental Health Journal*, *32*(4), 341-352. doi:10.1007/bf02249452
- Francis, P., Balbo, S., & Firth, L. (2009). Towards co-design with users who have autism spectrum disorders. *Universal Access in the Information Society*, 8(3), 123-135.
- Frauenberger, C., Good, J., & Alcorn, A. (2012). *Challenges, opportunities and future perspectives in including children with disabilities in the design of interactive technology.* Paper presented at the Proceedings of the 11th International Conference on Interaction Design and Children.

- Frauenberger, C., Good, J., Fitzpatrick, G., & Iversen, O. S. (2015). In pursuit of rigour and accountability in participatory design. *International Journal of Human-Computer Studies*, 74, 93-106.
- Frauenberger, C., Good, J., & Keay-Bright, W. (2011). Designing technology for children with special needs: bridging perspectives through participatory design. *CoDesign*, 7(1), 1-28. doi:10.1080/15710882.2011.587013
- Frauenberger, C., Good, J., & Pares, N. (2016). *Autism and technology: beyond assistance & intervention*. Paper presented at the Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems.
- Frauenberger, C., Makhaeva, J., & Spiel, K. (2016). *Designing smart objects with autistic children: Four design exposès.* Paper presented at the Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems.
- Freire, P. (1982). Creating alternative research methods: Learning to do it by doing it. *Creating knowledge: A monopoly*, 29-37.
- Fuad-Luke, A. (2013). Design activism: beautiful strangeness for a sustainable world. In *Book Design activism: beautiful strangeness for a sustainable world*: Routledge.
- Gabriels, R. L., & Hill, D. E. (2010). Growing up with autism: Working with schoolage children and adolescents. In *Book Growing up with autism: Working with school-age children and adolescents*: Guilford Press.
- Gerhardt, P. F., & Lainer, I. (2011). Addressing the Needs of Adolescents and Adults with Autism: A Crisis on the Horizon. *Journal of Contemporary Psychotherapy*, *41*(1), 37-45. doi:10.1007/s10879-010-9160-2
- Getliffe, K. A. (1996). An examination of the use of reflection in the assessment of practice for undergraduate nursing students. *International journal of nursing studies*, *33*(4), 361-374.
- Gillberg, C. (2010). The ESSENCE in child psychiatry: early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in developmental disabilities*, 31(6), 1543-1551.
- Godden, R., & Hys, J. (2016). Universal Design and Its Discontents. *Disrupting the Digital Humanities*.
- Greenspan, S. I., Wieder, S., & Simons, R. (1998). The child with special needs: Encouraging intellectual and emotional growth. In *Book The child with special needs: Encouraging intellectual and emotional growth*: Addison-Wesley/Addison Wesley Longman.
- Grynszpan, O., Weiss, P. L., Perez-Diaz, F., & Gal, E. (2014). Innovative technologybased interventions for autism spectrum disorders: a meta-analysis. *Autism*, *18*(4), 346-361.
- Gummesson, E., Mele, C., Polese, F., Mele, C., Spena, T. R., & Colurcio, M. (2010). Co-creating value innovation through resource integration. *International Journal of Quality and Service Sciences*.
- Gutstein, S. E., & Whitney, T. (2002). Asperger syndrome and the development of social competence. *Focus on Autism and Other Developmental Disabilities*, 17(3), 161-171.
- Halskov, K., & Hansen, N. B. (2015). The diversity of participatory design research practice at PDC 2002–2012. *International Journal of Human-Computer Studies*, 74, 81-92.
- Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of vocational rehabilitation*, 32(2), 125-134.

- Hermann, J. F., & Colón, Y. (2005). Cancer support groups: a guide for facilitators. In *Book Cancer support groups: a guide for facilitators*: American Cancer Society.
- Ho, B. S. (2002). Application of participatory action research to family-school intervention. *School Psychology Review*, *31*(1), 106.
- Hoenig, H., Donald H. Taylor, J., & Sloan, F. A. (2003). Does Assistive Technology Substitute for Personal Assistance Among the Disabled Elderly? *American Journal of Public Health*, 93(2), 330-337. doi:10.2105/ajph.93.2.330
- Holmlid, S. (2008). Towards an understanding of the challenges for design management and service design. Paper presented at the Design Management Conference, Paris.
- Hook, J., Verbaan, S., Durrant, A., Olivier, P., & Wright, P. (2014). A study of the challenges related to DIY assistive technology in the context of children with disabilities. Paper presented at the Proceedings of the 2014 conference on Designing interactive systems.
- Hourcade, J. P., Bullock-Rest, N. E., & Hansen, T. E. (2012). Multitouch tablet applications and activities to enhance the social skills of children with autism spectrum disorders. *Personal and Ubiquitous Computing*, *16*(2), 157-168. doi:10.1007/s00779-011-0383-3
- Hsieh, G., Munson, S. A., Kaptein, M. C., Oinas-Kukkonen, H., & Nov, O. (2014). Personalizing behavior change technologies. In CHI'14 Extended Abstracts on Human Factors in Computing Systems (pp. 107-110).
- Ingold, T. (2008). *Anthropology is not ethnography*. Paper presented at the Proceedings of the British Academy.
- Ivey, M., & Sanders, E. (2006). Designing a physical environment for co-experience and assessing participant use. Paper presented at the Wonderground, Design Research Society International Conference.
- Iwarsson, S., & Ståhl, A. (2003). Accessibility, usability and universal design positioning and definition of concepts describing person-environment relationships. *Disability and rehabilitation*, 25(2), 57-66.
- Janesick, V. J. (1991). Ethnographic inquiry: Understanding culture and experience. *Forms of curriculum inquiry*, 101-119.
- Johnson, R., Bianchi-Berthouze, N., Rogers, Y., & van der Linden, J. (2013). *Embracing calibration in body sensing: using self-tweaking to enhance ownership and performance.* Paper presented at the Proceedings of the 2013 ACM international joint conference on Pervasive and ubiquitous computing.
- Kagohara, D. M. (2011). Three students with developmental disabilities learn to operate an iPod to access age-appropriate entertainment videos. *Journal of Behavioral Education*, 20(1), 33-43.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-253.
- Kashinath, S., Woods, J., & Goldstein, H. (2006). Enhancing generalized teaching strategy use in daily routines by parents of children with autism. *Journal of Speech, Language, and Hearing Research*, 49(43), 466.
- Katterfeldt, E.-S., Zeising, A., & Schelhowe, H. (2012). *Designing digital media for teen-aged apprentices: a participatory approach.* Paper presented at the Proceedings of the 11th International Conference on Interaction Design and Children.
- Kemmis, S., McTaggart, R., & Nixon, R. (2013). The action research planner: Doing critical participatory action research. In *Book The action research planner:*

Doing critical participatory action research: Springer Science & Business Media.

- Khan, M. S., Mohamadali, N. A. K., Maher, Z. A., Nisa, S. Q., Shaikh, H., & Shah, A. (2019). Information Technology (IT) Based Intervention Among Individuals with ASD (Autism Spectrum Disorder): A Review. Paper presented at the 2019 IEEE International Conference on Innovative Research and Development (ICIRD).
- Kidd, S. A., & Kral, M. J. (2005). Practicing participatory action research. *Journal of counseling psychology*, 52(2), 187.
- Kientz, J. A., Goodwin, M. S., Hayes, G. R., & Abowd, G. D. (2013). Interactive technologies for autism. *Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies*, 2(2), 1-177.
- Kindon, S., Pain, R., & Kesby, M. (2007). Participatory action research approaches and methods: Connecting people, participation and place. In *Book Participatory action research approaches and methods: Connecting people, participation and place*: Routledge.
- King, S. A., & Moreggi, D. (2007). Internet self-help and support groups: The pros and cons of text-based mutual aid. In *Psychology and the Internet* (pp. 221-244): Elsevier.
- Kivunja, C., & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of Higher Education*, *6*(5), 26-41.
- Kontio, J., Lehtola, L., & Bragge, J. (2004). Using the focus group method in software engineering: obtaining practitioner and user experiences. Paper presented at the Proceedings. 2004 International Symposium on Empirical Software Engineering, 2004. ISESE'04.
- Koumpouros, Y., & Kafazis, T. (2019). Wearables and mobile technologies in Autism Spectrum Disorder interventions: A systematic literature review. *Research in Autism Spectrum Disorders, 66*, p101405.
- Krippendorff, K. (2006). The semantic turn: A new foundation for design. *ARTIFACT-ROUTLEDGE-*, 1(11), 51.
- Kuo, M. H., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2014). Media use among adolescents with autism spectrum disorder. *Autism*, 18(8), 914-923.
- Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *OTJR: Occupation, participation and health, 26*(2), 69-79.
- Lau, F. (1999). Toward a framework for action research in information systems studies. *Information Technology & People, 12*(2), 148-176.
- Laugeson, E. A., & Ellingsen, R. (2014). Social skills training for adolescents and adults with autism spectrum disorder. In *Adolescents and adults with autism spectrum disorders* (pp. 61-85): Springer.
- Laurin, K., & Pleasant, J. S. (2008). Low-Tech Assistive Technology. *Helal et al. The Engineering Handbook of Smart Technology for Aging, Disability, and Independence*, 129-142.
- Lewin, K. (1946). Action Research and Minority Problems. *Journal of Social Issues*, 2(4), 34-46. doi:10.1111/j.1540-4560.1946.tb02295.x
- Lewis, R. B., & Lewis, R. B. (1998). Assistive technology and learning disabilities: Today's realities and tomorrow's promises. *Journal of learning disabilities*, *31*(1), 16-26.

- Liamputtong, P. (2010). Research methods in health: foundations for evidence-based practice. In *Book Research methods in health: foundations for evidence-based practice* (pp. 117).
- Liamputtong, P. (2013). Qualitative research methods. In *Book Qualitative research methods* (pp. 118).
- Löfman, P., Pelkonen, M., & Pietilä, A. M. (2004). Ethical issues in participatory action research. *Scandinavian Journal of Caring Sciences*, 18(3), 333-340.
- Mace, R. L. (1991). Accessible environments: Toward universal design. Design interventions: Toward a more humane architecture, In: Preiser, W., Vischer, X., & White, E.T. (Eds.)(Innovation by design), 203-227.
- Mace, R. L. (1998). Universal Design in Housing. *Assistive Technology*, *10*(1), 21-28. doi:10.1080/10400435.1998.10131957
- Madsen, M., Kaliouby, R. e., Eckhardt, M., Hoque, M. E., Goodwin, M. S., & Picard, R. (2009). Lessons from participatory design with adolescents on the autism spectrum. Paper presented at the CHI '09 Extended Abstracts on Human Factors in Computing Systems, Boston, MA, USA.
- Maguire, M. (2001). Methods to support human-centred design. *International Journal* of Human-Computer Studies, 55(4), 587-634.
- Makhaeva, J., Frauenberger, C., & Spiel, K. (2016). *Creating creative spaces for codesigning with autistic children: the concept of a Handlungsspielraum*. Paper presented at the Proceedings of the 14th Participatory Design Conference: Full papers-Volume 1.
- Malinverni, L., Mora-Guiard, J., Padillo, V., Mairena, M., Hervás, A., & Pares, N. (2014). Participatory design strategies to enhance the creative contribution of children with special needs. Paper presented at the IDC '14 Proceedings of the 2014 conference on Interaction design and children, Aarhus, Denmark.
- Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism*, 11(2), 111-122.
- May, T., Sciberras, E., Brignell, A., & Williams, K. (2017). Autism spectrum disorder: updated prevalence and comparison of two birth cohorts in a nationally representative Australian sample. *BMJ open*, 7(5), e015549.
- Mazurek, M. O. (2013). Social media use among adults with autism spectrum disorders. *Computers in Human Behavior*, 29(4), 1709-1714.
- Millen, L., Cobb, S., & Patel, H. (2011). *A method for involving children with autism in design*. Paper presented at the Proceedings of the 10th International Conference on Interaction Design and Children.
- Millen, L., Cobb, S., Patel, H., & Glover, T. (2014). A collaborative virtual environment for conducting design sessions with students with autism spectrum disorder. *International Journal of Child Health and Human Development*, 7(4), 367.
- Minkler, M. (2005). Community-based research partnerships: challenges and opportunities. *Journal of urban health*, 82(2), ii3-ii12.
- Mirenda, P. (2001). Autism, augmentative communication, and assistive technology: What do we really know? *Focus on Autism and Other Developmental Disabilities*, 16(3), 141-151.
- Moggridge, B. (1993). Design by story-telling. Applied Ergonomics, 24(1), 15-18.
- Morgan-Trimmer, S., & Wood, F. (2016). Ethnographic methods for process evaluations of complex health behaviour interventions. *Trials*, *17*(1), 232.

- Muller, M. J. (1991). *PICTIVE—an exploration in participatory design*. Paper presented at the Proceedings of the SIGCHI conference on Human factors in computing systems.
- Myers, M. D., & Avison, D. (2002). Qualitative research in information systems: a reader. In *Book Qualitative research in information systems: a reader*: Sage.
- Nastasi, B. K., Varjas, K., Sarkar, S., & Jayasena, A. (1998). Participatory model of mental health programming: Lessons learned from work in a developing country. *School Psychology Review*, 27, 260-276.
- National Disability Insurance Scheme. (2020). What is the NDIS. Retrieved from <u>https://www.ndis.gov.au/understanding/what-ndis</u>
- Neale, H., Cobb, S., & Kerr, S. (2003). An inclusive design toolbox for development of educational Virtual Environments. *Include2003, Royal College of Art, London*, 25-28.
- Nganji, J. T., & Brayshaw, M. (2017). Disability-aware adaptive and personalised learning for students with multiple disabilities. *The International Journal of Information and Learning Technology*.
- Nganji, J. T., & Nggada, S. H. (2011). Disability-aware software engineering for improved system accessibility and usability. *International Journal of Software Engineering and Its Applications*, 5(3), 47-62.
- Norman, D. A. (2005). Human-centered design considered harmful. *interactions*, 12(4), 14-19.
- Norman, D. A., & Draper, S. W. (1986). User centered system design; new perspectives on human-computer interaction. In *Book User centered system design; new perspectives on human-computer interaction*: L. Erlbaum Associates Inc.
- Nygren, G., Cederlund, M., Sandberg, E., Gillstedt, F., Arvidsson, T., Gillberg, I. C., . . . Gillberg, C. (2012). The prevalence of autism spectrum disorders in toddlers: a population study of 2-year-old Swedish children. *Journal of Autism* and Developmental Disorders, 42(7), 1491-1497.
- O'Day, B., & Killeen, M. (2002). Research on the lives of persons with disabilities: The emerging importance of qualitative research methodologies. *Journal of Disability Policy Studies, 13*(1), 9-15.
- O'Keeffe, G. S., & Clarke-Pearson, K. (2011). The impact of social media on children, adolescents, and families. *Pediatrics*, 127(4), 800-804.
- Odom, S. L., Thompson, J. L., Hedges, S., Boyd, B. A., Dykstra, J. R., Duda, M. A., . . Bord, A. (2015). Technology-aided interventions and instruction for adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(12), 3805-3819.
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, *34*(3), 245-256.
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(11), 2710-2719.
- Osmond, J., & Darlington, Y. (2005). Reflective analysis: Techniques for facilitating reflection. *Australian social work*, 58(1), 3-14.
- Papavasiliou, S., Saridaki, M., Mourlas, C., & Van Isacker, K. (2014). *Providing* assistive ICT learning for people with disabilities through a personalised mobile application. Paper presented at the 2014 IEEE 14th International Conference on Advanced Learning Technologies.
- Parker, A., & Tritter, J. (2006). Focus group method and methodology: current practice and recent debate. *International Journal of Research & Method in Education*, 29(1), 23-37.
- Parner, E. T., Thorsen, P., Dixon, G., De Klerk, N., Leonard, H., Nassar, N., . . . Glasson, E. J. (2011). A comparison of autism prevalence trends in Denmark and Western Australia. *Journal of Autism and Developmental Disorders*, 41(12), 1601-1608.
- Parsons, D., Cordier, R., Lee, H., Falkmer, T., & Vaz, S. (2019). A randomised controlled trial of an information communication technology delivered intervention for children with autism spectrum disorder living in regional Australia. *Journal of Autism and Developmental Disorders*, 49(2), 569-581.
- Petrie, H., & Bevan, N. (2009). The Evaluation of Accessibility, Usability, and User Experience. *The universal access handbook*, *1*, 1-16.
- Phillips, B., & Zhao, H. (1993). Predictors of assistive technology abandonment. *Assistive Technology*, 5(1), 36-45.
- Pinheiro Mota, C., & Matos, P. M. (2013). Peer attachment, coping, and self-esteem in institutionalized adolescents: the mediating role of social skills. *European Journal of Psychology of Education*, 28(1), 87-100. doi:10.1007/s10212-012-0103-z
- Plattner, H., Meinel, C., & Leifer, L. (2010). Design thinking: understand-improveapply. In *Book Design thinking: understand-improve-apply*: Springer Science & Business Media.
- Ploog, B. (2010). Educational computer games and their applications to developmental disabilities. *Educational games: Design, learning and applications. Hauppauge: Nova Science Publishers, Inc*, 281-297.
- Ploog, B. O., Scharf, A., Nelson, D., & Brooks, P. J. (2013). Use of computer-assisted technologies (CAT) to enhance social, communicative, and language development in children with autism spectrum disorders. *Journal of Autism* and Developmental Disorders, 43(2), 301-322.
- Pope, A. M., & Brandt Jr, E. N. (1997). Enabling America: Assessing the role of rehabilitation science and engineering. In *Book Enabling America: Assessing the role of rehabilitation science and engineering*: National Academies Press.
- Porayska-Pomsta, K., Frauenberger, C., Pain, H., Rajendran, G., Smith, T., Menzies, R., . . . Bernadini, S. (2012). Developing technology for autism: an interdisciplinary approach. *Personal and Ubiquitous Computing*, 16(2), 117-127.
- Poulson, D., & Richardson, S. (1998). USERfit–a framework for user centred design in assistive technology. *Technology and Disability*, 9(3), 163-171.
- Pulier, M. L., & Daviss, S. (2016). A call for a global digital health consortium. *Journal of Technology in Behavioral Science, 1*(1-4), 16-21.
- Riessman, C. K. (1993). Narrative analysis. In *Book Narrative analysis* (Vol. 30): Sage.
- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). Qualitative research practice: A guide for social science students and researchers. In *Book Qualitative research practice: A guide for social science students and researchers*: Sage.
- Rizzo, A., Schutt, S., & Linegar, D. (2012). *Imagine that: creating a'third space'for* young people with high functioning autism through the use of technology in a social setting. Paper presented at the Proceedings of the 24th Australian Computer-Human Interaction Conference.

- Sanders, E. B. N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, 4(1), 5-18. doi:10.1080/15710880701875068
- Sanoff, H. (2008). Multiple views of participatory design. *International Journal of Architectural Research*, 2(1), 57-69.
- Scherer, M. J. (2002). Assistive technology: Matching device and consumer for successful rehabilitation. In *Book Assistive technology: Matching device and consumer for successful rehabilitation*: American Psychological Association.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 33(6), 565-581.
- Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, 2, 197-204.
- Shamrova, D. P., & Cummings, C. E. (2017). Participatory action research (PAR) with children and youth: An integrative review of methodology and PAR outcomes for participants, organizations, and communities. *Children and Youth Services Review*, 81, 400-412.
- Shic, F., & Goodwin, M. (2015). Introduction to technologies in the daily lives of individuals with autism. In: Springer.
- Shore, J. (2007). The Art of Agile Development: Pragmatic guide to agile software development. In *Book The Art of Agile Development: Pragmatic guide to agile software development*: " O'Reilly Media, Inc.".
- Shujah, Z., & Mulligan, A. (2017). Differences between DSM-IV and DSM-5 as applied to child and adolescent psychiatry and neurodevelopmental disorders. *Irish Journal of Psychological Medicine*, 1-7.
- Shumaker, S. A., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. *Journal of Social Issues, 40*(4), 11-36.
- Simonsen, J., & Robertson, T. (2012). Routledge international handbook of participatory design. In *Book Routledge international handbook of participatory design*: Routledge.
- Sinzig, J., Morsch, D., Bruning, N., Schmidt, M. H., & Lehmkuhl, G. (2008). Inhibition, flexibility, working memory and planning in autism spectrum disorders with and without comorbid ADHD-symptoms. *Child and adolescent psychiatry and mental health*, 2(1), 4.
- Solomon, O. (2008). Language, autism, and childhood: An ethnographic perspective. *Annual Review of Applied Linguistics*, 28, 150-169.
- Soysa, A. I., & Mahmud, A. A. (2018). Assessing tablet applications focused on social interactions: what functionalities do Sri Lankan practitioners want for children with ASD? Paper presented at the Proceedings of the 30th Australian Conference on Computer-Human Interaction.
- Spinuzzi, C. (2005). The methodology of participatory design. *Technical communication*, 52(2), 163-174.
- Spitzer, S. L. (2003). Using participant observation to study the meaning of occupations of young children with autism and other developmental disabilities. *American Journal of Occupational Therapy*, 57(1), 66-76.
- Steen, M. (2013). Co-design as a process of joint inquiry and imagination. *Design Issues*, 29(2), 16-28.
- Story, M. F. (2001). Principles of universal design. Universal design handbook.
- Story, M. F., Mueller, J. L., & Mace, R. L. (1998). The universal design file: Designing for people of all ages and abilities.

- Strauss, A., & Corbin, J. (1990). Basics of qualitative research. In *Book Basics of qualitative research*: Sage publications.
- Strunk, J. A., Pickler, R., McCain, N. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with autism spectrum disorder: The parents' experience. *Families, Systems, & Health, 32*(3), 328.
- Suchman, L. A. (2002). Practice-based design of information systems: Notes from the hyperdeveloped world. *The information society*, *18*(2), 139-144.
- Sutherland, J., & Schwaber, K. (2013). The scrum guide. *The definitive guide to scrum: The rules of the game. Scrum. org, 268.*
- Tanaka, A., Parkinson, A., Settel, Z., & Tahiroglu, K. (2012). A Survey and Thematic Analysis Approach as Input to the Design of Mobile Music GUIs. Paper presented at the NIME.
- Tobin, M. C., Drager, K. D., & Richardson, L. F. (2014). A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders*, 8(3), 214-229.
- Turner-Brown, L. M., Lam, K. S., Holtzclaw, T. N., Dichter, G. S., & Bodfish, J. W. (2011). Phenomenology and measurement of circumscribed interests in autism spectrum disorders. *Autism*, 15(4), 437-456.
- Uchino, B. N., Bowen, K., de Grey, R. K., Mikel, J., & Fisher, E. B. (2018). Social support and physical health: Models, mechanisms, and opportunities. In *Principles and concepts of behavioral medicine* (pp. 341-372): Springer.
- Valencia, K., Rusu, C., Quiñones, D., & Jamet, E. (2019). The Impact of Technology on People with Autism Spectrum Disorder: A Systematic Literature Review. *Sensors (Basel)*, 19(20). doi:10.3390/s19204485
- Van Someren, M., Barnard, Y., & Sandberg, J. (1994). The think aloud method: a practical approach to modelling cognitive. In *Book The think aloud method: a practical approach to modelling cognitive*: Citeseer.
- Venter, A., Lord, C., & Schopler, E. (1992). A follow-up study of high-functioning autistic children. Journal of Child Psychology and Psychiatry, 33(3), 489-597.
- Wainer, A. L., & Ingersoll, B. R. (2011). The use of innovative computer technology for teaching social communication to individuals with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 96-107.
- Walker, N. (2014). Neurodiversity: Some basic terms and definitions. NEUROCOSMOPOLITANISM NICK WALKER'S NOTES ON NEURODIVERSITY, AUTISM, AND COGNITIVE LIBERTY, 29.
- Ward, S. L., Sullivan, K. A., & Gilmore, L. (2016). Practitioner perceptions of the assessment and diagnosis of autism in Australia. *Australian Psychologist*, 51(4), 272-279.
- Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics*, 127(5), e1303-e1311.
- Weidle, B., Bolme, B., & Hoeyland, A. L. (2006). Are Peer Support Groups for Adolescents with Asperger's Syndrome Helpful? *Clinical Child Psychology* and Psychiatry, 11(1), 45-62. doi:10.1177/1359104506059119
- Weiss, M. J., & Harris, S. L. (2001). Teaching social skills to people with autism. *Behavior modification*, 25(5), 785-802.
- Williams, C., Wright, B., Callaghan, G., & Coughlan, B. (2002). Do children with autism learn to read more readily by computer assisted instruction or traditional book methods? A pilot study. *Autism*, 6(1), 71-91.

- Williams, K., MacDermott, S., Ridley, G., Glasson, E. J., & Wray, J. A. (2008). The prevalence of autism in Australia. Can it be established from existing data? *Journal of paediatrics and child health*, 44(9), 504-510.
- Wilson, C., Brereton, M., Ploderer, B., & Sitbon, L. (2019). Co-Design Beyond Words: 'Moments of Interaction'with Minimally-Verbal Children on the Autism Spectrum. Paper presented at the Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems.
- Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: is the prevalence rising? *Developmental Disabilities Research Reviews*, 8(3), 151-161.
- Wood-Harper, A. T., Antill, L., & Avison, D. E. (1985). Information systems definition: the Multiview approach.
- Wright, C. A., Wright, S. D., Diener, M. L., & Eaton, J. (2014). Autism spectrum disorder and the applied collaborative approach: A review of community based participatory research and participatory action research. *Journal of Autism*, I(1), 1.
- Wulff, W., Evenson, S., & Rheinfrank, J. (1990). *Animating interfaces*. Paper presented at the Proceedings of the 1990 ACM conference on Computer-supported cooperative work.
- Xin, J. F., & Leonard, D. A. (2015). Using iPads to teach communication skills of students with autism. *Journal of Autism and Developmental Disorders*, 45(12), 4154-4164.
- Zabala, J. (1995). The SETT Framework: Critical Areas To Consider When Making Informed Assistive Technology Decisions.
- Zahavi, D. (2003). Husserl's phenomenology. In *Book Husserl's phenomenology*: Stanford University Press.
- Zuber-Skerritt, O. (1992). Action Research in Higher Education: Examples and Reflections. In *Book Action Research in Higher Education: Examples and Reflections*: ERIC.

Appendices

Appendix A

Information Sheet



INFORMATION SHEET

PROJECT TITLE: Co-Designing software with adolescents diagnosed with autism spectrum disorder: A Participatory Action Research approach

You are invited to take part in a research project to find out how adolescents with ASD can be involved in software design. The study is conducted by Randy Zhu Zhiwei and will be included in his Ph.D. thesis in Doctor of Philosophy (Information Technology) at James Cook University.

During this research, Randy will be collecting the following types of information:

1. Data concerning what types of information technology devices do adolescents with ASD currently use. They include wearables, mobile phones, the Internet, computers, or game systems.

2. Data concerning the type of software that you would like to create. This may include what the device can do, how a device would operate and how you might use it.

3. Feedback on the developed software. If it is easy to use or does the software actually help you in completing a task?

4. Feedback on the experience to be part of the software design team

Your involvement in the project:

You are invited to be involved in the project by taking part in group discussion sessions, design drawing sessions and as trial users of the software. Each workshop last for 2 hours. You can take part in any or all stages of this project and may quit at any time, for any reason. At any point time throughout the project, you can quit the project without having to explain your reasons.

Benefits of being part of the project:

You have the chance to help create a smartwatch software. You will learn about how software is designed and created and after which, you will also be part of the design team to create a smartwatch software. Finally, you will also have the opportunity to use the smartwatch with the developed software during offsite trials.

Description of the workshops:

Workshop 1 – Group discussion and design drawing session (July 2018)

A group discussion will be conducted to understand your area of interest. During the group discussion, you will be asked with questions where you share your thoughts and ideas. After which, you will be asked to draw scenarios where you think a software might help you in accomplishing a task. You will also be asked to draw what you think the screen of the software might look like.

Workshop 2 – Group Discussion (August 2018)

You will get to see the first version of the software and given a walkthrough on how to use the software. After which, you can bring the smartwatch back for offsite trial.

Workshop 3 – Group discussion and design drawing session (September 2018)

Two group discussion will be conducted. The first group discussion is to get your feedback on the first version of the software. You can use pictures taken of yourself

during testing or draw scenes that can help you recall specific events to share your feedback (optional). You can also use drawings to explain situations where the software is not usable or the screen of the software where you find it difficult to use. The second group discussion will be asking your feedback on your involvement as part of the design team.

Workshop 4 – Group Discussion (October 2018)

You will get to see the second version of the software and given a walkthrough on how to use the software. After which, you can bring the smartwatch back for offsite trial.

Workshop 5 – Group discussion and design drawing session (November 2018)

Two group discussion will be conducted. The first group discussion is to get your feedback on the second version of the software. You can use pictures taken of yourself during testing or draw scenes that can help you recall specific events to share your feedback (optional). You can also use drawings to explain situations where the software is not usable or the screen of the software where you find it difficult to use. The second group discussion will be asking your feedback on your involvement as part of the design team.

Workshop 6 – Group Discussion (December 2019)

You will get to see the final version of the software and given a walkthrough on how to use the software. After which, you can bring the smartwatch back for offsite trial.

Workshop 7 – Group Discussion (January 2019)

Two group discussion will be conducted. The first group discussion is to get your feedback on the final version of the software. The second group discussion will be asking your feedback on your involvement as part of the design team.

What will happen in the workshops:

You will be asked some questions about your current interest. Next, we will discuss what sort of technology you are using, such as wearables, mobile phones, computers and the Internet. We will also discuss your area of interest and what technology you would like to have in these areas. As part of the group discussion, you will also be asked to use drawing or photos to express your thoughts and to give design ideas.

Method of gathering information at the interview:

In addition to taking notes during the group discussions, we will ask your permission to audio record the workshops.

Are there any possible risks to you being involved in the research?

We recognise that talking about personal challenges may be distressing for some participants. Support services are available from the below services:

Kids Helpline: 07 4759 2008

Lifeline: 13 11 14

North Queensland Autism Support Group: 07 4774 0637

The data from the study will be used in research publications and in a Ph.D. thesis. You will not be identified in any way in these publications.

If you have any questions about the study, please contact – Randy Zhu Zhiwei and Dr Dianna Hardy.

Principal Investigator:	Supervisor:
Randy Zhu Zhiwei	Name: Dr Dianna Hardy
College: College of Business, Law and	College: College of Business, Law and
Governance	Governance

James Cook University

James Cook University

Phone:

Phone:

Email: zhiweirandy.zhu@my.jcu.edu.au

Email: dianna.hardy@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:

Human Ethics, Research Office

James Cook University, Townsville, Qld, 4811 Phone: (07) 4781 5011 (ethics@jcu.edu.au) Appendix B

Information Consent

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Appendix C

Recruitment Ad



Participants Needed for Research Study

This study looks at how adolescents with ASD can be involved in software design and will be conducted under the direction of Randy Zhu, PhD (Information Technology) student from James Cook University (Townsville).

IF you are interested, we are looking for individuals:

- 12 to 18 years old
- Formal diagnosis of DSM V ASD (specifier: without language or intellectual impairment) OR formal diagnosis of DSM IV Asperger's Disorder
- High school students

Study involves:

- 7 workshops. 2 weeks 2 months apart during the NQASG IT Club. (Workshop ~ 2 hours each)
- Group discussion
- Drawing of software interfaces and scenarios where the software will be used.
- Trial use of wearables application (Smart watches)

For more information, please contact:

Randy Zhu at , email: zhiweirandy.zhu@my.jcu.edu.au

Appendix D

Workshop Guide

Phase Two Pilot Workshop 1 Date: 13 May 2018 Venue: NQ Employment

Orientation and Project Introduction (2:00pm - 2.30pm)

[R] Hi all, thank you for your time for in participating in this research program. My name is Randy Zhu, a PhD candidate from James Cook University. Before we proceed further, I would like to hand out the inform consent form and run through what we will do or collect in all the workshops.

Researcher to hand out consent forms to participants and their parents. Researcher to introduce the research project, highlighting the session will be audio recorded and the reason behind audio recording. Go through the consent forms and obtain participants and parents signature.

[R] Now, let's make our comfortable. First, shall we gather and sit around this table where we can get to see each other? *Researcher to prompt participants to sit around the table.*

[R] We are mainly going to use group discussion and drawings in all the workshops to help us gather thoughts and explain an idea. Let's first go through what is a group discussion then drawing.

A group discussion is like how we chit chat. I ask some questions, anyone can answer, add on or even ask another question that is related. There are no right or wrong answers, it is just like casual talk. Example: I asked how is your day? I can say I went for jog in the morning. [Participant name] can say "I have walked the dog or just finished my homework". Someone else can then add on to say about his day. I have also prepared paper and pencils where you can use drawing to express your idea as well. You are free to use drawing at any point of time to illustrate your idea in the group discussion. Some time, it is easier to illustrate an idea through drawing. Example: Do you find it hard to use YouTube at times? When and why? It might be easier to draw out the YouTube page and highlight the buttons or feature that you can find it hard to use.

Researcher to prompt participants to sit around the table.

Introduction to research goal (2:30pm – 2.45pm)

[R] The goal of the research is for us to design a game together. We will first go a series of discussion to find out about your understanding about technology and how you have been using technology. Subsequently, I will show you some game design methods and we can start working together on designing a game. Group discussion (2:45pm - 3.15pm)

[R] Let's start our first discussion. Tell me how many times and when do you use technology in your daily lives? Technology relates to anything that is electronic, easiest example would be like phones and computers.

[R] Tell me more. Do you find these applications or devise easy or difficult to use? Why?

Depending on participants responses, researcher to follow up questions relating to UI, UX and design decisions.

Have you been consulted about these applications? How do you feel when using these applications or devices? If given a chance, would you be keen to participate in the design process? Do you think that your contribution will make the application easier to use?

Co-design nature of the game (3:15 pm - 3.50pm)

[R] Now, let's start designing some games. First, we need to know some basics of game design. I will show you some examples of game design. Some terms and how to do start designing a simple maze game.

Researcher to explain 2D vs 3D game. The use of leveling in game design. Using paper to draw level.

[R] Let's all start designing some games. Discuss and draw out some ideas of the games you have in mind. *Researcher to round and refine participants game idea.*

Summary (3:50 pm - 4.00pm)

[R] Ok! I hope you all have fun taking part in this exercise. The next session, we will come together to put forward a game design and we will create some drawings or levels to show the game play so I hope do see you in the next session. The next session will be on XXXX.

Phase Two Pilot Workshop 2 Date: 10 June 2018 Venue: NQ Employment

Orientation and Project Introduction (2:00pm - 2.15pm)

[R] Hi all, thank you for coming back to the second workshop. A quick recap on the purpose of these two workshops. We are going to design a game together or at least part of a game. In terms of design, we are going to draw out how the game will work (controls and other game element) and also at least stage. These paper design can eventually be used as design reference in the actual creation of the game just like how commercial games are made.

Member checking of Workshop 1 (2:15pm – 2.30pm)

[R] I found a few interesting topics from our last workshop and I would like to find out more with you.

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Group Discussion Game Design (2:45pm – 3.15pm)

[R] First, we will take 10mins for you think about the game then as a group, we will go round the table for you talk about your ideas of game that you wanted to design. *Researcher to prompt participants to provide details of the game* Low-fi game prototype (3.15 pm - 3.45 pm)

[R] Now, let's take the next 30 mins to draw out one level of the game. Put in as much details as you can. Reflection (3:45 pm – 4.00pm)

[R] Now, let's take last 15mins to reflect our last two sessions. Do you enjoy the two workshops? Why?[R] How do you feel about making your own game? Do you feel more interested and

confident in joining a session like this in the future?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise and I hope you learned something about game design or maybe even developed an interest in game design.

Phase Three Workshop 1 Date: 15 July 2018

Orientation and Project Introduction (2:00pm - 2.30pm)

[R] Hi all, thank you for your time for in participating in this research program. My name is Randy Zhu, a PhD candidate from James Cook University. Before we proceed further, I would like to hand out the inform consent form and run through what we will do or collect in all the workshops.

Researcher to hand out consent forms to participants and their parents. Researcher to introduce the research project, highlighting the session will be audio recorded and the reason behind audio recording. Go through the consent forms and obtain participants and parents signature.

[R] Now, let's make our comfortable. First, shall we gather and sit around this table where we can get to see each other? *Researcher to prompt participants to sit around the table.*

[R] Next, let's have a simple game for everyone where all of us can get to know each other a little better. We will go round the table and everyone will first do short introduction like what's your name, age and hobby and etc. Every one of you needs to remember 3 things about any one person from the table. Example: His name is XXX, her age is XX and his hobby is XXX. *Researcher to start ice breaker*

[R] Ok! Now that we know everyone. Let's get ready to learn some new stuff that can help us communicate ideas better. Before I carry on, any one has any questions? Introduction to group discussion and design sketching (2:30pm - 2.45pm)

[R] We are mainly going to use group discussion and drawings in all the workshops to help us gather thoughts and explain an idea. Let's first go through what is a group discussion then drawing.

A group discussion is like how we chit chat. I ask some questions, anyone can answer, add on or even ask another question that is related. There are no right or wrong answers, it is just like casual talk. Example: I asked how is your day? I can say I went for jog in the morning. [Participant name] can say "I have walked the dog or just finished my homework". Someone else can then add on to say about his day. I have also prepared paper and pencils where you can use drawing to express your idea as well. You are free to use drawing at any point of time to illustrate your idea in the group discussion. Some time, it is easier to illustrate an idea through drawing. Example: Do you find it hard to use YouTube at times? When and why? It might be easier to draw out the YouTube page and highlight the buttons or feature that you can find it hard to use.

[R] Ok! Now that we are familiar with what we will be doing. Before we start our first group discussion, we will go for a short 15mins break. Snacks provided. Group discussion and design sketching (3:00pm – 3.45pm)

[R] Ok! We are going to start our first group discussion. Relax and as I mentioned earlier, it is just like having a chit chat. No right or wrong answer. Just what you

think and what you want to share. You can also discuss in smaller groups (2-3). Researcher to assign small groups.

[R] How many of you know what a smart phone is? Try drawing your current phone

[R] How many of you own a phone? You can raise your hands if you own one.

[R] How many of you know what a computer tablet is? Try drawing a tablet

[R] Ok, that's quite a few. How many of you own a tablet like an iPad? You can raise your hands if you own one.

[R] How many of you know what a smart watch is?

[R] Ok, that's quite a few. How many of you own a smart watch like a Samsung gear/Apple watch? You can raise your hands if you own one.

[R] How easy is it for you use a smart phone or tablet? No issue in changing settings, downloading new applications or games? Tell me something that is easy and something that is hard.

[R] What applications do you have on these devices? Do you find them easy to use and why do you like them? In pair/group, draw the application you have on these devices.

[R] What are applications that you find it hard to use? Why? You can draw or someone in the group can draw as well.

Researcher to lead the participants in drawing.

[R] Do any of you use any applications in your daily lives today? Let's say calendar to help you keep track of timetable or health application to keep track of your sleep. [R] What are some of your daily challenges you face? It can be in school or at home. Example: keeping track of time table, not knowing when you are talking too loud? For me, sometimes I cannot remember the names of my students.

[R] These are screen shots of a smartwatch app. Take some time now, looking back at the challenges you mentioned. If you have an app that can help you with the challenge, what do you think the app can do? Try sketching your big idea in 5 mins then use a number drawings to show how the solution work, similar to drawing a comic strip. Use these drawings to share with me your thoughts. Reflection and summary (3:45pm - 4.00pm)

[R] Now, let's take last 15mins to reflect our session today. Do you enjoy today workshop? Why?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise. I will look into what we have talked about and they will determine what application will be built. The next

session, you will get the first look at the application created and test them so I hope do see you in the next session. The next session will be on XXXX.

Once again, thank you for your time and feel free to contact me if you have any questions.

Phase Three Workshop 2 Date: 12 August 2018

Recap of last meeting (2:00pm – 2.15pm)

[R] Ok! Let's do a quick recap of the team progress. We have identified some challenges faced by the group and came up with a set of solutions. A mobile + watch app. Together as a team, we will be designing the application by determining the features and the looks and feel of the application. We came up with some idea of what the application will do and look like. Today, you will get a first look of the application and bring them to test it out. Member checking of Workshop 1 (2:15pm – 2.30pm)

[R] First, I found a few interesting main points from our workshop. Let me share them with you

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Introduction to InterestMe V1 (2.30 pm - 2.45pm)

[R] Now, let me show you the application we have designed together. *Researcher to state the functionalities of the application and run through both mobile and watch interface.* Installation to InterestMe V1 (2.45 pm – 3.30pm)

[R] I will now install InterestMe onto your phone and after that, we can do a test a few functions together.

Researcher to install software onto participants mobile phone and pair WearOS with participants phone.

Introduction to note-taking (3.30 pm – 3.45pm)

[R] You now have InterestMe on your mobile and smartwatch. At this stage, we are going into the testing phase where we test and verify our design and refine the application. So, can I ask you to use the application on either platform at least twice a week? When you are using the application, please take note of

1) your surrounding?

2) When and Why you are using it?

3) How do you feel when using the application?

4) Any particular screen that you find it "fun", "enjoyable" or "bad"?

You can note down in the note pad that is included in your welcome pack. You can help the group by sharing your test results and these notes will help you recall details of the test.

Reflection (3:45 pm - 4.00 pm)

[R] Now, let's take last 15mins to reflect our session today. Do you enjoy today workshop? Why?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise. See you in the next workshop

Phase Three Workshop 3 Date: 9 September 2018

Recap of last meeting (2:00pm – 2.15pm)

[R] Ok! Let's do a quick recap of the team progress. We have identified some challenges faced by the group and came up with a set of solutions. A mobile + watch app. Together as a team, we will be designing the application by determining the features and the looks and feel of the application. You have the mobile app installed and smart watch given to you in our last meet up. Today, we are gathering feedback so that we can together improve the application. Member checking of Workshop 2 (2:15pm – 2.30pm)

[R] First, I found a few interesting main points from our last workshop. Let me share them with you

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Group Discussion (2:30pm – 3.45pm)

[R] Now, let's go round the table and share your experience with the application.You can consider answering the following:How many times have you used it?What notes have you taken and tell us more about your test?

Researcher to go round table to prompt participants and follow up with questions depending on their responses.

User familiarisation with the app

[R] OK, looks like there is a lot to take in and some of you may find it hard to actually use the application. We should note this down cause we are going to expect anyone who just installed the application to face the same problem. Before we look at the +/- chart, let's do a few rounds of testing by getting each of you send a few messages to the group and private chat.

Researcher to go round table to guide each participants to send a few messages to the group and private chat with other participants from both mobile and watch app. The good and the bad chart

[R] Based on your previous or the "last 10 mins" experience, lets list down the good and bad experience about the application so far. Then we can look at what we can change in the next version based on the chart.

Researcher to go round table to guide participants to list down the good and bad pointers about the application. Researcher can prompt in the area of Features Usefulness Usability Hardware Researcher to write these points on the white board. The Change [R] OK, looks like we have quite a number of items on the board. Let me run through all the pointers with everyone.

Researcher to go run through the pointers and at the same time, marking down repeated point.

[R] We definitely have quite a lot to work on together. Let's first identify the important things to change. I have marked down the points that were mentioned more than once, do everyone agree we should start from this list or are there any important area that you need should be fix or implemented in the next change? *Researcher to wait for participants input.*

[R] OK, these are key things that we should be looking at to change. Let's put a list of priority. 1 - 5. *Researcher to get inputs from participants.*

[R] Let's run through the list 1-5. Discuss the concern, propose a solution and if possible, draw out how you think the app should look like after the change. *Researcher to get inputs from participants.* Reflection (3:45 pm - 4.00pm)

[R] Now, let's take last 15mins to reflect our session today. Do you enjoy today workshop? Why?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise. See you in the next workshop

Phase Three Workshop 4 Date: 14 October 2018

Recap of last meeting (2:00pm – 2.15pm)

[R] Ok! Let's do a quick recap of the team progress. We have identified some challenges faced by the group and came up with a set of solutions. A mobile + watch app. Together as a team, we will be designing the application by determining the features and the looks and feel of the application. We came up with InterestMe V1. You have tested the application and give our feedback in our last workshop. Taking in your design input, I have came up with InterestV2. Member checking of Workshop 3 (2:15pm - 2.30pm)

[R] First, I found a few interesting main points from our workshop. Let me share them with you

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Introduction to InterestMe V2 (2.30 pm - 2.45pm)

[R] Now, let me show you the application we have designed together. *Researcher to state the functionalities of the application and run through both mobile and watch interface.*

Installation to InterestMe V2 and Introduction to remote updates (2.45 pm - 3.30 pm)

[R] I will now install InterestMe onto your phone and after that, we can do a test a few functions together.

Researcher to install software onto participants mobile phone and pair WearOS with participants phone.

[R] The new InterestV2 is from official Google PlayStore so just like any other apps that you have on your mobile, you can update the latest version from PlayStore directly. This way, I can push design updates onto devices quicker. Once there is an update on the application, you should be able to see an "update" available on PlayStore. Separately, I will email your parents to inform them that there is an update to the application.

Researcher to show PlayStore and how to perform an update. Reflection (3:30 pm – 4.00pm)

[R] Now, let's take last 15mins to reflect our session today. Do you enjoy today workshop? Why?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise. See you in the next workshop

Phase Three Workshop 5 Date: 11 November 2018

Recap of last meeting (2:00pm - 2.15pm)

[R] Ok! Let's do a quick recap of the team progress. We have identified some challenges faced by the group and came up with a set of solutions. A mobile + watch app. Together as a team, we will be designing the application by determining the features and the looks and feel of the application. You have done some testing on InterestV2. Today, we are gathering feedback so that we can together improve the application.

Member checking of Workshop 4 (2:15pm – 2.30pm)

[R] First, I found a few interesting main points from our last workshop. Let me share them with you

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Group Discussion (2:30pm – 3.45pm)

[R] Now, let's go round the table and share your experience with the application.You can consider answering the following:How many times have you used it?What notes have you taken and tell us more about your test?

Researcher to go round table to prompt participants and follow up with questions depending on their responses.

User familiarisation with the app

[R] OK, let's we look at doing the +/- chart, let's do a few rounds of testing by getting each of you send a few messages to the group and private chat. *Researcher to go round table to guide each participants to send a few messages to the group and private chat with other participants from both mobile and watch app.* The good and the bad chart

[R] Based on your previous or the "last 10 mins" experience, lets list down the good and bad experience about the application so far. Then we can look at what we can change in the next version based on the chart.

Researcher to go round table to guide participants to list down the good and bad pointers about the application. Researcher can prompt in the area of Features Usefulness Usability Hardware Researcher to write these points on the white board. The Change

[R] OK, looks like we have quite a number of items on the board. Let me run through all the pointers with everyone.

Researcher to go run through the pointers and at the same time, marking down repeated point.

[R] We definitely have quite a lot to work on together. Let's first identify the important things to change. I have marked down the points that were mentioned more than once, do everyone agree we should start from this list or are there any important area that you need should be fix or implemented in the next change? *Researcher to wait for participants input.*

[R] OK, these are key things that we should be looking at to change. Let's put a list of priority. 1 - 5. *Researcher to get inputs from participants.*

[R] Let's run through the list 1-5. Discuss the concern, propose a solution and if possible, draw out how you think the app should look like after the change. *Researcher to get inputs from participants.* Reflection (3:45 pm - 4.00pm)

[R] Now, let's take last 15mins to reflect our session today. Do you enjoy today workshop? Why?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise. See you in the next workshop

Phase Three Workshop 6 Date: 9 December 2018

Recap of last meeting (2:00pm - 2.15pm)

[R] Ok! Let's do a quick recap of the team progress. We have identified some challenges faced by the group and came up with a set of solutions. A mobile + watch app. Together as a team, we will be designing the application by determining the features and the looks and feel of the application. We came up with InterestMe V2. You have tested the application and give our feedback in our last workshop. Taking in your design input, I came up with InterestV3. Member checking of Workshop 5 (2:15pm - 2.30pm)

[R] First, I found a few interesting main points from our workshop. Let me share them with you

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Introduction to InterestMe V3 (2.30 pm - 2.45pm)

[R] Now, let me show you the application we have designed together. *Researcher to state the functionalities of the application and run through both mobile and watch interface.* Installation to InterestMe V3 (2.45 pm – 3.00pm)

[R] I will now install InterestMe onto your phone and after that, we can do a test a few functions together.

Researcher to install software onto participants mobile phone and pair WearOS with participants phone.

Introduction of software release (3.00 pm – 3.45pm)

[R] We have come a long way and completed three iteration (cycle) of InterestMe. We made quite a number changes and improved the application along the way. Let's discuss about implementing the application for the wider community or in this case, at lease with other NQASG members onboard.

[R] What are your views and opinions of getting other NQASG members onboard of InterestMe?

Reflection (3:45 pm - 4.00 pm)

[R] Now, let's take last 15mins to reflect our last two sessions. Do you enjoy the two workshops? Why?

[R] How do you feel about making your own game? Do you feel more interested and confident in joining a session like this in the future?

[R] Anything that you want to highlight that can improve or make the workshops better for you?

[R] Ok! I hope you all have fun taking part in this exercise. See you in the final workshop

Phase Three Workshop 7 Date: 13 January 2019

Recap of last meeting (2:00pm – 2.15pm)

[R] Ok! Let's do a quick recap of the team progress. We have identified some challenges faced by the group and came up with a set of solutions. A mobile + watch app. Together as a team, we will be designing the application by determining the features and the looks and feel of the application. We came up with InterestMe V3. We discussed how we can get other NQASG members on board InterestMe. Today session is mainly about reflecting on our this long journey together. Member checking of Workshop 6 (2:15pm - 2.30pm)

[R] First, I found a few interesting main points from our last workshop. Let me share them with you

Researcher to show themes from Thematic Analysis and prompt participants if they have said those quotes and if they matched with the themes. Reflection (2:30 pm – 4.00pm)

[R] We spent the last six months designing and testing InterestMe. Let's take some time to reflect on this process.

[R] How do you find this design experience on the whole? You like this team? Which part of the workshop is your favorite? How do you find the communication methods in the workshop? Using drawing and discussion? *Researcher to prompt further with follow up questions.*

[R] Which part of the design process do you like the most? Which part of the design process do you think can be improved? *Researcher to prompt further with follow up questions.*

[R] Would you join another design process like this again? Why? *Researcher to prompt further with follow up questions.*

[R] Ok! I hope you all have fun taking part in this exercise and thank you for being part of this amazing journey. InterestMe will continue to move forward with NQASG and we can continue to improve on InterestMe together.