Protecting the Online Safety, Security and Privacy of Autistic Children and Young People

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Abstract

The aim of this PhD thesis was to investigate *how* autistic children and young people experience online safety risks and *what* could help them to navigate such risks in the future. In Study 1, two groups of parents (autistic children, n = 63; non-autistic children, n = 41) completed an online survey about their child's online safety behaviours and wellbeing. Study 2 involved semi-structured interviews with 14 autistic young people aged 11-17 years investigating their first-hand accounts of their online safety experiences. Study 3 piloted two low-fidelity prototype solutions to common online safety scenarios with 11 autistic young people aged 11-18 years, who fed back how these could be improved to help keep themselves safe in the future.

Results indicated that autistic children experienced significantly more online safety risks than non-autistic children and poorer wellbeing than autistic children who did not experience online safety risks.. Secondly, autistic young people reported being victims of cyberbullying and online sexual harassment and a desire for more design support to block online comments and/or individuals. Thirdly, autistic young people fed back that visual cues in low-fidelity prototypes of online safety solutions were beneficial in informing their online safety risk management.

To conclude, this PhD thesis highlights that autistic children and young people are at risk pertaining to certain online safety risks. The findings will benefit designers looking to develop online safety interventions in ways that autistic children will both accept and can actively benefit from. This research will shape the direction of future interventions and policy for this population and thus will help to protect autistic children and young people online.

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First and foremost, I would like to say a massive thank you to all of the autistic young people, and their parents/carers who took part in this PhD research. Without their invaluable input, this PhD thesis would not exist. A special thank you to the autistic adults who gave invaluable feedback at the design stages of the studies. I am so grateful to everyone who took part and that you trusted me to try and make this research with you, and not about you. You have taught me how the world can be a much more interesting and better place if people align themselves with the neurodiversity movement. Ultimately, I hope that the findings from this PhD thesis enlighten others as to how we can help to improve the lived experiences of autistic children and young people.

I will be forever grateful to my PhD supervisors, Dr Tessa Berg and Dr Mike for their expertise, patience and guidance throughout my PhD. Both of you brought refreshing insights and perspectives to my research. This has helped to make me a more rounded researcher, for which I am forever grateful. Ultimately, I would not have got to this point without your support and belief in me, so I cannot thank you enough.

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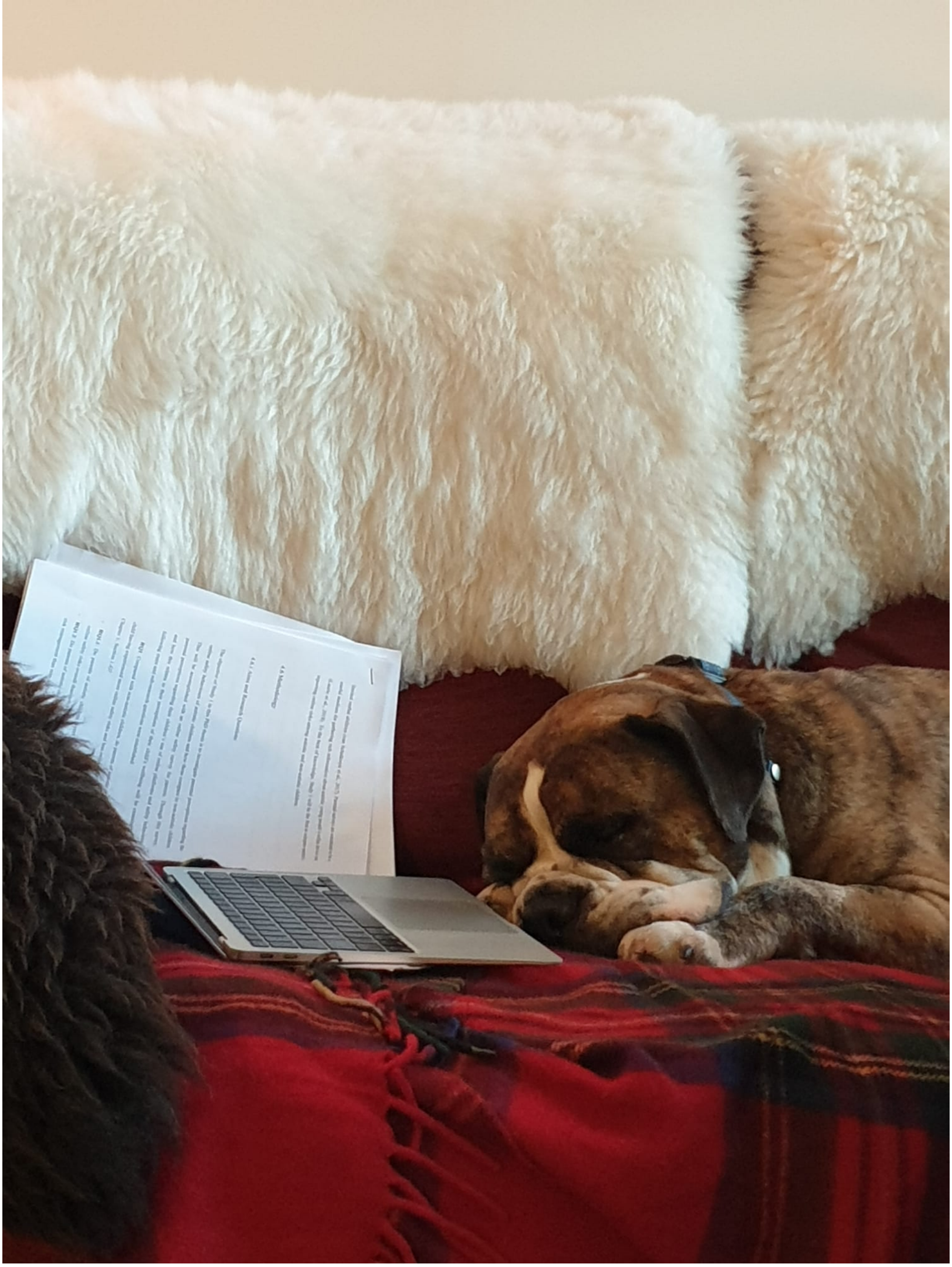
Charles (the family dog) mainly snored as I attempted to write, so he does not get thanked.



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Author 2	Dr Tessa Berg. Contribution: Writing – review & editing
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Author 4	Dr Mary Stewart. Contribution: Writing – review & editing
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Please included additional citations as required.

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List of Publications

This PhD thesis includes two peer reviewed publications:

Chapter 4: Macmillan, K., Berg, T., Just, M., & Stewart, M. (2020). Are autistic children more vulnerable online? Relating autism to online safety, child wellbeing and parental risk management. *Proceedings of the 11th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society (NordiCHI '20),* Association for Computing Machinery. https://doi.org/10.1145/3419249.3420160.

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Language Statement

Within the field of autism research, the language used to describe autism, and those with a diagnosis of autism, has been heavily discussed and debated (Bury et al., 2020; Kenny et al., 2016; Vivanti, 2020). It is often portrayed as a simplistic choice between two terms: person-first ("person with autism") or identity-first ("autistic person")." Both of these terminologies have varying levels of acceptance and preferences between different individuals, and across stakeholder groups, including autistic people, parents, and professionals. For instance, a survey on the language preferences of each of these three groups concluded "the data clearly show that there is not one preferred term to describe autism" (Kenny et al., 2016).

Nevertheless, my primary goals are to use language that is respectful to the autistic population, recognise the challenges that children and adults on the autism spectrum and their families encounter, without singling out autism as a problem that must be eradicated. It is becoming increasing recognised that functioning labels such as "high-functioning and/or low-functioning autism" are inappropriate as an ability to function is not dependent on an intellectual capacities and can vary across time and contexts. For example, studies indicate that autistic adults without an intellectual disability are less likely to transition into supported programmes post-secondary education than autistic adults with a reported intellectual disability (Shattuck et al., 2011; Taylor & Seltzer, 2011). In many cases, these labels do not accurately reflect an autistic person's day to day capabilities and experiences. Therefore, functioning labels can be inconsistent and misrepresentative, leading a majority of the autistic community to reject these terms (Bottema-Beutal et al., 2021l; Fletcher-Watson & Happé, 2019; Silberman, 2015). Therefore, I will not use any functioning labels, such as "high/low functioning" throughout this PhD thesis. Instead, where appropriate, I will refer to “autistic people with or without an intellectual/learning disability,” or “with or without additional support needs.”

An online survey by Kenny et al (2016) revealed that 60% of autistic respondents advocated for the use of identity-first language “autistic” to communicate about autism. This demonstrates that identity-first language has strong support from the autistic community. However, the survey reported that 30% of autistic respondents preferred the person-first stance “has autism” and 25% of the group selected “has autism/Asperger’s syndrome” or “person with autism/Asperger’s Syndrome”. A study of 198 adults who reported having a diagnosis of autism, ‘Autistic’, ‘Person on the Autism Spectrum’, and ‘Autistic Person’ were rated most preferred and least offensive terms (Bury et al., 2020). In order to honour the diversity in language preferences of autistic people and stakeholder groups, I will therefore be using a mixture of terms throughout this PhD thesis. This will include “autistic children/young people”, and “children/young people on the autism spectrum”. Where research on children without autism is described, I will use a mixture of terms such as “non-autistic children”, and “neurotypical children.” As recommended by Gernsbacher (2017), I will not use different language constructions in the same sentence to describe different groups, to avoid stigmatisation.

It is worth noting that the current diagnostic criteria in the fifth edition of the *Diagnostic and Statistical Manuel of Mental Disorders* (DSM-V; APA, 2013) uses the term “Autism Spectrum Disorder” (ASD). However, it is well documented that the use of the word “disorder” is disliked and rejected by many autistic people and stakeholders (Fletcher-Watson & Happé, 2019; Bottema-Beutal et al., 2021). From now on, I will use “autism” rather than “ASD” in this PhD thesis.

1. Chapter 1: Introduction

1.1 Chapter Summary

The overarching aim of this thesis is to explore the online safety behaviours among autistic children and young people, specifically investigating how this population experiences online safety risks and what factors help them to manage them. Despite evidence that online platforms are beneficial to autistic people, a literature review (see Chapter 2) indicates that autistic children and young people could be considered an “at risk” group for online safety issues. Concerns regarding the impact of online devices are common among researchers, policymakers, and the general public, with particular questions about the way that technology might influence social development in children and young people (Hollis et al., 2020; Livingstone et al., 2020). For autistic children and young people, who may experience difficulties in social interaction and communication, these worries may be exacerbated (Laurie et al., 2019). This PhD thesis includes three main studies which aim to explore *how* autistic children and young people experience online safety risks and *what* could help them to navigate these scenarios in the future. The first section of this chapter will define key terminology before outlining the structure of this PhD thesis. Finally, I will outline the key research questions.

1.2 Definition of Key Concepts and Categorisations

Online safety risks can be categorised into **contact risks** (where the child participates in risky peer or personal communication), **content risks** (where the child is a recipient of unwelcome or inappropriate communication) and **conduct risks** (where the child acts themselves to contribute to the risky contact or content) (Hasebrink et al., 2008; Staksrud & Livingstone, 2009). Examples of contact risks include sexual grooming and cyberbullying. Content risks cover phishing attacks and downloading harmful malware, while conduct risks include, but are not limited to, inappropriate posting and unauthorised spending.

‘Smart’ also known as ‘online’ devices (from here on out ‘online devices’) can be defined as objects capable of communication and computation which range from simple sensor nodes to more advanced technological appliances (Risteska Stojkoska & Trivodaliev, 2017). The term ‘online devices’ will mostly be used throughout this PhD thesis to describe devices used that connect via the internet e.g., smartphones, tablets.

Technology systems (i.e., machines) refer to devices or software which take input (i.e., information, such as the push of a button), process or change this information, and produce an output (i.e., a response, such as changing the channel on a television, or new information). Such systems can include devices which people typically use in everyday modern life, such as smartphones, tablets, and computers (Laurie, 2020, p.1).

In this PhD thesis, I will explore whether autistic children and young people are subject to all or certain types of online safety risks. I will focus on how autistic children and young people experience online safety risks and what could help them to navigate these scenarios in the future. The remainder of this general introduction will provide an overview of the PhD thesis structure and research questions.

For clarity, ‘autistic children’ will refer to autistic children aged 11 years and under. Therefore, the term ‘autistic young people’ will be used to refer to those aged 11-17 years and ‘autistic adults’ for those aged 18+ years throughout this PhD thesis, where appropriate.

1.3 PhD Thesis Structure

Chapter 2 will provide a background to autism, particularly communication and focussed interests. Developmental theories of autism will be discussed. Research regarding online device use among the autistic population will be evaluated. Next, the existing literature regarding online safety behaviours among autistic people and stakeholders will be evaluated.

Chapter 3 will discuss the methodological considerations for this PhD thesis. Considering the existing literature review discussed in the previous chapter, the inclusion of a non-autistic comparison group, confounding variables and generalisability of the existing findings among autistic adults to autistic children and young people will be discussed. In this chapter, strategies to tackle the representation of autistic children and young people with limited or no expressive language in research will be discussed. In terms of qualitative methodologies, these will be discussed in terms of capturing autistic children and young people’s lived experiences. With regards to the growing shift away from a medical framework, the moves taken towards inclusive methods for autism research will be outlined. Together these will provide the context for the PhD thesis methodologies.

Chapter 4 will outline the background, methodology and results from a peer-reviewed, published article from this PhD thesis (Macmillan et al., 2020). In this chapter, parental perceptions regarding autistic and non-autistic children's use of online platforms and safety behaviours, and how this relates to child wellbeing and parental self-efficacy will be investigated. This will address a key question from this PhD thesis (see Section 1.4; **RQ1**). The chapter will focus on whether or not parents of autistic children report their child having experienced more online safety risks and less online safety risk management.

Chapter 5 focusses on a recently published, peer-reviewed interview study regarding autistic young people's lived experiences of online safety (Macmillan et al., 2022). The background, methods, results and discussion will be outlined. To date, limited research has explored autistic young people's perceptions of their online safety experiences. This qualitative study explored autistic young people's experiences of communicating with others online, as well as their online safety experiences (see Section 1.4; **RQ2**). The findings will be discussed in relation to the next steps of this PhD thesis.

Chapter 6 will outline the final study from this PhD thesis. From the very few published studies in this area, most have focussed on parental perspectives regarding their autistic children's online safety. To the best of knowledge, no co-participatory research has examined the preferences of autistic children, regarding how they keep themselves safe online. This chapter will include the background literature, methods, results and findings from the final, re-designed enquiry from this PhD thesis. In line with ethical guidelines during the COVID-19 pandemic, the data collection phase consisted of virtual, one to one co-design interviews. The aim of this study was to investigate autistic young people's perceptions of online safety scenarios and explore their online management preferences (see Section 1.4; **RQ3**). This helped to address one of the key research questions regarding what online safety tools autistic young people desired and envisage themselves using to help inform future studies.

In Chapter 7, a general discussion will summarise the findings of this PhD thesis. Limitations of this PhD thesis and future directions for this area will be highlighted. This chapter will evaluate the potential implications of these for informing autistic people, stakeholders, researchers, practitioners and policy makers about how to help keep autistic children and young people safe online. Overall, recommendations will be made regarding the design of future online safety tools to aid autistic young people's online independence.

1.4 Research Questions

In summary, the key questions of this PhD thesis are:

RQ1: Compared with non-autistic children, do parents of autistic children report their child having experienced more online safety risks and less online safety risk management (see Chapter 4)?

RQ2: What are autistic young people's lived experiences of online safety, managing online safety risks and preferences in terms of improving their online safety experiences (see Chapter 5)?

RQ3: What online safety tools do autistic young people desire and envisage themselves using, and specifically what features do they require from these tools (see Chapter 6)?

The following chapter will introduce the reader to a background in autism, and developmental theories. This will include existing literature regarding communication and focussed interests among this population. In turn, this will allow a greater understanding of how and why autistic children and young people use online devices. Limited research has investigated autistic online safety behaviours and experiences. These will be evaluated in the literature review. Consequently, this will outline the rationale for this PhD thesis.

2. Chapter 2: Literature Review

2.1 Chapter Summary

This chapter will provide an overview of the existing research literature in this area. A background to autism will be provided, with an emphasis on studies examining communication and focussed interests among this population. Autism online device use will be explored and how these relate to areas of interest in autism. This will lead to a discussion regarding the current literature regarding online safety behaviours and experiences among autistic children, young people, adults and stakeholders.

2.2 Background to Autism

Autism (American Psychiatric Association [APA], 2013) is characterised by difficulties in social interaction and communication skills, accompanied by a restricted repertoire of interests and behaviours and by atypical sensory reactivity. Prevalence rates are estimated to be 1/132 worldwide (Baxter et al., 2015) and 1/100 in the United Kingdom (UK) (Baird et al., 2006; Shtayermman, 2007). However, more recent estimates suggest that these may be closer 1.5-2% of the global population (Christensen et al., 2016).

Research suggests that the discrepancies between current estimated prevalence and the true prevalence rates of autism are influenced by changes in diagnostic criteria (Wing et al., 2011), including increased diagnosis of autism without learning difficulties (Gernsbacher et al., 2005), and diagnostic misattribution of autism over mental health conditions (Charman et al., 2009). A survey of over 1,000 parents of autistic children revealed that barriers to receiving or accessing an autism diagnosis are impacted by intersectional factors such as being from a minority community, socioeconomic status, and issues in the provision of autism services across the UK. Autism is highly heritable and persists across the lifespan (Mandy & Lai, 2016). Therefore, autistic children and young people transition into adults on the autism spectrum. On one hand it can be challenging to diagnose autism in children aged less than 2 years (Howlin & Moore, 1997). Given that issues regarding the reliability and validity of autism assessment exist as well as barriers to receiving a diagnosis, many autistic people choose to self-verify or diagnose (Lewis, 2016; Lewis, 2017; McDonald, 2020), therefore it is important that this population is included and represented in research. Nonetheless, diagnosis rates are increasing among autistic adults (Blumberg et al., 2013; Brugha et al., 2011).

Autism is diagnosed more commonly among males than females, with a male to female ratio among clinical samples of around 4:1 (Fombonne, 2009). However, in non-clinical samples, the ratio decreases to 3:1 (Loomes et al., 2017; Sun et al., 2015). This suggests that many females who meet the criteria for autism do not come to clinical attention. There are gender-differences in autism presentation. Autistic females have been found to demonstrate greater social motivation (Sedgewick et al., 2016), fewer externalising behaviours (Mandy et al., 2012) and fewer restricted and repetitive behaviours (van Wijngaarden-Cremers et al., 2014) than their male-counterparts. Compared with males with similar levels of autistic characteristics, females need to exhibit more intellectual or behavioural problems in order to meet the diagnostic criteria (Dworzynski et al., 2012). Researchers have argued that autistic females are at an elevated risk of being misdiagnosed or undiagnosed (Lai & Baron-Cohen, 2015). Compared with males, autistic females who do gain a diagnosis tend to receive this diagnosis later in life (Begeer et al., 2013). Therefore, it is important that autistic females are included, and represented in the research field.

Having autism often co-occurs with an intellectual disability (Elsabbagh et al., 2012). It is important to distinguish between the characteristics of autism from co-occurring conditions, which may be misattributed to autistic traits. In terms of expressive language, the evidence from the current literature indicates a large amount of heterogeneity within the autistic population. One study, sampling children in a UK health district, reported low levels of verbal ability in a high proportion of autistic mainstream pupils (Keen & Ward, 2004). Research within the past decade suggests that between 15 and 25% of autistic children are minimally or non-verbal (Norrelgen et al., 2015), but most people on the autism spectrum do develop a degree of expressive verbal language (Brignell et al., 2018). At this point, it is important to acknowledge many autistic people who may be described as “non-speaking” prefer and choose other forms of communication over speech (Poulsen et al., 2022). Therefore, it should be acknowledged that this is not necessarily related to intellectual disability and it is important that the views and perspectives of non-speaking autistic people are included in research.

Research has highlighted that autistic individuals experience higher rates of distress in response to stress (Jang et al., 2011; Murphy et al,. 2009) and mental health issues, including anxiety and depression (Simonoff et al., 2008; White et al., 2009). Although it difficult to pinpoint a specific underlying cause underlying this increased vulnerability, it has been put forward that autistic people who engage in higher levels of masking (also known as camouflaging) whereby they try to avoid behaving in ways that are associated with being autistic are more likely to have anxiety and depression than those who do not engage in as much masking regardless of gender or intellectual disability (Hull et al., 2021). Therefore, it is important to investigate factors relating to wellbeing among individuals in this often vulnerable population.

2.3 Developmental Theories of Autism

Within autism research, it has been put forward that a theory that explains for the social differences in autism should be able to: explain all features of autism that systematically occur together; be applied universally to all autistic people; and is unique to autism (see Tager-Flusberg, 2007 for a review). To date, the following cognitive theories have been examined in terms of how much they align with the above statements.

Proponents of the ‘Theory of Mind’ hypothesis have claimed that autism is caused primarily by a specific inability to impute mental states to oneself and others (Baron-Cohen et al., 1985; see Tager-Flusberg, 2007). However, other studies have reported no significant differences in theory of mind abilities in autistic people (Bowler, 1992; Bowler, 1997; Ozonoff et al., 1991; White et al., 2006). Moreover, a more recent review concluded that various theory of mind tasks failed to relate to each other and replicate previous findings, thus argued that this theory is empirically questionable, and harmful in terms of societal understanding of autism (Gernsbacher & Yergeau, 2019).

Alternatively, others have proposed that the autism behavioural phenotype emerges from more pervasive problems either in executive function, higher order cognitive processes that underlie purposeful, goal-directed behaviour (Hill, 2004; Russo et al., 2007) or in central coherence, the ability to process information in context (Mottron & Burack, 2001; Plaisted, 2001). Both hypotheses have supporting and limiting evidence. On one hand, the primary problems in specific domains have been criticized for being too narrow and not accounting for the full range of autistic symptoms. On the other hand, those that propose more general information processing difficulties have been criticized for being too broad, thereby not accounting for strengths that are also characteristic of autism (Rajendran & Mitchell, 2007).

According to Happé et al (2006), it is likely that a combination of cognitive risk factors (i.e., deficits or delays in theory of mind, executive functioning and weak central coherence) give rise to the core aspects of the behavioural phenotype. Evidence suggests that autistic people show differences across all of these domains (Pellicano et al., 2006). This demonstrates that there is a continuum of social and cognitive ability across the autism spectrum.

In recent years, there has been growing momentum for a social model of autism. Before this, difficulties in social interaction have been traditionally conceptualised as an autistic impairment. However, there is increased recognition that these difficulties may arise from a bidirectional mismatch of communication styles between autistic and non-autistic people, also known as the ‘double empathy problem’ (Milton, 2012a). Earlier research proposed that autistic people had challenges understanding complex facial emotions of non-autistic people (Baron-Cohen et al., 1997). Recent evidence indicates that non-autistic people demonstrate difficulties understanding the mental states of autistic people (Edey et al., 2016). This lends support to the theory that there are two-way communication challenges between autistic and non-autistic people. Moreover, it has been demonstrated that communication occurs more effectively within pairs where both members are autistic than within mixed autistic/non-autistic pairs (Crompton et al., 2020a). Therefore, there is evidence that autism can be better understood using a social model, such as Milton’s (2012a) double-empathy framework, which states that successful interactions will involve co-operation from both autistic and non-autistic people.

Alternatively, it has been put forward that the core features of autism are best explained by a difference in the way autistic people distribute their attention, thus account for the restricted range of interests in the diagnostic criteria for autism. This is known as theory of monotropism (Murray et al., 2005). The authors suggested that the amount of information available to an autistic person at any given is limited. Compared with non-autistic autistic people who have a broad use of attention, they indicate that autistic people are genetically predisposed to focus their attention on interests (Milton, 2012b). Murray et al (2005) proposed that language and the shifting of object attention rely on having a broad attention, therefore may explain why these can vary among autistic people who tend to have concentrated attention. Moreover, it could account for sensory processing difficulties reported by autistic people due to hyper- and hyposensitivity of sense within the attentional tunnel (Milton, 2012b; Murray, 2019). It is acknowledged that limited published research has assessed the validity of this theory. Researchers have posited that theoretical differences in how it is measured in different disciplines and clinical practice makes it a challenge to investigate (Ashinoff & Abu-Akel, 2021). Nevertheless, a study conducted with 10 autistic secondary school pupils indicated that being allowed to pursue their focussed interests in school helped them to improve their social and academic participation in school (Wood, 2021). Overall, more research involving autistic children and adults will help to test the applicability of this theory in understanding the daily experiences of autistic people.

2.4 Communication in Autism

Autism is characterised by deficits, delays and deviancies in communication skills (APA, 2013). It is widely reported that autistic people experience difficulties in communicating (Wing & Gould, 1979). However, studies of emotion processing have yielded inconsistent results. Studies using a recognition paradigm with basic emotions (e.g., happy, sad, angry) often report ceiling effects or fail to find differences between autistic and non-autistic individuals (Loveland et al., 2008; Rutherford & Towns, 2008; Spezio et al., 2007a, 2007b). Nevertheless, emotion recognition research which has used either more complex emotions (e.g., guilt), dynamic stimuli, or emotions with lower intensity have indicated impaired performance in autistic adults (Baron-Cohen & Wheelwright, 2001; Golan et al., 2006; Philip et al., 2010). Moreover, it is well documented that many autistic children and adults struggle with direct eye contact and will try to avoid it (Sengu & Johnson, 2008; Madipakkam et al., 2017). These results suggest that autistic children and adults may struggle with the demands of complex emotion recognition and communication.

There is a strong consensus among researchers that having positive peer relationships is important for developmental outcomes (Bierman, 2005). As autism is associated with differences in social communication, this is likely to have an impact on peer relationships, particularly if autistic people are engaging with non-autistic people who may not share the same communication preferences. Therefore, communication differences associated with autism can have a negative impact on peer relationships. Evidence suggests that this is a challenge for the autistic population. Non-autistic people have been found to give more negative interpersonal ratings of autistic adults based on “thin slices” of information (Sasson et al., 2017; Stagg et al., 2014). Studies have reported that autistic children have fewer friends (Humphrey & Symes, 2011) and experience higher levels of loneliness (Bauminger & Kasari, 2000) and more peer rejection compared with their non-autistic peers (Humphrey & Lewis, 2008a; Humphrey & Lewis, 2008b; Symes & Humphrey, 2010).

Autistic adults who strive for more social connectedness are more likely to be at risk for depression and social anxiety (Mazurek, 2013). Previous research has highlighted that social isolation has a negative effect on self-worth (Boulton et al., 2010). Studies have highlighted that autistic children and adults experience higher rates of distress in response to stress (Jang et al., 2011; Murphy et al., 2009) and mental health issues, including anxiety and depression (Simonoff et al., 2008; White et al., 2009). Therefore, autistic children and adults are at a higher risk of experiencing poorer wellbeing due to communication difficulties.

2.5 Focussed Interests in Autism

Focussed (sometimes referred to as ‘special’) interests have been described as “restricted”, “circumscribed” and “obsessions” in autism diagnostic criteria and previous research (Grove et al., 2018). However, autistic advocacy groups have encouraged people to consider them as “deeply focussed thinking and passionate interests in specific subjects” (ASAN). Between 75 and 95% of autistic people report having a focussed interest in particular topic area (Klin et al., 2007; Turner-Brown et al., 2011). Therefore, it is an area of which has a large degree of importance to the autistic community.

There is much debate surrounding the impact of focussed interests in the autistic community. On one hand, some authors claim that these interests lead to difficulties in social interaction (Klin et al., 2007) and functional impairment (Turner-Brown et al., 2011). However, others argue that focussed interests have a more positive impact and are associated with areas of strength and ability, such as increased social interaction, enthusiasm, and motivation (Mercier et al., 2000; Winter-Messiers, 2007). Recent studies suggest that these interests are also of significant importance to autistic adults. A qualitative study asked autistic young people to identify their strengths and coping methods. Participants reported that their focussed interests allowed them positive emotions and coping strategies and included skills or activities that induced a sense of pride (Teti et al., 2016). Another study among autistic adults reported that focussed interests were identified by the participants as calming and had helped, rather than hindered them in life (Koenig & Williams, 2017). Consequently, focussed interests are indicated to be important for wellbeing in the autistic population. Therefore, it is important to consider how these influence autistic children and young people's daily experiences. Studies have reported that online devices have been ranked as a frequent interest among autistic adults (Grove et al., 2018). Considering this, it is likely that an interest in online devices will have a large impact on autistic children and young people's online safety experiences to a large extent.

2.6 Autistic Online Device Use

2.6.1 Online Device Use Among Neurodivergent Groups

Online platforms may provide a haven for people who are neurodivergent. Researchers have suggested various explanations. This includes the lack of nonverbal feedback, social status cues, anonymity and different pace of online communication, thus neurodivergent individuals are more likely to use online platforms to enable self-expression and form new relationships (Guo et al., 2005; McKenna & Bargh, 1998; Morahan-Martin & Schumacher, 2003). This is supported by findings that lonely individuals use social networking sites to establish close relationships with peer groups that may be the individuals' primary sources of social support and can reduce loneliness and depression and increase their life satisfaction (Reinecke & Trepte, 2014; Dienlin et al., 2017; Utz & Breuer, 2017). Studies indicate that up to 97% of students with intellectual disabilities have access to the internet (Didden et al., 2009). Therefore, online platforms can help to alleviate loneliness among vulnerable individuals, particularly those with developmental disabilities.

2.6.2 Online Device Use and Communication Among Autistic People

Autistic people report high levels of use of technology and online devices for both leisure purposes and academic study (Hedges et al., 2018; Grove et al., 2018; Kuo et al. 2014; MacMullin et al. 2016; Mazurek & Wenstrup 2013). Previous studies suggest that autistic children spent more time playing video games per day than typically developing children (Mazurek & Engelhardt, 2013), typically developing siblings (Mazurek & Wenstrup, 2013), and those with other disabilities (Mazurek et al., 2012). Anecdotal reports indicate that the internet promotes social interactions among autistic people via chat rooms, bulletin boards and discussion lists (Blume, 1997). Among typically developing individuals, social networking site use has been found to predict high social support, which in turn related to low levels of depression and high life satisfaction (Frison & Eggermont, 2015). This would suggest that autistic people would use social media sites to communicate with other people. van Schalkwyk, Ortiz-Lopez et al (2017) found that social media use positively correlated with friendship quality in a sample of autistic young people. Moreover, a qualitative study with 58 autistic adults indicated that around 20% of them played videogames for social connection (Mazurek et al., 2015), echoing the findings from the previous research literature.

According to Powell (1995), online platforms will 'begin to put the individual with autism into situations which are *custom built* to provide learning about human thinking and behaviour' (p. 131). Autistic adults have reported social media as a comfortable medium for communicating with other people (Mazurek, 2013). It is possible that online devices remove factors associated with common difficulties in autism such as direct eye-contact, unpredictability, processing concurrent speech and facial expressions at given times, thus autistic young people and adults may find social media more beneficial than their non-autistic peers. Gillispie-Lynch et al (2014) found that autistic adults rated social media as more useful than the non-autistic participants, in particular such sites allowed them more time to formulate a response than in-person interactions. This is supported by other findings that online devices reduce the discomfort and anxiety that autistic adults feel in face-to-face interaction because they can interact in a familiar place and it makes communication more predictable (Bagatell, 2010; Benford & Standen, 2009; Murray, 1997). From the few studies that have investigated autistic young people's online communication, results have indicated that autistic young people who use social media report greater security and quality in their friendships (Kuo et al., 2014) and the platforms removed offline barriers such as eye contact (Gillespie-Smith et al., 2021). Therefore, there are associated benefits of online devices in terms of communication for autistic children, young people and adults.

2.6.3 Online Device Use and Focussed Interests Among Autistic People

Despite difficulties linked with associated with focussed interests, technology is one of the most popular items of areas of interest in the autistic population, and research has revealed that these are paramount to wellbeing in autistic people (Grove et al. 2018). Symbolic play refers to pretend play behaviors, including object substitutions to represent real life concepts (Smith & Jones, 2011). Studies have suggested that when autistic children are engaged in a task in a more structured setting, levels of symbolic play increase (Rowland & Schweigert, 2009). One study reported that three out of five autistic adolescents who had the "best" friendships had similar interests, such as computer games (Barnhill, 2001). This is supported by previous studies that high quality peer relationships among autistic adolescents tend to revolve around specific shared interests (Church et al., 2000). Studies suggest that children on the autism spectrum are motivated by computer-based instruction and are particularly skilled at using computers (Moore & Calvert, 2001). Researchers have put forward that such platforms may provide a window of opportunity where children on the autism spectrum can encounter tools and symbols that could be used to support and enrich social interactions (Jacklin & Farr, 2005).

Online gaming has emerged as a favoured platform among many autistic children and young people. In a pilot study, a group of autistic children's social skills were assessed with the Eyberg Childhood Behaviour Inventory before and after the online computer game Minecraft, together with group exercises. The results indicated an increase in parent rated social skills in seven out of the eight autistic children, post intervention (Frank et al., 2013). It is worth noting here that social skills rating scales are often based on neurotypical norms, thus may mask observations and appreciation for autistic led style of play. This is supported by other evidence that children on the autism spectrum more readily communicate and play together whilst using technology compared to analogue counterparts (Farr et al., 2010; Hetzroni & Tannous 2004). A study of 85 autistic adolescents and adults and 71 non-autistic controls compared self-reported online gaming, loneliness and friendships. Within the autistic group, those who played online games had more friends than those who did not. Moreover, over 40% of the autistic sample stated that they had met a close friend through an online game (Sundberg, 2018). These results suggest that such increases in social interactions help to alleviate feelings of loneliness commonly reported in this population.

Autistic people are also believed to have strong interests in technology and can be highly skilled in using technology (Clark & Adams, 2020; Ramdoss et al., 2011). Concerns about the impact of technology on the social interaction of autistic children have been shared by both parents (Mazurek & Engelhardt, 2013; Mazurek & Wenstrup, 2013) and educational practitioners (Clark et al., 2015; King et al., 2014, 2017). However, other studies have suggested that technology could be a beneficial way for autistic people to socially connect with others, particularly through online platforms such as social media and video games (Durkin & Conti-Ramsden, 2014; Gillespie-Lynch et al., 2014; Mazurek et al., 2015), but also through developing connections with others through shared media interests, such as cartoons (Fletcher-Watson & Durkin, 2015).

2.6.4 Concerns Regarding Autistic People's Use of Technology

Nevertheless, while online device use may help to facilitate social communication among autistic individuals, authors have reported that more time is spent in non-social online activities than social online activities (Mazurek et al., 2012). Other researchers have argued that preoccupation with screen time activities can become problematic among this group of users (Mazurek & Wenstrup, 2013; Nally et al., 2000). One study estimated that autistic adolescents spend around two hours per day watching television and five hours playing electronic games (Kuo et al., 2014). High screen time has been associated with poor health outcomes such as increased sleep problems and has also been identified as a barrier to physical activity among autistic children (Engelhardt et al., 2013; Must et al., 2015). Other researchers have claimed that autistic adults are more likely to develop compulsive internet usage than non-autistic adults (Finkenauer et al., 2012). Nevertheless, other large-scale studies have refuted these findings. The National Survey of Children's Health 2011-2012 asked parents of autistic children (n = 1, 393) and non-autistic children (n = 64, 163) to report their child's average daily media use. Compared with the non-autistic children, autistic children did not spend significantly more time online (3.21 hours vs 3.46 hours per day) (Montes, 2016). In a recent cross-sectional study, the authors reported that when they compared time spent on social media between 26 autistic and 24 non-autistic young people, there was no significant difference in time spent online (Alhujaili et al., 2022). Therefore, although previous findings indicate that autistic children and young people use social media and spend time online for other purposes, assumptions regarding autistic screen time should be treated with caution.

2.7 Autism and Online Safety

As mentioned previously (see Chapter 1; Section 1.2), online safety risks can be categorised into contact risks (where the child participates in risky peer or personal communication), content risks (where the child is a recipient of unwelcome or inappropriate mass communication) and conduct risks (where the child acts themselves to contribute to the risky contact or content). Each category and associated research (where possible) will be outlined in the following sections.

2.7.1 Online Contact Risks

With regards to contact risks (see Chapter 1; Section 1.2), existing studies suggest that autistic young people may be susceptible to experiencing these. One concept is that online contexts promote a more "autism friendly" environment for this population to communicate. Many autistic adults use social media for interactions, with some stating a preference for online over face-to-face communication (Gillespie-Lynch et al., 2014; Mazurek & Wenstrup, 2013). An online survey of 291 autistic adults responses revealed that online contexts allowed for more control over the pace and increased comprehension of online interactions (Gillespie-Lynch et al., 2014). Psychological theories posit that autistic and non-autistic people have difficulties understanding each other, which can lead to breakdowns in two-way social interactions (Milton, 2012a). The increased reliance of online communication, together with difficulties understanding communication with non-autistic people, may together increase the risk of cyberbullying victimisation.

Recent evidence suggests that autistic adults are socially motivated, desire interactions with others and this is beneficial to mental health and wellbeing contrary to the social motivation hypothesis (Maitland et al, 2021). Therefore, autistic people may seek out online interactions. However, previous researchers have proposed that online platforms may allow people to misrepresent themselves to autistic users, placing them at risk of being exploited (Benford, 2008). Adult studies have raised some of the issues that autistic females face. A recent study found that 79% of autistic women had suffered sexual exploitation or abuse compared with 26% of non-autistic women (Sedgewick et al., 2019). Another qualitative study used semi-structured interviews with six autistic women aged 19 to 29 years. Key themes from the interviews included relationship violence and abuse, child sexual exploitation and rejection. One participant disclosed that she had experienced online grooming (Landon, 2016). These results indicate that autistic females may be vulnerable to online sexual exploitation. However, it is unclear if the same pattern exists for all autistic young people, or if it is specific to autistic young females. Page et al (2022) carried out an ethnographic study using field observation with eight autistic adults, four parents of autistic adults and 10 staff working at an autistic support service. Using an iterative coding process, the findings indicated that autistic adults shared personal information such as addresses and phone numbers that were linked with online sexual exploitation and cyberbullying. These indicate that autistic adults are subject to specific types of online contact risks.

To date, few studies have probed the online safety behaviours of autistic children and young people. A focus group study involving school staff supporting autistic pupils reported concerns that pupils were talking to strangers online (Laurie, 2020). To date, few published studies have examined autistic young people’s attitudes regarding online safety risks. One qualitative study carried out semi-structured interviews with eight autistic young people and six parents regarding their experiences of online social media relationships and risks. Barriers to online engagement detailed abusive interactions and talking to strangers (Gillespie-Smith et al., 2021). This supports previous findings that autistic children could be vulnerable to cyberbullying. In a recent study, Rocheleau and Chiasson (2022) conducted interviews with 12 autistic (mean age = 14.9 years) and 16 non-autistic young people (mean age = 14.7 years). Thematic analyses revealed that were more averse to talking to others online. These findings suggest that autistic young people may avoid chatting to others online as a means of protecting themselves. Nevertheless, further investigation is warranted in order to explore whether autistic young people report similar experiences, and this exists regardless of gender.

2.7.2 Online Content Risks

Phishing or hacking involves the "unauthorised use of, or access into, computers or network resources, which exploits identified security vulnerabilities in networks" (McGuire & Dowling, 2013, p.5). Therefore, detecting these attempts will involve identifying visual cues that such links are fake or untrustworthy. Autistic adults can outperform their non-autistic peers on visual search tasks (Shirima et al., 2017). Such enhanced perceptual abilities may help autistic children and young people detect potential content risks (see Chapter 1; Section 1.2). A recent phishing study compared 15 autistic versus 15 non-autistic adults performance on distinguishing between real websites from fake counterparts. No significant differences in detection accuracy were reported (Neupane et al., 2018). There have been no studies testing such theories among autistic children and young people. Research suggests that autistic children struggle to inhibit responses and actions to risky scenarios (Christ et al., 2007), particularly if it is associated with an area of interest or reward (Mosconi et al., 2009). Thereby, the heterogenetic nature of autism may make some autistic children and young people less prone to certain online safety risks such as phishing than other risks. Nonetheless, no published studies out with this PhD thesis to date have investigated these hypotheses among this population.

2.7.3 Online Conduct Risks

Considering the evidence regarding potential inhibitory control among autistic children and young people, this may account for why they may be subject to "conduct" risks (see Chapter 1; Section 1.2). Just and Berg (2017) reported on the results of two workshops with 16 parents/carers of autistic children and young people in which they used pictures and group discussions to identify online safety concerns. Focus group findings revealed that risks included unauthorised purchases and inappropriate posting on social media sites. These findings suggest that autistic children and young people may experience difficulties anticipating the potential consequences of their online decision making. However, these studies were carried out with parents/carers of autistic young people. Given that online safety risks may not all be captured by parental reporting and few studies have been conducted in this area, it is important that more research is conducted in this area, particularly involving autistic children and young people.

2.8 Overview of the Current Research

To date, little research has examined *how* and *what* autistic children and young people's online safety experience, in terms of their online safety risks. From the few studies published, these have been predominantly carried out with autistic adults, parents/carers or have lacked a control group. Moreover, there is a lack of research that investigates the lived experiences of autistic children and young people with regards to how they experience online safety. With regards to autism and technology interventions, authors have highlighted issues, particularly a lack of efficacy and ecological validity (Fletcher-Watson & Durkin, 2015; Valencia et al., 2019). Researchers have highlighted that inconsistencies in published success rates of online interventions for autistic people can be largely attributed to a lack of user involvement in the design process (Fletcher-Watson et al., 2016). Therefore, it is crucial that these are investigated before recommending the design of online safety tools. It is thereby necessary to ensure that the online safety incidents, behaviours and overall experiences of autistic children and young people are studied more closely, before any discussion regarding solutions or interventions can be considered.

3. Chapter 3: Methodological Considerations

3.1 Chapter Summary

This chapter will discuss various methodologies which have been employed in the field of autism and online safety. Recurring issues in autism research will be outlined. This will include the generalisability of results from autistic adult samples to autistic children and young people. The inclusion of autistic children and young people with limited or no expressive language will be highlighted and strategies for representing them in this PhD thesis will be highlighted. Moreover, methodologies focussed on autistic children and young people's lived experiences will be discussed. In this chapter, the existing literature regarding inclusive methods for autism research will be outlined. Together, these will provide the context and rationale for the methodologies and methods chosen for this PhD thesis.

3.2 Generalisability of Research Findings Among Autistic Adults to Autistic Children and Young People

From the few existing studies that have investigated online contact and content risks among the autistic population, these have been conducted predominantly with autistic adult samples (Landon, 2016; Neupane et al.. 2018; Sedgewick et al., 2019). Autistic children and young people transition into adults on the autism spectrum (Mandy & Lai, 2016). Therefore, these findings may give some insight into how these risks could affect younger autistic people. Nevertheless, it is unclear if these findings can be generalised to the wider population of autistic people, including children and young people. Moreover, it is likely that age influences online device use. For example, studies have indicated that non-autistic children access the internet from mobile devices at increasingly younger ages and demonstrate awareness of content risks (Mascheroni & Ólafsson, 2016; Zhao et al., 2019). Therefore, it is important to investigate online safety behaviours and experiences among children and young people to examine if findings among adult samples extend to or converge from this age group. Consequently, the studies outlined in this PhD thesis will investigate online safety behaviours and preferences among autistic children and young people (see Chapter, 4, 5 and 6, respectively).

3.3 Autism Specificity Regarding Online Risk Behaviours

It is important to understand if online device use and online safety behaviours vary between autistic and non-autistic children. Prior studies have found inconsistent results as to whether autistic children and young people engage in less in socially interactive media than non-autistic children and young people (Alhujaili et al., 2022; Mazurek et al., 2012). Considering that contact risks will involve interaction with others' in online contexts, it is possible that these may be less likely to affect certain autistic children and young people? However, the majority of previous research did not have a non-autistic, comparison group. This makes it difficult to establish if any differences are specific to autism. Given that there is limited research investigating online safety risks experiences and strategies used by autistic children and young people, this PhD thesis will include a foundational study, comparing parental perceptions of online safety risks and behaviours of autistic and non-autistic children (see

Chapter 4). Therefore, it will include a non-autistic, comparison group. By doing so, this will help to explore if an increased vulnerability to all or certain risks online is autism specific.

3.4 Confounding Variables Regarding Online Device Use

Previous research has predominantly measured only time spent online to gage peoples online behaviours (de Vreese & Neijens, 2016; Mazurek et al., 2015; Stiller & Mößle, 2018). Nevertheless, it is unclear whether the amount of time spent online or devices used is a reliable predictor of online safety risks experienced. Having a sole focus on screen time fails to consider how individuals use online devices and if other important factors such as age or pre-existing conditions influence the likelihood of encountering online safety risks. Furthermore, estimates of time may be confounded by simultaneous use of multiple devices (Smith & Boyles 2012), and therefore existing data regarding screen time should be interpreted with caution. Moreover, it is difficult to make comparisons of online device use across different days of the week. For instance, autistic children have been found to access more technology on a typical weekend than during the week (Mazurek & Wenstrup, 2013). It is paramount that research controls for these variables in order to interpret data regarding the correlation between screen time and online risks experienced. Therefore, Study 1 investigating the parent/carer reports of online safety risks incidences (see Chapter 4), will also explore whether this variable relates to the online safety risks experienced by children on the autism spectrum.

3.5 Representation of Autistic Children and Young People with Limited or No Verbal Speech

To date, online device research has largely focused on verbal self-reporting by autistic adolescents and adults (Hedges et al. 2018; Mazurek and Wenstrup 2013). Considering that between 15 and 25% of autistic children are indicated to be non-speaking (Norrelgen et al., 2015), exclusively using data collection methods that rely on speech will exclude a large number of autistic children and young people (Elsabbagh et al., 2012). Selective mutism is a diagnostic term used to describe children who choose not to speak or respond when spoken to by others in specific situations such as unfamiliar scenarios with unknown people but do speak in other contexts such as home with their family members (Muris & Ollendick, 2021). High co-occurring rates of selective mutism and autism (62.9% of 97 children aged 4-18 years) have been reported (Steffenburg et al., 2018). Therefore, it is important that study methodologies in this PhD thesis consider these potential factors. This can include written communication such as live webchat and paper based methods, including such as photovoice (Do et al., 2021).

Parental surveys are reported to be a useful medium for gathering rich information about autistic young people's online device use (Laurie et al., 2019). Therefore, this can be useful for representing minimally verbal or non-speaking autistic children. Moreover, previous research indicates that parental attitudes to online technology will shape, and in turn, be shaped by their child's use of technology, as well as by external factors. Therefore, by carrying out a parental survey (see Chapter 4), this will add to the existing literature regarding autistic children's online device use, safety behaviours and how this relates to parental attitudes. Given that few studies have examined online safety risks among autistic children, a large scale, parental survey will help to explore this under-researched area. This will take place in Study 1 (see Chapter 4).

On the other hand, there are other means of including the perspectives of autistic children and young people with limited or no verbal speech in research. For some autistic people who cannot or choose not to speak, they can express themselves if other communication formats e.g., writing, are offered to them. A recent study asked 245 autistic adults to rank seven communication scenarios in their order of preference. In unknown situations, including research scenarios, written forms of communication (e.g., instant messaging, text messaging and email) were preferred over methods of communication which relied exclusively on speech such as phone calls (Howard & Sedgewick, 2021). Therefore, it is crucial that other modes of communication are available for autistic people to choose from, depending on their preferences. Study 2 in this PhD thesis (see Chapter 5) is focussed on autistic young people's first-hand accounts of their online safety experiences. In order to widen opportunities for autistic young people who cannot or choose not to speak to take part in the study, live webchat was provided as a choice for participants who preferred this over verbal forms of interview e.g., face-to-face, phone call and videocall (see Chapter 5; Section 5.3.4)

3.6 Focus on Autistic Children and Young People's Lived Experiences

A qualitative approach is focussed on gaining an in-depth understanding of factors underlying a phenomenon (Bourgeault et al., 2010; Cresswell, 2003). Therefore, it can be useful for exploring factors related to an individual's lived experiences. Within the field of autism, qualitative research has often received less consideration and funding (Bölte, 2014). Nevertheless, existing studies in this field have highlighted the benefits of the rich, in-depth data that they can provide on autistic people's lived experiences (Howard et al., 2019). In recent years, researchers have highlighted that "insider perspectives" are often lacking in autism research (Fletcher-Watson et al., 2019; Pellicano et al., 2013). To date, few studies have examined autistic young people's lived experiences of online safety (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022). To the best of knowledge, no published study has examined autistic young people's first-hand accounts of multiple online safety risks. Therefore, Study 2 will take the form of a qualitative format, utilizing semi-structured interviews to gain insider perspectives from autistic young people regarding their online safety experiences (see Chapter 5).

3.7 Move Towards Participatory Approaches in Autism Research

From the very few published studies in this area, most have focussed on parental perspectives regarding their autistic children's online safety (Just & Berg, 2017). Autistic narratives have highlighted the benefits of co-production, including originality of thought that autistic people provide to research (Crompton et al., 2020b; MacLeod, 2019). Participatory research is focussed on “incorporating the views of autistic people and their allies about what research gets done, how it gets done and how it is implemented” (Fletcher-Watson et al., 2019). Therefore, participatory, co-designed and produced research involves shared decision making power between researchers and community members (Cornwall & Jewkes, 1995; Israel et al., 2005). One key principle of this approach is the recognition and efforts to remediate the traditional power imbalance between participants and researchers (Nelson & Wright, 1995). Researchers have proposed that the majority of previous studies in the field of autism research involved tokenistic to no power for autistic participants (Chown et al., 2017; Fletcher-Watson et al., 2019; Nicolaidis et al., 2011). Another key principle of participatory research is inclusion. This involves adapting methodologies and the dissemination of findings to promote accessibility, thus engagement of the target populations (Fletcher-Watson et al., 2019). Therefore, a list of protocols was created to promote engagement with autistic young people (see Appendix L for a full list). All of the materials in each of the main PhD studies were piloted with members of the autistic community to make sure that they were ready accessible (Appendix L.1). For Study 2 and 3 which involved the recruitment of autistic young people (see Chapters 5 and 6 respectively), all of the listed protocols (Appendix L.1-10) were implemented to promote their inclusion and participation in these studies.

Specifically, co-design involves the participation of the end users in decision making and idea generation (Sanders & Stappers, 2008). With regards to online device use, previous studies have reported benefits of adopting a co-participatory design approach with autistic children and young people (Spiel et al., 2017; Spiel et al., 2019). However, from the few studies examining online media preferences of this population, these have been conducted with parents (Martins et al., 2020). Considering the evidence along with a growing call for autistic involvement in research (Fletcher-Watson et al., 2019; Pellicano et al., 2013), this posits that online safety tool prototypes will benefit from consultation with the target population. In this PhD thesis, two studies are focussed on utilizing the direct input from autistic young people regarding what factors would help to improve their online safety experiences. In Study 2 (see Chapter 5), the interview script will contain a question explicitly asking autistic young people to describe what would make going online better for them (see Chapter 5; Section 5.3.4). Study 3 (see Chapter 6) investigates autistic young people's perceptions of online safety scenarios and their online management preferences. Online vignettes of a contact and content risk scenario (see Chapter 1; Section 1.2) will be presented to autistic young people along with low-fidelity protype solutions for each for them to evaluate and give their feedback on (see Chapter 6; Section 6.7.5).

These studies mark a series of steps taken to incorporate participatory efforts as part of this PhD thesis. Arnstein's 'Ladder of Participation' (Arnstein, 1969, p.217; see Figure 1) uses eight rungs to measure degrees of citizen participation, ranging from high to low. The bottom level (Rungs 1 and 2) marks non-participation of the participants in the process and enable those in power to "cure" them (p.217). The middle level (Rungs 3, 4 and 5) reflects levels of tokenism. These allows for participants to be informed about research and offering varying degrees of opportunities for them to feedback, but these are limited. Rung 5 depicts the highest level of tokenism as this allows participants advise, but decision-making processes lie ultimately with the power holders. The top level (Rungs 6, 7 and 8) depicts scenarios where participants have direct power over the process. This ranges from partnerships, where participants can negotiate and be involved in joint planning and implementation to full control of the process.

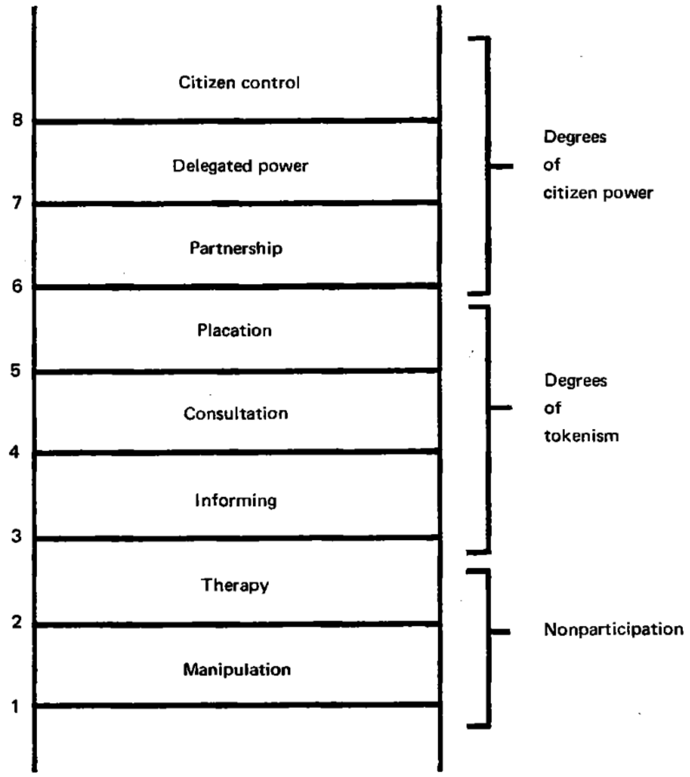

Figure 1: Arnstein (1969, p.217) 'Ladder of Participation'

In terms of evaluating participatory efforts in this PhD thesis, Arnstein's Ladder of Participation (Arnstein, 1969) will be used to assess the degree to which autistic children, young people and their families were involved in each study (see Chapter 7; Section 7.5).

3.8 Context for Designing Online Safety Risk Management and Interventions

Few studies have investigated children's desires regarding these online safety tools. To date, some work has investigated non-autistic children's concepts within areas such as cyberbullying (Ashktorab & Vitak, 2017; Bowler et al., 2014). One study investigated neurotypical children's perceptions of parental mobile monitoring technologies. A sample of

12 children were asked to review and re-design an existing mobile monitoring application. The results showed that children preferred and designed controls that emphasized restriction e.g., blocking unwanted content over monitoring e.g., parental supervision and that taught risk coping (McNally et al., 2018). This highlights the benefits of co-designing online safety tools with children and young people.

However, to the best of knowledge, no study has investigated this among autistic children and young people. Cooperative Inquiry (CI) is where researchers and the users work together as design partners to create technologies that are more relevant to users wants and needs (Fails et al., 2012; Guha et al., 2013). Previous studies have reported benefits of adopting a co-participatory design with autistic children and technology (Spiel et al., 2017; Spiel et al., 2019). Researchers have advocated for the involvement of children's input on the design of online safety tools, including mobile monitoring software (Hartikainen et al., 2016; Wisniewski et al., 2017). Therefore, in order to develop online safety tools that autistic children and parents will both use and benefit from, it is important that autistic young people are consulted on the design of these interventions. Therefore, Study 3 will involve one to one, co-design sessions with autistic young people (see Chapter 6).

3.9 Implications for the PhD Thesis Methodologies

Considering the evidence from the existing research literature, together they give rise to the following chosen methodologies and methods for each study and corresponding research questions (see Chapter 1; Section 1.4):

3.9.1 Study 1: Parental Survey

Previous studies have investigated single types of online safety among autistic adults. However, the majority are limited by a lack of a control group. To date, no published studies have compared the rates of multiple online risk incidents among autistic children. By comparing these with a sample of non-autistic children, it will be possible to investigate whether autistic children experience more online safety risks overall or if they are vulnerable to certain online risks. For instance, no significant differences in phishing detection have been reported between a sample of autistic and non-autistic adults (Neupane et al., 2018). Therefore, it is possible that autistic children may be at risk pertaining to specific online safety risks instead of being susceptible to all various onlinr risks. In Study 1 (see Chapter 4), a parental survey will be used to attempt to gather a large amount of data from these two groups and include that of minimally verbal or non-speaking autistic children. The aim of this study (see Chapter 4; Section 4.6.1) is to answer the following key research question of this PhD thesis:

RQ1: Compared with non-autistic children, do parents of autistic children report their child having experienced more online safety risks and less online safety risk management?

3.9.2 Study 2: Interviews with Autistic Young People

In order to investigate autistic young people's lived experiences of communicating with others online and safety experiences, Study 2 will use qualitative, semi-structured interviews will be used to explore factors relating to this area (see Chapter 5). The aim of this study (see Chapter 5; Section 5.3.1) is to address the following key research question of this PhD thesis:

RQ2: What are autistic young people in the sample's lived experiences of online safety, managing online safety risks and preferences in terms of improving their online safety experiences?

3.9.3 Study 3: Co-Participatory Study with Online Safety Vignettes

Research evidence indicates that autistic people can provide valuable insights in co-participatory research (Crompton et al., 2020b; MacLeod, 2019). Considering that autistic children and young people have been reported to successfully inform the co-design of online device prototypes (Spiel et al., 2017; Spiel et al., 2019), Study 3 (see Chapter 6) will adopt a CI design approach. Due to COVID-19 restrictions, the original proposal for Study 3 was paused and redesigned (see Chapter 6; Section 6.1) . The revised study investigates autistic young people's perceptions of online safety scenarios (see Chapter 6; Section 6.7.1). Therefore, it will examine the final key research question of this PhD thesis:

RQ3: What online safety tools do autistic young desire and envisage themselves using, and specifically what features do they require from these tools?

4. Chapter 4: Study 1 Parental Survey

4.1 Chapter Acknowledgements

A preliminary version of the background, methodology and results reported here have been published in the *NordiCHI 2020* conference (Macmillan et al., 2020).

4.2 Introduction

Autistic children are heavy users of technology, with parents reporting them spending more time online than non-autistic children (Hedges et al., 2018, Macmullin et al., 2016). Challenges in this population include communication challenges and focussed interests (American Psychiatric Association, 2013). However, many autistic children use social media and online gaming sites for social connection and to share interests (Gillespie-Lynch et al., 2014; Grove et al., 2018).

Despite the findings that online platforms are beneficial to autistic people, studies have suggested that this population finds it challenging to come offline and switch to another activity (Kuo et al., 2014, Nally et al., 2000). Mazurek and Wenstrup reported that autistic children spend higher amounts of time using online devices compared with non-autistic children (Mazurek & Wenstrup, 2013). Studies have reported a positive correlation between the likelihood of children experiencing online security risks and time spent online (Rideout, 2013, Rideout, 2017), though the latter studies did not focus on autistic children. Therefore, autistic children and young people could be considered an ‘at risk’ group for online safety issues, though to the best of knowledge, no study has examined the relationship.

Thus, there are gaps in knowledge of the impact that autism might have for children’s online safety. To date, few studies have investigated online safety risks experienced among autistic children, young people and adults. From a review of the literature, the majority of previous research on the online safety risks for autistic children is limited by the lack of a control group. This makes it difficult to determine if vulnerability to a certain risk type is “autism specific”. Thus, it is important to investigate if online safety risks experienced vary between autistic and non-autistic children and how this impacts on child wellbeing. Also, it is unclear if there are differences in parental online risk management strategies and how this relates to parental self-efficacy (PSE) between parents of autistic and non-autistic children. Past studies have predominantly focused only on measuring screen time as an indicator of online vulnerability. However, these results may be ignoring other variables that could also impact the online safety risk.

4.3 Online Safety Risks

4.3.1 Online Contact Risks

There is evidence that contact risks are particularly relevant to the autistic population. Psychological theories posit that autistic and non-autistic people have difficulties understanding each other, which can lead to breakdowns in two-way social interactions (Milton, 2012a). Compared with non-autistic children, autistic children spend less time chatting to others online, however many use social media to communicate with others (Gillespie-Lynch et al., 2014, Mazurek & Wenstrup, 2013) with some autistic people stating a preference for online versus face to face communication. Reasons for this preference include control over the pace and increased comprehension of online social interactions (Gillespie-Lynch et al., 2014). It is possible that time spent online and a reliance of online rather than offline communication may increase the risk of cyberbullying.

Cyberbullying is thought to be more prevalent among the autistic population than other forms of bullying. A review which included children with various disabilities, including autism and examined rates of all types of bullying, suggested that autistic young people are twice as likely to be victims of cyberbullying versus non-autistic counterparts (Rose & Monda-Amaya, 2012). Moreover, one qualitative study carried out semi-structured interviews with eight autistic young people and six parents regarding their experiences of online social media relationships and risks. Thematic analysis revealed two themes, including barriers to online engagement (Abusive Interactions and Talking to Strangers) (Gillespie-Smith et al., 2021). These findings suggest that autistic children could be vulnerable to experiencing cyberbullying. However, the review and the majority of past studies have focused on rates of traditional bullying as opposed to cyberbullying and examined children with various disabilities (Good & Fang, 2015; Little, 2002). This makes it difficult to determine if an increased vulnerability to cyberbullying is autism specific. Moreover, it is unclear if cyberbullying is more likely to occur between members of the same neurotype e.g., autistic or between different neurotypes e.g., non-autistic peers. In a recent paper, Rochleau and Chiasson (2022) conducted interviews with 12 autistic (mean age = 14.9 years) and 16 non-autistic young people (mean age = 14.7 years).

Thematic analysis revealed that cyberbullying was more of a recurrent scenario for autistic than non-autistic young people and it was exacerbated by misunderstandings in online contexts. Moreover, the themes posited that autistic young people avoid chatting to others online as a means of protecting themselves. Therefore, it is unclear if they are more susceptible to this particular type of contact risk compared with non-autistic children.

Online sexual grooming/exploitation is a growing area of concern regarding autistic children. Numerous surveys have shown a near double increase in prevalence of sexual abuse among victims with disabilities than those without disabilities (Mansell et al., 1988; Powers et al., 2002). This suggests that autistic children may be at a higher risk of online sexual exploitation. One qualitative study used semi-structured interviews with six autistic women aged 19-29 years. Key themes from the interviews included relationship violence and abuse, child sexual exploitation and rejection. Half of the women had experienced physical emotional and sexual abuse or threats from men that they had been romantically involved with, including one experiencing online grooming and child sexual abuse (Landon, 2016). A recent ethnographic study conducted semi-structured interviews with eight autistic adults, four parents of autistic adults and 10 staff working at an autism support service. The findings indicated that autistic adults shared personal information such as phone numbers and addresses which was linked with online sexual exploitation (Page et al., 2022). These posit that autistic children may be vulnerable to sexual exploitation/violence. However, previous studies were conducted only with a small number of autistic adults so it is unclear if the same pattern exists for autistic children.

Online dating by autistic adults was studied by Roth and Gillis (2015). Of their 17 autistic interviewees, around half had tried online dating. However, the autistic participants reported drawbacks, including concerns about online safety. The authors reported that the autistic participants tended to be overly trusting, found too much choice to be overwhelming and found communication to be harder online. This sample size is too small to generalise to the general autistic population, and there was no control group to compare whether reported concerns were autism specific, or common to all online daters. A recent sample of women found that 79% of autistic women had reported having suffered sexual exploitation or abuse compared with 26% of non-autistic women (Sedgewick et al., 2019). To date, no study has directly compared the rates of online sexual grooming/exploitation between autistic and non-autistic children. This makes it difficult to determine if this online safety issue is 'unique' to autistic children and young people.

4.3.2 Online Content Risks

However, it is possible that not all online safety risks are necessarily more prevalent in the autistic population. Previous research suggests that content risks, such as phishing, may occur to a similar degree in autistic and non-autistic children. Being able to spot hacking or phishing attempts relies on identifying particular visual cues from the website or link that appears fake. Perceptual theory models put forward that the perceptual systems of autistic people may out-perform their non-autistic peers (Mottron et al., 2016). Data from visual search tasks reveal that autistic people demonstrate particular strengths for the most difficult, conjunctive search tasks (Shirima et al., 2017). These skills may make autistic people less susceptible to hacking or phishing attempts. Indeed, in a recent study comparing 15 autistic adults with 15 non autistic adults no differences in detecting phishing were found between the two groups. Both groups were able to successfully distinguish between real websites from fake counterparts (Neupane et al., 2018). Previous studies have been conducted with adults; it is therefore important to determine if this is also the case with children. It is possible that the perceptual abilities in some autistic children will make them less prone to succumbing to certain online safety risks such as phishing than others.

4.3.3 Online Conduct Risks

Nonetheless, there is evidence that autistic children may be subject to "conduct" risks. This category covers incidences where the child acts themselves to contribute to the risky contact or content. Just and Berg (2017) reported on the results of two workshops with 16 parent carers of children on the autism spectrum in which they used pictures and group discussions to identify carers' concerns. Risks experienced included unauthorised purchases and inappropriate posting on social media sites. The workshop did not include the perspectives of parents of non-autistic children. Thus, it cannot fully be deciphered if autistic children are more vulnerable to examples of online conduct risks without a control group. Nevertheless, these findings suggest that protecting the online safety of autistic children is challenging for parents.

4.4 Managing Online Risks

Online safety risks are suggested to have negative consequences for child wellbeing. Studies have found that autistic adolescents and those with disabilities were more likely to report distress following cyberbullying victimization compared with non-autistic peers (Wells & Mitchell, 2014). This corresponds with evidence that cyberbullying victimization and peer rejection is associated with depression and anxiety in autistic adolescents (Wright, 2017, Wright & Wachs, 2019). From the current findings, it is unclear whether potential perceptual differences of cyberbullying or trauma from other adverse life experiences could account for elevated rates of cyberbullying and wellbeing measures among autistic children and young people. Nevertheless, the current evidence emphasises the negative impact that online safety risks have for autistic children's wellbeing.

Parental mediation has been identified as a key protective factor against harm resulting from negative online experiences (Livingstone & Smith, 2014). Therefore, it is important to examine parent online risk management of autistic children. Many parents of autistic children restrict their childrens' online use via parental apps or switch off and remove device(s) (Clark et al., 2015; Sasse, 2015). However, there is a debate as to how justifiable apps are as they often involve a compromise between a reduced likelihood of experiencing risks online and limiting childrens' independence (Ghosh et al., 2018; Livingstone & Haddon, 2009). Given the methodical nature often reported in autism (Kaldy et al., 2016; Shirima et al., 2017) and evidence that many autistic children are particularly adept with computers and other online devices (Pellicano et al., 2011), it is possible that such software may be overused or not readily accepted by autistic children compared with non-autistic children. In contrast, nudging solutions, for example one that reminds users about the audience for their social media post might allow users to consider potential risks whilst independently browsing the internet (Acquisiti et al., 2017; Wang et al., 2014). However, no research to date has examined their effectiveness or efficacy in the autistic population.

Parental Self Efficacy (PSE) can be defined as the expectation caregivers hold about their ability to parent successfully (Staksrud & Livingstone, 2009) and positively correlates with parent and child adjustment (Jones & Prinz, 2005). Many parents experience difficulties trying to protect their children online. Evidence suggests that they find it socially and technically challenging for which they feel ill-equipped and under-resourced to administer (Livingstone, 2009). Therefore, many parents are challenged by the task of protecting their children's safety online, and thus will be likely to have lower parental self-efficacy (PSE). To date, no research has examined the relationship between PSE and online safety incidents in autistic children. Just and Berg (2017) described that many of the parents reported that they lacked the confidence and skill to deal with risk scenarios when they arise, so it is likely that parents of autistic children will feel less equipped to manage their online safety. An international survey of 388 parents of autistic children revealed that concerns with their child using technology positively correlated with the child's screen time (Laurie et al., 2019). Based on evidence that many autistic children are active online users, it is likely that their parents will be apprehensive about the amount of time their children spend online. Parents may be worried that technology use detracts from or replaces "real life" interaction (Valkenburg & Peter, 2009). Alternatively, parents may lack the skills needed to tackle the technical aspects of online safety protection (Livingstone, 2009). Therefore, parental online safety knowledge is likely to affect their parental online risk management and their PSE.

Evidence from the previous literature discussed suggests that parents of autistic children are more likely to have poorer PSE, though the studies lacked a control group. Therefore, it is likely that parental online safety knowledge will negatively relate to PSE, particularly among parents of autistic children. If PSE were to relate to parent risk management, digital interventions can be designed to help improve PSE with regards to online safety.

4.5 Study 1: Context and Motivation

Previous research has predominantly measured only time spent online to gage people's online behaviours (de Vreese & Neigens, 2016; Mazurek et al., 2015; Stiller & Mößle, 2018). However, estimates of time may be confounded by simultaneous use of multiple devices (Smith & Boyles, 2012). Having a sole focus on screen time fails to consider how children use online devices and if other important factors such as child age or pre-existing conditions influence the likelihood of encountering online safety risks. For example, online device use has been reported to increase with age (Rideout, 2013; Rideout 2017). Children access the internet from mobile devices at increasingly younger ages (Mascheroni & Ólafsson, 2016). Zhao et al (2019) conducted focus groups with children aged 6-10 years and presented various online safety scenarios. The children showed awareness of certain online risks e.g., who might access their sensitive information and were able to suggest a range of techniques to safeguard this space e.g., verifying identities through face-to-face interactions or avoiding using real names as usernames. Therefore, it is important to investigate online safety behaviours among younger children as they access online content and have an awareness of online safety risks so should be included in research.

In addition, research points towards a third to two-thirds of autistic children and adults having a co-occurring Learning Disability (LD) (Charman et al., 2011; Elsabbagh et al., 2012; Newschaffer et al., 2007) and/or Attention Deficit Hyperactivity Disorder (ADHD) (Leitner, 2014). Past studies which failed to categorise autistic children into groups depending on whether or not they have a co-occurring condition may have masked a potential effect of having a condition such as LD/ADHD on an autistic child's online vulnerability. Therefore, it is important to control for these to examine if higher incidents of a particular risk are unique to autistic children and young people.

It is possible that these factors may be more robust predictors of online safety risks experienced. Study 1 will assess for these variables to investigate if increased vulnerability to online risks is autism specific. Little research has examined autistic children's online safety experiences. With regards to autism and technology interventions, authors have highlighted issues, particularly a lack of efficacy and ecological validity (Fletcher-Watson & Durkin, 2015; Valencia et al., 2019). It is crucial that these are investigated before recommending the design of digital tools. Previous studies have investigated single types of online safety in the autistic population to varying extents. However, the majority are limited by a lack of a control group. From the extensive literature search, no studies to date have compared the rates of multiple online risk incidents in autistic children. By comparing these with a sample of non-autistic children, this chapter will examine if autistic children experience more online safety risks overall or if they are vulnerable to certain online risks. Past research on content and media preferences has focused specifically on adolescents (Mascheroni & Ólafsson, 2016) or has not reported the age of participants (Shane & Ducoff, 2008). Considering that online risks positively correlate with child age, relevant data regarding this will be collected.

To date, online device research has largely focused on self- reporting by autistic adolescents and adults (Elsabbagh et al., 2012; Hasebrink et al., 2008). However, solely relying on self-report measures would exclude the large number of people on the autism spectrum with limited verbal abilities (van Schalkwyk et al., 2017). Parental surveys are considered to be a useful medium for gathering rich information about autistic young people's online device use (Laurie et al., 2019). To the best of knowledge, Study 1 will be the first to compare parent's reporting online risks among autistic and non-autistic children.

4.6 Methodology

4.6.1 Aims and Research Questions

The objective of Study 1 in this PhD thesis is to investigate parental perceptions regarding the online safety behaviours of autistic children and how these compare to non-autistic children. This will be accomplished with an online safety survey for parents. Through this survey, parental perceptions regarding their children's use of online platforms and safety behaviour, and how this relates to their perceptions of their child's wellbeing will be examined. The following main, sub-research questions and corresponding hypotheses were established:

RQ1: Compared with non-autistic children, do parents of autistic children report their child having experienced more online safety risks and less online safety risk management (see Chapter 1; Section 1.4)?

- **RQ1.1**: Do parents of autistic children report their child having experienced more online safety risks overall than non-autistic children?

From the few studies conducted, the findings suggest that the former are more likely to experience risks that involve direct contact such as cyberbullying (Rose & Monda-Amaya, 2012) and less likely to be subject to less socially direct ones such as phishing (Neupane et al., 2018). Given these findings, the first hypothesis (H1) predicts that:

- **H1**. Autistic children will experience more contact and conduct risks, but less content online safety risks than non-autistic children.

- **RQ1.2**: Do parents of autistic children report their child carrying out less online safety risk management than non-autistic children?

Study 1 will investigate if there is a difference in the total online safety risk management carried out by autistic and non-autistic children, according to the parents. From the few studies investigating autistic online safety, it has been suggested that autistic children can be "naive" to online safety risks (Just & Berg, 2017). Based on these findings, the second hypothesis (H2) states that:

- **H2**. Autistic children will carry out less overall online safety risk management than non-autistic children.

- **RQ1.3**: Do parents of autistic children carry out more overall online safety risk management than parents of non-autistic children?

  Parental online safety risk management will be compared between autistic and non-autistic children. Previous research suggests that parents will restrict or switch off devices to protect their children online, including those who care for autistic children (Charman et al., 2011; Rideout, 2017. However, there is no concrete evidence as to whether parents of autistic children engage in more parental online safety management than those of non-autistic children. The third hypothesis (H3) will be open-ended:

- **H3**. There will be a difference in total parental online safety management between parents of autistic and non-autistic children. It will be investigated if autistic children with higher total online safety risks have lower wellbeing scores than autistic children with lower online safety risks. Online device usage among autistic children will be split into "high" and "low users" and SDQ scores will be compared.
- **RQ1.4**: Do autistic children who experience a higher amount of total online safety risks have poorer wellbeing, according to the parental reports?

  Previous studies suggest an increased vulnerability online positively correlates with poorer wellbeing outcomes in autistic young people (Wright, 2017, Wright & Wachs, 2019). The fourth hypothesis (H4) thereby suggests that:

- **H4**. Autistic children who have higher total online safety risks will have lower SDQ scores than autistic children with lower total online safety risks.

- **RQ1.5**: Do parents of autistic children have lower parental self-efficacy than parents of non-autistic children who have experienced online safety risks?

  Study 1 will contrast PSE of parents of autistic and non- autistic children. Many parents of autistic children report difficulties trying to protect them online (Just & Berg, 2017). Considering that parents report difficulties trying to protect their children online as they find that they are socially ill-equipped and under-resourced to do (Livingstone, 2009) and many autistic children struggle to transition offline to online (Kaldy et al., 2016; Nally et al., 2000; Orsmond & Kuo, 2011), the fifth hypothesis (H5) states that:

- **H5**. Parents of autistic children will report lower PSE than parents of non-autistic children and variance will be accounted for by differences in child online safety risks predicted.

- **RQ1.6**: Is there a relationship between total online safety risks experienced and total time spent using online devices?

The survey will compare total screen time and online safety risks among autistic and non-autistic children. Given that past research posits a positive correlation between the likelihood of children experiencing online security risks and time spent online (Rideout 2013; Rideout, 2017): the sixth hypothesis (H6) indicates that:

- **H6**. There will be a positive correlation between total online safety risks experienced and total time spent using online devices.

4.6.2 Participants

Study 1 recruited 104 parents aged 27-54 (*M* = 40.16, *SD* = 8.73) in the United Kingdom (UK). The sample included 63 parents aged 28 to 54 years (*M* = 39.45, *SD* = 9.90) of autistic children. The control group was made up of 41 parents aged 27 to 52 years (*M* = 41.22, *SD* = 6.70) of non-autistic children. The Scottish Index of Multiple Deprivation (SIMD) was used to measure socioeconomic status among participants (ranking scores range from 1 = most deprived to 6,976 = least deprived). Across the whole sample, SIMD scores ranged from 1 to 5 (*M*= 3.3, *SD*= 1.4), with similar means and variations reported among parents of autistic (*M* = 3.2, *SD* = 1.4) and non-autistic children (*M* = 3.6. *SD* = 1.5). The exclusion criterion was children under the age of six years. Based on evidence that many autistic young people continue to live in the same household beyond the age of 16 years (Levy & Perry, 2011), no upper child age limit was set. For the survey, parents of children aged 6-22 years participated. Parents of autistic as well as non-autistic children were invited via social media, including Facebook and Twitter. In addition, parents of autistic children were approached by contacts with relevant organizations such as the National Autistic Society, Scottish Autism, Autism Initiatives Scotland and the Lothian Autistic Society.

Table 1. Child Demographics

		Autistic Children (n = 63)	**Non-Autistic Children (n = 41)**
Gender	Male	51	18
	Female	10	24
	Other	1	0
LD count		20	5
ADHD count		15	0

In terms of child demographics (see Table 1), 63 parents of autistic children and 41 parents of non-autistic children completed the survey. For the autistic group (n = 63), 51 of the children were reported as male, 10 as female and one was listed as “other” (a further description box named their gender as “asexual”) by their parents. 20 of the autistic children were reported to have a co-occurring learning disability (approximately 32%) and 15 as having a co-occurring diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) (around 24%). This was established by asking if their child had a diagnosis of an intellectual disability with examples provided e.g. Fragile X Syndrome (see Appendix B). If they selected “Yes”, they were asked to provide further information regarding the diagnosis. This was done to verify the responses and to establish that parents/carers were reporting on learning disabilities as opposed to learning differences e.g., Dyslexia. For the non-autistic group (n = 41), 18 of the children were listed as male and 24 as female. Five non-autistic children were reported as having an LD (approximately 12%). None of the non-autistic children were reported as having ADHD by their parents.

4.6.3 Design

The survey compared two groups: parents of autistic children and parents of non-autistic children aged six years and over. The dependent variables included: the total time spent using online devices and the total child online safety risks experienced. The survey was supplemented by questions examining reasons for online device use, child online safety awareness; child and parent online safety risk management, child wellbeing and parental self-efficacy (PSE).

4.6.4 Materials

Prior to distributing the survey to a wider audience, it was piloted with five parents of autistic adults to identify if any sections or language was unclear or could be changed to suit the preferences of the target sample. Based on this, examples and descriptions of closed and open-ended options were provided in the final version for clarity. There were four sections in the survey. Parents with multiple children were asked to respond for only one of their children. Section One measured demographic variables including parental age, child age, child gender as well as asking if the child had a diagnosis of autism and or other conditions, including a LD and ADHD. For example, "For the child that you've chosen for your responses to this survey, would you identify this child as being on the autism spectrum?". If they clicked "Yes" they were directed to further questions which asked them to verify the age that their child had received their diagnosis and if their child had been diagnosed by a medical professional.

Section Two asked parents about their child's online device use. Participants were invited to indicate their child's access to various online devices. Examples were given along with a description, e.g., Tablet (e.g., iPad, Android). Parents were also asked how many hours that they thought their child spends using each device on an average day.

Section Three focussed on the child's online safety behaviours. Examples of contact, content and conduct online safety risks (Hasebrink et al., 2008; Staksrud & Livingstone, 2009) were listed along with descriptive examples of each. For example, "Phishing/scamming (e.g., clicking on links to fake, lookalike websites)". An "Other (please describe)" box was provided to ensure coverage of all types of risks experienced online. Participants were asked to click "Yes" or "No" to any risks that their child had experienced and strategies which they used to keep themselves safe online e.g., "Relies on internet safety software". The total number of "Yes" clicks from each online safety risk section were summed together to give a total online safety risks experienced category. Similarly, parents were given a list of child online risk management strategies. For example, "He/She avoids or blocks people and/or online sites" and asked to click "Yes" or "No" to give a total for the child online risk management variable. Examples of online safety risks experienced and risk management strategies were taken from previous research in this area (Just & Berg, 2017). For each question, parents also had the option of responding that they were unaware of their child's safety behaviour.

Section Four assessed parental risk management. Parents were given a list of parent online safety risk strategies. For example, "Monitor online access via parental controls (e.g., Net Nanny, Boomerang)" and asked to click "Yes" or "No". These were summed to give a total parent risk management variable. Sections Two to Four of the survey also asked participants to respond to statements about their attitudes to their child's online device use with a five-point rating scale from "Strongly Disagree" to "Strongly Agree". Examples included "I believe that he/she has benefitted from using online devices". Parental online safety knowledge was measured totalling responses to five statements assessing confidence in online safety knowledge with a five-point rating scale from "Strongly Disagree" to "Strongly Agree". Examples included "I often find myself asking children for advice regarding online safety techniques". The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) consists of 25 items that form five subscales (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationships, and prosocial behaviour) was used to measure child wellbeing. As part of the SDQ, parents were asked to rate statements about their child such as “Often unhappy, down-hearted or tearful” on three point Likert scale that ranged from “Not True” to “Certainly True”. Scores on each subscale ranged from 0 to 10. The SDQ total score is calculated by summing the subscale scales together, apart from the prosocial scale. Total scores range from 0 to 40. Higher total scores point towards poorer child wellbeing. Studies have indicated that it distinguishes between children with and without psychiatric disorders (Goodman et al., 2000; Goodman et al., 2003; Salayev & Sanne, 2017) is a reliable scale for measuring wellbeing among typically developing children and autistic children (Russell et al., 2013; Salayev et al., 2016).

To measure parental self-efficacy, we used the ‘Me as a Parent’ (MaaP) four-factor scale of Hamilton et al (2015). This questionnaire measures global beliefs about self-efficacy, personal agency, self- management, and self-sufficiency. Parents were asked to rate 16 statements from “Strongly Disagree” to “Strongly Agree” on a five point Likert scale. Higher scores indicate higher levels of each construct, with the exception of personal agency. Personal agency scores are reversed to compute the total score with the sum of the other sections. Scores can range from 16 to 80 on the total scale, and 4 to 20 on each of the subscales. Moderate to high internal reliability has been demonstrated across the subscales (.45- .75) (Hamilton et al., 2015).

4.6.5 Procedure

Ethical approval was obtained from the Department of Computer Science’s Ethics Committee at Heriot-Watt University (see Appendix A). The survey was delivered via ‘Qualtrics’ online survey platform (see Appendix B). Participants were invited to read an embedded information form about the study, and to agree with the consent statements if they wished to take part. It was emphasised that participants could withdraw at any time. They were then directed to the survey questions. This was followed by an embedded debriefing form in the survey where and contact details for suitable mental health and autism support organisations were provided and participants were invited to provide their contact details if they wished to receive a summary of the results or take part in future research. Participant contact details were segregated and stored separately from anonymised survey responses. All of the participant data were stored in password protected databases, which is only accessible by the research team.

4.7 Results

The research questions are addressed from analysing the survey data.

RQ1.1: Do autistic children experience more online safety risks overall than non-autistic children?

As the data was normally distributed, an Independent T-Test was used to compare the total online safety risks experienced by autistic and non-autistic children, as reported by their parents. Autistic children experienced a significantly higher amount of overall online safety risks ($M = 0.76$, $SD = 1.03$) than non-autistic children ($M = 0.39$, $SD = 0.67$), $p = 0.027$, $d = 0.4$, confirming the hypothesis, though with a small effect size.

Table 2. Chi Square Tests of Online Safety Risks Experienced According to Type

Online Safety Risk Experienced	**Pearson Chi Square $\chi 2$**
Phishing/Hacking	0.411
Downloading Harmful Malware	3.595
Sexual Grooming/Exploitation	0.048
Cyberbullying	0.145
Buying goods services/online	4.281*
Other	0.370

$*p <0.05$; $**p <0.01$; $*** p < 0.001$

Chi-Square Tests were used to investigate if having autism was related to the “type” of online safety risk experienced. There were significant associations between having autism and unauthorised online purchases, $\chi 2(1) = 4.28$, $p = 0.039$. Based on the odds ratio, the odds of buying goods/services online were 4.61 higher if the children were autistic than if they were non-autistic. No significant associations were found between having autism and the other types of online safety risks experienced (see Table 2).

A One-Way ANOVA was conducted to investigate if autistic children with LD and/or ADHD experienced more online safety risks than autistic and non-autistic children without LD/ADHD. Autistic children with LD/ADHD (n = 32, *M* = 0.34, *SD* = 0.70 experienced fewer online safety risks than non-autistic children (n = 37, *M* = 0.65, *SD* = 1.03) and autistic children (n = 31, *M* = 0.81, *SD* = 0.946). However, there was no significant main effect of group on total online safety risks experienced, $F(2, 99) = 2.115$, $p = 0.126$, $\eta^2 = 0.04$.

RQ1.2: Do autistic children carry out less online safety risk management than non-autistic children?

An Independent T-Test was used to analyse if there was a significant difference in total online safety risk management strategies carried out between autistic and non-autistic children. Autistic children carried out less overall online safety risk management (*M* = 1.29, *SD* = 1.07) than non-autistic children (*M* = 1.63, *SD* = 1.07), $d = 0.3$. This supports the hypothesis with a small effect size. However, the difference was non-significant, $p = 0.107$.

Chi-square Tests were used to investigate if having autism was related to the “type” of online risk management strategy used. These are shown in Table 3. There were significant associations between having autism and blocking people and/or online sites, with just over a third of the autistic group blocking people and/or online sites, compared with approximately two thirds of non-autistic children $\chi2(1) = 9.54$, $p = 0.002$. Based on the odds ratio, the autistic group were 4.88 times less likely to block people and/or online sites than the non-autistic group. Having autism was significantly associated with “does not use any strategies”, $\chi2\ (1) = 4.739$, $p = 0.029$.

Moreover, the autistic group were 7.52 times less likely to use strategies to protect themselves online compared with the non-autistic group. No significant associations were found between having autism and the other types of online safety risks experienced.

Table 3. Chi Square Tests of Child Risk Management Strategies Used According to Type

Online Risk Management Strategy	**Pearson Chi Square $\chi2$**
Blocking people and/or online sites	9.538**
Asks others (including parent) for help	1.543
Relies on internet safety software	0.751
Unaware of what strategies he/she uses	0.755
Does not use any strategies	4.739*
Uses other strategies	0.026

**p <0.05; **p <0.01; *** p < 0.001*

RQ1.3: Do parents of autistic children carry out more overall online safety risk management than parents of non-autistic children?

An Independent T-Test was used to analyse if there was a significant difference in overall parental online safety risk management between parents of autistic and non-autistic children. Parents of autistic children reported significantly less overall parental online safety management ($M = 1.43$, $SD = 1.87$) than parents of non-autistic children ($M = 2.15$, $SD = 1.51$), $p = 0.008$, $d = 0.5$, with a mid-range effect size.

RQ1.4: Do autistic children who experience a higher amount of total online safety risks have poorer wellbeing?

A Two-Way ANOVA on group (autistic versus non-autistic children) and online safety risk group (no risks versus one or more online safety risks experienced) revealed a significant main effect of group, $F(1, 100) = 26.149$, $p = 0.000$, $\eta^2 = 0.395$, such that autistic children had higher SDQ total scores on the whole, compared with non-autistic children and the effect size was large. There was a significant main effect of online safety risk group, $F(1, 100) = 10.571$, $p = 0.002$, $\eta^2 = 0.096$, such that children who experienced one or more online safety risks had higher SDQ total scores than children who experienced no online risks and the effect size was in the mid to large range. There was no significant group by online safety risk group interaction: both groups scored a similar mean difference between SDQ scores for high and low risk groups,

$p = 0.658$, $\eta^2 = 0.002$, with a small effect size. Group differences in SDQ scores are displayed in Figure 2.

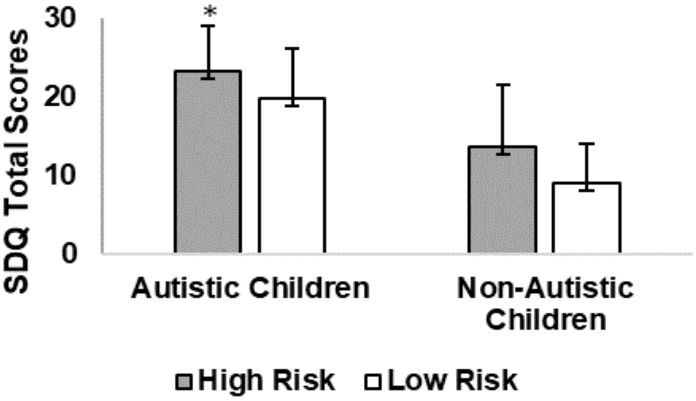

Figure 2: Group Differences in Child Wellbeing Scores

$*p < 0.05$; $**p < 0.01$; $***p < 0.001$

Follow-up Independent T-Tests were used to check if there were significant differences in SDQ scores groups. The total SDQ scores were significantly higher among autistic children who experienced one or more online safety risks (n = 30) ($M = 23.33$, $SD = 5.67$) than autistic children who were reported as having experienced no online safety risks (n = 33) ($M = 19.82$, $SD = 6.27$), $p = 0.023$, confirming expectations with a mid-range effect size, $d = 0.6$. Similar results were found with the non-autistic group, with children who had experienced one or more online safety risks (n = 13) having higher SDQ scores ($M = 13.77$, $SD = 7.71$), than those with no risks (n = 28) ($M = 9.14$, $SD = 4.93$), with a mid-range effect, $d = 0.7$. However, the difference was non-significant, $p = 0.064$.

RQ1.5: Do parents of autistic children have lower parental self-efficacy than parents of non-autistic children who have experienced online safety risks?

A Mann Whitney U-Test was performed due to the difference in size between the two groups of parents. Parents of autistic children who completed the MaAP (n = 61) reported significantly lower PSE scores (*M* = 60.82, *SD* = 7.96) than parents of non-autistic children who did not (n = 35), (*M* = 65.11, *SD* = 7.96), *p* = 0.016, *d* = 0.6, confirming the hypothesis with a mid-range effect size.

A Mann Whitney U-Test was used to analyse if there was a significant difference in PSE between parents of autistic children who have experienced one or more online safety risks and those who have not. Parents of autistic children (n = 30) who have experienced one or more online safety risk reported lower total PSE (*M* = 58.48, *SD* = 6.81) than parents of non-autistic children (n = 11) (*M* = 59.74, *SD* = 7.64), but the difference was non-significant, *p* = 0.50, *d* = 0.2.

A linear regression analysis was calculated to predict the impact of autism diagnosis, parental age, child age, child gender and parent's online safety knowledge on total MaAP scores. The model emerged significant, *F*(5, 86) = 8.600, *p* = 0.000, accounting for 29.5% the variance (Adjusted R^2 = 0.295). The unstandardised and standardised regression coefficients are displayed in Table 4. Autism diagnosis and parental online safety knowledge emerged as significant predictors of total MaAP scores, but the others were non-significant.

Table 4. Regression coefficients for variables entered into the RQ1.5 model (n = 92)

Predictor Variable	**B**	**SE B**	**β**
Autism Diagnosis	-1.70	2.70	-0.03*
Child Age	0.97	0.33	0.17
Child Gender			
• Male	2.53	2.68	0.05
• Female			
Parental Age	0.33	0.13	0.14
Parental Online Safety Knowledge	4.32	0.27	0.83**

**p <0.05; **p <0.01; *** p < 0.001*

RQ1.6: Is there a relationship between total online safety risks experienced and total time spent using online devices?

A Pearson Correlation was conducted to investigate if there was a significant positive correlation between total online safety risks experienced and total time spent using online devices. No significant correlation was found, n = 104, $r = 0.133$, $p = 0.180$.

Additional Pearson Correlation analyses were carried out to investigate if significant correlations existed between total online safety risks and other variables. There was a significant positive correlation between child age and total online safety risks reported, n = 104, $r = 0.227$, $p = 0.020$.

4.8 Discussion

4.8.1 **RQ1**: Compared with non-autistic children, do parents of autistic children report their child having experienced more online safety risks and less online safety risk management?

Study 1 findings posit that parents of autistic children report them as experiencing significantly more online safety risks than those of non-autistic children. No significant difference in total child risk management scores between parents of autistic and non-autistic children was demonstrated. Having autism was significantly associated with specific online safety risks experienced and online risk management strategies. These are discussed in the following sections examining the sub-questions of the main research question.

Each sub-research question and corresponding hypothesis related to the results is outlined and discussed in the following sections.

4.8.2 **RQ1.1**: Do parents of autistic children report their child having experienced more online safety risks overall than non-autistic children?

H1. The aim was to investigate online safety behaviours of autistic children, according to the parents perceptions. In particular, finding out if autistic children experienced more types or overall online safety risks than non-autistic children. It was hypothesised that there would be a difference between the two groups. Parents of autistic children reported them as significantly more likely to experience more overall online safety risks compared with the control group. This corresponds with previous literature suggesting that autistic children and adults may experience different online safety risks to varying degrees (Just & Berg, 2017; Gillespie-Smith et al., 2021; Neupane et al., 2018; Rochleau & Chiasson, 2022; Rose & Monda-Amaya, 2012; Sedgewick et al., 2019).

The autistic children with LD/ADHD experienced fewer online safety risks than non-autistic and autistic children without LD/ADHD, respectively ($\eta^2 = 0.395$). It is possible that this group experiences fewer risks because they are more protected due to the co-occurrence of multiple conditions. Moreover, this suggests an increased vulnerability to online safety risks is autism specific. Therefore, future interventions should be designed with care and be cautious when stating the target population e.g., autistic children without LD.

Interestingly, when associations between having autism and individual “types” of online safety risks were examined, autistic children were significantly more likely to buy goods/services online. This is supported by research which utilised parental focus groups (Just & Berg, 2017). The results suggest that autistic children are susceptible to this risk. Previous research suggests that special interests are important to autistic people (Grove et al., 2018). It is possible that a desire to purchase items/services relating to them online makes this group more susceptible to unauthorised purchases. Therefore, future interventions should consider helping autistic children and parents become aware of this issue and what to look out for in terms of how money can be taken out of their online accounts without their knowledge and steps available to prevent this.

Cyberbullying and sexual exploitation were not significantly associated with having autism. This contrasts with the few past studies conducted in this area (Gillespie-Smith et al., 2021; Landon, 2016; Page et al., 2022; Rochleau & Chiasson, 2022; Sedgewick et al., 2019). On one hand, it is possible that contact risks are not as prevalent in the autistic population as originally thought. For instance, autistic children may have less direct contact with others online than their non-autistic peers. Mazurek and Wenstrup reported that autistic children compared with their non-autistic siblings spent more time watching television, playing videogames, but less time using social media or socially interactive videogames (Mazurek & Wenstrup, 2013). It may be that autistic children spend less time interacting with others online compared with their non-autistic counterparts, thereby reducing the likelihood of online bullying and sexual exploitation. Among autistic children and young people, the evidence suggests that there is an increased focus on peer relationships and move away from parents throughout childhood (Carter et al., 2014). Considering this, it is possible that parents may have been unaware of existing online contact risks, thus underestimated the prevalence of them in this survey. Some studies have suggested that parents may underestimate incidents of cyberbullying in neurotypical children (Dehue et al., 2008; Sorbring & Lundin, 2012). No research to date has directly investigated this among parents of autistic children, so it is unknown whether this pattern carries over to the latter.

Having autism was not associated with a reduced likelihood of phishing risks. Nevertheless, one previous study reported no evidence of a more systematic approach in autistic children compared with non-autistic children when they compared foraging behaviours (Pellicano et al., 2011). Therefore, it is possible that autistic children are not less prone to experiencing content risks compared with non-autistic children. Alternatively, the heterogeneity in the sample may have accounted for these findings. Study 1 is one of the few which have compared rates in the autistic population (Neupane et al., 2018). In addition, to the best of knowledge, it is the only study that has compared phishing incidents in autistic children. It is important that more research investigates this among autistic children before implementing interventions, particularly if results suggest that this is not the greatest risk, if at all, to autistic children. To summarise the outcome of the first hypothesis (H1), the results suggest that autistic children are more vulnerable to certain risks online.

4.8.3 **RQ1.2**: Do parents of autistic children report their child carrying out less online safety risk management than non-autistic children?

H2. It was expected that parents of autistic children would report them as less likely to carry out overall online safety risk management than non-autistic children. On one hand, there was no significant difference in total child risk management scores between the two groups. However, there were significant associations between having autism and not blocking people and/or online sites or using strategies to protect themselves online. The autistic group were almost five times less likely to block people and/or online sites compared with the non-autistic group. These results suggest that autistic children may feel less confident in their judgment of blocking people online overwhelming so avoid it more than non-autistic children. Compared with non-autistic children, autistic children have been reported to use social media less (Mazurek & Wenstrup, 2013). This may mean that autistic children are less aware of and adept with steps and/or digital tools for blocking people and sites. More work is needed to design interventions to enable autistic children to feel more confident independently managing unwanted online contact/content. Moreover, they were almost eight times less likely to use strategies to protect themselves online. This highlights that a large number of autistic children are not in control of keeping themselves safe online. It is important that autistic children can be independent online as much as possible. The findings support H2 and highlight that future interventions should focus on improving the ability of autistic children to protect themselves online, in particular block people/and or sites.

4.8.4 **RQ1.3**: Do parents of autistic children carry out more overall online safety risk management than parents of non-autistic children?

H3. Further, it was predicted that there would be a difference in total parental online safety management between parents of autistic and non-autistic children. Parents of autistic children carried out significantly less overall parental risk management than the non-autistic parents. On one hand, the findings refute those from studies suggesting that parents of autistic children restrict their online device use more than non-autistic children (Mazurek et al., 2015; Sasse, 2015). On the other hand, it is possible that a reduction in parental risk management is indicative of a parent's reduced confidence in their capacity to protect their child online. Therefore, future interventions should focus on involving parents of autistic children in online safety programmes to help improve their knowledge and confidence handling online risks and involvement in the online protection of their autistic children.

4.8.5 **RQ1.4:** Do autistic children who experience a higher amount of total online safety risks have poorer wellbeing, according to the parental reports?

H4. It was hypothesised that autistic children who experienced more online safety risks would have higher SDQ scores than autistic children with lower total online safety risks. Higher SDQ total scores indicate poorer child wellbeing. It was important to establish if there was an effect of autism group and online safety risk group on total SDQ scores. There was a significant main effect of each on SDQ scores, with large effect sizes respectively, $\eta^2 = 0.395$; $\eta^2 = 0.096$. SDQ scores were significantly higher among autistic children who experienced one or more online safety risks than autistic children who were reported as having experienced no online safety (Cohens $d = 0.5$). Similar results were found with the non-autistic group, with children who had experienced one or more online safety risks having significantly higher SDQ scores than those with no risks (Cohens $d = 0.7$). This highlights that having a higher SDQ may mean that this group is more vulnerable to risks. These are backed up by previous studies indicating the negative consequences that risks such as cyberbullying can have on mental health in the autistic population (Wright, 2017; Wright & Wachs, 2019). This indicates that there may be a more negative impact on autistic children, thus highlighting the importance of conducting research to reduce online safety risks in this population. Overall, the results suggest that autistic children are at risk of experiencing poorer wellbeing than non-autistic children, and this deteriorates if they experience online safety risks. It is paramount that work is done to address this issue. Researchers can measure autistic children's wellbeing pre- and post-intervention to investigate if there is an improvement following future online safety intervention(s).

4.8.6 **RQ1.5**: Do parents of autistic children have lower parental self- efficacy than parents of non-autistic children who have experienced online safety risks?

H5. It was expected that parents of autistic children would report lower PSE than parents of non-autistic children and subsequently found this to be true in the study. Parents of autistic children who had experienced one or more online safety risk reported lower total PSE than parents of non-autistic children who had experienced risks, but the difference was non-significant. Variance in PSE scores were significantly accounted for by autism diagnosis and parental online safety knowledge. This recognises the impact of having an autistic child and online safety knowledge on PSE. This highlights the need for interventions that improve online safety knowledge among parents of autistic children. Currently, parents tend to rely on self-guided online searches, as opposed to systematic and well- researched resources (Willard, 2012).

Future intervention designs should consider scaffolding autistic children's online safety knowledge as well as facilitating the active involvement of their parents (Belland, 2017; Hartikainen et al., 2016). It is important that this is done in consultation with autistic children and their families. A recent review of autism and technology use called for looking closely at how autistic children can be involved in the technology design process (Spiel et al., 2019). This is supported by a study from Putnam et al (2008) who interviewed parents, teachers and other clinicians about autism and technology use. The interviewees highly valued research supporting efficacy. Therefore, it is important that interventions have the research basis to support them and are co-designed with the target population where possible.

4.8.7 **RQ1.6.** Is there a relationship between total online safety risks experienced and total time spent using online devices?

H6. Interestingly, there was no significant correlation between total online safety risks and total online device use ($p > 0.05$). This emphasises that future research should consider moving away from screen time as an indicator of online vulnerability. Autistic children are active online users, but it is possible that time spent using online devices is not a robust predictor of online safety risks experienced. Furthermore, large scale survey evidence suggests that autistic children do not differ in their media use compared to other children (Montes, 2016). Therefore, this must be considered in future studies. Online safety interventions should move away from restricting children's screen time as a means of protecting children online. This will help to nurture children's independence, in particular for autistic children to socialize and pursue interests online that are important to them.

4.9 Limitations

It is unclear to what extent the survey data can be generalised. Study 1 focused on parental perceptions of their children's online safety risks, which may not capture all online safety risks experienced by children. Using the opportunity sampling method and the wording of the recruitment call will have likely incurred some bias. However, low numbers of autistic children diagnosed in the UK, in particular those with regular access to online devices meant that it would have been unrealistic for us to recruit in another way without running a high risk of low numbers which would have biased the results to a larger extent. It should also be acknowledged that children parents of autistic children had lower PSE, which may have influenced the findings in this study. The surveyed autistic group was majority-male and had high co-occurring rates of LD/ADHD. In addition, low numbers of risk incidences reported by parents may have reduced the power of the analyses. However, the data from Study 1 corresponds strongly with existing literature reporting on individual autistic online safety risks and emergent findings regarding child and parental risk management. Therefore, Study 1 adds an empirical investigation of multiple online risks in autistic children and comparing with non-autistic children to the literature.

Future studies should consider replicating the methodology with more autistic girls and conducting mixed methods investigations to examine this area in more depth. Further, researchers should investigate the differences in online vulnerability for autistic children versus autistic children with other co-occurring conditions, such as LD or ADHD. In addition, considering that there are distinct autistic gender profiles (Loomes et al., 2017), varying interventions can be designed to help autistic girls and boys based on the likelihood of them experiencing a particular online safety risk. Nevertheless, further research is warranted before drawing firm conclusions regarding this matter.

4.10 Implications

Overall, this piece of research highlights that parents perceive that autistic children experience significantly more online safety risks than non-autistic children and are subject to poorer wellbeing than autistic children who did not experience online safety risks. It is crucial that more work is done to address these differences. Parents of autistic children reported poorer PSE and carried out significantly less risk management. Having an autistic child and parental online safety knowledge were significant predictors of PSE. Future design interventions should help improve autistic children's and parent's confidence in their online risk management, ideally in a co-participatory set up. To date, few studies have examined online safety risks experienced among autistic children. Without investigating this, it is impossible to inform ecologically valid design recommendations for autistic children and their families. Parental surveys provide a useful outlet to investigate the online safety behaviours and wellbeing of autistic children, particularly those with co-occurring conditions. To the best of knowledge, this is the first study to empirically compare multiple online safety risks and behaviours by autistic and non-autistic children. The survey findings should help to support the design of digital tools to aid autistic childrens' and parents' online safety decisions. Consequently, it is hopeful that this research will shape the direction of future interventions and policy for this population and thus will help protect autistic children online.

In light of these findings, the following implications are discussed:

4.10.1 Implication 1

Further research regarding contact risks e.g., cyberbullying and online exploitation is warranted before specific technological interventions are designed to ensure they are reflective of autistic children's online safety experiences.

4.10.2 Implication 2

Researchers should look specifically at conduct risks (e.g., unauthorised purchases and why autistic children may be particularly vulnerable to them to help inform designers of future interventions).

4.10.3 Implication 3

Parents, practitioners and policy makers should avoid inferring screen time with elevated online vulnerability among autistic children.

4.10.4 Implications for the PhD Thesis

Study 1 contributes knowledge to the broader domain of privacy and security literature and field of interaction design for children, in relation to autism by confirming situations in which autistic children are at more risk than non-autistic children. Design-specific recommendations to improve the online experiences of autistic children in terms of how they and their parents manage online risks are given. Based upon the current results and other findings, caution is recommended before piloting interventions without consulting with autistic young people and their parents. The results pinpoint that future online safety interventions, e.g., blocking people and/or sites will be more readily accepted and ecologically valid if they are co-designed with autistic children and their parents. In terms of future directions for this thesis, it is important that this PhD does not focus solely on one group of the autism community, specifically parents of autistic young people. No research to date has investigated the first-hand accounts of autistic young people's online safety experiences. By conducting research with the latter, this will allow greater insight as to whether their experiences align with parental reports, including contact incidents.

5. Chapter 5: Interviews with Autistic Young People

5.1 Chapter Acknowledgements

A preliminary version of the background, methodology and results reported has been peer-reviewed and published as a journal article in 'Research in Autism Spectrum Disorders' (Macmillan et al., 2022).

5.2 Introduction

Autistic young people are active online users (Hedges et al., 2018; MacMullin et al., 2016), many use social media and online gaming sites for social connection and to share interests (Grove et al., 2018; Mazurek et al., 2015; van Schalkwyk et al., 2016). This population can have difficulty pausing and/or switching off their online devices and engaging in other hobbies (Mazurek et al., 2015, Mazurek & Wenstrup, 2013). Studies have reported a positive correlation between the likelihood of children experiencing online security risks and time spent online (Rideout, 2013; Rideout, 2017). Therefore, autistic young people could be considered an "at risk" group for online safety issues.

5.2.1 Online Risks

These incorporate a heterogeneous set of intended and unintended experiences which increase the likelihood of harm to an individual (see Chapter 1; Section 1.2). These include contact risks (where the child participates in risky peer or personal communication), content risks (where the child is a recipient of unwelcome or inappropriate mass communication) and conduct risks (where the child acts themselves to contribute to the risky contact or content) (Hasebrink et al., 2008; Staksrud & Livingstone, 2009). Contact risks cover sexual grooming and cyberbullying, content risks include phishing attacks and downloading harmful malware, conduct risks encapsulate, but are not limited to, inappropriate posting and unauthorised spending. Each of these will be discussed as to whether autistic young people are at risk pertaining to certain, or all online safety risks.

5.2.2 Online Contact Risks

With regards to contact risks, autistic young people may be susceptible to experiencing these. Existing studies suggest that online contexts promote a more “autism friendly” environment for this population to communicate. Many autistic adults use social media for interactions, with some stating a preference for online over face-to-face communication (Gillespie-Lynch et al., 2014; Mazurek & Wenstrup, 2013). On one hand, there are benefits to online communication for autistic adults, including increased comprehension and control of the pace (Gillespie-Lynch et al., 2014). However, online risks and miscommunication can occur. Psychological theories posit that autistic and non-autistic people have difficulties understanding each other, which can lead to breakdowns in two-way social interactions (Milton, 2012a). The increased reliance on online communication, together with difficulties understanding communication with non-autistic people, may together increase the risk of cyberbullying victimisation. One qualitative study carried out semi-structured interviews with eight autistic young people and six parents regarding their experiences of online social media relationships and risks. Thematic analysis revealed two themes, including barriers to online engagement (Abusive Interactions and Talking to Strangers) (Gillespie-Smith et al., 2021). These findings suggest that autistic young people could be vulnerable to experiencing cyberbullying. Rocheleau and Chiasson (2022) conducted interviews with 12 autistic (mean age = 14.9 years) and 16 non-autistic young people (mean age = 14.7 years). The findings indicated that autistic participants were more averse to talking to others online than non-autistic participants. Interestingly, this posits that autistic young people may avoid chatting to others online as a means of protecting themselves. Therefore, further investigation is warranted in order to explore whether autistic young people report similar experiences across other studies in terms of cyberbullying and avoiding online contact.

On one hand, there is some evidence that autistic people are less likely to engage in communication with others. For example, the social motivation theory suggests that autistic people are less motivated in pursuing social relationships (Chevallier et al., 2012). This would suggest that autistic young people would be susceptible to contact risks, where there is an emphasis on interacting with others. Nevertheless, recent evidence suggests that autistic adults desire interactions with others and this is beneficial to mental health and wellbeing contrary to the social motivation hypothesis (Maitland et al., 2021). Although these findings cannot be generalised to autistic young people, the latter will transition into autistic adults; hence an increased desire to interact with others may place autistic young people at risk for online contact scenarios. Adult studies have raised some of the issues that autistic females face. A recent study found that 79% of autistic women had suffered sexual exploitation or abuse compared with 26% of non-autistic women (Sedgewick et al., 2019). Another qualitative study used semi-structured interviews with six autistic women aged 19 to 29 years. Key themes from the interviews included child sexual exploitation. One participant disclosed that she had experienced online grooming (Landon, 2016). In a recent ethnographic study utilizing interviews with eight autistic adults, four parents and 10 staff working at an autism support service, autistic adults were reportedly providing personal information online such as phone numbers and addresses which were linked with incidents of online sexual exploitation (Page et al., 2022). These results indicate that autistic adults who are female may be vulnerable to online sexual exploitation. However, it is unclear if a similar pattern exists for all autistic young people. Therefore, it is important to explore whether autistic young people report similar experiences, regardless of gender.

5.2.3 Online Content Risks

Detecting content risks, such as phishing, will involve identifying visual cues that indicate the link is fake. Autistic adults can outperform their non-autistic peers on visual search tasks (Shirima et al., 2017). These enhanced skills may help autistic young people detect potential content risks. One phishing study compared 15 autistic versus 15 non-autistic adults performance on distinguishing between real and fake websites. No significant differences in detection accuracy were reported (Neupane et al., 2018). To the best of knowledge, there have no studies investigating the ability to detect phishing attempts among autistic young people. Inhibitory control refers to the suppression of goal-irrelevant stimuli and subsequent behavioural responses (Tiego et al., 2018). Research suggests that autistic children struggle to inhibit responses and actions to risky scenarios (Christ et al., 2007), particularly if it is associated with a focussed interest or reward (Mosconi et al., 2009). Depending on the perceived reward, the heterogenetic nature of autism may make some autistic young people less prone to phishing attempts than others. It is possible that if a reward is in line with an autistic young person's interests, they may be less likely to spot potential content risks. However, if not, the perceptual abilities of some autistic young people may act as a protective factor. Nonetheless, no studies to date have investigated first-hand experiences of these among this population.

5.2.4 Online Conduct Risks

Considering the evidence regarding potential inhibitory control among autistic young people, this may play a role in whether they are subject to "conduct" risks, where they contribute themselves towards the risky contact or content. Just and Berg (2017) reported on the results of two workshops with 16 parents/carers of autistic children and young people in which they used pictures and group discussions to identify online safety concerns. Risks experienced included unauthorised purchases and inappropriate posting on social media sites. In Study 1 of this PhD thesis (see Chapter 4), a parental survey of parents of autistic and non-autistic children and young people reported significant associations between having autism and unauthorized online purchases (Macmillan et al., 2020). These findings suggest that autistic young people may experience difficulties anticipating the potential consequences of their online decision making. However, these studies were carried out with parents/carers of autistic young people. Given that online safety risks may not all be captured by parental reporting, it is important that autistic young people are involved in research about their online safety experiences.

5.2.5 Managing Online Safety Risks

From the few studies addressing online safety risk management, parents are reported to restrict autistic children's online use via parental apps or switch off and remove device(s) (Clark et al., 2015; Sasse, 2015). However, this is likely to involve a compromise between reducing the likelihood of a child experiencing risks online and limiting their independence (Livingstone & Haddon, 2009). Considering the benefits of online devices for social interaction and sharing interests, restricting autistic young people's online device use will remove opportunities for pleasure and managing risks themselves. Moreover, the settings on parental app(s) may be switched off or not readily accepted by autistic young people. To date, few studies have investigated autistic young people's accounts of online risk management. It is therefore important to understand their lived experiences to increase insight regarding their online safety awareness and how this affects their risk management strategies. Therefore, it is crucial that a framework is chosen that focusses on how an autistic young person makes sense of their online safety experiences.

5.2.6 Study 2: Context and Motivation

Within the field of autism, qualitative research has often received less consideration and funding (Bölte, 2014). There is a growing call for research that engages stakeholders, including autistic people (Fletcher-Watson et al., 2019). Autistic narratives have highlighted the benefits of co-production, including originality of thought, that autistic people provide to research (MacLeod, 2019). A review has highlighted that qualitative interviews have been successfully utilized to investigate the lived experiences of autistic people (Howard et al., 2019). Study 2 will use a qualitative methodology to explore the online safety experiences of autistic young people, to improve understanding of autistic online safety behaviours by providing insight into their subjective experiences.

Interpretative Phenomenological Analysis (IPA) requires researchers to consider the impact of their own experiences and preconceptions on research design and procedures. This reflexivity acknowledges potential discrepancies between the participant's words and the researcher's interpretation of them. Therefore, a 'double hermeneutic' forms, whereby the researcher is making sense of the participant's account, who is, at the same time, making sense of their own experiences (Smith et al., 2009). Given IPA's reflective nature, autism researchers have argued that this helps to alleviate the 'double empathy problem' that can reduce the credibility of autism research as well as being an effective research tool (Howard et al., 2019; MacLeod et al., 2018; Milton, 2012a).

In autism research, there is a growing move away from the traditional medical model which relies on judging people's experiences from the outside (Williams, 1996). IPA encourages exploration of how societal factors influences an individual's experience, (Lopez & Willis, 2004). Considering that autistic young people's lived experiences are largely shaped by such factors (Cresswell et al., 2019), IPA is useful for exploring these (Howard et al., 2019). There is limited understanding of 'insider interpretations' (Pellicano et al., 2013), therefore IPA will be used in Study 2 to develop more in depth understanding of autistic online safety experiences.

5.3 Methodology

5.3.1 Aims and Research Questions

The aim of Study 2 was to explore autistic young people's online safety experiences. It sought to answer the following research questions:

RQ2: What are autistic young people in our sample's lived experiences of online safety, managing online safety risks and preferences in terms of improving their online safety experiences?

- **RQ2.1**: What are the lived experiences of online safety among autistic young people?
- **RQ2.2**: What are the lived experiences of managing online safety risks among autistic young people?
- **RQ2.3:** What are the preferences in terms of improving online safety among autistic young people?

5.3.2 Participants

Study 2 used purposive sampling for participant recruitment with the following inclusion criteria; that they had a medical diagnosis of autism in the UK, were aged between 11 to 18 years, and used online devices. 14 autistic young people aged 11 to 17 years (*M* = 14.0, *SD* = 2.2). This included eight males (*M* = 13.9, *SD* = 2.1) and six females (*M* = 14.5, *SD* = 2.5). No other co-occurring conditions e.g., LD and/or ADHD were reported. Participants' and parents of those under the age of 16 years responded to a recruitment call for autistic young people aged 11-18 years who used online devices. This was distributed via social media, including Facebook and Twitter. In addition, it was shared by relevant organizations such as the National Autistic Society, Scottish Autism, Autism Initiatives Scotland and the Lothian Autistic Society.

All of the participants (and parents where appropriate) confirmed that they had an autism diagnosis via email. A small, homogeneous sample size was selected and is in line with the wider body of IPA autism research and adheres to the framework principles (Howard et al., 2019).

5.3.3 Materials and Design

The semi-structured interviews were designed to explore factors relating to the autistic young people's online safety experiences. Interviews were recorded on a Sony ICD-B140 dictation machine before being transcribed. A debriefing form (see Appendix F) was emailed to participants aged 16 years and over at the end of the interview. If the participant was under the age of 16 years, the parent/guardian who consented for them to take part in the research was emailed the debriefing form.

5.3.4 Procedure

Ethical approval was granted from the Department of Computer Science Ethics Research Panel at Heriot-Watt University (see Appendix C). Before collecting any data, participants were directed to complete a physical or online information and consent form. Parents of autistic young people under the age of 16 years were required to read an information form and consent to their child taking part in the interview (see Appendix D). Participants aged 16 years and over were directed to read and approve their own information and consent form (see Appendix E). All were required to consent before proceeding further.

Upon receiving the completed consent form, participants were given the choice of the interview format. Studies suggest that some autistic people find face to face communication and direct eye contact uncomfortable (Madipakkam et al., 2017), so interview options included having it via phone call, Skype or live webchat, as well as face to face. Phone call interviews have been cited as a useful method for conducting qualitative research (Sturges & Hanrahan, 2004). Moreover, phone calls have been used successfully in IPA research as a method of interviewing autistic children/adults (Petalas et al., 2015). IPA studies in the autism research field have used a range of data collection methods (Tsai et al., 2018), so options were provided, including live webchat. To the best of knowledge, no IPA studies with autistic young people have utilized live webchats for data collection. However, research suggests that many autistic adults prefer online communication over face-to-face interaction (Gillespie-Lynch et al., 2014; MacLeod et al., 2018). Moreover, a recent survey indicated that autistic adults prefer written forms of communication (e.g., instant messaging) over methods of communication which rely on speech such as phone calls in unknown situations, including research studies (Howard & Sedgewick, 2021). Considering these factors, a live-webchat option was included.

Interviews were conducted face to face (n = 1), phone call (n = 2), Skype (n = 8) or live web chat (n = 3). In line with previous studies (Maloret & Scott, 2018; Petalas et al., 2015; Tierney et al., 2015), the interview questions were piloted with an autistic adult and revised to ensure that they were readily understood and an appropriate length for participants. For example, it was fed back that the original wording of "technological devices" was unclear and the phrase "online devices" was clearer, so this was changed to reflect this feedback. An outline of the interview questions was emailed ahead of time to allow participants time to familiarise themselves with it. Previous autism studies have done this to help reduce any potential anxiety regarding what to expect in the interview (Cridland et al., 2014; Huws & Jones, 2015; Petalas et al., 2015). Each interview was audio recorded to ensure an accurate record of interviewees' perspectives. Participants were interviewed individually but were given the option to be accompanied by an adult. One participant chose to have a parent present. Prior to the interviews, it was emphasised that participants could stop the interview at any time and/or move onto the next question. Before beginning, the PhD researcher asked participants an introductory question about their interests. This was done to try and make participants feel comfortable as these are important to autistic people and discussion about said interests have been noted to help build a rapport (Grove et al., 2018; Howard et al., 2019).

A semi-structured approach and interview script was used to allow the PhD researcher to guide each participant through their online experiences (see Table 5). To facilitate this process, reflecting and probing techniques (e.g., 'You mentioned that … tell me a little bit more about that?') were utilized. This allowed the participants to direct the content of the interview and prioritise issues, which they felt were important to talk about. Previous literature in the area were reviewed and interview questions were based on these as well as a previous study conducted by the PhD researcher which identified key areas in autistic children and young people's online safety behaviours (Macmillan et al., 2020). The PhD researcher wished to understand how the sample viewed online communication given that there is published evidence that autistic young people are active online users and use online activities for social participation. The PhD researcher sought clarification throughout ensure that they were interpreting the participant's account appropriately.

Table 5: Study 2 Interview Script

1	a. What kind of online devices do you use? b. Where do you use online devices? c. Why do you use online devices?
2	a. How do you find communicating with other people online? b. How do you find this compares with how you communicate with other people face-to-face?
3	Can you please describe what online safety means to you?
4	Can you please describe what kind of online safety risks you have experienced?
5	a. How do you find going online makes you feel? b. Can you please describe anything positive or negative?
6	Can you please describe how you try to keep yourself safe online?
7	a. Can you please describe what others do to try to keep you safe online? b. Can you please describe who does that/these things?
8	Can you please describe what things would make going online better for you?

Ethical protocols were in place for instances where disclosures were made. For instance, four out of the six autistic females reported unwanted online sexual contact e.g., sexual comments. One was under the age of 16 years and three were aged 16+ years. Based on the follow up actions that they described with risks that they disclosed e.g., blocked the unwanted contact, told their parents/school, a risk assessment of each instance did not indicate immediate safeguarding issues. In all interviews, participants were encouraged to seek support where necessary in the interview and were signposted to relevant support organisations in the debriefing form (see Appendix F). Moreover, these were discussed post-interview with the supervisory team to ensure appropriate ethical procedures were followed. Interviews with the autistic young people lasted on average 30 minutes, ranging between 19 and 45 minutes. None of the participants indicated distress pre, during or post interview. Each participant received a £20 Amazon gift voucher as a thank you for participating. This was unconditional to them finishing the interview.

5.3.5 Analyses

All interviews were recorded, anonymised and transcribed verbatim in English. These were analysed using IPA. In order to ensure that this was the most appropriate analysis, an IPA researcher was consulted regarding the length and depths of the transcripts prior to data analysis. Therefore, these were deemed appropriate to undergo IPA in order to explore the linguistic features and meaning in the data. In order to maintain an idiographic approach (Smith et al., 2009), each transcript was analysed separately. Each participants' perceptions of their experiences were considered, without extensive prior theorising. This is in line with the phenomenological aspect of IPA (Smith et al., 2009; Smith, 2017). The first interview transcript was read and re-read line by line in search of descriptive, linguistic and conceptual significance. A process of repeated reading, annotation, and reflection was carried out. Once an initial list of themes was established, the other transcripts were analysed, and amendments were made where necessary. This process then led to the clustering of superordinate themes followed by subsequent readings of the transcripts to confirm the suitability of these themes (Smith et al., 2009). Following checks, insignificant and over-lapping themes of the sample data were then discarded or collated to create a master list of superordinate and subordinate themes. The prevalence of themes across participants is recorded in the results section (see Section 5.4).

Smith's (2011) guide for evaluation of IPA research was used to increase the rigour of the analyses. Reflections were written down during the data collection and analysis process. Moreover, prior assumptions regarding the area of research were discussed with the PhD supervisory team before and during these two stages to check for any potential biases. The themes were checked and evaluated by all of the Study 2 supervisors (see Macmillan et al., 2022 for the full list of authors) in order ensure that this process was carried out with more than one with perspective. In instances when there was disagreement, these were discussed with the Study 2 supervisory team and, where necessary, amended the subthemes and superordinate themes. For example, following checking of the extracts, a subtheme formerly referred to as "Yearn to Block Unwanted Contact" was revised to "Support to Block Unwanted Contact" following discussions that the latter captured participants experiences of wanting support to block unwanted contact, as opposed to doing this completely independently by themselves more accurately than the former. This process was carried out until the whole of the Study 2 research team agreed on each of the superordinate and subthemes. In the write up of the results section, Study 2 endeavoured to adhere to four quality indicators of high quality IPA research: constructing a compelling, unfolding narrative; developing a vigorous experiential and/or existential account; close analytic reading of participants' words; attending to convergence and divergence (Nizza et al., 2021). As for the abbreviation at start of the quotes, F marks extracts from female participants, and M marks those male participants. The second letter stands for the participant ID. It is noteworthy that [...] represents missing text.

5.4 Results

Three superordinate and nine subordinate themes were extracted from the Study 2 data (see Table 6).

Table 6: Study 2 Emergent Themes

Superordinate Theme	**Subtheme**
Impact of Online Activity	Benefits of Online Communication Drawbacks of Online Communication Challenging to Inhibit Online Responses (male participants) Unwanted Online Sexual Harassment (females participants)
Online Risk Management	Avoids Online Contact Parental Mediation Checks for Visual Clues
Desire for Practical Solutions	Require Contemporary Training in Schools Support to Block Unwanted Contact

The first superordinate theme, ‘Impact of Online Activity’, illustrates the impact of online contexts on participants experiences. The second, ‘Online Risk Management’ refers to the strategies participants perceive as keeping them safe online. The third, ‘Desire for Practical Solutions’ encapsulates what participants reported would help to improve their online safety experiences. Each subtheme is outlined with extracts from the participants’ own words to capture the nuances of their online safety experiences to increase ‘internal coherence’ (Smith, 1996).

5.4.1 ‘Impact of Online Activity’

a. Benefits of Online Communication

With regards to online communication, this subtheme draws upon the associated benefits compared with offline. Participants highlighted that online contexts facilitated the removal of direct eye contact (M2: “don’t have to look at them’), which reduced pressure on online social interactions (F5: “means I can talk to my friends without being pressured to make eye-contact”). One participant vividly highlighted the allowances that online platforms offered her:

> F3: ‘It’s easier than in person. It’s not as intimidating, and you don’t get as anxious because they can’t see you and you have more time to think about what you are going to say rather than saying something very quickly. Because I am autistic I don’t really recognise social cues. I struggle to make eye contact and if people are getting bored I won’t notice. I sometimes won’t know what to say so need to think for a bit longer and you can’t really do that when someone is talking to you or waiting for an answer.’

Specifically, participants described it enabled more clues for gaging online interactions. One participant specifically noted the benefits of online profiles providing information for her to draw on in online conversations:

> F2: '[...] let's say you see a stranger on the let's say you see a stranger on the street, you are not going to be able to gage too much from them, but if you have someone online and you want to talk to them they will have this profile where you go and see what they look like and they like this and ooh I can bring that up in conversation or go onto that. So, you have this backlog of stuff to look at I guess'.

b. Drawbacks of Online Communication

This subtheme relates to the lived experiences of flaws specific to online communication. Participants reported that there was a lack of clues (F1: "When you're online you don't know what they're doing so you don't have that don't have that physical reaction"), including physical reactions to utilise in online interactions:

> F3: 'Sometimes it's harder to communicate what you mean because you haven't got intonation in what you say online'.

In relation to the lack of cues to help assist them in gaging their own responses in online settings, participants reported how the lack of online context exacerbated misunderstandings between them and other parties:

> F2: ‘I think sometimes you can say something, and you do not know the adverse reaction that some people are going to have to it, and they will pile on to you and you will just be left in the dark. I mean like, you’ll post something that you either think isn’t serious or like it’s a joke, people will understand what I am trying to say. Then all of a sudden people don’t get it or people will get really angry, and you don’t understand why they have reacted in that way because you think you have made something really, really clear and people don’t get it all. I think it’s just miscommunication because online you can’t tell if someone is being sarcastic or it’s satire’.

c. Challenging to Inhibit Online Actions

This sub-theme was only observed from the male participants’ data. This captures the difficulties they experienced with controlling their online reactions. One participant highlighted that online contexts enabled him to make faster decisions, which could lead to consequences in the future:

> M4: ‘It is kind of down to technology because it allows you to make split second decisions that you wouldn’t make otherwise. It is a lot easier to send a text with an unsavoury photograph than it is to save it, print it off and put it in a letter. Because you have that process where you have time to think about if you are going to do it whereas online it is very easy to send it as you think and you instantly regret it’.

In situations, where there was an incentive that interested them, male participants found the reward aspect appealing:

> M7: ‘This one time, this random thing came up saying that I had won a laptop or an iPhone 6S or an Xbox. I was so excited at first, but then I learned literally the next day and by my dad that these people just need your information’.

Another participant described a scenario he had experienced where there was an online incentive that interested them, so they had entered personal information, which caused them issues at a later stage:

> M8: ‘There was one time when I signed up for a thing, then I got a load of spam, so eventually I had to create a new email address. It was just a thing I signed up for. Can’t remember exactly what it was, but I signed up for it and it gave me a lot of spam so I stopped using that email address.’

d. Unwanted Online Sexual Harassment

This subtheme was extracted exclusively from data of female participants. This reflects their lived experiences of receiving un- wanted contact of a romantic and/or sexual nature in online contexts. For participants, such experiences were often unexpected:

> F1: 'There was a time when a boy was trying to chat me up on social media and I was like "this should not be happening!'

When such scenarios arose (F6: "when they start asking personal questions"), female participants found it difficult to handle these unwanted interactions:

> F2: [...] 'sometimes people kind of draw you in, and they will start talking to you and all of a sudden, it turns sexual and it's really uncomfortable because you have started talking to this person that you enjoy talking with and then all of a sudden you know they are like "let's make it about sex" and you are like "woah!" It's too much, I don't like it! And you're really un- comfortable because you want to be polite, but you don't want to be in that situation anymore'.

5.4.2 ‘Online Risk Management’

a. Avoids Online Contact

Participants reported that they avoided online contact with others to keep themselves safe online. Specifically, they described how they limited online contact (F6: “staying away from creeps”) and kept their online contacts to a small, trusted circle of family members and/or friends:

> M1: ‘As a precaution for online safety, I only really speak to my friends, most of the time’.

By avoiding online contact, participants restricted sharing of information about themselves in online contexts (F3: “don’t share everything”). Specifically, one participant vividly described their rules for what they were and not willing to share online:

> M3: ‘Not sharing your email/password. Not sharing where you live. Don’t trust anyone because you don’t know them because you could be sharing information with anyone.’

b. Parental Mediation

Participants reported various form of parental involvement in their online risk management. These included a range of monitoring and restrictive strategies (M2: “set up all my social media accounts”). One participant spoke about her experiences of online parental monitoring:

> F5: ‘[...] know that my family has done quite a few things to help me stay safe, but I can’t remember exactly what. My mummy installed something on my phone that tells her what I’m looking at.’

Despite the impact on their independence, participants highlighted that they understood that parents restricted their online activity to help prevent risky scenarios online:

> F4: ‘Parental controls are a good thing because it helps me stay safe online. I have the chat on the online games turned off so people can’t chat to me online.’
>
> M7: ‘She (mother) checks my phone to see that I am not clicking on anything unsuitable by accident’.

On the other hand, some participants were unaware of what strategies their parents used to manage their online risks (F5; "can't remember exactly what"); (M3: "ask mum and dad"). One participant noted how her parents managed an unwanted online contact scenario on her behalf:

> F1: 'So I went to my parents, and I didn't know what they were going to do because it's parents! They did their magic parent mojo thing, and he didn't bother me again.'

c. Checks for Visual Clues

In terms of strategies, participants reported checking for visual clues to help them detect potentially unsafe websites (M3: "I check if the website url has https in it"). One participant described how they spotted a potential phishing attempt:

> M5: 'The website was all black market themed and there was 'get a £ 100 Amazon gift voucher for free!' Just give us lots of personal information. Also, when I looked at the actual post, it was quite obvious it was someone pretending to be this famous person saying that. It was just because it was in a comments section of a YouTube video, and someone had made it so that it looked exactly like the YouTuber's channel then said, 'Do this please and stuff". That was the first time I saw it, but they do that quite a lot. I

> think it is just an automated computer thing. YouTube had a thing which highlighted the person who made the actual videos, so you know that is not the actual YouTuber'.

This corresponds with another participant's strategy of looking for specific visuals as part of his online safety risk management: M8: 'Usually if you don't have the padlock thing, you don't put any details in.'

5.4.3 'Desire for Practical Solutions'

a. Require Contemporary Training in Schools

In terms of future solutions, online safety training was extracted from the participant data. Specifically, participants reported a lack of up to date online safety awareness updates in schools. One participant recalled that the scenarios she was given were not ones that she had hoped for:

> F3: 'School gives us online safety talks, but I always find them extremely unrealistic. The scenarios they put in don't seem like they could ever happen. They could, but not frequently.'

This resembles the accounts from other participants who reported fatigue with the lack of changes to the online safety strategies offered to them:

> M7: ‘Every year just like any other, the school shows the same online safety video over and over and over again. “Don’t share anything like your password or information, make sure you have a stable account, blah blah blah” so I do them as they are engraved on my memory and never removed ever again [...].’

b. Support to Block Unwanted Contact

In terms of future solutions, participants reported that they would like more practical support to block unwanted online contact (F2: have more control) Specifically, participants noted that support to manage message requests would be beneficial to avoid engaging in unwanted contact:

> F3: ‘It would be useful to know what to do if someone message requests you so you don’t answer them because some people will and will end up having long conversations with them’.

With regards to the support to block people, participants highlighted that the tools had to be appropriate and effective for the online platform (F5: "someone who checks over messages"). For instance, one referred to current programmes which he had experienced which filtered unwanted messages, however these had restrictions which he found frustrating:

> M7: 'Nintendo has proven that they can block certain messages that are not suitable for online, but they only allow you to say nine different things. You can type things while playing levels, but that is restricted. Why can't they do it all online?'

5.5 Discussion

Using the IPA framework, this study sought to explore 'insider' accounts of 14 autistic young people's online safety experiences. The findings offer valuable insights regarding autistic young people's perspectives of communicating with others online and demonstrate the complexity and diversity of their online safety experiences. The superordinate themes and subthemes are discussed in relation to the research questions and the existing literature.

5.5.1 **RQ2**: What are autistic young people lived experiences of online safety, managing online safety risks and preferences in terms of improving their online safety experiences?

Study 2 findings indicate that while autistic young people's online experiences varied, many shared lived experiences of specific online contact risks (cyberbullying and online sexual harassment) and conduct risks (unauthorized purchases). Moreover, there were commonalities in terms of their risk management strategies (avoiding online contact) and preferences (a desire for more support to block online comments and/or individuals). These will now be discussed in the Study 2 sub-question sections.

5.5.2 **RQ2.1**: What are the lived experiences of online safety among autistic young people?

The superordinate theme 'Impact of Online Activity' encompassed 'Benefits of Online Communication' and 'Drawbacks of Online Communication' as subthemes. On one hand, the former described positive aspects to online communication for autistic young people. Some participants highlighted that the removal of direct eye contact facilitated their online social interaction. This is in line with previous findings that many autistic people find eye contact uncomfortable (Madipakkam et al., 2017). Online contexts were cited as useful in allowing autistic young people to engage in interactions by allowing more time to process information and not have to rely on offline cues such as eye contact. This is supported by existing literature with autistic adults (Gillespie-Lynch et al., 2014) and young people (Gillespie-Smith et al., 2021). In Study 2, autistic young people reported positive aspects of online communication, particularly for socialising with their friends and others who shared similar interests to them. This aligns with previous findings that autistic young people who visit online sites and platforms for social interaction reported more positive overall friendships than those who did not (Kuo et al., 2014). Therefore, there were aspects to online communication which some autistic young people found easier compared with offline communication.

On the other hand, the latter subtheme captured challenges autistic participants associated with online communication. This included a lack of physical reactions to gage social interactions. This challenge has been previously reported in large scale social media surveys (Burke et al., 2010). An existing study has suggested that autistic children draw on integrated clues, including facial, vocal expressions as well as body language for emotion recognition (Friedenson-Hayo et al., 2017). Online contexts may remove information that autistic young people rely on to understand others. Moreover, some of the participants described how their communication could be misconstrued, which could lead to negative online experiences. Considering the prevalence rates of autism, it is likely that they were interacting with a majority of non-autistic people online. Therefore, this can support evidence regarding the double empathy problem theory, that autistic and non-autistic people have difficulties understanding each other, which can lead to breakdowns in two-way social interactions (Crompton et al., 2020a; Milton, 2012a). A lack of physical reactions may increase the likelihood of miscommunications between autistic young people and others in online contexts, which may make them vulnerable to experiencing contact risks.

In Study 2, autistic young people specifically disclosed instances of where others harassed them online, particularly social media sites. This finding is supported by previous interview studies examining online social media risks (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022). Interestingly, this contrasts with the Study 1 parental survey results (see Chapter 4; Section 4.6) which revealed that cyberbullying and sexual exploitation were not significantly associated with having autism (Macmillan et al., 2020). Contrary to previous theories that autistic young people tend not to use social media, which could account for a lower incidence of cyberbullying, Study 2 findings indicate that autistic young people actively use social media, which can explain their experiences of cyberbullying and other contact risks.

It is noteworthy that gender-specific subthemes were extracted from the data. In the Study 2 sample, autistic females reported unwanted online sexual contact (see Section 5.3.4 for further discussion of ethics procedures). Previous studies with parents and autistic adults have suggested a possible vulnerability of autistic female adults to sexual exploitation (Cridland et al., 2014; Landon, 2016; Page et al., 2014 Sedgewick et al., 2019). This is the first study to report lived accounts of unwanted online sexual harassment among autistic young females. Some of the autistic female participants reported being overwhelmed when presented with these scenarios, and still wanting to come across as ‘polite’. Studies have suggested that many autistic adults ‘camouflage’ their autistic traits by trying to hide behaviour that might be viewed as socially undesirable to seem socially confident and is often motivated by a desire to make friends (Hull et al., 2017; Tierney et al., 2016). Compared with autistic males, autistic female adults have been reported to engage in higher rates of camouflaging (Lai et al., 2017; Milner et al., 2022). One potential explanation is that autistic young people who identify as female try harder to come across well in online social situations than autistic males, thus potentially increasing the likelihood of someone else trying to take advantage of them. Consequently, elevated camouflaging among autistic females may put them at increased vulnerability of experiencing online sexual exploitation.

Autistic male participants’ reported challenges with inhibiting online responses. Previous studies suggest that autistic young people have difficulty inhibiting responses in online contexts, particularly inappropriate posting and unauthorized purchases (Just & Berg, 2017; Macmillan et al., 2020), so the subtheme supports these recent findings. Compared with young females, males are posited to engage in more risk taking behaviours (Renier et al., 2016). Therefore, it is possible this extends to the autistic male participants in the Study 2 sample. Interestingly, some of the male participants described how online contexts allowed them less time to change their mind about carrying out actions, which they went on to regret. In addition, some participants described scenarios where they were tempted by the incentive of a reward e.g., an iPhone in return for providing personal information. This backs up previous suggestions that autistic people are vulnerable in terms of others misrepresenting themselves to them in online contexts (Benford, 2008). Spear phishing is a type of attack that is more targeted than other types of phishing as it uses social engineering to target an individual (Amro, 2018). For example, fraudulent emails are sent to an individual from an individual or company providing smartphones in exchange for personal information to carry out such attacks. Considering that focussed interests or hobbies, particularly online devices are motivating for autistic people (Grove et al., 2018), it is possible that autistic males are at risk pertaining to examples of spear phishing. Therefore, the findings suggest that autistic young males experience challenges with regards to conduct risks.

5.5.3 **RQ2.2**: What are the lived experiences of managing online safety risks among autistic young people?

In terms of autistic young people's online risk management, the participants' in Study 2 reported avoiding online contact. This is in line with the existing literature regarding online risk management among autistic young people (Gillespie-Smith et al., 2021; Rocheleau &

Chiasson, 2022). Some participants in the sample described only interacting with a small, trusted circle of family or friends. This corresponds with the findings of a small scale qualitative study of autistic children who reported preferring to be alone/and or have a small group of friends (Calder et al., 2013; Petrina et al., 2014). This may help to avoid unwanted contact risks. However, it may be that autistic young people want to reach out to more people online but are wary of experiencing contact risks. Participants within the sample also reported avoiding giving out personal information as a means to protecting themselves. To date, no research has examined this strategy. It would be beneficial to investigate if this particular behaviour is reported in future studies. However, the findings suggest many autistic young people follow this rule when trying to keep themselves safe online.

Parental mediation was extracted from the data as a subtheme. Participants reported a degree of parental involvement in their online risk management. This included accounts of monitoring and/or restrictive parental techniques. This supports previous findings that parents of autistic children restrict their online use via parental apps (Clark et al., 2015; Sasse, 2015). Given that evidence suggests that autistic people like to keep their trusted circle small (Calder et al., 2014), parents may act as an additional protective factor. Nevertheless, this will involve a trade-off between reducing risks online and an autistic young person’s independence. It is unclear how parental mediation will benefit autistic young people as they transition into adulthood. Therefore, it will be beneficial to examine ways in which future interventions can help to increase autistic young people’s confidence in managing their online safety risks independently.

Interestingly, autistic young people in the Study 2 sample described using visual search strategies in their online risk management. This included checking for verification symbols or text that looked suspicious. This supports previous research from Neupane et al (2018) which found that many autistic adults were able to differentiate between real and fake websites and noted differences, including that ‘URLs and logos were different’ (p. 474). Whilst it should be acknowledged that not all participants reported this, for some autistic young people, these strategies could help to reduce the likelihood of them experiencing content risks. Therefore, it is important to establish if this finding extends to other studies, as it could be utilized in online safety interventions.

5.5.4 **RQ2.3**: What are the preferences in terms of improving online safety among autistic young people?

In terms of future solutions, two subthemes were extracted from the Study 2 data. Autistic young people in the sample described a lack of contemporary online safety training in schools. Given the variety of online devices and contexts are expanding at an elevated rate (Fletcher-Watson & Durkin, 2015), it is likely that school resources are unable to keep up with the most up to date online safety developments. To date, there has been no published study investigating autism online safety interventions in education. Thereby, it would be useful if future collaborations could involve autistic young people and educators to find out more about how online safety training in schools, specific to autism, could be improved.

Support to block unwanted contact was extracted from the Study 2 data as a subtheme. Considering that all of the participants reported avoiding online contact, this would allow them to have agency over their online interactions, whilst being able to independently use online devices. Autistic young people in the Study 2 sample noted issues or restrictions with existing online platforms e.g., lack of options available. Visual symbols are recommended in supporting autistic people in clinical practice (Rutherford et al., 2020a; b), so future interventions should focus on harnessing visual cues that some autistic people will find useful. Researchers have advocated for the involvement of non-autistic children's input on the design of online safety tools (Hartikainen et al., 2016; Wisniewski et al., 2017). More researchers are advocating for a co-participatory design approach with autistic children and technology (Spiel et al., 2019; Spiel et al., 2017). To develop online safety tools that autistic young people will both use and benefit from, it is important that this population is consulted and involved in the design of future online safety interventions.

5.6 Limitations

Study 2 included 14 speaking; autistic young people aged 11 to 17 years. Therefore, the study findings cannot be generalised to all autistic people, including nonspeaking autistic young people out with the age range. All participants were based in the UK; so, the Study 2 findings may not apply to autistic young people in other countries as online safety experiences may not translate across cultures. Ethnicity and co-occurring conditions were not assessed in Study 2. Further investigations in this area, whilst exploring factors related to ethnicity, socio-economic class will be beneficial.

Non-binary autistic young people were not represented in this study. Considering that more autistic people identify as non-binary than non-autistic people (Warrier et al., 2020) and report gender-diverse experiences (Kourti & MacLeod, 2019), future research should endeavour to include non-binary autistic young people. The majority of interviews were carried out remotely. Diagnosis was not verified with medical records for Study 2 as this would not have been feasible. However, every participant's autism diagnosis was confirmed via email with the PhD researcher in response to the recruitment call. Some of the autistic participants' whose parents/guardians gave consent for them take part may have been unaware that they had an autism diagnosis, so this was not relayed to them during the interview. Study 2 specifically investigated the perspectives of autistic young people. On one hand, steps were taken to involve autistic people in the development of this research e.g., asking an autistic adult to review the initial interview script. Nevertheless, it was not a participatory action research study. Future research may benefit from involving autistic young people and parents to examine further how autistic young people's online safety experiences converge and diverge e.g., a co-operative enquiry design involving small, separate groups of autistic young people and groups of parents input on low-fidelity prototypes of online safety tools.

5.7 Implications

The implications of Study 2 for this PhD thesis are outlined in the following sections.

5.7.1 Implication 1

Online contexts can facilitate autistic communication e.g., removal of eye contact. However, a lack of physical clues in internet-mediated environments can exacerbate online miscommunications for autistic young people, thus increase the likelihood of them being subject to online contact risks.

5.7.2 Implication 2

Gender-specific online safety risks exist among autistic young people. In this study sample, autistic males struggled to inhibit online responses, whereas autistic females reported instances of being subject online sexual harassment. Further research is warranted to investigate the generalizability of these findings. Nevertheless, the results point towards the need to take gender into account with regards to autistic online risk management.

5.7.3 Implication 3

Autistic young people may want more online contact but are wary of unwanted solicitation. Therefore, designing online tools or interventions that allow autistic young people more ease of control over potential unwanted online interactions will give them more independence to manage them.

5.7.4 Implications for the PhD Thesis

Following on from the previous chapter, this study contributes further knowledge to the privacy and security as well as interaction design. It provides in-depth qualitative data regarding the first-hand accounts of autistic young people's online safety experiences. Moreover, it allows more evidence regarding what design approaches will inform online safety interventions for this population. The findings reiterate that such tools will be more readily accepted and ecologically valid if they are co-designed with the target population i.e., autistic young people. With regards to the next steps, this PhD will take the resulting themes from this chapter and design low-fidelity prototypes solutions related to them (see Chapter 6). These will be presented to autistic young people and their feedback and suggestions on future iterations will be sought. Consequently, the proceeding chapter will take a participatory action research approach.

Chapter 6: Co-Participatory Study with Online Safety Vignettes

6.1 Impact of COVID-19 Pandemic

Prior to the COVID-19 pandemic, this study was going to mirror the methodology of McNally et al (2018) study using Co-Operative Inquiry. Therefore, the plan was to involve face-to-face co-participatory design sessions with small groups of autistic young people aged 11-18 years old to evaluate existing prototypes and design online safety tools. However, due to the Coronavirus (COVID-19) crisis in the UK, the research stage was changed to be in line with the University Research Ethics Committee (UREC) ethical guidelines which stated that all research should be conducted remotely or paused. Therefore, this study was redesigned to take place via online formats. During the COVID-19 pandemic, the community partnerships who had been organised to take part in the study e.g., Lothian Autistic Society were closed. Considering evidence that autistic young people often prefer to work in small groups of people that are known to them (Spiel et al., 2017) and potential privacy concerns, Study 3 took place as part as virtual, one to one co-design interviews, instead of online focus groups.

6.2 Chapter Acknowledgements

A preliminary version of the background, methodology and results discussed in this chapter is being prepared for submission as a peer-reviewed article in the 'International Journal of Child-Computer Interaction'.

6.3 Introduction

As mentioned in previous chapters (see Chapter 1; Section 1.2), online risks incorporate a heterogeneous set of intended and unintended experiences which increase the likelihood of harm to an individual. These include contact risks (where the child participates in risky peer or personal communication), content risks (where the child is a recipient of unwelcome or inappropriate mass communication) and conduct risks (where the child acts themselves to contribute to the risky contact or content) (Hasebrink et al., 2008; Staksrud & Livingstone, 2009). Online contact risks cover sexual grooming and cyberbullying, content risks include phishing attacks and downloading harmful malware, conduct risks encapsulate, but are not limited to, inappropriate posting and unauthorised spending. Based upon the findings of previous studies, this chapter will focus on unwanted online contact and phishing attacks.

6.4 Online Safety Risks Pertaining to Autistic Young People

To date, few studies have investigated specific online safety risks experienced by autistic young people. On one hand, evidence suggests that autistic young people are subject to online contact risks, particularly cyberbullying. An interview study involving eight autistic young people and five parents indicated that autistic young people are at risk of experiencing unwanted online contact from known and unknown people (Gillespie-Smith et al., 2021). A recent study conducted semi-structured interviews with 12 autistic and 16 non-autistic young people with screenshots of various online social media safety scenarios to probe autistic young people's understanding of them. Thematic analysis revealed that autistic young people were more concerned about being cyberbullied by people they know in real life than the non-autistic participants. Macmillan et al (2022) found that autistic young people (aged 11-17) shared a desire to be able to block comments and/or individuals online as well as being able to detect fake websites. However, some of the privacy settings e.g., report and block, were unappealing to the autistic young people (Rocheleau & Chiasson, 2022). Consequently, it is important that online safety tools are designed which focus on supporting autistic young people to block unwanted online contact.

Previous studies suggest that autistic young people have difficulty inhibiting responses in online contexts, particularly inappropriate posting and unauthorized purchases (Just & Berg, 2017; Macmillan et al., 2020). "Challenging to Inhibit Online Responses" emerged as a sub-theme from interview data gathered from 14 autistic young people (see Chapter 5). For example, some participants described scenarios where they were tempted by the incentive of a reward e.g., an iPhone in return for providing personal information. Spear phishing is a type of attack that is more targeted than other types of phishing as it uses social engineering to target an individual (Amro, 2018). Fraudulent emails are sent to an individual from a company providing smartphones in exchange for personal information to carry out such attacks. Considering that special interests, particularly online devices are motivating for autistic people (Grove et al., 2018), it is possible that autistic young people are at risk pertaining to examples of spear phishing. Therefore, it is crucial that future research explores what factors can help autistic young people to detect such clues in order to avoid experiencing these types of online risks.

6.5 Co-Participatory Design of Online Safety Tools

From the very few published studies in this area, most have focussed on parental perspectives regarding their autistic children's online safety (Clark et al., 2015; Sasse, 2015).

Co-design relies on researchers involving the target population in decision making and idea generation (Sanders & Stappers, 2008). In this participatory process, the end users can be involved in several stages to help focus ideas for interventions and evaluate them (Trischler et al., 2018). Studies indicate that autistic people feel disenfranchised from a lack of involvement in decisions that affect them (Lory, 2019; Pellicano et al., 2014). Therefore, it is crucial that steps are taken to include their perspectives in research. The disability rights mantra “nothing about us, without us” advocates for autistic people being involved in research that explores issues that impact on them (Chown et al., 2017; Friesen et al., 2021; Pellicano et al., 2022). Therefore, participatory research helps to re-address the power dynamic predominantly adopted between researchers and participants (Nelson & Wright, 1995).

To the best of knowledge, no co-participatory research has examined the preferences of autistic children or young people, regarding how they keep themselves safe online. One study investigated non-autistic children’s perceptions of parental mobile monitoring technologies. A sample of 12 children were asked to review and re-design an existing mobile monitoring application. The results showed that children preferred and designed controls that emphasized restriction over monitoring and that taught risk coping (McNally et al., 2018). This highlights the benefits of co-designing online safety tools with the target population. Previous studies have reported benefits of adopting a co-participatory design with autistic children and technology (Spiel et al., 2017; Spiel et al., 2019). These posit that it would be useful for investigating autistic online safety preferences. In a qualitative study, the authors interviewed 31 parents of autistic children regarding their children’s online media preferences. Following thematic analysis, the main themes and subthemes indicated that ease of control and accessibility was important to autistic children (Martins et al., 2020). Nonetheless, few published studies have investigated autistic children or young people's desires regarding online safety tools.

To date, some research has investigated non-autistic young people's ideas within areas such as cyberbullying (Ashktorab & Vitak, 2017; Bowler et al., 2014). However, to the best of knowledge no study has investigated this among autistic children and young people. In terms of online media preferences, one study reported that autistic young people reported a preference for animated/cartoon content (Kuo et al., 2014). Stiller and Mößle (2018) conducted a systematic review of 47 studies examining online device use among autistic children and young people. The results indicated that they preferred role playing/simulation games. Nevertheless, these have never been investigated as part of autistic young people's preferences for online safety tools.

6.6 Study 3: Context and Motivation

Previous studies have reported benefits of adopting a co-participatory design with autistic children and technology (Spiel et al., 2017; Spiel et al., 2019). Researchers have advocated for the involvement of children's input on the design of online safety tools, including mobile monitoring software (Hartikainen et al., 2016; Wisniewski et al., 2017). To date, few published studies have investigated online safety experiences among autistic young people (Gillespie-Smith et al., 2021; Macmillan et al., 2022; Rocheleau & Chiasson, 2022). In order to develop online safety tools that autistic young people will both use and benefit from, it is important that autistic young people are consulted on the design of these interventions.

Online vignettes represent a research method, whereby a hypothetical short story or narrative (the vignette) is presented to participants who then respond to a series of open-ended questions (Braun et al., 2017). For this study, autistic young people would be writing or verbalising their feedback about a hypothetical scenario so would not have to have had any direct experience of the online safety scenario presented. It can be useful for exploring issues that may be difficult for participants to directly talk about e.g., cyberbullying (Braun et al., 2017). Prototypes represent models which are designed to develop and evaluate interfaces for user groups (Walker et al., 2002). In Study 3, two online safety prototypes will be created and piloted with autistic young people based on the evidence from the existing literature regarding autistic online safety risks. Therefore, online safety vignettes and low-fidelity prototypes will be employed to investigate autistic young people's perceptions of online safety tools.

6.7 Methodology

6.7.1. Aims and Research Questions

The aim of Study 3 was to investigate autistic young people's perceptions of online safety scenarios and explore their online management preferences. It sought to answer the following main research question (see Chapter 1; Section 1.4) and the subsequent sub-questions:

RQ3: What online safety tools do autistic young people desire and envisage themselves using, and specifically what features do they require from these tools?

- **RQ3.1**: What online safety tools do autistic young people desire and envisage themselves using?
- **RQ3.2**: What features do autistic young people require from these tools?

These were examined via online, one to one, co-design sessions with autistic young people. The rationale and creation of the low-fidelity prototype solutions will be discussed in the following section.

6.7.2 Creation of the Low-Fidelity Prototypes

For the purpose of Study 3, it was important that prototypes of online safety solutions that would be most relevant to autistic young people were selected and designed. Previous research has reported that autistic children and young people avoid online contact on social media as part of their online risk management (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022). This corresponds with the findings of studies within this PhD thesis which have indicated that autistic young people are less likely to block unwanted online contact (Macmillan et al., 2020, see Chapter 4) and would like support to block unwanted online contact (Macmillan et al., 2022; see Chapter 5). Based on these findings, it was determined that solution prototype to an online contact risk scenario should be included as one prototype in Study 3. With regards to the existing literature, research suggests that autistic young people have difficulty inhibiting responses in online contexts (Just & Berg, 2017). Within this PhD thesis, the findings from Study 1 and 2 reported similar behaviours (Macmillan et al., 2020; Macmillan et al., 2022). In Study 2, some autistic young people were enticed by the incentive of a reward e.g., an iPhone in exchange for personal information. This type of online risk is often referred to as spear phishing (Amro, 2018). A common way to carry out this type of online attack is via fraudulent emails. To the best of knowledge, no published study has investigated how autistic young people detect fake links or websites. Therefore, the second prototype solution in Study 3 centred on how to detect a fake link to an email login.

With regards to how these online safety solutions were presented, the PhD researcher carefully considered the options on how the prototypes were presented. Low-fidelity prototypes are typically presented hand-drawn examples or mock-ups of an interface and are often paper based (Walker et al., 2002). These contrast from high-fidelity prototypes which mimic the closest representation of an interface for users to carry out an activity or task on. Low-fidelity prototypes are indicated to act as useful medium for investigating the usability of interfaces designed for autistic children and young people, such apps to help transition from activities that they find challenging (Varnava et al., 2020). They are often used to test solutions and creating concepts with autistic young people in co-design research (Zhu et al., 2019). Considering evidence that autistic people can have difficulty with fluency and generating ideas (see Pennisi et al., 2020 for a systematic review and meta-analysis), low-fidelity prototypes could help autistic young people recruited to communicate their feedback regarding potential online safety solutions. Considering the time constraints of the PhD project and having limited funds to reimburse autistic young people for their contributions in this study, the PhD researcher chose to design the low-fidelity prototypes which were reviewed by a young autistic adult before data collection commenced. The subsequent feedback on these prototypes could help to evaluate whether these potential solutions should be incorporated into further research utilizing high-fidelity prototypes. With regards to what online platforms to incorporate into the low-fidelity prototypes, recent statistics indicate that Facebook and Gmail are the largest social media and email sites used respectively (Dixon, 2022; Statistics and Data, 2022). Therefore, these platforms were utilized in the online low-fidelity prototypes in this study. These were hand-drawn by the PhD researcher and reviewed with the PhD research team and an autistic adult prior to data collection. Photographs of the low-fidelity prototypes were taken and presented in the co-design sessions with each autistic young person recruited in this study (see Figures 3 and 4 in Section 6.7.7).

6.7.3 Participants

Table 7: Study 3 Participant Demographics

Participant ID	**Age (years)**	**Gender**	**Co-Occurring Conditions**
M1	18	Male	NR*
F12	14	Female	NR*
M2	14	Male	NR*
M3	16	Male	NR*
M4	16	Male	NR*
M5	15	Male	NR*
F2	16	Female	NR*
F3	12	Female	Dyslexic
M6	15	Male	NR*
F4	11	Female	NR*
M7	12	Male	NR*

NR: co-occurring conditions not reported*

Study 3 used purposive sampling for participant recruitment with the following inclusion criteria; that they had a diagnosis of autism in the UK and were aged between 11-18 years of age and used online devices. 11 autistic young people aged 11-18 years (M = 14.45, SD = 2.11), including 7 males (M = 15.14, SD = 1.86) and 4 females (M = 13.25, SD = 2.22) were recruited (see Table 7). Therefore, they were all diagnosed based on the Diagnostic and

Statistical Manual of Mental Disorders (4th ed.; (DSM); American Psychiatric Association (APA), 1994). This sample size is in line with the wider body of thematic analysis in autism research (Cage et al., 2016; Crompton et al., 2020b). Questions regarding participant demographics such as co-occurring conditions were only asked if it was deemed relevant to participants ability to take part in the study.

6.7.4 Design

Online vignettes were used to explore participants' meanings and interpretations of two online safety scenarios and low-fidelity prototypes in one to one co-participatory sessions.

6.7.5 Materials

Materials included online contact and content risk vignettes, low-fidelity prototypes for blocking a person online via social media and detecting a fake website respectively and a session debriefing form. Each session was recorded on a Sony ICD-B140 4GB dictation machine before being transcribed. The debriefing form was emailed to participants aged 16 years and over. If the participant was under the age of 16 years, the parent/guardian who consented for them to take part in the research were emailed the debriefing form.

6.7.6 List of Protocols Taken to Promote Engagement With Autistic Young People in Co-Design Sessions

Prior to data collection, the PhD researcher searched for existing guidance on how to engage autistic young people in online co-design sessions. To the best of knowledge, no specific, published protocols exist for this population in online safety, co-design research. Therefore, the PhD researcher utilized findings from previous literature which advocated for the involvement of autistic young people in research (see Scott-Barrett et al., 2019). Following this, a list of 10 protocols in order to promote engagement with autistic young people in the co-design sessions in Study 3. Each protocol is outlined with supporting evidence as to why this was carried out in Study 3.

1. Pilot materials with members of the autistic community prior to data collection

In line with previous research (Macmillan et al., 2022; Maloret & Scott, 2018; Petalas et al., 2015; Tierney et al., 2016), the co-design session questions were piloted with a young autistic adult. This was to ensure that they were readily understood and an appropriate length for autistic young people. It also provided the opportunity for any potential issues to be raised and remedied prior to recruiting autistic young people in this study.

2. Prepare autistic young people as much as possible prior to data collection

An outline of the session was emailed ahead of time to autistic young people taking part and where appropriate, their parents if they were under the age of 16 years. This was done to allow them time to familiarise themselves with what would happen in the session e.g., look at drawings of online safety tools and ask to provide their feedback on them. Evidence suggests that autistic people tend to experience anxiety when faced with uncertain situations (see Jenkinson et al., 2020 for a systematic review and meta-analysis). Previous studies have indicated that preparing autistic young people as to what can be expected to happen in a research study can help reduce potential anxieties associated with taking part (Cridland et al., 2014; Huws & Jones, 2015; MacLeod et al., 2018; Petalas et al., 2015). Therefore, preparations were made to prepare autistic young people as to what would happen in the co-design session and they were encouraged to ask the PhD researcher any questions they had beforehand to help make them feel more comfortable.

3. Give autistic young people the choice of the co-design session format

In Study 3, autistic young people (and parents/carers for those under the age of 16 years) were asked to indicate their preference for how they wanted to have their co-design session. This included having it via videocall and live webchat. Previous research has indicated many autistic people find direct eye contact uncomfortable (Madipakkam et al., 2017). Therefore, autistic young people who took part in videocall co-design sessions (n = 9) were asked if they would prefer the PhD researcher to have her camera turned on or off. Moreover, findings suggest that some autistic people prefer online communication over face-to-face interaction (Gillespie-Lynch et al., 2014; MacLeod et al., 2018). Therefore, participants were also given the option to have their co-design session via live webchat. At the time of data collection, the UREC ethical guidelines stated that all research had to be conducted remotely or paused. Therefore, it was not possible to carry out face-to-face, in person co-design sessions in this study. However, out with the exceptional circumstances that Study 3 took place in, this option would have been available.

4. Emphasise autistic young people's right to autonomy in co-design sessions

In the online co-design sessions, multiple steps were taken to increase autistic young people's choices and right to autonomy throughout the study. For instance, all participants were given the option to be accompanied by an adult in the co-design sessions if it made them feel more comfortable. Prior to and at the beginning of the co-design sessions, it was emphasised that the autistic young people could stop the session at any time and/or move onto the next question. Such measures were carried out in Study 2 of this PhD thesis and were deemed to have helped give autistic young people more power in the researcher-participant paradigm (Macmillan et al., 2022; see Chapter 5). Therefore, these were taken forward in Study 3.

5. Engage in topics that are important to autistic young people

Before introducing the online vignettes and low-fidelity prototypes, autistic young people who took part in the study were asked to tell the PhD researcher a little bit about themselves and what hobbies they liked to do in their spare time. Previous research has highlighted that interests/hobbies are important to autistic people in terms of their wellbeing (Grove et al., 2018). In addition, engaging autistic young people in conversation about topics that matter to them has been reported to help build a rapport and trust with researchers (Grove et al., 2018; Howard et al., 2019; Macmillan et al., 2022). It was also done to help gage whether autistic young people participating came across as potentially anxious or stressed. Therefore, this step helped to build trust and rapport with participants, as well as helping to look after their wellbeing.

6. Be flexible on how autistic young people provide feedback

In the co-design sessions, autistic young people were given the option to draw, write/type or verbalise their feedback regarding the low-fidelity prototypes. If only one option to feedback was provided, this would have excluded a potential number of autistic young people from participating. For example, challenges in using fine motor skills and motor coordination have been reported among autistic children and adults (see Fournier et al., 2010; Ohara et al., 2020 for systematic reviews). Therefore, only relying on autistic young people to draw their feedback would have been limiting. Having autism can co-occur with developmental dyslexia (Meilleur et al., 2020). This influenced the methodological decision to include options other than just writing. It is estimated that between 15 and 25% of autistic children who are diagnosed are non-speaking (Norrelgen et al., 2015). Researchers have advised that relying on participants capacity to speak exclude a large number of autistic young people from research (Elsabbagh et al., 2012). Therefore, the PhD researcher provided multiple options for autistic young people in Study 3 to feedback their ideas. All autistic young people who took part in the online co-design sessions were encouraged to give their feedback at that time. Nevertheless, they were also provided the option to create feedback in their own time and send it back within a week of the online session if it made them feel more comfortable.

7. Provide adjustments to help ensure that autistic young people's responses are being correctly interpreted

A semi-structured approach was used to guide each autistic young person through the online safety scenarios and to allow time for them to give their feedback on the low-fidelity prototypes. To facilitate this process, a technique utilized in Study 2 (see Chapter 4) of reflecting and probing (e.g., ‘You mentioned that … can you tell me a little bit more about that?’) was adopted. This allowed autistic young people to take control regarding the direction of the co-design session and prioritise issues, which they felt were important regarding the online safety scenarios and low-fidelity prototypes. In every co-design session, clarification was sought throughout to ensure that participants’ accounts were interpreted appropriately.

Research has reported that autistic children, young people and adults can take longer to process and respond to sensory input than those who are non-autistic (Jones et al., 2020; Uljarević et al., 2017). Therefore, the PhD researcher did not restrict the duration of any of the co-design sessions. After asking questions, she took care to wait for autistic young people taking part to respond and not interject with a follow up response too soon in case they were still processing and/or responding to what she had just asked of them. In Study 3, all autistic young people participating were encouraged to take as much time as they needed to consider and feedback their responses.

8. Keep autistic young people’s wellbeing at the forefront

Studies have highlighted that autistic children, young people and adults can become emotionally distressed in stressful environments (Jang et al., 2011; Murphy et al., 2009). Considering that taking part in a research study is a largely unfamiliar, novel situation, this could be potentially triggering for autistic young people. Therefore, it paramount that steps are taken to ensure that they are looked after prior to, during and post-research. In Study 3, autistic young people were briefed about the aim of the study and what they would be asked to do a pre-prepared script (see Appendix J). In this script, it was emphasised that they could take breaks in the session. Moreover, it was emphasised that they did not have to discuss anything that they did not want to and that they could skip any questions that they did not wish to answer. Autistic young people were informed that they stop the session at any time. At the beginning of the co-design session, autistic young people were informed that they would be presented with two separate online safety scenarios and low-fidelity prototypes of online safety measures (blocking an individual on an online chat; and detecting a phishing link). This did not involve asking autistic young people to reflect on their online safety experiences so minimal chance of distress was avoided.

In each co-design session, the PhD researcher gave autistic young people multiple opportunities to take breaks. Autistic young people were monitored for signs of stress throughout the co-design sessions. In Study 3, no autistic young person who took part displayed signs of stress pre, during or post-session. However, if they had, the PhD researcher's protocol would have been to stop the co-design session with immediate effect. After each session, all autistic young people (or parents/carers for those under the age of 16 years) were emailed the debriefing form (see Appendix K). This included the contact details of relevant support organisations (ChildLine and the National Autistic Society). The same protocols were in place for Study 2 of this PhD thesis which helped to keep autistic young people's wellbeing at the forefront of the study (Macmillan et al., 2022; see Chapter 5).

9. Explain how autistic young people's input will be utilized

In Study 3, the PhD researcher took efforts to explain how autistic young people's data would be used. The online consent forms for autistic young people under the age of 16 (see Appendix H) and those aged 16 years and above (see Appendix I) contained the following statement that participants were required to read and agree to prior to data collection, “I understand that anonymised data may be published and/or presented at academic conferences”. At the end of the session, autistic young people were thanked for taking part. It was emphasised that their feedback was important and would help to inform research. This was reiterated in the Study 3 debriefing form (see Appendix K). It stated that ‘Your feedback will help us to develop tools to help autistic young people be more independent online’. Previous participatory research has emphasised the importance of informing autistic people of how their data will be used (Crane et al., 2019). Therefore, autistic young people were informed at multiple stages of Study 3 as to how their feedback would be utilized.

10. Provide opportunities for autistic young people to feedback on what they believe is important

In Study 3, the PhD researcher encouraged autistic young people to take control regarding the direction of the co-design session and to prioritise issues. In every co-design session, clarification was sought throughout to ensure that participants’ accounts were interpreted appropriately. The semi-structured approach to questions and follow-up probes also helped to promote this. At the end of each co-design session, autistic young people were asked “Do you have anything else that you want to ask, or is there anything that I didn’t ask you that you would like to talk about?” This gave autistic young people who took part the chance to highlight any areas that had not been covered in the co-design sessions that they thought were relevant to the study. Therefore, steps were taken to involve autistic young people’s input as much as feasibly possible. The “nothing about us, without us” mantra emphasises the importance of involving autistic people in research that impacts them (Chown et al., 2017; Friesen et al., 2021; Pellicano et al., 2022). Therefore, the PhD researcher made efforts to try and re-address the power dynamic predominantly adopted between autism researchers and autistic participants in order to re-shift the balance so that autistic young people in Study 3 had opportunities to feedback on what they felt was important.

6.7.7 Procedure

Ethical approval was granted from Heriot-Watt University's School of Mathematical and Computer Science Ethics Committee (see Appendix G). Before collecting any data, participants were directed to complete a physical or online information and consent form. Parents of autistic young people under the age of 16 years were required to read an information form and consent to taking part in the online session (see Appendix H). Participants aged 16 years and over were directed to read and approve their own information and consent form (see Appendix I). All were required to consent before proceeding further.

Upon receiving the completed consent form, a convenient date and time for the one-to-one sessions were arranged with each participant and/or their parents where appropriate. Due to the COVID-19 pandemic, all of the sessions were conducted remotely in line with the UREC ethical guidelines which state that all research must be conducted remotely or paused. The co-design sessions were conducted via videocall (n = 9) and live web chat (n = 2). Each session was audio recorded to ensure an accurate record of autistic young people's perspectives, and all were conducted in English.

Firstly, a contact threat scenario was presented and read out—cyberbullying via instant messaging. A gender neutral name was used to describe a young person experiencing the scenario "*Sam is using a social media messaging app to communicate with others online. A* *message from another person pops up with comments that make Sam feel uncomfortable*". Next, the following phrase was read out, "*When we spoke to other young people like you, many said that they would like help to block someone chatting to them online. I am now going to show you a picture of how this can look from a drawing I have made up*". A low-fidelity prototype of how to block a person on an online chat example (see Figure 3) was then presented.

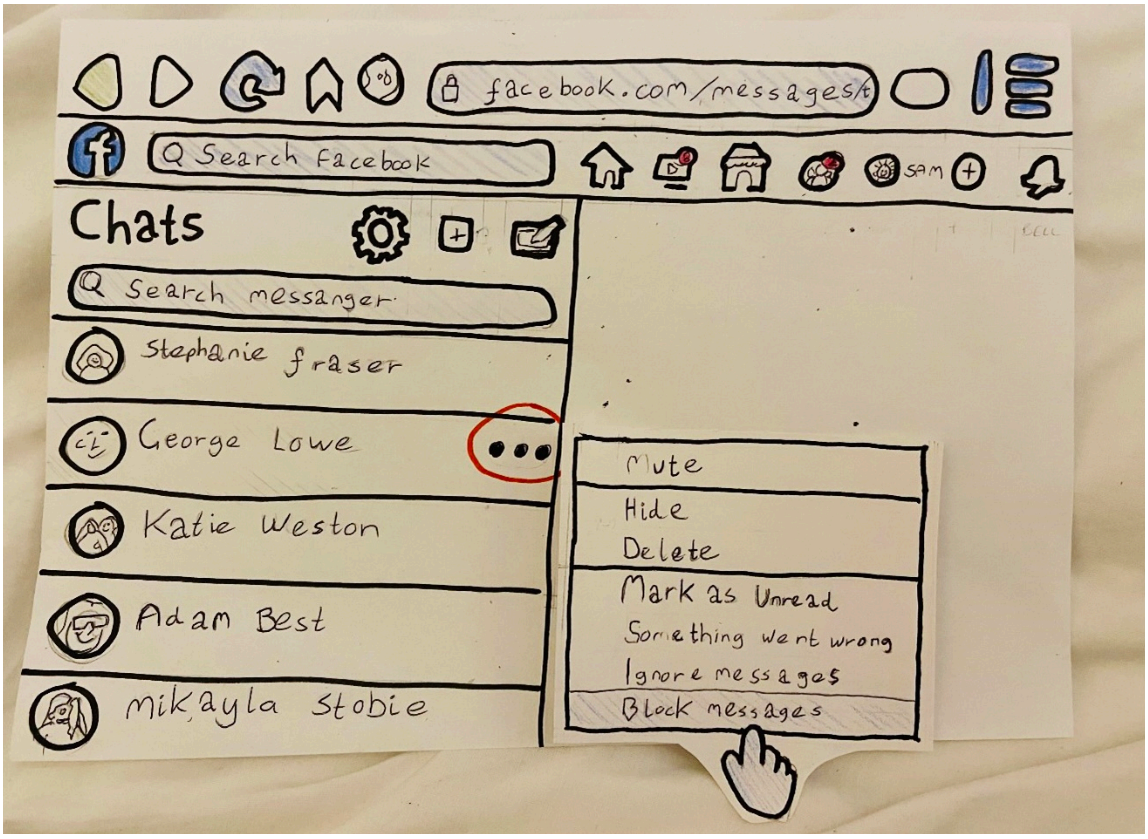

Figure 3: Copy of Contact Risk Low-Fidelity Prototype

Next, participants were asked "*Can you please describe how you think this would change the way Sam can stay safe online?*" Participants were encouraged to speak or type their answers in the live chat. The following phrase was then read out, "*Great, I would now like you to draw or write down what you think would make this more useful to help keep someone like*

Sam safe online. On a sheet of white paper at home, you can draw or write any changes to the picture that I am showing you, take a photograph of it and email it back to me. You can also describe to me or write in the chat box what you think would help to make it better. There are no right or wrong answers and you get to choose how you would like to show me what you would like. All participants who took part via videocall chose to verbalise their ideas (n = 9) and the two participants who took part via live webchat typed their feedback into the live messaging window (n = 2).

Secondly, the content threat scenario was presented and read out- exposure to a fake website where the participant is being invited to enter personal information. The same gender neutral name was used to describe a young person experiencing the scenario "*Sam has been directed to a website. It looks like the Gmail account login page. Sam has been prompted to enter their username and password. However, the page is fake and it is possible that Sam's personal information could be stolen and exploited*". Next, the following phrase was read out, "*When we spoke to other young people like you, many said that they would like help to spot clues that a website might be fake. I am now going to show you a picture of how this can look from a drawing I have made up*". A low fidelity prototype of how to detect clues that a website may be fake (see Figure 4) was presented. Participants were then asked "*Can you please describe how you think this can help to keep someone like Sam safe online?*" They were encouraged to speak or type their answers in the live chat. Next, the following instruction was read out "*Great, I would now like you to draw or write down what you think would make this more useful to help keep someone like Sam safe online. On a sheet of white paper at home, you can draw or write any changes to the picture that I am showing you, take a photograph of it and email it back to me. You can also describe to me or write in the chat box what you think would help to make it better. There are no right or wrong answers and you get to choose how* *you would like to show me what you would like".* As with the contact risk prototype, all participants who took part via videocall chose to speak about their feedback to the PhD researcher (n = 9). The two participants who took part via live webchat typed their ideas into the live messaging window (n = 2).

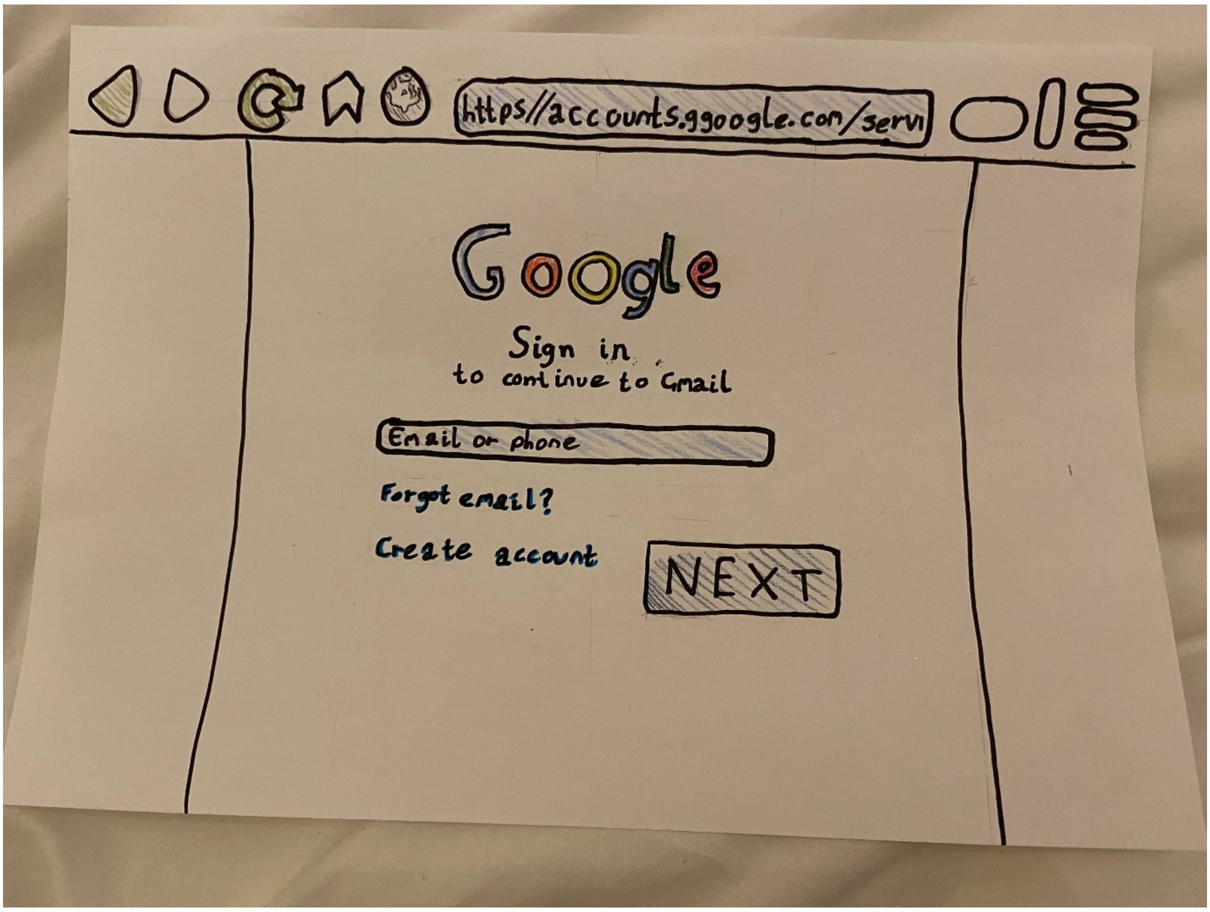

Figure 4: Copy of Content Risk Low Fidelity Prototype

No participants reported having directly experienced online contact or content risks described in this study. After the participants provided their feedback, they were emailed the debriefing form (see Appendix K). This included the contact details of support organisations (ChildLine and the National Autistic Society).

The co-design sessions on average lasted 32 minutes (18.44 – 78.47 minutes). Debriefing occurred at the end of session and appropriate information for gaining additional support regarding autism and online safety issues were available if required. None of the participants indicated distress prior to, during and post each co-design session. Each participant received a £15 Amazon voucher as a thank you for participating. This was unconditional to them finishing the co-design session.

6.7.8 Analyses

Reflexive Thematic Analysis was applied using a six-phase framework (Braun & Clarke, 2006; 2021) to identify key patterns in the transcript and visual data. An inductive approach was adopted. This was used in order to allow a flexible interpretation of the data that did not rely on an existing framework in order to interpret (Braun & Clarke, 2021). This allows new knowledge to be created, as suitable for this emerging and under-researched area (Braun & Clarke, 2021; Willig, 2013). Data was coded at the semantic level. It should be noted that the PhD researcher has an autistic family member and works in support services for autistic children/young people, therefore remained mindful that they have lived experience of working with autistic children and young people to support their online safety decisions. Moreover, the PhD researcher aligns themself with the principles of the neurodiversity movement, rather than the traditional medical model (Pellicano et al., 2021). A constructivist method was chosen as it focusses on the experiences, meanings and the reality of participants (Braun & Clarke, 2006). The six stage analysis process involved familiarisation with the data through reading and re-reading each transcript. Initial ideas were noted and recorded. Interesting features of the data were highlighted across the entire data set to produce initial codes relevant to these features. This involved the creation of a table of 'key quotes'. Next, there was a search for themes. These were reviewed to ensure that they related back to the initial codes, defined and named (see Figure 5). All themes were defined and checked by all members of the PhD research team for consistency. Data extracts outlined in the following section have been selected to evidence each theme.

6.8 Results

Three main themes were identified in the Study 3 data (see Figure 5). These included (1) '*How* information is conveyed'; (2) 'Desire for autonomy and choices' and (3) 'Need for technological solutions'. The following section will use extracts from the participants in order to discuss the shared meaning in these themes and corresponding sub-themes.

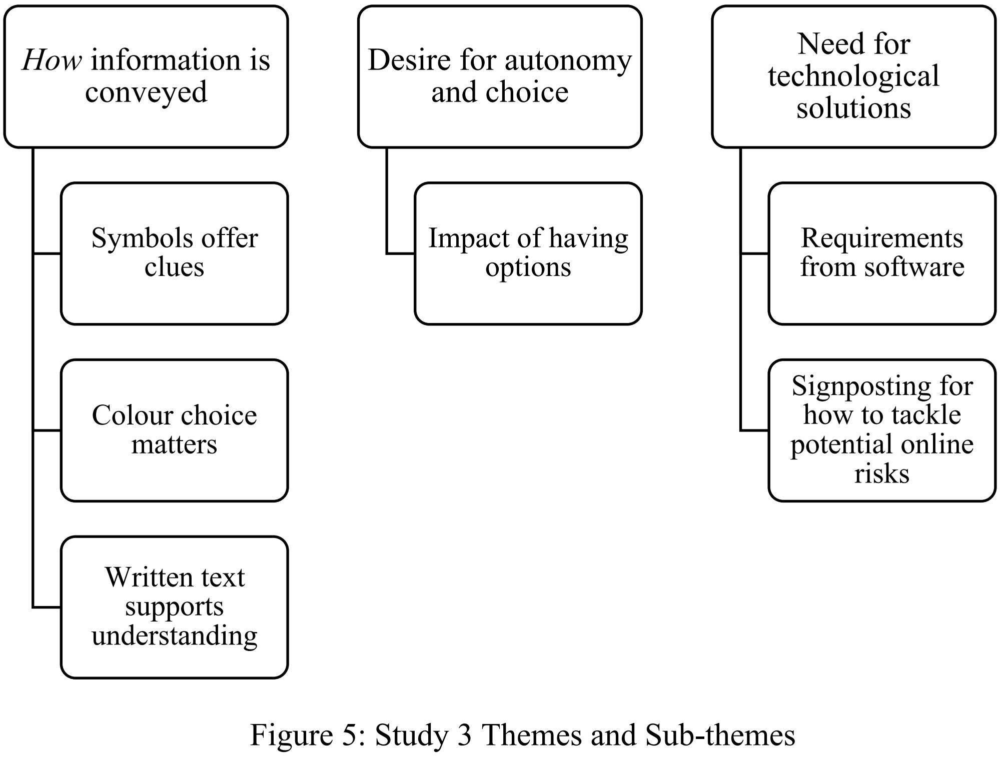

Figure 5: Study 3 Themes and Sub-themes

6.8.1 Theme 1: ‘*How* information is conveyed’

Many of the participants who took part in Study 3 described their observations regarding how the information in the low-fidelity prototypes was presented to them and subsequently understood. Within the participant data, two sub-themes were identified. These focussed on (a) the belief that symbols aided their understanding of the messages being conveyed in the prototypes (b) different colours indicate that varying actions should be taken and (c) written content aided comprehension.

a. ‘Symbols offer clues’

Participants highlighted that “an illustration helps to demonstrate what the meaning is” (M1). For instance, within the online contact risk low-fidelity prototype, autistic young people described how this led to them understanding the steps within the prototype.

> F1: “Visual cues like go to the three dots, so going by what is on the picture.”
>
> F4: “He (Sam) can press on the three dots. It shows you how you can block them.”

Symbols i.e., a mark or a sign that represent objects, concepts and relationships were described by the majority of the participants. Specifically, the concept of a padlock was mentioned in terms of how participants understood certain social media applications as well as verifying websites:

> M3: “A lock can tell you visually with an image that this person has a hidden account and they do not want you to see it essentially.”
>
> M4: “If I want to make sure it is a secure page, I would look for a padlock like on the shared garage doors, I would see where the URL is and the padlock is on, I know it is a secure page. If it is not, then I know it is a fake website and I wouldn’t go onto it.”

Nevertheless, some suggested further ways that symbols such as padlocks could be modified to aid their understanding of potential online security risks.

> M6: […] with the padlock, if it is unlocked it means it is not secure”
>
> M4: “If the padlock is an open one, not a closed one, he (Sam) knows it is a fake website.”

Moreover, additional symbols not included in the contact risk low-fidelity prototypes were highlighted:

> M7: “The delete option could have a picture of a bin on it because a bin is supposed to be where you put stuff away and it can be like throw away a contact that is not very nice away from your account.”

b. ‘Colour choice matters’

Participants frequently described colour when describing how information was and could be displayed in the low-fidelity prototypes. In terms of features they desired, many stated a preference for the colour red:

> M1: “Maybe in a situation where you were going to block someone, I would probably use the colour red”.

In particular, participants reported that they associated red with warning signs and dangerous situations:

> M2: “[…] red is usually like the sign for danger like with stop signs and warning signs”
>
> M6: “Well because red is danger and it is something you need to look out for. Like if you see a red light at a traffic light, you know to stop and just wait for it to say it’s ok.

> If there is red underlined in a spelling mistake, you obviously know it is incorrect and that is something that you need to fix."

Compared with other colours, red was described as having different connotations in terms of the actions participants decided to take:

> F3: "Green means go ahead, that it's safe that it is good, whereas red means that it is bad, that you should stop and you shouldn't do it."
>
> M4: "Red means you can take them off. If it's green, it makes it positive, so you can make them a favourite. If it's red, you can mute, hide, delete or block. Red would be the safest one".

Participants highlighted that they associated red with specific information that they needed to comprehend in other existing social media applications:

> M3: "On Instagram, it tends to be fully black and white. The important details such as the block, follow or hide is in a red colour so you know exactly where you need to go to be able to see them and hide yourself."

With regards to the low-fidelity prototype centred on how to detect fake websites, participants offered explanations as to how colour could be utilized in order to evaluate the authenticity of a website:

> F3: “Maybe at the top of the website it could have an amber dot if it’s not sure that it is a fake website and a red one if it is definitely not safe where the link is. If it is green, it’s a safe one, if it is amber, not one that is always safe but can be and red means it is definitely not a safe website at all.”

c. ‘Written text supports understanding’

Participants indicated that written information in the existing prototypes and future designs benefitted their comprehension of the underlying aims of the online safety solutions. This was demonstrated by some highlighting written aspects of the existing prototypes (M4: “the ‘block message’ bit”). Combined with the symbols described, written text warnings were indicated to aid participants’ understanding, (F3: “Probably the words above it giving a warning”).

With regards to how personal information could be avoided being stolen, participants highlighted that certain solutions would be better presented in written form as opposed to pictorially:

F1: “Probably with two-step authorisation, it would work better if it was written down because it would be complicated to draw it in my opinion”.

In terms of improving how written information is presented, some participants suggested that closed-text options would help to make choosing whether to block unwanted contact more accessible:

M7: “yes or a no option if you just have one option you can’t block it.”

M1: “a yes/no button next to the picture is maybe something I would have added.”

In addition, while written information was indicated to improve comprehension of online safety solutions, some participants highlighted that the content of the written message should be clear and concise where possible:

M6: “notification saying ‘this is not a secure website- do you wish to continue?’ ”

M1: “You don’t want it going into a massive paragraph of text, so something short that gets the message across. Maybe a box with “Warning, fake website, personal information could be stolen, proceed at your own caution”. Something like that rather than a long paragraph of text.”

Furthermore, other participants suggested that written text could enhance the comprehension of symbols given in solutions designed to help people detect potentially fake websites:

> F2: "perhaps having arrows saying hover over this or press on this on parts of it to make it easier to follow."

6.8.2 Theme 2: 'Desire for autonomy and choice'

When discussing what they valued in the low-fidelity prototypes presented, many participants advocated for being able to have choice and autonomy in their online safety decision making. Both context and person-specific factors influenced how they felt about taking certain steps in these processes.

a. 'Impact of having multiple options'

With regards to receiving potential unwanted online contact, many participants highlighted that not being limited to one option was beneficial, (M7: "more options can be easier"). Specifically, participants described that having other options in the existing low-fidelity that reduced the amount of online contact that they received was useful as opposed to just having the option to block all contact:

> M1: […] “so if he (Sam), doesn’t feel confident to block them completely, maybe he can just hide that message or mute the person for a little bit until maybe he feels confident making that decision.”

This indicates that autistic young in this sample may feel more comfortable having more options to control the amount of online contact that they view depending on how confident they feel about blocking unwanted contact.

Participants also expressed an understanding that other people could send messages that they would go onto regret, so they may prefer to mute their contact as opposed to blocking the contact altogether:

> F3: “the person maybe just messed up or said something by accident and like if you were to block them and they were to realise, you would have to find another way. Say you just didn’t want to talk to them for a while, you can see there are other ways to do that.”

> M3: “If you only have a block option, there is a chance that you may feel bad, have a conscious and think maybe they didn’t mean to, so maybe hiding the message and not having as many consequences back [...]”

Moreover, some participants highlighted that having extra options regarding how to deal with potential unwanted online contact could be beneficial:

> M6: “if you could report to an administrator that could have control over what happened, that would be an easy way to never talk or hear from them again and be able to ignore them for as long as you can. If you are able to report the user, then not only can they possibly be blocked from you, but also they can have consequences for their actions.”

On one hand, these extracts capture the benefits of having multiple options to deal with potential unwanted online contact. On the other hand, some participants described how having too many options presented could be challenging for them to manage:

> F2: “Because there are so many options in the menu it could be stressful but that could be hard to avoid if it's programmed into the social media site itself…if possible reducing the amount of options on the list could be helpful to make it less overwhelming.”

This emphasises that having choice regarding potential online safety tools can include having fewer options presented in order to promote autonomy in autistic young people's online safety decisions.

6.8.3 Theme 3: 'Need for technological solutions'

In terms of future online solutions, participants fed back their suggestions on features and/or programmes that they would like to see. This included their expectations and reasoning for how these could help to improve online safety experiences in the future.

a. 'Requirements from software'

Many participants reported that they would benefit from software programmes that carried out specific functions that were relevant to them. With regards to blocking potentially unwanted contact, participants described how a filter could help them to avoid receiving messages containing specific content from others online:

> M2: "maybe censor like rude words if they are getting sent like if people are sending like rude words and you can customise the censoring as well and if the word that is getting sent is rude then it would be put in chat like this [censored]."

> M6: “I once saw this a while ago where you could filter out messages from certain people and if had like poor language or if was scandem like you had certain things that you didn’t want to see, then they would sent to somewhere else. Like if you had been ready for it to be rude or whatever.”

This indicates that a filter that can catch harmful content can possibly help autistic young people in this sample avoid receiving contact that they do not want to receive.

Some participants also highlighted that this could help give them autonomy over their online safety risk management and avoid them having to take other actions to prevent unwanted online contact:

> M1: “You could have a sensitivity filter or something just sort of something that could be at the top of the menu that could be turned on or off or if someone does say something that is offensive that could notify the person then maybe that could potentially resolve any conflicts without anyone needing to be blocked and if they have done it accidentally and not knowing something is going to offend. If it was something that could be changed. Maybe if it was something like swearing or more personal, a potentially racist or sexist remark or something along these lines.”

With regards to being able to detect potentially fake links/websites, participants discussed how malware software could help to resolve this issue:

> M5: “Make sure there is a security grid or firewall in it so no one can access it from the inside”.

Participants described how such malware software and applications could help them with online safety risk management:

> M2: “well if there was like an app on their (Sam’s)phone or on their computer that could check if url are genuine then it would definitely be easier to spot scam websites.”
>
> M1: “If there was software that could be downloaded to help verify if a website was real or not I think could be very useful.”

Therefore, participants expressed certain requirements and expectations in terms of what they expected from software to help them avoid the risks highlighted in the existing low-fidelity prototypes presented in Study 3.

b. ‘Signposting for how to tackle online risks’

Whilst participants discussed how specific features could be incorporated into the existing low-fidelity prototypes, many highlighted how being directed to verified links or information that could help promote awareness of potential online risks and how to manage them. With regards to detecting potentially fake websites, participants discussed how being given information when they operated a programme would help to inform them what to look out for:

> M1: “maybe a bit of information, an email that he receives when he (Sam) first opens a google account so he is aware that it could be a possibility with ways he could identify a fake website would be useful. Maybe a short video, a couple of PowerPoint slides that have a few images of fake websites that you could compare, spot the difference, informing of subtle differences.”

Participants also suggested that being able to consult a guide as to what to look out for could help them navigate such risks in the future:

> F2: “A list of things to check for in the url that may suggest it's not the real site like spelling errors, dots etc. and maybe a list of other things to look out for on pages that may hint they're dangerous.”

6.9 Discussion

The aim of Study 3 was to explore autistic young people's perceptions of online safety scenarios along with their online management preferences. Participants in this study offered valuable feedback regarding what online safety features and tools would enhance online safety experiences. The main themes and sub-themes are discussed below in relation to the research questions and the existing literature.

6.9.1 **RQ3**: What online safety tools do autistic young people desire and envisage themselves using, and specifically what features do they require from these tools?

Study 3 findings indicate that many autistic young people in the sample valued choice and autonomy in their online safety risk management (having options on how to deal with unwanted online contact). They emphasised how it mattered how information in low-fidelity prototypes was visually presented to them (symbols, colours and written text). Moreover, there were commonalities in terms of what they desired from technology (software requirements and signposting). These will now be discussed in the Study 3 sub-question sections.

6.9.2 **RQ3.1**: What online safety tools do autistic young people desire and envisage themselves using?

Importantly, 'Desire for choice and autonomy' was extracted as a main theme from the Study 3 data. Autistic young people in the sample advocated for the right to be given choices in online tools on how to deal with unwanted online contact. 'Impact of having multiple options' was captured as a sub-theme. On one hand, some autistic young people fed back that having too many options presented on how to manage unwanted contact could be "overwhelming", indicating that it would be good to control how many options were presented. On the other hand, many autistic young people in the sample highlighted that having multiple options on how to manage unwanted contact was beneficial. Some described how having options to mute and hide unwanted messages gave them other options as opposed to just blocking the online contact. This indicates that autistic young people benefit a variety of options from online tools/support to block unwanted online contact. Therefore, this corresponds with previous findings from this PhD thesis that having autism is associated with a reduced likelihood of blocking online contact (Macmillan et al., 2020; see Chapter 4) and that autistic young people desire more online support to block unwanted contact (Macmillan et al., 2022; see Chapter 5). Moreover, the data supports research out with this PhD thesis reporting that autistic young people avoid online contact as part of their risk management (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022). Consequently, the findings from Study 3 add to the steadily growing evidence base indicating that autistic young people use social media sites and applications, but value appropriate online supports/tools to manage potentially uncomfortable or harmful online contact.

The main theme 'Need for technological solutions' encompassed the sub-theme 'Requirements from software'. Within this sub-theme, the data provided by autistic young people indicated that they would potentially benefit from certain software programmes and applications to help manage online safety risks. With the online contact risk prototype, autistic young people in the sample described how incorporating a filter that removed harmful words/content could be beneficial. This supports the IPA findings from Study 2 in this PhD thesis, where other autistic young people reported that filtering software would make going online better for them (Macmillan et al., 2022; see Chapter 5). Moreover, autistic young people in the sample described how this could give them more control on how to manage potentially unwanted contact. For instance, some reported how it could remove the need to block someone and/or avoid potential conflict. Previous co-design studies conducted with non-autistic children have indicated that they prefer controls that promote risk coping and restriction (McNally et al., 2018). To date, no published study out with this PhD thesis has examined what specific software and controls autistic young people would value. Therefore, the findings from Study 3 indicate that like their non-autistic peers, autistic young people value software that allows them to haver autonomy regarding their online risk management. It is acknowledged that filters like the ones described may already exist across various social media sites and applications. However, the findings from Study 3 indicate that either autistic young people are unaware that such software exists or such filters need re-designed and presented so that they can readily understand and utilize them when required.

In terms of the content risk vignette and low-fidelity prototype evaluated in this study, autistic young people discussed if potential software could be designed and implemented to help resolve this type of online risk, as well as similar issues. Specifically, they fed back that having malware programmes that can detect potentially fake links and websites could be useful. To date, few published studies have investigated autistic people's knowledge and use of malware software. Neupane et al (2018) reported that only two autistic adults out of the autistic group (n = 30) fed back that they had heard about firewalls and had knowledge about secure connections. Therefore, it is important that when such programmes are rolled out, work is done with the user groups to help promote awareness of these solutions. To the best of knowledge, no published study has examined what autistic young people desire from malware software. Future research and design should endeavour to involve autistic children and young people in order to better understand their pre-existing knowledge and requirements from malware software.

‘Signposting for how to tackle online risks’ was extracted as sub-theme. Many autistic young people emphasised that being directed to verified information regarding potentially unsafe links would help in online safety risk management. Examples included a checklist of things to look for in a URL, as well as short videos and pictures depicting how to spot fake websites. This highlights that autistic young people in this sample valued having access to online support that would allow them to make informed decisions on how to manage scenarios in the future. In this PhD thesis, Study 2 indicated that autistic young people desire contemporary training and resources in order to manage online risks (Macmillan et al., 2022; see Chapter 5). Therefore, the findings from Study 3 lead on from this by providing specific examples of how web designers could educate autistic young people in managing such risks in the future. Overall, this suggests that autistic young people value existing tools that allow them to restrict unwanted contact. Nevertheless, the data from Study 3 indicates that they would like more options including accessible filtering and malware software.

6.9.3 **RQ3.2**: What features do autistic young people require from these tools?

In terms of what features autistic young people require from such tools, ‘*How* information is conveyed’ was extracted as a main theme. Autistic young people emphasised that they attended to particular aspects of the low-fidelity prototypes and offered suggestions on how these could be harnessed in future designs.

Specifically, autistic young people described how symbols such as padlocks allowed them to interpret the authenticity of websites (‘Symbols offer clues’). A symbol refers to an illustration that intends to represent an object or concept (DeLoache, 2004). Symbols have been reported to aid referential understanding of concepts among autistic children (Hartley & Allen, 2015b). Studies report that non-autistic children tend to rely less on icons with age, whereas autistic children are indicated to benefit from dual representation and symbolic references to understand objects and tasks associated with daily living (Hartley & Allen, 2014; 2015a; Wainwright et al., 2020). Considering evidence that visual symbols are recommended in supporting autistic people in clinical practice (Rutherford et al., 2020a; b), it is possible that these could aid autistic children and young people’s understanding of online safety scenarios, thus aid their online risk management. This corresponds with evidence from this PhD thesis that autistic young people used visual searches to verify whether websites could be trusted (Macmillan et al., 2022; see Chapter 5). In Study 3, autistic young people advocated for future designs having more symbols such as bins to aid understanding or modifying existing ones such as padlocks to be opened or closed to aid their understanding. Therefore, these findings indicate that autistic young people value symbols and that these should be incorporated into future designs where possible to improve understanding and accessibility for them.

‘Colour choice matters’ was extracted as a subtheme from the Study 3 data. Many autistic young stated a preference for the colour red for identifying important features and associated it with danger and a need to take appropriate actions. According to the colour-in-context theory, different colours convey varying meanings and associations (Elliot & Maier, 2012). For instance, red is typically associated with warning signs, danger and the need to remain vigilant (Pravossoudovitch et al., 2014). This corresponds with the data related to this sub-theme. Few published studies have investigated colour preferences among autistic children and young people. One study investigated this among 29 autistic boys aged 4-17 years and 38 non-autistic, aged-matched boys. Colours included red, pink, yellow, brown, green and blue. Autistic boys aged 11-17 years overall preferred blue, followed by red, green, brown, yellow and pink (Grandgeorge & Masataka, 2016). The study is limited as it only recruited autistic boys and the possibility of ceiling effects cannot ruled out. However, the initial findings indicate that red is a preferred colour among autistic young people. In terms of colour perception, one study administered the Cambridge Colour Test to 20 autistic children 36 non-autistic children. The results indicated that 30% of autistic children showed colour vision losses and 30% showed an elevated threshold for colour (Zachi et al., 2017). It is possible these findings can be accounted for by hyper and hypo sensory reactivity reported associated with autism (APA, 2013). Regardless, the findings from Study 3 indicate that colour is an important cue used by autistic young people, thus should be utilized further by designers to incorporate in online safety tools for autistic children and young people. It should be noted that cultural variations exist with regards to colour preferences. For instance, the colour red is typically associated with good luck and success in countries such as China (Pontes & Williams, 2020). Research has reported Asian participants were less averse to taking risks when exposed to the colour red than white participants (He, 2009). Therefore, the findings regarding colour preferences may not extend to autistic young people in Eastern, collective cultures who may view colours in a different way to those based within the UK.

In addition, autistic young people indicated that written messages in the existing prototypes and potential future designs would benefit their comprehension and engagement with future online safety tools (‘Written text supports understanding’). Generally speaking, reading involves decoding written words (graphemes) and transforming them into phonological representations (Baixauli et al., 2021). The simple view of reading model suggests that reading comprehension is a result of linguistic comprehension and decoding skills (Hoover & Gough, 1990). Previous studies have indicated that autistic young people without LD/ID are able to utilize their decoding skills which in turn helps them in terms of their reading performance (Jones et al., 2009; Norbury & Nation, 2011; Solari et al., 2017). A recent study compared the literacy skills of autistic young people without LD/ID (n = 30) and non-autistic young people aged 12-14 years. No significant differences between the two groups were reported on measures of reading comprehension (Baixauli et al., 2021). Therefore, it is possible that some autistic young people utilize their reading skills to comprehend written messages, thus increase their understanding and use of potential online safety tools. In Study 3, some autistic young people fed back that potentially combining written text with symbols could help to help to improve potential online safety tools. This corresponds with evidence indicating that autistic children benefit from multi-modal methods of teaching in education (Djatmika et al., 2020). Future designers could consider how these visual cues could be harnessed together in online safety prototypes. However, it should be acknowledged that there is a high co-occurrence rate between autism and LD/ID (Elsabbagh et al., 2012). Thereby, written text in online safety tools may not necessarily work for autistic young people with an LD/ID. More research is needed before drawing firm conclusions regarding this area. Nevertheless, written text was highlighted by autistic young people in this study as being useful for aiding their comprehension.

6.10 Limitations

Study 3 piloted two low-fidelity prototypes to two online safety scenarios- blocking unwanted contact and detecting fake websites, so the results may not apply to all potential online safety solutions. Online vignettes were used to elicit participant responses to hypothetical scenarios. This decision was made in order to make the low-fidelity prototypes tangible for the autistic young people to provide their feedback and ideas on them. However, it is acknowledged that some of the data elicited was specific to these scenarios and may not represent the participants real life experiences of online safety risks. 11 autistic young people aged 11 to 17 years. They chose to take part orally (n = 9) or via live webchat (n = 2). Although the methods were adapted so that the study was not only conducive to speaking autistic young people, the findings cannot be generalised to non-speaking autistic people, as well as those out with the selected age range.

All participants were based in the UK; so, the Study 2 findings may not apply to autistic young people in other countries as online safety experiences may not translate across cultures. As previously mentioned, red is associated with luck and success in Eastern cultures (Pontes & Williams, 2020). Therefore, the findings regarding colour preferences may not extend to autistic young people out with the UK. In Study 3, ethnicity was not assessed. Further investigations in this area, whilst exploring factors related to ethnicity, socio-economic class will be beneficial. With regards to gender, there were no non-binary autistic young people in the sample. Due to the growing number of autistic people who report gender-diverse experiences (Kourti & MacLeod, 2019), future research should endeavour to include non-binary autistic young people, where possible. All of the co-design sessions were carried out remotely. Due to feasibility issues, diagnosis was not verified with medical records in this Study. However, every participant's autism diagnosis was confirmed via email in response to the recruitment call. Some of the autistic participants' whose parents/guardians gave consent for them take part may have been unaware that they had an autism diagnosis, so this was not relayed to them during the co-design session.

Study 3 investigated autistic young people in the sample's perceptions of online safety scenarios and explored their online management preferences. In this participatory action research study, steps were taken to involve autistic people in the development of this research e.g., asking an autistic adult to review materials and asking the participants to feedback on existing prototypes based on the feedback from autistic young people in a previous study in this PhD thesis (see Chapter 5). Due to feasibility and time constraints of this PhD thesis, participants were not involved in every stage of Study 3. Future research will benefit from grants that allow autistic young people to be paid for their contributions at all stages of the project in order to maximise the collaboration and partnerships with the target audience.

6.11 Implications

The following implications of Study 3 for this PhD thesis are outlined in the sections below.

6.11.1 Implication 1

With regards to managing unwanted online contact, autistic young people value having options on how to manage this. This includes but is not limited to being able to mute, filter and block unwanted contact. Autistic young people fed back that this allowed them to have autonomy, depending on the context of the online contact. Therefore, the findings indicate that future online tools/designs should consider how these can be incorporated, so that autistic young people can have choice and control over their online risk management.

6.11.2 Implication 2

In Study 3, autistic young people indicated that signposting on how to manage various online risks, including how to report unwanted online contacts and detect fake websites would be beneficial in terms of keeping safe online. These findings indicate that online safety tools/programmes that promote awareness of risks would be beneficial for autistic young people. To the best of knowledge, no published research has investigated autistic young people's online safety requirements. Study 3 was conducted to try and explore this area to help inform people as to what tools and features could help to improve autistic young people’s online safety experiences. Overall, co-design research that involves autistic young people in the design process of this will likely yield prototypes that are readily accessible to autistic young people.

6.11.3 Implication 3

Autistic young people described how symbols, colour and written text helped them to understand how to take steps in keeping themselves safe online. They advocated for examples included in the existing prototypes and offered suggestions on how these could be incorporated in online safety tools. Nevertheless, the findings emphasize the potential value of visual cues being incorporated into online safety tools to aid autistic young people's comprehension and online risk management.

6.11.4 Implications for the PhD Thesis

Together with the previous studies in this PhD thesis, Study 3 adds to the existing literature and further knowledge to the field of privacy and security as well as interaction design. It provides in-depth qualitative data regarding what online safety tools autistic young people would find useful. Moreover, Study 3 investigated what features autistic young people in the sample desired from such tools. To the best of knowledge, this study is the first co-design study that investigated the feasibility of online safety prototypes with autistic young people. Although it is a small scale study, the findings reiterate that such tools will be more readily accepted and ecologically valid if they are co-designed with autistic young people. Going forward, future research should endeavour to take a participatory action approach, involving autistic young people in all stages where possible. The implications will now be evaluated in the general discussion of this PhD thesis (see Chapter 7).

7. Chapter 7: Discussion

7.1 Overview

This PhD thesis investigated *how* autistic children and young people experience online safety risks and *what* could help them to navigate such risks in the future. Before this PhD thesis was conducted, few studies had explored online safety experiences and behaviours among the autistic population. Previous findings were predominantly limited to small samples of autistic adults (Landon, 2016; Neupane et al., 2018; Sedgewick et al., 2019). Moreover, it was unclear if autistic children and young people were indicated to be more vulnerable to all or specific types of online safety risks compared with non-autistic peers. Prior to this PhD thesis, little to no published research had examined direct or indirect online risk management strategies carried out by autistic children and young people. Through a series of studies, this PhD thesis investigated online safety behaviours among autistic children and young people, including what risks they were subject to as well as their online risk management strategies.

Before exploring any potential solutions to help autistic children and young people navigate such risks, it was paramount that this PhD thesis investigated the incidences of online safety risks among this population compared with non-autistic children and young people. Study 1 (see Chapter 4) utilized a parental survey to the frequency of multiple types of online safety between autistic and non-autistic children.

Turning to autistic lived experiences, there had been a lack of published research examining how autistic young people experience online safety risks. Study 2 (see Chapter 5) focussed on autistic young people's lived experiences of online communication and safety, using a qualitative, IPA framework.

The findings from Study 1 and 2 (see Chapter 4 and 5, respectively) indicated that autistic children and young people were less likely to block people and/or online sites than non-autistic controls (see Chapter 4, Section 4.6) and desired more support to block unwanted contact (see Chapter 5, Section 5.4.3). Study 3 involved the piloting of a low fidelity prototype solution- how to block a person on an online chat example was piloted with a sample autistic young people. Moreover, the Study 1 results (see Chapter 4; Section 4.6) indicated that there was an association between having autism and unauthorized purchases, corresponding with Study 2 findings that autistic young people, specifically males had difficulty inhibiting online responses, especially if there was a perceived incentive or reward (see Chapter 5; Section 5.4.1). Study 3 (see Chapter 6) also presented a low-fidelity prototype solution- how to detect clues that a website may be fake to autistic young people. Utilizing a participatory action approach, autistic young people in the sample were invited to give their feedback on the existing prototypes and their expertise on what ways the prototypes could be improved to help keep themselves safe online in the future.

The results of the three studies will now be discussed with regards to the main research questions of this PhD thesis (see Chapter 1; Section 1.4).

7.2 **RQ1**: Compared with non-autistic children, do parents of autistic children report their child having experienced more online safety risks and less online safety risk management?

For Study 1 (see Chapter 4), a data set was collected from a parental survey investigating their child's online safety behaviours (including risks experienced, management strategies), wellbeing and PSE including from those of autistic (n = 63) as well as non- autistic children (n = 41) (Macmillan et al., 2020). With regards to first main research question of this PhD thesis (**RQ1;** see Chapter 1; Section 1.4**)**, parents of autistic children reported them as significantly more likely to experience more overall online safety risks compared with those of non-autistic children. Compared with parents of non-autistic children, those of autistic children reported them as less likely to carry out online safety risk management strategies. However, the difference was non-significant. The sub-questions of RQ1 (see Chapter 4; Section 4.6.1) will now be discussed.

Study 1 results indicated that autistic children experienced significantly more online safety risks than non-autistic children, according to parental reports (**RQ1.1**). This supports previous findings indicating that autistic children and adults are subject to varying online safety risks (Just & Berg, 2017; Gillespie-Smith et al., 2021; Neupane et al., 2018; Rochleau & Chiasson, 2022; Rose & Monda-Amaya, 2012; Sedgewick et al., 2019). Interestingly, parents of autistic children with LD/ADHD reported them as having experienced fewer online safety risks than non-autistic and autistic children without LD/ADHD, respectively ($\eta^2 = 0.395$) (see Chapter 4; Section 4.6). In terms of potential explanations, it is possible that autistic children with LD/ADHD differ from autistic children who do not have an LD or ADHD in terms of how they access online devices. For instance, they may have more parental supervision or are less likely to access online platforms where particular risks such as cyberbullying may arise. Nevertheless, further investigation is warranted before firm conclusions can be made. This finding indicates that the increased vulnerability to online safety risks is autism, rather than disability-specific, adding to the current literature regarding online safety in children with disabilities (Rose & Monda-Amaya, 2012).

In terms of contact risks (see Chapter 1; Section 1.2), no significant associations were found between having autism and cyberbullying and unwanted online sexual grooming/exploitation (see Chapter 4; Table 2). This contrasts with the few published studies in this area, positing that autistic children and young people are vulnerable to experiencing cyberbullying (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022) and online sexual grooming (Page et al., 2022). On one hand, it is possible that differences in how autistic children and young people use online devices (Mazurek & Wenstrup et al., 2013) may mean that they are less likely to experience such contact risks. Nevertheless, recent studies have indicated that there is no significant difference in the amount of time autistic young people use social media sites compared with non-autistic peers (Alhujaili et al., 2022). Therefore, this may not be able to account for this Study 1 finding.

In terms of content risks (see Chapter 1; Section 1.2), having autism was not significantly associated with a reduced likelihood of experiencing phishing, according to parental reports. This finding indicates that autistic children are not less prone to experiencing content risks compared with non-autistic children. It is possible that autistic children and young people use certain strategies e.g., checking for visual clues or others that help them to identify potential misleading links that make them no less vulnerable to content risks, such as phishing than non-autistic children. This corresponds with the findings from a phishing study which compared autistic (n = 15) and non-autistic adults (n = 15) and found no significant difference in detecting fake websites between the two groups (Neupane et al., 2018).

With regards to online conduct risks (see Chapter 1; Section 1.2), there were significant associations between having autism and unauthorised online purchases. This supports previous findings from parent/carer focus groups (Just & Berg, 2017). This suggests that autistic children and young people are at risk pertaining to certain types of online conduct risks. This prompted further investigation as to whether similar experiences were reported by autistic young people in Study 2 (see Chapter 5). Research conducted among parents of non-autistic children suggests that they may underestimate the degree to which their child is subject to cyberbullying (Dehue et al., 2008; Sorbring & Lundin, 2012). To the best of knowledge, no published research has investigated this among parents of autistic children and young people. Therefore, this provided further census to investigate autistic young people's first-hand accounts of their online safety experiences in Study 2 (see Chapter 5) to see whether their experiences aligned to those reported by parents of autistic children.

In terms of the answering the second part of the first main research question of this PhD thesis (see Chapter 1: Section 1.4), there was no significant reported differences in total child risk management scores between autistic and non-autistic children. However, there were significant associations between having autism and not blocking people and/or online sites or using strategies to protect themselves online (**RQ1**; **RQ1.2**, see Chapter 4; Section 4.7). Autistic children were almost five times less likely to block people and/or online sites compared with non-autistic children, based on the parental perspectives. This is supported by recent findings that autistic young people avoid online contact as a means of self-protection (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022). The findings from Study 1 (see Chapter 4; Section 4.7) suggests that autistic children and young people may have difficulty utilizing this strategy. It is possible that autistic children and young people are less aware of and/or proficient with steps and/or digital tools for blocking people and/or online sites, potentially due to time spent on and reported differences in how they use social media (Alhujaili et al., 2022; Mazurek & Wenstrup, 2013). Overall, it highlights that more work is needed to design solutions that enable autistic children and young people to feel in control of blocking people and/or online sites and using strategies to help keep themselves safe online.

In terms of answering the other **RQ1** sub research questions (see Chapter 4; Section 4.6.1), Study 1 reported that parents of autistic children carried out significantly less overall parental risk management than the non-autistic parents (**RQ1.3**, see Chapter 4; Section 4.7), contrasting with previous expectations and findings that parents of autistic children restrict their online device use more than non-autistic children (Mazurek et al., 2015; Sasse, 2015). This may be explained by a potential reduced confidence among parents of autistic children and young people in their capacity to manage their child's risks online. Alternatively, it is possible that they carried out less parental risk management as they were unaware of all of the potential risks that their child incurred. Future investigation as to whether this finding is replicated across other studies would be beneficial in understanding how parents of autistic children and young people play a role in their child's online risk management.

Study 1 reported that SDQ scores were significantly higher among autistic children who experienced one or more online safety risks (indicating poorer overall child wellbeing) than autistic children who were reported as having experienced no online safety risks (**RQ1.4,** see Chapter 4; Section 4.7). This corresponds with previous findings from studies involving autistic adults that online safety risks such as cyberbullying has associated negative consequences for mental wellbeing (Wright, 2017; Wright & Wachs, 2019). Therefore, it is paramount that work is undertaken to address this issue and establish whether any potential interventions are having an impact on autistic children and young people's wellbeing post-intervention (see Section 7.9)

In Study 1**,** parents of autistic children who had experienced one or more online safety risk reported lower total PSE than parents of non-autistic children who had experienced risks, but the difference was non-significant (**RQ1.5**, see Chapter 4; Section 4.7). A linear regression analysis revealed that a variance in PSE scores was significantly predicted by autism diagnosis and parental online safety knowledge. This highlights the need for interventions that improve online safety knowledge among parents/carers of autistic children and young people.

The last sub question of Study 1 revealed no significant correlation between total online safety risks and total online device use (**RQ1.6,** see Chapter 4; Section 4.7). This contrasts with previous research indicating a positive correlation between screentime and online safety risks (Rideout, 2013; 2017). Evidence from a large scale survey indicates that autistic children and young people do not spend significantly more time online compared to non-autistic children (Montes, 2016). This finding from Study 1 iterates that future research should moving away from using screen time as a predictor of online vulnerability, thus future online safety interventions should not restrict autistic children and young people's screen time.

To summarise the outcomes of the first main research question of this PhD thesis (**RQ1**; see Chapter 1; Section 1.4), the Study 1 results (see Chapter 1) indicate that:

- **RQ1**: Autistic children and young people are significantly more likely to experience more overall online safety risks compared with those of non-autistic children (**RQ1.1**).
- Having autism is significantly associated with unauthorised purchases (**RQ1.1**). Having autism is associated with not blocking people and/or online sites or using strategies to protect oneself online **(RQ1.2).**

7.3 **RQ2**: What are autistic young people's lived experiences of online safety, managing online safety risks and preferences in terms of improving their online safety experiences?

Using an IPA framework, Study 2 explored how autistic young people communicated with others online, focussing on their online safety experiences (see Chapter 5). Regarding the second main research question of this PhD thesis (**RQ2**, see Chapter 1; Section 1.4), Study 2 findings indicated that while autistic young people's online experiences varied, many shared lived experiences of specific online contact risks (cyberbullying and online sexual harassment) and conduct risks (unauthorized purchases). Moreover, there were commonalities in terms of their risk management strategies (avoiding online contact) and preferences (a desire for more support to block online comments and/or individuals). This PhD thesis strengthens the evidence-base for autistic children and young people being vulnerable pertaining to certain online safety risks by providing qualitative data indicating a wide variation in autistic young people's online safety risks. Study 2 will now be discussed in relation to the study sub questions (**RQ2.1**, **RQ2.2**; **RQ2.3**, see Chapter 5; Section 5.3.1) in the following paragraphs, with references to the superordinate and sub-themes where appropriate

In terms of autistic young people's lived experiences of online safety, they reported that online contexts allowed for the removal of direct eye contact and increased processing time that helped to facilitate their online social interaction. ('Benefits of Online Communication'). This supports previous findings that online contexts facilitate autistic young people's online interactions by removing barriers such as eye contact (Gillespie-Smith et al., 2021). Nevertheless, a lack of physical reactions to gage social interactions led to miscommunications and harassment, particularly on social media sites ('Drawbacks of Online Communication'). This corresponds with research indicating that autistic children can utilize multiple physical clues to identify other people's emotions (Friedenson-Hayo et al., 2017) and that miscommunication can occur between autistic and non-autistic people (Crompton et al., 2020a; Milton et al., 2012a). It contradicts the Study 1 finding that having autism was not significantly associated with an increased risk of cyberbullying (Macmillan et al., 2020). Gender-specific subthemes were extracted. Autistic males described how online contexts allowed them to carry out actions, which they went on to regret, particularly if there was an incentive of a reward ('Challenging to Inhibit Online Responses'). This is in line with the findings from parental focus groups and surveys that autistic children and young people are vulnerable to unauthorised online purchases (Just & Berg, 2017; Macmillan et al., 2020). Autistic females reported feeling uncomfortable when presented with unwanted online comments, while still wanting to across as 'polite '('Unwanted Online Sexual Harassment'). This supports previous findings that autistic women are vulnerable to sexual grooming/exploitation (Cridland et al., 2014; Landon, 2016; Page et al., 2022; Sedgewick et al., 2019) In sum, the Study 2 findings indicate that while autistic young people's online experiences vary, they share first-hand experiences of cyberbullying, online sexual harassment and unauthorized purchases (**RQ2.1**).

With regards to online risk management, autistic young people described only interacting with a small number of trusted people ('Avoids Online Contact'). This supports recent evidence that autistic young people avoid unwanted contact in online settings (Gillespie-Smith et al., 2021; Rocheleau & Chiasson, 2022). Autistic young people reported instances of their parents monitoring and restricting their online activity ('Parental Mediation'). This corresponds with previous findings that parents of autistic children limit their child's online activity (Clark et al., 2015; Sasse, 2015). While autistic young people's experience diverged, some described looking for particular verification symbols or suspicious text ('Checks for Visual Clues'). This backs up research reporting that autistic adults use similar strategies to detect suspicious links (Neupane et al., 2018). Overall, autistic young people avoided online contact, while relying on parental support and the ability to detect visual clues as means of protecting themselves online (**RQ2.2**).

Focussing on autistic young people's preferences for improving their online safety experiences, they reported a lack of up to date training in schools ('Require Contemporary Training in Schools'). Moreover, autistic young people fed back issues with existing online platforms with regards to dealing with unwanted online contact ('Support to Block Unwanted Contact'). Therefore, autistic young people in this study expressed a preference for up to date training in education as well as tools to help them block unwanted online contact (**RQ2.3**).

To summarise the outcomes of the second main research question of this PhD thesis (**RQ2**; see Chapter 1; Section 1.4), Study 2 findings (see Chapter 5; Section 5.4) indicate that:

- **RQ2**: autistic young people share commonalities in terms of their online experiences, including first-hand experiences of cyberbullying, online sexual harassment and unauthorized purchases (**RQ2.1**).
- In terms of online risk management, autistic young people avoid online contact, have parental support and check for visual clues. (**RQ2.2**). With regards to their preferences, autistic young people value up to date online safety training in schools and support to block unwanted online contact **(RQ2.3)**.

7.4 **RQ3**: What online safety tools do autistic young people desire and envisage themselves using, and specifically what features do they require from these tools?

Utilizing a participatory action approach, Study 3 investigated autistic young people's perceptions of two online safety scenarios. Two online vignettes and low-fidelity prototypes were created and piloted to explore their online risk management preferences (see Chapter 6). With regards to the final main research question of this PhD thesis (**RQ3**, see Chapter 1; Section 1.4), the Study 3 findings suggest that there are commonalities in terms of what online safety tools autistic young people desire and envisage themselves using. This includes applications that allow them to select options on how to restrict unwanted online contact, filtering software and signposts to online safety management advice. In terms of what features autistic young people desire from such tool, the Study 3 data indicates that autistic young people benefit from visual cues, including symbols, certain colours, and written text warnings to inform their online risk management. This final study outlined in the PhD thesis contributes to the evidence-base indicating that autistic children and young people are able to advocate for what they believe would improve their lived experiences. Moreover, the findings highlight that co-production with autistic young people yields valuable data regarding what design features will benefit them. Study 3 will now be discussed in relation to the study sub questions (**RQ3.1**, **RQ3.2**; see Chapter 6; Section 6.9.1) in the following paragraphs.

In terms of what online safety tools autistic young people desired and envisaged themselves using, autistic young people in the sample reported that that they appreciated having choice and autonomy with regards to dealing with unwanted online contact ("Impact of having options"). On one hand, autistic young people reported that having too many options available at once could be overwhelming. Thereby, it would be beneficial to have more control over the design. In the future, this could be modified as a flexible sidebar or option menu depending on the online platform. Nevertheless, the majority of autistic young people fed back that they valued having choice for restricting unwanted contact. For instance, some autistic young people described that having options to mute and report comments could help to prevent having to block people. This is in line with the main theme ("Desire for choice and autonomy") extracted from the data. Moreover, the findings correspond with previous findings that autistic young people would like guidance on how to manage unwanted online contact (Macmillan et al., 2022).

Within the main theme ("Need for technological solutions"), two sub-themes including ("Requirements from software") and ("Signposting on how to tackle online risks") were captured from the Study 3 data. For the online contact risk low-fidelity prototype, autistic young people in the sample suggested that a filter that removed potentially harmful content could help to improve online safety experiences. This backs up findings from the second study in this PhD thesis indicating that filtering software would make going online better for them (Macmillan et al., 2022). Furthermore, this sub-theme corresponds with studies indicating that non-autistic children prefer online safety tools that allow them control over how they restrict online contact (McNally et al., 2018). For the content risk low-fidelity prototype, autistic young people fed back that having potentially inbuilt software could help to prevent personal data being exploited. Previous research has indicated that few autistic adults were aware of firewalls and secure connections (Neupane et al., 2018). To date, no published research has investigated autistic young people's requirements from malware software. Therefore, the Study 3 findings provide valuable insight regarding what potential malware software would benefit autistic young people.

In addition, autistic young people highlighted that being signposted to verified information on how to manage online risks would be beneficial ("Signposting on how to tackle online risks). This corresponds with previous qualitative findings that autistic young people would like contemporary training and resources to help keep themselves safe online (Macmillan et al., 2022). Therefore, autistic young people desired existing online platforms that allowed them to manage unwanted online contact in more than one manner, and for more online safety tools to incorporate filtering, malware software and signposting links (**RQ3.1**).

With regards to what features autistic young people required from these tools, ("*How* information is conveyed") was extracted as a main theme. First of all, autistic young people fed back that symbols such as padlocks helped them to interpret the authenticity of potentially fake websites. They advocated for having more symbols including rubbish bins in online safety tools (see Section 6.8.1). This supports evidence that autistic children and young people benefit from symbolic references to aid their understanding of activities associated with daily living (Hartley & Allen, 2014; 2015a; Wainwright et al., 2020). Therefore, the findings indicate that symbols should be incorporated into online safety tools targeted at autistic young people.

Secondly, autistic young people emphasised that various colours gave certain cues ("Colour choice matters"). Specifically, many autistic young people mentioned that they related the colour red with danger and taking important actions. This corresponds with evidence that red is associated with warnings and remaining vigilant, thus lends support to the colour-in-context theory (Elliot & Maier, 2012; Pravossoudovitch et al., 2014). Therefore, this sub-theme contributes knowledge to existing research literature in this field. Moreover, it highlights how colours can be utilized in UK based online safety tools and programmes.

Lastly, autistic young people described how written warnings could aid their comprehension of such tools ("Written text supports understanding"). This supports evidence that autistic young people without LD/ID apply their decoding skills to read and comprehend written messages (Baixauli et al., 2021). Some autistic young people suggested that combining written earnings with symbols could help to improve the usability of online safety tools. This backs up previous findings that autistic children benefit from multi-modal inputs of communication (Djatmika et al., 2020). Further research is called for before drawing firm conclusions as to whether the Study 3 findings can be generalised to a wider number of autistic young people. Nonetheless, autistic young people advocated for online safety tools to include symbols, certain colours and text features (**RQ3.2**)

To summarise the outcomes of the third and final main research question of this PhD thesis (**RQ3**: see Chapter 1; Section 1.4), the findings from Study 3 indicated that:

- **RQ3**: In terms of online risk management, autistic young people desire specific online safety tools and features.
- In terms of online safety tools, autistic young people fed back positively about existing platforms that allowed them to manage unwanted online contact in various ways. Nevertheless, they called for online tools to incorporate filtering, malware software and signposting links (**RQ3.1**).
- Specifically, autistic young people stated that such tools should include symbols, appropriate colours and written text warnings (**RQ3.2**).

7.5 Evaluation of Participatory Efforts in PhD Thesis

In Chapter 3, a rationale for using participatory research in this PhD was outlined (see Chapter 3; Section 3.7). Therefore, attempts were made to channel this where possible within the studies of this PhD thesis. This section will evaluate the degree to which Study 1 (see Chapter 4), Study 2 (see Chapter 5) and Study 3 (see Chapter 6) were participatory in nature. As previously discussed, the rungs in Arnstein's Ladder of Participation (Arnstein, 1969) represent varying levels of community involvement in research. These will be used to evaluate how involved autistic children; young people and their allies were in each study of this PhD project.

In all three studies and throughout this PhD thesis, care has been taken to use respectful language to describe autism (see "Language Statement", p.21). Recent studies have highlighted the need for universities to incentivise participants taking part in research (Redman et al., 2021). In Study 1, parents were entered into a prize draw to win a £100 Amazon voucher. In Study 2, all autistic young people received a £20 Amazon voucher. In Study 3, autistic young people taking part received a £15 Amazon voucher. In Study 2 and 3, receiving the voucher was unconditional to participants completing the study, thus efforts were made to endorse autistic young people and their allies for their contributions to this PhD thesis. Moreover, time was taken and efforts were made to modify the research environment across the studies in this PhD thesis. These will be discussed in the following subsections.

7.5.1 Study 1: Participatory Efforts

The first study of this PhD thesis involved two groups of parents (autistic children, n = 63; non-autistic children, n = 41) completing an online survey about their child's online safety behaviours. Evidence indicates that finding out what environments are most appropriate for helping autistic people achieve the best outcomes is in the top 10 research priorities of autistic people (Cusack & Sterry, 2016). Investigating what online risks affect autistic children and young will help to explore potential solutions to help reduce these scenarios, Study 1 aligns within this priorities in this research call. In Study 1, the survey was piloted with five parents of autistic adults to identify if sections were unclear or could be improved to improve the experience of parents completing the form on behalf of their autistic children (see Chapter 4; Section 4.6.5). At the end of the survey, opt-in options were provided for participants to receive a summary of the results and be kept up to date with the research in this PhD. Therefore, efforts were made to disseminate the findings of this study. Study 1 went on to be peer reviewed and published (Macmillan et al., 2022). The accepted manuscript was shared on PhD researcher's Twitter and ResearchGate page to improve accessibility options to autistic people and allies who do not have institutional access. According to Arnstein's Ladder of Participation, the 'Consultation' level focusses on inviting community members to give their opinions. Therefore, the participatory efforts in Study 1 are deemed to fall within the level of 'Consultation'.

7.5.2 Study 2: Participatory Efforts

The second study focussed on autistic young people's first-hand accounts of their online safety experiences, utilizing an IPA framework with semi-structured interviews. Before data collection, the interview script and materials were piloted with a young autistic adult to ensure that these were an appropriate length and readily understood by an autistic person. In the second study, time and care was taken to help build a rapport with autistic young people taking part and to provide a range of environments e.g., face to face, videocall and live webchat options for interviews. This was done to provide participants the opportunity to have autonomy, thus feel valued and included. These participatory efforts are consistent with those taken by 12 autism researchers who were interviewed about the steps that they took to meaningfully engage autistic young people in research (Scott-Barrett et al., 2019).

Study 2 specifically asked autistic young people what would make going online better for them (see Chapter 5; Table 5). The feedback from this went on to inform the low-fidelity prototypes designed for the final study of this PhD thesis. The results and implications were presented at the Autistica 2021 Discover Conference. This provided an invaluable opportunity to have this study peer-reviewed by the autistic community. The talk received positive written feedback as well as support for a concluding point as part of the panel on inclusive environments to ask autistic people what they would find useful to help inform design. An autistic adult contacted me during the conference to talk about how the study findings resonated with her own online experiences. Study 2 also went onto be peer-reviewed and published as an article (Macmillan et al.. 2022). As before, the PhD researcher shared a copy of the accepted manuscript on Twitter and ResearchGate to improve accessibility options to autistic people and allies who do not have institutional access. Therefore, the second study met the threshold for 'Placation' in terms of participatory efforts.

7.5.3 Study 3: Participatory Efforts

The third and final study of this PhD thesis explored autistic young people's preferences and feedback regarding two low-fidelity prototype solutions to common online safety scenarios. Prior to recruitment, the co-design session materials were reviewed by a young autistic adult to ensure that they were clear and readily understood. In line with Study 2, time and effort was taken to get to know the participants and build a rapport with them,. Like the second study, a range of environments e.g., videocall and live webchat options for the co-design sessions were offered to give participants the choice regarding what they would prefer. The final study methodology was presented as part of the Department of Psychology Seminar Series at Heriot-Watt University. An autistic university student who attended the talk contacted the PhD researcher after the talk. She praised the co-design elements of the third study and emphasised that research about autistic online experiences was important to her. Although it should be acknowledged that one autistic person's views do not represent those of the entire autistic community, it highlights the relevance and implications of Study 3 as well as the participatory efforts in this PhD thesis. According to Arnstein's Ladder of Participation, 'Placation' represents a higher level of involvement than 'Consultation'. This level allows community members to advise and steer research, but with the ultimate responsibility lying with the power holder. In Study 3, autistic young people advised on what online safety tools and features would help to improve online safety experiences, with the responsibility lying with the PhD researcher to demonstrate the legitimacy of their feedback via data analysis and the dissemination of findings. Overall, the final study aligns with the level of 'Placation' in terms of participatory research.

7.5.4 Summary of Participatory Efforts in PhD Thesis

In summary, the studies in this PhD involved participatory research, from consulting to placation. These sit within the broader level of tokenism (Arnstein, 1969). On one hand, this

PhD succeeds in avoiding levels of non-participation. Both autistic and autism researchers have indicated that the majority of previous studies in this field have failed to incorporate any involvement of autistic people and their allies (Chown et al., 2017; Fletcher-Watson et al., 2019). By publishing and disseminating the methods taken to involve autistic young people and their parents in this PhD thesis, it is hope that this will help to endorse the findings, thus have a positive impact on autistic children, young people and their allies. Nevertheless, it is recognised that the degrees of participation were limited due to time and cost restraints within this PhD thesis.

It should be acknowledged that some participants prefer to be incentivised in other ways such as direct payment. Ideally, it would have been preferred if the autistic adult and parents who provided feedback on the study materials could have been paid for their expertise. However, the current institutional regulations at university regarding payroll and pre-funding constraints meant that this option was not feasible as part of this PhD project. This corresponds with research indicating that early career researchers are keen to carry out participatory research often lack the resources and support to incorporate this fully into their projects (Fletcher-Watson et al., 2019; Pickard et al., 2022). A recent article investigating participatory practices among 14 early career autism researchers and 11 established autism researchers reported that time constraints and a lack of funding available, particularly among PhD students with pre-assigned, funded project, limited their capacity to fully involve autistic participants to the extent that they to in their research (Pickard et al., 2022). Consequently, there needs to be both cultural and structural shifts in academia so that autistic young people can be fully accommodated, especially in PhD projects. By advocating for systemic change in autism research, this will hopefully lead to more time, costs, training and resources being incorporated into PhD and other early career research projects from the get-go.

7.6 PhD Thesis Implications

In the past and current time, an excuse used for not involving autistic people in participatory research is that this reduces the integrity of the findings (Fletcher-Watson et al., 2019). On the contrary, the contributions that this PhD thesis adds to the existing literature would not have been possible without the participation and engagement of autistic children and young people. Their lived experiences, insight and expertise and their allies enriched the findings from the studies and fed into one another. Without their input, this PhD thesis would be limited in terms of its implications and relevance for the very people it attempts to represent.

7.6.1 Implications for Autistic Children and Young People

The key implication for autistic children and young people is that the findings from this PhD thesis indicate that they are risk pertaining to specific types of online safety risks (cyberbullying, online sexual grooming/exploitation and unauthorized purchases). Having this awareness that they may be subject to these may help autistic children and young people to pre-empt such scenarios and potentially take steps to help overcome such challenges. This PhD thesis has demonstrated that autistic young people can self-reflect and report on their own experiences. This contracts previous assumptions that autistic children and young people are incapable of introspecting (Bolte et al., 2008; Lombardo et al., 2007). Therefore, the findings from this PhD thesis iterate that autistic children and young people should be provided opportunities to communicate their experiences in research. By respecting and viewing autistic children and young people as experts of their own worlds, they can be empowered to help inform others of what would help to improve their online experiences. Ultimately, any future interventions that do not involve the input of autistic children and young people will be ineffective to a large extent.

7.6.2 Implications for Parents and Carers of Autistic Children and Young People

The findings from this PhD thesis can help to guide parents and carers of autistic children and young people in understanding their child's online safety experiences. First of all, they may benefit from the evidence that screentime does not equate to online vulnerability. Considering previous results that parents of autistic children and young people limit their online device use, the findings from this PhD thesis challenge prior assumptions that screentime increases the likelihood of experiencing online safety risks in this population. The subtheme ('Benefits of Online Communication') from Study 2 (see Chapter 5) highlighted that there were many positive aspects of online communication for autistic young people including interacting with friends and sharing interests. These findings indicate that parents and carers should consider the potential loss of meaningful opportunities for autistic children and young people if they limit their child's screentime. 'Parental Mediation' also extracted from the Study 2 data as a subtheme. Therefore, parents and carers of autistic children and young people play an important role in their child’s online safety risk management. The outcomes from this PhD thesis can potentially increase knowledge of what online risks autistic children and young people may experience, thus help them to check for signs that they may be experiencing these. Moreover, the findings from this PhD thesis can help them to consider strategies that can help to increase their child’s online autonomy e.g.., block unwanted contact. In sum, parents and carers should carefully reflect on ways to support autistic children and young people to keep safe online, without removing opportunities for their children to connect with others and pursue online interests.

7.6.3 Implications for Staff and Educators Working with Autistic Children and Young People

Considering that support staff and educators play an important role in the daily lives of autistic children and young people, the potential implications from this PhD thesis for this group of professionals should be discussed. In Study 2 (see Chapter 5), autistic young people fed back a lack of up to date online safety training in schools that were relevant to them (‘Require Contemporary Training in Schools’). Therefore, staff and educators should consider the current resources that they are using and evaluate how relevant and appropriate they are for autistic children and young people in the present time. Moreover, the other main findings of this PhD regarding what online risks autistic children and young people are vulnerable to could help focus educators efforts to detect signs of these while autistic children and young people are in school. Moreover, the outcomes from this PhD thesis can be used as a potential springboard for educators to work with autistic children and young people to design programmes to increase online safety awareness and strategies for autistic children and young people. This could also be extended to non-autistic children so that they can understand how autistic children and young people's online experiences could vary and equip them with a plan on how they can help to support their autistic peers to stay safe online e.g., help them to block unwanted contact.

7.6.4 Implications for Practice Based Research

In terms of implications for practice based research, the findings from this PhD thesis can provide a potential background foundation for future research. The methodological decisions undertaken in this PhD thesis demonstrate that incidences of multiple online safety risks can be investigated among autistic children, young people and their parents. Therefore, it is possible for other researchers to explore the prevalence of online contact, content and conduct risks among autistic children and young people to examine if the findings from this PhD thesis extend to other studies. Considering that online device use did not significantly correlate with total online risks experienced (see Study 1; Chapter 4), researchers should move away from focussing on this variable as a prominent predictor of online vulnerability amongst autistic children and young people. Study 2 findings pinpoint towards the potential benefit of researchers exploring if gender influences online safety experiences among autistic children and young people. Above all, the outcomes from this PhD indicate that designing online tools with autistic children and young people will help to inform future interventions. Therefore, practice based research should endeavour to be participatory and involve autistic children and young people in both design and testing project phases.

7.6.5 Implications for Research Based Practice

The findings from this PhD thesis indicate that autistic children and young people’s online experiences vary. Nonetheless, the results suggest that they are subject to significantly more online safety risks than non-autistic children. While autistic young people’s experiences were diverse, online devices and contexts placed them at risk for specific online contact and conduct risks. Moreover, many avoided blocking online contact and using strategies to keep themselves safe. Therefore, it is illogical for autistic children and young people to receive the same signposting and access to online safety training and interventions that are targeted towards non-autistic children and young people. Autism-specific recommendations are needed. In the course of this PhD project, representatives from the Middletown Centre for Autism, Scottish Autism, Policy Hub Scotland and Autistica reached out to seek up to date advice and research summaries regarding online safety risks experienced among autistic children and young people. Therefore, the findings from this PhD thesis can help to inform potential policies and recommendations for this population. Overall, by acknowledging the commonalities in autistic children and young people’s online safety experiences and preferences for future solutions, future practices will be research informed, thus help to improve autistic children and young people’s online experiences for the better.

7.7 Strengths of the PhD Thesis

The studies outlined in this PhD thesis have a number of strengths. As previously discussed, endeavours were made to utilize participatory steps. By promoting inclusive practices and re-shifting the power dynamic that allows autistic children and young people to feel in control and involved in the research process, this aided both the recruitment and engagement of autistic young people and their allies in this PhD thesis. Above all, these efforts helped participants to provide feedback on their experiences in ways that suited them, this enriched the findings of this PhD thesis.

The overarching aim of this PhD thesis was to investigate how autistic children and young people experience online safety risks and what could help them to navigate such risks in the future. Study 1 (see Chapter 4) compared reported incidents of multiple online safety risks and behaviours between autistic and non-autistic children, in a parental survey. To the best of knowledge, this is the first published study to empirically investigate this. Study 2 (see Chapter 5) investigated the lived online safety experiences of autistic young people, utilizing an IPA framework. As far as one is aware, this is the first published study to explore autistic young people's first-hand accounts of various online risks and manage strategies. Therefore, this adds to the few existing studies which have examined autistic young people's experiences of single online risks or platforms, such as social media. Study 3 (see Chapter 6) researched autistic young people's perceptions of online safety scenarios and online risk management preferences. According to the existing evidence, this is the first co-design study to explore these with autistic young people and make design-specific recommendations.

Overall, the studies in this PhD thesis contribute knowledge and understanding to the field of autism, domains of privacy, security and interaction design. This includes quantitative and qualitative data. This PhD thesis compared multiple online safety risks and management strategies between autistic and non-autistic children (**RQ1**), explored the lived experiences of online safety risks among autistic young people (**RQ2**) and examined design-specific recommendations with autistic young people for future online safety tools (**RQ3**). Thereby, the findings from this PhD thesis adds knowledge that will help to better understand how autistic children and young people experience online safety and what will help them use online devices and platforms whilst navigating such risks in the future.

7.8 Limitations of the PhD Thesis

The methodologies chosen for the studies in this PhD thesis (see Chapter 3) were chosen to explore factors that influenced how autistic children and young people experienced online safety risks and what they fed-back would help them to keep safe online. Therefore, the small sample sizes are an upfront limitation of this PhD thesis, thus reduce the extent to which the findings can be generalised to all autistic children and young people. Nevertheless, as previously discussed, insider perspectives are often lacking in autism research. This point is particularly relevant in terms of autistic children and young people's online safety experiences. The main goal of this PhD thesis was to explore how autistic children and young people experience online safety and what could help them navigate such risks in the future. Thereby, the contributions of the findings from the PhD thesis should be considered within the boundaries of what they can postulate about the online safety experiences of autistic children and young people.

The studies outlined in this PhD thesis relied on opportunity sampling. Thereby, self-selected participants completed a parental survey (see Chapter 4), were interviewed about their online safety experiences (see Chapter 5) and took part in co-design sessions (see Chapter 6). To that end, it can be assumed that all of the participants in this PhD thesis were interested in online safety risks experienced by autistic children and young people. Therefore, it is plausible that the personal accounts may differ among those who do not share the same awareness and/or motivation regarding autistic online safety experiences.

A broader limitation, not specific to individual studies within this PhD thesis, was that participation with autistic young people was limited to those aged 11-18 years (see Chapters 5 and 6, respectively). Therefore, the findings from the PhD thesis cannot be directly attributed to autistic children and young people, out with this age range. While attempts were made to include non-speaking autistic children and young people in this PhD thesis, the extent to which this this population was represented is limited. On one hand, upcoming, innovative methodologies such as photovoice are helping to facilitate the engagement of non-speaking autistic people (Do et al., 2021). Nevertheless, the field of autism research has a long way to go in terms of fully including their perspectives in research (Fletcher-Watson et al., 2019). Therefore, it is fully accepted that this a drawback of this PhD thesis.

7.9 Directions for Future Work

Considering the strengths and limitations of this PhD thesis, this section will highlight and discuss specific areas that future studies in the field of online safety research can potentially explore. One possible avenue would be to examine if there are certain online platforms or devices that online risks are more likely to place on for autistic children and young people. In a recent study, no significant difference in average time spent using social media was reported between autistic (n = 26) and non-autistic young people (n = 24). However, the two groups differed in their preferences for specific social media sites and reason for use. For instance, the autistic group preferred YouTube, whereas the non-autistic group primarily used Snapchat (Alhujaili et al.. 2022). Therefore, a future study could investigate if online safety risks experienced by autistic children and young people are associated with specific online platforms. This would help to pinpoint specific online sites or mediums that could be targeted in potential online safety interventions for autistic children and young people.

In Chapter 6, it was highlighted that the original plan for the final study was to conduct face to face co-participatory design sessions with small groups of autistic young people from existing support groups within the city of Edinburgh. The aim was to evaluate existing protocols and design online safety tools. However, this project had to be paused and redesigned in line with COVID-19 ethical guidelines prohibiting face to face research. Recent studies have advocated for autism specific peer support for young autistic adults (Crompton et al., 2022). Moreover, previous studies have highlighted that having small groups of autistic young people who know each other can help to foster ideas and collaborations in design (Spiel et al., 2017).

Therefore, if this was investigated as part of a research project, it could help to build upon the findings in this PhD thesis regarding autistic children and young people's preferences for online safety tools.

Above all, future research should aim for higher levels of involvement from autistic children, young people and their allies. If cultural and structural changes are made within academia, these steps can be accommodated. Funding could be incorporated into grant proposals to pay autistic children and young people for their work and contributions. Autistic led organisations such as Autistica have insight research groups where autistic people can advise researchers on stages of their projects. For instance, PhD project proposals could be written in collaboration with autistic mentors or consultants. Therefore, autistic children and young people can be involved in several decision making stages of a project such as methods and dissemination of findings. These steps can help take research projects to a "partnership" level of participation. Recent studies which have utilized such measures have yielded positive feedback from the autistic community (Crompton et al., 2020a; b).

7.10 Concluding Remarks

This PhD thesis has collected, analysed, and evaluated data from parents of autistic children and young people and autistic young people themselves regarding their online safety behaviours, experiences and hopes for the future. It investigated what online safety risks autistic children and young people experience and what strategies they used, according to parental perspectives. This PhD thesis explored autistic young people's first-hand accounts of their online safety experiences and what designs/features they would like future online safety interventions to have in the future. Therefore, the findings from this PhD thesis provide novel insights into how autistic children and young people, parents/carers, staff, educators, designers and policy makers could work together to improve the online safety experiences of autistic children and young people. By working in partnership with autistic children and young people, meaningful online safety features and tools can be created that will work for this population. To conclude, the findings and contributions from this PhD thesis will help promote the online safety and independence of autistic children and young people, thus enable them to have opportunities for online interactions and engagement with interests that are meaningful to them.

8. References

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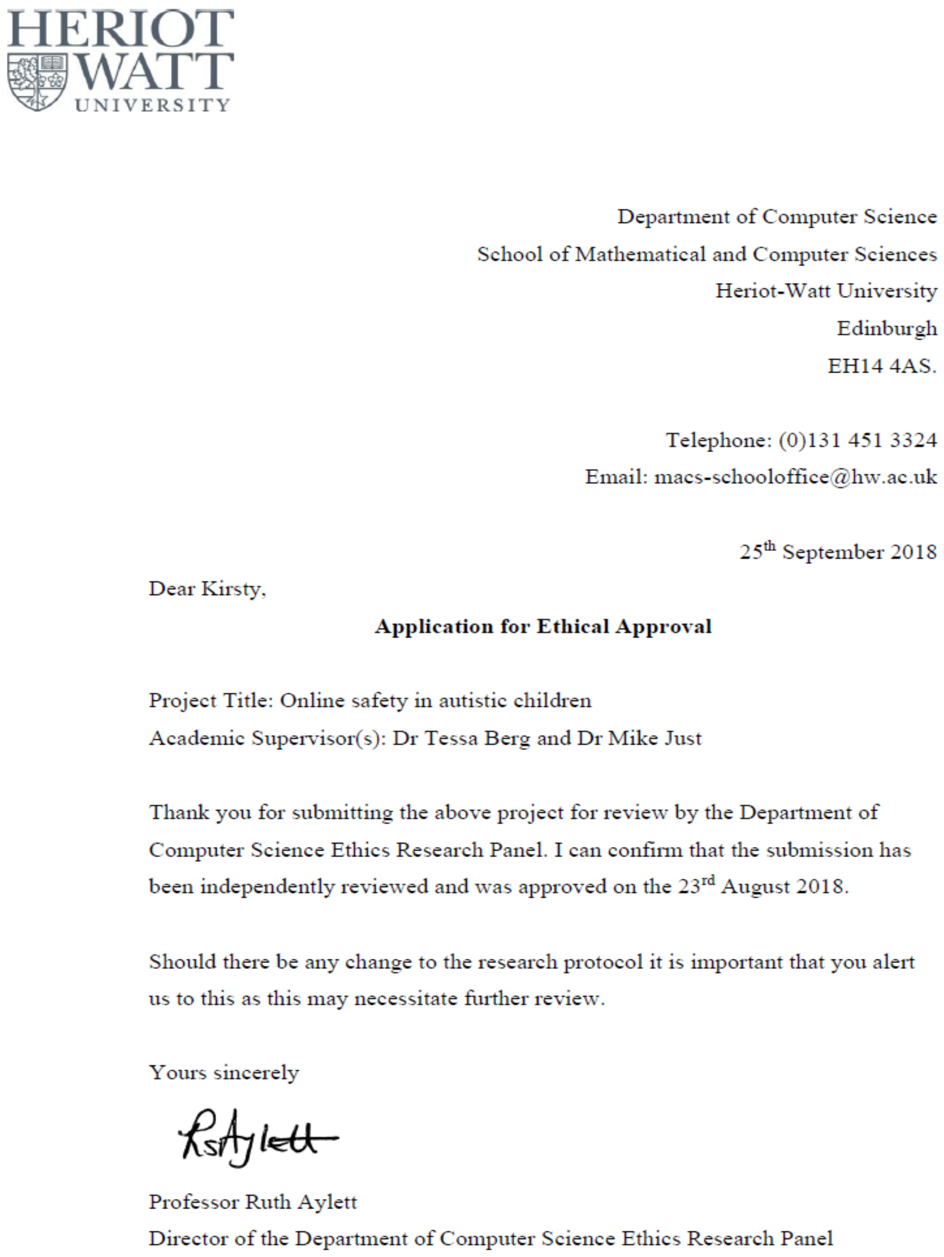
9. Appendices

Appendix A: Study 1 Ethical Approval Letter



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25th September 2018

Dear Kirsty,

Application for Ethical Approval

Project Title: Online safety in autistic children
Academic Supervisor(s): Dr Tessa Berg and Dr Mike Just

Thank you for submitting the above project for review by the Department of Computer Science Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 23rd August 2018.

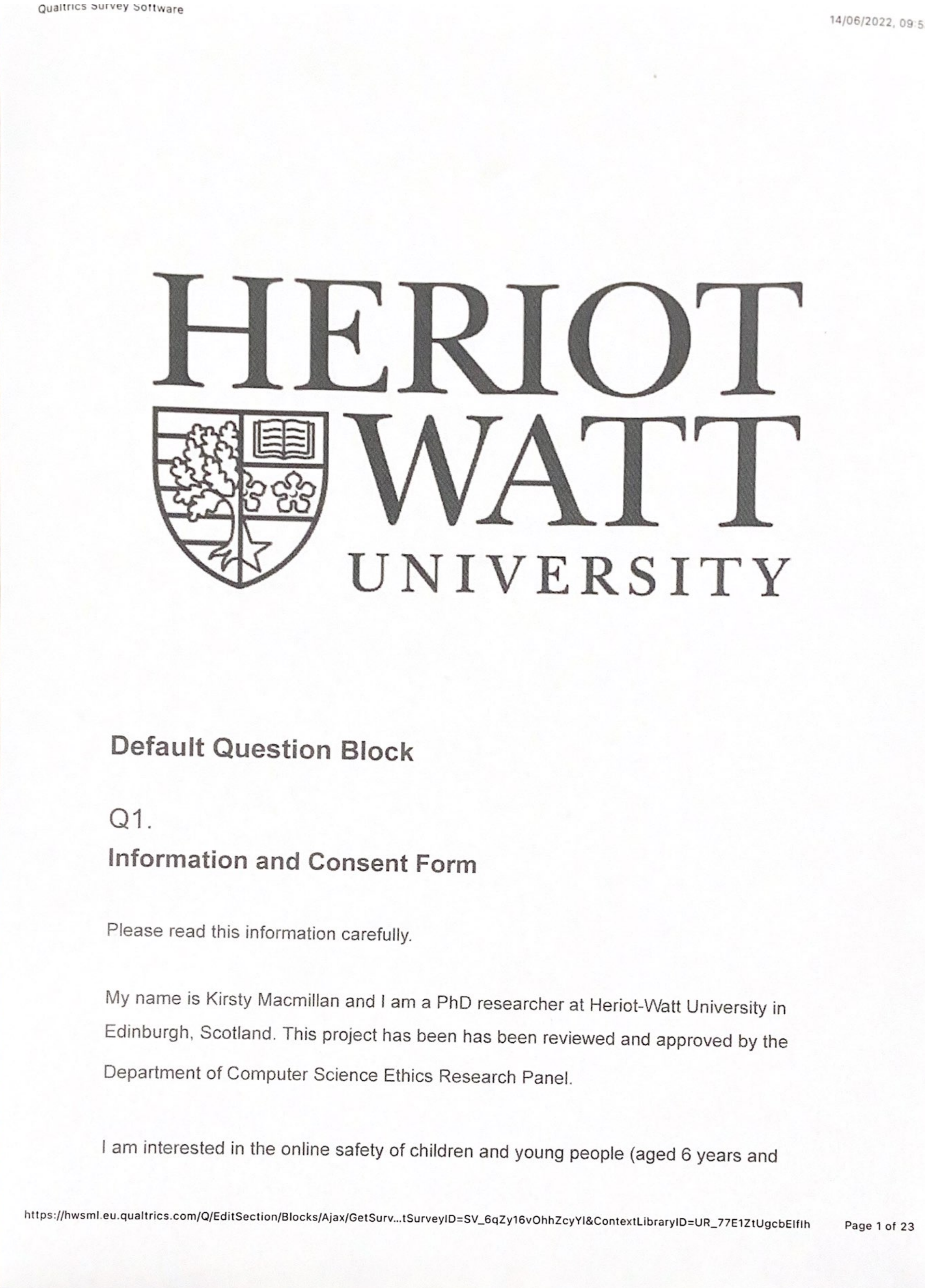
Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely

RSAylett

Professor Ruth Aylett
Director of the Department of Computer Science Ethics Research Panel

Appendix B: Copy of Parental Survey (Information and Consent, and Debriefing Forms Embedded)



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HERIOT WATT UNIVERSITY

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Q1.

Information and Consent Form

Please read this information carefully.

My name is Kirsty Macmillan and I am a PhD researcher at Heriot-Watt University in Edinburgh, Scotland. This project has been has been reviewed and approved by the Department of Computer Science Ethics Research Panel.

I am interested in the online safety of children and young people (aged 6 years and

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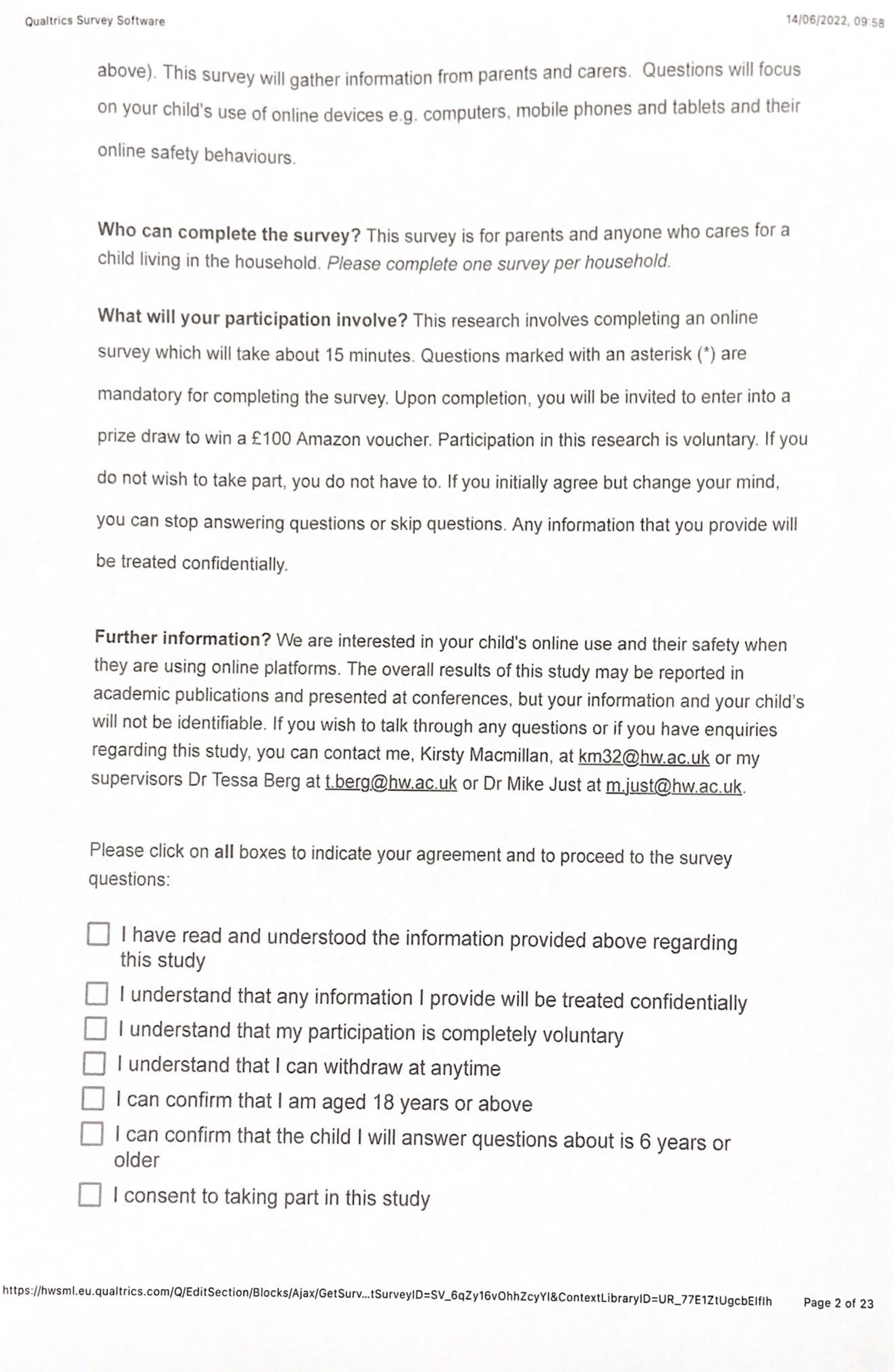


above). This survey will gather information from parents and carers. Questions will focus on your child's use of online devices e.g. computers, mobile phones and tablets and their online safety behaviours.

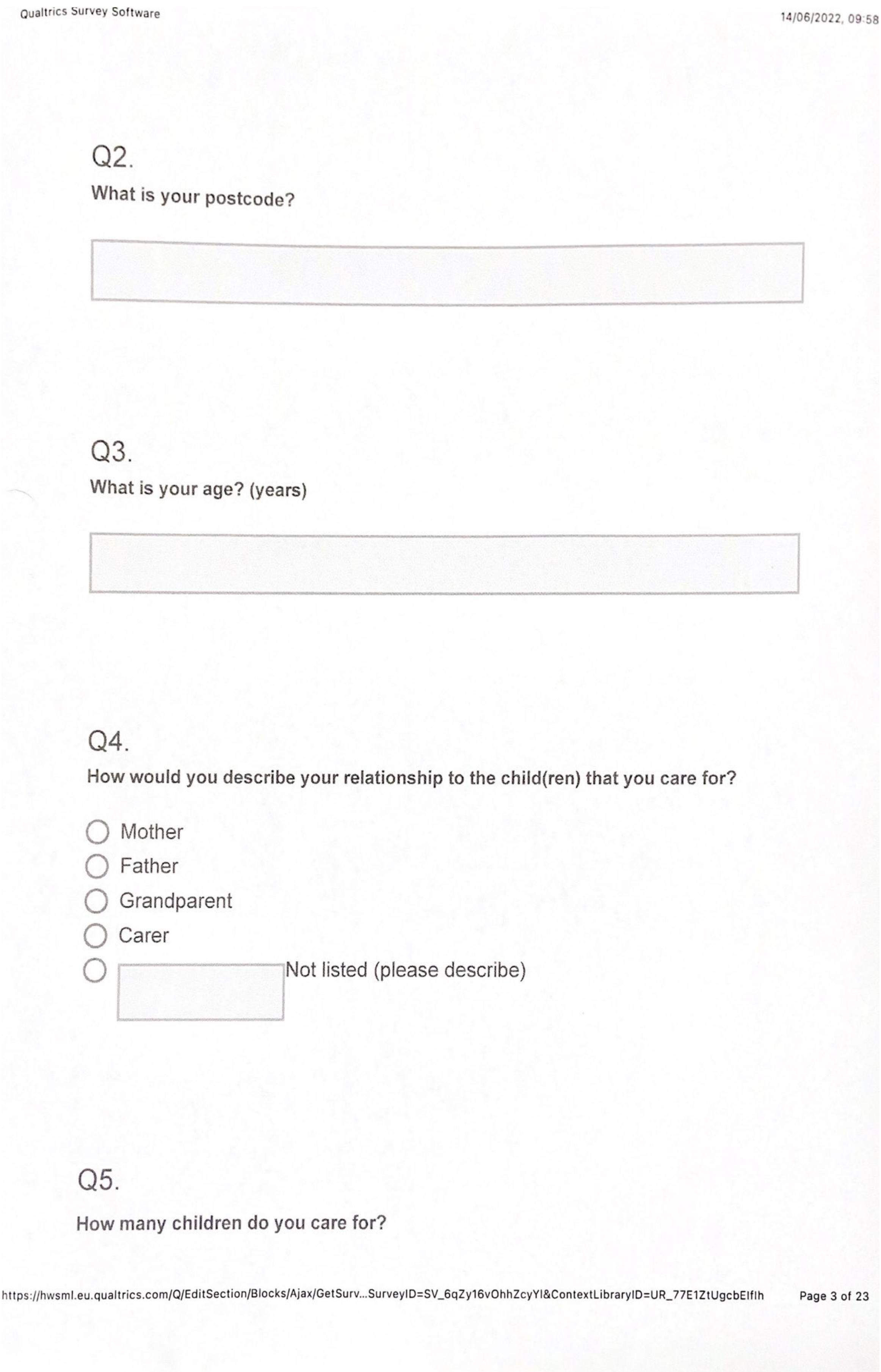
Who can complete the survey? This survey is for parents and anyone who cares for a child living in the household. *Please complete one survey per household.*

What will your participation involve? This research involves completing an online survey which will take about 15 minutes. Questions marked with an asterisk (*) are mandatory for completing the survey. Upon completion, you will be invited to enter into a prize draw to win a £100 Amazon voucher. Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you initially agree but change your mind, you can stop answering questions or skip questions. Any information that you provide will be treated confidentially.

Further information? We are interested in your child's online use and their safety when they are using online platforms. The overall results of this study may be reported in academic publications and presented at conferences, but your information and your child's will not be identifiable. If you wish to talk through any questions or if you have enquiries regarding this study, you can contact me, Kirsty Macmillan, at km32@hw.ac.uk or my supervisors Dr Tessa Berg at t.berg@hw.ac.uk or Dr Mike Just at m.just@hw.ac.uk.

Please click on **all** boxes to indicate your agreement and to proceed to the survey questions:

☐ I have read and understood the information provided above regarding this study
☐ I understand that any information I provide will be treated confidentially
☐ I understand that my participation is completely voluntary
☐ I understand that I can withdraw at anytime
☐ I can confirm that I am aged 18 years or above
☐ I can confirm that the child I will answer questions about is 6 years or older
☐ I consent to taking part in this study



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Q2.

What is your postcode?

Q3.

What is your age? (years)

Q4.

How would you describe your relationship to the child(ren) that you care for?

- ○ Mother
- ○ Father
- ○ Grandparent
- ○ Carer
- ○ Not listed (please describe)

Q5.

How many children do you care for?

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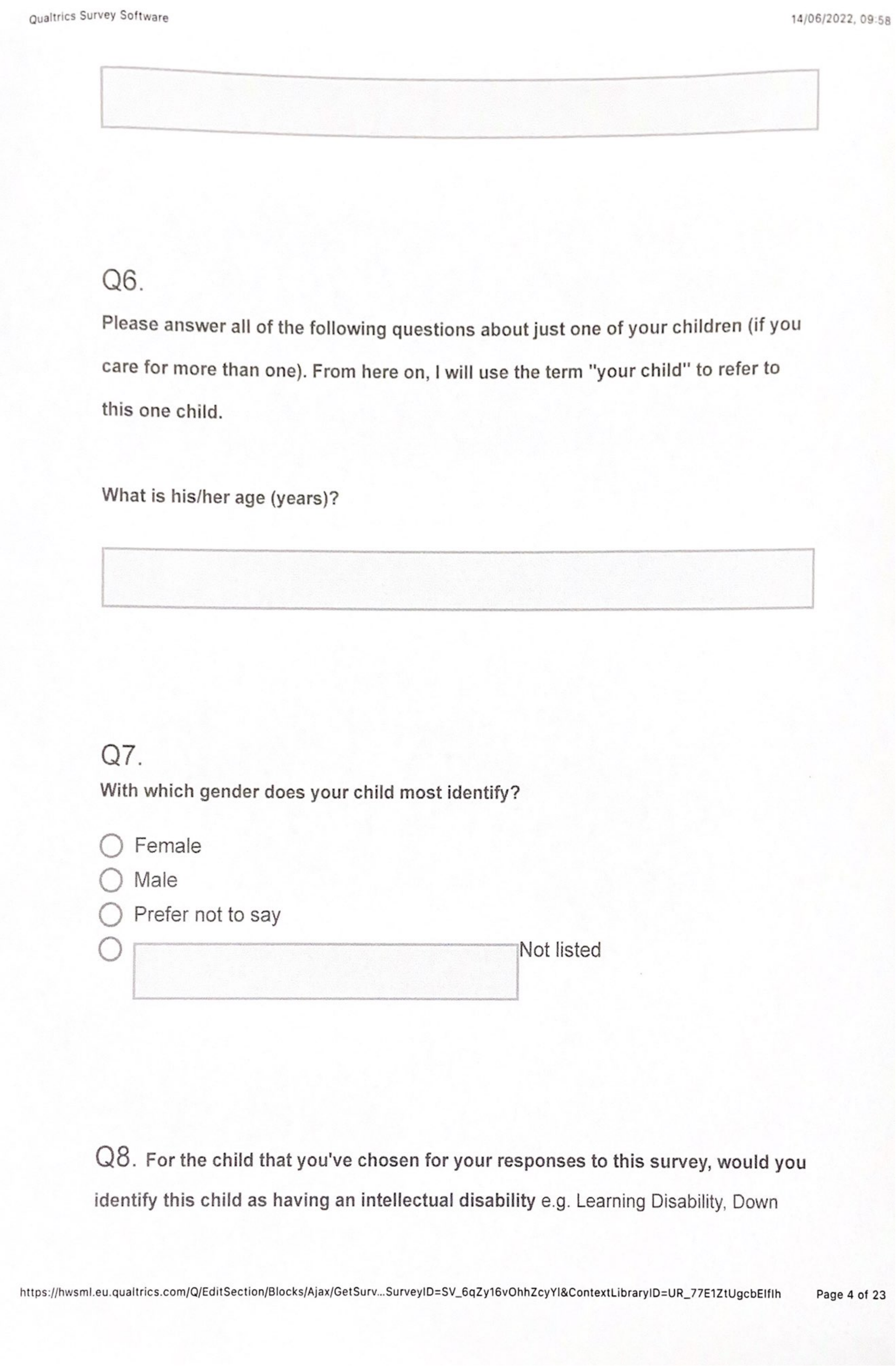

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Q6.

Please answer all of the following questions about just one of your children (if you care for more than one). From here on, I will use the term "your child" to refer to this one child.

What is his/her age (years)?

Q7.

With which gender does your child most identify?

○ Female
○ Male
○ Prefer not to say
○ Not listed

Q8. For the child that you've chosen for your responses to this survey, would you identify this child as having an **intellectual disability** e.g. Learning Disability, Down

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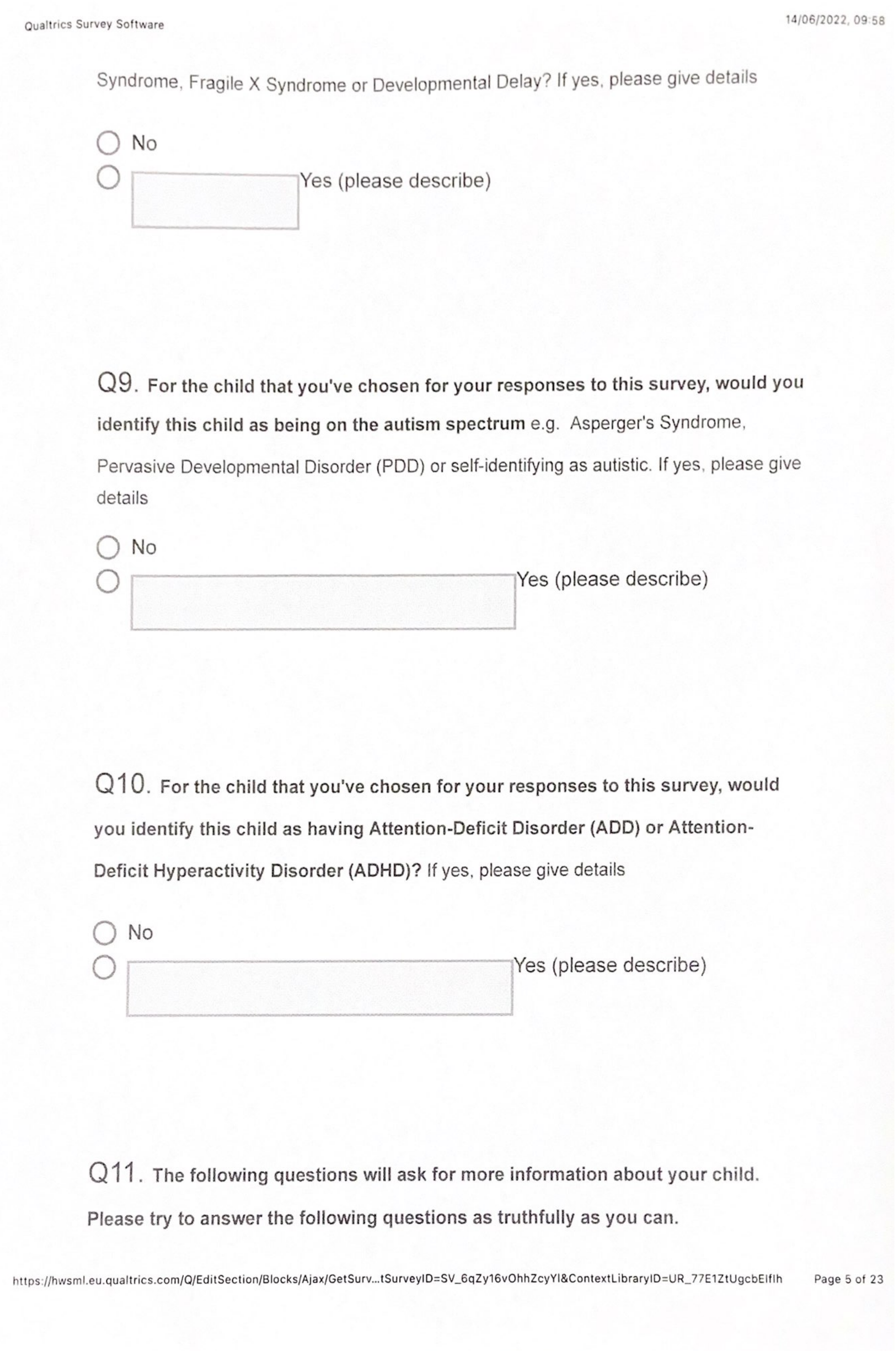


Syndrome, Fragile X Syndrome or Developmental Delay? If yes, please give details

○ No

○ ☐ Yes (please describe)

Q9. **For the child that you've chosen for your responses to this survey, would you identify this child as being on the autism spectrum** e.g. Asperger's Syndrome, Pervasive Developmental Disorder (PDD) or self-identifying as autistic. If yes, please give details

○ No

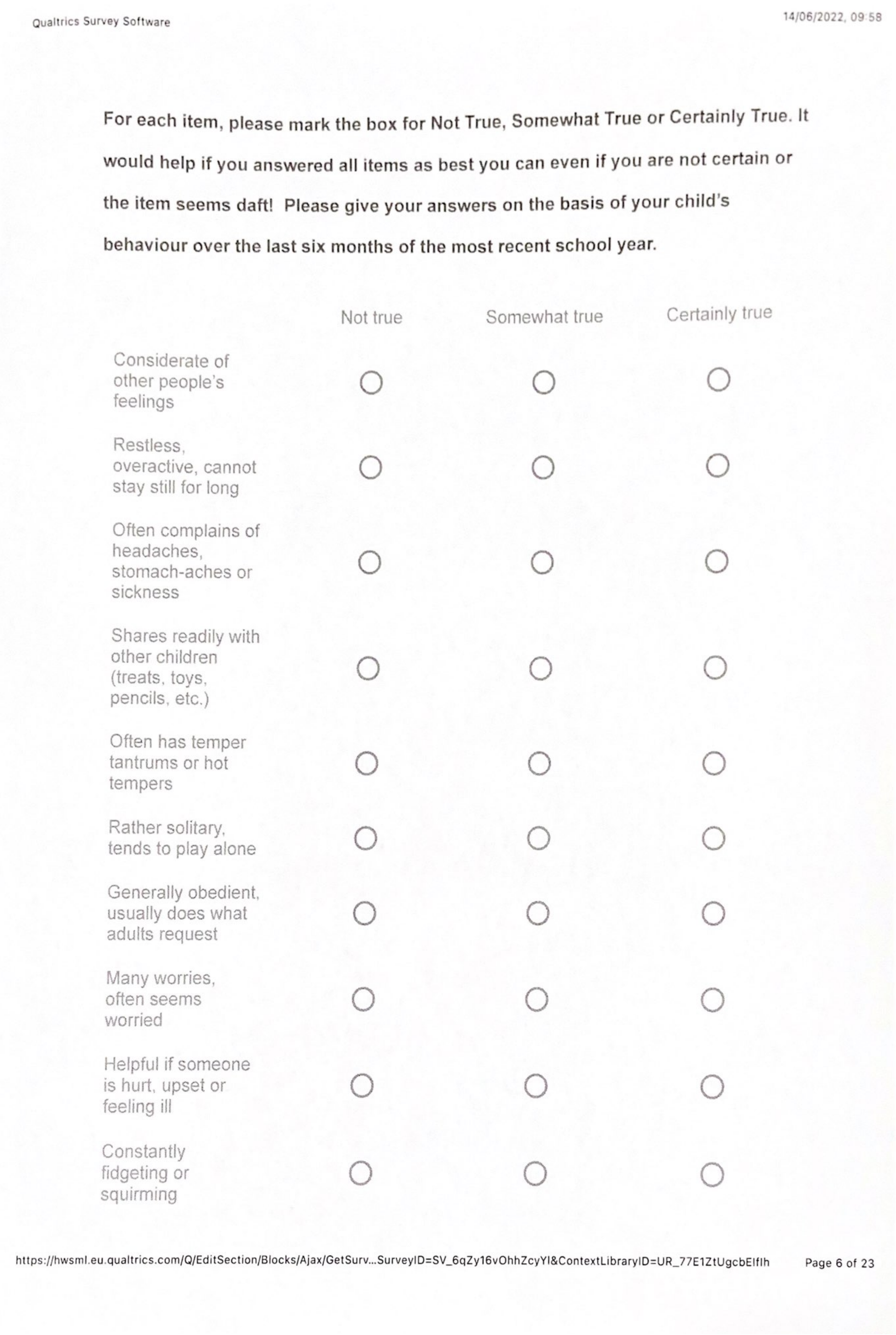
○ ☐ Yes (please describe)

Q10. **For the child that you've chosen for your responses to this survey, would you identify this child as having Attention-Deficit Disorder (ADD) or Attention-Deficit Hyperactivity Disorder (ADHD)?** If yes, please give details

○ No

○ ☐ Yes (please describe)

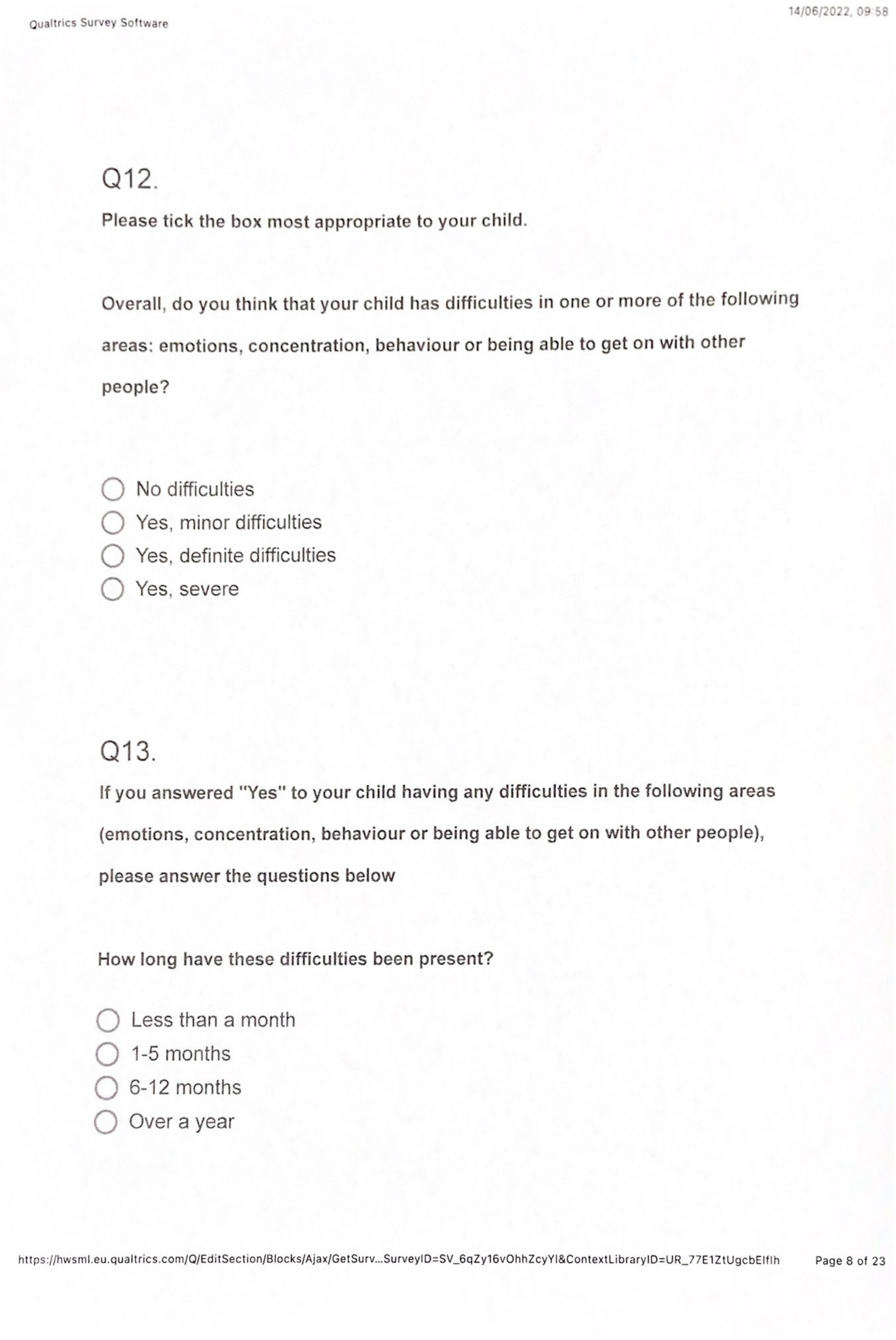
Q11. **The following questions will ask for more information about your child. Please try to answer the following questions as truthfully as you can.**



For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help if you answered all items as best you can even if you are not certain or the item seems daft! Please give your answers on the basis of your child's behaviour over the last six months of the most recent school year.

	Not true	Somewhat true	Certainly true
Considerate of other people's feelings	○	○	○
Restless, overactive, cannot stay still for long	○	○	○
Often complains of headaches, stomach-aches or sickness	○	○	○
Shares readily with other children (treats, toys, pencils, etc.)	○	○	○
Often has temper tantrums or hot tempers	○	○	○
Rather solitary, tends to play alone	○	○	○
Generally obedient, usually does what adults request	○	○	○
Many worries, often seems worried	○	○	○
Helpful if someone is hurt, upset or feeling ill	○	○	○
Constantly fidgeting or squirming	○	○	○

Has at least one good friend	○	○	○
Often fights with other children or bullies them	○	○	○
Often unhappy, down-hearted or tearful	○	○	○
Generally liked by other children	○	○	○
Easily distracted, concentration wanders	○	○	○
Nervous or clingy in new situations, easily loses confidence	○	○	○
Kind to younger children	○	○	○
Often lies or cheats	○	○	○
Picked on bullied by other children	○	○	○
Often volunteers to help others (parents, teachers, other children)	○	○	○
Thinks things out before acting	○	○	○
Steals from home, school or elsewhere	○	○	○
Gets on better with adults than with other children	○	○	○
Many fears, easily scared	○	○	○
Sees tasks through to the end, good attention span	○	○	○



Q12.

Please tick the box most appropriate to your child.

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

○ No difficulties
○ Yes, minor difficulties
○ Yes, definite difficulties
○ Yes, severe

Q13.

If you answered "Yes" to your child having any difficulties in the following areas (emotions, concentration, behaviour or being able to get on with other people), please answer the questions below

How long have these difficulties been present?

○ Less than a month
○ 1-5 months
○ 6-12 months
○ Over a year

Q14. **Do the difficulties upset or distress your child?**

○ Not at all
○ Only a little
○ Quite a lot
○ A great deal

Q15. **Do the difficulties interfere with your child's everyday life in the following areas?**

	Not at all	Only a little	Quite a lot	A great deal
Home life	○	○	○	○
Friendships	○	○	○	○
Classroom learning	○	○	○	○
Leisure activities	○	○	○	○

Q16. **Do the difficulties put a burden on you or the family as a whole?**

○ Not at all
○ Only a little
○ Quite a lot
○ A great deal

Q17.

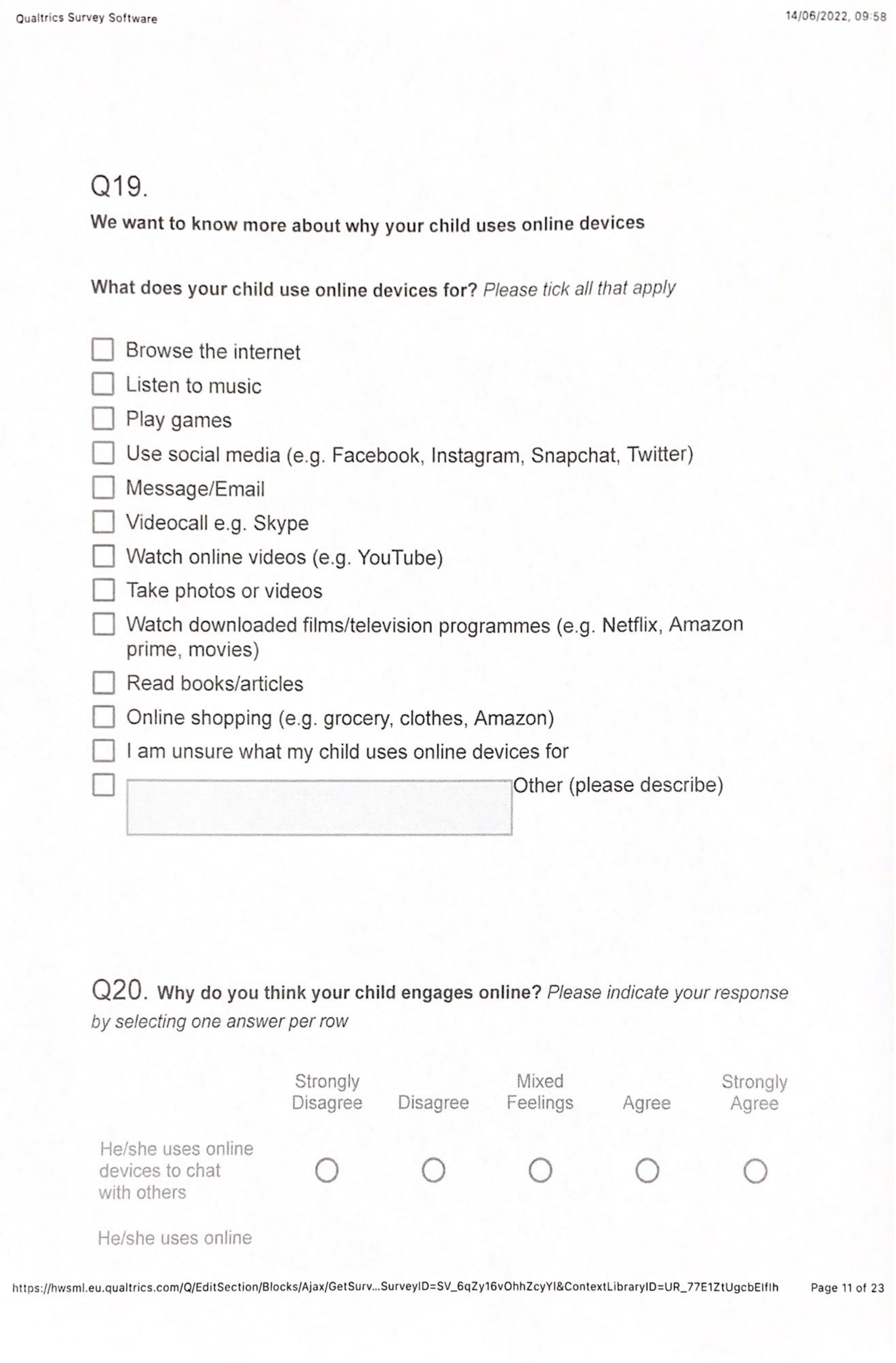
The following sections will ask you for some information about the online devices (i.e. devices which use the internet e.g. a computer, mobile phone or tablet) **which your child uses regularly at home:**

Does your child have regular access to any of the following online devices? *Please select all that apply and indicate how many hours that you think he or she spends using each on an average day.*

Select 0 hours if your child does not have regular access to the device(s).

Smart phone (e.g. iPhone, Samsung Galaxy)	
Tablet (e.g. iPad, Android)	
Personal Computer/Laptop	
E-Reader (e.g. Kindle)	
Game console (e.g. Xbox, Playstation)	
Smart Television	
Other (please describe)	

Q18. **Are any of the above a shared family device?** *If yes, please describe in box below*



Q19.

We want to know more about why your child uses online devices

What does your child use online devices for? *Please tick all that apply*

☐ Browse the internet
☐ Listen to music
☐ Play games
☐ Use social media (e.g. Facebook, Instagram, Snapchat, Twitter)
☐ Message/Email
☐ Videocall e.g. Skype
☐ Watch online videos (e.g. YouTube)
☐ Take photos or videos
☐ Watch downloaded films/television programmes (e.g. Netflix, Amazon prime, movies)
☐ Read books/articles
☐ Online shopping (e.g. grocery, clothes, Amazon)
☐ I am unsure what my child uses online devices for
☐ Other (please describe)

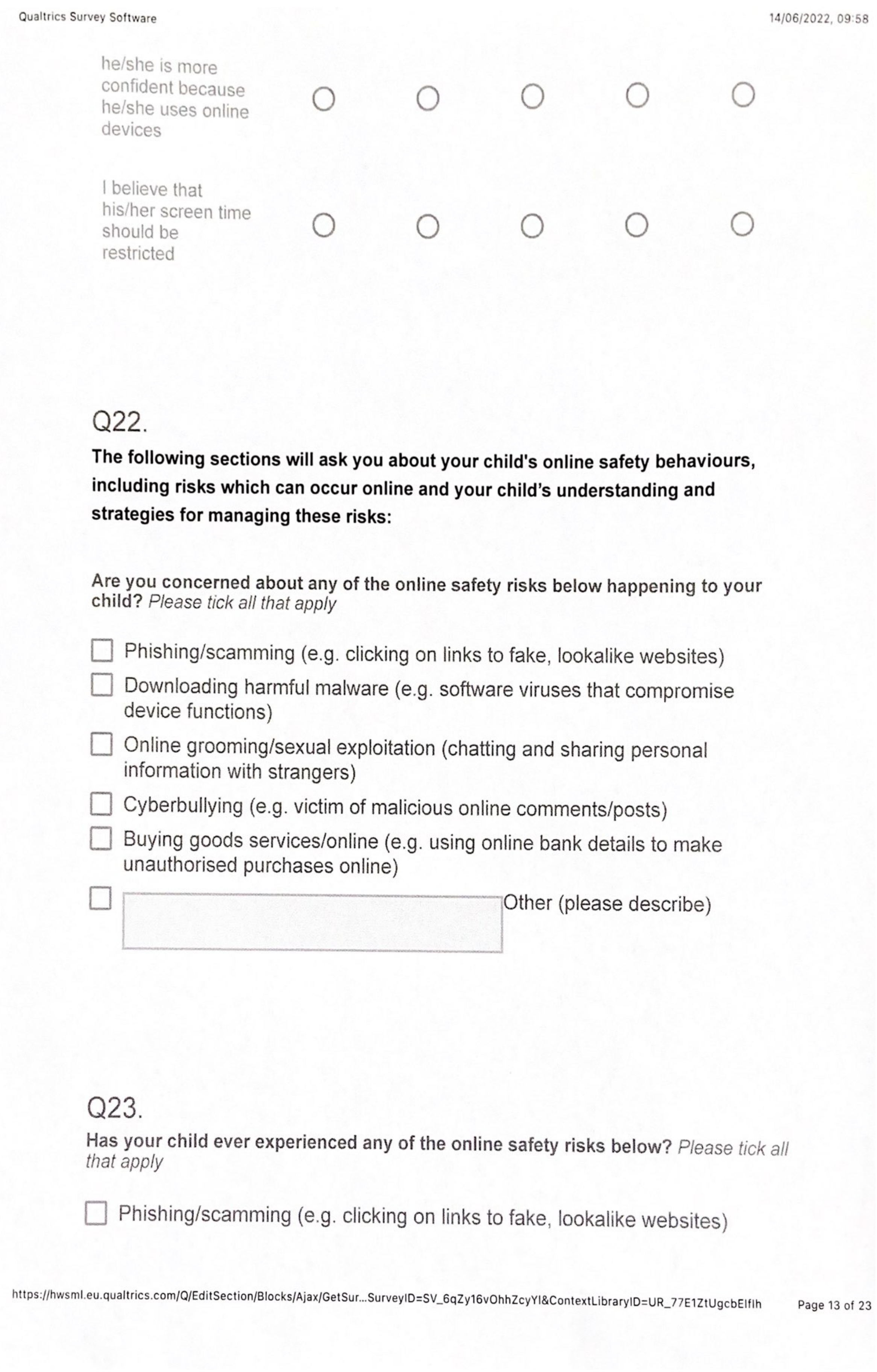
Q20. **Why do you think your child engages online?** *Please indicate your response by selecting one answer per row*

	Strongly Disagree	Disagree	Mixed Feelings	Agree	Strongly Agree
He/she uses online devices to chat with others	○	○	○	○	○
He/she uses online					

devices to pursue his/her interests	○	○	○	○	○
He/she chats with others online about his/her interests	○	○	○	○	○

Q21. **How do you feel about your child's online engagement?** *Please indicate your response by selecting one answer per row*

	Strongly Disagree	Disagree	Mixed Feelings	Agree	Strongly Agree
I believe he/she enjoys using online devices	○	○	○	○	○
I believe he/she spends too much time using online devices	○	○	○	○	○
I believe that he/she has benefited from using online devices	○	○	○	○	○
I worry that he/she is at risk of becoming obsessed with using online devices	○	○	○	○	○
I believe that online devices expand his/her knowledge	○	○	○	○	○
I believe it is important to supervise him/her whilst he/she is using online devices	○	○	○	○	○
I believe that					



he/she is more confident because he/she uses online devices	○	○	○	○	○
I believe that his/her screen time should be restricted	○	○	○	○	○

Q22.

The following sections will ask you about your child's online safety behaviours, including risks which can occur online and your child's understanding and strategies for managing these risks:

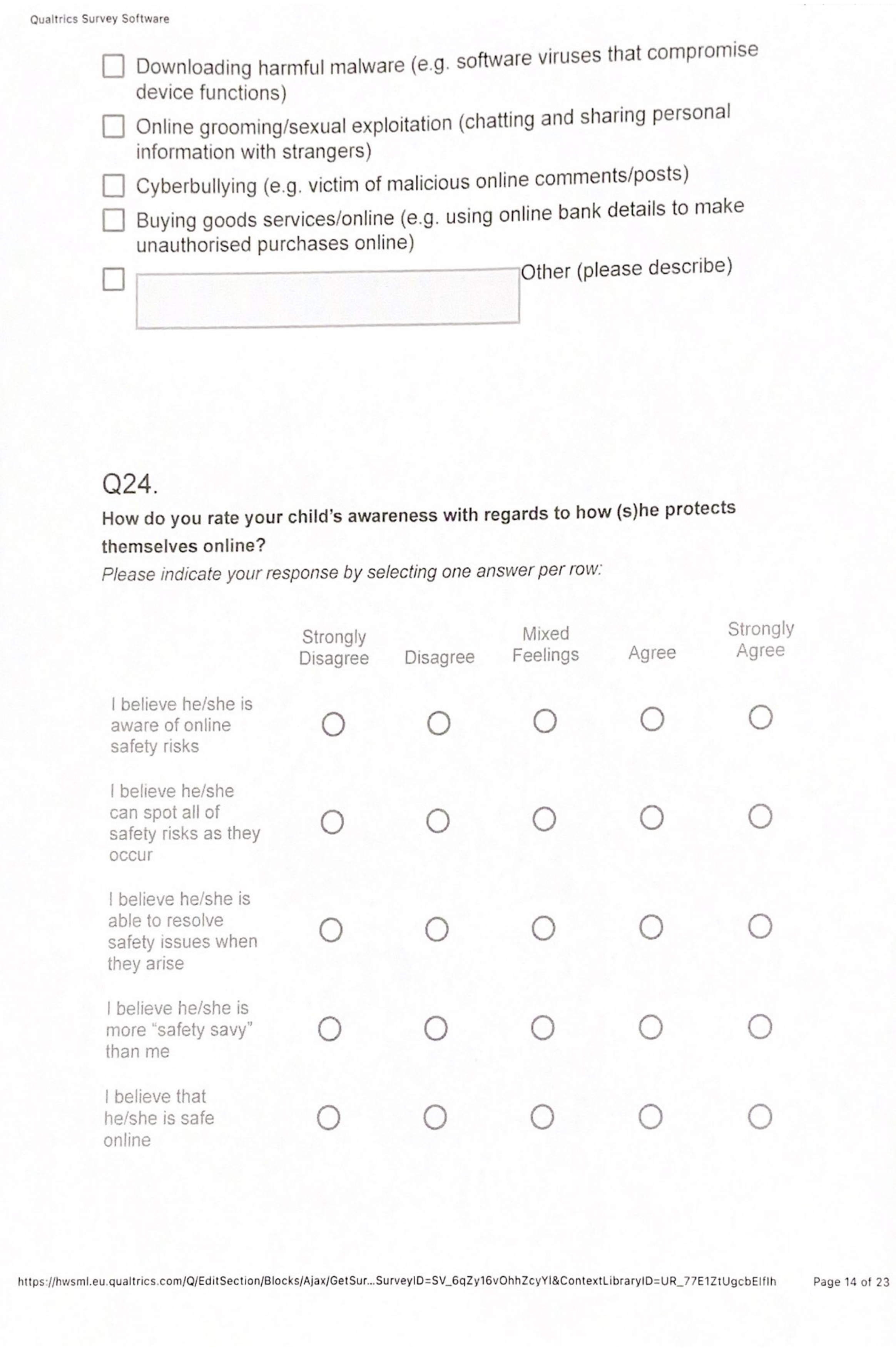
Are you concerned about any of the online safety risks below happening to your child? *Please tick all that apply*

- ☐ Phishing/scamming (e.g. clicking on links to fake, lookalike websites)
- ☐ Downloading harmful malware (e.g. software viruses that compromise device functions)
- ☐ Online grooming/sexual exploitation (chatting and sharing personal information with strangers)
- ☐ Cyberbullying (e.g. victim of malicious online comments/posts)
- ☐ Buying goods services/online (e.g. using online bank details to make unauthorised purchases online)
- ☐ Other (please describe)

Q23.

Has your child ever experienced any of the online safety risks below? *Please tick all that apply*

- ☐ Phishing/scamming (e.g. clicking on links to fake, lookalike websites)



☐ Downloading harmful malware (e.g. software viruses that compromise device functions)

☐ Online grooming/sexual exploitation (chatting and sharing personal information with strangers)

☐ Cyberbullying (e.g. victim of malicious online comments/posts)

☐ Buying goods services/online (e.g. using online bank details to make unauthorised purchases online)

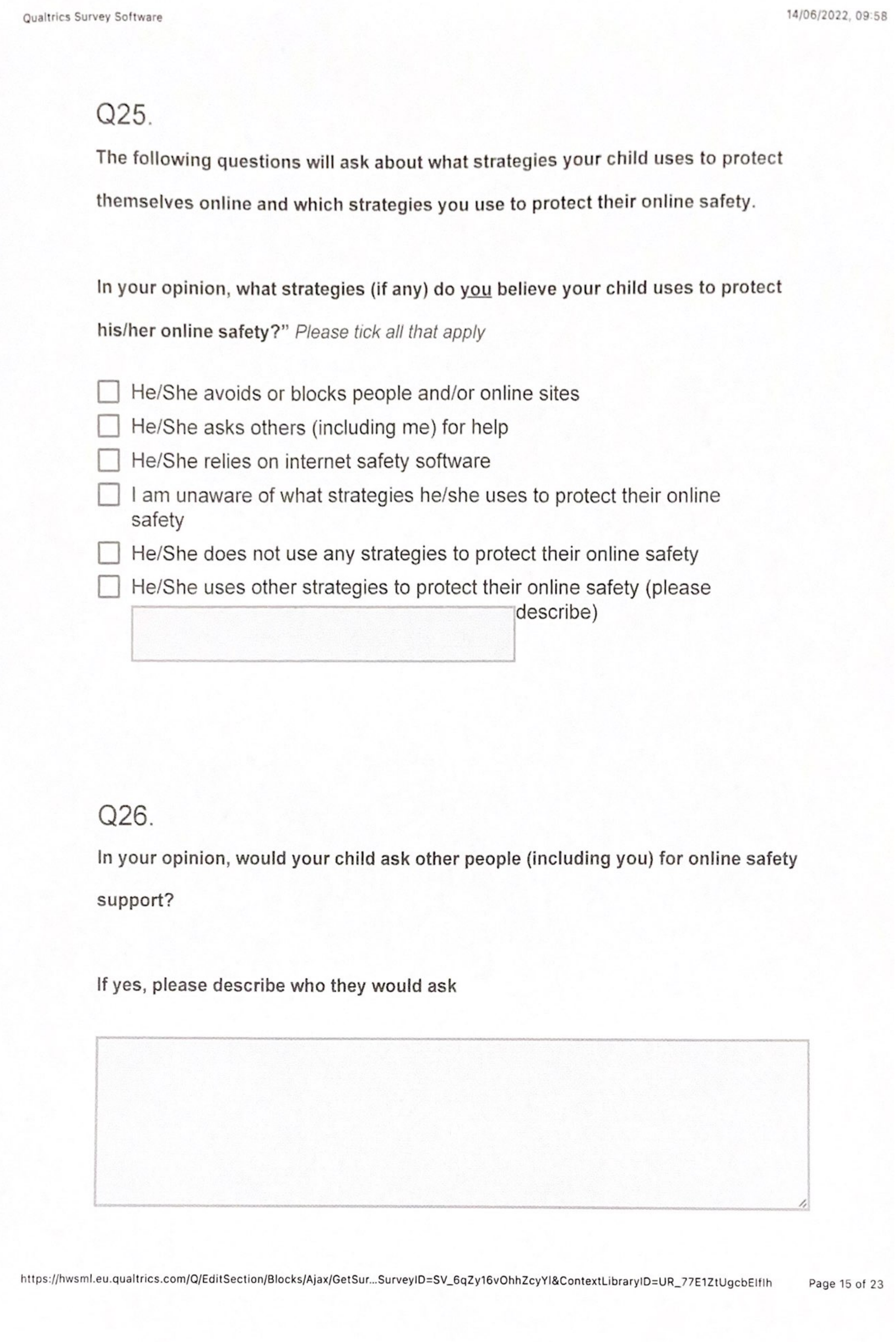
☐ ☐ Other (please describe)

Q24.

How do you rate your child's awareness with regards to how (s)he protects themselves online?

Please indicate your response by selecting one answer per row:

	Strongly Disagree	Disagree	Mixed Feelings	Agree	Strongly Agree
I believe he/she is aware of online safety risks	○	○	○	○	○
I believe he/she can spot all of safety risks as they occur	○	○	○	○	○
I believe he/she is able to resolve safety issues when they arise	○	○	○	○	○
I believe he/she is more "safety savy" than me	○	○	○	○	○
I believe that he/she is safe online	○	○	○	○	○



Q25.

The following questions will ask about what strategies your child uses to protect themselves online and which strategies you use to protect their online safety.

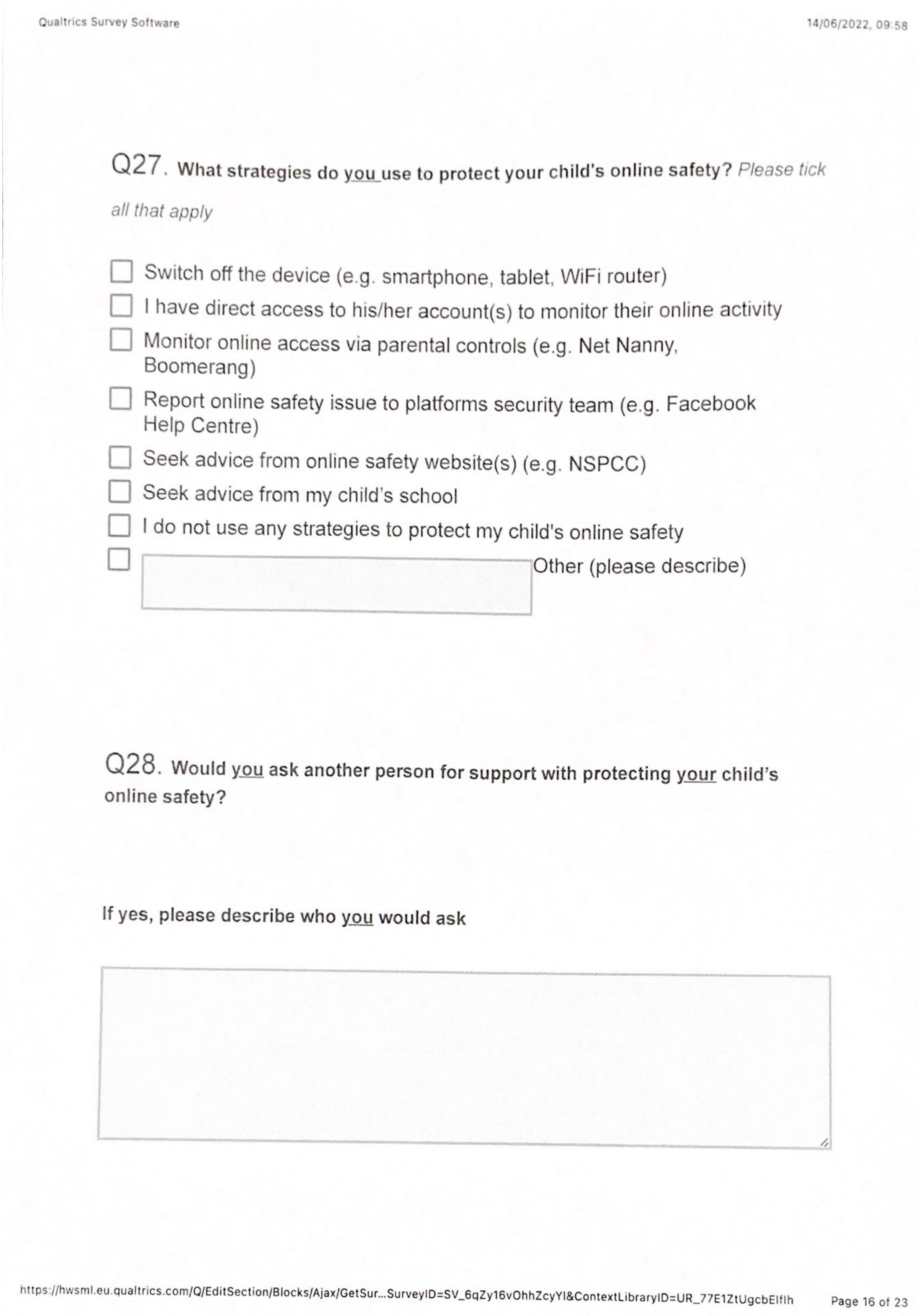
In your opinion, what strategies (if any) do you believe your child uses to protect his/her online safety?" *Please tick all that apply*

☐ He/She avoids or blocks people and/or online sites
☐ He/She asks others (including me) for help
☐ He/She relies on internet safety software
☐ I am unaware of what strategies he/she uses to protect their online safety
☐ He/She does not use any strategies to protect their online safety
☐ He/She uses other strategies to protect their online safety (please describe)

Q26.

In your opinion, would your child ask other people (including you) for online safety support?

If yes, please describe who they would ask



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Q27. **What strategies do <u>you</u> use to protect your child's online safety?** *Please tick all that apply*

- ☐ Switch off the device (e.g. smartphone, tablet, WiFi router)
- ☐ I have direct access to his/her account(s) to monitor their online activity
- ☐ Monitor online access via parental controls (e.g. Net Nanny, Boomerang)
- ☐ Report online safety issue to platforms security team (e.g. Facebook Help Centre)
- ☐ Seek advice from online safety website(s) (e.g. NSPCC)
- ☐ Seek advice from my child's school
- ☐ I do not use any strategies to protect my child's online safety
- ☐ Other (please describe)

Q28. **Would <u>you</u> ask another person for support with protecting <u>your</u> child's online safety?**

If yes, please describe who <u>you</u> would ask

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Q29. **How do you rate the following statements regarding <u>your</u> online safety knowledge?** *Please indicate your response by selecting one answer per row:*

	Strongly Disagree	Disagree	Mixed Feelings	Agree	Strongly Agree
I believe that I can spot all of my child's online safety risks as they occur	○	○	○	○	○
I believe that I am able to resolve online safety issues as they arise	○	○	○	○	○
I believe that I am more 'safety savvy' than my child(ren)	○	○	○	○	○
I often find myself asking peers for advice regarding online safety techniques	○	○	○	○	○
I often find myself asking child(ren) for advice regarding online safety techniques	○	○	○	○	○

Q30.

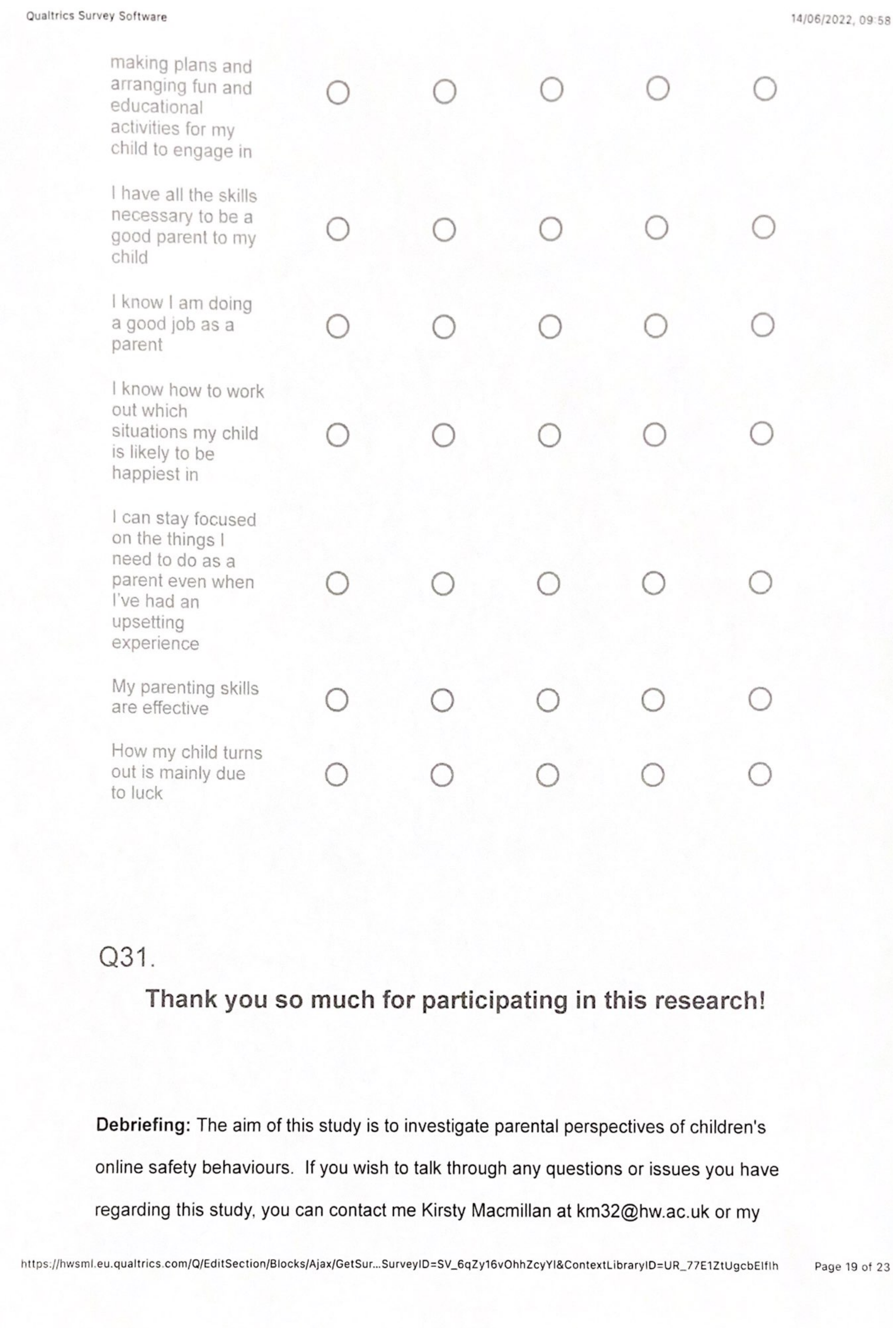
The following questions will ask you to reflect on your relationship with your child.

Please answer them as truthfully as you can!

How strongly do you agree or disagree with these statements? *Please indicate your response by selecting one answer per row:*

	Strongly Disagree	Disagree	Mixed Feelings	Agree	Strongly Agree
When something goes wrong between me and my child, there is little I can do to fix it	○	○	○	○	○
I know how to solve most problems that arise with parenting	○	○	○	○	○
I have confidence in myself as a parent	○	○	○	○	○
My child usually ends up getting their own way, so why try	○	○	○	○	○
I have the skills to deal with new situations with my child as they arise	○	○	○	○	○
When changes are needed in my family I am good at setting goals to achieve those changes	○	○	○	○	○
I can find out what's needed to resolve any problems my child has	○	○	○	○	○
I meet my expectations for providing emotional support for my child	○	○	○	○	○
I often feel helpless about my child's behaviour	○	○	○	○	○

I am good at



making plans and arranging fun and educational activities for my child to engage in	○	○	○	○	○
I have all the skills necessary to be a good parent to my child	○	○	○	○	○
I know I am doing a good job as a parent	○	○	○	○	○
I know how to work out which situations my child is likely to be happiest in	○	○	○	○	○
I can stay focused on the things I need to do as a parent even when I've had an upsetting experience	○	○	○	○	○
My parenting skills are effective	○	○	○	○	○
How my child turns out is mainly due to luck	○	○	○	○	○

Q31.

Thank you so much for participating in this research!

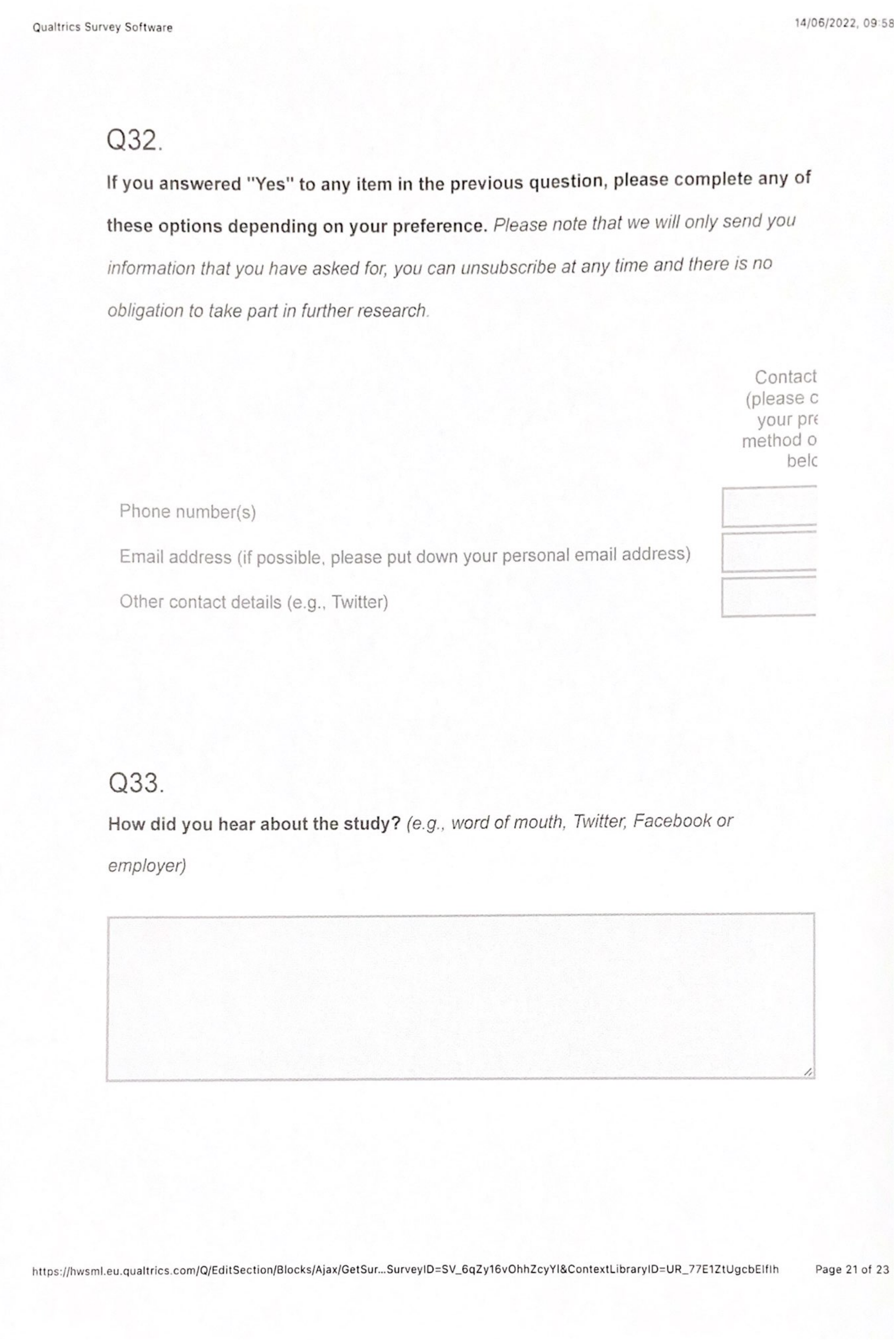
Debriefing: The aim of this study is to investigate parental perspectives of children's online safety behaviours. If you wish to talk through any questions or issues you have regarding this study, you can contact me Kirsty Macmillan at km32@hw.ac.uk or my supervisors Dr Tessa Berg at t.berg@hw.ac.uk or Dr Mike Just at m.just@hw.ac.uk.

If you would still like to be entered into the prize draw to win a £100 Amazon voucher, please complete the sections below:

Further research: I am looking to conduct follow up interviews with parents and young people on the autism spectrum regarding online safety behaviours. If you or your child is interested in taking part, please answer the section below:

Would you like to hear more from us?

	Yes	No
Receive a summary of the survey results	☐	☐
Receive general news about this research	☐	☐
For you or your child(ren) to take part in an interview (please note that this can be conducted face to face, via Skype, live web chat or whatever format suits you best)	☐	☐
Receive invitations to take part in future research	☐	☐



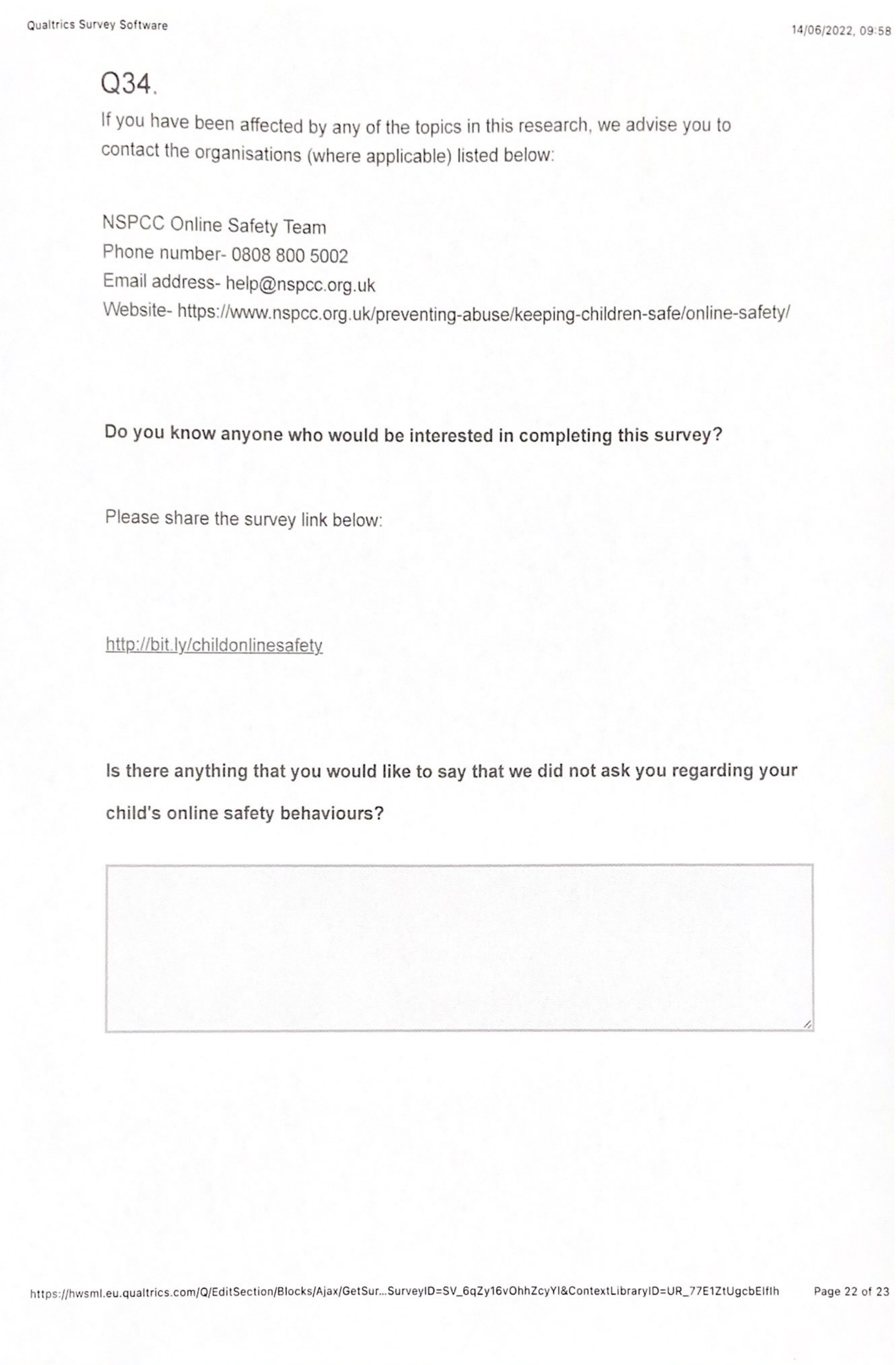
Q32.

If you answered "Yes" to any item in the previous question, please complete any of these options depending on your preference. *Please note that we will only send you information that you have asked for, you can unsubscribe at any time and there is no obligation to take part in further research.*

	Contact (please c your pre method o belc
Phone number(s)	
Email address (if possible, please put down your personal email address)	
Other contact details (e.g., Twitter)	

Q33.

How did you hear about the study? *(e.g., word of mouth, Twitter, Facebook or employer)*



Q34.

If you have been affected by any of the topics in this research, we advise you to contact the organisations (where applicable) listed below:

NSPCC Online Safety Team
Phone number- 0808 800 5002
Email address- help@nspcc.org.uk
Website- https://www.nspcc.org.uk/preventing-abuse/keeping-children-safe/online-safety/

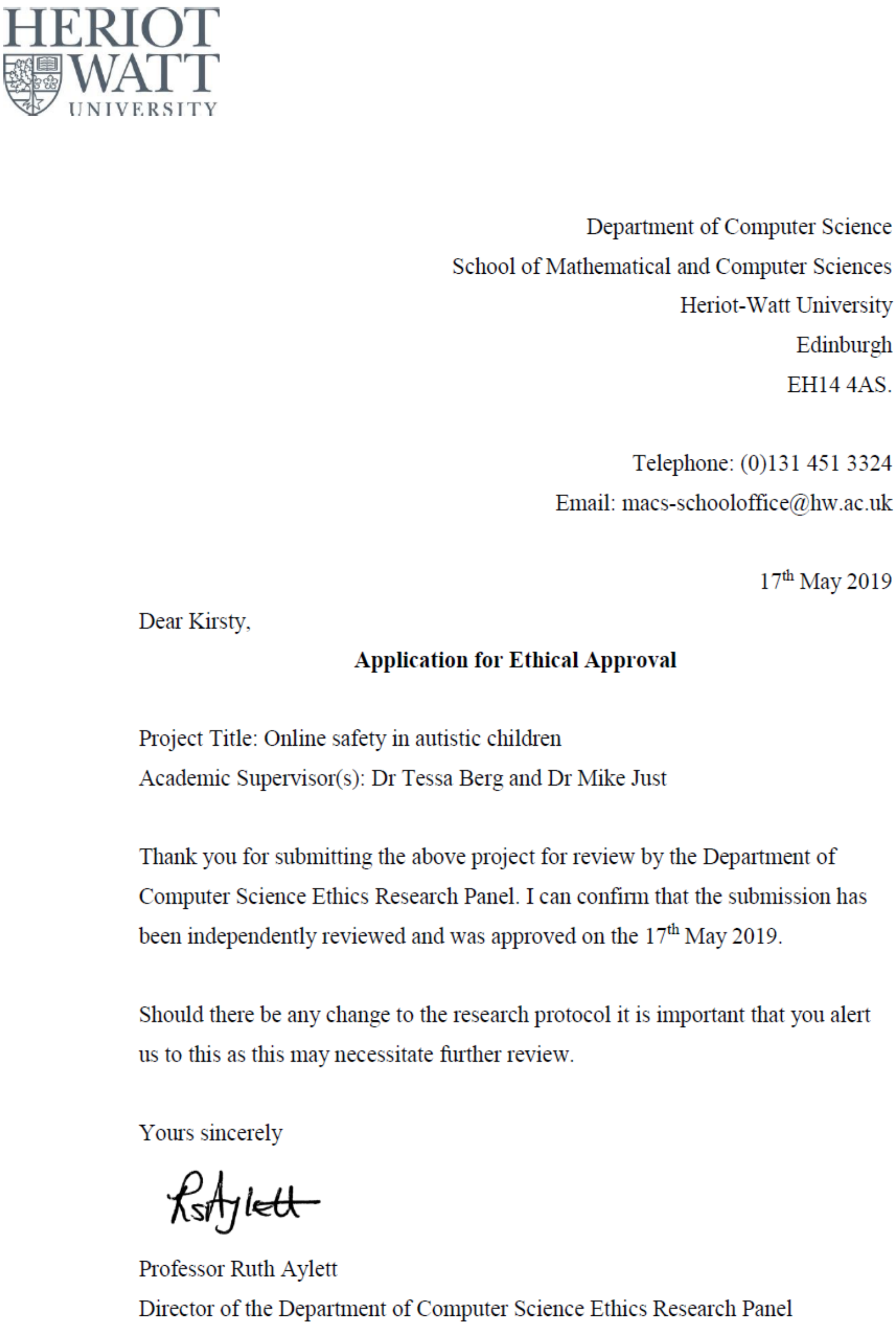
Do you know anyone who would be interested in completing this survey?

Please share the survey link below:

http://bit.ly/childonlinesafety

Is there anything that you would like to say that we did not ask you regarding your child's online safety behaviours?

Appendix C: Study 2 Ethical Approval Letter



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Department of Computer Science
School of Mathematical and Computer Sciences
Heriot-Watt University
Edinburgh
EH14 4AS.

Telephone: (0)131 451 3324
Email: macs-schooloffice@hw.ac.uk

17th May 2019

Dear Kirsty,

Application for Ethical Approval

Project Title: Online safety in autistic children
Academic Supervisor(s): Dr Tessa Berg and Dr Mike Just

Thank you for submitting the above project for review by the Department of Computer Science Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 17th May 2019.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely

Professor Ruth Aylett
Director of the Department of Computer Science Ethics Research Panel

Appendix D: Study 2 Information and Consent Form (Participants Under the Age of 16 Years)

Information and Consent Form

How Do Young People Keep Themselves Safe Online

Invitation

Your child has been invited to take part in an interview. The aim of the research is to find out more about how young people use online devices. I am interested in finding out more about how your child keeps themself safe online. This research has been vetted and approved by the Department of Computer Science Ethics Research Panel, Heriot-Watt University. The research is being carried out by PhD researcher Kirsty Macmillan, under the supervision of Dr Tessa Berg and Dr Mike Just.

What will happen

In the interview your child will be asked questions about how he/she uses online devices and keeps themself safe online. We can do this face-to-face at your home or a place of your choice in Edinburgh, on the phone, or via Skype, or a live web chat. You can let me know what you would prefer. The interview is expected to last between 30-45 minutes. Your child can answer the questions at your own pace and can take breaks during the interview. At the end of the interview, a £20 Amazon voucher will be provided as a thank you for participating.

Your rights

Participation in this research is voluntary. If your child does not wish to take part, he/she does not have to. If your child initially agrees but change his/her mind, they can stop answering questions or skip questions. You can also choose to withdraw your child’s information at the end of the interview if you want to.

Confidentiality/Anonymity

Any information provided will be treated confidentially. Your child's data will be saved with an anonymous code. It will only be seen by the research team and will not be linked to any identifying information (e.g., name, address, email) that you supplied. The overall results of this study may be reported in academic publications, but your child's name and information will not be identifiable.

For further information

The researchers will be glad to answer your questions about this study at any time and can inform you about the results of the study once we have completed our results. If you have any questions, you can contact:

Kirsty Macmillan:
km32@hw.ac.uk

Dr Tessa Berg:
t.berg@hw.ac.uk

Dr Mike Just:
m.just@hw.ac.uk

If you are happy for your child to take part in this interview study, please tick to indicate your agreement with the following statements:

- ☐ I have read and understood the information about this study
- ☐ I understand that any information provided will be treated confidentially
- ☐ I understand that my child's participation is completely voluntary
- ☐ I understand that my child can withdraw from the study at any time
- ☐ I understand that anonymised data may be published and/or presented at academic conferences
- ☐ I agree for my child to take part in this research
- ☐ I agree for my child's interview to be video and audio recorded (does not apply for live-chat interviews)

Parent Name (PRINT)…………………………………………………………………………
Parent Signature………………………………………………………………………………

Appendix E: Study 2 Information and Consent Form (Participants Aged 16+ Years

Information and Consent Form

How Do Young People Keep Themselves Safe Online

Invitation

You have been invited to take part in an interview. The aim of the research is to find out more about how young people use online devices. I am interested in finding out more about how you keep yourselves safe online. This research has been vetted and approved by the Department of Computer Science Ethics Research Panel, Heriot-Watt University. The research is being carried out by PhD researcher Kirsty Macmillan, under the supervision of Dr Tessa Berg and Dr Mike Just.

What will happen

In the interview you will be asked questions about how you use online devices and keep yourself safe online. We can do this face-to-face at your home or a place of your choice in Edinburgh, on the phone, or via Skype, or a live web chat. You can let me know what you would prefer. The interview is expected to last between 30-45 minutes. You can answer the questions at your own pace and can take breaks during the interview at any time if you need them. At the end of the interview, you will receive a £20 Amazon voucher as a thank you for your participation.

Your rights

Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you initially agree but change your mind, you can stop answering questions or skip questions. You can also choose to withdraw your information at the end of the interview if you want to.

Confidentiality/Anonymity

Any information that you provide will be treated confidentially. Your data will be saved with an anonymous code. It will only be seen by the research team and will not be linked to any identifying information (e.g., name, address, email) that you supplied. The overall results of this study may be reported in academic publications, but your name and information will not be identifiable.

For further information

The researchers will be glad to answer your questions about this study at any time and can inform you about the results of the study once we have completed our results. If you have any questions, you can contact:

Kirsty Macmillan:
km32@hw.ac.uk

Dr Tessa Berg:
t.berg@hw.ac.uk

Dr Mike Just:
m.just@hw.ac.uk

If you want to take part in this interview study, please tick to indicate your agreement with the following statements:

- ☐ I have read and understood the information about this study
- ☐ I understand that any information that I provide will be treated confidentially
- ☐ I understand that my participation is completely voluntary
- ☐ I understand that I can withdraw from the study at any time
- ☐ I understand that anonymised data may be published and/or presented at academic conferences
- ☐ I agree to take part in this research
- ☐ I agree for my interview to be video and audio recorded (does not apply for live-chat interviews)

Participant Name (PRINT)…………………………………………………………………...
Participant Signature…………………………………………………………………………

Appendix F: Study 2 Debriefing Form

Interview Debriefing

How Do Young People Keep Themselves Safe Online

Thank you so much for participating in this research!

The aim of this study is to investigate how young people keep themselves online. I am interested in finding out more about this so that we can develop interventions to help young people to be more independent online.

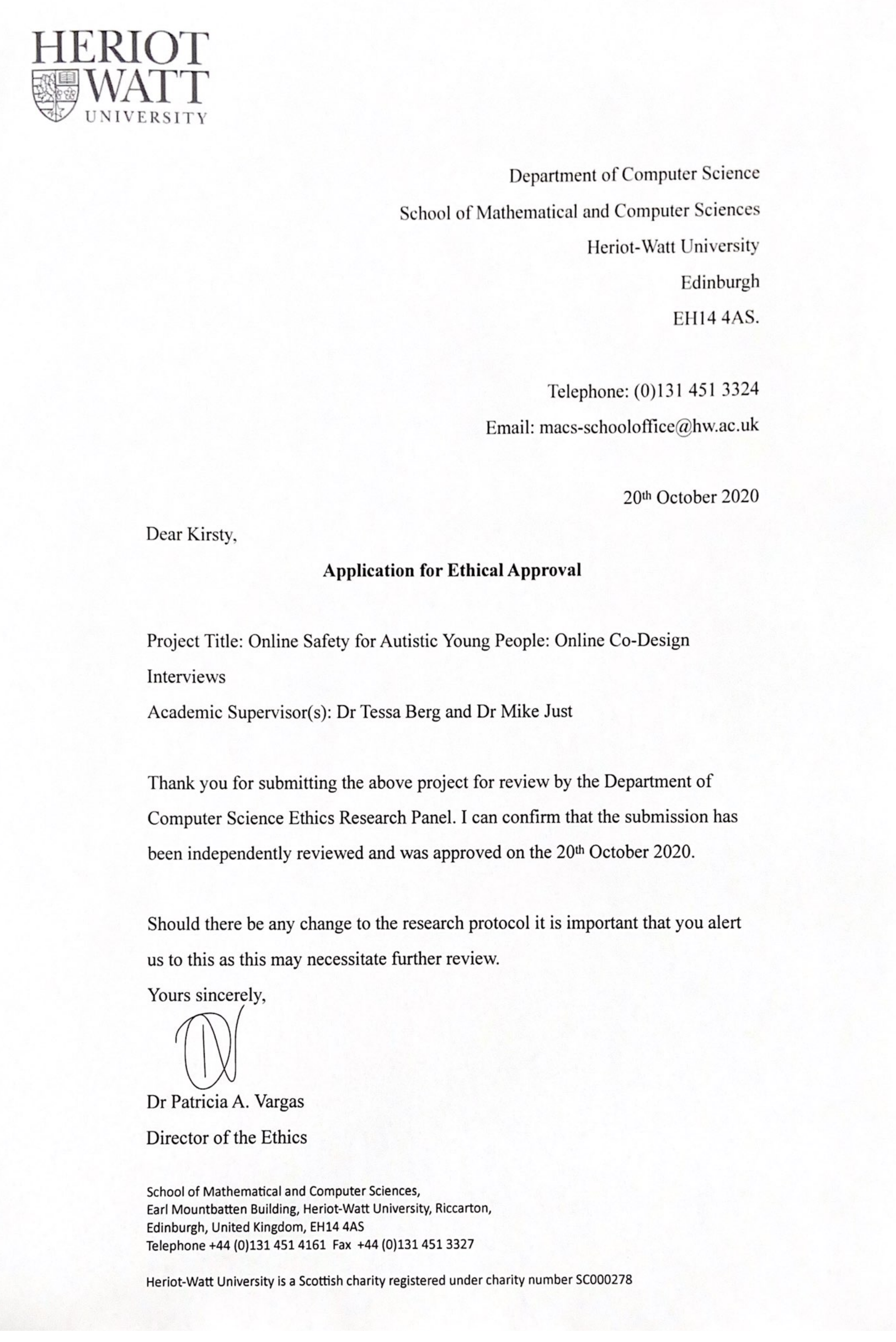
If you wish to talk through any questions or issues you have regarding this study, you can contact me at km32@hw.ac.uk or my supervisors Dr Tessa Berg at t.berg@hw.ac.uk or Dr Mike Just at m.just@hw.ac.uk.

If you have been affected by any of the topics in this research, we advise you to contact your GP or the organisations listed below:

ChildLine:
Phone number- 0800 1111
Email address- see website below for details
Website- https://www.childline.org.uk/

The National Autistic Society:
Phone number- 0808 800 4104
Email address- nas@nas.org.uk
Website- http://www.autism.org.uk/

Appendix G: Study 3 Ethical Approval Letter



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Department of Computer Science
School of Mathematical and Computer Sciences
Heriot-Watt University
Edinburgh
EH14 4AS.

Telephone: (0)131 451 3324
Email: macs-schooloffice@hw.ac.uk

20th October 2020

Dear Kirsty,

Application for Ethical Approval

Project Title: Online Safety for Autistic Young People: Online Co-Design Interviews
Academic Supervisor(s): Dr Tessa Berg and Dr Mike Just

Thank you for submitting the above project for review by the Department of Computer Science Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 20th October 2020.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Dr Patricia A. Vargas
Director of the Ethics

School of Mathematical and Computer Sciences,
Earl Mountbatten Building, Heriot-Watt University, Riccarton,
Edinburgh, United Kingdom, EH14 4AS
Telephone +44 (0)131 451 4161 Fax +44 (0)131 451 3327

Appendix H: Study 3 Information and Consent Form (Participants Under the Age of 16 Years)

Information and Consent Form

Helping Autistic Young People to Keep Themselves Safe Online

Invitation

Your child has been invited to take part in an online individual workshop. The aim of the research is to find out more about what would help to keep autistic young people safe online. I will present online safety scenarios to your child and drawings/pictures of online safety of ideas that have come up when we asked autistic young people what they think would help keep them safe online. This research has been vetted and approved by the Department of Computer Science Ethics Research Panel, Heriot-Watt University. The research is being carried out by PhD researcher Kirsty Macmillan, under the supervision of Dr Tessa Berg and Dr Mike Just.

What will happen

In the online 1:1 session, your child will be given online safety scenarios and asked to give their feedback. We can do this via videocall (e.g., Microsoft Teams, Skype) or a live web chat. You can let me know what your child would prefer. The session is expected to last between 30-45 minutes. Your child can complete the activities at your own pace and can take breaks during the session at any time if you need them.

Your rights

Participation in this research is voluntary. If your child does not wish to take part, they do not have to. If your child initially agrees but changes their mind, they can stop answering questions or skip questions. You can also choose to withdraw your child's information at the end of the session if you want to.

Confidentiality/Anonymity

Any information that your child provides will be treated confidentially. Your child's data will be saved with an anonymous code. It will only be seen by the research team and will not be linked to any identifying information (e.g., name, address, email) that your child supplies. The overall results of this study may be reported in academic publications, but your child's name and information will not be identifiable.

For further information

The researchers will be glad to answer your questions about this study at any time and can inform you about the results of the study once we have completed our results. If you have any questions, you can contact:

Kirsty Macmillan:
km32@hw.ac.uk

Dr Tessa Berg:
t.berg@hw.ac.uk

Dr Mike Just:
m.just@hw.ac.uk

If your child wants to take part in this study, please tick to indicate your agreement with the following statements:

- ☐ I have read and understood the information about this study
- ☐ I understand that any information that my child provides will be treated confidentially
- ☐ I understand that my child's participation is completely voluntary
- ☐ I understand that my child can withdraw from the study at any time
- ☐ I understand that anonymised data may be published and/or presented at academic conferences
- ☐ I agree to my child taking part in this research
- ☐ I agree for my child's online session to be video and audio recorded (does not apply for live-chat sessions)

Participant Name (PRINT)………………………………………………………………...
Parental Signature…………………………………………………………………………

Appendix I: Study 3 Information and Consent Form (Participants Aged 16+ Years)

Information and Consent Form

Helping Autistic Young People to Keep Themselves Safe Online

Invitation

You have been invited to take part in an online individual workshop. The aim of the research is to find out more about what would help to keep autistic young people safe online. I will present online safety scenarios to you and drawings/pictures of online safety of ideas that have come up when we have asked people like you what they think would help to keep them safe online. This research has been vetted and approved by the Department of Computer Science Ethics Research Panel, Heriot-Watt University. The research is being carried out by PhD researcher Kirsty Macmillan, under the supervision of Dr Tessa Berg and Dr Mike Just.

What will happen

In the online 1:1 session you will be given online safety scenarios and asked to give your feedback. We can do this via videocall (e.g., Microsoft Teams, Skype) or a live web chat. You can let me know what you would prefer. The session is expected to last between 30-45 minutes. You can complete the activities at your own pace and can take breaks during the session at any time if you need them.

Your rights

Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you initially agree but change your mind, you can stop answering questions or skip questions. You can also choose to withdraw your information at the end of the session if you want to.

Confidentiality/Anonymity

Any information that you provide will be treated confidentially. Your data will be saved with an anonymous code. It will only be seen by the research team and will not be linked to any identifying information (e.g., name, address, email) that you supplied. The overall results of this study may be reported in academic publications, but your name and information will not be identifiable.

For further information

The researchers will be glad to answer your questions about this study at any time and can inform you about the results of the study once we have completed our results. If you have any questions, you can contact:

Kirsty Macmillan:
km32@hw.ac.uk

Dr Tessa Berg:
t.berg@hw.ac.uk

Dr Mike Just:
m.just@hw.ac.uk

If you want to take part in this study, please tick to indicate your agreement with the following statements:

- ☐ I have read and understood the information about this study
- ☐ I understand that any information that I provide will be treated confidentially
- ☐ I understand that my participation is completely voluntary
- ☐ I understand that I can withdraw from the study at any time
- ☐ I understand that anonymised data may be published and/or presented at academic conferences
- ☐ I agree to take part in this research
- ☐ I agree for my online session to be video and audio recorded (does not apply for live-chat sessions)

Participant Name (PRINT)……………………………………………………………...
Participant Signature………………………………………………………………

Appendix J: Study 3 Briefing Script

Hi, my name is Kirsty and let me start off by saying, thank you for taking the time to take part in this session about online safety tools today. It's greatly appreciated.

Today, I will show you two separate online safety scenarios and drawings/pictures of online safety ideas that have come up when we have asked people like you what they think would help to keep them safe online. I will then ask you draw, write down or tell what you think would make these ideas more useful to help keep you safe online.

Please try to answer in as much detail as you can. There are no right or wrong answers, so please feel free to tell me what you think. At any point of our chat, please let me know if you need a break, if there is anything you would prefer not to discuss or whether there is anything that you would like to address in more detail. You can also stop the session at any time. If you have any concerns related to this session, please do not hesitate to ask me.

Is there anything you would like to ask me, or is it ok to begin?

Appendix K: Study 3 Debriefing Form

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Helping Autistic Young People to Keep Themselves Safe Online

Thank you so much for participating in this research!

The aim of this study is to investigate what would help autistic young people keep themselves safe online. Your feedback will help us to develop tools to help autistic young people be more independent online.

If you wish to talk through any questions or issues you have regarding this study, you can contact me at km32@hw.ac.uk or my supervisors Dr Tessa Berg at t.berg@hw.ac.uk or Dr Mike Just at m.just@hw.ac.uk.

If you have been affected by any of the topics in this research, we advise you to contact your GP or the organisations listed below:

ChildLine:
Phone number- 0800 1111
Email address- see website below for details
Website- https://www.childline.org.uk/

The National Autistic Society:
Phone number- 0808 800 4104
Email address- nas@nas.org.uk
Website- http://www.autism.org.uk/

NSPCC Online Safety Team:
Phone number- 0808 800 5002
Email address- help@nspcc.org.uk
Website- https://www.nspcc.org.uk/preventing- abuse/keeping-children-safe/online-safety/

Appendix L: List of Protocols to Promote Engagement with Autistic Young People

1. Pilot materials with members of the autistic community prior to data collection
2. Prepare autistic young people as much as possible prior to data collection
3. Give autistic young people the choice of the co-design session format
4. Emphasise autistic young people's right to autonomy in co-design sessions
5. Engage in topics that are important to autistic young people
6. Be flexible on how autistic young people provide feedback
7. Provide adjustments to help ensure that autistic young people's responses are being correctly interpreted
8. Keep autistic young people's wellbeing at the forefront
9. Explain how autistic young people's input will be utilized
10. Provide opportunities for autistic young people to feedback on what they believe is important