Feasibility of a smartphone application to identify young children at risk for Autism Spectrum Disorder in a low-income community setting in South Africa

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Declaration

I, *Aubrey Jonathan Kümm*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Neuroscientist, colleague and friend.

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Abstract

Introduction and aims

More than 90% of children with Autism Spectrum Disorder (ASD) live in Low- and Middle-Income countries (LMICs) where there is a great need for culturally appropriate, scalable and effective early identification and intervention tools. Smartphone technology and applications ('apps') may potentially play an important role in this regard. The Autism&Beyond iPhone App was designed as a potential screening tool for ASD risk in children aged 12-72 months. Here we investigated the technical feasibility, accessibility and cultural appropriateness of using a smartphone App to determine the risk for ASD in children aged 12-72 months in a naturalistic, low-income South African community setting.

Methodology

37 typically-developing African children and their parents/carers were recruited from community centres in Khayelitsha Township, Cape Town, South Africa. We implemented a mixed-methods design, collecting both quantitative and qualitative data from participants in 2 stages. In stage 1 we collected quantitative data. With appropriate ethics and consent, parents completed a short technology questionnaire about their familiarity with and access to smartphones, internet and apps, followed by electronic iPhone-based demographic and ASD-related questionnaires. Next, children were shown 3 short videos of 30s each and a mirror stimulus on a study smartphone. The smartphone front facing ("selfie") camera recorded a video of the child's facial expressions and head movement. Automated computer algorithms quantified positive

emotions and time attending to stimuli. We validated the automatic coding by a) comparing the computer-generated analysis to human coding of facial expressions in a random sample (N=9), and b) comparing automated analysis of the South African data (N=33) with a matched American sample (N=33). In stage 2, a subset of families was invited to participate in focus group discussions to provide qualitative data on the accessibility, acceptability, and cultural appropriateness of the App in their local community.

Results

Most parents (64%) owned a smartphone of which all (100%) were Android based, and many used Apps (45%). Human-automated coding showed excellent correlation for positive emotion (ICC = 0.95, 95% CI 0.81-0.99) and no statistically significant differences were observed between the South African and American sample in % time attending to the video stimuli. The South African children, however, smiled less at the Toys&Rhymes [SA mean (SD) = 14% (24); USA mean (SD) = 31% (34); p=0.05] and Bunny videos [SA mean (SD) = 12% (17); USA mean (SD) = 30% (0.27); p=0.006]. Analysis of focus group data indicated that parents/carers found the App relatively easy to use and would recommend it to others in their community, provided that the App and data transfer were free.

Conclusion

The results from this pilot study suggested the App to be technically accurate, accessible and culturally acceptable to families from a low-resource environment in South Africa. Given the differences in positive emotional response between the groups, careful consideration should be given to identify suitable stimuli if % time smiling is to be used as a global marker for ASD risk across cultures and environments.

Key terms

ASD, smartphone, App, screening, LMIC

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Abbreviations

ASD	Autism Spectrum Disorder
ADOS	Autism Diagnostic Observation Schedule
HICs	High-income Countries
ICC	Intra-class correlation
ICT	Information and communication technologies
IRR	Inter-rater reliability
IVC	Interactive videoconferencing
LMICs	Low- and middle-income countries
M-CHAT	Modified Checklist for Autism in Toddlers
SSA	Sub-Saharan Africa
TD	Typical development

Key Terms

App

Autism spectrum disorder (ASD)

Computational marker

Cross-cultural

Low- and middle-income countries (LMICs)

mHEALTH

Screening

Smartphone

Technology

Chapter 1

Feasibility of the Autism&Beyond iPhone App to detect risk for Autism Spectrum Disorder in a South African setting

1.1 Background to the dissertation

This dissertation will focus on a feasibility study of the Autism&Beyond smartphone application as a potential tool to identify young children at risk for Autism Spectrum Disorder (ASD) in a low-income community setting. Chapter 1 starts out with background information on a range of potential uses of technology for ASD in low-income settings and discusses the potential opportunities and challenges related to these in Low- and Middle-Income Countries (LMICs). In Chapter 2 we discuss the methodology and present the results of the study followed by a discussion of the findings. Chapter 3 draws together the conclusions from the feasibility study.

1.2 Autism Spectrum Disorder in Low- and Middle-Income Countries

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by a wide range of symptoms, including difficulty with social interaction and communication, restricted interests, and stereotyped behaviours (American Psychiatric Association, 2013). Comorbidities such as intellectual disability, motor impairment, sleep problems, mood disturbances and epilepsy are common, and add to the complexity of ASD symptoms (Moyal et al., 2014). Individuals with ASD have varying degrees of abilities, allowing some to lead independent and productive lives with varying levels of support, while others are severely affected by these challenging symptoms that persist throughout life, and are associated with a significant burden of care and treatment (Farley et al., 2009). However, early identification and treatment can reduce the symptoms and improve the functional outcomes of ASD for many affected individuals (Rogers and Dawson, 2010; Dawson et al., 2012; Bradshaw et al., 2015).

Current estimates suggest a global prevalence of 1 in 160 children, with boys consistently outnumbering girls with ratios ranging from 1.33:1 to 15.7:1 (Fombonne, 2009; Elsabbagh et al., 2012). Estimates from High-Income Countries (HICs) in Europe and North America are significantly higher at 1 in 68 children affected (Christensen et al., 2016). Prevalence rates reported in the literature for LMICs are typically lower than those reported for HICs (Elsabbagh et al., 2012). However, there is no reason to believe that there is a true difference in the prevalence between HICs and LMICs. There is general consensus that this discrepancy is likely to reflect the multi-layered disparities that exist in health, social and societal systems, including in awareness and access to resources between HICs and LMICs (World Health Organization, 2013; de Vries, 2016; Franz et al., 2017).

The World Health Organisation (WHO) regards ASD as a growing global public health concern and a major cause of disease burden in children and adolescents (World Health Organization, 2013). Governments of LMICs typically spend less than 1% of their health budgets on mental health and only a fraction of that on neurodevelopmental disorders such as ASD (Saxena et al., 2007; Chisholm et al., 2016). Communicable diseases such as Measles, Human Immunodeficiency Virus (HIV), Tuberculosis (TB), and Malaria are widely accepted as major causes of childhood mortality and regarded as public health priorities, receiving the bulk of funding and resources (Saraceno et al., 2007; Bakare et al., 2014). It is, however, important to recognise that successful treatment and prevention programmes that significantly reduces childhood mortality (Rajaratnam et al., 2010) are also associated with more children surviving to be later diagnosed with developmental delays or disabilities, including ASD (Grantham-McGregor et al., 2007). Current estimates suggest that more than 90% of children with ASD live in LMICs (Franz et al., 2017). Many remain either undiagnosed or are diagnosed very late in comparison to children living in HICs (Daley, 2004; Lagunju et al., 2014). In a recent study from Nigeria, parents expressed concern about their child's development when the child was 22.5 months old, yet diagnoses were typically not made until age 44.7 months (Lagunju et al., 2014). Some studies report the typical age of diagnosis ranging between 8 years to adolescence (Bakare and Munir, 2011).

Disparities in access to ASD screening, diagnosis, and treatment in low-resourced communities exist globally (Patel et al., 2008). Factors such as symptom severity, geographic location, socio-economic status (SES), ethnicity and culture impact both the age of first assessment and subsequent intervention (Lagunju et al., 2014; Williams et al., 2015). With a mere 60 specialist child and adolescent psychiatrists and even fewer developmental paediatricians in sub-Saharan Africa (SSA), most communities in SSA face significant challenges in accessing skilled professionals and appropriate services (Saxena et al., 2007; de Vries, 2016; Franz et al., 2017). Parents living in low-resourced areas typically have to travel considerable distances for their children to receive the health services they need. The lack of reliable transport infrastructure, shortage of trained professionals and lengthy waiting lists result in these visits taking days rather than hours (Daley, 2004; Durkin et al., 2015). People living in rural or remote areas of LMICs typically have limited awareness of and poor knowledge about ASD. This, unfortunately, includes education and healthcare professionals (Bakare et al., 2009; Ruparelia et al., 2016; de Vries, 2016; Franz et al., 2017). In SSA for example, many believe in supernatural causes and parents often pursue treatments from traditional healers (Gona et al., 2015; Ruparelia et al., 2016). Lack of knowledge about ASD, local culture and traditional beliefs contribute to social stigma and discrimination, often depriving this vulnerable group of people of opportunities to improve their health, education and community involvement (Keusch et al., 2006; Michels et al., 2006; Khan et al., 2012; Harrison, Slane et al., 2017; Harrison, Bradshaw et al., 2017).

Most of what we know today about child and adolescent mental health in general, and ASD specifically, is based on studies involving individuals of high SES, living in HICs (Kieling et al., 2011; Franz et al., 2017). A recent comprehensive scoping review of ASD in SSA (Franz et al., 2017) found only 53 relevant peer reviewed articles reporting data from only 9 SSA countries. Consistent with earlier reviews (Elsabbagh et al., 2012; Abubakar et al., 2016) no epidemiological studies from SSA were found. In addition, Franz and colleagues identified a paucity of research about phenotype, genetic and environmental risk factors, screening, diagnosis and early intervention for ASD, as well as inadequacies in professional knowledge. The absence of standardised, validated and accessible tools for ASD screening and diagnosis (Franz et al., 2017) preclude whole population (primary) and/or at-risk population (secondary) screening common in HICs (McKenzie et al., 2016). “Gold Standard” screening and diagnostic tools are not easily accessible to professionals working in LMICs (Smith et al., 2017). These proprietary tools are expensive and require extensive training as well as considerable time to administer (Durkin et al., 2015; Ruparelia et al., 2016). Screening instruments such as the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2014) and diagnostic instruments such as the Autism Diagnostic Observation Schedule-2 (ADOS-2) (Lord et al., 2012) were developed in English and require translation and validation before it can be used in other languages and cultures. Notwithstanding the potential of existing tools to characterise ASD symptoms across language and culture (Chambers et al., 2017; Smith et al., 2017) the cost, time and resources required for translation and adaptation of these tools to be valid and culturally acceptable, are major barriers to their use in culturally and linguistic diverse LMICs. Nonetheless, standardised phenotyping tools are a prerequisite to performing high-quality epidemiological research (Rice et al., 2012). Franz et al. (2017) recommended whole-population counts of children with known disabilities or in specialist schools for ASD as a first step to assess the scope of health and educational needs. The absence of ASD diagnoses in health and educational records of low-income communities in South Africa for example, suggests that these children are not receiving timely access to necessary services and support (Malcolm-Smith et al., 2013).

Addressing the widening knowledge and treatment gaps in LMICs require large-scale clinical, training, and research programmes (Franz et al., 2017). Given the inadequacies in clinical services, knowledge, and pathways to care in low-income regions, capacity needs to be built across the health and education systems, focussing particularly on affordable, widely available and accessible resources as well as community participation (Patel et al., 2008). Collaborative care and creating a diverse mental health workforce of appropriately trained and supported community health care providers can aid in addressing the challenges of scaling up mental health services in LMICs (Lund et al., 2016). These challenges involve not only establishing what services to implement, but also how these services are to be implemented (Lund et al., 2016; Franz et al., 2017).

In recent years, there has been a rapid increase in utilising technology in interventions and teaching strategies to address the various challenges in delivering health care to families living with ASD (Ploog et al., 2013; Odom et al., 2014; Grynszpan et al., 2014). Technology-based interventions have the potential to address those challenges in LMICs. Unlike traditional service delivery models (involving highly skilled professionals in one-to-one, in-person sessions), technology has the capacity to increase access on a large scale at relatively low cost, utilising a diverse workforce in local settings where these services are poor or non-existent and remedy the disparities in the delivery of services between communities living in HICs and those who live in LMICs.

1.3 Technology and Autism Spectrum Disorder

Technology involves the utilisation of scientific knowledge for practical purposes, specifically usage and knowledge of instruments and techniques to help us control and adapt to our natural environments (Bölte et al., 2010). For those living with ASD, technology-based interventions may involve assistive tools designed for indefinite use, or as learning tools used only until a certain goal has been achieved. For those caring for or providing services to individuals with ASD, technology may assist screening, diagnosis, rehabilitation, education and training.

An expanding body of evidence shows important positive outcomes of technology-based interventions for people with ASD and those who care for them (Bölte et al., 2010; Grynszpan et al., 2014; Shic and Goodwin, 2015). However, most studies on the potential use of technology for ASD have focused on high-income countries (Bölte et al., 2016). In fact, Franz et al (2017) identified no studies using technology in SSA. In other parts of the world, studies relating to the use of technology to detect early signs of ASD for instance, typically involve Electroencephalography (EEG), Magnetic Resonance Imaging (MRI) and eye tracking (Costanzo et al., 2015; Bölte et al., 2016). These technologies are expensive, require highly skilled professionals and are not easily portable. For these reasons, such technologies are unlikely to impact families in low-income environments. However, technology could provide the tools needed to escalate the pace and scope of autism research, identification and treatment in LMICs (Goodwin, 2008).

Information and communication technologies (ICT) such as personal computers (PCs), smartphones, and tablets have become integral to our daily lives. These devices are also part of the lives of individuals living with ASD. Given the increasing availability of these technologies globally, they could potentially provide culturally-acceptable, widely accessible and affordable tools for individuals with ASD, and for those who care for them. In addition to the technologies developed specifically for individuals with disabilities, hardware and software created for mainstream markets may be easily adaptable to their needs (Shane et al., 2012). In December 2015, the *Journal of Autism and Developmental Disorders* published a special issue on technology. The issue included review papers, brief reports and original research to give a glimpse on how technology could play a vital role in the lives of people with ASD and those who support them. Technologies included a variety of options from ubiquitous smartphones to futuristic interactive robotics (Bölte et al., 2010; Grynszpan et al., 2014; Odom et al., 2014). Given the known advantages of technology use for individuals with ASD (Panyan, 1984), the increasing number of commercially available technologies developed for this community in recent years is not surprising (Mazurek et al., 2012; Ramdoss et al., 2012). Unfortunately, technologies for ASD are often adopted without sufficient scientific evidence supporting its use (Fletcher-Watson, 2014; Odom et al., 2014; Wong et al., 2015). As an example, more than 13 000 health Apps (software applications for iPhone or iPad) intended for use by consumers are available for download in the Apple App Store (Donker et al., 2013). Approximately 6% of these Apps target mental health outcomes (Donker et al., 2013). Although these Apps have the potential to improve access to mental healthcare, they mostly lack robust scientific evidence about their efficacy, validity, reliability and acceptability (Donker et al., 2013). Technology, it seems, is moving faster than science. This being said, a body of evidence is steadily emerging from a rapidly growing community of researchers, designers, developers and clinicians collaborating to develop evidence-based technologies for ASD.

1.4 Evidence-based technologies for Autism Spectrum Disorder

Technology could assist individuals living with ASD to reach their full potential and contribute productively to society. Successful implementation and utilisation of technology-based interventions will depend on the end user's needs remaining central in the process from first concept to completion (Fletcher-Watson, 2014). As shown in **Figure 1.1**, this should include determining who the end-user will be (the user), where the technology will be used (the setting), what it will be used for (the purpose) and which deficit or challenge it will address (the area) (Odom et al., 2014). Here we provide a brief review of a range of technologies currently available or under investigation for ASD and reflect on their potential application in LMIC settings.

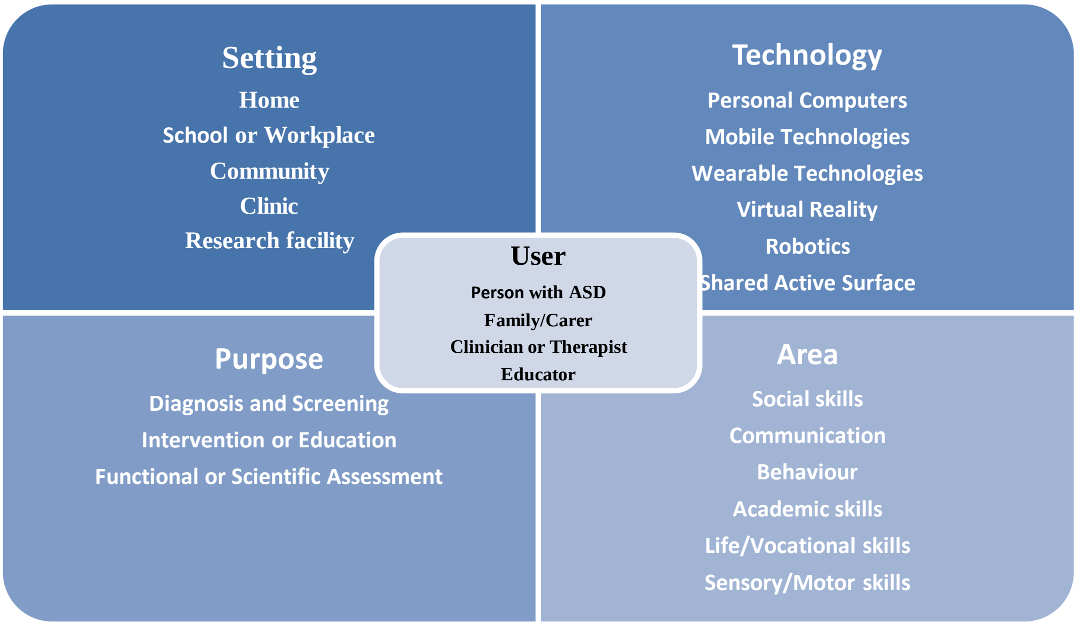

Figure 1.1 Factors to consider when determining the ideal user-technology match (adapted from Odom et al., 2014)

1.4.1 Personal Computers

Personal Computers (PCs) can be found in most homes, schools, universities, offices and shops in most high-income countries (ICT, 2010). Since the first PCs were made available to the public in the early 1980s, the keyboard, mouse, and monitor have become integral to our daily lives. Over the past four decades, PCs have evolved to become multimedia tools for communication, commerce, education, training and creativity. Interestingly, PCs have a longer and more comprehensive history of use for and by persons living with ASD than any of the other information and communication technology (ICT) platforms reviewed here. In fact, computer-based interventions for autistic children have been known since the early 1970s (Colby and Smith, 1971;

Colby, 1973). The emergence of PCs in the 80s and the publically available World Wide Web (WWW) in the mid 90s brought about an increase in peer-reviewed publications relating to autism and computers (Ploog et al., 2013).

Hardware and software developed for PCs make it possible for education (Computer Assisted Learning) and healthcare (Telemedicine) services to be delivered to homes, schools and clinics in remote settings globally. Websites such as 'Autism Navigator' (www.autismnavigator.com) **(Figure 1.2)** and 'Learn the Signs. Act Early' (www.cdc.gov/actearly) **(Figure 1.2)** offer online courses, tools, and resources for families and service providers which are freely accessible 24 hours a day. Even without internet access, PC-based audio-visual presentation of educational material about ASD to healthcare professionals, teachers and carers can improve knowledge about this disorder (Chuthapisith et al., 2009). Interactive video conferencing (IVC) enables remotely delivered education and training to under-resourced communities. Vismara and colleagues (2009, 2013) found IVC and self-directed DVD or web-based training in the Early Start Denver Model (ESDM) (Rogers and Dawson, 2010) to be at least as effective as in-person community based didactic training, significantly increasing knowledge and skills in implementing ESDM. Remote diagnostic assessments and consultations for ASD is made possible by IVC technology, virtually transporting specialist clinicians to meet with primary care providers and/or families in their own communities (Reese et al., 2013; Pearl et al., 2014).

Even though computer-assisted learning and telemedicine can play a tremendous role in providing universal access to mental health services (Pickard et al., 2016), it is not without potential challenges in LMIC settings. For instance, PC ownership in low-income areas remains limited (Calandro et al., 2012). A research report published by the Pew Research Centre in March 2015 estimated that one quarter or fewer of households in SSA owned a working computer (Pew Research Center, 2015). People living in low-income communities often also lack the technical skills or level of proficiency required to use PCs (Penard et al., 2015). Where PCs are available, they are often of low specifications and outdated models (Adjorlolo, 2015). In addition, electricity and internet infrastructure are often non-existing, or insufficient and unreliable (Adjorlolo, 2015). Where families have access to electricity and internet, it may be an expensive resource to them relative to their income and the resources required for food, housing, education and transport. Even for the most readily-available forms of technology, there are therefore questions around accessibility and affordability in LMIC settings.

1.4.2 Robotics

Robot-based interventions for ASD is a rapidly developing area of research in HICs, with a range of robots being developed for use in clinical settings (Giullian et al., 2010). Three main areas for the potential clinical use of robots for ASD have been identified. Firstly, to elicit target behaviours for diagnosis or therapy such as joint attention. Secondly, to teach and improve skills such as social interaction and communication (Kim et al., 2013), and thirdly, to reinforce or correct a skill during the learning process (Scassellati, 2007; Diehl et al., 2012; Boucenna, Anzalone et al., 2014).

The intended goal of the interactions influences the design of the robots, specifically the levels of realism and complexity of movements. Social robots (SR) can interact with humans through speech, gestures, or other media. Assistive robots (AR) on the other hand, can help and support people with disabilities (Scassellati et al., 2012). Socially-assistive robots (SAR) provide assistance through social, rather than physical interaction (Feil-Seifer and Mataric, 2005). These robots can track facial expressions and eye gaze and are being developed to teach individuals with ASD communication and social interaction skills (Kim et al., 2013; Dickstein-Fischer and Fischer, 2014). SAR act as social mediators that elicit social interactions between two or more people, or assume the role of a therapist by demonstrating appropriate social behaviour or even enabling children to express their feelings and desires (Scassellati et al., 2012). KASPAR (Kinesics and Synchronization in Personal Assistant Robotics) **(Figure 1.2)** is a humanoid SAR designed to mediate turn-taking behaviour in ASD therapy sessions to teach social interaction skills (Robins et al., 2009). Dickstein-Fischer et al. (2011) are developing a low-cost, compact, portable and user-friendly robot PABI (Penguin for Autism Behavioural Intervention) **(Figure 1.2)** for ASD behavioural therapy in school, clinic or home settings.

Researchers investigating SAR interventions for ASD typically report increased engagement and levels of attention when robots are part of the interaction, including individuals who routinely are unlikely or unwilling to interact socially with their healthcare provider and teachers (Scassellati, 2007; Diehl et al., 2012). Interactions with robots tend to be highly predictable and repetitive, and therefore suggested to be less stressful than face-to-face human interaction for many children with ASD (Dautenhahn and Werry, 2004). In some individuals, interacting with these robots elicit novel social behaviours such as joint attention and spontaneous imitation (Scassellati et al., 2012).

Studies testing the effectiveness of robots for ASD screening, diagnosis and treatment are limited, with variable results (Pennisi et al., 2016). Support for the use of robot-assisted interventions for ASD are mostly anecdotal and outcomes lack generalisation (Ricks and Colton, 2010). No studies to date have identified who among individuals with ASD may be best suited for interventions using robots, in which setting robots would be best used or how robots could best be incorporated with interventions for ASD (Boucenna, Narzisi et al., 2014). Robots are regarded by many investigators as a promising technological aid for ASD research and treatment (Pennisi et al., 2016). However, robots cannot operate autonomously and require skilled operators, they have very limited availability and their costs are substantial, ranging from several hundreds to upwards of thousands of U.S. dollars. Despite the clear scientific rationale and interesting examples developed in high-income settings, it is very difficult to imagine how this particular technology could easily become accessible and affordable in LMIC settings.

1.4.3 Virtual Reality

Advanced 3D computer graphics create a variety of simulated real-world training environments that are safe and repeatable, therefore especially well-suited as assessment and interventional technology for ASD (Parsons et al., 2004; Standen and Brown, 2005). These virtual environments (VEs) are inhabited by Avatars (an icon or figure representing a person in video games) or depictions of participants that interact with virtual objects by means of navigation-control devices (e.g. joystick and computer mouse) and natural user interfaces (physical gestures as a means of control). Interactions are displayed on a variety of Virtual Reality (VR) technology devices with differing levels of interactivity and immersion. Blue rooms (animations projected onto the walls and ceilings of a screened space), video headsets and goggles (e.g. Oculus Rift™) for example, provide a perceptually surrounded experience where the user feels enveloped by, included in, and interacting with the virtual scenes (Blascovich et al., 2002). Some of the most sophisticated systems also provide sensory feedback such as touch or motion. The realism of VEs causes people to act and respond in remarkably similar fashion as they would in real-world situations (Yee et al., 2007). Investigators suggest that skills learnt through VR training may therefore be better transferable to real life (Kandalaft et al., 2013).

VR technology applications for ASD mainly focus on developing the critical skills associated with independent living and employment. Interventions include improving social skills (Kandalaft et al., 2013), teaching individuals how to navigate and cross streets (Saiano et al., 2015), use public transport, find a table in a café or restaurant (Parsons et al., 2006), and VR job interview training to assist in gaining employment (Trepagnier et al., 2011; Irish, 2013; Smith et al., 2014). Virtual learning environments have been used for distance education to teach social and communication skills in low or under-resourced areas (Stichter et al., 2014).

Most interventions utilising VR technology are in early development and limited to mainly scientific assessment of persons with ASD in research labs (Grynszpan et al., 2014). Furthermore, not many studies to date have reported on generalisation of skills to real-world situations. Current state-of-the-art VR technologies require powerful computers with advanced specifications and access to high speed broadband internet. Cost and inadequate technological infrastructure therefore limit its use in most low-resourced communities (Stichter et al., 2014). In addition, it is not known how culturally acceptable VEs, the use avatars, or participating in VR-based activities would be for individuals who live in LMICs.

1.4.4 Shared Active Surfaces

Shared Active Surface (SAS) or Collaborative Interface (CI) technologies are large touch-screen computer-based interactive surfaces that can be placed on table tops and can be operated by more than one person simultaneously. Unlike smaller single user tablet computers such as iPads, these multi-user interactive technologies can be utilized to enhance social and collaborative face-to-face interaction among multiple users. In addition, these technologies are more forgiving of rough motor skills and imprecise manipulation, accommodating the varying motor abilities associated with ASD (Battocchi et al., 2010; Chen, 2012; Travers and Fefer, 2017).

The DiamondTouch (DT) and SMART Tables are large, multiple-user, multiple-input touch screen SAS devices developed for educational use. The CI technology recognises and keeps track of the actions of multiple participants (Dietz and Leigh, 2001; Travers and Fefer, 2017). Several published studies have documented the potential of using SAS technologies and cooperative games to improve social skills such as eye contact and sharing of emotions as well as showing interest toward a partner and collaborative play in children with ASD (Ben-Sasson et al., 2013; Bauminger-Zviely et al., 2013; Gal et al., 2015). Games included digital drawing and colouring (Travers and Fefer, 2017), puzzle building (Ben-Sasson et al., 2013) and collaborative story telling (Gal et al., 2009). “Join-In Suite” for DT is a practitioner-controlled cooperative game based on Cognitive Behavioural Therapy (CBT) intervention for social interaction and emotional expression difficulties. SIDES (Shared Interfaces to Develop Effective Social Skills) employed a four-player cooperative DT game to teach turn taking, attentive listening and negotiating skills (Piper et al., 2006).

SAS/CI technologies have only been investigated as potential interventions for ‘high-functioning’ individuals with ASD with average or above-average intellectual ability, without difficulties in motor coordination, verbal communication or visual motor integration, and mainly focussed on collaborative skills training (Chen, 2012). Multi-user surfaces such as DT are not easily transportable due to their size and weight. By its nature, touchscreen devices are not hardwearing and therefore very susceptible to damage that could render them unserviceable and very expensive to repair or replace. It is possible that this technology could be useful in very specific settings such as specialist schools or centres. However, they do not represent a very naturalistic opportunity for assessment or intervention for individuals with ASD. Taking together all these challenges, shared activity surfaces are unlikely to be feasible in the majority of LMIC settings where they will be neither affordable nor accessible and scalable.

1.4.5 Sensing Technologies

Sensing technologies for ASD include a variety of devices for tracking eye movement, physical activity, electro-dermal activity (EDA) as well as vocal prosody and speech detectors. Embedded in everyday accessories such as wrist watches, clothing, or ultra-thin adhesive epidermal patches, these sensors can measure a variety of parameters and collect specific data that can be used to identify symptoms specific to ASD.

Studies using eye-tracking technology have shown individuals with ASD prefer focussing on areas around a person's mouth rather than their eyes when looking at their face (Klin et al., 2002; Wesolowski et al., 2012; Constantino et al., 2017). Point-of-view cameras worn by an adult collect video footage of the child's eyes and face which can then be analysed to measure eye contact (Ye et al., 2012). Similarly, gaze tracking glasses worn by a child provide information about visual behaviour that, in turn, could be used to identify specific markers for early detection of ASD (Vidal et al., 2012).

EDA is used to measure stress levels in humans (Critchley, 2002). In addition to moisture collecting under the skin increasing electrical conductivity, the sympathetic nervous system also increases heart rate and pulse volume during times of stress and anxiety. People with ASD, especially those who are minimally verbal, often have sudden and unexpected episodes of agitated and disruptive behaviour, sometimes escalating to self-harm or harming those around them (Richards et al., 2012; Maskey et al., 2013). Detecting changes in heart rate, respiration rate, and EDA could communicate feelings of stress and anxiety prior to them engaging in and escalating these unwanted behaviours, allowing timely intervention (Goodwin et al., 2006).

3-Axis accelerometers are devices that measure movement. In wearable form, accelerometers can detect repetitive and stereotyped movements such as body rocking and hand flapping (Min and Tewfik, 2010; Goodwin et al., 2011). These behaviours can inhibit the development of appropriate social and adaptive behaviours, and can escalate into self-injurious behaviours (Richards et al., 2012). Devices capable of detecting these behaviours could give caregivers the opportunity to intervene early and prevent serious injury (Goodwin et al., 2011).

The *iCalm* is a wearable device capable of detecting and communicating heart rate, EDA, movement, and ambient temperature wirelessly (Fletcher et al., 2010). It is available commercially as the E4 wristband (Empatica, S.r.l., Milano, Italy). The developers of the device proposed that the ability to communicate internal state changes in naturalistic settings, may support persons with ASD to be better understood and supported by their family and caregivers.

Language delay and prosodic (intonation) differences in children with ASD compared to those with typical development (TD) children have been widely described (De Giacomo and Fombonne, 1998; Shriberg et al., 2001; Wetherby et al., 2004; Paul et al., 2005). LENA™ (Language ENvironment Analysis) is a device designed to observe the language development and the language environment of young children (Ford et al., 2008). It does so by combining a wearable audio recorder able to record up to 16 hours of a child's natural audio environment, with automated vocal analysis software that processes the auditory data. The software provides information about adult word count, child vocalization count, and conversational turn count as well as the amount of background noise, electronic sounds, meaningful speech, and silence which comprised the child's auditory environment. Automated screening using LENA™ can differentiate vocalisations from typically developing children and children with ASD or language delay (Oller et al., 2010), and has been suggested as an unobtrusive and objective automatic screening tool for ASD (Xu et al., 2009). However, it is less reliable when attempting to differentiate ASD from language delay (Oller et al., 2010). The system offers a reliable and efficient method for collecting data related to the language environment of the child in a variety of locations, and these data can effectively be utilised to assess language development, exposure to and participation in conversation and electronic media exposure (Warren et al., 2010; Dykstra et al., 2013; Burgess et al., 2013; Ambrose et al., 2014).

Sensing technologies are relatively expensive and typically require additional computer software and hardware, as well as highly skilled professionals to analyse and use collected data. Many wearable physiological and physical activity-sensing devices require direct contact with the skin and may not be tolerated by some children with ASD. To date, most studies involving LENA™ have been limited to high SES English speaking families (Ganek and Eriks-Brophy, 2016). Given the known impact of SES (and parental education levels) on language development outcomes (Hartas, 2011) as well as the limited studies involving languages other than English, the available evidence for expanding LENA™ to non-English speaking LMICs is insufficient. In Africa, for instance, many languages include clicking sounds, and it is not known how automated systems such as LENA would encode and analyse these language characteristics. Overall, despite the plausible rationale for the use of these sensing and wearable technologies, much further work will be required in LMIC settings to evaluate their feasibility.

1.4.6 Mobile Technologies/Portable Devices

Unlike specialised technologies designed for a specific use by targeted users, smartphones and tablets are not intrusive, are socially acceptable and offer a wide range of uses. Not surprisingly, persons with disabilities have found ways to utilise smartphones and tablets for their social or leisure pursuits, and to increase their independence (Kagohara et al., 2013; Stephenson and Limbrick, 2015).

Most people have readily adopted the "non-verbal" means of communication that mobile devices offer, especially those who have difficulty with, or are not able to communicate verbally. Today, most of us are familiar with "texting" or "tweeting" (Power and Power, 2004). Simple smartphone features such as tasks and address book applications can improve the independence of school-going young people with ASD (Gentry et al., 2010). In addition, there are many "Apps for ASD" available to purchase and download from iOS and Android App Store (www.autismspeaks.org/autism-apps). Proloquo2Go™ allows tablets to function as speech generating devices (King et al., 2014). *iCAN* is an App to assist teaching cognitive, language, and communication skills (Chien et al., 2015). "*My Daily Tasks"* is a video-based self-prompting and scheduling App designed to improve and expand daily living and vocational independence for people with ASD and is available in a variety of languages.

Many children with ASD enjoy playing computer games just as much as their TD peers (Kuo et al., 2014; Mazurek et al., 2015). 'Serious games' employ the core components of game design i.e. story line, goal and reward, to create enjoyable and captivating learning experiences for specific, challenging, and often unrewarding skills (Whyte et al., 2015). **"***CopyMe*" is a serious game designed to teach the player facial expression and emotion recognition skills using a touchscreen tablet (Tan et al., 2013). "*Zody*" is a collaborative serious game for teaching social relationship skills (Boyd et al., 2015). Recently, commercially available serious games combined with the touchscreen and kinematic features of tablets were shown to accurately identify motor patterns associated with ASD (Anzulewicz et al., 2016). Computational markers such as these could potentially be used to develop objective assessment tools for ASD. *"*Autism&Beyond*"* for example, is an iPhone App developed by a multi-disciplinary team at Duke University (Hashemi, Campbell et al., 2015) utilising computer vision algorithms that automatically detect and track facial landmarks to quantify a child's emotional reactions and attention to presented video stimuli (Hashemi, Qui et al., 2015).

The myriad of available Apps and games for people with ASD suggest smartphones and tablets may have endless possibilities for those who live with this disorder. However, serious games typically show little evidence of learning generalisation or improvement in psychosocial outcomes (Kientz et al., 2013). Most of the Apps available for ASD function as assistive technologies such as augmentative and alternative communication devices, skills training, or modelling programmes. Apps that are claiming to be screening tools for ASD usually are routine screening instruments such as the M-CHAT-R/F in electronic format adapted for smartphone operating systems, without any peer-reviewed corroborative studies about their accuracy (Al Mamun et al., 2016; Bardhan et al., 2016).

Mobile technology and its adaptation to improve the care of those living with ASD is promising, and the proliferation of mobile technology has given rise to a novel domain of healthcare referred to as mobile health or mHealth. However, published evidence supporting the effectiveness of mHealth interventions for ASD in general, and screening and diagnosis specifically, remain lacking. Despite these obvious concerns, smartphone technology using portable touchscreens are increasingly popular with parents of children with ASD and may be a valuable tool to use in screening, diagnosis, interventions, teaching and training as well as other aspects of research (Whyte et al., 2015).

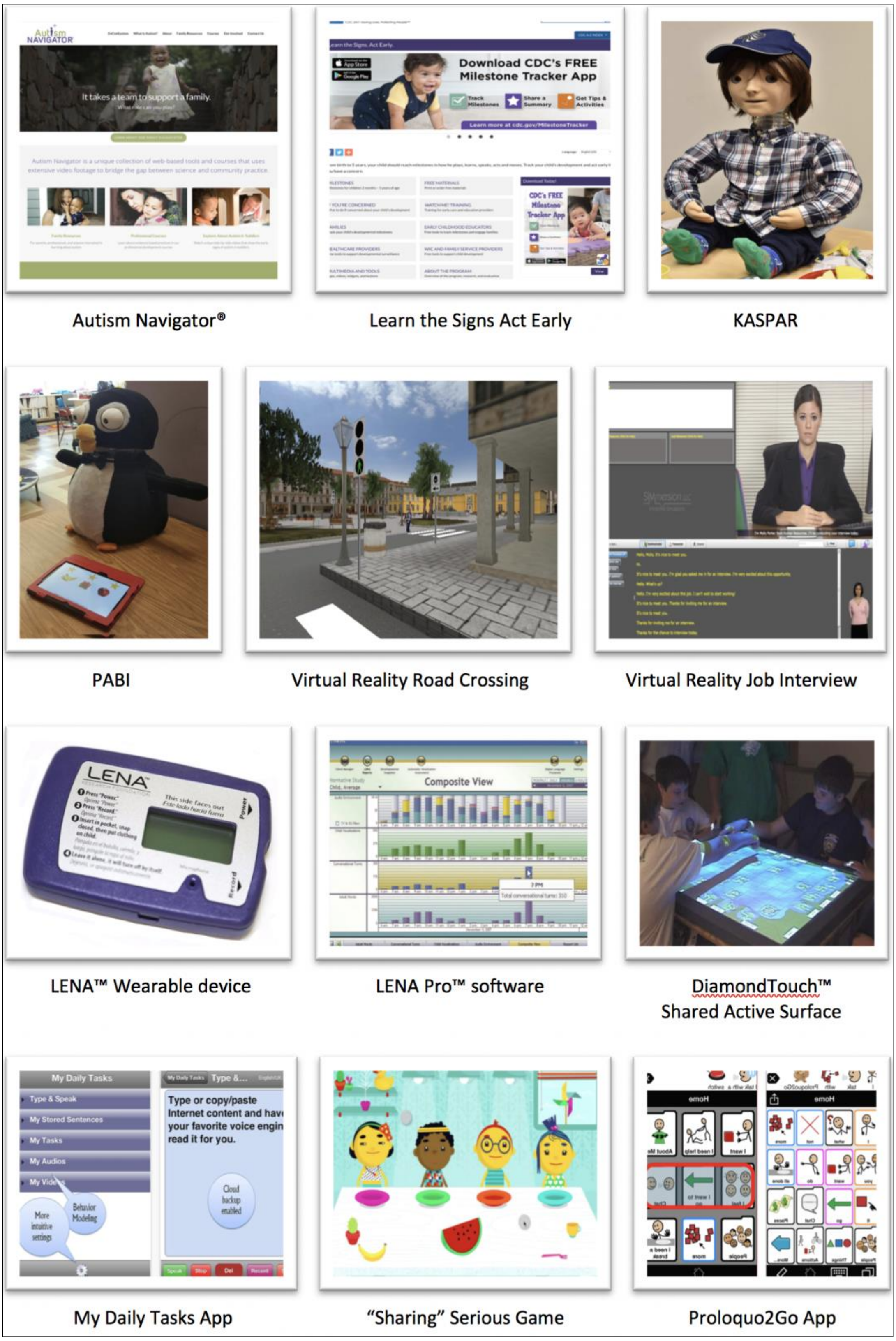

Figure 1.2 Examples of evidence-based technologies for Autism Spectrum Disorder

1.5 Challenges in the use of technology for Autism Spectrum Disorder in Low- and Middle-Income Countries

Efforts to utilise technology to address the practical challenges people affected by ASD face every day, are laudable and important. However, the global ASD community is culturally, linguistic, socio-economically and geographically immensely diverse. If our overarching goal is to address the disparities in access to ASD screening, diagnosis, and treatment in low- income settings using technology, these technologies need to be designed from the outset with this specific context, community and end-user in mind (Fletcher-Watson, 2014; Odom et al., 2014). In the examples listed above, we outlined a few of the potential challenges that different technologies may have in LMICs. The feasibility of the use of such technologies will depend on their accessibility, affordability, appropriateness, and scalability (de Vries, 2016). Here we will summarise some of the key implementation science considerations required for the 'scale-up' or 'scale-out' (Aarons et al., 2017) of technology in low-income environments. In **Table 1.1** we provide a summary of the technologies discussed, their relative costs and feasibility for use in LMICs.

1.5.1 Accessibility

The "digital divide" comprises gaps in physical access to ICT and the skills required to use these technologies (Dutta et al., 2015). Access to and usage of technology is typically associated with gender, level of education, literacy, urbanisation and socioeconomic status (Alozie and Akpan-Obong, 2017). In most LMICs, use of ICT is skewed towards young educated males of higher SES living in large towns or cities (Gomez, 2014; Wesolowski et al., 2015). Most technologies reviewed here, require access to reliable power supply. In SSA 60% of people and in South Asia 30% of people do not have access to electricity (State of Electricity Access Report (SEAR) 2017). In addition, health services such as remote consultations utilising interactive video conferencing (telemedicine) depend on access to a PC and reliable internet connection with sufficient speed and bandwidth. Fewer than 25% of households in SSA own a working computer, and even fewer connect to the internet using fixed (wired) broadband services (Gillwald, 2013). Access to PCs is becoming more widespread in LMICs as public access computing venues including libraries and Internet cafes are being set up in many towns and villages (Gomez, 2014). In many underserved communities in Africa, mobile phone sharing or informal telecentres, where mobile phones can be used for a fee, are also improving access to ICT services. Close to 70% of people living in the poorest 20% of households globally have access to and are familiar with mobile phones (The World Bank, 2016). Familiarity and proficiency with the technology are known to contribute to implementation success of technology-based healthcare initiatives (Zurovac et al., 2011; Zurovac et al., 2012). It therefore seems that smartphone technologies have a reasonable chance in low-income communities, but the actual access will need to be established within target communities.

1.5.2 Affordability

Of the technologies reviewed here, robots are by far the most expensive, ranging from several hundreds to upwards of thousands of U.S dollars, and typically require highly skilled technicians to operate and maintain them (Scassellati et al., 2012). Costs associated with purchasing and installation of specialist equipment, software licencing, training and maintenance are likely to limit or even preclude the use of most technology platforms in low- and middle-income community settings (Weiss et al., 2014). In most LMICs the internet connection speed and bandwidth required for technologies like telemedicine, IVC and VR are typically only available in large cities and up to four times more expensive than in HICs (International Telecommunication Union (ITU), 2016). It is also cheaper to access the internet using pre-paid mobile broadband data than fixed broadband services (International Telecommunication Union (ITU), 2016) in these countries. Given the lower cost of smartphones and greater access to cheaper mobile broadband services, an estimated 6 billion people worldwide will be connecting to broadband internet services using their smartphones by 2020, 80% of whom will be from LMICs (Groupe Spéciale Mobile Association (GSMA), 2015). Kumar et al. (2016) reported that in Kenya with an estimated population of 44 million people, 88% of people have access to a mobile phone and use it to access the internet 99% of the time. Therefore, it is conceivable to imagine that mHealth-based service delivery models could offer promising means for increasing access to ASD screening, diagnosis, and treatment in low-income settings.

1.5.3 Acceptability and Cultural Appropriateness

Telemedicine can virtually transport specialist clinicians to meet with families in their homes in low-resourced communities where in-person care is not available. However, telemedicine may not be acceptable to all. Some cultural groups do not allow any photography or video recordings of people at all (Boujarwah et al., 2011). Similarly, in some cultures it is not acceptable for females to use mobile phones in public areas (Wei and Kolko, 2005). Cultural beliefs often limit the adoption and use of technologies in LMICs (Bartneck et al., 2007; Rojas-Méndez et al., 2017). Many investigators of mHealth have highlighted the fact that access to mobile phones do not necessarily mean ownership of the device (Kumar et al., 2016). Sharing of or paying for mobile phone use is common practice and important in many African societies (Wesolowski et al., 2012). Ethical issues around confidentiality of health information and stigma therefore need careful consideration when determining if such services are appropriate (Kaplan, 2006). However, given the increasing availability of cheaper mobile phones, the practice of sharing seems to be declining (Wesolowski et al., 2015; Kumar et al., 2016). Engaging the intended end-user community early, will facilitate addressing local cultural, as well as practical challenges which may impede successful implementation (Grinker et al., 2012; Pickard et al., 2016).

1.5.4 Scalability

Technology can potentially address several challenges for people with ASD who live in LMICs. Successful use of such tools will depend on it being effective, acceptable, affordable and – importantly – have the capacity to reach individuals in under-served areas and to be applied on a large scale in a variety of settings (Kazdin and Rabbitt, 2013). A very overt aim of technology in health should therefore be to reach people wherever they are. Enabling community participation can further build capacity by increasing the number of people who can deliver services to those in need (Patel et al., 2008). Technology best suited to achieve this in LMICs globally, would have to be familiar and widely used, not dependent on uninterrupted electricity supply, and be able to receive and send information effectively and at low cost from almost anywhere. Advanced technologies such as VR and robotics typically require highly skilled people to operate and maintain them, as well as reliable and powerful internet and electricity infrastructure. Very high procurement and service costs are additional and important barriers to their widespread use. PCs are accessible to many people in LMICs and telemedicine is gaining traction as a novel means of providing services to those in need who live in areas not well served by healthcare professionals. Mobile phones today can perform most of the functions traditionally done on PCs. Accessing the internet via widely available mobile broadband services, using solar powered batteries to recharge the mobile phone's power supply, sharing of phones or informal telecentres are just some of the ways in which mobile phones overcome many of the unique challenges regarding access, faced in LMICs. The evolution of mobile technology, the ever-expanding mobile broadband network as well as phones and data becoming more affordable, gives mobile health (mHealth) the potential to substantially increase the reach of mental health services to those in need.

Table 1.1 Evidence-based technologies for Autism Spectrum Disorder

	Technology					
	Robotics	Virtual Reality	Shared Active Surfaces	Wearable Technology	Personal Computers	Mobile Technologies
Relative Cost in $100s-$100 000s	$$-$$$$	$-$$$	$$-$$$	$-$$	$-$$	<$
User	R C/T	R C/T E PA	R C/T E	R C/T E PA F/C	R C/T E PA F/C	R C/T E PA F/C
Setting	RF Cl	RF Cl S H	RF Cl S	RF Cl S W H Co	RF Cl S W H	RF Cl S W H Co
Purpose	I/E	D/S I/E A	I/E	D/S I	D/S I/E A	D/S I/E A
Feasibility in LMIC/Low-resource settings	Very Low	Low - Medium	Low - Medium	Low - Medium	High	Very High

R researcher; **C/T** clinician/therapist; **E** educator; **PA** person with ASD; **F/C** family/carer **RF** research facility; **Cl** clinic; **S** school; **W** work; **H** home; **Co** community **I/E** intervention and education; **D/S** diagnosis and screening; **A** functional or scientific assessment

1.6 Conclusion

Evidence-based technologies for ASD can play a tremendous role in ensuring that the majority of people living in under-served areas have timely access to appropriate services and support. In this chapter, we set out to review a range of technologies that have been explored for use in ASD identification and rehabilitation, and to reflect on their potential application in LMIC settings. The research reported in this review suggests that technology may provide the tools needed to ameliorate the knowledge and treatment gap in LMICs. However, the feasibility of the use of such technologies in LMICs will depend on the fundamental principles of affordability, accessibility, acceptability and cultural appropriateness. These will determine the likely scale-up (increasing the reach in the community of interest) and scale-out (expanding the reach to new or different communities) (Aarons et al., 2017).

Given the widespread usage of mobile and smartphones and the increasing availability of affordable high speed mobile internet access in the majority of LMICs, mHealth may have the potential to increase access to ASD screening, diagnosis and treatment globally. There is, however, a striking difference between the large number of Apps available for public download and the small number of tested, evidence-based Apps. To our knowledge, there are no Apps for ASD to date that have been evaluated specifically for a LMIC setting. To address the disparities in access to ASD screening, diagnosis, and treatment in low-resource settings using technology, research will be required to establish the feasibility of using mobile applications to provide access to quality metal health services and care to the culturally, linguistic, socio-economically and geographically diverse global ASD community.

Chapter 2

Autism&Beyond: The South African feasibility study

2.1 Background to the Study

As outlined in Chapter 1, most people with ASD live in Low- and Middle-Income Countries (LMICs) where access to early identification, treatment and expertise is very limited. Technology is increasingly seen as a potential tool to reach individuals in low-resource communities. A growing number of technologies have been developed and are under investigation in High-Income Countries (HICs). Very few, if any, have been evaluated in LMIC settings. However, there are many potential implementation science challenges to scale-out (expanding the reach to new or different communities) and scale-up (increasing the reach in the community of interest). For instance, in the scale-out of technology from HICs to LMICs, careful consideration should be given to aspects such as appropriateness for the setting (e.g. language and culture), affordability and accessibility. Given the real potential of specifically mobile phone-based technology, we were keen to perform an empirical feasibility study of a USA-developed App in a low-resource South African Environment.

2.1.1 Autism&Beyond – A ResearchKit App

The ResearchKit App Autism&Beyond was developed and launched as a population-based study by a multi-disciplinary team of researchers at Duke University (Durham, North Carolina). ResearchKit® (http://researchkit.org) is an open source framework created by Apple® to encourage researchers and developers to create iOS® (iPhone Operating System) Apps for medical research. The ResearchKit® tools allow for in-app informed consent, real-time dynamic active tasks, and surveys. Approved ResearchKit® Apps can then be shared with the community via the Apple® App Store.

The objective of the Duke University ResearchKit® Autism&Beyond study was to create and test a mobile application as a potential self-administered screening tool to identify children at risk of ASD and other developmental difficulties. The aim was therefore to have an App that could do remote collection of specific questionnaire data, observational video data of a child reacting to various video stimuli while in his/her natural environment, and automated coding of the observational video data. The App was designed to incorporate demographic questionnaires - a report survey about parental concerns about their child's development, emotions, and behaviours, a three-question Duke Temper Tantrum Screen, and a digital version of the full Modified Checklist for Autism in Toddlers Revised including follow-up questions (M-CHAT-R/F). The M-CHAT-R/F is a widely used questionnaire-based screening tool for ASD in children aged between 16 and 30 months (Robins et al., 2001). The Autism&Beyond App was designed so that parents of children outside of that age window (based on mandatory child date of birth response field reported in the demographic section) would not be asked to complete the M-CHAT-R/F. In addition to the in-app questionnaires, three short video stimuli (Bubbles, Bunny and Toys & Rhymes) and a mirror stimulus were incorporated into the App **(Figure 2.1)**. These stimuli were presented to children in the designated age range by their parents with the aim of eliciting positive emotional and social responses, as well as attention. Using the front facing ('selfie') camera on the mobile device, video images of the child were recorded during the stimulus presentation and saved at 640 x 480 resolution and at 15 frames per second. Computer vision algorithms automatically detected and tracked multiple facial landmarks around the eyes, nose, and mouth (Hashemi, Campbell et al., 2015). From the tracked facial landmark locations **(Figure 2.2)**, multiple characteristics including head position, facial emotional classification, and blink rate **(Figure 2.3)** were gathered. Responses to stimuli were analysed individually to determine the emotional responses elicited by each stimulus. Previous studies have shown that individuals with ASD produce atypical facial emotional expressions (Grossman and Tager-Flusberg, 2012; Brewer et al., 2016), particularly when attempting to express positive emotion (Faso et al., 2014). Impairments in attention are seen from an early age, and persists throughout life (Keehn et al., 2013; Chawarska et al., 2016). Facial expressions were classified as being neutral, positive (happy), or negative (anger, disgust, and sad) (Hashemi, Qui et al., 2015). A pre-defined change in head position indicated loss of attention to the mobile phone screen.

Figure 2.1 Bubble, Bunny, Toys&Rhymes and Mirror stimuli of the Autism&Beyond App designed to elicit positive social and emotional responses and attention

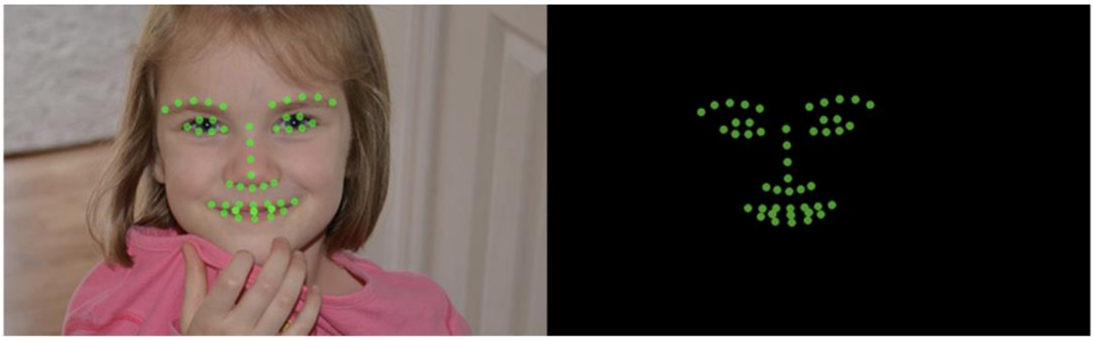

Figure 2.2 Computer vision algorithms automatically detect and track multiple facial landmarks around the eyes, nose, and mouth to determine head position and classify facial emotional expression

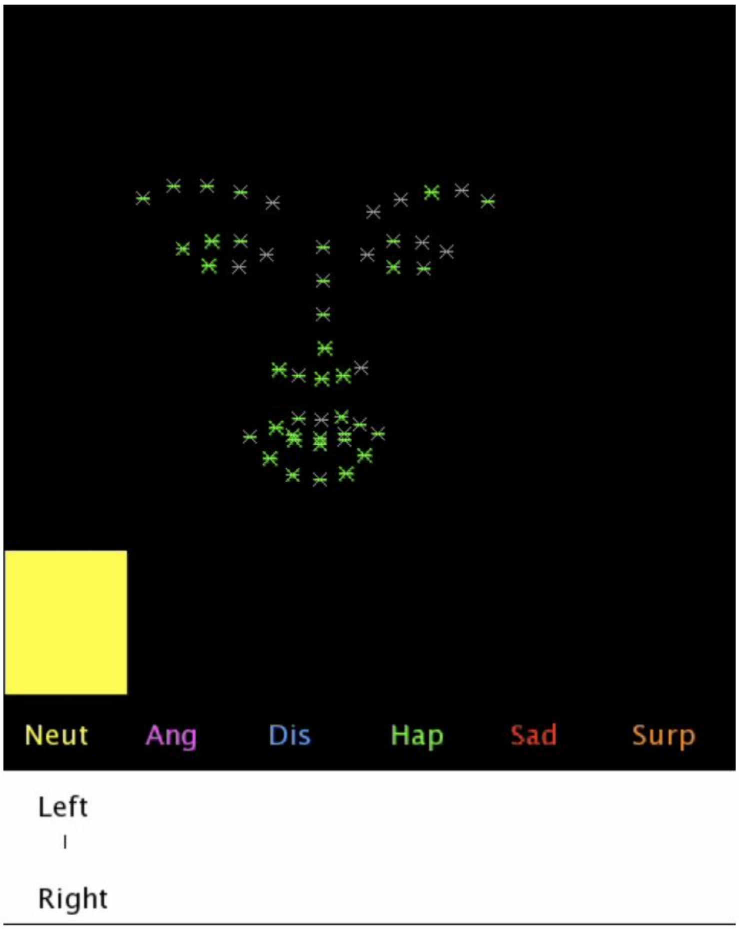

Figure 2.3 Automatic classifier codes emotional expression [Neutral (Neut), Anger (Ang), Distress (Dis), Happy (Hap), Sad, Surprise (Surp)] and head position (left and right) by detecting and tracking specific facial landmarks in response to the video stimuli

Duke University carried out a technical validity and feasibility study of the App prior to it being made available to the public (Hashemi, Campbell et al., 2015). Parents of children visiting a paediatric care clinic for an 18 or 24-month well-child examination were approached at the end of their visit, after the child had undergone routine screening for ASD. Data were collected from 47 children in total, 20 of whom (16 - 30 months old) were selected to participate in the study. The selected subjects included both children with typical development (TD) and children who received a formal diagnosis of Autism Spectrum Disorder (ASD) from a child psychologist, including using the Autism Diagnostic Observation Schedule – Toddler Module (ADOS-T) (Lord et al., 2012). The 20 participants were shown video stimuli on an iPad while sitting on a parent's lap. The user facing camera of the iPad recorded video footage of the child's behaviours in real-time. Automated computer vision algorithms coded emotions and social referencing to quantify ASD risk behaviours. The researchers validated the automatic computer coding by comparing the computer-generated analysis of facial expression and social referencing to human coding of these behaviours. Results of the study suggested good agreement (mean 75%, range 30-96%) between the coder and the automatic classifier. The study demonstrated that it was feasible to show children video stimuli and collect usable data on a mobile device in a paediatric clinic, and that observational behaviours used to indicate possible risk for ASD could be elicited and automatically quantified with the App (Hashemi et al., 2017). Given that children are likely to respond differently in their home or at school, the study was expanded to include these settings.

Following the feasibility study, the Autism&Beyond App was made available free of charge on the Apple App store in the USA. The broader Autism&Beyond study aimed firstly, to determine if large-scale survey and video data could be collected in naturalistic settings that were of sufficient quality for analysis; secondly, to perform correlational analyses between rating scale and facial expression data; and thirdly, to evaluate test-retest reliability of measures by repeating some assessments at intervals. The study had an open enrolment to any USA-based parent of a child aged between 12 and 72 months who had an iPhone and access to the Apple App Store.

Presenting their results at the International Meeting for Autism Research in San Francisco California (Egger et al., 2017), the researchers reported that in the first six months of the study, close to 900 families downloaded the study App, consented to participate, and completed the study tasks in their homes. The results of the study suggested that it was feasible to collect and automatically classify video stimuli data at scale (Hashemi et al., 2017) and that it was possible to identify differences between children with and without a high risk for ASD (Egger et al., 2017).

2.1.2 The need for an Autism&Beyond feasibility study in a LMIC setting

As outlined above, the conceptual idea of the USA study was to determine whether responsive facial expression data could be used validly and reliably as a proxy risk marker for ASD. The majority of children with ASD live in Low- and Middle-Income Countries (LMICs), where resources for screening, diagnosis and intervention are very limited (Saxena et al., 2007; de Vries, 2016; Franz et al., 2017). In Chapter 1 we discussed the potential value of technology in low-resource environments such as in LMICs. We concluded that mobile-based technologies appeared to have the greatest likelihood of being useful in LMICs, but we also pointed out a range of feasibility challenges in LMICs that have not been considered for most technologies to date.

It was therefore clear that a logical next step for the Autism&Beyond App would be to perform a feasibility study in a LMIC setting. We selected South Africa as the site for the first feasibility evaluation for a number of reasons. Firstly, no previous feasibility of this or any other App for ASD has been performed in an African setting, and it was therefore unknown what the technical feasibility would be for families who live in low-resource environments to complete an iPhone-based App. For instance, it was not known how familiar families would be with iPhones, with Apps or with the internet, or how much access they would have to these resources. Secondly, the automated coding of facial expressions incorporated into the Autism&Beyond App was developed using mixed, but predominantly Caucasian facial landmarks. It was therefore not known whether automated coding algorithms would be sufficiently accurate at classification of facial expressions using non-Caucasian landmarks. Thirdly, it was not known whether non-USA children would show similar attention and emotional expression in response to the stimuli included in the App. Fourthly, it was not known whether families would find this approach acceptable in a local cultural context. For instance, most low-resourced South African families hold pluralistic beliefs about supernatural and 'medical' causes of ASD (Franz et al., 2017) and video recordings of children's faces may therefore not be deemed culturally appropriate. Finally, it was not known what localisation may be required to make a USA-developed App applicable in a South African setting. For instance, it was not known to what extent the language of the App was clear and understandable in a South African setting. We therefore set out to evaluate these aspects of feasibility in a low-resource South African setting to address some of the unanswered questions.

2.1.3 Aims of the study

A. Technical Feasibility:

To determine the technical feasibility of a smartphone application for measuring ASD risk behaviours in children, aged 12 - 72 months, in a naturalistic South African community setting.

1. Ascertain smartphone and internet accessibility, proficiency and use.
2. Determine if the quality of video obtained in home recordings collected on iPhones would be sufficient for automatic behavioural encoding as needed for early childhood ASD screening.
3. Evaluate the reliability of the automated computer vision algorithms to code emotions and attention on African face datasets collected in a low-resource South African community setting.
4. Determine if the video clips designed and developed by researchers in the USA to elicit shared enjoyment and attention would elicit the same emotional responses in African children.

B. Accessibility, Acceptability and Cultural Appropriateness:

To determine the accessibility, acceptability and appropriateness of the smartphone app for measuring ASD risk behaviours in young African children in a South African community setting.

1. Ascertain parental attitudes and views about the accessibility, acceptability and cultural appropriateness of the App, including content of the App, digital modality of the observational assessments for young children, appropriateness of uploading a video recording of their child, and likelihood of use in their local community.

2. Ascertain the content and information of the App that may require ‘localisation’ to a South African context.

2.1.4 Hypotheses

We predicted that most parents living in a South African low-income community would not have access to internet enabled smartphones that were capable of downloading applications and recording videos, that they typically would not be familiar with and proficient in using such phones, and that they were not likely to have access to mobile-based broadband internet. Furthermore, we hypothesised that the quality of the video obtained in home recordings using study smartphones would be sufficient for automatic coding of facial expressions, that the automated computer algorithm would accurately classify facial emotional responses and attention to video stimuli in South African children and that the video stimuli would elicit similar emotional reactions and attention to age- and gender-matched children living in the USA. We also predicted that the smartphone App may not be universally acceptable or be deemed appropriate across cultures and that some app content would require localisation.

2.2 Methods

2.2.1 Design

The South African feasibility study implemented a mixed-methods design, collecting both quantitative and qualitative data from participants in 2 stages. In Stage 1 we used a quantitative study design similar to the primary Duke study (Hashemi, Campbell et al., 2015). In–app electronic surveys collected demographic data about the child and family **(Appendix 1a)**, as well as data about the concerns parents had about their child’s development, emotions, and behaviours **(Appendix 1b and 1c)**. In addition, parents of children aged between 16 and 30 months completed the electronic M-CHAT-R in the App. Videos were presented to participants in standard sequence and recorded data were uploaded upon completion of all videos (see **Appendix 2** for in-app screenshots). Automated coding on a subset of the uploaded video data were compared with human coding to determine reliability of the automated coding algorithm on the South African dataset. To determine whether the video stimuli would elicit the same emotional reactions and attention in South African children as in American children, results of the automated coding of the South African dataset were compared to an age- and gender-matched dataset from the USA Autism&Beyond ResearchKit study. Given that our study was an early-phase feasibility study, we did not perform any test-retest reliability of measures. Instead, participants were asked to provide feedback about their access to, proficiency with and use of smartphones and the internet by completing a simple technology questionnaire **(Appendix 3)**.

In Stage 2, we collected qualitative data using focus groups of participants from Stage 1. A subset of participant parent/carers were invited to provide in-depth qualitative feedback about the technology and content of the App, and to determine the information that required localisation to a South African context. Focus group discussions were held 5 weeks after Stage 1 data collection was completed.

2.2.2 Research Site

The project was conducted at the Division of Child & Adolescent Psychiatry at the University of Cape Town, South Africa in collaboration with Duke University (Durham, N.C). Stage 1 and Stage 2 data were collected from participants in a typical private dwelling in the Khayelitsha township, Cape Town. To maintain confidentiality, data collection took place in a private space within the home. Khayelitsha means ‘new home’ in isiXhosa and is situated approximately 30 kilometres from the Cape Town city centre. With a total population of just under 400 000 (Statistics South Africa (SSA), 2012), it is the second largest township in South Africa after Soweto in Johannesburg. It was officially established in 1983 to resettle African residents from the Western Cape. Most people live in informal housing or shanties. According to the Affordable Land and Housing Data Centre (2012) approximately one third of families live in formal housing. Built houses are typically small (less than $60m^2$) consisting of a family room, kitchen and two bedrooms. Seventy-five percent of families have access to electricity for cooking purposes, but only 35% of families have piped water inside their dwelling. At least two thirds of households have an average income of less than R3600 (equivalent to ~$300) per month (Western Cape Government, 2016).

2.2.3 Participants

For Stage 1, participants were recruited from local community centres and churches through word-of-mouth. To be eligible for the study, participants had to be at least 18 years of age, resident in the Khayelitsha township, Cape Town, and be the parent or legal guardian of a child who was between 12 and 72 months of age. No restrictions were placed on the sample in terms of gender. Local community members were approached and asked if they were interested in participating. We deliberately recruited participants whose first language was not English. However, participants had to have a sufficient understanding of English to allow participation. The study set out to recruit a total of 50 children and their parents/legal guardians for Stage 1 data collection.

For Stage 2 (focus groups), the study employed representative convenience sampling of parents/legal guardians who participated in Stage 1. We therefore invited two groups of 7 (N=14) suitable participants to the focus groups. Here, participants were deliberately selected to represent the diverse range of socio-demographic, cultural and language variables of the community.

2.2.4 Procedures

Participants (parent or legal guardian of the child) provided informed consent by first signing a paper-based informed consent document **(Appendix 4)** followed by a self-guided in-app electronic consent process **(Appendix 5)**. After the initial informed consent was obtained, participants were asked to complete a simple technology questionnaire **(Appendix 3)** prior to launching the App. Participants were then handed a study iPhone to access the Autism&Beyond App. Once opened, the App started with an overview and introduction section. The overview included a demonstration of the video component of the study, allowing the participants to see the type of video data collected in the study (see **Appendix 2** for in-app screenshots) before proceeding. Participants were then prompted to verify inclusion criteria for the study. This was done by answering five yes/no questions (see **Appendix 2** for in-app screenshots). Participants had to answer “yes” to all five questions to be eligible to participate in this study and proceed to the consent portion of the App. After in-app electronic consent was obtained, participants were able to access the study activities of the App (i.e.

dashboard). The in-app activities of the study consisted of (i) demographic questionnaire **(Appendix 1a)**; (ii) parental concern survey **(Appendix 1b)**; (iii) Duke Temper Tantrum Screen **(Appendix 1c)**; (iv) M-CHAT-RF questionnaire; and (v) video assessment.

Focus groups were held 5 weeks after quantitative data collection to gather in-depth qualitative feedback about the technology and content of the App, and to determine the information that required localisation to a South African context. Focus group participants were requested to read an information sheet and a written consent form before taking part **(Appendix 6)**. To protect anonymity, only first names were used. Open-ended questions were asked to guide the focus group discussion. Each focus group discussion was digitally audio recorded and transcribed verbatim. An assistant was present and took notes as a back-up, should any of the recording devices fail to record. An isiXhosa speaking co-facilitator was present to ensure adequate language coverage in the focus groups. The focus group data were transcribed into English for subsequent analysis. isiXhosa and Afrikaans data were transcribed in the original language and translated into English.

2.2.5 Ethical considerations

This South African sub-study was conducted in compliance with the Declaration of Helsinki. The protocol was peer-reviewed in the Department of Psychiatry at the University of Cape Town and submitted for Ethical approval at the Faculty of Health Sciences, Human Research Ethics Committee (Ethics Ref: 596/2016) **(Appendix 7a and 7b)**, Red Cross War Memorial Children's Hospital **(Appendix 7c)**, as well as Duke Institutional Review Board (IRB) **(Appendix 7d and 7e)**. This was a minimal risk study to parents/legal guardians and their children who participated in this study. Messaging within the App instructed parents/guardians that if their child did not want to participate or became upset during participation, they should stop and either try again later or opt out of the video assessment portion of the study. Participants were supported by two researchers during the process and participants were informed that they could end their participation in the study at any time and without any penalty.

Stage 1 data collection was done in a private space with the researcher present to facilitate parents to administer the App with their child. A unique login ID and password for access to the App on the study iPhone was created for each participant. All data collected in the App were transmitted to servers at Duke University via encrypted transmission. The electronic data were stored on servers that reside with Duke Health Technology Services. Participants were informed that they could request for all their data to be removed at any stage. The consent process entailed a paper-based informed consent document **(Appendix 4)** followed by a self-guided in-app electronic consent process **(Appendix 5)**. The in-app consent was designed to explain the nature and procedures of the study and cover all the elements of informed consent. It involved 3 consecutive steps: (i) brief introduction screen, (ii) learn more screen, and (iii) full consent (see **Appendix 2** for in-app screenshots and **Appendix 5**). All participant parents/legal guardians were required to sign both the written and electronic consent forms for themselves and their children. The signed in-app electronic consent forms were automatically transmitted to the Duke servers and a copy emailed to a secure study email address associated with the participant during the in-app consent process. Given that the children were all under 6 years of age, assent was not sought. However, parents/guardians were informed that should any child object to participating in any part of the protocol or became distressed, the assessments could be stopped.

Focus group (Stage 2) data were collected on digital recording devices for transcription and analysis. Focus groups took place in a private room and recorded data were only made available to the research team. Transcribed data were anonymised and will never be linked to specific participants. Participants were asked to maintain confidentiality with other focus group participants but were also advised that such confidentiality could not be guaranteed. A paper-based informed consent document **(Appendix 6)** designed to explain the nature and procedures of Stage 2 of the study and covering all the elements of informed consent had to be signed by all participants.

Participants received a supermarket voucher to the value of ZAR100 (~$10) as token of gratitude for their participation in Stage 1. A further R100 voucher was given to each of the participants who participated in the focus groups.

2.2.6 Measures

Several quantitative and qualitative measures were obtained. Some of these were built-in to the Autism&Beyond App, and others were constructed specifically for the South African feasibility study (technology survey and focus group guide questions). This study did not attempt to adapt, translate or validate the study measures contained within the App for a South African context.

2.2.6.1 In-app demographic questionnaire **(Appendix 1a)**

This questionnaire was built-in to the Autism&Beyond ResearchKit App and collected demographic data from participants. No changes were made to this survey for the South African feasibility pilot study. A mandatory 'date of birth' field established eligibility to take part in the study. If the child was determined to be younger than 12 months or older than 72 months, access to the activities part of the study was denied.

2.2.6.2. In-app parental questionnaires about their child's behaviour **(Appendix 1b and 1c)** – not used in this study

The parental concern survey, Duke Temper Tantrum Screen and M-CHAT questionnaire were all designed to collect information about a child's development and behaviour from participants electronically. Tantrums are common in early childhood and often a concern for parents (Potegal, 2003). The Modified Checklist for Autism in Toddlers (M-CHAT) is one of the most widely used screening tools for ASD in children aged 16 – 30 months globally (Robins et al., 2001). The revised version (M-CHAT-R) contained within the App, consisted of 20 yes/no questions and usually takes around 5 minutes to complete (Robins et al., 2014). Children who screen positive, i.e. at risk for ASD, are usually referred to a child mental health professional for follow-up questions (M-CHAT-R/F) and assessment. Participants in the South African study were also asked to complete these questionnaires. Given that the questionnaires contained within the Autism&Beyond ResearchKit App have not been validated for use in a South African context, results could not be passed on to the parent/legal guardian participants of the South African study. Given that the purpose of this study did not include any validation of the M-CHAT-R/F or other questionnaires, these were not included in this study for further analysis.

2.2.6.3. Tickbox technology survey **(Appendix 3)**

This questionnaire was constructed to collect information about participants' mobile phone ownership and usage, social media participation, use of email and the internet, and their proficiency using a mobile phone.

2.2.6 4. Video assessment

For the video portion of the study, the child was asked to sit on their parent's lap or a chair with a study iPhone positioned at eye level for the child and in such a way that the child's entire face was captured on the screen. A circle on the screen guided the participant to correctly position the phone in relation to the child. Participants were asked to remain quiet and not direct the child's attention or behaviour once the video stimuli began, unless the child became distressed or attempted to leave. The child was shown three videos and a mirror image, each of approximately 30 seconds in duration. Videos were viewed in the order they appeared in the App. A researcher was present to support the participant with the iPhone and App. The user facing ("selfie") camera in the iPhone recorded video footage throughout the stimuli presentations and saved it at 15 frames per second (fps) and 640 x 480 resolution. While the user facing camera on the device recorded the video of the child, computer vision software for facial analytics extracted features around specific regions of the mouth, nose and eyes to classify facial expressions and track changes in head position **(Figure 2.2)**. The algorithm automatically returned a "not visible" tag on individual frames where sufficient landmarks for analysis were not present, e.g. the child's face not being completely visible and/or the position of the head is such that both eyes are not visible at any one time. In addition, video data for each stimulus were only regarded sufficient for emotional coding if the child attended to the video stimulus for at least 50% of the time. Parents/carers could choose to consent to upload of full-face or non-identifiable facial landmarks only video data (see **Appendix 2** for in-app screenshots). The videos were uploaded as encrypted files and securely transmitted to servers located at Duke University.

2.2.6.5 Focus group guide questions

Four open-ended questions were used to guide qualitative discussions **(Appendix 8)**. These included a question on the ease of use (“Thinking back to when you used the Autism&Beyond iPhone App, how did you find using the App? Do you think people in your community would find it easy or difficult if they were to use the App?”), on the accessibility of the technology (“How many of you would use this App if it was available? How many people in your community would use it? Who would not use it? Why?”), on the acceptability of the App (“Do you think a smartphone App like the one we used would be acceptable to people in your community? What would be unacceptable or worrying to people about the App?”), and on localisation required (“Referring to the questionnaires you had to answer in the App (on the phone) about your family background, tell us what you think about the questions and choice of answers given on the form.”).

2.3 Data analysis

2.3.1 Quantitative data

Descriptive statistics were generated for sample demographics and dependent variables of interest in the South Africa sample.

2.3.1.1 Demographics

Basic descriptive statistics regarding the gender, language, relation to the child, marital status, highest level of education and employment status of adult participants. Demographic information regarding the children who participated in the study included only age and sex. This data was collected via self-report in the electronic socio-demographic questionnaire contained in the App.

2.3.1.2 Technology questionnaire

Data collected from the completed technology questionnaires were analysed for frequency measures of mobile phone ownership, proficiency and usage, access to and usage of the internet and smartphone applications.

2.3.1.3 Recorded video data

A. Reliability of the automated computer vision algorithms (Inter-rater reliability)

Statistical analyses and generation of figures were carried out in R, using the packages psych, XLConnect, dplyr, ggplot2, Matching, and ICC.Sample.Size (R Core Team, 2014; Revelle, 2014; Wickham and Francois, 2015).

To determine reliability of the automated coding algorithm on the non-Caucasian South African dataset, we compared automated coding with human coding on a subset of the video data. Power calculations were performed for human vs computer rating prior to human coding of videos. The pilot study undertaken in the USA reported human-computer reliability intra-class correlation (ICC) of 0.89 (95% CI 0.77-0.94) (Hashemi, Campbell et al., 2015). Therefore, to be comparable to the USA pilot study, minimum acceptable human-computer reliability level was chosen to be ICC = 0.77. Two-way consistency average-measure ICC on the total sample of 37 subjects from South Africa determined the minimum sample to be 8 (20%) to achieve adequate power to detect reliability. The human rater therefore coded 9 subjects to ensure adequate power.

Emotional classification of facial expression was based on the use of anatomic units from the Baby Facial Action Coding System (Baby-FACS). Baby-FACS is a modification of the Facial Action Coding System (FACS) for infants and young children, a human-observer- based system designed to detect subtle anatomical changes in facial expression. Facial expression was only rated as positive, negative, or neutral to maximize reliability and generalisability (Camras et al., 2002). Previously published studies have shown that observers can classify these emotions in young children with high accuracy (Oster et al., 1992; Hashemi, Campbell et al., 2015). Applying the methodology used by Hashemi, Campbell et al. (2015) (see **Appendix 9** for Coding manual) we coded positive emotion expression or smiling when the zygomaticus major muscle pulled the lip corners of the mouth upward or if the cheeks were elevated (laughing was included). Negative emotion was coded when the action of the corrugator supercilli muscle lowered the brow, with or without horizontal lip stretching and with or without mouth opening (crying was included). Where none of these muscle movements were present, a neutral coding was assigned. Instances where not enough of the face was visible to determine facial expression, when the child moved too fast to reliably identify an expression, or when the child turned his/her face by 90 degrees (i.e. away from the FaceTime HD camera), we assigned the code 'not visible'. Coding was done in Noldus Observer XT software version 11.0 (Noldus Information Technology, 2015). The researcher travelled to Duke University, Durham, NC, USA and first trained on a reliability dataset until agreement greater than 75% with the training dataset was reached. The researcher then coded video data from 9 randomly selected participants from the complete South African dataset of subjects for manual coding. We used an online list randomiser (www.Random.org) to select the video data for manual coding. A trained and experienced rater from Duke University coded a randomly selected subset of the coded dataset to verify inter-rater reliability. Raters were blind to stimuli and videos were muted during coding to prevent the influence of vocalisations on the coding of facial expression. Inter-rater agreement for total time when raters gave the same code to a behaviour was 94% (86%-95% range).

Next we compared coding of the automatic classifier with human coding. Automatic coding for facial analytics rely on state-of-the-art computer vision algorithms extracting features around specific regions on a face, such as the mouth, eyes, and nose for analysis and coding of expression as well as head position (Sandbach et al., 2012). IntraFace (IF) is a publicly available software package for automated facial analysis (Human Sensing Laboratory). The facial expression classifier is based on a learned dictionary and the standard Cohn-Kanade dataset (includes 2105 digitised image sequences from 182 adult subjects of varying ethnicity) of 3 emotional classes: Neutral, Positive (Happy) and Negative (Anger, Disgust, and Sad) (Kanade et al., 2000). Classifying change in head position is done using the head pose output of the IF software. Each video stream consists of consecutive images or frames. An emotion label and head position estimate is given for each frame independently. We quantified frequency by extracting the distinct instances of smiling lasting greater than 0.5 seconds (15 frames) to limit measurement of small movements in the child's face, which represent noise due to the high sampling rate rather than true expressions (Matsumoto and Hwang, 2011). Any given frame without a visible face, or if the face exhibits a drastic change in position relative to the camera (> 45° or < 45° lateral rotation or yaw), the algorithm classifies that frame as “Not Visible”. We compared frame-by-frame behaviour coding between the human coder and the automatic classifier to determine percentage time in agreement for positive emotion (smiling). The agreement between two or more raters who independently rate features of a set of subjects can be quantified by assessing the inter-rater reliability (IRR) (Hallgren, 2012). Intraclass correlation coefficient (ICC) assesses the consistency between raters of a set measures of the same class (Hallgren, 2012). Inter-rater reliability between human and automated computer coding was tested on video data from 9 randomly selected participants from the complete South African dataset for frequency of positive emotion (smiling) as a potential outcome measure by calculating the Intraclass Correlation Coefficient (ICC) using the package ‘irr’ in R (Fox and Weisberg, 2011). We used a two-way, consistency, average measure ICC (Hallgren, 2012).

B. Quality of video data

To determine whether the quality of video data obtained in home recordings were sufficient for analysis, areas around the eyes, mouth and nose of the child’s face had to be visible at least 50% of the time during each video stimulus. Only video data where the computer vision algorithms were able to automatically detect and track specific landmarks for automatic coding of facial emotional expression and head position were analysed.

C. Comparison of South African versus USA responses to video stimuli

To determine whether the video stimuli in the App elicited similar emotional responses in South African and USA children, statistics were generated for the dependent variables (i) percentage time attending to the stimulus (frames with face detection) and (ii) percentage time displaying positive emotion (frames with face smiling) in the South African sample and an age and gender-matched USA sub-sample obtained from the larger USA Autism&Beyond ResearchKit study. Paired non-parametric t-tests were used to compare the matched samples. Statistically significant evidence of a difference between samples was accepted at the alpha=0.05 level.

2.3.2 Qualitative data

Qualitative focus group data were analysed using summative content analysis (Hsieh and Shannon, 2005), which consisted of identifying, counting and comparing keywords and concepts followed by interpretation of the underlying context. Representative meaningful phrases were extracted for each summative theme.

2.4 Results

2.4.1 Stage 1 Quantitative Data

2.4.1.1 Demographic characteristics

Fifty (50) participants were recruited to participate in the study. Forty-Eight adult participants were native isiXhosa speakers, one was a Sotho speaker, and one participant did not provide this information. All participants were of African ethnicity, from low SES backgrounds (earning less than $300 per household per month), and lived in Khayelitsha. Adult participants were typically unemployed (n = 19, 51%), female (n = 34, 92%), had some high school education (n = 28, 76%), and were single/never married (n = 28, 76%).

Of the 50 families recruited, 8 children did not meet the age cut-off and were therefore excluded. Of the remaining 42, a further 5 children were excluded on the basis of parental report that their child had previously received a professional diagnosis of a neurodevelopmental disorder. Demographic data of the parents are presented in **Table 2.1**.

Table 2.1 Demographic data of adult participants (N=37)

Gender	Female Male Not given	34 2 1
Relationship to child	Parent Caregiver Not given	34 2 1
Relationship status	Single, never married Married or domestic partnership Widowed Not given	34 1 1 1
Level of education	Some High school High school diploma Some college but no degree Not given	28 5 3 1
Employment status	Not employed, not looking for work Not employed, looking for work Stay-at-home caregiver not working Employed working 1 - 39 hours per week Employed working 40 or more hours per week Self-employed Not given	2 16 1 4 12 1 1
Home language	IsiXhosa IsiXhosa and English SeSotho Not given	34 1 1 1

Table 2.2 Demographic data of children in the study

		N = 37
Gender	Male	20
	Female	17
Age	Mean age in months (SD)	40.5 (18.43)
	Range in months	12 – 72 months

2.4.1.2 Technology questionnaire

The frequency of mobile phone ownership, proficiency and usage, access to and usage of the internet and smartphone applications are shown in **Figure 2.4**. The majority of parents (27/37, 64%) owned a smartphone and 100% of the phones where Android based. Most (24/37, 57%) rated their proficiency using their smartphone as good to very good (>7/10). Only 5/37 (12%) reported access to Wi-Fi but 24/37 (57%) reported using mobile data. Nineteen of the 37 (45%) purchased and downloaded Apps such as WhatsApp (a text messaging App for smartphones utilising the internet to send messages).

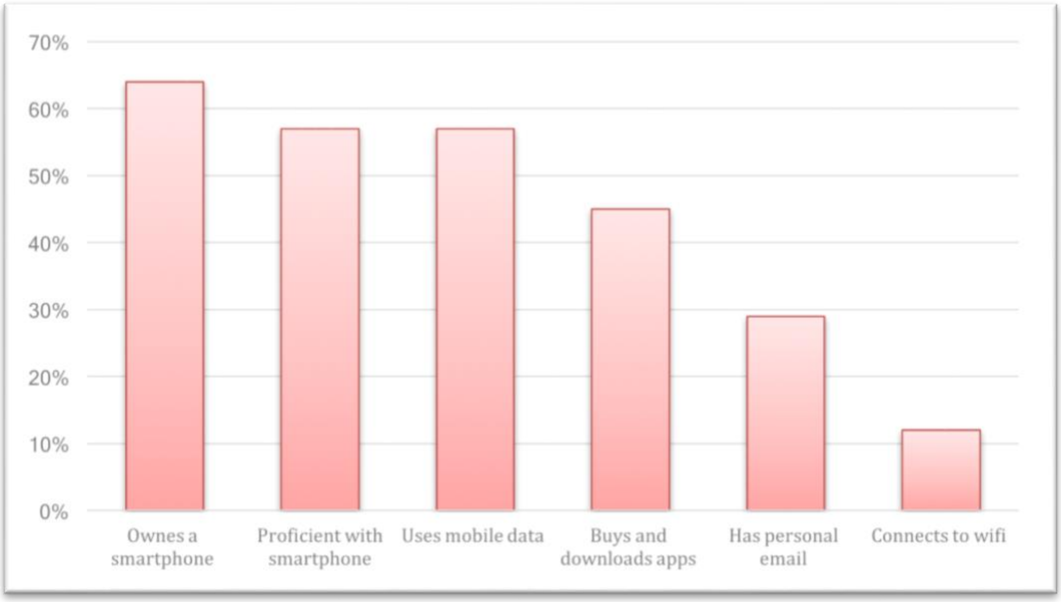

Figure 2.4 Technology questionnaire frequency measures (%)

2.4.1.3. Recorded video data

A. Reliability of the automated computer vision algorithms (Inter-rater reliability)

Human-automated coding for positive emotion (% time smiling) showed excellent inter-rater reliability with ICC of 0.95 (n=9, 95% CI 0.81-0.99) as shown in **Figure 2.5**.

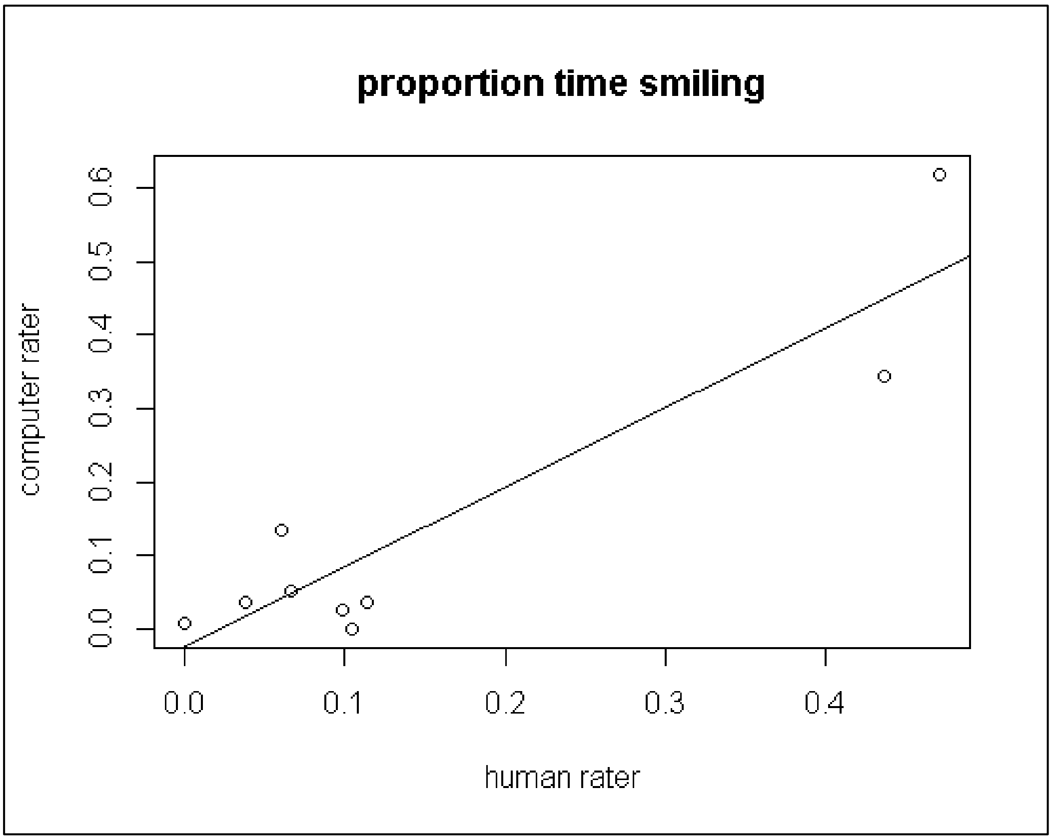

Figure 2.5 Human-Computer inter-rater reliability in the South African sample (n=9, ICC= 0.95, 95% CI [0.81,0.99], p= 0.000051).

B. Quality of video data

Video data were collected from 37 participating children **(Table 2.2)**. Each participant completed 4 video activities in the App, producing a total of 148 videos for potential analysis. As shown in **Table 2.3**, of the 148 video activities completed, only 118 (79.7%) videos from 33/37 participants (89.2%) were successfully uploaded to, and available for analysis on the Duke servers. For 16/37 (43.2%) participants, a complete set of 4 videos were uploaded to the Duke servers, for 13/37 (35.1%) three videos were uploaded, for 7/37 (18.92%) two videos, and for 1/37 (2.7%) only 1 video was uploaded.

Not all the uploaded videos were sufficient for analysis. The number of videos uploaded and the number sufficient for analysis reduced with each subsequent video activity (see **Table 2.4** for summary of usable video data**).** Video data for the Bubbles stimulus were of suitable quality for analysis in 33/37 (89.2%) South African children, 20 of whom were male, 13 were female with a mean age of 40.89 months and range 12 -72 months. Subsets for other stimuli depended on availability of video data**.**

Table 2.3 Video data transmitted for each participant

Video Stimulus					
Subject	Bubble	Bunny	Mirror	Toys&Rhymes	Total videos uploaded
1	✓	✓	✓	✓	4
2	✓	✓	✓	✓	4
3	✓	✓	✓	✓	4
4	✓	✓	✗	✗	2
5	✓	✓	✓	✓	4
6	✓	✓	✓	✓	4
7	✓	✓	✓	✗	3
8	✓	✓	✓	✗	3
9	✓	✗	✗	✗	1
10	✓	✓	✓	✗	3
11	✓	✓	✓	✓	4
12	✓	✓	✓	✓	4
13	✓	✓	✓	✓	4
14	✓	✓	✓	✗	3
15	✓	✓	✓	✗	3
16	✓	✓	✓	✗	3
17	✓	✓	✗	✗	2
18	✓	✓	✗	✗	2
19	✓	✓	✓	✓	4
20	✓	✓	✓	✗	3
21	✓	✓	✓	✓	4
22	✓	✓	✓	✗	3
23	✓	✓	✓	✗	3
24	✓	✓	✓	✓	4
25	✓	✓	✓	✓	4
26	✓	✓	✓	✗	3
27	✓	✓	✗	✗	2
28	✓	✓	✗	✗	2
29	✓	✓	✓	✓	4
30	✓	✓	✓	✓	4
31	✓	✓	✓	✗	3
32	✓	✓	✓	✓	4
33	✓	✓	✓	✗	3
34	✓	✓	✓	✗	3
35	✓	✓	✓	✓	4
36	✓	✓	✗	✗	2
37	✓	✓	✗	✗	2
Total:	**37**	**36**	**29**	**16**	

Table 2.4 Usable video data

Video Stimulus	Total videos uploaded for analysis	Total Videos usable for analysis	Total videos not uploaded	Total uploaded videos not useable for analysis
Bubbles	37	33	0	4
Bunny	36	31	1	5
Mirror	29	25	8	4
Toys & Rhymes	16	12	21	4
Total:	**118**	**101**	**30**	**17**

C. Comparison of responses to the video stimuli between South African and USA subjects

Comparison of % time smiling and % time attending to stimuli between the South African (SA) and matched American (USA) group is shown in **Table 2.5 and Figures 2.6 - 2.13**. No significant differences were observed between the SA and USA sample in % time attending to any of the video stimuli. There were no significant differences in % time smiling between the SA and USA children for the Bubbles (n = 33 SA; n = 33 USA) and Mirror stimuli (n = 25 SA; n = 25 USA). However, SA children spent significantly less time than the matched USA sample smiling at the Toys&Rhymes video (SA mean % time (SD) = 14 (24), n = 12; USA mean % time = 31 (34), n = 12; p = 0.05) and Bunny videos (SA mean % time (SD) = 12 (17), n = 31; USA mean % time = 30 (27), n = 31; p=0.006).

Table 2.5 Comparison of reaction to the video stimuli between South African and USA children

	SA	USA	Result
Bubbles	n = 33	n = 33	
Mean % Time attending (SD)	92 (20)	93 (16)	No difference p=1 (95%CI -0.057 to 0.066)
Mean % Time Smiling (SD)	20 (27)	30 (28)	No difference p=0.16 (95%CI -0.242 to 0.035)
Bunny	n = 31	n = 31	
Mean % Time attending (SD)	92 (20)	90 (20)	No difference p=0.62 (95%CI -0.038 to 0.058)
Mean % Time Smiling (SD)	12 (17)	30 (27)	**Greater in USA sample** **p=0.006** (95%CI -0.326 to -0.049)
Rhymes	n = 12	n = 12	
Mean % Time attending (SD)	97 (8)	95 (15)	No difference p=0.62 (95%CI -0.14 to 0.20)
Mean % Time Smiling (SD)	14 (24)	31 (34)	**Greater in USA sample** **p=0.05** (95%CI -0.43 to -0.0005)
Mirror	n = 25	n = 25	
Mean % Time attending (SD)	96 (6)	89 (16)	No difference p=0.14 (95%CI -0.012 to 0.15)
Mean % Time Smiling (SD)	19 (25)	37 (28)	No difference p=0.07 (95%CI -0.037 to 0.013)

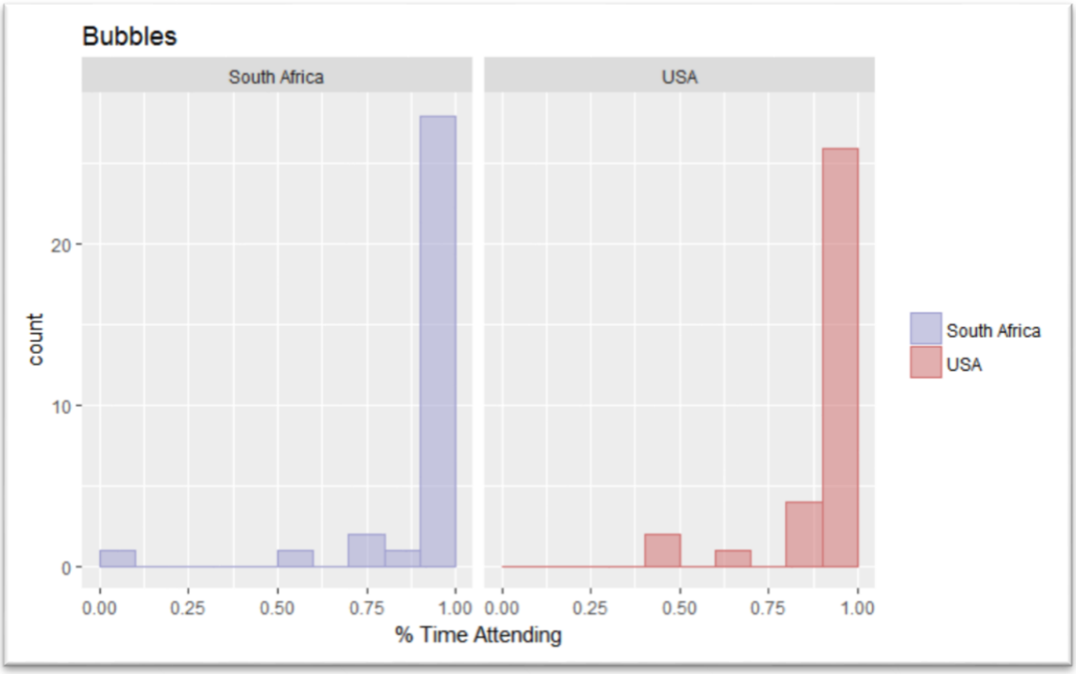

Figure 2.6 Percentage time attending to Bubbles stimulus (SA mean % time attending (SD) = 92 (20); USA mean % time attending (SD) = 93 (16); p=1). Sample SA n= 33; USA n= 33.

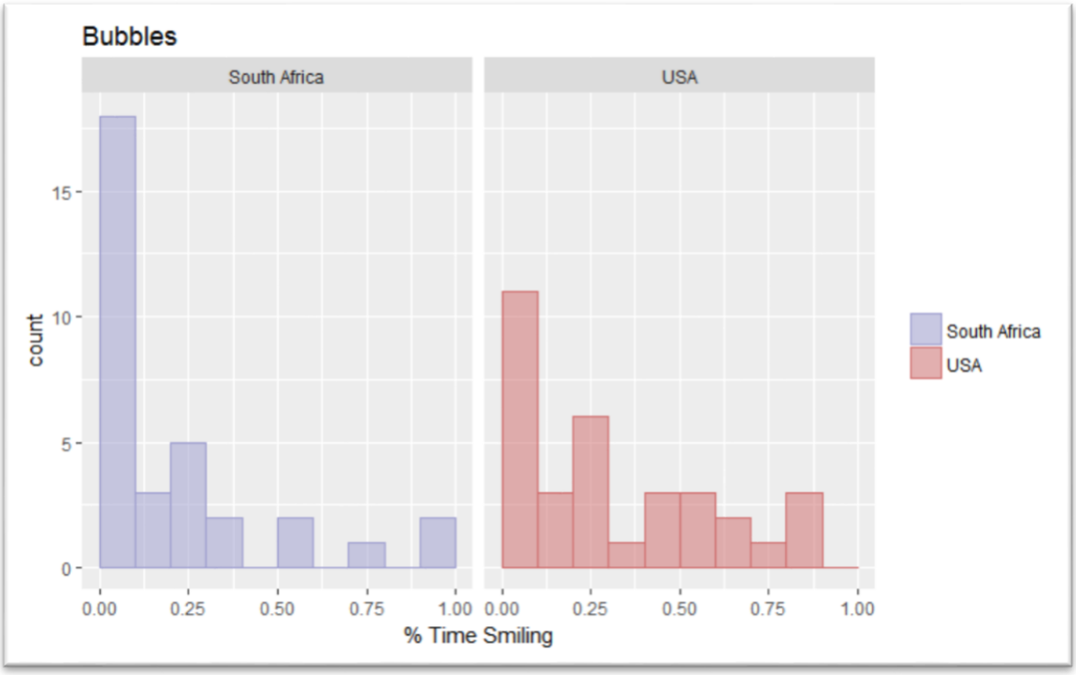

Figure 2.7 Percentage time smiling at Bubbles stimulus (SA % time smiling mean (SD) = 20 (28); USA % time smiling mean (SD) = 30 (28); p=0.16). Sample SA n = 33; USA n = 33.

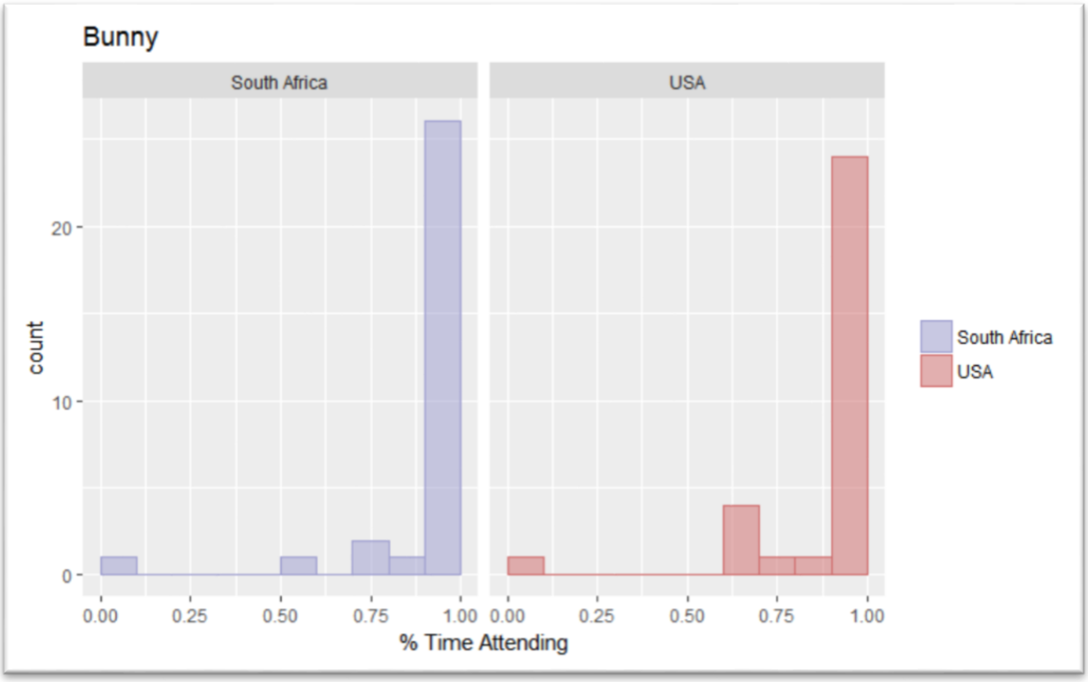

Figure 2.8 Percentage time attending to Bunny stimulus (SA % time attending mean = 92 (20); USA % time attending mean = 90 (20); p=0.62). Sample SA n = 31; USA n = 31.

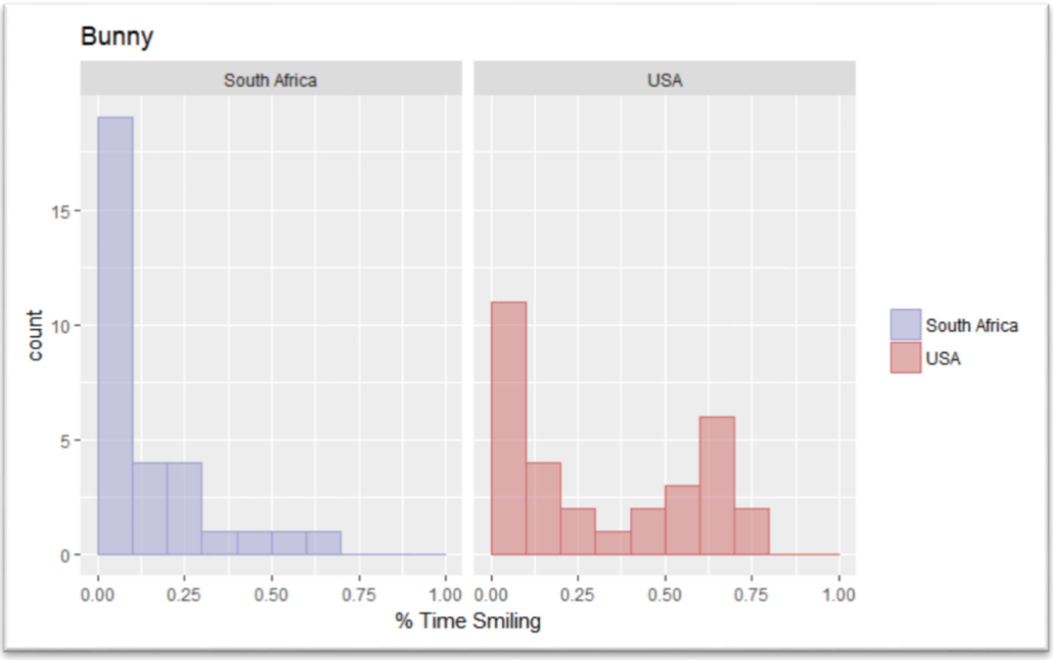

Figure 2.9 Percentage time smiling at Bunny stimulus, (SA % time smiling mean = 12 (17); USA % time smiling mean = 30 (27); p=0.006). Sample size SA n = 31; USA n = 31.

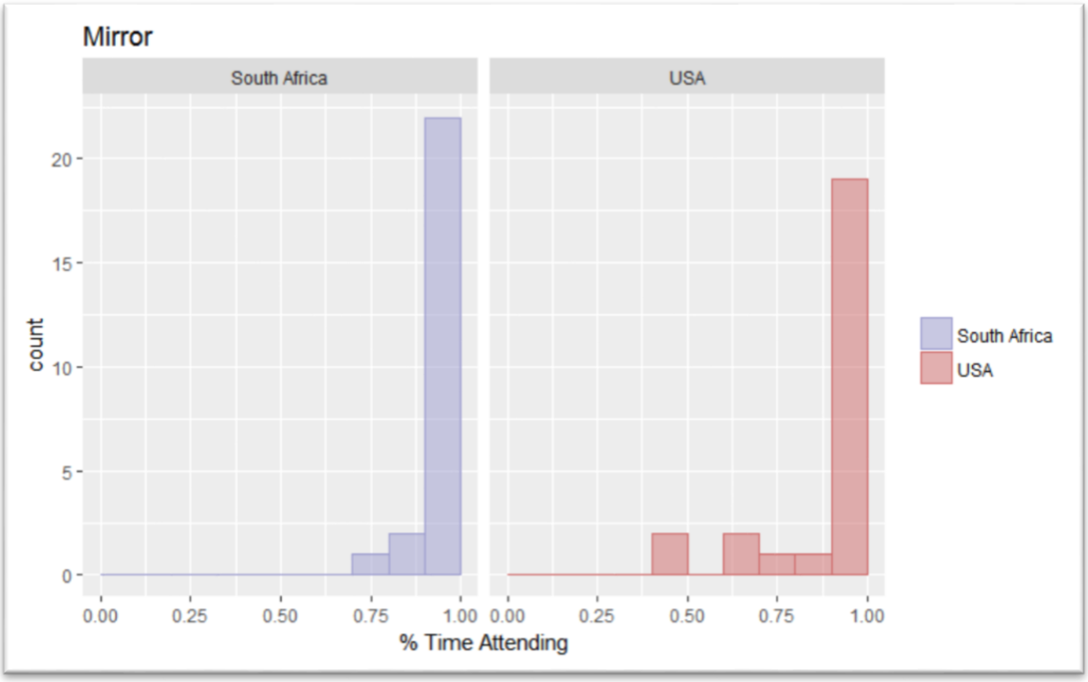

Figure 2.10 Percentage time attending to Mirror stimulus, (SA mean = 96 (6); USA mean = 89 (16); p=0.14). Sample size SA n = 25; USA n = 25.

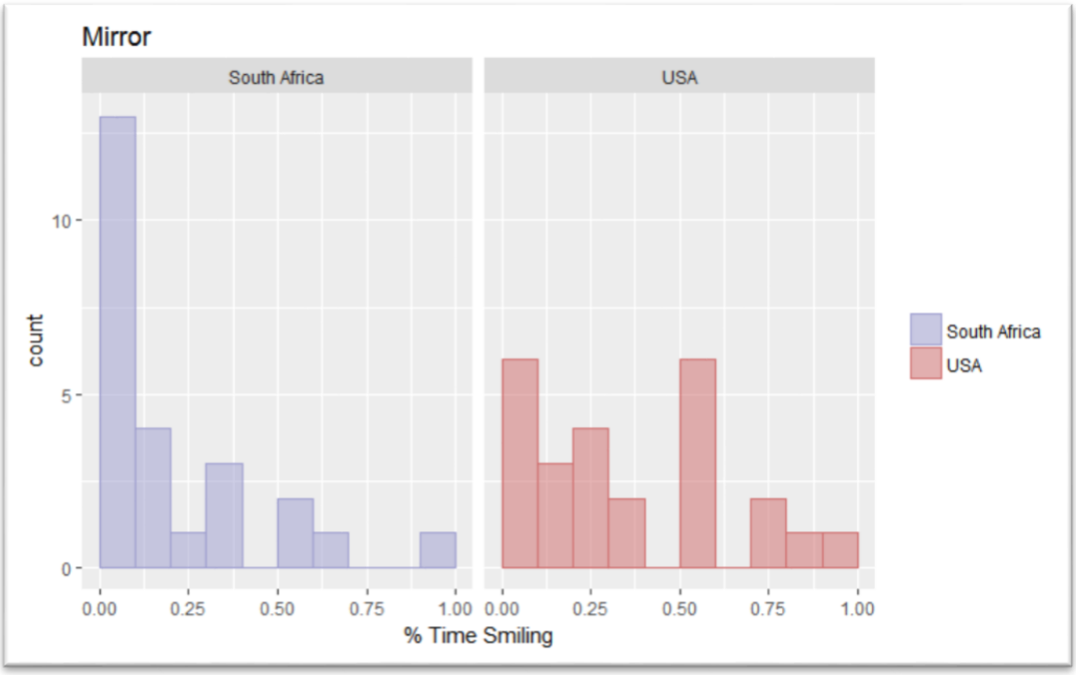

Figure 2.11 Percentage time smiling at Mirror stimulus, (SA mean = 19 (25); USA mean = 37 (28); p=0.07). Sample size SA n = 25; USA n = 25.

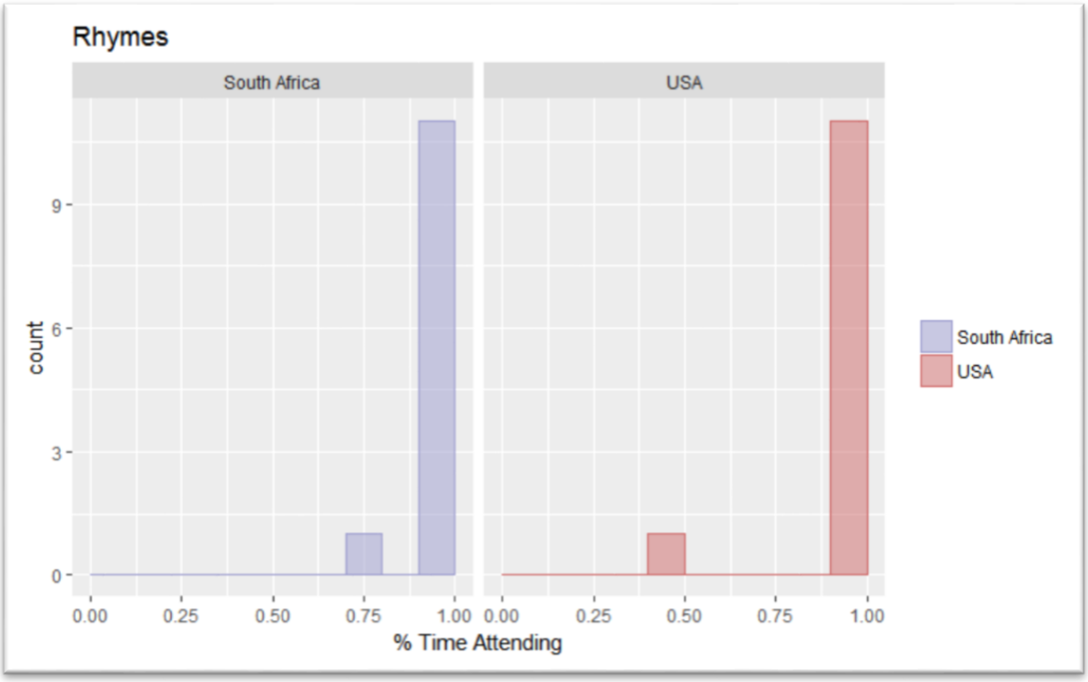

Figure 2.12 Percentage time attending to Toys&Rhymes stimulus, (SA mean = 97 (8); USA mean = 95 (15); p=0.62). Sample size SA n = 12; USA n = 12.

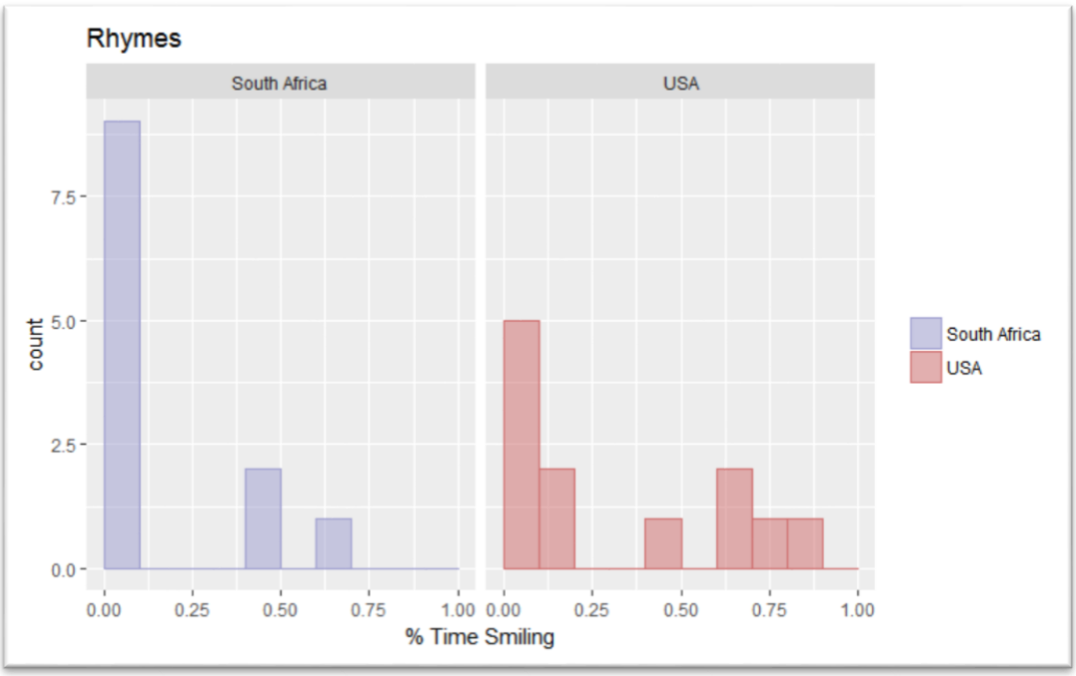

Figure 2.13 Percentage time smiling at Toys&Rhymes stimulus, (SA mean = 14 (24); USA mean = 31 (34); p=0.05). Sample size SA n = 12; USA n = 12.

2.4.2 Stage 2 Qualitative Data

2.4.2.1 Focus group results

For qualitative analysis, all comments made by the parents/guardians invited to participate (n = 14) were used. **Table 2.6** provides a summary of themes and representative quotes.

A. Ease of use

Parents typically felt comfortable using smartphones to access the internet and smartphone applications. Participants said that most people in their communities owned and used Android rather than Apple smartphones given the cost of iPhones. Participants therefore felt unfamiliar with the iOS (iPhone Operating System) platform, were more used to the Android operating platforms, and suggested that people living in their communities may have a similar experience if they had to use iPhones. Some activities, such as using their index finger to sign the in-app consent form electronically, reading and following instructions to record specified video sequentially and moving from one activity to the next within the App, were identified by many participants as technical challenges. The electronic consent process was found to be time-consuming and tiresome.

B. Accessibility and Affordability

Participants agreed that most people in their communities had access to or owned a smartphone. Access to Wi-Fi and the internet, however, was only possible using paid-for mobile phone internet data as there was no free Wi-Fi available in their community. Accessing the internet was regarded as a luxury that members of their community struggle to afford. Being able to access and download Apps was considered to be important when choosing a phone, however most parents said they typically only download and use Apps that were available for free.

C. Acceptability

The focus groups generally had positive perceptions about the acceptability of the Autism&Beyond App. Being able to assess their child without having to visit a clinic or hospital and be subjected to long waiting times was regarded as a particular advantage of this and similar Apps. The content of the App as well as recording a video of their child for assessment were also regarded as acceptable to people in their community. Parents did not feel that the USA-themed video stimuli were unacceptable, given that most children in their community are familiar with American children's television shows broadcast on South African television channels. The use of the Bunny in the video stimulus was found to be acceptable, however, the parents did suggest that certain animals such as reptiles, dogs and monkeys should not be used in videos for children as it may cause anxiety or make them recoil.

D. Localisation

Parents felt that they were not able to answer all the questions relating to their child's development. Their children play outdoors from a very young age, supervised by older siblings or children of neighbours. Unless their child showed obvious signs of being unwell, for example not eating or sleeping more than usual, most parents would not be aware of developmental delays or behavioural problems. Although most parents would seek healthcare advice and treatment from conventional healthcare professionals such as nurses and doctors, some parents felt that, depending on the problem, they may also consult traditional healers.

Table 2.6 Representative quotes from focus groups

Qualitative Themes	Participant Feedback
Ease of use	"Understanding iPhones are a bit more difficult than Samsung. I cannot make the video like with my phone" (108TuF) "What I've noticed is that our young people, most of the time they use smartphones. It's easy for us. We prefer them." (110TuM] "I cannot do the signature. You showed me. Then I do it." (310ThF)
Accessibility and Affordability	"Nowadays we have smartphones and everybody love these phones. It's quite easy to get them." (112TuM) "Not iPhones. Too expensive." (203TuF) "There's no Wi-Fi here in Khayelitsha. You must go to town." (312TuF) "People are using the app if it's free of charge. Data is too expensive. It's something that we don't have money to buy." (110TuM)
Acceptability	"It is a good app. We can also make it our habit to use those apps in order for us to see our child's development, how they think, and everything." (110TuM) "I think it's great because it notifies us about our children and it can be used at home, in schools. And most of the time in these health facilities, you will find that there are queues and it's long and you can't even stand there for hours." (312TuF) "Remember this is for the children, so the children know Twinkle Little Star. I think it's fine." (113TuF) "The bunny is fine, you know, but not a dog. We are scared." (104ThF) "No! Not a frog." (218ThF)
Localisation	"I didn't understand the words and I asked the lady. The tantrums. I don't understand this. I couldn't understand until she had to make an example. That's when I understand." (111ThF) "Because a motor function for us it's strictly cars, vehicles, it's not bodily." (204ThF) "So it is our culture, we don't take note of everything. If I can put it like this, unless my child is sleepy, sick and everything, we don't care about what he is doing outside and everything. That's us." (113TuF)

2.5 Discussion

The purpose of this study was to determine the technical feasibility, accessibility, acceptability and cultural appropriateness of a smartphone application designed and developed in the USA to identify young children at risk of Autism Spectrum Disorder for 'scale-out' to a low-income community setting in South Africa. The study used a mixed-method approach in two phases to achieve these aims. To determine technical feasibility, the study evaluated access to and proficiency with use smartphones and the internet, and whether video data of sufficient quality could be obtained. To determine whether these video data could reliably be analysed for emotional responses in a South African setting, we determined whether automated coding correlated well to a local human coder, and whether emotional responses to the video stimuli in South African children were similar to children in the USA. In order to establish whether the smartphone App would be perceived as accessible, appropriate and acceptable in a South African community setting, we ascertained parental attitudes and opinions about the content of the App, about digitally delivered observational assessments and video recordings of their children and identified the content of the App that would require localisation to a South African context.

2.5.1. Technical feasibility

Results from our technology questionnaire showed that 64% of our participants owned a smartphone, and 57% considered themselves to be competent users. These results are interesting given that the majority of parents/carers in our study were female (92%) and from low SES background. Data published by the Groupe Spéciale Mobile Association (GSMA) on the mobile economy in Sub-Saharan Africa (SSA) suggested smartphone ownership of 27% in SSA and indicated females to be 17% less likely than men to own a mobile phone (Groupe Spéciale Mobile Association (GSMA), 2017). This may suggest that smartphone ownership and usage may be different in urban and peri-urban South African townships compared to overall low-resourced environments in SSA. Most parents (57%) accessed the internet using mobile data and only 12% of parents connected to the internet using Wi-Fi. Given the very limited Wi-Fi infrastructure in South African townships, those who live here, typically have little choice when accessing the internet (Phokeer et al., 2016). Overall, these results were therefore encouraging and suggested that, at least in urban South African settings, smartphone-based Apps may be technically viable for mHealth purposes.

To determine whether the video data obtained were sufficient for automated coding and analysed reliably for emotional responses in a low resourced setting, we compared results from the computer-generated analysis to human coding of facial expressions in a random sample of the South African data. Human-automated coding showed excellent correlation for positive emotions. This was an important and fundamental finding in terms of the transferability or 'scale-out' of the technology to an African context. However, not all data from the completed video activities were received for upload to the Duke servers. Both the number of video activities completed and the number of videos sufficient for analysis reduced for each subsequent video activity. Videos obtained in home recordings collected on the study iPhones had to be sufficient for the state-of-the-art computer vision algorithms to extract features from specific areas of the face around the eyes, mouth and nose for analysis and automatic coding of facial emotional expression and head position. This required that enough of the child's face had to be visible at least 50% of the time for the computer vision algorithms to automatically detect and track the specific multiple facial landmarks. We collected a total of 148 videos from 37 participants, however, only 118 (79.7%) videos from 33 participants (89.2%) were successfully uploaded to the Duke servers and 101 (85.6%) were successfully analysed. This does compare well to the much larger population-based USA study (N=878 children) where the child's face was detected on average during 84 to 92% of the video stimulus (Hashemi et al., 2017). However, we interpret these data with caution as we used expensive, high specification iPhones with built-in high-resolution digital cameras that may not represent the quality of smartphones accessible to people living in low-income communities. Given that the researchers observed and ensured that all participants completed all video activities, the significant loss of video data may have been due to incomplete upload and transmission of data. The Autism&Beyond App was not designed for multi-subject participation using a single smartphone. We suspect that loss of data was most likely to have occurred when progressing from one participant to the next due to logging out before transmission of data was completed. A simple solution may be to add a progress indicator to inform the user when to proceed to the next activity and when uploading and transmission of data was completed.

Scaling-out of the App will depend on selecting stimuli that would elicit similar emotional responses in children across cultures and languages. Our study showed that in two of the four video stimuli presented, similar emotional responses were elicited in the SA and USA groups and differed in the remaining two. Caution is therefore required when interpreting these results until further cross-cultural studies have been performed to validate the use of these stimuli. Smith et al. (2017) when administering the ADOS-2 found that the remote-controlled bunny was "very unfamiliar" to families from low-middle socio-economic status backgrounds in the Western Cape. The toys shown in the video stimuli may not be familiar to the children in our study and therefore they may not have perceived viewing the video on the phone as positive or pleasurable, despite the intention of the design. Similarly, the rhymes were in American English and may not have been familiar to the mainly isiXhosa-speaking South African children. The *Toys&Rhymes* video was a combination of social (biological) and non-social (non-biological) stimuli. It was not possible in this analysis to divide the data to determine whether there may have been differential smiling at biological and non-biological activities (Wright et al., 2016). There is also evidence of cross-cultural variability in facial emotional expression (Elfenbein et al., 2007; Elfenbein, 2013). Reliable detection of risk for ASD across cultures and languages utilising automatic objective computer classifiers to detect social and communication markers will require identifying culturally appropriate stimuli to reduce bias.

2.5.2. Acceptability and Appropriateness

Summative analysis of focus group discussions indicated that families found the App relatively easy to use, and would recommend it to others in their community. A key theme from families was the importance that the App must be free of charge, and that data transfer should not be at a cost to them. In addition, Android rather than iOS (Apple iPhone) Apps were regarded as more appropriate for their communities. iPhones are perceived as more expensive and people from their communities typically do not own or have access to iPhones. Findings suggesting clear predominance of

Android phones as opposed to other type of operating systems in townships have been reported in the literature (Phokeer et al., 2016). In fact, according to the Groupe Spéciale Mobile Association (GSMA) 2017 report on SSA, growth in smartphone ownership in LMICs has been largely due to the increasing affordability of smartphones from mostly Asian manufactures (<$100 phones) as well as the second-hand market (Groupe Spéciale Mobile Association (GSMA), 2017).

Most focus group participants found the instructions and terminology used difficult to understand. Given that the App was developed for the American user, demographic classifiers for ethnicity (e.g. African-American, Native American, Hispanic) were not relevant to the communities our participants represented. Technical terms such as "Motor Skills", "Temper Tantrums" and "Social Skills" were not familiar to most parents. Language has the potential of introducing method bias when tools developed in high income, mostly English-speaking countries are introduced to multi-lingual LMICs (de Vries, 2016; Franz et al., 2017; Smith et al., 2017). Translating and adapting these instruments to incorporate local language and culture make it possible for these instruments to be used with high fidelity and validity in linguistic and culturally diverse LMICs (Soto et al., 2015; Chambers et al., 2017; Smith et al., 2017). Interestingly, parents did not have any concerns about the fact that videos were 'American'. *Sesame Street* is an American television show broadcast to millions of children globally, including in some of the world's poorest regions (Mares and Pan, 2013). It is conceivable that the increased exposure of children's television programmes created in the USA to a global audience may familiarise children and their parents to the American language and culture (Moran, 2006). Parents did, however, suggest that using animals such as dogs or reptiles may not be appropriate due the potential of eliciting negative behaviours including anxiety and disgust in South African children. In their ethnographic study evaluating the cultural appropriateness of an Afrikaans translation of the ADOS-2, Smith et al. (2017) similarly found that certain animals are regarded as inappropriate in some South African cultures.

People living in low-resourced settings often have to travel far and queue for hours to access healthcare (Daley, 2004; Durkin et al., 2015). These barriers to accessing health services for their children represented an underlying theme that resonated with most families in our study. Parents felt that the potential of saving costs of travel and reducing time away from home or work by doing in-home developmental assessments using a smartphone App would be a significant benefit to families in their communities.

2.6 Limitations of the study

Even though our initial findings were mostly positive, it is important to consider potential limitations. Firstly, the sample size was small and based in an urban township. We therefore acknowledge that some of the findings may have been different in, for instance, a rural community. However, this was the first feasibility study of the Autism&Beyond App in any African setting. Further studies are now required to explore the feasibility of the App in larger samples, and across cultures and geographic locations. Secondly, we acknowledge that the study was conducted with high-specification study iPhones. As confirmed by our focus groups, Android-based smartphones are predominantly used in low-resource communities. We therefore do not know whether Android phones would have the technical specifications to collect the quality data required for analysis. Development of an Android-based App would clearly be a next step based on our findings. Thirdly, a researcher was present to observe and assist parents while using the iPhone. Subsequent research will be required to determine whether families could follow the whole process of App download, consent, and data collection with similar accuracy without any support.

2.7 Conclusion and future directions

Despite the limitations outlined above, we provided empirical evidence of the technical feasibility, acceptability, accessibility and cultural appropriateness of smartphone-based Apps as potential screening tools for ASD in an African setting. Larger-scale cross-cultural studies will be required to develop appropriate video stimuli that may be robust across settings. Focusing on Android rather than iOS-based platforms is needed to reach the majority of smartphone users in LMICs. Scale-up will require free Apps with free data to end-users. Localising of Apps will require modifications to the language to accommodate the variable educational and literacy levels of the full range of SES communities.

Chapter 3

Conclusions of the Study

3.1. Thesis summary

Autism Spectrum Disorder (ASD) is an early-onset, life-long neurodevelopmental disorder characterised by impairments in social interaction and communication, and restricted patterns of behaviour, interests and activities (American Psychiatric Association, 2013). As outlined in Chapter 1, most people with ASD live in low- and middle-income countries (LMICs) where resources and access to expertise are very limited. Reduced access to evidenced-based care, particularly in rural areas, often result in families using unproven and ineffective treatments, if any at all (de Vries, 2016; Franz et al., 2017). However, with early diagnosis and proper treatment, many individuals with ASD can reach their full potential and lead productive and fulfilling lives (Rogers and Dawson, 2010; Dawson et al., 2012; Bradshaw et al., 2015). To meet the needs of people living with ASD in low-resourced settings, we require innovative solutions for capacity building, guided by the principles of accessibility, affordability, appropriateness, and scalability from the outset (de Vries, 2016). Technology has the potential to reach people wherever they are.

We therefore set out to do two things in this thesis. In Chapter 1, we reviewed a range of technologies of potential value to individuals with ASD who live in LMICs, and considered the feasibility of implementing some of those in low-resource environments. In Chapter 2 we proceeded to examine the feasibility of a specific smartphone-based App developed as a potential screening tool for young children at risk of ASD. We performed the feasibility study of the Autism&Beyond App in a low-resource township community in South Africa.

We concluded in Chapter 1 that, of all the technologies being developed for ASD in high-income settings, mobile health (mHealth) and smartphone-based technologies have the greatest potential to increase the reach of mental health services to individuals and families in low- and middle-income countries (LMICs). The Groupe Spéciale Mobile Association (GSMA) estimates that by 2020, around 80% of people living in LMICs will be connecting to broadband internet services (3G or above) using their smartphones (Groupe Spéciale Mobile Association (GSMA), 2015). Smartphone connections in Sub-Saharan Africa (SSA) alone may well reach 500 million by the same year (Groupe Spéciale Mobile Association (GSMA), 2017). It is therefore possible to imagine that smartphone-based mental health services have the potential to be applied on a large scale. Furthermore, the ubiquity of the mobile phone allows for these services to be provided in everyday settings.

In Chapter 2 we proceeded to collect data in a low-resourced South African setting. The results of our technology survey showed that most families (64%) living in a low-income African setting owned a smartphone. Other studies have shown that in many African countries, even more people have access to smartphones by way of phone sharing (Wesolowski et al., 2015; Kumar et al., 2016). Despite these encouraging findings (Chapter 2), successful implementation of smartphone-based mental health services depends on more than internet access and ownership of the device.

We therefore wanted to investigate the feasibility of using a specific App in an African setting. We reported that all the participants in our study owned Android-based smartphones and acknowledged that we did not determine whether Android phones would have the technical specifications to collect the quality of video required for analysis. Android-based smartphones from manufacturers based in Asia are typically inexpensive and of low specification. Inadequate camera resolution, picture quality and processing speeds for instance, could affect the accuracy and reliability of smartphone-based interventions negatively and may therefore not be suitable for all mHealth applications. In addition to mobile internet access and smartphones of suitable quality, the feasibility of mHealth Apps also depends on the App itself.

We purposefully chose to conduct our study and administer the App in a home typical for low-resourced township communities in South Africa. Facial expression recognition systems are very vulnerable to the ambient recording conditions such as illumination (Sandbach et al., 2012). Many homes in LMIC do not have access to electric lighting (http://esmap.org/SEAR). In addition, many of the automated facial expression classifiers that are available today, are trained on posed facial expression datasets of mostly Caucasian faces under laboratory conditions (Sandbach et al., 2012). As we concluded in Chapter 2, our findings suggest that the algorithm behind the Autism&Beyond App could reliably detect and track the required facial landmarks to classify the emotional expressions and attention of South African children in their natural environment automatically. Notwithstanding the limitations of our sample size, we did find meaningful differences in the positive emotional responses between the South African and USA groups to two of the video stimuli (Bunny and Toys&Rhymes). Unfamiliarity with the toys shown in the videos could reasonably explain the observed discrepancies. Studies have reported on the potential for cultural background to influence ASD identification and diagnosis, as well as the potential cultural biases of ASD assessment tools (Kang-Yi et al., 2013; Norbury and Sparks, 2013; Harrison, Slane et al., 2017). Smith et al. (2017) and Chambers et al. (2017) found that some specific activities and objects used with the ADOS-2 were not appropriate for some South African cultures. In addition, other studies identified differences in facial expressiveness between individuals from different cultures (Vrana and Rollock, 2002; Elfenbein et al., 2007; Elfenbein, 2013). Further work on stimulus-selection to elicit emotions is clearly required if these were to be used as markers of ASD risk in cross-cultural global settings.

Smartphone Apps are increasingly being used in mHealth programmes across the globe (Eng and Lee, 2013). Consistent with other studies (Proudfoot et al., 2010; Donker et al., 2013; Aranda-Jan et al., 2014; Naslund et al., 2017) we showed in Chapter 2 that smartphone services for mental and neurodevelopmental healthcare is acceptable and even preferable to users. Financial benefit including saving on travel expenses and reducing loss of income due to absence from work were some of the perceived benefits for the community. Given that the majority of parents/caregivers in our study were unemployed (51%), using this and similar Apps would largely depend on it being available free of charge and without having to use their own paid-for data. Language and literacy have also been reported as significant barriers to successful implementation of mHealth services (Aranda-Jan et al., 2014). Our results showed that parents found some specific aspects of the language and terminology used in the App unfamiliar and therefore difficult to understand (Chapter 2). Given the lack of healthcare resources and budgetary constraints in the majority of LMICs (Abubakar et al., 2016; de Vries, 2016; Franz et al., 2017), screening and diagnostic tools created in high-income, mostly English speaking countries, are increasingly translated for use in these culturally diverse settings (Soto et al., 2015; Chambers et al., 2017; Smith et al., 2017). Notwithstanding the importance of translating these tools into local languages, identifying and adapting unfamiliar terminology and concepts (such as "Temper Tantrums" and "Motor Skills") are fundamental to ensuring that the target population sufficiently understands and successfully utilises these instruments.

This was the first study to explore the feasibility and acceptability of using the Autism&Beyond App as a potential scalable screening tool for ASD risk in a LMIC. Taken together, we showed technical feasibility of this and similar Apps to be used in a low-resourced African setting, particularly given the trend of increasing access to smartphones and the internet. Given that our findings showed different patterns of positive emotion to the video stimuli in South African and American children, further cross-cultural studies are needed to identify appropriate stimuli to elicit emotions before it can be used as markers of ASD risk across different cultural settings. Overall, the acceptability and appropriateness data for the App are encouraging, but key considerations included type of device used, and ensuring free access to Apps and internet data.

3.2. Limitations of the study

We acknowledged the limitations of the study in Chapter 2. In addition to the small and geographically circumscribed study population, use of expensive high specification smartphones, and assisting participants while using the App, overarching limitations to implementing mHealth initiatives in LMICs should also be considered. Firstly, according to the World Bank State of Electricity Access Report (SEAR) 2017, only 37% of the total population in Sub-Saharan Africa (SSA) have access to electricity. In rural areas, where more than half of the region's population live, the estimate is only 15% (The World Bank, 2017). Without electricity, smartphones cannot be charged. Secondly, mHealth interventions are also negatively impacted by underdeveloped mobile broadband infrastructure and unreliable connectivity. More than 70% of the world's rural population was still without reliable mobile broadband access in 2017

(International Telecommunication Union (ITU), 2017). Interrupted internet connections could potentially lead to inaccurate assessments, unreliable diagnoses and therefore negatively impact clinical outcomes (Adjorlolo, 2015). Thirdly, given the high levels of unemployment in LMICs, access to free internet and data is a key requirement for scalability. Free access is very limited in LMICs and typically not available, particularly in rural communities. Fourthly, the 'digital-gender divide' has shown that, in most African countries, it is typically urbanised young educated men of high SES who own and use smartphones (Gomez, 2014; Wesolowski et al., 2015). In contrast to the global trend, the number of women who live in Africa and use the internet has declined since 2013 (International Telecommunication Union (ITU), 2017). Fifthly, the ethical challenges related to data privacy, confidentiality and stigma will all require careful consideration to ensure successful mHealth implementation in LMIC given, for instance, the high levels of phone sharing (Kaplan, 2006). Users will be more confident using mental health Apps if they were satisfied that their information would be protected and kept private (Carter et al., 2015).

3.3. Future directions

Scaling-up and scaling-out of smartphone-based mental health services to those in LMICs may be fundamentally different from implementing similar mHealth applications in High-income Countries (HICs). Successful implementation of mHealth projects should include the participation of the end-user community from the outset. This is important not only to include their wants and needs when these services are developed, but also to establish the local cultural and practical challenges that may impact on the successful implementation of smartphone Apps for ASD (Grinker et al., 2012; Pickard et al., 2016). High levels of unemployment and low levels of disposable income typical of most LMICs warrants the development of innovative programmes such as reverse billing of data, enabling users to access specific Apps free of charge. In Africa alone between 2000 and 3000 languages are spoken by people from diverse cultural backgrounds, beliefs and parenting styles. Measures that are completely unbiased by culture, language and literacy is therefore the ultimate goal. Computational markers such as eye tracking to determine patterns of social visual engagement (Constantino et al., 2017), facial expression recognition systems to classify emotional response (Hashemi, Campbell et al., 2015) and touch-screen as well as movement sensors to detect fine motor patterns (Anzulewicz et al., 2016) related to ASD have the potential to be developed as objective, scalable, language-free and culturally-fair markers for ASD. Utilising these and similar technologies in future Apps to reliably screen for ASD will, if successful, have to be embedded into clinical systems enabling those who require next step assessment and treatment to do so. This, however, will remain a challenge in most LMICs for some time to come.

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Appendix 1a: Electronic demographic survey

DOMAINS	QUESTIONS	ANSWERS	LOCALIZATION
PLEASE TELL US ABOUT YOUR CHILD"			
Child's sex	Is your child a boy? A girl?	Boy, girl	
Child's DOB	When was your child born?	Month, day, year	
Race/ethnicity	What is your child's ethnicity?		
		Black/African American	
		Caucasian	
		Native American	
		Hawaiian or Other Pacific Islander	
		Middle Eastern	
		Caribbean	
		South Asian	
		East Asian	
		Hispanic, Latino or of Spanish origin	
		Other	
INFORMATION ABOUT THE PARENT INFORMANT			
"PLEASE TELL US ABOUT YOURSELF"			
Relationship to child	Are you (child's name)'s	Parent, Legal Caregiver	
Sex	What is your gender?	Male, female, other, prefer not to answer	
Parental date of birth (DOB)	When were you born?	Month, day, year	
Ethnicity	What is your ethnicity? (drop down for definition of ethnicity, see after table)		
		Black/African American	
		Caucasian	
		Native American	
		Hawaiian or Other Pacific Islander	
		Middle Eastern	
		Caribbean	
		South Asian	
		East Asian	
		Hispanic, Latino or of Spanish origin	
		Other	
Education	What is the highest level of school that you have completed or highest degree you have received?	Doctoral degree (e.g., PhD, MD, JD, etc)	
		Master's Degree	
		Bachelor's Degree	
		Associate degree	
		Some college but no degree	

		High School Diploma/GED	
		Some high school	
Employment	Which of the following categories best describes your employment status	Employed working 40 or more hours per week	
		Employed working 1-39 hours per week	
		Not employed, looking for work outside of the home	
		Not employed, NOT looking for work outside of the home	
		Self-employed	
		Stay-at-home caregiver not working outside of the home	
		Retired	
		Disabled, not able to work outside of the home	
		Other	
Marital status	What is your current relationship status?	Single, never married	
		Married or domestic partnership	
		Widowed	
		Divorced	
		Separated	
		Other	
Learn about Study	How did you learn about the Autism & Beyond Study (select all that apply)?	Social Media	
		Email from a friend	
		Health professional or health center	
		Advertisement(e.g., in iTunes, print media	
		Searching online (e.g., Google, etc)	
		General media coverage (e.g., news study, radio, print, TV, on-line)	
Further contact	May we contact you be e-mail about possible participation in future studies	Yes, No	
"PLEASE TELL US ABOUT YOUR FAMILY"			
# of children in home?	How many children live in your household?	#	
Primary Language	What is the primary language spoken	Open response	

	in your home?		
Thank you	Thank you for completing this survey. Please click Done to save your responses.		

Appendix 1b: Electronic parental Concerns Questionnaire

DOMAINS	QUESTIONS	ANSWERS	LOCALIZATIONS
Parental Concerns	**In this survey we will ask you about any concerns you have about your child's development. We will also ask about any services your child has received.** **[Each question begins with "Do you have concerns about your child's . . ."]**		
Language	Use of words or gestures to communicate with others	Yes, no, not sure	
Hearing	Hearing?	Yes, no, unsure	
Motor Skills	Motor development?	Yes, no, unsure	
Social Behavioral	Social interactions?	Yes, no, un sure	
		Interacting with you	
		Interacting with other adults	
		Interacting with other children	
Sleeping	Sleep?	Yes, no, unsure	
Managing Emotions	Manages emotions?	Yes, no, unsure	
		Anxiety/fear	
		Sadness	
		Anger	
Temper tantrums	Temper tantrums?	Yes, no, unsure	
Attention	Pay attention?	Yes, no, unsure	
Hyperactivity	Activity level?	Yes, no, unsure	
Support	Have you talked with others about your concerns?	Yes, no, unsure	
	Can check more than one answer	With your partner?	
		With other family member(s)?	
		With your child's medical doctor?	
		With a developmental or mental health professional?	
		With a teacher or daycare provider?	
		With a friend?	
		With clergy?	

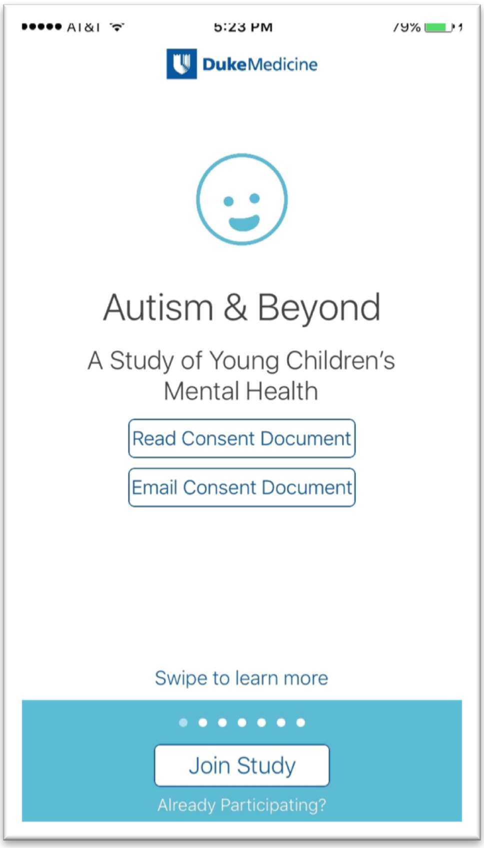
DOMAINS	QUESTIONS	ANSWERS	LOCALIZATIONS
Evaluation	Has your child ever had a developmental evaluation or mental health evaluation?	Yes, no, unsure	
	When was that?	mm/dd/yyyy	
Disorders	Has your child been diagnosed with any of the following:		
	Can select more than one answer	Language Delay	
		Developmental Delay	
		Autism Spectrum Disorder	
		Attention deficit/ Hyperactivity Disorder	
		Behavior Disorder	
		Anxiety Disorder	
		Depression	
		Genetic Disorder	
		Chronic medical illness	
		Other? (text)	
		No	
Barriers	Faced barriers getting help for child	Yes, No, Not Applicable	
		Can't get an appointment	
		On a waiting list	
		Costs too much	
		Don't have transportation	
		Not available where I live	
		Language barrier	
		Insurance does not cover	
		Feel embarrassed	
		Feel scared	
		Feel confused	
		Other (text)	
Energy	Have energy to handle challenges that your child faces?		
		Never	
		Not often	
		Sometimes	
		Most of the time	
		Always	
Happiness Today	How happy are you today?	Completely Unhappy –	

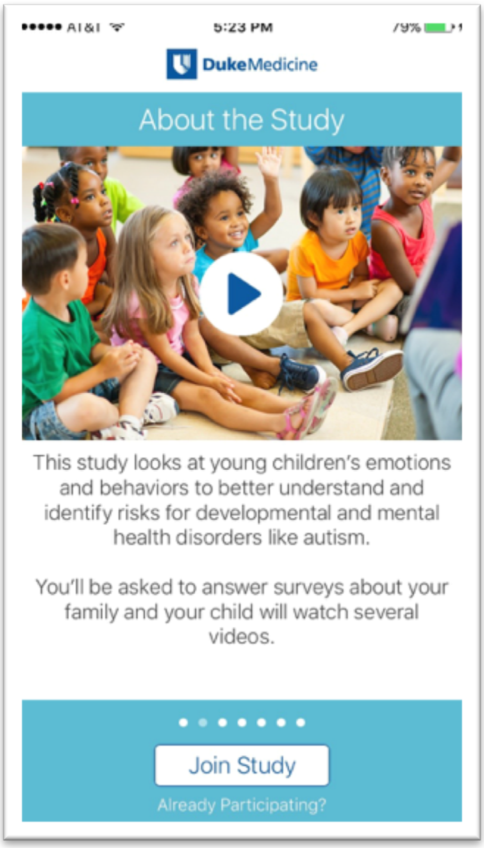
DOMAINS	QUESTIONS	ANSWERS	LOCALIZATIONS
		Completely Happy (100 point scale)	
Anything else you want us to know about your child and family	Is there anything else that you would like to share with us about your child or family?	Text	
Anything else you want us to know about being a parent	Is there anything else that you would like to share with us about being a parent?	Text	
Exit Screen	Thank You Thank you for completing this survey. Please click Done to save your responses	Done	

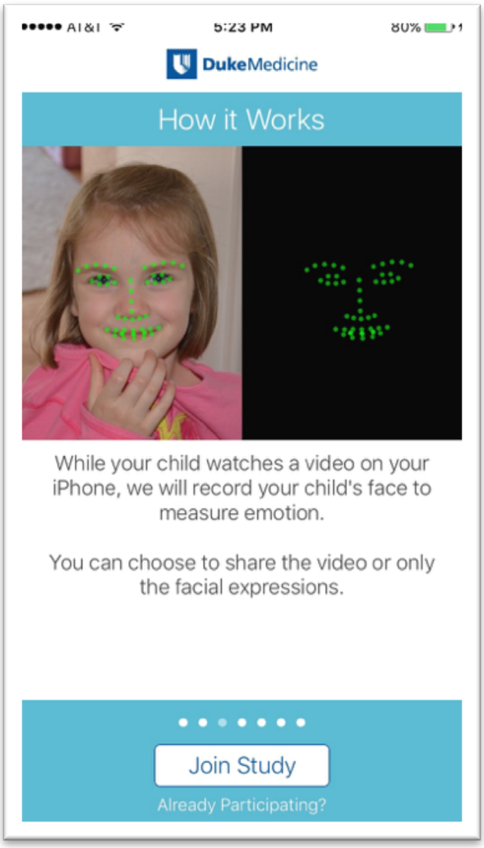
Appendix 1c: Duke Temper Tantrum Questionnaire

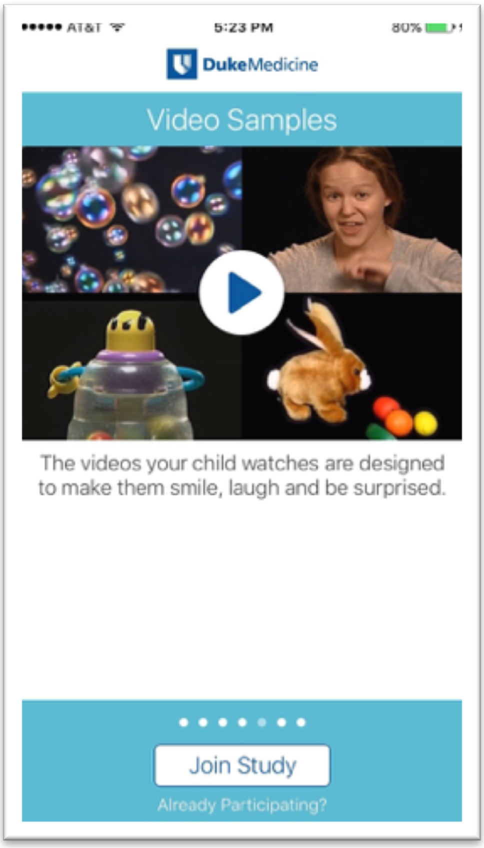
DOMAINS	QUESTIONS	ANSWERS	LOCALIZATIONS
Intro Page	Duke Temper Tantrum Survey In this survey, we will ask you about your child's behavior.	Get Started	
Having temper tantrums	In the last month has your child had a temper tantrum?	Yes, no, (if no or skipped then don't do following questions)	
If question above is "yes" then ask these two questions			
Frequency	In the last month has your child had a temper tantrum nearly every day?	Yes, no,	
Aggressive/ destructive behavior during tantrum	In the last month during a temper has your child:		
	Hit someone?	Yes, no,	
	Bitten someone?	Yes, no,	
	Kicked someone	Yes, no,	
	Hit self?	Yes, no,	
	Bitten self?	Yes, no,	
	Broken an object (like a toy, a cup)?	Yes, no,	
Exit Pages	Thank you	Done	
	Thank you for completing this survey. Please click Done to save your responses.		

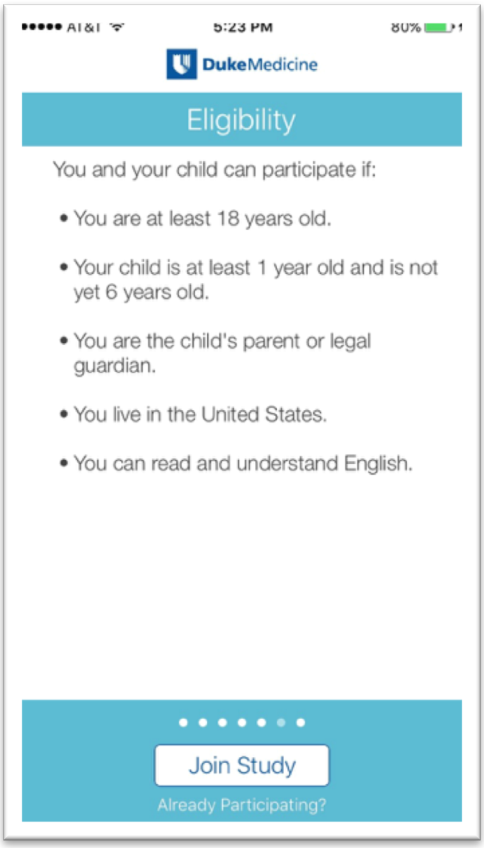
Appendix 2: In-app Screenshots







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5:23 PM
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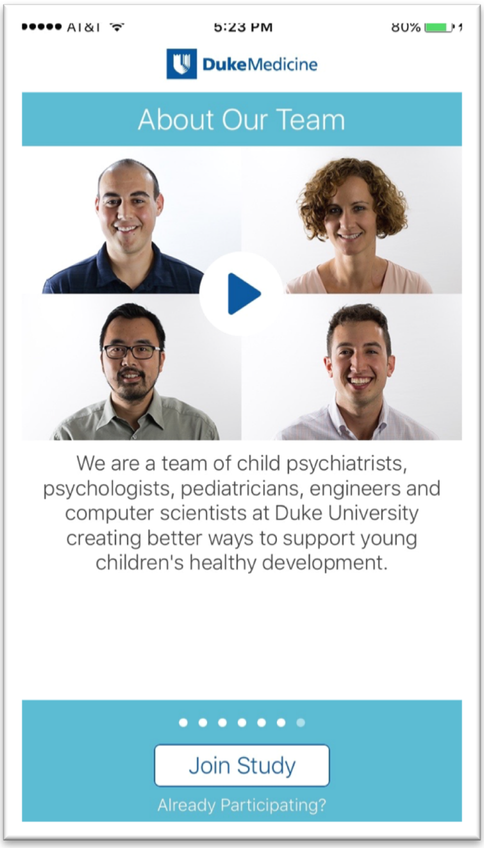
DukeMedicine
Eligibility
You and your child can participate if:
• You are at least 18 years old.
• Your child is at least 1 year old and is not yet 6 years old.
• You are the child's parent or legal guardian.
• You live in the United States.
• You can read and understand English.
Join Study
Already Participating?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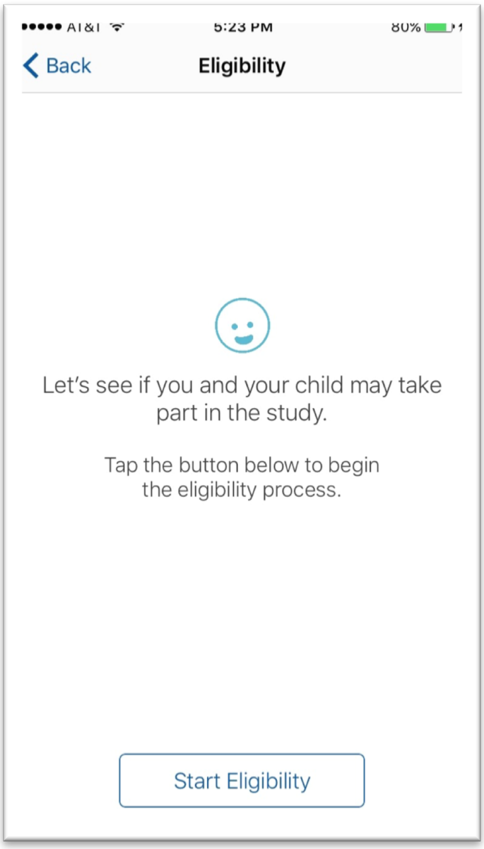
DukeMedicine
About Our Team
We are a team of child psychiatrists, psychologists, pediatricians, engineers and computer scientists at Duke University creating better ways to support young children's healthy development.
Join Study
Already Participating?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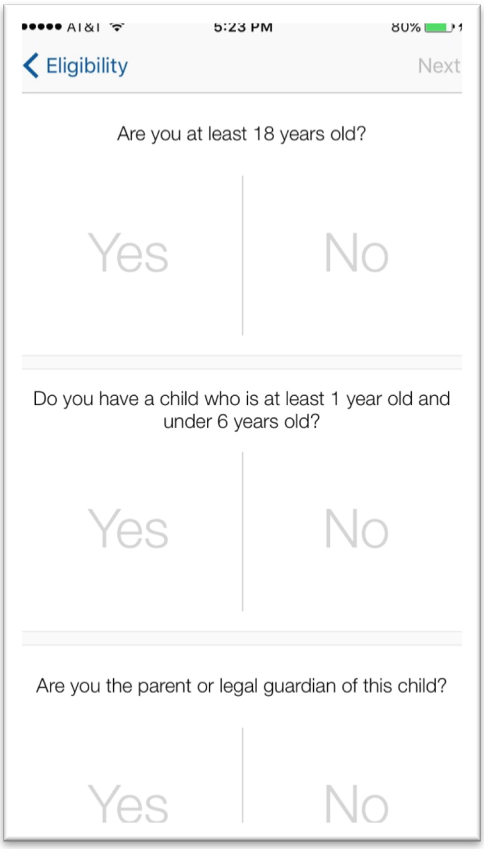
Back
Eligibility
Let's see if you and your child may take part in the study.
Tap the button below to begin the eligibility process.
Start Eligibility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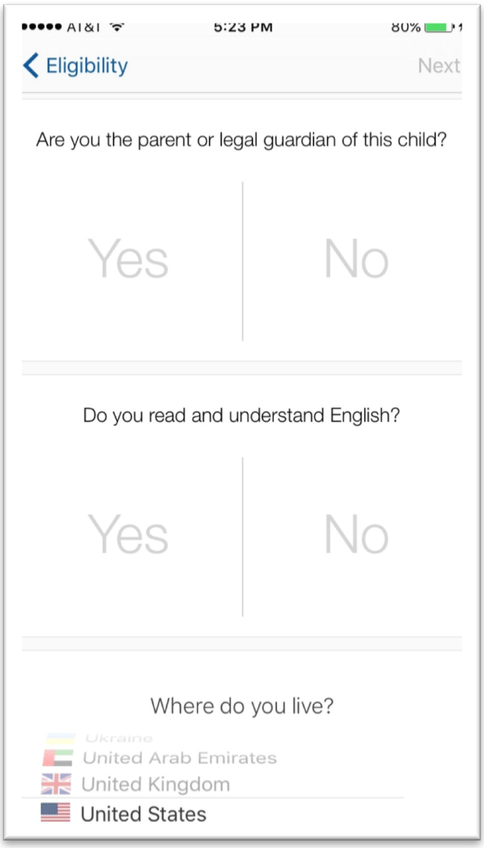
Eligibility
Next
Are you at least 18 years old?
Yes
No
Do you have a child who is at least 1 year old and under 6 years old?
Yes
No
Are you the parent or legal guardian of this child?
Yes
No



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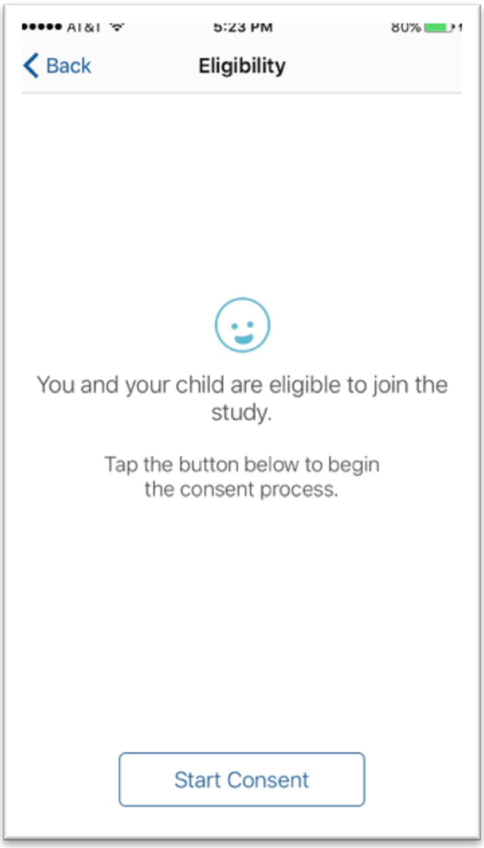
Eligibility
Next
Are you the parent or legal guardian of this child?
Yes
No
Do you read and understand English?
Yes
No
Where do you live?
Ukraine
United Arab Emirates
United Kingdom
United States



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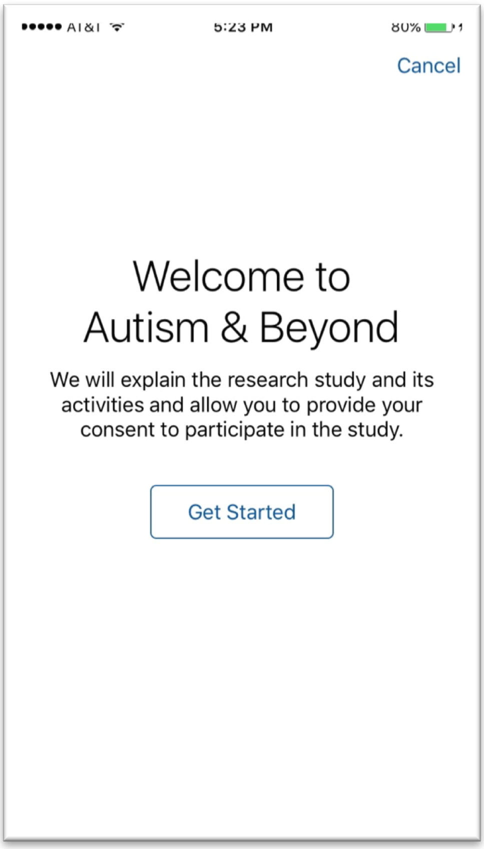
Back
Eligibility
You and your child are eligible to join the study.
Tap the button below to begin the consent process.
Start Consent



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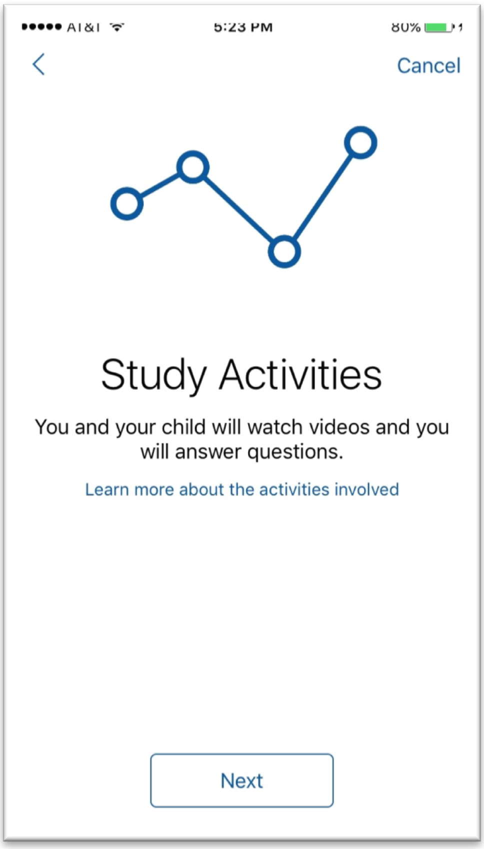
80%
Cancel
Welcome to Autism & Beyond
We will explain the research study and its activities and allow you to provide your consent to participate in the study.
Get Started



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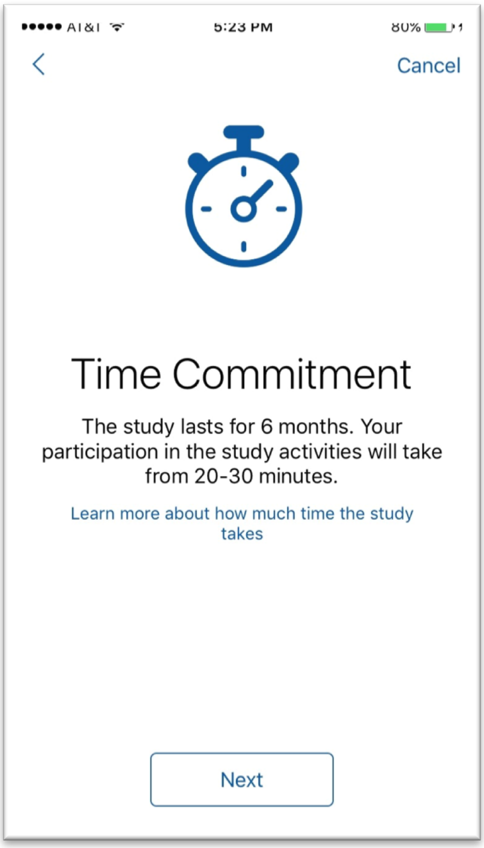
Cancel
Study Activities
You and your child will watch videos and you will answer questions.
Learn more about the activities involved
Next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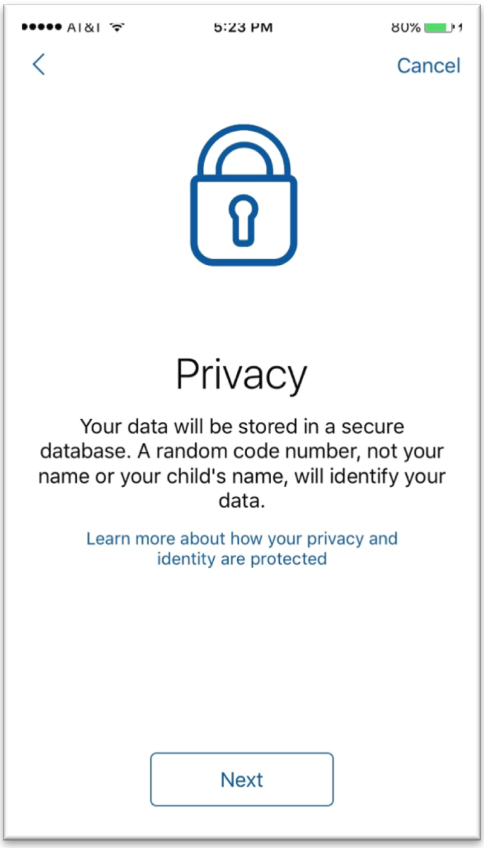
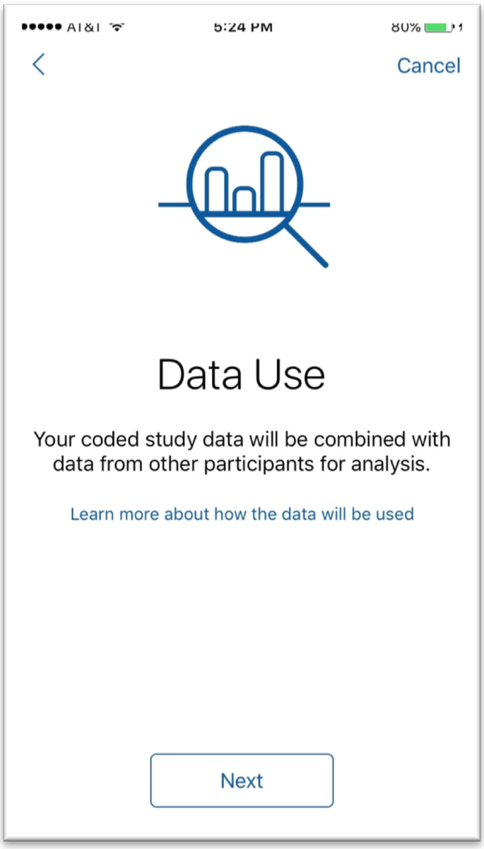
Cancel
Time Commitment
The study lasts for 6 months. Your participation in the study activities will take from 20-30 minutes.
Learn more about how much time the study takes
Next


AT&T
5:23 PM
80%
Cancel
Privacy
Your data will be stored in a secure database. A random code number, not your name or your child's name, will identify your data.
Learn more about how your privacy and identity are protected
Next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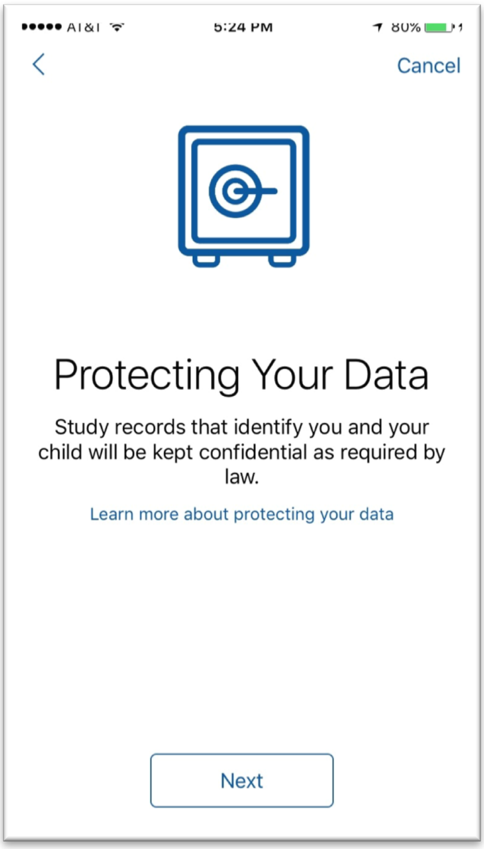
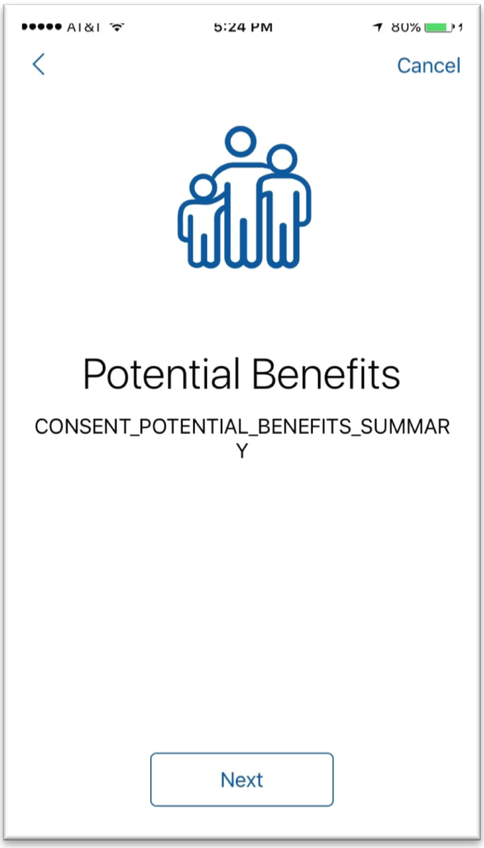
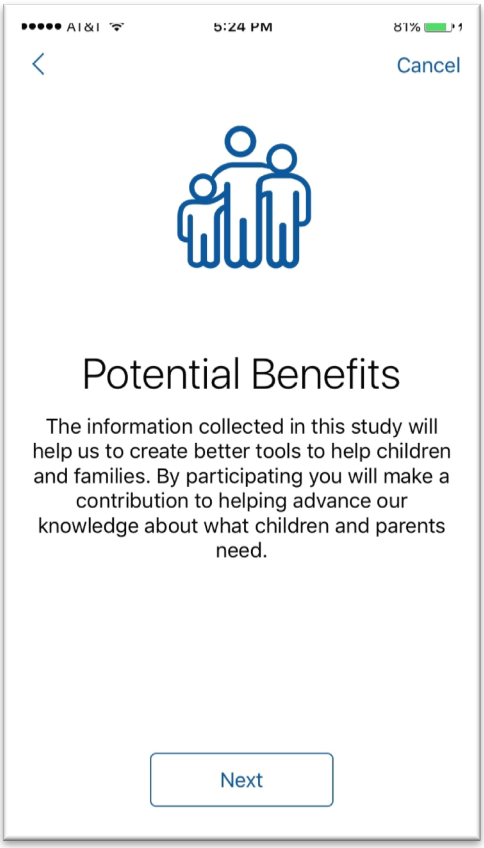
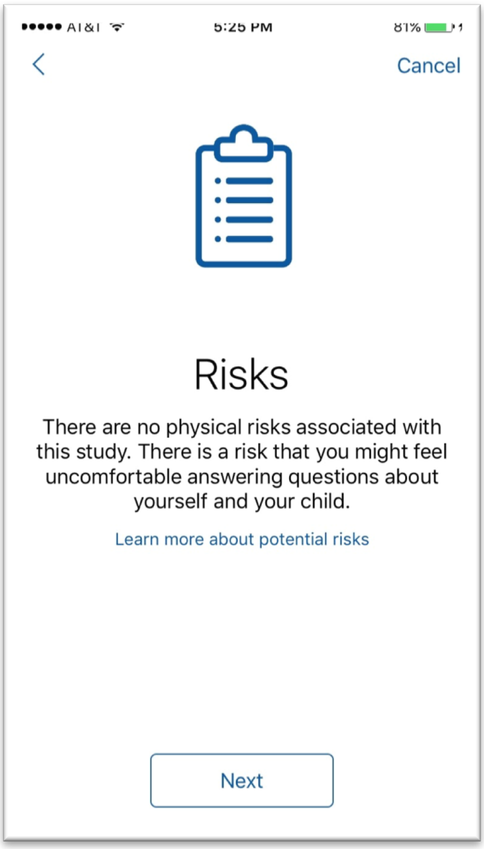
5:24 PM
80%
Cancel
Data Use
Your coded study data will be combined with data from other participants for analysis.
Learn more about how the data will be used
Next

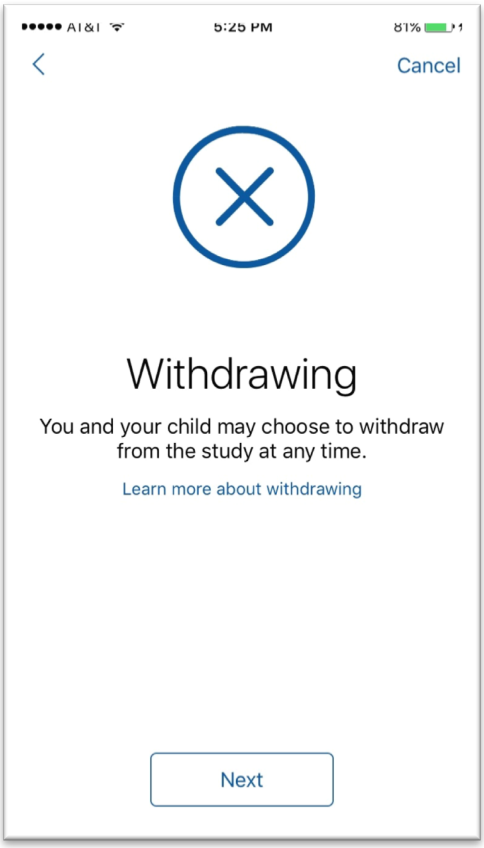

AT&T
5:24 PM
80%
Cancel
Protecting Your Data
Study records that identify you and your child will be kept confidential as required by law.
Learn more about protecting your data
Next

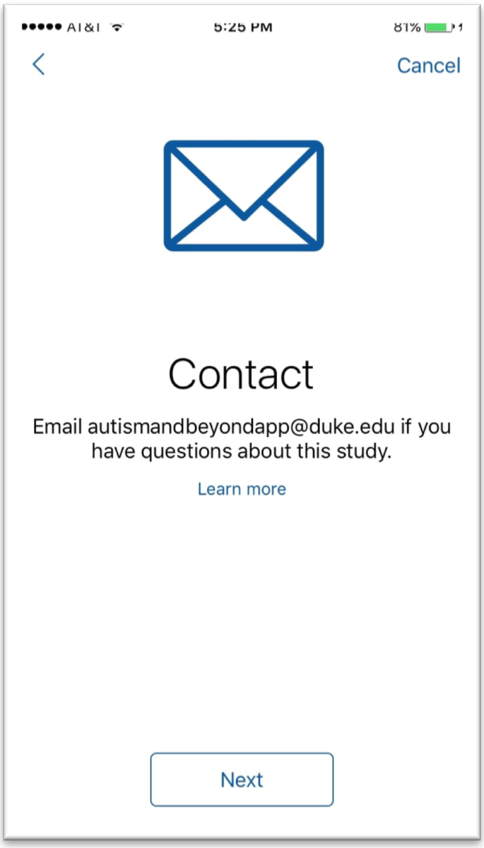

Cancel
Potential Benefits
CONSENT_POTENTIAL_BENEFITS_SUMMARY
Next


Cancel
Potential Benefits
The information collected in this study will help us to create better tools to help children and families. By participating you will make a contribution to helping advance our knowledge about what children and parents need.
Next

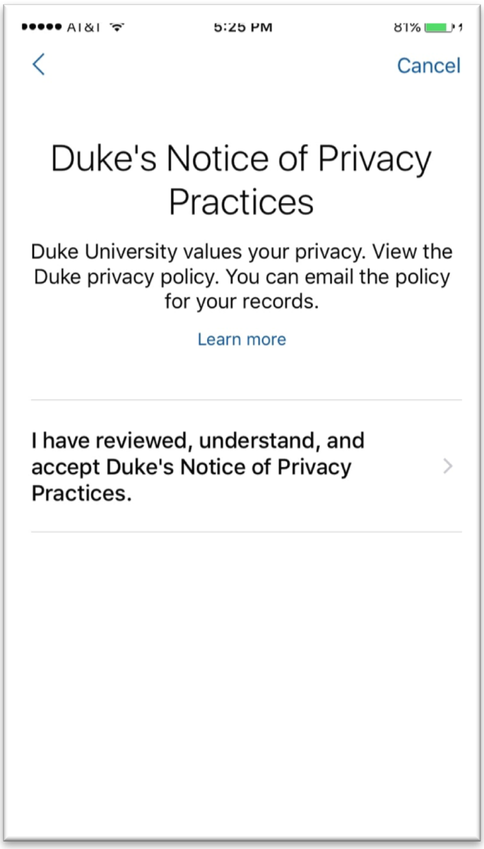

Cancel
Costs and Compensation
CONSENT_COSTS_SUMMARY
Learn more about costs and compensation
Next

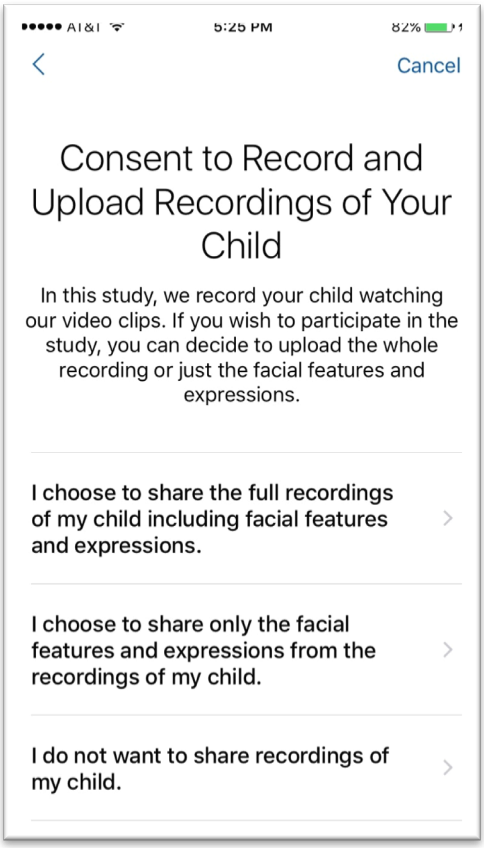

Cancel
Risks
There are no physical risks associated with this study. There is a risk that you might feel uncomfortable answering questions about yourself and your child.
Learn more about potential risks
Next

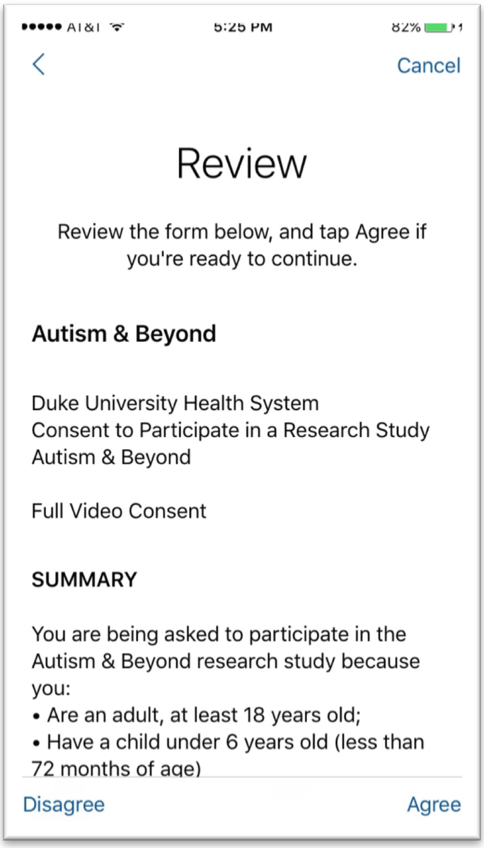

Cancel
Withdrawing
You and your child may choose to withdraw from the study at any time.
Learn more about withdrawing
Next

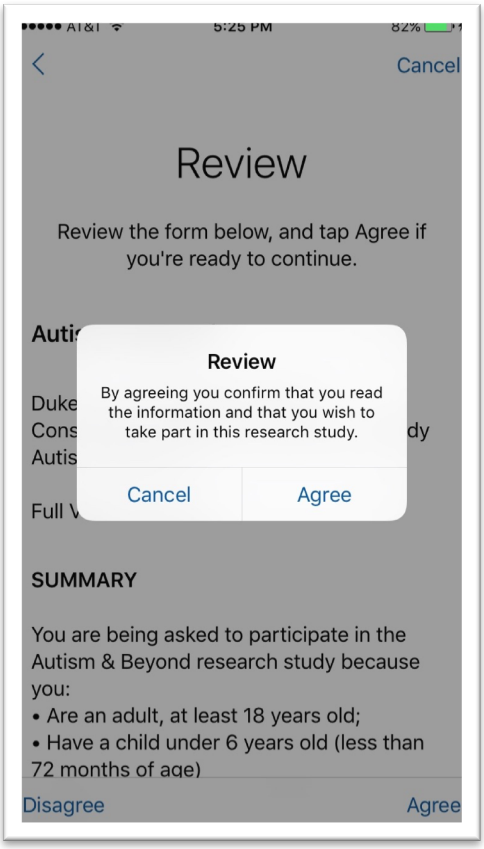

Cancel
Contact
Email autismandbeyondapp@duke.edu if you have questions about this study.
Learn more
Next

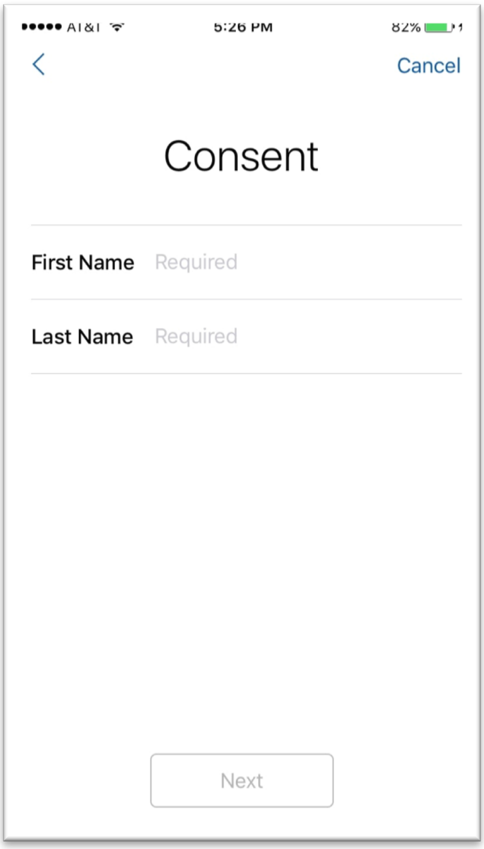

Cancel
Video Recordings
In this study, the iPhone camera records videos of your child watching short video clips. The recordings will then be uploaded to Duke's secure servers.
Learn more about the recordings
Next


Cancel
Duke's Notice of Privacy Practices
Duke University values your privacy. View the Duke privacy policy. You can email the policy for your records.
Learn more
I have reviewed, understand, and accept Duke's Notice of Privacy Practices.

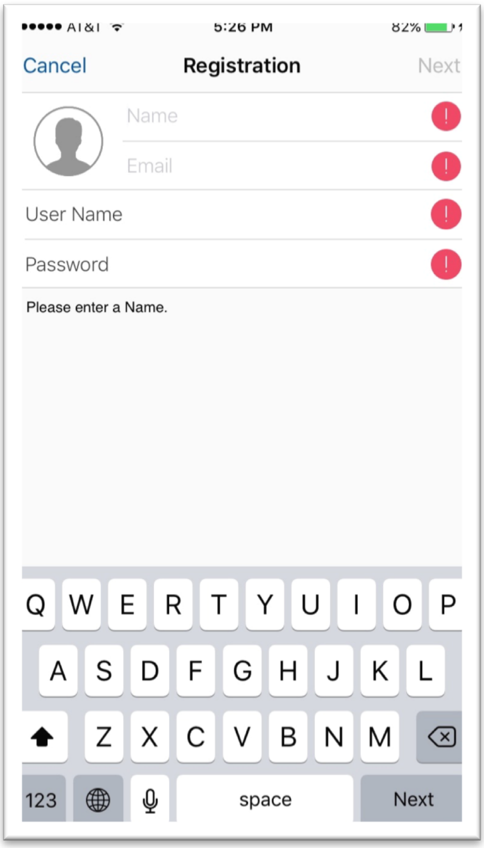

AT&T
5:25 PM
82%
Cancel
Consent to Record and Upload Recordings of Your Child
In this study, we record your child watching our video clips. If you wish to participate in the study, you can decide to upload the whole recording or just the facial features and expressions.
I choose to share the full recordings of my child including facial features and expressions.
I choose to share only the facial features and expressions from the recordings of my child.
I do not want to share recordings of my child.


AT&T
5:25 PM
82%
Cancel
Review
Review the form below, and tap Agree if you're ready to continue.
Autism & Beyond
Duke University Health System
Consent to Participate in a Research Study
Autism & Beyond
Full Video Consent
SUMMARY
You are being asked to participate in the Autism & Beyond research study because you:
• Are an adult, at least 18 years old;
• Have a child under 6 years old (less than 72 months of age)
Disagree
Agree

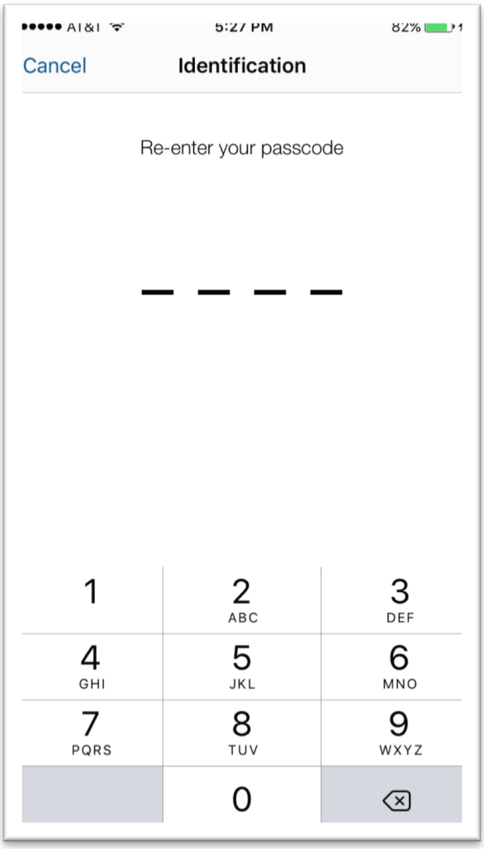

AT&T
5:25 PM
82%
Cancel
Review
Review the form below, and tap Agree if you're ready to continue.
Review
By agreeing you confirm that you read the information and that you wish to take part in this research study.
Cancel
Agree
SUMMARY
You are being asked to participate in the Autism & Beyond research study because you:
• Are an adult, at least 18 years old;
• Have a child under 6 years old (less than 72 months of age)
Disagree
Agree

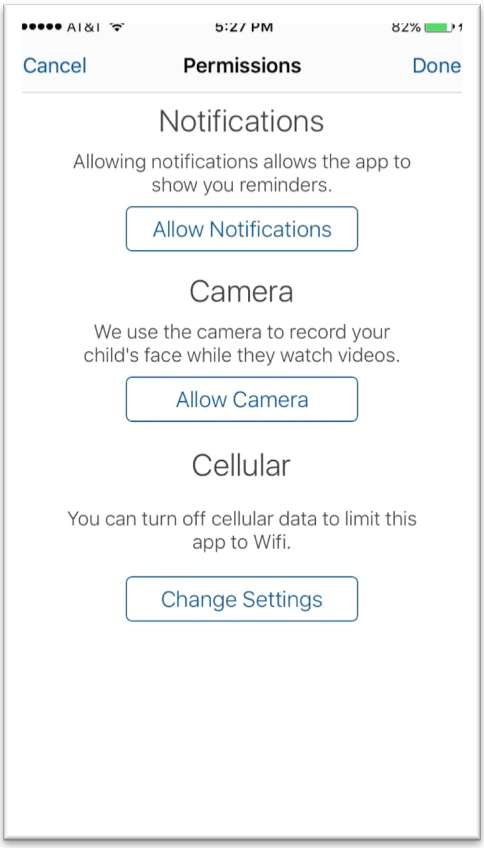

AT&T
5:26 PM
82%
Cancel
Consent
First Name
Required
Last Name
Required
Next

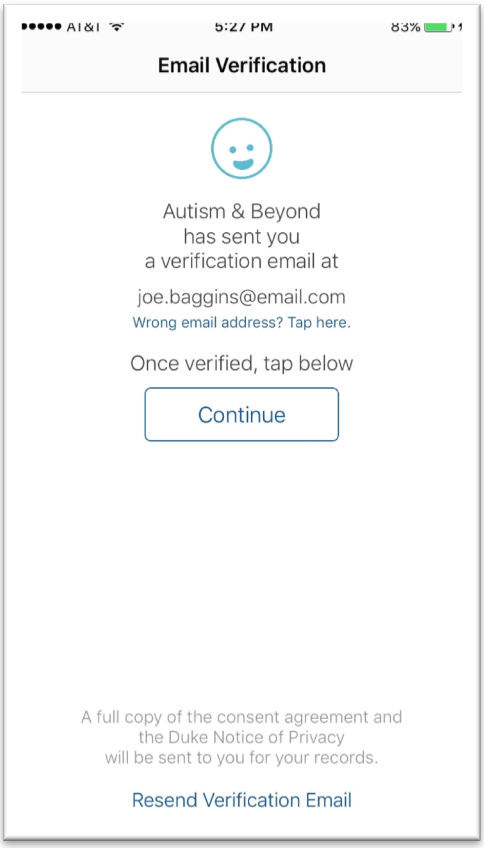

AT&T
5:26 PM
82%
Cancel
Signature
Please sign using your finger on the line below.
Sign Here
Done

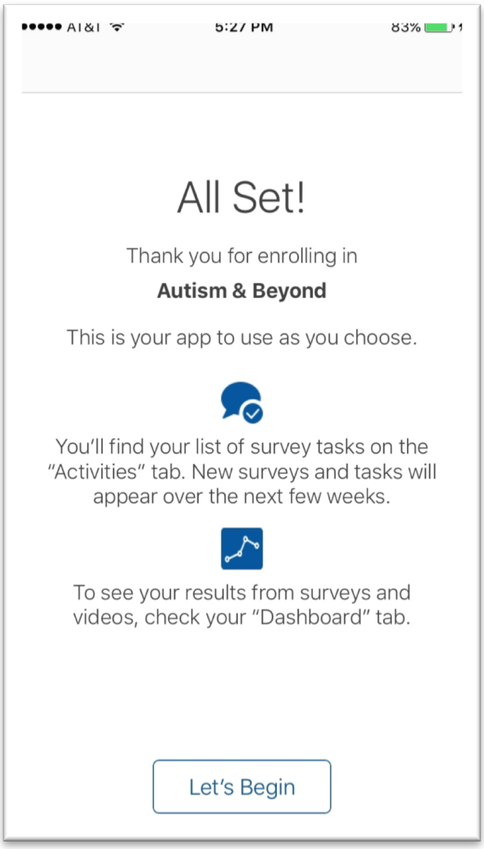

AT&T
5:26 PM
82%
Cancel
Registration
Next
Name
Email
User Name
Password
Please enter a Name.
Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M
123
space
Next

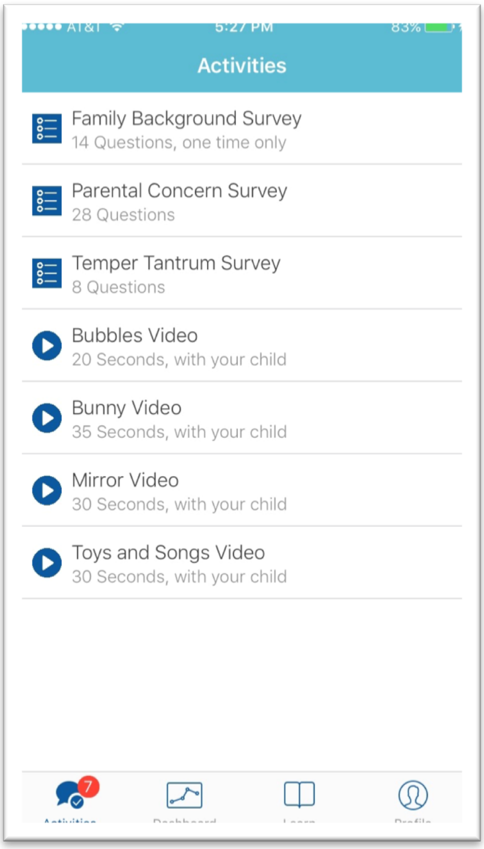

AT&T
5:26 PM
82%
Cancel
Identification
Select a 4-digit passcode. Setting up a passcode will help provide quick and secure access to this application.
1
2 ABC
3 DEF
4 GHI
5 JKL
6 MNO
7 PQRS
8 TUV
9 WXYZ
0

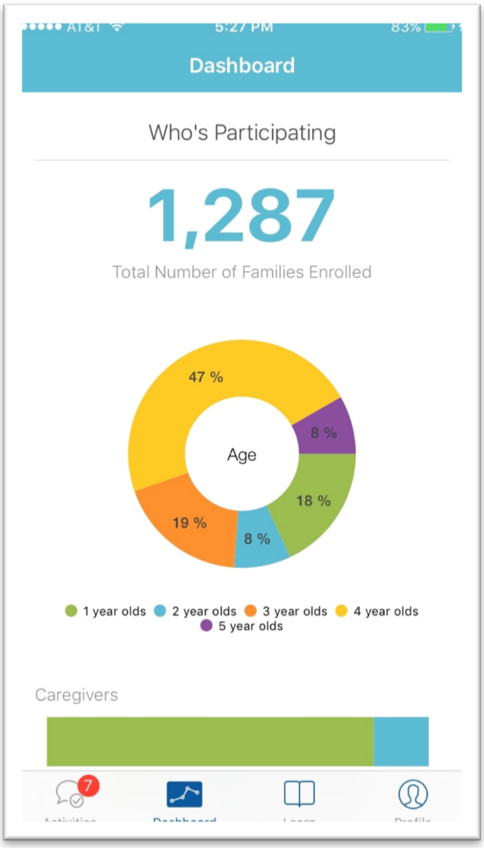

AT&T
5:27 PM
82%
Cancel
Identification
Re-enter your passcode
1
2 ABC
3 DEF
4 GHI
5 JKL
6 MNO
7 PQRS
8 TUV
9 WXYZ
0

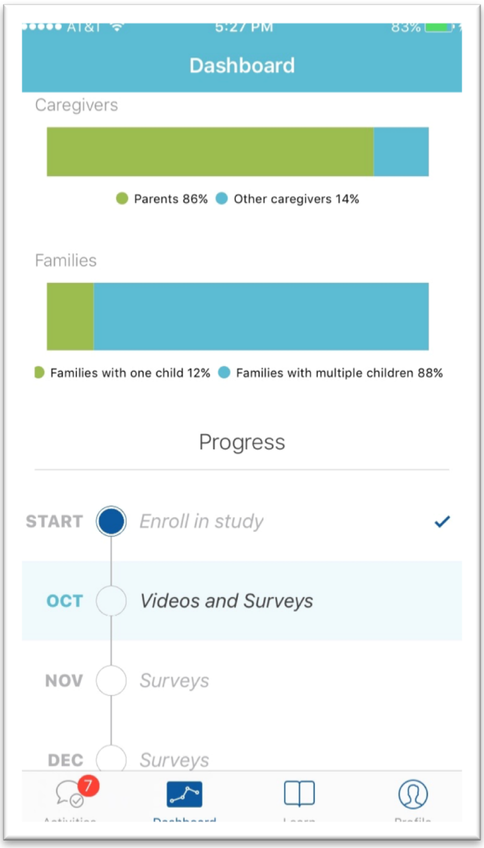

Cancel
Permissions
Done
Notifications
Allowing notifications allows the app to show you reminders.
Allow Notifications
Camera
We use the camera to record your child's face while they watch videos.
Allow Camera
Cellular
You can turn off cellular data to limit this app to Wifi.
Change Settings

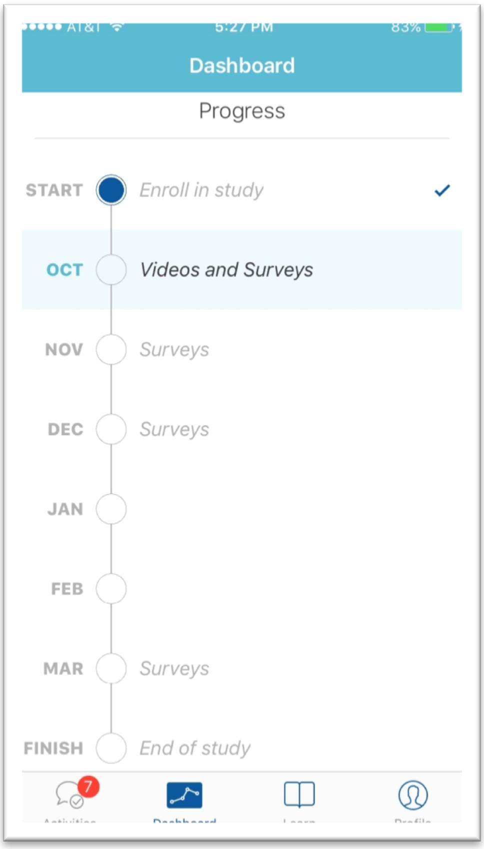

Email Verification
Autism & Beyond has sent you a verification email at
joe.baggins@email.com
Wrong email address? Tap here.
Once verified, tap below
Continue
A full copy of the consent agreement and the Duke Notice of Privacy will be sent to you for your records.
Resend Verification Email

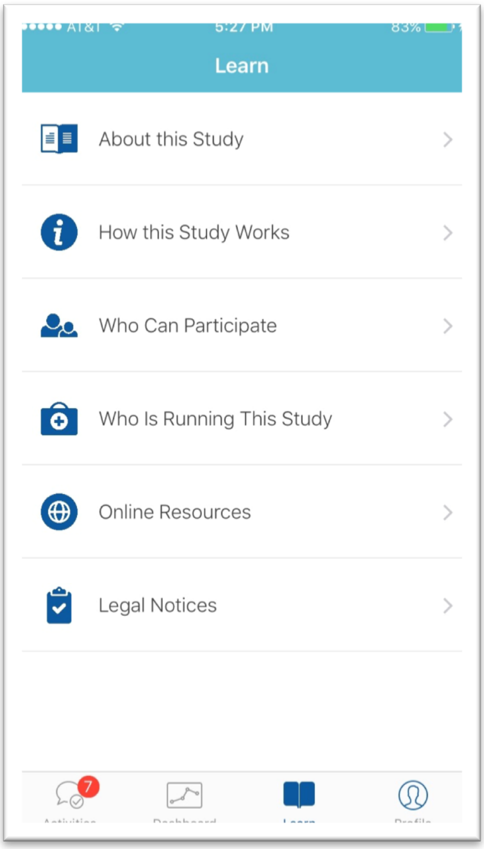

All Set!
Thank you for enrolling in
Autism & Beyond
This is your app to use as you choose.
You'll find your list of survey tasks on the "Activities" tab. New surveys and tasks will appear over the next few weeks.
To see your results from surveys and videos, check your "Dashboard" tab.
Let's Begin

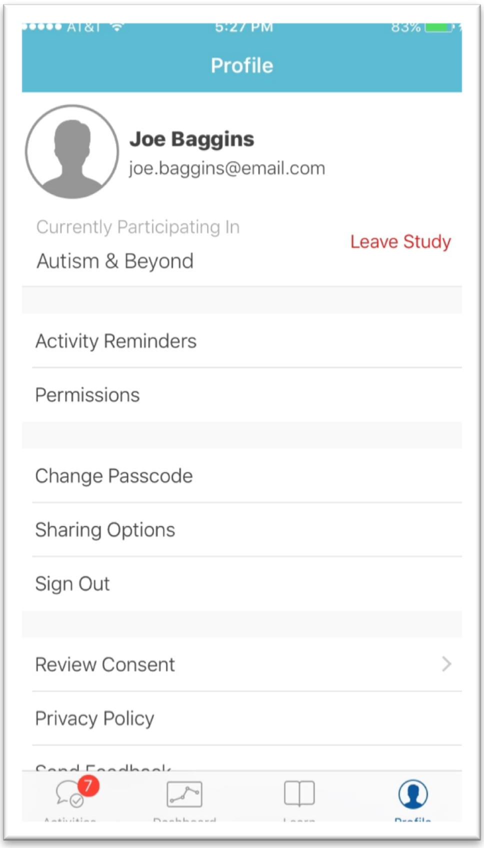

Activities
Family Background Survey
14 Questions, one time only
Parental Concern Survey
28 Questions
Temper Tantrum Survey
8 Questions
Bubbles Video
20 Seconds, with your child
Bunny Video
35 Seconds, with your child
Mirror Video
30 Seconds, with your child
Toys and Songs Video
30 Seconds, with your child
7


Dashboard
Who's Participating
1,287
Total Number of Families Enrolled
47 %
8 %
Age
18 %
19 %
8 %
1 year olds
2 year olds
3 year olds
4 year olds
5 year olds
Caregivers


Dashboard
Caregivers
Parents 86%
Other caregivers 14%
Families
Families with one child 12%
Families with multiple children 88%
Progress
START
Enroll in study
OCT
Videos and Surveys
NOV
Surveys
DEC
Surveys


Dashboard
Progress
START
Enroll in study
OCT
Videos and Surveys
NOV
Surveys
DEC
Surveys
JAN
FEB
MAR
Surveys
FINISH
End of study


Learn
About this Study
How this Study Works
Who Can Participate
Who Is Running This Study
Online Resources
Legal Notices


Profile
Joe Baggins
joe.baggins@email.com
Currently Participating In
Autism & Beyond
Leave Study
Activity Reminders
Permissions
Change Passcode
Sharing Options
Sign Out
Review Consent
Privacy Policy
7

Appendix 3: Technology Questionnaire

TECHNOLOGY USE QUESTIONNAIRE

	Question	Yes	No	Notes	Notes
1	Do you own a cell phone?				
2	What kind of cell phone?				
	Smart phone (Internet;Apps;Video)				
	Standard Cell Phone (Voice and SMS, no video or internet)				
3	Do you have a personal email address?				
4	Do you have any social media accounts?				
	Facebook				
	Whatsapp				
	Twitter				
	Other				
5	Where do you connect to the internet?				
	Home				
	Work				
	Community eg Library, Coffee shop etc.				
6	How do you connect to the internet at home?				
	We have our own modem and internet service				
	We connect via free community WiFi				
	We connect via paid WiFi				
	We use cellphone data				
7	On a scale of 1 (very poor) to 10 (excellent) , rate your own skill with using cell phone technology				
	1			6	
	2			7	
	3			8	
	4			9	
	5			10	

Faculty of Health Sciences
Division of Child and Adolescent Psychiatry
University of Cape Town
46 Sawkins Road,
Rondebosch
7700
Tel. (021) 685 4103 Fax. (021) 685 4107

Principal Investigator: Prof. Petrus J de Vries
M.Sc. student (and project coordinator): Dr. Aubrey Kumm

INFORMED CONSENT FORM

Autism & Beyond South African sub-study to determine the feasibility of collecting phone-based assessments and video observation data in a South African community setting.

Background

Autism & Beyond is an Apple iPhone app to test new cell phone technology that can record and analyse a child's emotion and behaviour. The idea behind this technology is to one-day screen young children in their natural environments, such as their homes, for autism and other mental health challenges. The app was developed by a team of researchers from Duke university in the United States of America. As part of a larger study conducted by the team at Duke, the University of Cape Town is conducting a small study to test the app for use in South African communities.

Invitation to participate

You are being asked to participate in the Autism & Beyond research study because you:

- Are an adult, at least 18 years old;
- Have a child who is at least 1-year-old but not yet 6 years old
- Are the parent or legal guardian of this child;
- Speak and read English;
- Live in the Cape Town Metropolitan area
- Willing to use the iPhone provided by the researcher to participate in this study.

Your participation in this study is entirely voluntary; research studies include only people who choose to take part. To be in a research study you must give your informed consent. The purpose of this form is to help you decide if you want to participate in this study. Please read the information carefully. If you decide to take part in this research study, you will be provided with a copy of this signed and dated consent form. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time. You should not participate in the research study until all of your questions are answered.

We encourage you to read the Privacy Policy as well as the informed consent.

Participating in a research study is not the same as receiving medical care. The decision to participate or not participate in the research study will not affect your medical benefits. The South African sub-study is being conducted by Prof. Petrus J De Vries and Dr Aubrey J Kümm, University of Cape Town. The U.S.A. study is being conducted by Drs. Helen Egger, Geraldine Dawson, Guillermo Sapiro, and Richard Bloomfield, Duke University.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to test new methods for collecting information about children's behaviour and emotions. These tools include the iPhone, or other smart devices and the Apple ResearchKit platform, as well as the smartphone application ("app") designed by the research team. New technologies will allow people to interact with researchers from all across the country. This study will test if it is possible to accurately capture information about emotion and attention in young children using the camera in the device. This information may help researchers develop distance-based tools for screening young children for developmental and emotional problems. The long-term goals of the project are to increase access to childhood mental health screening, to make tools that are accessible to parents and educators, and to help target diagnostic evaluations toward the children who most need them. The University of Cape town is conducting the study in collaboration with Duke university in the U.S.A. The South African study forms part of a larger study conducted by Duke university in the U.S.A.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

We anticipate enrolling 50 subjects in this feasibility pilot-study, however we may at a later stage enrol as many participants as are interested and eligible when the app becomes available via the App Store in South Africa. This study forms part of a larger study conducted by Duke university in the United States of America where the Autism&Beyond app is currently available for download from the USA app store for USA residents.

WHAT IS INVOLVED IN THE STUDY?

If you agree to join the study, you will need to register an account and confirm your agreement to participate in this study via the study app on our mobile device. The information you will be providing us will include your responses to questionnaires, as well as video recordings of your child's face while watching short videos. We may also ask you to again answer questions and/or perform activities on our mobile device at a later stage.

- *Register to participate in the study:* You will follow the prompts on the app to register an account and confirm your agreement to participate in this study. The registration will include entering your name, email address, other demographic information about yourself and answering a few questions to verify your eligibility. You can cancel the registration process or request to be removed from the study at any time without further explanation and without any negative consequences.

- *Video Observation:* Your child will watch some short videos on the iPhone screen. Using the camera in the phone, the app will record your child's reaction to the things they see on the screen. We will ask you to have your child sit on your lap or in a car seat, highchair, or booster seat where the device can be held stable in front of them during this activity. The videos are all designed to be happy or neutral to young children, none are meant to upset or frighten your child. You will not be given feedback regarding this video assessment.

- *Questionnaires:* You will be asked to provide some basic information about yourself and your child. This will include your child's date of birth and your age, gender, race and ethnicity, and the area where you live. You will also be asked to answer some questions about your child's social and communication behaviour, about any concerns you may have around these areas, and about tantrums your child might have.

- *Feedback:* You will be asked to provide feedback about the app and the study. We may contact you at a later stage to ask you to participate in new portions of the project, or to provide additional feedback. New portions of the study will have a separate consent form to explain the purpose and the activities involved in participating. Participating in this study does not mean you have to participate in any future portions of the study or agree to being contacted again at a later stage if you do not want to.

HOW LONG WILL I BE IN THIS STUDY?

Your participation in the study will last up to six months.

WHAT ARE THE RISKS OF THE STUDY?

There are no known physical risks to you or your child associated with this proposed study.

One possible risk of this study is the discomfort that some people feel when answering questions about personal or emotional issues. Some of the questions we will ask you and your child as a part of this study may make you feel uncomfortable. You may refuse to answer almost any of the questions, and you may take a break at any time during the study. We do require that you enter your child's date of birth so that we can determine eligibility to participate in the study. You and your child may stop being in this study at any time. We ask that if your child gets upset by the video observation or indicates that they no longer wish to take part, that you stop, and either take a break or withdraw from the study.

There is also the potential risk of loss of confidentiality. Every effort will be made to keep your information confidential, however, this cannot be guaranteed. There is a risk that study data might be subpoenaed for legal purposes. Except under circumstances covered under the mandated child abuse reporting laws, no information about the child or family will be shared with any individual or agency without prior written consent.

The researchers may voluntarily disclose, without your consent, information that would identify you as a participant in the research project only if research personnel notice evidence of child abuse or neglect. In such cases a child psychiatrist, will review the material. If there is evidence of abuse or neglect, the child psychiatrist will inform the appropriate authorities as per the national guidelines for child protection of the Republic of South Africa.

Apple does not have access to any data collected by this ResearchKit app

These permissions can be revoked/cancelled by you at any time. Data from the study will be stored at Duke but may also be stored, at least temporarily, on our device.

This is a feasibility study of the Autism & Beyond app. and you will therefore not receive any information or feedback based on the use of this mobile app. You should discuss health issues and decisions directly with your healthcare provider.

How will this focus group benefit me?

Your participation in this study will not directly benefit you or your child. However, the information you provide during the focus group is very important and will help us develop mental health apps beneficial for your communities

WHAT ALTERNATIVES ARE THERE TO PARTICIPATION IN THIS STUDY?

Since no medical treatments are provided during this study there are no alternative therapies. The only alternative is to not participate.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?

Study records that identify you or your child will be kept confidential as required by law. National Privacy Regulations provide safeguards for privacy, security, and authorized access. Except when required by law, you and your child will not be identified by name, Identity number, address, telephone number, or any other direct personal identifier in study records. For records disclosed to other researchers for study purposes, you and your child will be assigned a unique code number. This information will be stored in a password-protected network computer location on a server at Duke university, and access to the information will be restricted to the research personnel.

You and your child’s records may be reviewed in order to meet United States federal or state regulations. Reviewers may include representatives of the Office of Human Research Protection and the Duke University Health System Institutional Review Board.

The study results will be retained in your and your child’s research record for six years after the study is completed, or until your child reaches the age of 21, whichever is longer. At that time, either the research information not already in your child’s medical record will be destroyed or information identifying your child will be removed from such study results at Duke University.

If this information is disclosed to outside reviewers for audit purposes, it may be further disclosed by them and may not be covered by the privacy regulations.

While the information and data resulting from this study may be presented at scientific meetings or published in a scientific journal, neither your identity nor your child’s identity will be revealed.

Video Observation Data

As a part of this study we ask that you submit video recordings of your child watching a video on the mobile device. The video data files may be large, and will need to be stored temporarily on your device before they are uploaded to the Duke servers. This may impact the available storage you have on your device. Once the videos have been confirmed as successfully transmitted they will be deleted by the app.

You may also be concerned about recording and transmitting videos of your child. Videos transmitted to the researchers at Duke will be done using secure (encrypted) transmission methods, and they will be retained on servers located at Duke. These servers are built to meet all standards for storage of electronic Protected Health Information (ePHI) as required by the Health Insurance Portability and Accountability Act (HIPPA) and The Health Information Technology for Economic and Clinical Health Act (HITECH).

If you do not feel comfortable sharing the video with the researchers you will also have an option to share only data of your child's facial landmarks (such as, points around the eyes, nose, mouth) In the app you will be able to see what the landmarks look like. If you decide to share only the landmarks, data about the landmarks will be uploaded, not the entire video. When the landmarks have been uploaded, the video of your child will be erased from your phone.

WHAT ARE THE COSTS?

Other than possible travel costs, there will be no cost to you for taking part in the study.

WHAT ABOUT COMPENSATION?

As a token of our appreciation we will give all participants in the study R100.00 that can also be used towards your travel expenses.

WHAT ABOUT MY RIGHTS TO DECLINE PARTICIPATION OR WITHDRAW FROM THE STUDY?

You or your child may choose not to be in the study. If you and your child agree to be in the study, you and your child may withdraw from the study at any time. To withdraw you can select "Leave Study" on the profile tab in the app or let the researcher know at any time during the study. If you and your child withdraw from the study, no new data about your child will be collected for study purposes unless the data concern an adverse event (a bad effect) related to the study. We will retain any data already collected in the study before you withdrew.

You can also request, via an email to kmmaub001@myuct.ac.za or sms message to 0722645450, that the researchers delete any of the video observation data on your child that has already collected as part of study.

Your or your child's decision not to participate or to withdraw from the study will not involve any penalty or loss of benefits to which you or your child are entitled, and will not affect your or your child's usual access to health care services.

WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

Should you have any questions or queries about the research or your participation, please do not hesitate to contact Dr Aubrey Kümm: (cell) 072 2645450, (email) KMMAUB001@myuct.ac.za or Professor Petrus de Vries: (telephone) 021 6854103, (email) petrus.devries@uct.ac.za

Dr Aubrey Kümm
M.Sc. student
University of Cape Town
KMMAUB001@myuct.ac.za (072 2645450)

Prof Petrus de Vries
Sue Struegmann Professor
Division of Child and Adolescent Psychiatry
University of Cape Town
petrus.devries@uct.ac.za

You may contact the **UCT Faculty of Health Sciences Human Research Ethics Committee (HREC)** with any ethical concerns or questions about you welfare as study participants.
Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory,
7925
021 4066338

STATEMENT OF CONSENT

I hereby confirm that:

a. I have read and understand the consent form. Yes/No

b. I agree to participate in the focus group. Yes/No

c. I am aware that an audio recording of the focus group interview will be made and agree to be audiotaped. Yes/No

d. I understand that the material will become available to authorized researchers only and that no information will be shared for purposes other than research. Yes/No

e. I understand that that individual persons cannot be identified in the results of the study but that confidentiality cannot be guaranteed. Yes/No

I confirm below with my signature that I consent to participation in the study and handling of my personal information as described above.

___________________________________	______________________________
Parent/Legal guardian Signature	*Parent/Legal guardian Name (Print)*

____

Date

___________________________________	______________________________
Witness Signature	*Witness Name (Print)*

____

Date

I have explained the study to the participant, and in my opinion s/he understands that participation is voluntary and is able to give informed consent.

_________________________________ _____________________________

Researcher Signature *Researcher's name (in print)*

____

Date

Form
M0345

DUKE UNIVERSITY HEALTH SYSTEM

Consent To Participate In A Research Study
Autism & Beyond

SUMMARY

You are being asked to participate in the Autism & Beyond research study because you:

- Are an adult, at least 18 years old;
- Have a child who is at least 1 year old but not yet 6 years old;
- You are the parent or legal guardian of this child;
- Speak and read English;
- Live in the United States of America; and,
- Have an iPhone you are willing to use to participate or participate through a clinic, preschool or day care center.

Your participation in this study is entirely voluntary; research studies include only people who choose to take part. To be in a research study you must give your informed consent. The purpose of this form is to help you decide if you want to participate in this study. Please read the information carefully. If you decide to take part in this research study, you will be emailed a copy of this signed and dated consent form to the address associated with the Apple account used to enroll in the study. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time.

You should not participate in the research study until all of your questions are answered. We encourage you to read the Privacy Policy as well as the informed consent.

Participating in a research study is not the same as receiving medical care. The decision to participate or not participate in the research study will not affect your medical benefits.

This study is being conducted by Drs. Helen Egger, Geraldine Dawson, Guillermo Sapiro, and Richard Bloomfield.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to test new methods for collecting information about children's behavior and emotions. These tools include the iPhone, or other smartdevices and the Apple ResearchKit platform, as well as the smartphone application ("app") designed by the research team.

New technologies will allow people to interact with researchers from all across the world. This study will test if it is possible to accurately capture information about emotion and attention in young children using the camera in the device. This information may help researchers develop distance-based tools for screening young children for developmental and emotional problems. The long-term goals of the project are to increase access to childhood mental health screening, to make tools that are accessible to parents and educators, and to help target diagnostic evaluations toward the children who most need them.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
We anticipate enrolling 20,000 subjects in this study, however this is a new type of research and we will enroll as many participants as are interested and eligible.

WHAT IS INVOLVED IN THE STUDY?
If you decide to join the study you will need to download the free study app on your mobile device, register an account and confirm your agreement to participate in this study. You may also be able to participate through an event at a clinic, preschool or day care center. Then, periodically we will ask you to answer questions and/or perform activities on your mobile device. If you have used a study-owned device at an event, you can make arrangements with study staff if you would like to complete future study activities. Your study data will include your responses to surveys and activities and measurements from the phone itself about how you are moving and interacting with others as described below.

- Register to the study: You will follow the prompts on the app to register an account and confirm your agreement to participate in this study. There will be an electronic consent process explaining the risks and benefits of using the app. The registration will include entering your name, email address, other demographic information about yourself and answering a few questions to verify your eligibility. You can cancel the registration process at any time.
- Video Observation: Your child will watch some short videos on the device screen. Using the camera in the phone the app will record your child's reaction to the things they see on the screen. If you normally block your camera, you will need to unblock it during the times your child is watching the video. We will ask you to have your child sit on your lap or in a car seat, highchair, or booster seat where the device can be held stable in front of them during this activity. The videos are all designed to be happy or neutral to young children, none are meant to upset or frighten your child. You will not be given feedback regarding this video assessment.
- Questionnaires: You will be asked to provide some basic demographic information about yourself and your child. This will include date of birth for yourself and your child, gender, race and ethnicity. You will also be asked to answer some questions about your child's social and communication behavior, about any concerns you may have around these areas, and about tantrums your child might have. One of these questionnaires is the Modified Checklist for Autism in Toddlers (M-CHAT). This measure has only been developed for use in children between the ages of 16 and 30 months of age, so if your child is not in that age range you will not be asked to complete the M-CHAT. The M-CHAT provides some information about the risk of Autism Spectrum Disorders in young children, and if you complete this measure you will receive feedback with your child's risk level (low, moderate, or high). This information is not a diagnosis, and should be conveyed to your child's pediatrician if you have any concerns. We cannot diagnose Autism Spectrum Disorders using this app.

- Device measurements: Through the study app, we will also collect the following items that your device normally records: such as the type of device, iOS version, and the IP address.
- Feedback: You will be asked to provide feedback about the app and the study.

We may send notices (called "push notifications") to your device or email asking you to complete these activities and surveys. You may choose to act at your convenience, (either then or later) and you may choose to participate in all or only in some parts of the study. These surveys and activities should take you about 20 minutes to complete. You can adjust the app settings to turn on and off sending data at any time. Occasionally we may re-contact you to ask you to participate in new portions of the project, or to provide additional feedback. New portions of the study will have a separate consent document to explain the purpose and the activities involved in participating. Participating in this study does not mean you have to participate in any future portions of the study or complete additional contacts if you do not want to.

HOW LONG WILL I BE IN THIS STUDY?
Your participation in the study will last up to six months, but may involve only one (1) session if you participated through an event at a clinic, preschool or day care center on a study owned device. If you have participated on your personal device, you will be asked to complete all the activities initially after you download the app and provide consent. You will be notified asked to repeat the 3 questions on child tantrums 1 week from when you enroll and again 1 month later. We hope that you will complete all of the questionnaires again at 3 months and 6 months from when you first enroll. You will be notified when you have a task to complete.

WHAT ARE THE RISKS OF THE STUDY?
There are no known physical risks to you or your child associated with this proposed study.

One possible risk of this study is the discomfort that some people feel when answering questions about personal or emotional subjects. Some of the questions we will ask you and your child as a part of this study may make you feel uncomfortable. You may refuse to answer almost any of the questions, and you may take a break at any time during the study. We do require that you enter your child's date of birth so that we can determine if the M-CHAT is applicable. You and your child may stop being in this study at any time. We ask that if your child gets upset by the video observation or indicates that they no longer wish to take part that you stop, and either take a break or withdrawal from the study.

There is also the potential risk of loss of confidentiality. Every effort will be made to keep your information confidential, however, this cannot be guaranteed. There is a risk that study data might be subpoenaed for legal purposes. Except under circumstances covered under the mandated child abuse reporting laws, no information about the child or family will be shared with any individual or agency without prior written consent.

The researchers may voluntarily disclose, without your consent, information that would identify you as a participant in the research project only if research personnel notice evidence of child abuse or neglect. In such cases a child psychiatrist, will review the material. If there is evidence of abuse or neglect, the necessary Child Protective Services law report will be filed with the Department of Social Services.

All Duke ResearchKit mobile applications or 'apps' have a Privacy Policy which you should read carefully. Apple does not have access to any data collected by ResearchKit apps. Any mobile app that is downloaded carries potential security risks, and Duke cannot guarantee that these mobile apps are free of risk. As you use the app, it will ask you for specific permissions, which you choose whether to allow. These permissions can be revoked by you at any time. You are encouraged to limit personal identifiers you enter into mobile applications (particularly your name, date of birth, address, place of employment, and other details that could allow someone to identify you) only to those that you wish to voluntarily share with others. Data from the study will be stored at Duke but may also be stored, at least temporarily, on your device.

It is recommended that you run a current operating system (OS) on your device, review the privacy/security settings often, and restrict any unnecessary access. These applications may run in the background of your device. Mobile apps may have unanticipated impact on the operations of your device (such as battery drainage). If you do not have an unlimited data/text plan, you may incur additional charges. At the conclusion of the study, you may remove the mobile app from your device.

We are not asking you to make any health decisions based on the use of these mobile apps. You should discuss health decisions directly with your healthcare provider.

WHAT ALTERNATIVES ARE THERE TO PARTICIPATION IN THIS STUDY?
Since no medical treatments are provided during this study there are no alternative therapies. The only alternative is to not participate.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?
Study records that identify you or your child will be kept confidential as required by law. Federal Privacy Regulations provide safeguards for privacy, security, and authorized access. Except when required by law, you and your child will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of Duke University Health System (DUHS). For records disclosed outside of DUHS, you and your child will be assigned a unique code number. This information will be stored in a password-protected network

computer location on a server at Duke, and access to the information will be restricted to the research personnel.

You and your child's records may be reviewed in order to meet federal or state regulations. Reviewers may include representatives of the Office of Human Research Protection and the Duke University Health System Institutional Review Board.

The study results will be retained in your and your child's research record for six years after the study is completed, or until your child reaches the age of 21, whichever is longer. At that time, either the research information not already in your child's medical record will be destroyed or information identifying your child will be removed from such study results at DUHS.

If this information is disclosed to outside reviewers for audit purposes, it may be further disclosed by them and may not be covered by the federal privacy regulations.

While the information and data resulting from this study may be presented at scientific meetings or published in a scientific journal, neither your identity nor your child's identity will be revealed.

Video Observation Data

As a part of this study we ask that you submit video recordings of your child watching a video on the mobile device. The video data files may be large, and will need to be stored temporarily on your device before they are uploaded to the Duke servers. This may impact the available storage you have on your device. Once the videos have been confirmed as successfully transmitted they will be deleted by the app.

You may also be concerned about recording and transmitting videos of your child. Videos transmitted to the researchers at Duke will be done using secure (encrypted) transmission methods, and they will be retained on servers located at Duke. These servers are built to meet all standards for storage of electronic Protected Health Information (ePHI) as required by the Health Insurance Portability and Accountability Act (HIPPA) and The Health Information Technology for Economic and Clinical Health Act (HITECH).

If you do not feel comfortable sharing the video with the researchers you will also have an option to share only data of your child's facial landmarks (such as, points around the eyes, nose, mouth) In the app you will be able to see what the landmarks look like. If you decide to share only the landmarks, data about the landmarks will be uploaded, not the entire video. When the landmarks have been uploaded, the video of your child will be erased from your phone.

WHAT ARE THE COSTS?

There will be no cost to you or your insurance for taking part in the study. If you do not have an unlimited data/text plan, you may incur additional charges. The default option for uploading the video observation data to Duke is to wait until your device is signed into WiFi to avoid using mobile data, but you can change this setting, which may result in increased data usage and potential charges if you exceed your plan.

WHAT ABOUT COMPENSATION?
You will not be compensated for being in this study.

WHAT ABOUT RESEARCH RELATED INJURIES?
Immediate necessary medical care is available at Duke University Medical Center in the event that you are injured as a result of your participation in this research study. However, there is no commitment by Duke University, Duke University Health System, Inc., or your Duke physicians to provide monetary compensation or free medical care to you in the event of a study-related injury.

For questions about the study or research-related injury, contact Dr. Helen Egger at 919-687-4686 ext. 253 at any time.

WHAT ABOUT MY RIGHTS TO DECLINE PARTICIPATION OR WITHDRAW FROM THE STUDY?
You or your child may choose not to be in the study. If you and your child agree to be in the study, you and your child may withdraw from the study at any time. To withdraw you can select “Leave Study” on the profile tab in the app. You can also delete the app from your mobile device. If you and your child withdraw from the study, no new data about your child will be collected for study purposes unless the data concern an adverse event (a bad effect) related to the study. We will retain any data already collected in the study before you withdrew.

You can also request, via an email to AutismAndBeyondApp@Duke.edu, that the researchers delete any of the video observation data on your child that has already collected as part of study.

Your or your child’s decision not to participate or to withdraw from the study will not involve any penalty or loss of benefits to which you or your child are entitled, and will not affect your or your child’s access to health care at Duke.

We will tell you about new information that may affect your health, welfare, or willingness to stay in this study.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

DUKE UNIVERSITY HEALTH SYSTEM

Consent To Participate In A Research Study
Autism & Beyond

For questions about the study or a research-related injury, or if you have problems, concerns, questions or suggestions about the research, Dr. Helen Egger at 919-687-4686 ext. 253 at any time.

For questions about your rights as a research participant, or to discuss problems, concerns or suggestions related to the research, or to obtain information or offer input about the research, contact the Duke University Health System Institutional Review Board (IRB) Office at (919) 668-5111.

STATEMENT OF CONSENT
"The purpose of this study, procedures to be followed, risks and benefits have been explained to me. I have been allowed to ask questions, and my questions have been answered to my satisfaction. I have been told whom to contact if I have questions, to discuss problems, concerns, or suggestions related to the research, or to obtain information or offer input about the research. I have read this consent form and agree for my child to be in this study, with the understanding that I may withdraw my child at any time. I have been told that I will be given a signed and dated copy of this consent form."

Appendix 6

Faculty of Health Sciences
Division of Child and Adolescent Psychiatry
University of Cape Town
46 Sawkins Road,
Rondebosch
7700
Tel. (021) 685 4103 Fax. (021) 685 4107

Principal Investigator: Prof. Petrus J de Vries
M.Sc. student (and project coordinator): Dr. Aubrey Kumm

INFORMED CONSENT FORM

Autism & Beyond South African sub-study to determine the feasibility of collecting phone-based assessments and video observation data in a South African community setting.

Background

Autism & Beyond is an Apple iPhone app to test new cell phone technology that can record and analyse a child's emotion and behaviour. The idea behind this technology is to one-day screen young children in their natural environments, such as their homes, for autism and other mental health challenges. The app was developed by a team of researchers from Duke university in the United States of America. As part of a larger study conducted by the team at Duke in the USA, the University of Cape Town is conducting a small study to test the app for use in South African communities.

Invitation to participate

We would like to invite you to be part of a focus group to tell as what you think about the app, and to discuss how the people in your community may feel about using the app. The main purpose of the focus groups is to help us understand if this app will be useful to and acceptable for communities in South Africa. Your opinion about this app is important to help us determine what changes to make for the app to be appropriate and suitable for people in your community.

What will I have to do?

If you agree to help us, we will ask you to take part in a focus group along with 5-7 other people who also took part in the Autism & Beyond iPhone app study. You will have to travel to the venue on the given date. Your travel costs will be covered up to the value of R100.00. You will be asked a few questions about the Autism & Beyond app. Two facilitators will be present to guide the focus group and record the discussion. You are free ask the researcher questions about the study. If you agree to participate, you will be informed about the date, time and place of the focus group meeting at a later stage.

How long will a focus group take?

The focus group discussion takes 1-1.5 hours and will consist of 6-8 participants per group.

What will you do with the information gathered during a group?

The discussion will be audio recorded and information obtained during the focus group will be analysed by researchers at both Duke University and the University of Cape Town. Results of the study may be published in international scientific journals.

Will the focus groups be confidential?

The recordings will be stored in a safe place and will only be available to the researcher. Once the information has been analysed, the recordings will be deleted. All information gathered during the focus group will be strictly confidential. The research may be published in international scientific journals, but no-one will ever know what you specifically said. To do that we will give you a study code and make your information anonymous. Confidentiality will be discussed with all participants, but it cannot be guaranteed as some participants may choose to talk with others about what was said during the focus group discussion.

How will this focus group benefit me?

Your participation in the focus group will not directly benefit you or your child. However, the information you provide during the focus group is very important and will help us develop mental health apps beneficial for your communities

Are there any risks?

Taking part in the focus group does not have any known risks. Your participation in the study is completely voluntary and you can choose not to participate at any time without further explanation and without any consequences or further contact with the researcher.

Will I get paid for taking part?

As a token of our appreciation we will give all participants in the study R100.00 that can also be used toward travel expenses.

I hereby confirm that:

a. I have read and understand the consent form. Yes/No

b. I agree to participate in the focus group. Yes/No

c. I am aware that an audio recording of the focus group interview will be made and agree to be audiotaped. Yes/No

d. I understand that the material will become available to authorized researchers only and that no information will be shared for purposes other than research. Yes/No

e. I understand that that individual persons cannot be identified in the results of the study but that confidentiality cannot be guaranteed. Yes/No

I confirm below with my signature that I consent to participation in the study and handling of my personal information as described above.

__________________________________ ______________________________

Parent/Legal guardian Signature *Parent/Legal guardian Name (Print)*

____

Date

__________________________________ ______________________________

Witness Signature *Witness Name (Print)*

____

Date

I have explained the study to the participant, and in my opinion s/he understands that participation is voluntary and is able to give informed consent.

__________________________________ ______________________________

Researcher Signature *Researcher's name (in print)*

____

Date

Should you have any questions or queries about the research or your participation, please do not hesitate to contact Dr Aubrey Kümm: (cell) 072 2645450, (email) KMMAUB001@myuct.ac.za or Professor Petrus de Vries: (telephone) 021 6854103, (email) petrus.devries@uct.ac.za

Dr Aubrey Kümm
M.Sc. student
University of Cape Town
KMMAUB001@myuct.ac.za (072 2645450)

Prof Petrus de Vries
Sue Struegmann Professor
Division of Child and Adolescent Psychiatry
University of Cape Town
petrus.devries@uct.ac.za

Participants in this study may contact the **UCT Faculty of Health Sciences Human Research Ethics Committee (HREC)** with any ethical concerns or questions about their welfare as study participants.
Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory,
7925
021 4066338

Appendix 7a

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

16 September 2016

HREC REF: 596/2016

Prof Petrus De Vries
Child & Adolescent Psychiatry
46 Sawkins Road
Rondebosch
7700

Dear Prof de Vries

PROJECT TITLE: FEASIBILITY OF THE AUTISM & BEYOND IPHONE APP TO DETECT RISK FOR AUTISM SPECTRUM DISORDER IN A SOUTH AFRICAN SETTING (M.Sc-candidate-Dr A Kumm)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th September 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

The HREC acknowledge that the student, Dr Aubrey Kumm will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix 7b

HUMAN RESEARCH ETHICS COMMITTEE
25 JAN 2018
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☐ Approved	Annual progress report	Approved until/next renewal date	30 1. 2019
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	25/1/2018

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol Information

Date (when submitting this form)	24 January 2018		
HREC REF Number	596/2016	Current Ethics Approval was granted until	30 Sept 2017
Protocol title	Feasibility of the Autism & Beyond iPhone App to detect risk for Autism Spectrum Disorder in a South African setting.		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes ☑ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Prof Petrus J de Vries		
Department / Office Internal Mail Address	Division of Child & Adolescent Psychiatry 46 Sawkins Road, Rondebosch, 7700		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

1.1 Does this protocol receive US Federal funding?	☐ Yes	☑ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval? **Note:** Any annual approvals for **Full Committee** review MUST be submitted on the monthly HREC submission dates.	☐ Yes	☐ No

If yes in 1.2 please complete section 1.3 below for invoicing purposes

1.3 Annual Approval for **full committee** review	- R 3420 (inclusive of vat)

For invoicing purposes, please provide:

Sponsor's name	
Contact person	
Address	
Telephone number	
Email Address	

2. List of documentation for approval

None. Just renewal given that we are still writing up for publication.

Active work on project concluded in August 2017.

3. Protocol status (tick ✓)

☐	Open to enrolment
☑	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☑	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	50
Number of participants enrolled, since last HREC Progress report (continuing review)	n/a
Additional number of participants still required	0

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	0

6. Cumulative summary of participants

Total number of participants who provided consent	50
Number of participants determined to be ineligible (i.e. after screening)	8
Number of participants currently active on the study	Not active anymore
Number of participants completed study (without events leading to withdrawal)	42
Number of participants withdrawn at participants' request (i.e. changed their mind)	0
Number of participants withdrawn by PI due to toxicity or adverse events	N/A
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	0
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	N/A
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	N/A

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:
All research-related activities and data analysis were completed by July/August 2017. Since then we have been working on two research publications and Dr Kumm on a MSc(Med) Dissertation. We anticipate thesis to be submitted in February 2018 and manuscripts in the first 6 month's of 2018.

8. Protocol violations and exceptions (tick ✓ all that apply)

☑	No prior violations or exceptions have occurred since the original approval

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

☑	No prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded,** *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
None

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	☑ Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. MCC, FDA)?		
☐ Yes	☐ No	☑ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	☐ No	☑ Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☑ Not applicable
		DSMB report attached	☐ Yes	☐ No	☑ Not applicable

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	☑ No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
☑	Shown no change
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.

13. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	☑ No
If yes, please explain and if necessary attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

14. Signature

My signature certifies that the above is complete and correct.			
Signature of PI	[signature]	Date	23 JAN 2018

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Appendix 7c

Western Cape Government
Health

Dr AS Booysen
Manager: Medical Services
Email: Tony.Booysen@Westerncape.gov.za
Tel: +27 21 658 5788 fax: +27 21 658 5166

Dr AJ Kümm
Red Cross War Memorial Children's Hospital

Dear Dr AJ Kümm

APPROVAL OF RESEARCH

PROJECT TITLE: AUTISM AND BEYOND – A RESEARCH KIT APP PROJECT

It is a pleasure to inform you that approval is hereby granted to conduct the above-mentioned study at Red Cross War Memorial Children's Hospital.

Yours sincerely,

Dr AS Booysen
Manager: Medical Services
Date: 28.06.16

DukeMedicine
Institutional Review Board for Clinical Investigations

NOTIFICATION OF IRB APPROVAL

Protocol ID:	Pro00063608
Principal Investigator:	Helen Egger
Protocol Title:	OurChild: A ResearchKit smartphone application study of child behavior and development
Sponsor/Funding Source(s):	Department/Division/Faculty/PI Duke Institute for Health Innovations
Federal Funding Agency ID:	

Date of Declared Concordance with federally funded grant, if applicable: N/A

The Duke University Health System Institutional Review Board for Clinical Investigations has conducted the following activity on the study cited above:

Activity:	Initial Review	**Review Type:**	Expedited
Review Date:	6/8/2015		
Issue Date:	6/8/2015		
Expiration Date:	6/8/2016		

DUHS IRB approval encompasses the following specific components of the study:

Protocol, version/date:	--
Summary, version/date:	--5/1/2015
Consent form reference date:	--6/8/2015 - three consents
Investigator Brochure, version/date:	--
Pediatric Risk Category:	-- 1
Other:	--Demographic questions; ;Mock up on the on-boarding and consent screens; Parental concern questions; Privacy policy; Tantrum questions; M-CHAT

Privacy policy, Tantrum questions; M-CHAT

The DUHS IRB has determined the specific components above to be in compliance with all applicable Health Insurance Portability and Accountability Act ("HIPAA") regulations.

This study expires at 12 AM on the Expiration Date cited above. At that time, all study activity must cease. If you wish to continue specific study activities directly related to subject safety, you must immediately contact Dr. John Falletta or Jody Power. Continuing review submissions (renewals) must be received by the DUHS IRB office 60 to 45 days prior to the Expiration Date.

No change to the protocol, consent form or other approved document may be implemented without first obtaining IRB approval for the change. Any proposed change must be submitted as an amendment. If necessary in a life-threatening situation, where time does not permit your prior consultation with the IRB, you may act contrary to the protocol if the action is in the best interest of the subject. You must notify the IRB of your action within five (5) working days of the event.

The Duke University Health System Institutional Review Board for Clinical Investigations (DUHS IRB), is duly constituted, fulfilling all requirements for diversity, and has written procedures for initial and continuing review of human research protocols. The DUHS IRB complies with all U.S. regulatory requirements related to the protection of human research participants. Specifically, the DUHS IRB complies with 45CFR46, 21CFR50, 21CFR56, 21CFR312, 21CFR812, and 45CFR164.508-514. In addition, the DUHS IRB complies with the Guidelines of the International Conference on Harmonization to the extent required by the U. S. Food and Drug Administration.

DUHS Institutional Review Board
2424 Erwin Rd | Suite 405 | Durham, NC | 919.668.5111
Federalwide Assurance No: FWA 00009025

DukeMedicine
Institutional Review Board for Clinical Investigations

NOTICE OF PERSONNEL CHANGE APPROVAL

The purpose of this email is to notify you that the following personnel change request has been approved by the IRB.

Amendment ID: Amd018_Pro00063608
Protocol ID: Pro00063608
Protocol Title: Autism & Beyond: A ResearchKit smartphone application study of child behavior and development
Review Date: 3/21/2016

Personnel Added:
none
Personnel Removed:
none

DUHS Institutional Review Board
Hock Plaza, 2424 Erwin Rd.
phone: 919-668-5111
https://eirb.mc.duke.edu/eirb

eIRB DukeMedicine Institutional Review Board for Clinical Investigations

Margaret Pendzich | My Home | Logoff

eIRB Home Reports Administration Studies

Studies > OurChild > AMD #18 - Study Personnel Change

Current Status:

Approved

Form:

View Personnel Change

Go to:

Study Workspace

Amendment: AMD #18 - Study Personnel Change

Amendment ID:	Amd018_Pro00063608
Parent Study ID:	Pro00063608
Parent Study Title:	Autism & Beyond: A ResearchKit smartphone application study of child behavior and development
Study Organization:	Psychiatry
Principal Investigator:	Helen Egger
Primary Study Coordinator:	Margaret Pendzich
Primary Regulatory Coordinator:	Marissa Stroo
Review Type:	Exempt
Primary Reviewer:	Jody Power
Review Date:	3/21/2016
Amendment Action Notice:	View

Description of Changes: Dr. Petrus de Vries and Dr. Aubrey Kumm are collaborating on this research and are based at the University of Cape Town in South Africa. A collaboration agreement has been written by OCRC and is currently being review at the University of Cape Town. A copy will be uploaded as soon as it is signed.

Personnel Added:
none

Personnel Removed:
none

History | Certification

	Activity	Author	Activity Date
	Approved Personnel Change	Power, Jody F	3/21/2016 10:36 AM
IRBS	Assigned Expedited Reviewer	Barrett, Kasie M	3/21/2016 10:31 AM
	Adding outside kp.		
PI	Electronically Signed Amendment	Egger, Helen L	3/21/2016 10:15 AM
PI&S	Submitted Amendment	Pendzich, Margaret K	3/21/2016 9:29 AM

eIRB DukeMedicine Institutional Review Board for Clinical Investigations

View: Amendment - Amd018_Pro00063608

<< Back | Exit | Hide/Show Errors | Print... | Finish

02. Study Personnel Change Request

- Add, remove, or replace people on the page to reflect all of the requested personnel.
- For personnel changes that require changes to study documents (e.g. PI in consent form, study coordinator name in an advertisement), you must also create and submit a regular study amendment containing the revised documents.
- **Only people with current Human Subjects Protection (HSP) certification appear on the Select Person lists.** If you cannot find the person, go to the FAQ section of the eIRB Home page and click the link *I'm trying to add someone to my study, but I can't find their name.*

* **Principal Investigator:**
Helen Egger

Only people who may serve as Principal Investigator according to Duke policy appear on the PI and Co-PI Select Person lists.

Primary Regulatory Coordinator:
Marissa Stroo

if the study has multiple coordinators, one must be the primary contact person for the IRB and anything regarding regulatory issues.

Primary Study Coordinator:
Margaret Pendzich

If the study has multiple coordinators, this person is the primary contact regarding enrollment logs, subject billing and clinical issues.

Co-Principal Investigators:

First Name	Last Name	Department
Guillermo	Sapiro	Electrical Engineering
Geraldine	Dawson	Child & Adolescent Psychiatry
Richard	Bloomfield Jr	Pediatrics-Hospital & Emergency Medicine

If the study has multiple coordinators, this person is the primary contact regarding enrollment logs, subject billing and clinical issues.

Other Key Personnel:

	Name of Individual	Role on study	Edit Rights	Receive Email	CITI Expiration
View	Anna Bensley	Collaborator	no	no	11/11/2017
View	Samuel Brotkin	Study Coordinator	yes	yes	6/4/2018
View	Rebecca Brouwer	Study Coordinator	no	no	2/23/2018
View	Kathleen Campbell	Collaborator	yes	yes	6/1/2018
View	Kimberly Carpenter	Collaborator	no	no	12/20/2018
View	Zhuoqing Chang	Computer Programmer	no	no	1/6/2018
View	James Daniel	Computer Programmer	no	no	8/11/2017
View	Naomi Davis	Collaborator	no	no	7/14/2018
View	Steven Espinosa	Computer Programmer	no	no	2/15/2018
View	Jordan Hashemi	Analyst	no	no	1/20/2018
View	Christian Mauro	Collaborator	no	no	4/13/2018
View	Johanna O'Dell	Data Manager	no	no	8/17/2018
View	Margaret Pendzich	Study Coordinator	yes	yes	10/1/2017
View	Qiang Qiu	Computer Programmer	no	no	9/16/2017
View	Jessica Revels	Interviewer	no	no	7/8/2018
View	Kendra Rosa	Collaborator	no	no	3/29/2018
View	Jana Schaich Borg	Collaborator	no	no	1/28/2018
View	Mary Shepherd	Collaborator	no	no	4/6/2018
View	Kristen Stefureac	Collaborator	no	no	2/12/2017

Note - If you want to change Edit/Email preferences for existing personnel, that can be done via the "Modify Existing Personnel" button which is located on the study workspace.

View	Mariano Tepper	Computer Programmer	no	no	11/10/2017

Key Personnel - Outside Duke:

Document Name	Date Created	Last Modified	Revision
de Vries HSP	3/21/2016 9:27 AM	3/21/2016 9:27 AM	0.01
Kumm HSP	3/21/2016 9:27 AM	3/21/2016 9:27 AM	0.01
Outside Key Personnel Form	3/21/2016 9:26 AM	3/21/2016 9:26 AM	0.01

See Download Forms for current form templates.

Make sure to submit the request after you hit the finish button. The item will be located in your tasklist's presubmission tab.

<< Back   Exit | Hide/Show Errors | Print...   Finish

Faculty Of Health Sciences
Division of Child and Adolescent Psychiatry
University of Cape Town
46 Sawkins Road,
Rondebosch
7700
Tel. (021) 685 4103 Fax. (021) 685 4107

Principal Investigator: Prof. Petrus J de Vries
M.Sc. student (and project coordinator): Dr. Aubrey Kumm

Focus Groups: Guide questions about the Autism & Beyond iPhone app

Autism & Beyond South African sub-study to determine the feasibility of collecting phone-based assessments and video observation data in a South African community setting.

Theme 1. Ease of use

Question 1.

Thinking back to when you used the Autism & Beyond iPhone app, how did you find using the app? Do you think people in your community would find it easy or difficult if they were to use the app?

a) Was the language easy to understand?
b) Did you understand the questions asked?
c) Was it easy to follow the instructions?
d) Did you have any difficulties operating the phone to use the app?

Theme 2. Accessibility

Question 2.

How many of you would use this app if it was available? How many people in your community would use it? Who would not use it? Why?

a) How many people in the community have smartphones with internet connectivity and video recording facility?
b) Do you think a lot of people in the community have an "iTunes" or App Store" account?
c) How do people in your community access the internet?
d) Do you think people in your community would be concerned about the cost of data use when using the app?

Theme 3. Acceptability

Question 3.

Do you think a smartphone app like the one we used would be acceptable to people in your community? What would be unacceptable or worrying to people about the app?

a) Do you think there are any cultural reasons why people in your community might be worried about using this app?
b) How do you think people in your community would feel about making video recordings of their child?
c) How do you think people in your community would feel about using a phone app to tell them if there could be something wrong with their child's development?
d) Do you think parents in your community would use parenting apps?

Theme 4. Localization

Question 4.

Referring to the questionnaires you had to answer in the app (on the phone) about your family background (see Questionnaires provided in your hand-outs), tell us what you think about the questions and choice of answers given on the form.

a) Do you think there are any questions or words members in your community would have difficulty understanding/answering?
b) Do you think some members in your community may find any of these questions inappropriate? If yes, tell us which questions?
c) What do you think needs to be changed?
d) Please give us examples of questions and answer options more suited to your community.

Harnessing Technology to Improve Screening for Autism and other Developmental Disabilities
Pro00053509

Duke Center for Autism and Brain Development

Video Coding Manual – Affect and Social Communication in toddlers with and without autism

Created June 2015 by Kathleen Campbell and Sam Marsan

Advisors: Geraldine Dawson, PhD and Kimberly Carpenter, PhD

Last updated by:

K. Campbell 09/23/15

Table of Contents

4. Validity
5. References
6. Appendix A: Stimuli used and data collection procedures

3. Specific Behaviors:

a. Affect

We chose to code affect in our subjects in terms of positive or negative hedonic tone. This system was chosen in part because of studies of baby affect showing that hedonic tone can be reliably coded without specialized training (Camras 1997). Additionally, our stimuli were designed to elicit smiling and surprise, rather than the more fine-grained expressions such as disgust and anger, so we wanted a simple classification system. Infant coding systems such as babyFACs state that positive and negative hedonic tone can be distinguished with simple facial movements (described below).[i] More complex classification of anatomical units is beyond the scope of our work.

We code the hedonic tone in a hierarchy where decision-making starts at the top and you work your way down. So the first question you ask yourself is "is this child showing positive hedonic tone". If the criteria are not met, you mentally move down to Negative and so on until you reach neutral or not visible.

Guidelines: you may skip back to the beginning of a behavior a maximum of 3 times to re-watch, then you must assign a code. If you cannot make a decision, you must assume it is too ambiguous and assign neutral. However, remember that the hierarchy begins with the thought "If I can call this positive, I should call it positive." You should code an expression if you can see it in real time regardless of how brief it is and whether they can be considered a transition or not. When subjects are partially covering their mouths, you should code the expression if you can see it. Also, you should code "not visible" if a subject moves too fast to reliably identify an expression. Drag the playback control grid such that it aligns with 2/3 of the monitor screen from top to bottom. Video frame should occupy more than half the screen.

i. Positive Hedonic Tone/Smiling or Surprise: Consists of corners of the mouth upturning OR cheek elevation. May also involve mouth opening, eye constriction, and/or laughing.

(ref image)

ii. Negative Hedonic Tone: brow lowering, with or without horizontal lip stretching, with or without mouth opening with or without cry face = square, open mouth.

(ref image)

iii. Surprise: Mouth open and eyebrows raised.

(ref image)

iv. Neutral: lack of positive or negative tone and not showing surprise. Face relaxed and mouth flat.

(ref image)

v. Not visible: 1) cannot see enough of face to determine hedonic tone. 2) When a subject moves too fast to reliably identify an expression. 3) if face is turned 90 degrees, code not visible.

   a. Special case: if the face moves away from the screen in such a way that both eyes are no longer visible (e.g., one eye is completely visible, but the other one is only partially visible), then code not visible.

(ref image)

vi. Special Cases:

   a. Vocalizations: If the child is vocalizing, use the hierarchy to assign hedonic tone. Remember that your default is neutral if the expression is ambiguous. Vocalizations are coded in a separate layer on a separate pass of coding.
   b. Sucking on fingers or pacifier: If you can see the child's mouth/changes in affect, code to the best of your ability. If you feel the mouth is too obscured, code as not visible

Notes: When subjects are partially covering their mouths, you should code the expression if you can see it.

b. Arm Movement

-Pointing requires that the child coordinates gaze with arm movement either right before or during the instance of pointing. Code pointing as 1 of these 3 mutually exclusive behaviors: hand pointing, finger pointing, or reaching.

1. Finger pointing: arm partially or fully extended towards the screen, one finger is significantly separated from the others and fully extended. The other fingers should be partially or fully curled back. If you are unsure but think the child is separating one finger from others, go ahead and code as finger pointing
1. Hand pointing: arm(s) partially or fully extended towards the screen where no attempt of grabbing the screen is observable (No leaning towards the screen). Index finger is not significantly separated from the others, which may result in a broader range of possible hand configurations. Do not code hand point if the child appears to be clapping their hands or waving
2. Reach: rapid and significant forward leaning accompanied by arm extension towards the screen.
3. Waving: Arm is raised and hand moves from side to side
4. Other: code “Other” when arm movement does not meet any of the criteria covered above, but has some aspects of those above (i.e. code other when the kid produces a gesture different from the ones described above, such as waiving hands, clapping, blowing kisses, etc.)
5. Do not code when there is observable parent interference or subject is leaning backwards (e.g. against their parents) and tries to return to a sitting position.

	Components							
Behaviors	Arm Extension	Towards the Screen	Gaze	Other Fingers Curled Back	Index Finger Separation	Leaning Forward	Parent Interference	Return to Sitting Position
Finger point	✓	✓	✓	✓	✓	✗	✗	✗
Hand Point	✓	✓	✓	~	✗	✗	✗	✗
Reach	✓	✓	✓	~	✗	✓	✗	✗
Other	✓	✓	~	~	~	~	✗	✗
No Code	~	~	~	~	~	~	~	~

✓	=	Yes
✗	=	No
~	=	Either

c. Engagement

i. Screen

ii. Parent or Examiner

-Mute the volume when coding social referencing; then, re-watch the video with the audio on and name call

-code start and stop of looking at parent or examiner, no distinction between who they are looking at

-don't worry about whether or not you think child makes eye contact (you cannot really tell from this angle), rate based on whether head is **oriented to the adult's head**

-similar to affect, watch the entire behavior in real time, decide you will code it as a "looking at adult", then go back and get the onset and offset

-code onset from time head movement started from a static position (or if constantly moving when crosses midline position)

-code offset at time head is no longer facing adult and is in a static position (or if constantly moving when crosses midline position)

-if child is just looking around the room where there is no person, do not code it

-if you are not sure but child is "not visible" code it

-if child is turning head into parent for comfort, they get credit only if they orient their head toward parents head .

-if you did not observe the start of the behavior (eg child was already referencing parent when video starts) do not code it… it may have already been coded in previous video. If social reference starts when child is out of field of view estimate onset whenever you could observe the child social referencing.

-if video ends during a reference, code offset at end of video (I think this is automatically done)

-at the end of coding, visualize the entire video to make sure you did not miss anything

iii. Disengagement

-when child is not looking at the iPad, this can be judged either from eye position (eg looking down at the ground or at hands) or from head position

-do not code social referencing as disengagement, these are mutually exclusive categories and social referencing supersedes disengagement

iv. Not Visible

v. Name Call

-go to point of name call in bunny, go back 2 seconds, hover over pause button and as soon as you hear the beginning of the sound of name call click pause as fast as you can. Code name call at this point. If there was more than one name call in this video only code the first.

References

i. Oster et al chapter 10. 2005. Emotional Development: Recent Research Advances By Jacqueline Nadel, Darwin Muir