Lessons on Collecting Data from Autistic Children using Wrist-worn Sensors

Maria Bell
University College London
United Kingdom

Elise Robinson
Queensmill School
United Kingdom

Thomas J Gilbert
University College London
United Kingdom

Sally Day
University College London
United Kingdom

Antonia F de C Hamilton
University College London
United Kingdom

Jamie A Ward
Goldsmiths, University of London
United Kingdom

ABSTRACT

Autism is a diverse neurodevelopmental condition that has a hugely varying impact of the lives of autistic people. It is only in the last decades that a greater understanding and public awareness of the autism spectrum has come about, in-part thanks to a growing body of research into the condition. Wearable technology offers great promise in furthering autism research by providing an ability to do detailed behavioral analysis in real-life settings, such as in schools, with minimal intrusion. Such work is particularly crucial in exploring behaviours of those with complex needs and intellectual disabilities, a group who traditionally have been under-served. To achieve this there is a need for wearables that are both practical and acceptable to the individuals being studied. This paper presents our findings from a human-centred design approach to developing and deploying wrist-worn sensors among a diverse population of 16 autistic and 12 neurotypical children over a period of several months. Findings and recommendations from this work highlight the need to take both sensory factors and emotional dysregulation into account when designing wearables for autism. Individual aesthetic and social considerations are particularly important for older children. Equally, a period of sensor desensitisation is necessary when working among those with more complex needs.

CCS CONCEPTS

• **Human-centered computing → Empirical studies in ubiquitous and mobile computing**;

KEYWORDS

wearable technology; autism spectrum condition; autism; minimally verbal; emotional dysregulation; human-centred design

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1 AUTISM AND WEARABLES

Autism Spectrum Condition (ASC) is a neurodevelopmental condition that has an estimated prevalence of 1-2% of the worldwide population [21]. Autism is defined by persistent deficits in social communication and evidence of restrictive, repetitive behaviours [3].

Researchers have identified several contexts in which wearable technology (WT) devices may be useful for young people with autism [6, 8]. Many studies use WT to automatically recognise repetitive movement patterns in autism like stimming [2, 24, 29], or to conduct behavioural assessments [23]. WTs can be used as the intervention themselves, such as by providing self-regulation strategies for the wearer, or to monitor wearer outcomes during intervention sessions [15]. WTs provide an objective and more ecologically valid way to explore fundamental mechanisms that influence behaviour, than, for example, observational work [8]. Equally, they allow researchers to investigate autism in a group as well as individual setting [28].

1.1 Heterogeneity in Autism

However, WT has primarily been explored in a limited group of autistic children. Autism is a spectrum condition, with huge variation in the presentation of autistic characteristics and traits. As a result, ASC can cover a wide variety of people who require varying levels of support. In the Diagnostic and Statistical Manual of Mental Disorders [4], a diagnosis of autism is further categorized into three levels, depending on the severity of the disorder and the level of support required by the individual in their daily life. Autistic individuals with Level 3 support needs require very substantial support to function in our society and may not express themselves verbally or non-verbally in a way that researchers traditionally have the methods for understanding [12]. Some psychologists have proposed for the term 'profound autism' to be adopted for such individuals, although there is hesitancy in using this administrative label for children under 8 years old [21].

Minimanlly verbal autistic children with complex profiles and those needing very substantial support are regularly excluded from research, often through the use of standardised tests for IQ or similar [10]. This selection bias is present throughout all fields of autism research, with 94% of autistic research participants not having an intellectual disability [25], despite recent global estimates predicting that 50% of autistic individuals have an intellectual disability [11]. However, minimally verbal autistic children with the 'highest level of impairment' can demonstrate higher cognitive potential when alternative methods of assessment are employed, such as perceptual tasks [12]. While previous research has not been representative of the heterogeneity of individuals that fall under the autism spectrum, excluding minimally verbal autistic children with complex profiles limits our understanding of autism and the impact of interventions. While WT has proven to be a beneficial tool in autism intervention, the practicalities of using WT among a diverse autistic population are yet to be explored.

1.2 Hurdles in wearables research

A review of publications in WT found that, compared to work in areas like health and fitness, there are relatively few recent studies related to education and child-care [1]. Successful long-term usage of WT is a common challenge, with the main impediments being social factors like user acceptance and design [13, 31]. Part of this challenge is the battle between proximity to the body (in order to make accurate measurements) with subtlety, fashion, and comfort. Many WTs are trialed in a lab, with few experiments in real-world conditions due to the difficulty with dealing with external variables such as change and noise.

Using WT in autism research presents several difficulties. For example, over 96% of autistic children are reported to have sensory processing difficulties [22]. Understanding of the mechanisms behind sensory function in autism is still limited [9], however overwhelming sensory stimuli has created barriers for autistic children to a range of services and spaces, from emergency care to classrooms [14, 17]. If WT are intended for use in long-term interventions, including in the classroom, sensory stimuli and possible distractions need to be considered in order for the WT to not be a barrier to learning.

Wrist-worn WTs are overwhelmingly the most popular style of wearables across domains [7], and are the preferred choice for autistic children [19, 27]. Familiarity of the device seemed to be a key determiner in the success of using WT in research. 47% of autistic children in one study preferred unnoticeable designs [19]. To increase the chances for continued wear, WTs need to blend in or be hidden from view, with vibrations or flashing lights minimised. WTs that stand out may become a source of distraction or discomfort, which may in turn influence the behaviour of the participant and the research outputs [27]. Flexible, lightweight materials were preferred, and ease of fitting and removal was highlighted [19].

1.3 Human-centred design

Using a human-centred design approach to wearables research and design may improve data collection and address design issues before taking a product to the commercial level. Human-centred design is an approach to problem-solving that involves the human perspective in all elements, mitigating the risk of innovation by ensuring that the design incorporates the key needs, desires and contexts of the user. The first key step of human-centred design is to get together a multidisciplinary team to lend different advice to the design [26].

Using a human-centred design approach in this context is crucial, such as through seeking the perspective of autistic individuals and their families to influence the design of the WT. Conducting a user study prior to developing a sensor design will help to develop our understanding of specific user requirements and lead to the design of more appropriate interfaces and applications [1]. Failure to consider the personal needs of the target group could lead to rejection of the WT and limit data collection. Equally, a 'one-size-fits-all' approach here would be inappropriate, due to the unique experiences of different autistic people on the spectrum. Customisability of the WT is likely to improve acceptance of WT in ASC [18].

1.4 Current investigation

This work explores the wearability of different wrist-worn devices in diverse groups of autistic children to provide insight for both researchers working with autism and WT designers. Further understanding of the potential sensory factors faced by autistic children while using WT can inform the design of WT to increase likelihood of acceptance and longevity of wear. Utilising a human-centred design methodology will highlight issues with the WT throughout the study, allowing the prototypes to be updated and thus minimising potential issues in data collection and financial loss.

2 METHODS

2.1 Groups

Data was collected from 3 distinct groups of children from 3 different schools. 9 primary aged autistic pupils from an SEN school, 7 secondary aged autistic pupils who attended an SEN unit in a mainstream school, and 12 neurotypical (NT) early years pupils from a mainstream primary school (see Table 2).

Autism diagnosis for the pupils was confirmed by the school. Data regarding presence of intellectual disability was not made available to the researchers. However, the following SCERTS categorisations shown in Table 1 were provided to give further information about the children's developmental stages, as standardised testing to ascertain IQ or verbal ability was inappropriate for these groups. These Partner Stages are used widely throughout SEN schools to provide a general understanding of a child's communication ability.

Table 1: SCERTS partner stages of developmental transition

Social (6-12 months)	Communicate with purpose/intent, acquire & use conventional gestures/vocalisations
Language (1-2 years)	First words, word combinations
Conversation (School age)	Sentence grammar, conversational discourse

Primary aged pupils, who were minimally verbal with complex profiles, were categorized as Social Partners or Language Partners, with 4 and 5 in each group, respectively. All secondary aged pupils were in the Conversation Partner Stage. To suit the staffing and timetabling needs of the schools, the primary school ASC group were split into two groups for the purpose of the study: an early years group aged 5 to 6 and an older primary group aged 8 to 11.

2.2 Development of 3 designs

Following the methodology of human-centred design, researchers conducted multidisciplinary meetings with SEN teachers, psychologists, and engineers, to explore casing options for the WT design.

Table 2: Breakdown of number and ages of boys and girls in each group.

	Boys	Girls	Age	Mean (std)
ASC Early years	4	0	5-6	5.8 (.59)
ASC Primary	4	1	8-11	9.45 (1.24)
ASC Secondary	3	4	12-17	14.85 (1.91)
NT Early years	4	8	4-5	5.06 (.54)

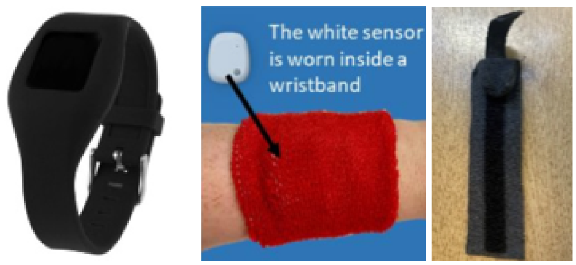

Figure 1: Three sensor-embedded wristbands (left to right): rubber strap, cotton sweatband, felt band.

Considerations about materials were discussed, as well as familiarity of the design. Three prototypes, shown in Figure 1, were designed for the casing of the WT: rubber strap, sweatband, and felt band.

The rubber casings were purchased from the designer of the sensors, Mbientlab Inc., USA. These are designed like watch straps, with an adjustable metal buckle and several holes punched into the strap. The material is a soft, flexible rubber that is easy to wash and waterproof. Researchers added new holes to the watch strap to be adjustable to suit smaller wrists of children.

The sweatband design was conceptualized after a visit with some highly complex autistic pupils at the SEN school, where researchers noticed that several of the children were already wearing sweatbands on their wrists for comfort and sensory stimulation. These were available in several different bright and neutral colours. The sensor was fitted inside the material of the sweatband which was closed with a small plastic snap fastener.

The final prototype design was a soft piece of felt-covered velcro that could be wrapped around the wrist and fastened. The sensor was contained in a small pouch on the inside of the strap.

2.3 Desensitization/Familiarisation

Autistic children often show low tolerance towards novel technology [19] but research has shown that repetitive exposure to new devices can improve their acceptance [30], and previous research recommends planned desensitisation sessions, for example in a ramp-up systematic desensitisation model [16] to improve the chances of user acceptance and data collection [27]. Sensor and wristband prototypes were sent to the SEN schools ahead of data collection. The following communication was received from one of the SEN school teachers following the planned desensitisation.

> "We have been trialling the wristbands this week. One of the biggest things we noticed is that EVERY pupil at [SEN school] wanted to take the sensor out and managed to do so within 10 seconds! This is something to consider in terms of securing the sensors into the wrist bands - especially considering if the sensors are removed they tend to immediately put them in their mouth. However, pupils are getting more used to it and some have worn it all day with the sensor in! Some pupils like the [felt and Velcro] designs but most liked the [sweatbands]."

Table 3: Number of times wristbands are played with, removed or rejected for ASC and NT

	Played with	Removed	Rejected
ASC	78	17	14
NT	27	10	0

Following this communication, plastic snap fasteners were added to the the sweatbands to secure the sensors within them.

Secondary aged autistic students were also shown the wristbands designs prior to data collection, however all pupils preferred the rubber watch strap and did not require desensitisation.

2.4 Sessions

Data was collected during drama lessons at both SEN schools. In the two younger ASC groups, there were 3 teachers present to support the groups of 4 and 5 children. These sessions were tailored to the developmental stage of the children in the groups, incorporating music, dance, props, free play, and an interactive whiteboard. In the older ASC group, sessions incorporated drama games such as wink murder and charades, as well as written exercises.

Data was collected during an after-school club at the mainstream school. Sessions incorporated age-appropriate party games such as parachute games, Grandmother's Footsteps and Simon Says.

3 RESULTS/OBSERVATIONS

Sessions were observed by researchers and a record was kept of any unintended interactions with the sensors, e.g. played with, removed or completely rejected, as summarised in Table 3. Sensors were most frequently removed or totally rejected in the younger ASC groups. The teacher referred to these groups as the 'sensory groups', assessed as Social Partners or Language Partners, or in a developmental stage typical of a 6 month to 2 year old.

3.1 Reasons for acceptance

The neurotypical pupils generally were happy to wear the wristbands, which were never completely rejected. Pupils were observed to mostly forget about their wristbands as soon as they were put on. NT children generally preferred the sweatband design, and enjoyed choosing the colours they would wear.

Sensors were removed less frequently in the secondary ASC group than in the early years and primary groups. Most pupils were happy to wear the wristband throughout the session and did not remove them intentionally at all. One pupil remarked "it's just like my watch", which suggests they were accepting of the design due to its familiarity. This is in line with previous findings in WT research in autism [19, 27]. All the secondary ASC pupils opted for the watch strap design, with the teacher commenting that it was likely to make them feel "grown up" and "adult". A secondary ASC pupil commented "we have the same", comparing their wristbands to the researchers, showing that their approval of the WT was linked to the perceived approval of it by an adult. This suggests approval of the device due to conformity or fashion choices.

3.2 Reasons for rejection and removal

Overall, the younger autistic children struggled to keep the wristbands on more than the older children. Data collection was sporadic, with many children removing the sensors frequently or showing signs of distress during the data collection. For the purposes of analysis, reasons for sensor removal or rejection are categorized into sensory factors and emotional dysregulation.

3.2.1 Sensory factors. One early years child frequently removed his wristbands. He was often biting at his wrists, clothes and jumper cuffs, using his teeth to remove the wristbands. The researchers and teachers offered him all three wristband designs (sweatbands, Velcro straps, and watch straps), but none seemed to be better than another. He benefited from immediate distraction, which brought his attention away from the wristbands. However, when he was not engaged in one-to-one attention or became idle, he would then turn his attention back to the wristbands to remove them.

It was noted throughout the sessions that this child was often seeking objects to put in his mouth, including toys, paper and any other objects he could find in the room. This is characteristic of oral hyposensitivity, common in autistic children with sensory processing disorder [5]. Ensuring that children with hyposensitivity have their needs met in other ways, for example by providing chew toys, may help to distract their attention from the WT and onto a safe alternative. In future research, this child may benefit from WT in a different location, that was less noticeable and out of sight. For example, using sensors that can be sewn into clothing [20], which may be more lightweight and unnoticeable to the wearer. However, this is likely to be more expensive. Additionally, the movement data gained from a body worn accelerometer is not comparable to movement data garnered from a wrist worn accelerometer and may not pick up valuable behaviour data, for example from gestures.

Another young child was very overwhelmed during a couple of the sessions, crying and not wanting to join in with the games or activities. When upset, this child refused to wear the wristbands, however, on occasions when the child was calm and happy, they wore the wristbands without complaint. This could potentially be attributed to sensory overload.

3.2.2 Emotional dysregulation. Several of the younger autistic children appeared to reject the sensors due to difficulty in emotional regulation. One child, whose teacher explained was struggling in school generally with transitioning from one activity or room to another, did not want to enter the room where the study was taking place, nor put the wristbands on. While this type of issue will not be solved by altering WT design necessarily, it can help to inform researchers in terms of study design. If permitted, data recording could be conducted within the child's own classroom to make them feel more at ease, while concurrently improving ecological validity of the study.

Another child wore the sensors willingly in most sessions, however during one session, once other children arrived, they were quick to remove the WT. This cannot be attributed to sensory needs as the child happily wore the WT for 20 minutes before the other children arrived.

Only one pupil in the secondary group rejected the wristband. This pupil was highly curious about the technology and asked a lot of questions about the nature of accelerometers. Ultimately he rejected the sensor due to his understanding of the technology – he commented that he "wasn't a criminal" and didn't want to be "tracked". He rejected the wristband for the first several sessions, but by the last session he was happy to hold the wristband in his hand. While this would not provide researchers with any useable data, for this particular child this was a breakthrough, and suggests that perhaps an extended period of desensitization may be beneficial and improve acceptance of the technology, although this was not possible in the present study due to time constraints.

4 CONCLUSIONS AND RECOMMENDATIONS

These findings support previous research that, at least in older autistic children, main concerns regarding WT are to do with aesthetics, such as familiarity of the device and fashion, and comfort. In addition, some difficulties concerning use of WT in younger autistic children requiring very substantial support are presented. While the differences in acceptance of the WT seem to be split by age, the level of support required by the early years and primary ASC groups was far higher than that of the secondary ASC children. The younger children had far more complex needs and profiles, and it is likely that their rejection of the WT was more to do with this than their age, as the NT children were more accepting of the WT. It is clear that there is still a significant amount of adjusting of WT if they are intended for use by individuals with profound autism and complex needs.

Having a period of desensitisation for the children to become familiarized with the WT is crucial. This also gives researchers time to tweak their designs in favour of something the children would be more comfortable with. If data collection is infrequent or interrupted, it is recommended to have a re-familiarisation with very sensory children and the WT.

While wrist-worn WT are generally preferred due to their ease of access, some of the evidence makes the case for non-wrist worn WT. Wrist-worn WT are highly visible, and many children in this study were less likely to play with or remove their sensors if they were out of sight, such as with a sleeve pulled over it. However, this is not a foolproof method and so other, more discreet locations for the WT must be considered.

Beyond the scope of this research, long term usage is one of the main technical challenge of wearables, incorporating diverse issues related to battery life, comfort and aesthetics [13]. While this may not be an immediate issue for researchers seeking to use WT for the purposes of data collection in short bursts, it is worth considering what more can be done in design to improve long-term wear for potential commercial devices, or for longer-term research.

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