Anxiety and Autism: Towards Personalized Digital Health

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ABSTRACT

For many people living with conditions such as autism, anxiety manifests so powerfully it has a big impact on quality of life. By investigating the suitability of truly customizable wearable health devices we build on prior research that found each experience of anxiety in people with autism is unique, so 'one-suits all' solutions are not suitable. In addition, users desire agency and control in all aspects of the system. The participative approach we take is to iteratively co-develop prototypes with end users. Here we describe a case study of the co-development of one prototype, a digital stretch wristband that records interaction for later reflection called Snap. Snap has been designed to sit within a platform that allows the distributed and sustainable design, manufacture and data analysis of customizable digital health technologies. We contribute to HCI with (1) lessons learned from a DIY co-development process that follows the principles of modularity, participation and iteration and (2) the potential impact of technology in self-management of anxiety and the broader design implications of addressing unique anxiety experiences.

Author Keywords

Mental health; Anxiety; Personal Informatics; Autism;

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION

Most of us suffer from anxiety at some point in life: only 1 in 20 people in the UK report never being anxious[1]. To some, anxiety manifests itself so powerfully it has a dramatic impact on quality of life. This is particularly true when anxiety is associated with other conditions such as Autism. Autism is said to affect an individual's ability to communicate and interact socially with others and can result in profound isolation and anxiety with potentially devastating effects [2]. Our research focuses on anxiety in those diagnosed with autism and builds on two fundamental lessons learned from existing autism research in HCI [4, 7, 28, 31]: first, the uniqueness of anxiety experiences and the impracticality of *"one suits all"* solutions; second, end-users' desire for *agency and control* on the system: from aesthetics, to data capture and its use.

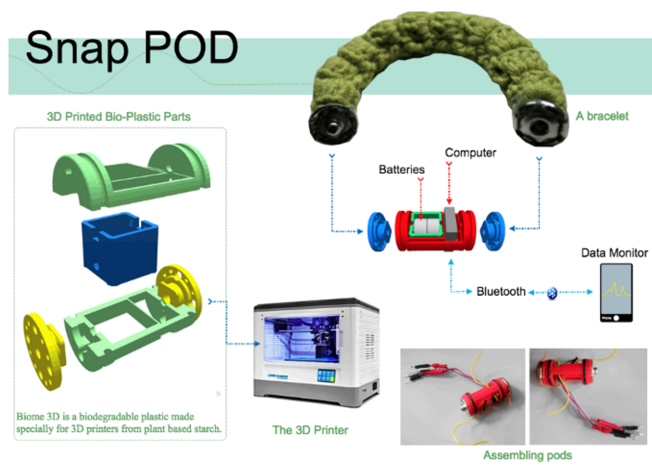

Figure 1 - Customizable Snap Device. Crochet wristband contains conductive cord that changes resistance when stretched, and connects via snap fasteners to a 3D printed pod containing batteries and microcontroller with Bluetooth 4.0.

Our aim is to investigate the challenges and opportunities of building systems that are not only capable of addressing highly unique anxiety management needs, but that can do so at scale. Our approach is to investigate *"by doing"* [19], specifically by combining the modularity of form and function [6, 26] with a participative and iterative co-development process [9, 18, 32]. Our vision is to develop a platform that allows the distributed design, manufacture and data analysis of families of customizable digital health services. This paper reports on the first step towards such a vision starting from the co-development of wearable health devices, using a prototype named Snap as a case study.

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[1] http://www.mentalhealth.org.uk/content/assets/PDF/publications/living-with-anxiety-report.pdf

Snap (Figure 1) is a customizable hand-made digital stretch wristband that records interactions for later reflection. It is powered by a *plug and play* 3D-printed (3DP) computing unit, which we refer to as the 'pod'. Snap emerged from a three-month co-development process with and for adults diagnosed with High-Functioning Autism (HFA) and their support. During this phase we engaged in three design workshops with 13 participants (7 people diagnosed with HFA and 6 supporters), followed by a three-week summer study that involved 5 participants and their support wearing a Snap device and reflecting on its value.

Snap co-development is part of a broader six-month participatory design and co-development process that has so far engaged over 300 people including health professionals, the general public, those diagnosed with autism, and supporters. The process follows a values-led, and technology-mediated innovation framework [9, 24, 32] shown in Figure 3. Our design approach is inspired by Phoneblok's **modularity** and **repairability**, Fairphone's approach to **fairness** and community **participation**, Misfit's **adaptability**, and Little Devices' **affordability**.[2] We consider such approaches as promising alternatives to mainstream *one-fits-all* digital health devices (e.g. Fitbit).

Through the co-development of Snap we explore how adults diagnosed with autism experience anxiety, reflect on the role of HCI in anxiety management, and extract lessons learned for anxiety conditions beyond autism. Our contribution to HCI is hence twofold: 1) lessons learned from the DIY co-development of personalized digital health devices following the principles of modularity, participation and iteration 2) the potential role of wearable technology in self-management of anxiety and the broader design implications of addressing unique anxiety experiences and needs.

BACKGROUND

Autism and Anxiety Management

Autism is a condition characterized by difficulties in three main areas, namely social communication, interaction and imagination, commonly referred to as the triad of impairment. Those with autism may have a very literal understanding of language, and think people always mean exactly what they say. They often have difficulty interpreting emotions and expressing their own. Difficulty with social imagination means it is hard to make sense of abstract ideas, and imagine situations outside daily routine[3]. Autism is often described by a 'spectrum'–while all people with autism share these difficulties, their condition will affect them in different ways. Those who are affected most are described as "Low Functioning" and those whose quality of life is impacted less described as "High Functioning".

Adults with HFA are a hard to reach group: their high functioning nature often makes their condition invisible to society, which perceives them as 'simply different' (HFA participant). The fact they are high functioning can make their condition 'invisible' to society, thus allowing them to fall between the gaps of public support. There are no prevalence figures for adults with autism in the UK. As a consequence, it is reasonable to argue that the large majority of adults with HFA lack a formal diagnosis. Not only do they live without an understanding of what make them different, but also in a society that is not aware of their challenges, especially the ones related to day-to-day social interactions. As Bellini puts it *"the anxiety associated with these seemingly simple acts can be devastating [2]"*.

This is a group with hidden needs and whose social interactions are often limited. Yet, interactions outside familiar circles are often sought by most adults with autism and can have a positive impact on their quality of life. However, these very interactions can be a source of great distress [3]: social anxiety has been identified [36,37] as the most common form of autism anxiety, usually affecting half of those with autism .

Prior research [4, 7, 28, 31] shows that the majority of HCI work on anxiety in autism focuses on children, young adolescents and people at the lower end of the autistic spectrum, "*Yet the needs of adults are very different to the needs of children and teenagers, regardless of ASD"* [31].

A similar research 'bias' is found in psychology research where there seems to be a limited number of studies looking at anxiety in adults diagnosed with HFA [14, 15, 34]. In addition, most of these studies are carried out from a statistical perspective to establish the presence of anxiety in association with other mental health conditions. These investigations may be useful to *quantify* the percentage of those diagnosed with autism that suffer from anxiety [3, 35], but few have tried to systematically *characterize* how anxiety is *experienced* in terms of triggers and responses, for example. We argue this is problematic since HCI needs guidance to start addressing the "uniqueness" [4, 31] of anxiety experienced in autism in a holistic way [23, 33].

In summary, anxiety in those diagnosed with autism is *experienced* in a multitude of *subjective* ways. To understand and adapt to its unique manifestations we adopt an iterative, participatory and agile approach to development and a modular approach to system design.

Personal Informatics and health self-management

At the start of our research we considered using and re-purposing a range of mainstream (e.g. Fitbit), emergent (e.g. Angelsensor), leading (e.g. Garmin xt920, Empatica Embrace), and affordable (e.g. Mibands) digital fitness and health tracking devices to explore how they can be used in anxiety self-management. However, after in-the-wild and desk-based evaluations carried out by the research team, we

[2] phonebloks.com; littledevices.org; misfit.com; fairphone.com

[3] http://www.autism.org.uk/about/what-is/asd.aspx

found that none of the above devices could suitably address our research aims for the following reasons: un-reliability of data capture, opacity of data-insight processes [16], black-box designs, patented algorithms, and costs. We argue that these aspects combined can have a 'lock-in' effect on both user and the device, fix them both into rigid functionality and potentially erode user agency and control.

Our main argument is therefore that current PI systems are more focused on the *informatics* aspects than on the *personal* ones. In other words, mainstream PI are simply not personal enough.

To address this shortfall, we expand Li *et al*.'s [23] concept of *iteration* as a potential route towards personalization "*the iterative property of personal informatics suggests that systems should be flexible to support users' changing information needs*". We do so by facilitating active participation with end-users in the system co-development process (see Figure 2). This process is enabled by a modular approach to design, where physical components and system functionalities can be selected, added or removed at any stage of the process.

The biggest challenge is hence to make this process not only relevant to people's needs but also respectful of their individual freedoms [10, 17, 38]. In doing so we find Li's reflections on the dialectic between *system-driven* and *user-driven* approaches particularly helpful in identifying the trade-offs between system automation and user intentions.

Affective vs. Intentive computing

The approach of exploring the role of technology in managing mental health in wearable HCI literature is focussed on tracking users with biosensors, and is typified by Picard et al [27] in the affective computing approach. This approach uses 'always on' biosensors and environment sensors to monitor an individual, and complex algorithms to interpret and present information to the individual in real time and for later reflection. The individual makes a conscious decision to wear a device, once worn the user is not necessarily conscious of what data the device is capturing or when trigger points are reached. Kirkham and Greenhalgh [22] discuss the tensions arising between social inclusion and privacy when developing such sensor driven real-time assistive wearable technologies for those with HFA. Blackwell [5] describes this position as 'prosthetic' – using technology to replace or augment absent ability.

An *intentive* action is defined as requiring the user to consciously and knowingly trigger a system – for example push a button or make a certain gesture. We introduce the concept of intentive computing as the study of the use of such a human-actuated system. Our research differs from the affective computing 'prosthetic' because of the 'intentionality' of actuated interactions. That is not to say the approaches are mutually exclusive – they can be complimentary: for example Fletcher [11] states the importance of synchronizing annotations with data by enabling the user to *"insert data markers to annotate the data as it is being collected".*

On the role of anxiety support, our argument is that such intentional interactions, not only could provide real-time tactile 'relief', but could also function as cognitive anchors for self-reflection and long-term learning. In this paper we explore the extent to which an intentive action can add value to the coping strategies of those who suffer from anxiety, through designing a modular system in a participatory, iterative and agile manner [9, 32].

DIY and Bespoke Assistive Computing

DIY and bespoke assistive technology (DIY-AT) has a long history for those with physical impairments. There is a high rate of abandonment of "one fits all" technology, estimated at around 35%, and this is used as a justification for individual adaptations to technology[20, 21]. Hurst and Tobias [21] explore how empowering novices to build their own solutions can improve the success and adoption of AT. They propose the use of rapid prototyping to quickly produce and iterate devices, and online sharing communities to expand the reach and discussion of designs. The barriers to uptake of DIY-AT, found through interview with parents of children with mobility impairments, include: lack of skills and time to make and repair devices; the limited practicality, robustness and aesthetics of devices; and concern about the safety and risk of conflict with medical care [20]. The DIY approach may conflict with social acceptability of devices, explored by Shinohara [30], who propose that design for social acceptance will reduce stigma of AT. The lessons learnt from these works on physical impairment are built on here, as we apply a DIY approach to technologies for self management of anxiety.

APPROACH

To engage in research partnerships with any community, and in particular with vulnerable groups, requires sustained motivation, skills, trust and care. The approach we use is a values-led and technology-mediated innovation framework that has been used in several domains involving hard-to-reach vulnerable groups in technology innovation projects [9, 24, 32]. We follow a traditional "plan, act and reflect" action research process [18] across four distinct and overlapping steps, (formative, co-design, co-develop, and sustain) which are shown in Figure 3 and are mapped against milestones and deliverables.

As Figure 2 shows, Snap development was part of a broader six-month participatory design and co-development process that engaged over 300 people including health professionals, the general public and academics from a range of disciplines. The first three months were riskier and more exploratory in nature and involved the **de-construction** of a range of digital health devices down to their core components (*data, materials* and *interactions*). These in turn were used as the basic ingredients for design fiction [8] activities (e.g. a pop-up *Technology Kitchen* at a national science festival) to broadly envision and reflect on digital-health challenges and possibilities.

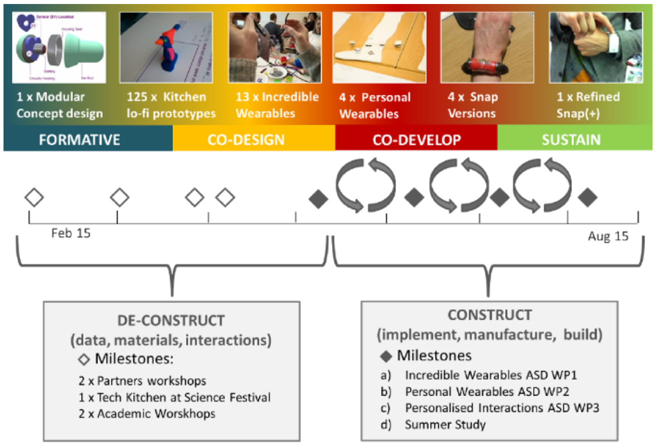

Figure 2 - Research Steps and Milestones

The first phase informed the second phase (**construction**), which is the focus of this paper and from which Snap emerged. During this second phase the majority of the activities were planned and carried out in partnership with a group of adults diagnosed with autism and their support. We held a series of workshops (WP1-WP3) designed to investigate the value of wearable digital health technologies to our user group. Most of these users have been diagnosed with anxiety problems. However, each of our participants described anxiety in different ways, with many not identifying with the language associated with anxiety.

Hence our research is focused on individual experiences of anxiety – how it manifests, its triggers and responses. To facilitate the expression of our participant's experiences, we organized a series of thematically connected 2-hour workshops: **Incredible Wearables (WP1)**, **Personal Wearables (WP2), and Personal Interactions (WP3)**. The timing for each workshop followed a two-week agile development cycle, which was well received by our participants and their support because of its structured approach and the anticipation that was created around the sessions. We found this structured approach to be essential to manage expectations and reduce unknowns for our participants with autism.

Paced by the two-week cycles of the workshops, the research team iteratively distilled design directions into implementable requirements that ultimately converged into 'Snap'. Snap emerged as a digital interaction-recording wristband, which could afford a variety of 'intentive' interactions (e.g. gripping, huddling, and stretching) and that could be fashioned into a variety of styles (e.g. functional, DIY, etc.). Snap was then put to test during a three-week ***Summer Study*** in which 5 participants wore their own Snap in everyday life for three weeks. During the study, feedback was obtained through a group induction, two one-to-one sessions for each participant, and a final group discussion.

Participants

A total of 13 participants were engaged in the workshops comprising 7 diagnosed with autism and 6 of their support (some of whom were also diagnosed with or self identified as suffering from anxiety). One of the challenges of working 'in the wild' outside of a controlled lab environment with people who have autism is the need to create an environment where they are comfortable, with familiar faces, and knowing what to expect well before the event. This is apparently in contrast to working in an agile, responsive manner. However, this challenge was negotiated through meeting in a 'familiar' place – a charity hosted the workshops in their function room, whilst key dates and an activity outline were set well in advance.

INCREDIBLE AND PERSONAL: WP1, WP2 AND WP3

The Incredible Wearables workshop (WP1) was designed to create a relaxed space and inspire participants with the freedom, creativity, and enthusiasm to come up with their very own technology inventions or *incredible wearables*. During the following Personal Wearables workshop (WP2) we narrowed the design scope by inviting participants to construct their previous inventions from a toolkit of parts, or *design tiles,* mimicking real electronics, to be joined together using wooden sticks (Figure 3). Finally the Personal Interactions workshop (WP3) expanded the design focus with an idea generation process, which explored meaningful ways to interact with a range of prototype wearable devices.

Incredible Wearables – WP1

The research aim for WP1 was twofold: first, to gain a broad understanding of the needs, capabilities and aspirations of our participants; second, to start understanding if and how such needs could be addressed by the design and development of personalized digital care technologies. This aim was addressed through the following objectives:

- Create a safe, enjoyable place for shared learning, building trust and mutual understanding in the team.
- Introduce the idea that all can be makers of technology innovation and inventions.
- Stress the importance of creativity and playfulness in learning and innovation.
- Expand the notion of what technology is (e.g. beyond screens and mobile phones).
- Reflect on what technology can and cannot do for us.

Researcher and support participants planned the event together and, most importantly, agreed to **avoid actively prompting ideas around anxiety**. The focus had to be on creativity and the capability of inventing something personal and of real benefit.

The workshop started with a table laid out with a range of objects of different shapes, size, colours and textures. Each participant was asked to select an object, and then people introduced themselves by describing why this object was selected and mattered to them. This gave some initial insight into what was important to each participant – some liked sharp textures and experienced them as calming.

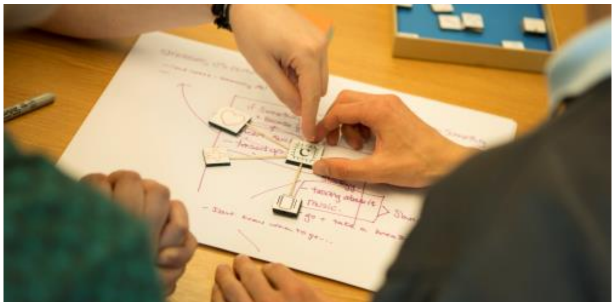

Figure 3 Developing personal wearables with *design tiles*

Participants then broke off into small groups to brainstorm and then prototype wearable technologies that would address their most pressing needs and aspirations. Lo-fi prototypes were built using play-doh, pipe cleaners, and 3DP 'sensor mimics' – small objects designed to mimic a multitude of sensors to which participants could attribute functions of their own choosing.

A total of 13 lo-fi prototypes were constructed, 7 were from those with an autism diagnosis and 6 from supporters. Most interestingly, 7 of these prototypes were designed to directly address stress and anxiety even though the facilitators avoided prompting for anxiety.

Three prototypes dealt with external **auditory triggers**: two by cancelling out noise (*Sound Blocker* and *Acoustic Inhibitor*) and one by providing haptic distractions. *Destresser,* for example, provided relief from high pitch sounds (e.g. children's cries) by stroking a hard yet smooth metallic plaque worn as a bracelet charm. The *Bubble Bracelet* provided stress relief through an actuated **tactile response** triggered by popping plastic bubbles.

Public speaking and demanding **social situations** were cited by the inventor of *Take a Breath* as a source of anxiety. Worn as a brooch, it would emit sounds and smells linked to happy memories inviting to take relaxing breaths. Two prototypes focused on automatically capturing internal **physiological signals** of anxiety: *TempSense* detected rising body temperature as a signal of discomfort; and *AMOK,* worn as a bracelet or an earpiece, monitored change in heart rate, sent messages to family and offered 'digital distractions' when anxious.

The remaining 6 prototypes were not directly related to anxiety. Three of these were related to **engagement**: *Time to Dance*, a pendant that sang bird songs when the wearer sat in one place for too long, was about **physical** engagement; *Contact Glasses*, a pair of glasses that facilitated serendipitous encounters, was about **social** engagement; the *Grounding Ring* was about **mental** engagement: it monitored brain signals and sent warnings when the wearer was perceived as 'zoning out'. The ring had a customizable tactile surface (e.g. sandpaper) that when stroked offered **a sensory snack** that helped re-engaging with reality. *Sonic Whiskers* shoe tag and *Object Detector* bracelet pre-warned the user of objects that could be damaged or cause injury if hit. Finally the *Tele-Personal Assistant* was a pen that helped to write as fast as the speed of thought.

Personal Wearable Devices - WP2

A key finding of WP1 was there is a multitude of ways of experiencing and communicating internal states. Unprompted our group reported anxiety as an uncomfortable experience that could be tackled by technology. For this, rather than designing individually unique devices, a toolkit approach was used to see how participants could assemble their own personal health wearable. The kit contained a DIY plug-together selection of devices and sensors modules or 'tiles' (see Figure 3). Each device had a core 'computing module' (mimicking a microcontroller) to which the sensors, actuators, communications and storage could be attached as required. This process facilitated discussion around how the device they had designed could be implemented.

Figure 4 Crochet Prototypes.

Personal Interactions – WP3

WP3 aimed to elicit, capture and map the range of gestures and interactions that participants find useful for dealing with anxiety. To prompt discussion, a range of artefacts inspired by WP2 and WP1 were rapidly prototyped by using crochet and knitting techniques (Figure 4). Participants were invited to select one each, discuss it in pairs and feedback to the group. After that, the participants were invited to list all the possible anxiety interactions that could be afforded by the handmade artefacts. The results of this exercise is shown in Figure 7 and discussed later in "Anxiety Interactions". After that, the first working prototype of Snap was demonstrated to elicit discussions around personal uses of the device.

SNAP DEVICE

The wearable devices designed by our participants are used to inform the design of a toolkit which would enable the construction of a range of personal devices, rather than for individual translation into working devices. The devices can be broadly assigned two functions: alerts based on automatic capture of physiological and environmental data, and tactile interaction (use of bubble wrap, tactile jewellery etc.). As discussed earlier, prior research comprehensively investigates the aspect of automatic capture of physiological and environmental signals in numerous health conditions. We find there is an opportunity to explore tactile intentive interactions where the user is aware of their actions. The first device used as a development case study, is a stretch wristband, called Snap and shown in Figures 1 and 5. The

Snap device focuses on intentive interaction and here we investigate its role in anxiety reflection. Embodied in Snap is a 3-pronged philosophy:

Sustainability: The approach is (human) values-driven [13] and has been designed with a three-dimension sustainability framework in mind: material, skills, and human freedom. Its modular design allows the distributed manufacture of each part and easy assemblage by the end-users and health practitioners with little or no engineering experience.

Promiscuity: The computing core (pod) is both independent and promiscuous. Independent because the pod is a complete stand-alone computing unit; promiscuous because is designed to be easily 'plugged in' to different sensors and substrates.

Reflectivity: Snap has been designed to establish a meaningful collaboration between human and machine, where the machine automatically captures data, extract insights and relies on the individual, personal experience to make sense of the data at hand.

Figure 5 - Snap prototypes: first (left) and as used in study with tactile beaded covering (right).

Snap is designed to be customizable physically, electronically and in terms of software functionality. Open source software and widely available 'maker' hardware was used along with DIY techniques such as crochet and 3D printing to build in customizability and DIY manufacture. This was intended to give the devices the widest possible reach: people can make and customise their own, hopefully leading to increased engagement through ownership and personalization.

A minimum-viable prototype of Snap (left of Figure 5) was quickly made with a battery, microcontroller and crochet wristband and taken to WP2 for feedback from participants, who then informed the version used in the study period.

This first prototype has an LED light that increases intensity according to the degree of stretch of the band and communicates this data to a laptop that plots a line on the screen in real time. The second prototype is encased in an enclosure and is described below.

Design and Components

Snap has two main physical components: the pod and the wristband (shown in Figure 1). 'Snap fasteners' of the type found in haberdashery stores are used to provide the mechanical and electrical connection to the wristband.

The pod shown by Figures 1 and 5 is constructed from a 3DP framework, using biodegradable Biome[4] bioplastic made from corn starch. This framework encases the electronic components, and a heat-shrink layer protects the components from the environment while allowing an LED light to show through. The design of the pod uses easily purchased materials and the design files for 3DP can be modified freely.

The wristband is made of conductive rubber cord that has a changing electrical resistance as it is stretched. This is attached to matching snap fasteners by conductive thread. The assembly is wrapped in a personalized outer, and can be encased in any number of outer materials that will allow stretch. We made a selection of wristbands from a variety of materials and styles (crochet in Figure 1 and beaded in Figure 5) inviting participants to choose their favourites to snap onto the pod.

We used a low cost Arduino-compatible RFDuino micro controller, giving access to the popular IDE and variety of open source libraries. Users are free to modify and extend the code and assemble their own devices connected to different sensors. The device can communicate real-time high resolution stretch data live to a Smart phone over Bluetooth (as first prototype) and onto cloud services or social networks, however our users cited trust and privacy concerns with a real-time approach – and indicated they would prefer data to be stored only on the device. This coincided with reduced power and memory demand. However we are aware that others may prefer operation in a similar manner to Clasp [31] and the prototype can be configured in both modes.

The wristband records a timestamp to memory when the device is stretched beyond a threshold value, and then again when the device is relaxed and not stretched for a timeout. This allowed us to record the length of interaction and the frequency of interaction.

Reflection Platform

While the participants were using the wristband during the study, the researchers designed and built a prototype interface to visualize the data collected by the Snap bands. The Snap Visualizer shown by Figure 6 is produced when the data is downloaded from the Snap pod. The Visualizer plots the times of the day over a period of a month when the Snap band has recorded interactions. At the end of the study, when the participant data was downloaded the design of this interface was discussed with each participant, and ideas for future features were ideated and discussed. There are a number of emerging design directions that can be taken with this interface, such as automatic pattern extraction and overlay with date from other sources such as GPS log, calendar entries, and physiological wearable.

[4] http://biomebioplastics.com/

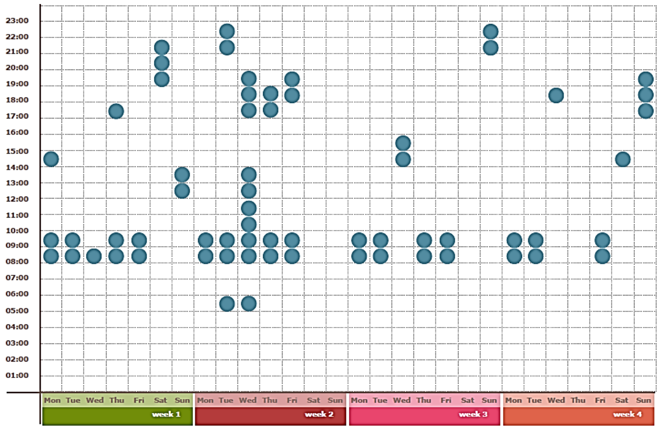

Figure 6 - Snap Visualizer. Interactions by days of the week along the horizontal and hours of the day on the vertical axis.

ANXIETY INTERACTIONS			STEPS
Cover	Play with	Rub	3. Prompted Individual; 2. Unprompted Individual; 1. Prompted Group
Feel	Push	Stretch	
Fiddle	Pull	Touch	
Grip	**Tug**		
Bite	Clip -Unclip	**Spin**	2. Unprompted Individual; 1. Prompted Group
Click	Flick		
Catch	Roll	Talk to	1. Prompted Group
Hold	Round-Walk	Tap	
Inhale	Scratch	Throw	
Pinch	Spring	Turn	
Poke	Squeeze	Twidle	
Pop	Stamp	Twist	
Press	Stroke	Wave	

Figure 7 - Mapping anxiety interactions: the three-step process elicited 37 anxiety interactions, 11 of which were used with Snap (shown in the inner dark grey square).

ANXIETY INTERACTIONS

During the process we explored a range of anxiety management strategies that could be afforded by wearable interactions. We did so iteratively in three steps: prompted group discussion, unprompted individual feedback, and prompted individual feedback. A total of 37 interactions were identified, and participants used 11 of these with the Snap device. The key findings for each step are summarized below and in Figure 7.

Step 1: Prompted - Group Discussion. During WP3 researchers invited the participants to list all the gestures and interactions that they do or may do to manage anxiety. We did so by using a range of prompts that included rings, belts, pouches, earpieces, brooches and shoe decorations. These prompts had been rapidly prototyped using crochet techniques (Figure 4) to quickly implement ideas that emerged during the WP2. As a result, 34 of the 37 interactions were captured at this stage as shown in Figure 7. The interactions 'spin', 'tug' and 'grip' are shown in bold as they appeared later in Steps 2 and 3.

Step 2: Unprompted - Individual Feedback. The three-week Summer Study included two cycles of individual feedback sessions with each participant. Each session included an unprompted feedback discussion on anxiety interactions followed by a structured discussion about the usage of Snap. The light grey and dark grey areas combined in Figure 7 plot the results of the unprompted part of these discussions, highlighting 13 anxiety management interactions: "*A click I think would be satisfying to me, some kind of, um, sound or click or movement [...] I have a flip cover on my phone, it has a magnetic connection and I just happened to have my phone in my hand and I was flicking it on my phone*". Figure 7 shows the interaction 'spin' in bold, as it was first mentioned at this stage *"natural for me [] I'm used to it because of spinning my ring [laughs]"*.

Step 3: Prompted – Individual Feedback The dark grey area in Figure 7 shows the 11 interactions participants actually used to interact with Snap. When anxious, excited or both, some of the participants pulled and pushed the band *"Yeah, well in anxiety I just push like that and then it calms things"*, or rubbed their fingers on the bracelets beads: *"My new puppy [] became very upset and ill. I was a bit stressed myself because she was not well so I was rubbing the beads onto my skin it felt nice"*. They also liked to fiddle or play with it just because it felt *"nice and soft"*. 'Gripping' onto the computing pod and 'tugging' the wristband were mentioned at this stage, "*I used my (Snap) bracelet when going into the doctors to pick up my prescription. I was nervous sat in the waiting room to collect my tablets in case someone spoke to me. I tugged a little on my bracelet in frustration of waiting nervously. Which didn't make my nerves go but took my mind off waiting 'cos I was focusing on the bracelet"*.

Design Implications

We draw two main design implications for Snap from the emerging anxiety interaction mapping:

Bite vs. Flick: positive and negative connotations

Different interactions can have different emotional connotations. For example, 'biting' and 'picking' have been described by a participant as harmful habits associated with negative emotions; in contrast 'flicking' or 'fiddling' were associated with a more positive state: *"Um, the harmful habits are when I'm anxious, [] but things like flicking lids I just do that whenever"*, *"to be able to bite it and that's usually what I do when I'm driving and anxious [] and that's a bad habit*", "*then the positive manifest as fiddling"*.

This reflection matches observations made by health professionals who also argued that only logging times of anxiety, stress and depression (negatives), will over time create a distorted and negative data history of someone's experience of their own life. This observation is echoed by one of the participants *"having something that could focus it [the positive aspect] would [be] beneficial because then there would [be a] positive thing to happen instead of harmful things to happen.*" For this, to design for anxiety and self-reflection could encourage people to be more mindful of positive experiences like happiness, satisfaction, productivity, and flow instead of the negatives. This logging could be done both automatically by the device and inventively by the user. For example, the device could automatically signal lack of interactions as a positive; or the user could actively log times of relaxation and playfulness by interacting with a device in a chosen mode.

INCONSPICUOUS ⟷					CONSPICUOUS	
Secret	Disguised	Functional	DIY/Maker	Fitness	Futuristic	
Hidden under garments, discreet when visible	Looks like ordinary jewelry or garments	Focus on function not on style	Unique, custom made	Matches sportswear, fashionable	Embodies utopian or dystopian visions	Style
When visible tries to blend with body or garments.	Sophisticated, delicate, crafted. Hidden electronics	Industrial, simple and clean. Hidden electronics	Exposed electronics. Hand stitches, boards. DYI, playful	A statement piece. Bright & colorful. Industrial & mass produced. Hidden electronics	Elaborate. Cyberpunk, steampunk, inspired in fiction.	Properties
Skin tones, neutral tones, natural materials	Metallic, jewel-like colors,	Black, grey, neutral tones	Colourful, various colors combined.	Bright, contrasting energy colors	Metallic, natural or geometric forms. Bright/ neon artificial	Colors
Rubber, elastics, adhesives, paint	Metal, wood, textiles, lights	Plastics, rubber, metal, lights	Textiles, plastic, metal, electronics, lights	Rubber, plastics, lights	Combination of materials, metal, natural, glass/ acrylic, plastics	Materials
Small & simple, economical	Pleasing, elaborate shapes and patterns	Straight clean lines, solid shapes, regular, no distractions	Irregular, to suit/follow the use of electronic parts	Clean lines, solid shapes, conveys movement & action	Innovative, elaborate, imaginative	Shapes

Figure 8 - Inconspicuous vs. Conspicuous wearable styles

In summary, the design of bespoke digital health wearables should help to investigate how positive experiences can be appreciated and encouraged as well as how the negatives are triggered and best managed.

Click vs. Stretch, two sides of the same data spectrum:
Snap has been specifically designed to explore intentive (user-actuated) interactions. We chose to use a stretchable wristband as our first 'intentive' prototype for reasons that included participants' feedback in relation to comfort and social acceptability of the device *"I don't think it would draw any attention if you were going like that [fiddling] on a bracelet, whereas if you were like reaching into your pocket and people would be... keep drawing attention to yourself"*. From a researcher perspective, Snap facilitated the exploration of a broad range of anxiety interactions that could be automatically captured, characterized, and analysed: the intensity, length and frequency of a stretch, for example. However, the participants' feedback from the everyday use of the device has highlighted three main challenges: (1) the characterization of the interaction (e.g. a strong pull for me may be a weak pull for another); (2) the ambiguity of the data captured; (3) the risk of false positives (e.g. pulling the band while putting on a jumper). One of the participants explicitly suggested a click button as both inherently satisfying *"I would definitely sit and click that all day"* and as means to reduce data ambiguity and false positives: *"think if it was a clicker that picked up every time you clicked it you have to do it on purpose, you can't do by accident"*.

SOCIAL AFFORDANCES

During our co-development process we asked participants how they felt about wearing Snap in social situations. Not surprisingly, some felt self-conscious about Snap's current *"bulky"* design, *"toy-like"* form, and *"bright colours"*. However, most also agreed that *"as whole the bracelet has a lot of potential"*. Reducing the size of the Snap pod would allow increased adaptability and personalization *"everyone has different likes"* "*I like black and plain things, some people like bright pink"*. Times of the day were mentioned as important factors "*glow in the dark material could be good wearing at night*". One participant suggested including the Autism logo in future designs, and to make it visible enough to be a conversation starter, but sufficiently discrete to be dismissed as a simple decoration.

Figure 9 - Concept Designs for Personal Interactions

Design Implications

These observations relate to the concept of "social affordance" that is the *"capability [of wearable devices] of adapting to different social contexts by changing its aesthetic properties and interaction modalities for fitting different social situations"* [29]. The challenge is to translate this concept into practice. We explore three ways:

1. Style taxonomies to guide personalized choices: Snap's modular nature allows personalization in terms of wearable substrate (e.g. where the computing component can be attached to) and styles (e.g. colours, and materials) to adapt to different interaction needs and social situations. Figure 8 shows our first attempt to create a taxonomy of possible styles which we summarized along a spectrum from inconspicuous to conspicuous.

2. Characterization of anxiety in physical designs. Another approach is to map personal anxiety gestures onto the actual form of the system components. For example, we are currently looking into how the 'computing pod' itself could be fashioned in different styles to suit a range of personal interactions. Figure 9 shows how different interchangeable casings could be designed to afford specific interactions. These casings could be affordably and locally manufactured using local 3DP bureau, and combined into functioning devices by health practitioners and users.

3. Putting it all together: the making as part of the therapy. One of the main lessons learned from the co-development process was the importance of the self-reflection activities that took place during the making of the artefacts themselves. During this process the participants, often to the surprise of their support, were able to articulate their experience of anxiety in a very deep, personal and engaged manner. There were several factors at play, including the common factors effect [1] well known in clinical psychology literature, that future studies will need to consider. In practice, the making of the device could be part of the therapy. For example, in one session the health practitioner and client could design their own 'Snap' by combining selected components (e.g. casings, sensors, and actuators) together. Figure 10 shows a 'making kit' prototype as a box of modular and interchangeable components to suit different needs.

Figure 10 - Make Your Own Device from a Kit of Components

DISCUSSION

Experiences of self-management with Snap

Through using the Snap prototype daily, the participants (names changed here) engaged in the summer study revealed much about their experiences and how such a device may be used. 4 of the 5 wore the wristband at some point most days of the duration of the study - only Jamie (male, HFA, early 30's) did not wear it as he does not like things touching his hands.

We learnt something different from each of the participants and their approach to Snap for self management of their condition. Louis (male, HFA, mid 20's) chose to wear Snap only when expecting to experience anxiety or excitement - perhaps Louis can recognise some triggers of his anxiety. Louis chose to wear snap either on the wrist or belt at work, when walking the dog, watching an exciting TV programme, visiting a sensory room (e.g. ball pool) and when tired. Louis liked the soft texture (specifically selected) and would pass it through the hands in use.

Henry (male, HFA, mid 20's) is really motivated to find a pattern to his anxiety. Henry and support are not sure what the triggers are, and think that Snap may help identify them. Henry liked the feel of their chosen wristband and wore it a lot - the band was visibly over stretched (broken) and dirty. Henry claimed the aesthetics weren't a problem for him, although perhaps in this case form follow function and the desire for answers overrides the look.

Susie (female, early 30's, the only non-HFA, but diagnosed with anxiety) usually finds herself *"picking her nails"* when anxious, and would prefer an interaction which can be hidden rather than the Snap requiring both hands. Susie found little satisfaction in stretching the band and would prefer a definite click. Susie described a desire to turn a negative response to anxiety into a positive outlet for that, instead of Susie *"picking her nails"* Snap would be recording interaction for later reflection that Susie would get overall benefit from.

Davina (female, HFA, early 20's) was not part of the initial development workshops, but immediately saw a benefit in Snap. Davina was very enthusiastic, contributing many ideas to improve the aesthetic - as it is, she would not wear it out of the house.

Designing with Adults with Autism

We found our participants wanted to know the time and location of the next meeting, and what to expect well in advance. We kept meetings to familiar places and regular times to minimise anxieties around visiting new places and people. The pacing of the agile development cycles enabled us to set advance milestones, and worked well as participants would know to expect new increments of designs they were contributing to. If plans changed, then significant notice should be given, and detailed explanation of what to expect should be given. During each workshop, accurate timings were given and each participant knew the others already.

In WP1 we asked participants to create their own wearable devices addressing their most pressing health need. Rather than ask directly about experience of anxiety, the creative process allowed participants to describe their experiences not just verbally, but through the physical objects they imagined and produced. In fact, half of the designs were directly addressing anxiety. This was remarkably successful, and support workers gained new insight from this into the experiences of participants.

The participants 'bought-in' to the process and took ownership of the devices they played a role in creating. This process of 'making' became a part of therapy and created a new, shared understanding between participant, support and researchers.

DIY and Bespoke Wearable Devices

WP2 showed participants how they could assemble their 'incredible wearables' using a kit of components. Each participant was able to translate their imaginary object into realistic components, showing how a kit of parts could be used in future DIY health applications. By starting from the imaginary and moving to the realistic, participants were allowed to explore the extremes rather than be restricted by what they know to be possible.

The degree of DIY involved in making DIY health technology - from simple customisation of aesthetics to modifying source code will be highly variable and individual-dependant. It is unlikely our group would modify source code themselves, however the WP2 demonstrates the potential a future DIY health wearable kit holds with suitable facilitation, and would reduce the barriers to making [20].

The participants chose to further personalise Snap by wearing it in a number of ways beyond as a wristband - clipped to the belt loop of jeans, high up on the arm, carried in a bag or pocket. Part of the reason was that the device itself was bulky and unattractive (Davina - *"looks like a bomb"*), nevertheless participants continued to use Snap as they saw benefits in it: Louis: *"I was a bit excited because usually on a Saturday there's some good programmes [] so that's why I wore it to calm me down a bit", "I wore it at work because I found out that somebody was leaving [] and I wore it here, to calm me down a bit".* The Snap form-factor, although more adaptable than other tactile prototypes [31], still poses challenges for being repurposed. The range of wristbands we created for the study was not wide enough; our users wanted further choice and had their own clear ideas about aesthetics of the device.

A major criticism of wearable activity tracking devices is that typically they show initial promise and promote behaviour change (increased physical activity) in the short term, but are typically worn only for 2 months and then abandoned with the user returning to former behaviour [12, 25]. The approach we have taken is not to encourage behaviour change but to facilitate an understanding and management of anxiety through device interactions and data capture. The process of designing and building these wearable devices has enabled our participants to discuss experiences of anxiety in a way their support indicated they had never before articulated - that in itself is a valuable process. In addition, once the process of learning and understanding is completed, the device itself may become redundant, and components can be passed on, re-used and repurposed for other people's needs. Perhaps as found with DIY-AT, DIY wearable devices will have longer sustained engagement [21] than off the shelf devices.

Deliberate, Intentive Interactions

Characterising when an individual has intended to interact with a device is a challenge - Snap recorded a high number of false positive interactions. Movement and activities like removing clothing would sometimes unintentionally actuate it. Our participants liked the tactile sensory feedback of Snap, but were not interested in recording the resolution of stretch – so the sensitive actuator we used was somewhat unnecessary. This tactile feedback could also be gained with different actuators, requiring more effort to interact (Figure 7) and therefore reducing false positives.

It is noted that participants like to fidget – and this fidgeting may be confused by the system as anxious use. One strategy would be to characterize both interactions for the individual and see if the two uses can be separated in the data. It is recognized that fidgeting has a therapeutic purpose, but clearly it is important for the purposes of reflection to separate usage when anxious from other uses.

Engagement outside of workshops

The participants all indicated they enjoyed the process of developing personal technologies, and want to continue to engage. How much influence this enjoyment had on engagement in the summer study in unknown. However, Davina had no prior engagement to the summer study, had heard of Snap and immediately saw benefit in it so was keen to start using it. In each case, devices are likely to be highly personalised and involve some degree of engagement through customization and use of the reflection platform.

Beyond Autism

Susie's involvement was key in beginning to explore the reach of Snap beyond HFA. Susie has her own experience, quite different from autism and found Snap held promise for her. In future studies we will be recruiting participants who experience anxiety in a wide range of conditions to see how this style of self-management through reflection and DIY assembly of personal technology can have impact.

CONCLUSIONS

We conducted an investigation with adults diagnosed with HFA and their support, to identify the potential role of DIY technology in self-management of anxiety. We explored this through co-developing a technology, from creative DIY prototypes to a 4-week evaluation of Snap. We have specifically looked at individual experiences of anxiety, what kinds of information should be captured and how it might be presented. We found our participants highly engaged in the process, and able to describe their experiences through the prototypes they made.

We propose that as well as helping to identify triggers to the negatives and how best to manage these, devices should help investigate how positive experiences can be appreciated and further encouraged. Focus on the negative may attach negative connotation to the device.

There is a delicate balance to be struck in the social affordance of devices - not only the aesthetic style but how conspicuous it is and how clearly the intended gestures map onto the physical design. This in particular is a challenge to the DIY approach used.

We find that participants both with HFA and without, including one who came late to the process (i.e. was not engaged in early workshops) found benefit in the use of Snap for the management of anxiety.

Indications are that a DIY approach to technology for self management of anxiety may enable design for the whole person, not just one 'component' of diagnosis, thus reducing abandonment and increasing benefits to users. The devices our users made were tailored to their own unique experiences.

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