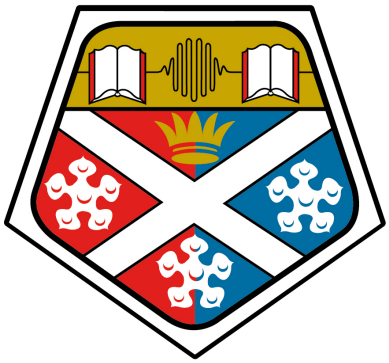
Investigating the Personal and Potential Use of Wearable Technology to Monitor Postural Tachycardia Syndrome (PoTS)



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Declaration of Authenticity and Author's Rights

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Abstract

Postural (Orthostatic) Tachycardia Syndrome (PoTS) is a chronic condition affecting between 0.2% and 1.5% of people in developed countries, predominantly women aged 15 to 50, who often have trouble seeking a diagnosis. Tracking technologies and wearables might enable people with PoTS to record and understand symptoms and facilitate interactions with healthcare professionals. An international survey (N=752 participants) was conducted to understand how and why people in this community currently use (or don't use) wearables to monitor their condition. Follow up interviews (N=20 participants) were conducted to explore lived experiences and how to design future wearables that support the needs of this overlooked population. Finally, a series of four asynchronous co-design workshops (N=15 participants), co-designed via survey, were conducted to generate guidelines for the design and development of future wearables to monitor PoTS. Results show that wearables can help validate physical symptoms, especially heart rate patterns, and form a useful part of a condition management system. However, there are still issues which need to be explored further, including device accuracy and trust, meaningful annotation of the data and linking this to daily lived experience.

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Chapter 1

Introduction

1.1 Motivation

This thesis is an exploration of the use of wearable technology by people living with Postural Tachycardia Syndrome (PoTS), specifically to monitor and manage their chronic condition(s) on a day-to-day basis (potentially as part of a wider system). It aims to centre the lived experiences of people with PoTS where possible.

Postural Tachycardia Syndrome (PoTS) is a chronic condition primarily experienced by women [P. A. Low and Sandroni 2012] which has low clinician awareness below a specialist level [Kavi et al. 2016]. It is a type of dysautonomia (an autonomic nervous system condition) characterised by orthostatic intolerance (symptoms that are present when standing and relieved by reclining), specifically an abnormal increase in heart rate when sitting up or standing [McDonald et al. 2014]. Other symptoms include fatigue, migraine, syncope (fainting), and heart palpitations [Flack and Fulton 2018]. PoTS and its symptoms, especially fatigue, can restrict people's lives by making it harder for them to undertake everyday tasks, maintain active lifestyles, or access work or education. Most cases emerge between the ages of 15 and 50 [P. A. Low and Sandroni 2012] and it often takes years for people with PoTS to gain a diagnosis [Kavi et al. 2016]. Clinicians are often reluctant to diagnose because of the relatively unknown and unreported symptoms. One of the key ways that people with PoTS manage their condition is by tracking their heart rate and wearables could be useful for doing so.

Wearable technology is the name given to electronic devices that are worn attached

to the body but unsupported by hands. They include multiple types of data tracking, including device-logged data and user-logged data, and can allow users to set alarms. Types of wearable technology include but are not limited to smartwatches, fitness bands, eyewear (including VR goggles), jewellery, and smart clothing. Wearable technologies, especially smartwatches and fitness bands, have become popular technologies and accessories in general, and are designed for and marketed to the general public as fitness and lifestyle devices. Standard data types monitored include heart rate, step count, distance walked, exercise type and duration, sleep tracking, calorie intake, and menstrual tracking, some or all of which can be accessed by users to monitor their day-to-day health, habits, and exercise regime. However, these features also mean that wearable technologies can provide a reasonably cheap, accessible, and unobtrusive way to monitor symptoms of chronic conditions, compared to complex medical equipment, with less stigma attached [Rukasha et al. 2020] [Albaghli, Raja, et al. 2017]. As PoTS is a condition that tends to involve significant self-management, wearables are perfectly placed to be of use in the monitoring of this condition.

There is a gap in the research when it comes to wearable technology and PoTS. From informal discussion with friends and relatives with PoTS followed by initial research, it became clear that people were using wearables to track their condition, but there was little to no mention of this in the literature. Through exploring the lived experiences of people with PoTS, this thesis seeks to better understand if and how wearables and tracking might empower people with PoTS to understand their own condition better and also to feel confident and empowered to communicate with health professionals about diagnosis, treatment, and day-to-day condition monitoring.

This doctoral research commenced in autumn 2019, prior to the emergence of the COVID-19 pandemic. At this time, there was comparatively little research into PoTS, and it remains a little-known condition. This has potentially changed since the initial outbreak of COVID-19 and the surge in PoTS diagnoses in people with Long COVID. Long COVID is a catch-all term for long-term health consequences and symptoms experienced by a proportion of people post-COVID-19 infection, specifically a continuation of COVID symptoms for more than 4 weeks after infection (NHS England, [England 2024]). As of the end of March 2023, when Office For National Statistics (ONS) updates

ended in the UK, an estimated 1.9 million people in the UK (2.9% of the population) were experiencing self-reported Long COVID symptoms [ONS 2023]. People with PoTS often take a long while to be diagnosed, and many doctors are unaware of the condition. When diagnosed, the focus is often on condition management techniques, something that wearable technology could help with (by tracking heart rate, for instance). There exists research about other uses of wearables but not this specific use.

1.2 Aims

The overall aim of this thesis is **to understand both how and why people with PoTS choose to use wearables on a day-to-day basis for condition monitoring**, as well as **how this could be improved**, ultimately **making recommendations on how to do so**. This overarching aim will be addressed through several smaller aims to approach the subject of this thesis in greater depth.

1. Investigate the popularity of wearable use among people with PoTS, understanding how wearables fit into wider individual condition monitoring systems on a day-to-day basis.

2. Seek to understand why people may choose not to use wearables for condition monitoring and their reasons for that choice.

3. Investigate issues encountered with the use of wearables for condition monitoring by people with PoTS.

4. Generate potential solutions to mitigate issues encountered when using wearables to monitor PoTS.

5. Create guidance for wearable designers and manufacturers for how to best serve this under-acknowledged user group.

1.3 Research Contribution

There is currently a dearth of research about the use of wearable technology to monitor PoTS (and other related chronic conditions). Therefore, it is hoped that this thesis will bring to light this example of a broader phenomenon, namely technology designed primarily by and for the ostensibly "healthy" or able-bodied being used by disabled and chronically ill people to track and monitor their condition(s), in the hope of greater understanding. The potential audiences of this thesis are those in the PoTS community or with a professional interest in PoTS, chronic health conditions in general, wearable technology design, and wearable digital innovations in healthcare.

1.4 Thesis Structure

This PhD thesis consists of seven chapters, including this introduction (Chapter 1). A background chapter (Chapter 2) serves to contextualise this research, reviewing current knowledge of PoTS, usage of wearables, and current literature. This is followed by a methodology chapter (Chapter 3) that justifies and explains the lens of this research and positional choices made, as well as introducing the methods chosen for each individual study.

The following three chapters (Chapters 4, 5, and 6) detail the studies conducted as part of this doctoral research. The first study (Chapter 4) consists of a survey (N=752 participants) which was conducted in order to understand how and why people with PoTS do or do not use wearables to monitor their condition. The second study (Chapter 5) consists of semi-structured interviews (N=20 participants) which were conducted to explore individual lived experiences and opinions of wearable technology for condition monitoring, specifically the monitoring of PoTS. The third study (Chapter 6) consists of four asynchronous group co-design workshops (N=15 participants) which sought to develop guidelines for the design of future wearables to monitor PoTS.

The study chapters are then followed by a Discussion and Conclusions chapter (Chapter 7) which relates the research conducted to prior research in the same field, as discussed in the Background chapter (Chapter 2), as well as stating the novel contributions of this

work and its importance. This final chapter also reinforces the overall findings of this research and serves to draw everything together, ultimately positing recommendations for future research.

Chapter 2

Background

2.1 Introduction

This chapter aims to contextualise this doctoral research within a broader scientific, technological, and societal context, providing the reader with the background information needed to understand this research. An overview of Postural Tachycardia Syndrome (PoTS) is given in Section 2.2, including symptoms, impacts, the typical diagnostic process, current treatments and condition monitoring, and Long COVID and its impacts upon the PoTS community. Following this, wearable technology is then explained to the reader in Section 2.3, including its history and use in healthcare, followed by the researcher's own definition of wearables. These two seemingly disparate strands are then woven together in Section 2.4 to explore current research about the use of wearables to monitor PoTS, as well as beginning to discuss the potential of wearables as a condition monitoring method.

2.2 Postural (Orthostatic) Tachycardia Syndrome

Postural Tachycardia Syndrome (PoTS), also known as Postural Orthostatic Tachycardia Syndrome (POTS) outside the United Kingdom, is a type of dysautonomia characterised by orthostatic intolerance, specifically an abnormal increase in heart rate when sitting up or standing [McDonald et al. 2014]. This refers to a tachycardia greater than 120 beats per minute (bpm) [Soliman et al. 2010], or an increase of over 30 bpm within 10 minutes

of standing up from a lying down position. Other symptoms include fatigue, migraine, syncope, and heart palpitations [Flack and Fulton 2018]. PoTS is a chronic condition that predominantly affects white women of childbearing age [Knoop, Picariello, et al. 2023] [Sebastian et al. 2022] and one that is often identified as an "invisible illness" due to the nature of its symptoms [Hollingsworth et al. 2021].

The term 'postural tachycardia syndrome' was first used by Rosen and Cryer in a 1982 publication studying one patient [N. P. Gall et al. 2022]. However, PoTS was not formally classified until 1993 by [Schondorf and P. Low 1993] but may have been recognised as early as 1916 in a British Medical Journal (BMJ) article entitled 'The Soldier's Heart' [Kavi et al. 2016], or even as early as 1862 during the American Civil War as 'irritable heart' by a physician named Jacob M Da Costa [N. Gall et al. 2020]. A lot of early PoTS history is linked to military investigations of conditions arising among soldiers. PoTS may also have been previously known as idiopathic orthostatic intolerance [Flack and Fulton 2018].

2.2.1 Symptoms and Impacts

PoTS may present in many different guises and thus it is important for any specialist to be aware of the condition. In his introduction to the 2020 book that he also co-edited, Nicholas Gall argued in favour of a multi-disciplinary management strategy for PoTS due to the multi-disciplinary nature of its symptoms [N. Gall et al. 2020].

In 2015, the Heart Rhythm Society defined PoTS in a consensus statement [Sheldon et al. 2015]:

> *Postural tachycardia syndrome (POTS) is defined as a clinical syndrome that is usually characterized by (1) frequent symptoms that occur with standing such as lightheadedness, palpitations, tremulousness, generalized weakness, blurred vision, exercise intolerance, and fatigue; (2) an increase in heart rate of $\geq$ 30 bpm when moving from a recumbent to a standing position held for more than 30 seconds (or $\geq$ 40 bpm in individuals 12 to 19 years of age); and (3) the absence of orthostatic hypotension (420 mm Hg drop in systolic blood pressure).*

More specifically, this increase in heart rate (orthostatic tachycardia) should be observed within 10 minutes of standing [N. Gall et al. 2020] (or an upright tilt on a tilt table [Fedorowski 2018]). A standing heart rate of above 120 bpm may often be observed [Sheldon et al. 2015], but this is not necessary for diagnosis [N. Gall et al. 2020]. People with PoTS experience greater increases in heart rate in the morning than the evening [Sheldon et al. 2015]. Patients must have **both** excessive tachycardia and symptoms of orthostatic intolerance in order to be diagnosed with PoTS [N. Gall et al. 2020]. Syncope (fainting) is observed in between 20-30% of cases according to Bourne et al. (2020) in [N. Gall et al. 2020], although some studies have recorded higher percentages of participants experiencing this particular symptom ([Kavi et al. 2016] recorded 58% of their 1005 survey respondents as experiencing syncope). However, it is not a necessary symptom for diagnosis. These symptoms typically need to have been present for 6 months or more for a patient to be eligible for diagnosis and symptoms may fluctuate across a person's menstrual cycle [Fedorowski 2018] [N. Gall et al. 2020]. The greater increase in heart rate necessary for younger individuals to be diagnosed is due to children and young people being more prone to physiological orthostatic tachycardia than adults [N. Gall et al. 2020].

Many PoTS symptoms, especially lightheadedness and palpitations, are also commonly observed in panic disorders and chronic anxiety [Sebastian et al. 2022]. This, combined with low clinician knowledge of PoTS, can lead to significant under-diagnosis of PoTS and/or misdiagnosis as these psychological conditions instead. Under-diagnosis of PoTS is particularly prevalent in adolescents [Soroken et al. 2022]. One quarter of PoTS patients may have a family history of similar complaints [N. Gall et al. 2020]. Symptom onset is often sudden, but no one particular event is known to cause PoTS. Instead, symptom onset may follow a wide range of precipitating incidents, including but not limited to illness (often viral), pregnancy, a complicated labour, a road traffic accident, trauma, psychological stress, or an operation [Mathias et al. 2011] [Knoop, Picariello, et al. 2023]. PoTS symptom onset may also follow a concussion [Miranda et al. 2018].

PoTS and its symptoms, especially fatigue, can severely impact a person's quality of life, potentially restricting mobility and the ability to access education or work, which

can have social, financial, and psychological impacts. Most PoTS patients have reduced quality of life and exhibit functional disability [N. Gall et al. 2020]. 84% of 779 survey respondents in [Kavi et al. 2016] experienced a reduction in quality of life. Meanwhile, [Flack and Fulton 2018] scored 40 patients on a scale of 0-10 to assess quality of life, before and with untreated PoTS. The pre-PoTS mean score of 7.5 halved upon developing the condition, showing a significant reduction in quality of life. This is less persuasive than the other study, however, due to the far smaller sample size and the self-rated scale. For both studies it is also key to be aware of how much patients' prior quality of life may differ between individuals.

Bourne et al. (2021) surveyed 5,556 people with PoTS (95% female) about the economic and employment impacts of their condition [K. Bourne et al. 2021]. Only 48.0% of respondents reported being in employment in the three months prior to responding, with 66.8% of total respondents saying that they would work more if not for their condition. 70.5% of respondents had lost income due to PoTS, and 95% of respondents reported spending money on PoTS-related out of pocket medical expenses since diagnosis. However, this paper only splits respondents into USA and non-USA, so it is hard to fully judge whether the non-universal (i.e. not free) nature of the American healthcare system is primarily responsible for the significantly higher reported spend on PoTS-related medical expenses since diagnosis by respondents in the USA, as it is unknown what proportion of non-USA respondents were also from countries with non-universal healthcare.

2.2.2 Diagnosis

Diagnosis of PoTS primarily takes place via tilt table test, at least in the UK (75% of survey respondents in [Kavi et al. 2016]), a process which [Fedorowski 2018] refers to as the 'golden standard' for PoTS diagnosis. Here, he specifically refers to a head-up tilt table test, accompanied by beat-to-beat haemodynamic monitoring. Active stand testing can also be used as a diagnostic test [N. Gall et al. 2020]. PoTS clinics sometimes exist within or adjacent to medicine for the elderly clinics due to said elderly clinics having often developed hospitals' tilt table services [N. Gall et al. 2020].

There is no current statement of the prevalence of PoTS in the UK but [McDonald

et al. 2014] suggest that the prevalence in the US is approximately 170 cases in 100,000 people, or just under 0.2% of the population. However, [S. R. Raj, Guzman, et al. 2020] remarks that the true US prevalence may be anywhere between 0.1%-1% of the population. Women are significantly more likely to develop the condition than men. According to [P. A. Low and Sandroni 2012], the "[f]emale:male ratio is about 4–5:1 and most cases occur between the ages of 15 and 50." The age range is supported by other studies, but the gender ratio tends to be even more predominantly female. The highest percentage of male patients in a sample was 19% (10 of 52 participants recruited via a PoTS clinic from [McDonald et al. 2014]), whilst the lowest was just 4% (3 of 84 participants recruited via the charity PoTS UK, from the same paper). The other two studies had 17.5% male participants (7 of 40 participants from a postal survey in [Flack and Fulton 2018]) and 8% male participants (from a sample of 779 participants recruited online via PoTS UK in [Kavi et al. 2016]). These lower percentage male samples may not be reflective of the true gender split and may instead suggest a potential bias issue: women appear to respond more to PoTS UK and/or online surveys than men.

The true prevalence of PoTS may be higher than expected due to significant under-diagnosis, including patients who are misdiagnosed. Clinician awareness of PoTS is low below a specialist level. Of the 779 respondents in the survey in [Kavi et al. 2016], only 7% had PoTS suggested as a potential diagnosis by their GP, whilst a fifth "had to suggest a diagnosis of PoTS to their healthcare professional themselves." Meanwhile, 34% of respondents had a cardiologist suggest PoTS as a diagnosis.

A significant issue affecting people with PoTS is the relative inaccessibility of a diagnosis. Many doctors may not have heard of the condition (indeed, PoTS UK has a readily available guide available on their website for people to show to their GPs if they think they have PoTS), and in general it can take a long time and a lot of doctors' appointments to receive a diagnosis [Kavi et al. 2016]. Potential misdiagnoses for PoTS include Chronic Fatigue Syndrome (also known as Myalgic Encephalomyelitis and abbreviated to ME/CFS, a potential co-morbidity), anxiety neurosis, panic attacks, depression, and hypochondriasis. In [Kavi et al. 2016] the mean time for participants between a first consultation with a medical professional after showing symptoms and a formal diagnosis was 3.7 years, suggesting significant hold-ups when attempting to gain a diagnosis in the

UK. Interestingly, 75% of the female participants in their study had been misdiagnosed, but only 25% of the male participants. The issue of patients being misdiagnosed with PoTS potentially due to clinicians misunderstanding the diagnostic criteria is mentioned in [S. R. Raj, Guzman, et al. 2020].

2.2.3 Current Treatments and Condition Monitoring

PoTS is not a condition that can be "cured" or "fixed" with a single treatment [Shaw et al. 2019]. Instead, a carefully crafted and assembled multidisciplinary system of condition monitoring, treatments, and lifestyle changes is assembled that varies from patient to patient according to each person's intersecting conditions and specific needs. In their recent paper, [Knoop and Dunwoody 2023] referred to the collection of non-pharmacological treatments used by their study participants as a "toolbox" that they selected useful methods and strategies from in order to manage specific aspects of their condition on a day-to-day basis.

According to [S. R. Raj, Guzman, et al. 2020], the ultimate goal of any treatment for PoTS should be to reach symptom remission. However, this may not be achievable, so they also suggest other aims, namely reducing symptoms, improving quality of life, patient education, and improving physical conditioning. Non-pharmacological methods should always be the first option. PoTS may be managed with prescribed medication, but it is also self-managed through lifestyle and dietary modifications, such as regular exercise, increased sodium consumption, and the wearing of compression socks or tights. A high salt intake is also popular (for those without hypertension) [Mathias et al. 2011]. Excessive consumption of caffeinated drinks should be avoided.

The most popular research priority for survey participants in [Kavi et al. 2016] was "effective lifestyle changes." Meanwhile, [Strassheim et al. 2018] emphasise the importance of careful activity management in order to manage fatigue. This lends itself to monitoring using wearables, especially smartwatches. Heart rate tracking is especially important, in order to measure the rapid changes in heart rate associated with PoTS, and the Canadian Cardiovascular Society (CCS) recommends smartwatches for this [S. R. Raj, Guzman, et al. 2020]. Rapp (2016) suggests that a smartwatch could passively encourage its wearer

to lead a more active lifestyle [Rapp 2016]. However, [Lucivero and Jongsma 2018] find this concept concerning, arguing that condition self-management often leads to patients following a strict medical regimen rather than improving self-determination.

PoTS is a condition that is often self-managed and/or one where condition management relies on tracked symptom data (primarily heart rate and blood pressure). The increased availability and affordability of wearables has made them more accessible and desirable for the general consumer. Most popular wearables are primarily marketed for fitness or other lifestyle purposes, rather than as potential medical assistance devices. This can decrease stigma for users, as a non-obvious method of condition management compared to devices more explicitly sourced from a healthcare provider, but can make it harder to work out how widely wearables are used for the purpose of condition monitoring.

2.2.4 Long COVID

In July 2019, a group of (primarily American) PoTS researchers participated in a National Institutes of Health (NIH) workshop in the United States of America, following a recommendation from US Congress [Committee 2018]. The purpose of this workshop was to discuss the state of PoTS research and clinical care at that time [Vernino et al. 2021], as well as identify then-current clinical needs, knowledge gaps, and PoTS research priorities [S. R. Raj, K. M. Bourne, et al. 2021]. These documents, whose contents have been discussed throughout this chapter, provide a fascinating and important snapshot of the state of pre-COVID pandemic PoTS research and attitudes. At the time of this symposium, it was hoped that the research priorities decided upon would act as a focus for PoTS research until 2025. Unfortunately, by the time the findings of this workshop were published in the Journal of Autonomic Neuroscience: Basic and Clinical in June 2021 the situation had changed unexpectedly and significantly due to the COVID-19 global pandemic.

In late 2019 a novel coronavirus known as SARS-CoV-2 emerged in Wuhan, China. The disease it caused, known as COVID-19, was declared a global pandemic in early 2020. The impact of the COVID-19 pandemic upon society as a whole cannot be overstated, and the PoTS community is very much included in this. People with PoTS experienced

significant changes to their daily routines, lifestyle, and condition management. For instance, telemedicine appointments became far more widely available and normalised, changing patients' experiences with specialists for both better and worse. However, there was other key changes experienced by the PoTS community (and indeed, broader society) during this time, namely a significant increase in the visibility of, and research about, the condition. This is at least partially due to Long COVID.

The National Institute for Health and Care Excellence (NICE) defines the long-term effects of COVID-19 infection as such [N. I. f. Health and (NICE) 2024]:

> ***Post-COVID-19 syndrome***
>
> *Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.*
>
> *In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).*

This "post-COVID-19 syndrome" is more broadly known as Long COVID, and will be referred to as such throughout this PhD thesis.

In February 2021, three months before the publication of the summary papers from the aforementioned NIH workshop, the American Autonomic Society (AAS) published an article in the journal of Clinical Autonomic Research entitled "Long-COVID postural tachycardia syndrome: an American Autonomic Society statement" [S. Raj et al. 2021]. This statement is aimed primarily at clinicians and sought to guide them when dealing with what had become a well-observed phenomenon, namely patients who had developed PoTS following an infection with the SARS-CoV-2 virus, better known as the disease COVID-19. This increased prevalence and awareness of PoTS has led to a greater volume

of research funding and output about the condition, as shown by a noticeable spike in research publications. This can be seen through PubMed records for the corresponding search term, as shown in Figure 2.1, which show a clear spike in research beginning in 2020 and continuing onwards to more than 50% above the previously observed maximum (95, in 2018).

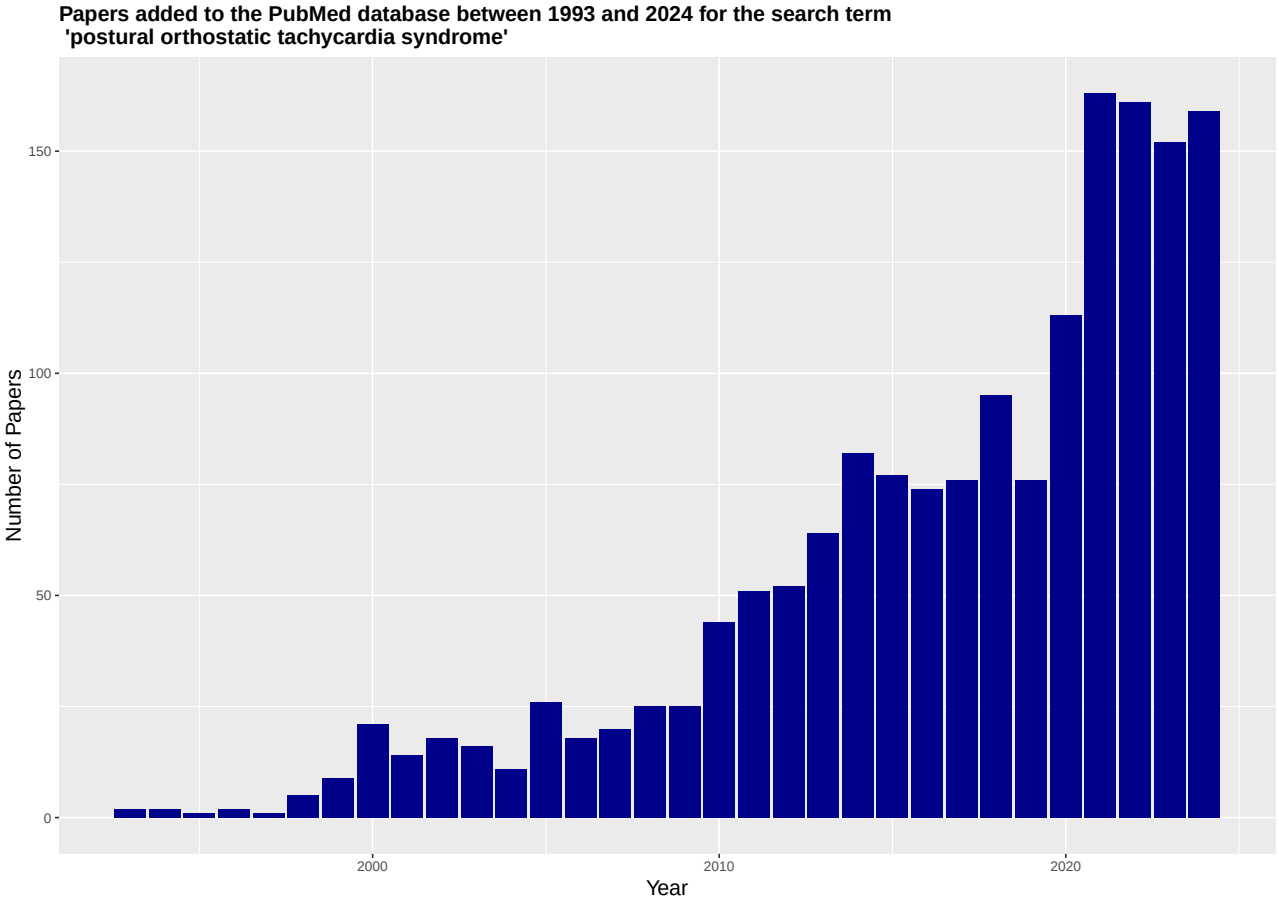

Figure 2.1: A graph showing the results of a search for the term *postural orthostatic tachycardia syndrome* on the PubMed database. This chart is a replication of the figure that appears on the PubMed web page to show the viewer when papers were added to the database. Papers represented in this graph were added to PubMed between 1993, when PoTS was formally classified, and the end of 2024.

A lack of knowledgeable physicians was already an issue before the pandemic [S. Raj et al. 2021] and an influx of new Long COVID patients is an issue that could lead to even greater delays in diagnosis and treatment due to overstretched services.

2.2.5 (Online) Community

Throughout this thesis, there is an emphasis on community, both in-person and online. In this section we consider the internet, and social media more specifically. When diagnosed with a chronic condition, people often seek out further medical information online in an attempt to understand what their symptoms might mean for them, based on others' experiences, including what should or should not be considered to be 'normal' [O'Kane et al. 2016]. This understanding of what is 'normal' can lead to a better understanding of what is abnormal, alleviating concern where necessary but also helping people to discern when further intervention may be needed. As well as this, improved condition knowledge can lead to better condition self-management [Merolli et al. 2013].

Another motivator for the use of the internet, especially social media, by people with chronic conditions is its ability to facilitate both communication and connection. Often, people know very few others in real life who share the same condition(s) as them, leaving them without a community of people who understand their lived experiences. As a result, they seek out these connections for social support, including information sharing, emotional support from peers, and empowerment [MacLeod, Bastin, et al. 2017] [Mankoff, Kuksenok, et al. 2011] [Merolli et al. 2013] [Pater et al. 2023], as well as understanding how to live with and manage their condition(s) [Nunes et al. 2015]. This communication may be asynchronous and can happen across a wide range of social media platforms with varying degrees of privacy and confidentiality in order to control the spread of information [Merolli et al. 2013] [MacLeod, Oakes, et al. 2015], albeit with an awareness of the risks of disclosing personal health information to comparative strangers [Sannon et al. 2019]. Through these conversations and communities, people gain a greater understanding of how experiences can vary across countries and healthcare systems, as well as having the chance to express themselves fully with people who understand their experiences with potentially stigmatised conditions [Sannon et al. 2019].

2.3 Wearable Technology

2.3.1 History

According to [Årsand et al. 2015], the concept of smartwatches was proposed as far back as 1985 but initially had little to do with healthcare. The IBM Linux Watch from 2000 is considered to be the first smartwatch by [Cecchinato et al. 2015], and their definition separates smartwatches from the broader field of wearables by the inclusion of a clock, although [Zeagler 2017] reminds the reader that symposiums on the broader field of wearable computers began in the late 1990s. Ten years ago [Årsand et al. 2015] did correctly predict that that the then-unreleased Apple Watch would help popularise the smartwatch, but it may not be fair to attribute increased interest in healthcare monitoring to one brand alone. The development of wearable technology has become increasingly rapid, and the wide range of available devices (not just smartwatches) are becoming increasingly accessible to the general public. Both [Chan et al. 2012] and [Dunn et al. 2018] list a range of available wearables with healthcare potential, and together they provide an interesting snapshot of how technology had changed in the intervening 6 years. For instance, [Dunn et al. 2018] discusses multiple wearables for maternal health, including trackers for fertility, contractions, and foetal heart rate, whilst [Chan et al. 2012] only references one item of wearable technological clothing for the last 4 weeks of pregnancy, suggesting a field that had developed significantly since 2012. [Berglund et al. 2016] concurs with this, suggesting that a rapid decrease in both the size and power consumption of necessary components led to an increase in smaller form factors of wearables, as opposed to larger garments.

The amount of and types of data available has increased over time, widening the scope of studies. Neshati et al. (2019) rightly points out that this is facilitated by improved battery life, something required by an increased number of sensors and trackable data types [Neshati et al. 2019]. However, [Lucivero and Jongsma 2018] critique the techno-optimist narrative that this is a "mobile revolution" for healthcare, as it is an overgeneralisation that does not consider ethical and accessibility issues present within the field. Wearables continue to be a rapidly growing technology, with the value of the wearable market being forecast to reach over €150 billion by 2028 [Ometov et al. 2021].

To tie this to PoTS, such devices may not have been suitable for PoTS management before a certain point in time. Studies conducted in 2011 and from 2014-2016 were considered by [Reeder and David 2016], who found successful heart rate monitoring in papers from 2015 onwards. However, not all the devices used to monitor heart rate managed to do so successfully, with both the Samsung Gear S and Tizen systems failing to "capture true heart measures." On the other hand, only 3 of the 17 studies included featured heart rate tracking, and it is uncertain whether they could be considered indicative of the full field of research at the time.

2.3.2 Design Considerations

Zeagler (2017) discusses considerations for where to place wearables on the human body, including wearable impacts on weight distribution, the user's perceptions of a wearable's size (proxemics), and appropriate body placement of devices to enable accurate data collection from the sensors contained [Zeagler 2017]. Wearables should also be worn in a reachable and viewable location if touching or checking the device is needed while it is being worn, with the motions necessary to do so needing to be socially acceptable if public adjustment or checking of the wearable is needed. This research, and the follow up research discussed in [Zeagler et al. 2022] enable wearable designers to consider accurate and accessible locations for their devices. Meanwhile [Islam et al. 2022] looks at preferred sleep data visualisation for wrist-worn wearables, specifically smartwatches and fitness bands, aiming to ensure readability of data visualisation on these devices.

When using wearables for condition monitoring, it is desirable for the devices to be unobtrusive and discreet, to avoid stigma, while also delivering necessary information in an unambiguous and comprehensible manner [Rukasha et al. 2020]. The importance of small wearable devices that are less obviously detectable than standard assistive devices or medical heart rate monitors was also recognised by [Albaghli, Raja, et al. 2017]. One other key inclusivity consideration is whether or not the sensors within a wearable will accurately track activity for people with mobility impairments [Malu and Findlater 2017]. According to [Shahmohammadi et al. 2017], a key advantage of smartwatches specifically is that they combine existing features of smartphones with continuous data monitoring,

and the integration of a screen allows for easy observation of data, alarms, and messages received.

2.3.3 Wearable Use in Healthcare

The use of wearable technologies to monitor specific health conditions is not a new idea, with papers addressing various conditions and concerns forming a key subset of digital health research, especially that centred around the Internet of Things (IoT). Examples of this research include [Singh et al. 2017], who used a researcher-designed wearable to sonify real-time movement for people with chronic pain, and [Mukhopadhyay et al. 2017], who used smartwatch data to attempt to detect cardiopulmonary disease. A smartwatch (Microsoft Band 2) was used in conjunction with a blood pressure monitor by [Iakovakis and Hadjileontiadis 2016] to record heart rate variability and drops in systolic blood pressure between reclining and standing in order to detect orthostatic hypotension. Indeed, in the mapping review of personal informatics literature conducted by [Epstein et al. 2020], chronic conditions were the second most frequent domain of study recorded after physical activity. A noticeable subset of wearable healthcare research focuses on care for the elderly [Baig et al. 2017] [Y.-H. Kim et al. 2022] [Zhang and Shahriar 2020], with [Vargemidis et al. 2020] noticing that the wearable systems studied favour supervising the elderly (others analysing and keeping track of their activity) rather than supporting them (enabling them to track their own activity). Using digital health to manage their multiple chronic conditions simultaneously was considered to be significantly more complicated by the older people studied by [Doyle et al. 2019]. Meanwhile, people with ME/CFS expressed concern about the use of commercial wearables to monitor their condition as the devices weren't designed specifically for it. They preferred tailored solutions where possible to meet their specific needs [Davies et al. 2019].

According to [Gan et al. 2021] and the sentiment analysis they conducted across ten years of texts (2010-2020), healthcare-oriented wearables were perceived positively by all four sectors studied (academia (PubMed and DBLP papers), entrepreneurs (Kickstarter and Indiegogo), news media (Google and Bing News), and Twitter users). This is especially of interest with regards to academia and social media, which held more negative

opinions of wearables as a whole than the other sectors. A surge in research into wrist-worn wearables specifically was also noticeable in the years leading up to 2020. Although wrist-worn wearables are popular, they have one key limitation: wrist-worn accelerometers cannot accurately gauge fine hand movements, reducing their utility in some specific healthcare situations that require detailed hand monitoring, such as stroke rehab [Y. Kim et al. 2019]. Here, smart rings may be of more use as they are able to successfully monitor both these fine hand movements and broader (gross) arm movements. Concerns are expressed about the limitations of fitness trackers by [Pernencar and Romão 2016] and [Gupta et al. 2020], specifically the limited amount of data types and activities that can be recorded, alongside accuracy issues.

An increasing number of wearable brands are seeking medical approval for specific features of their devices. For instance, Apple sought medical verification for the electrocardiogram (ECG) feature on the Apple Watch Series 4 [Inc. 2018] and conducted a scientific study as part of that process [Turakhia et al. 2018]. Publicising these features can lead to both greater awareness of the measurement type conducted (e.g. ECG) as well as suggesting to potential customers that a wearable could help with healthcare. Even if a device is not specifically marketed as one for healthcare, there could still be use for the data collected within a medical setting. Continuous heart rate data may be of interest to a specialist, for instance, although [Albaghli and Anderson 2016] discovered different priorities in their interviews with doctors: users flagging up potentially troubling symptoms, tools to screen for cardiac arrhythmias, avoiding false positives during medical appointments, and empowering users to track and examine their data regularly in order to have better awareness of their own health. Additionally, the goal-based nature of some wearable features (such as a customisable daily step count target) can assist with rehabilitation programmes. This is not to suggest that these built-in tracking features are universally positive, however. Continual and/or goal based tracking may have negative impacts on participants' mental health, and the intrusive nature of some aspects of technology may not lead to sustainable lifestyle changes if the device is only for temporary use [Lucivero and Jongsma 2018].

Wearable technology can improve a person's quality of life as the data and knowledge it provides can enable people to monitor their own body, as well as potentially shaping

doctor-patient relationships. This is a focus of [Chan et al. 2012] who look at design processes such as working out the fit and weight of smart gloves. Dellgren (2017) also mentions a way to improve patient quality of life, by devising treatments that replace restrictive technology with smartwatches, specifically using an Apple Watch and medical treatment instead of a worn heart pump [Dellgren 2017].

West et al. (2016) suggest that clinicians may be wary of self-logged data due to a lack of understanding of the device [West et al. 2016], while [Ancker et al. 2015] suggest clinician wariness is due to distrust in patients, specifically their lack of diligence and fear of consequences, and that technologically measured data is trusted more than self-logged data. This could be mitigated by working with clinicians when beginning treatment using wearable technology, or by establishing specific methods for data analysis [Rodriguez et al. 2018]. Data visualisation issues for smartphones are explored by [Neshati et al. 2019], who also suggest solutions, including ones that could be useful in a healthcare setting.

Current wearable trackers such as Fitbits and Apple Watches aim to increase a person's activity levels and as such contain goals for data types such as steps. However, these standardised goals may often be too high or undesirable for people with some chronic conditions, such as ME/CFS, who instead prefer to monitor their conditions through activity pacing to avoid overexertion, as discussed by [Davies et al. 2019]. Homewood (2023) is an autoethnographic paper about the author's experiences with Long COVID that also discusses her use of a Fitbit for activity pacing in a way that went against the device's designed use case - instead of maximising her activity levels, she sought to control and minimise them as necessary [Homewood 2023]. Therefore, her reaction to accidentally meeting the standard 10,000 step goal was concern and horror rather than the designers' anticipated feelings of success and fulfilment due to the fear that she had overexerted herself.

Adherence can be an issue for medical monitoring using smartwatches, due to technical issues, privacy concerns, or unfamiliarity with the technology. This is especially noticeable in [Wu et al. 2018], a study where only 16 of 28 enrolled participants completed the full 90 days. In this case issues cited included the bulkiness of the device, as well as issues with the technology and participant health. However, there was another pressing issue that both caused dropouts and impacted recruitment that is easily avoidable: the

researchers decided to use the smartwatch's built-in recording technology to see how much participants were coughing. This was perceived by some to be a significant privacy issue, leading to 23 people either not taking part in or not proceeding with the study. This recording highlights a significant ethical issue and presents a cautionary tale of how good intentions may alienate potential study participants. Chiauzzi et al. (2015) discuss how wearable users can stay motivated, stating that one third of US wearable users last less than six months from first use [Chiauzzi et al. 2015]. Comfort and device usefulness were described as factors that boosted wearable adherence, while technical difficulties, lack of device attractiveness, and a lack of willingness to monitor activities were described as factors that could lead to people stopping using wearables. A lack of time and motivation to track and examine wearable data on behalf of both the wearable user and their clinician was stated as a barrier to the use of wearables for health tracking by [Bhat and Kumar 2020].

Wearable technology could be considered a democratiser, as it is cheaper and potentially easier to understand for a patient than complex medical equipment. Developers are increasingly recognising this and are beginning to seek medical certification for features on their devices, such as the Apple Watch Series 4's ECG technology [Inc. 2018]. The validation of this feature was accompanied by [Turakhia et al. 2018], showing the methodology used. This study operated on a very large scale, with a sample size of over 420,000 people. However, this is mostly due to Apple recruiting customers who had already bought their new device. Also, the contents of [Turakhia et al. 2018] should be considered with care due to the potential for bias, as these researchers were carrying out this validation on behalf of Apple, the developers. This study is critiqued by [Isakadze and Martin 2020] for its high dropout rate and non-representative study population (skewed towards young, white, and male participants) and also raise a salient point about the broader accessibility of the Apple Watch (and indeed, direct-to-consumer wearables as a whole), namely that the adoption of this technology is restricted by socioeconomic and demographic factors. Earlier studies also feature attempts to replace more expensive medical equipment with smartwatches, such as [Hosseini 2015], which develops a novel algorithm to detect diabetic coma and is targeted at people who may not be able to afford implantable glucose sensors.

A key component of many digital health studies focused on wearables is designing applications to monitor specific conditions. The design and fine-tuning of these can be a long and exhaustive process. For instance, [Årsand et al. 2015] detailed a 9-month iterative design process for a diabetes diary smartwatch app, incorporating a 2-week test phase with 6 participants. The development process appears to be shorter for [Nwosu et al. 2017], as they mention students successfully programming an app within a "summer project" setting, but it is likely that a significant amount of prior development may have been done. Overall, app development could be a later goal of this research, but the needs of the user base would need to be investigated in more depth before attempting this. Kim et al. (2022) also engaged in the process of designing a monitoring app, specifically for the elderly, but they also carefully selected and designed for a specific device (the Fossil Gen 5, an Android watch) that best fitted the needs of their user group, namely one with a large display that would increase the visibility of the app's prompts [Y.-H. Kim et al. 2022].

As part of this background review an analytical product review was conducted that tracked mentions of wearables in papers by brand and form factor. The main finding from this review was an initial realisation of how broad the current wearables market is, with a large number of brands each producing ranges of devices at varying price points, especially smartwatches and other wrist-worn wearables. As well as the aforementioned smartwatch and fitness band form factors, more specialist labels such as sports watch were used to label devices, and brand motivations for entering the market varied widely. Brands producing these devices come from a wide range of backgrounds, including tech giants such as Apple and Samsung as well as brands like Garmin, best known for their satellite navigation systems and mapping technology. One smartwatch mentioned in prior reading was made by Casio, a company most famous for designing calculators. However, it could sometimes be difficult to discern the exact difference between specific form factors.

On paper, there appears to be little difference between many of the stated devices, suggesting a reasonably standard set of expected data types for a smartwatch to track at any budget. Step count is the most widely included feature, but none of these devices are listed as being pedometers. Aside from step count, nearly all of the devices that features had been recorded for tracked calories, distance, exercise, heart rate, and sleep.

With the potential exception of sleep these all form a logical and linked system based upon step count and heart rate. Distance can be approximated from step count, whilst heart rate, step count, and distance can be used to judge exercise and calories burned. Heart rate and activity level are relevant when discerning if the user is sleeping or not. This may not always be accurate, however - sometimes a fitness band may record a nap when the device has simply been left in a bag. More pressingly, there are ableism issues to consider in this context, specifically wheelchair users whose devices do not track their movement accurately [Loeppky 2020] [Malu and Findlater 2017]. Rarer data types tracked include VO2 max, ECG, and fall detection. VO2 max is primarily an exercise related feature, albeit one with potential use in healthcare, whilst ECG and fall detection are more explicitly healthcare related data types.

This analytical product review became a valuable resource whilst conducting both background reading and initial research. The most direct impact it has had on this research can be found in the design of the survey that formed Study 1, specifically when crafting questions about current and past wearable use. When participants were asked about the data types they track(ed), the multiple choice options available were based upon those listed in the review (with a few additions from pilot testing). As well as this, some of the other information recorded as part of this review could be used when deciding which devices to consider for use in future studies. For instance, a more affordable device could lead to a greater sample size. Only some devices track some data types, so it also provides an easy to check list of features to check against research requirements.

2.3.4 Definition

My definition of wearables used in this thesis was generated through conversations with other researchers following my initial reading. I developed this definition to more effectively categorise the devices I had been studying and to create effective inclusion/exclusion criteria for future devices encountered. This definition was also created using language that could be easily understood by the then future study participants.
My definition is as follows:

Wearable technology is the name given to electronic devices that are worn

attached to the body but unsupported by hands. Although often primarily marketed for fitness, they can prove useful for healthcare monitoring due to the wide variety of sensors often included in devices that are cheaper, more comfortable, and more accessible than medical equipment that could serve the same purpose.

Types of wearable technology include but are not limited to smartwatches, fitness bands, eyewear (including VR goggles), jewellery, and smart clothing. Mobile phones are not examples of wearable technology.

2.4 Wearables and PoTS

Part of monitoring PoTS includes heart rate monitoring, and this is a standard feature for many wearables, especially wrist worn ones such as smartwatches and fitness bands. These devices can provide (near-)constant heart rate monitoring at a low price. Other aspects of PoTS monitoring are suited to wearable use as well. People with PoTS had been previously surveyed by [McDonald et al. 2014], [Kavi et al. 2016], and [Flack and Fulton 2018], but none of those surveys mentioned wearables. The only PoTS paper encountered that mentions wearables being used to monitor PoTS specifically is [S. R. Raj, Guzman, et al. 2020], which suggests using "smart watches, or fitness wearable monitors" to continuously track heart rate. As well as this, [Mead 2022a] raises concerns about the potential suitability of wearables for PoTS monitoring based on research into another chronic condition, ME/CFS, due to the devices not being designed for people with chronic conditions and assuming inappropriate health goals as a result. Ultimately the author chose to focus on app development instead [Mead 2022b].

The suggestion from [S. R. Raj, Guzman, et al. 2020] is an area worth considering given that exercise is a recommended way to self-manage PoTS. Initially this could be investigated by conducting a survey, to gain a better idea of which data types are of most use to people seeking to self-manage their PoTS. Recruitment methods varied between surveys, but there were two primary vectors: hospital diagnostic clinics [Flack and Fulton 2018] and PoTS UK [Kavi et al. 2016]. Both organisation types were used by [McDonald et al. 2014] to recruit patients.

2.5 Conclusions

This chapter contextualises the research contained in this thesis and gives the reader background information about Postural Tachycardia Syndrome (PoTS), wearable technology, and the intersection of the two. It provides an overview of PoTS that should be accessible to the layperson, including symptoms, impacts, the diagnostic process, and current treatments and self-management methods. The impact of Long COVID is also discussed, as is the use of the internet by people with PoTS both for research and also to find community. Wearable technology is then defined and introduced, including its history, design features, and use in healthcare. The penultimate section, which brings PoTS and wearables together for the first time, hints at the direction of the research that will follow in Study 1 (Chapter 4).

This chapter shows the importance of this research through the identification of a gap in the research in which it fits, due to the dearth of papers mentioning, let alone about, the use of wearables to monitor PoTS. As this is a known method of condition monitoring within the PoTS community, there is therefore room to explore it further and in more depth from an academic standpoint.

Chapter 3

Methodology

3.1 Introduction

This chapter contains information needed to understand the researcher's background, experiences, and thought processes, as well as the lens that this research was conducted through. It also discusses the methodological choices made throughout this research and the reasoning behind them.

3.2 Positional Paragraphs

This section contains contextual information about me as a researcher and experiences of mine that have impacted my perspective when conducting this research, as well as information about the time in which this research was conducted, specifically during a global pandemic.

3.2.1 Personal Experience

I have prior experience of wearables, having worn a Fitbit on a day-to-day basis for several years, including significant time prior to the commencement of this research. I neither have PoTS nor specifically use wearables for any chronic condition monitoring purpose, but I have witnessed friends and family do so. My personal experience of PoTS (and partially an initial inspiration for this research) came from seeing a family member be

diagnosed and use wearables while establishing their own condition monitoring system. I also have a diabetic friend who uses an Apple Watch as part of their condition monitoring system, specifically linked to an in-arm blood glucose monitor whose data output, visualisations, and trends are available on both their smartwatch and their iPhone.

3.2.2 COVID-19 Pandemic

This doctoral research commenced in autumn 2019 and has continued until 2024, including the continuing duration of the COVID-19 pandemic. As a result, the pandemic has undoubtedly impacted and shaped this research, and the changing nature of the disease, global research, and pandemic mitigation measures including but not limited to vaccination and lockdowns means that the findings and attitudes expressed within should be considered through this lens. Participant responses throughout, especially in long-form interview and workshop prompt responses, could be considered a snapshot of individual experiences during this time.

3.2.3 Language Use

Throughout this thesis, the term Postural Tachycardia Syndrome (PoTS) will be used as default, as this is a PhD thesis being written in the United Kingdom. Although this research is international, it is being conducted from the UK and PoTS is the terminology used here, plus it is still a comprehensible acronym for international respondents.

However, there have been situations throughout this research where it has been necessary and/or advantageous to use the term Postural Orthostatic Tachycardia Syndrome (POTS) instead. Most specifically, the American non-profit Dysautonomia International (DI) required use of the term POTS in order for them to promote the survey study to their primarily American audience, thus that study and the joint Participant Information Sheet and consent form for the survey and interview studies use POTS as the preferred term. (See Chapter 4 and Appendices A and B.)

3.3 Lens

In order to sufficiently contextualise this research, we must first discuss the broader societal framework it sits within. Assistive technology, condition monitoring, and indeed chronic conditions as a whole can be considered within a disability rights framework, whilst the heavy female predominance and low clinician knowledge of PoTS lend themselves to discussion of gendered healthcare, more specifically issues related to research funding, misdiagnosis, and interactions with healthcare professionals. From an academic standpoint, we must also discuss the theories, frameworks, and methodologies relevant to this research, specifically co-production and user-centred design. This thesis aims to centre the lived experience of people with PoTS and this section links this aim to academic theory and research methods.

3.3.1 Disability Rights

A broad introduction to the topic of disability inclusivity for the field of assistive technology as a whole, which wearables could arguably be considered to be part of, is given by [Mankoff, Hayes, et al. 2010]. This paper assumes no prior knowledge of the field of Disability Studies, and provides an introduction to both that field and models of disability, as well as case studies, before showing how this theory could be linked to accessible technology research as a whole. Some of the texts referenced are foundational for specific disability advocacy groups, such as Jim Sinclair's seminal quotation about the impossibility of separating a person from their autism, which is commonly used both as an anti-cure argument and to argue for the use of identity first language when talking about autistic people. The authors of this paper came to their knowledge about this topic through different means (lived experience, work in technology design, or both) and the varying backgrounds enable a greater scope of discussion.

Overall, this informative paper provides a good overview but should be used as a springboard for future inquiry, rather than the sum total of a HCI researcher's entire knowledge of Disability Studies. This is especially key for British and other non-American researchers, as the authors deliberately chose a US-centric focus. Disability rights issues and indeed the field of Disability Studies as a whole can vary significantly between coun-

tries and researchers should strive to be aware of cultural differences and nuance. As well as this, the paper was written in 2010, and the field has significantly advanced since then. However, it did help the researcher to begin to realise the assumed background level of knowledge of disability inclusivity in her field.

The most important facet of this paper and its enduring legacy is the argument it makes for the active inclusion of disabled participants in research about disability and accessibility, namely that this should be a requirement throughout and not simply an afterthought. Nowadays, this is not a novel concept, but at the time it may well have surprised abled researchers. Indeed, the CHI workshop summary [Spiel et al. 2020] refers to [Mankoff, Hayes, et al. 2010] both as "seminal" and a "landmark paper" for doing so. This workshop, entitled "Nothing About Us Without Us: Investigating the Role of Critical Disability Studies in HCI", aimed to reflect upon the field ten years on from this paper and draw attention back to this area of research, through a lens focused on lived experience of disability.

The maxim "Nothing About Us Without Us" has been used in a disability rights context since at least the early 1990s. In his 1998 book "Nothing About Us Without Us: Disability Oppression and Empowerment", the American author and disability rights activist James Charlton states that he first heard the expression used on two separate occasions in 1993 by Michael Masutha and William Rowland, two leaders of the advocacy group Disabled People South Africa, but they had both heard it used by an Eastern European activist at an international disability rights conference [Charlton 1998].

3.3.2 Gendered Healthcare and Invalidation

PoTS is a condition that primarily affects women, specifically those "of childbearing age." According to [Waterman et al. 2021], the female predominance of PoTS is such that the female-to-male ratio of the condition is 5:1, a notable imbalance. Therefore, it is important to consider broader issues related to gender when looking at both PoTS research and the interactions people with PoTS have with healthcare professionals.

There is a significant gender disparity in research funding in both the US and the UK, with predominantly male conditions tending to be prioritised and better funded

than predominantly female ones. Historically, scientists have incorrectly assumed that females should be excluded from research studies due to variable data caused by the reproductive cycle [Tannenbaum et al. 2019], while the US Food and Drug Association (FDA) banned premenopausal females from participating in drug trials in the late 1970s due to concerns that participation could cause harm to their reproductive systems, with their participation only being mandated in 1993 [Stranges et al. 2023] [Hoffmann and Tarzian 2001]. (In Canada, the inclusion of females in clinical trials remained only a recommendation as of 2023 [Stranges et al. 2023].) Even when women are included, sex and/or gender are not considered as factors 80% of the time, nor are questions asked about whether outcomes reached may have been influenced by female-specific factors [Stranges et al. 2023]. This lack of inclusion of female data, alongside other aspects of medical misogyny, potentially leads to male data being seen as the default.

To this day, funding disparities still exist between conditions considered to be male-dominant and those considered to be female-dominant. (Here, using the definition from [Mirin 2021] and [Smith 2023], a condition is considered to be gender-dominant when 60% of the people diagnosed with it are of one specific gender.) Overall, research from [Mirin 2021], further discussed in [Smith 2023], showed that the US National Institutes of Health (NIH) disproportionately underfunded female-dominant conditions relative to almost all of the other conditions studied. One notably underfunded female-dominant condition is Chronic Fatigue Syndrome (ME/CFS), which has a significant symptom overlap with PoTS [Mead 2022a]. (However, it should be noted that Mirin also consistently uses the term "diseases" to refer to a wide range of conditions and types of neurodiversity, and referring to autism as a "male-dominated disease" is inaccurate and frankly stigmatising.) The underfunding of research into female-dominant conditions ultimately leads to less knowledge about the causes, symptoms, and impacts of these conditions, which in turn leads to worse health outcomes for people affected by them, especially women.

This systemic underfunding of health conditions that primarily affect women is not just a concern in the United States of America, with [Stranges et al. 2023] discussing this issue from a Canadian perspective. It also remains a concern in the UK, with the Royal College of Obstetricians and Gynaecologists (RCOG) giving a recommendation for how to tackle this concerning issue in their 2019 report [Obstetricians and Gynaecologists

2019] that focused on improving the health of women and girls:

> *There must be renewed effort to tackle the gender data gap by funding more studies which focus on women's health and responses to treatment to eliminate the gender bias evident in diagnosis, treatment and medical research.*

Despite the organisation's primary concern being obstetric and gynaecological health, this quotation and the report it is contained within focus on a broad range of conditions that affect women and girls, and thus this can be considered to be a more general statement. Here, the "gender data gap" mentioned feeds into a wider problem: the concept of a "gender health gap".

The "gender health gap" is defined by the private health company Benenden Health in their 2023 report on the subject (conducted in partnership with the Fawcett Society and featuring a survey of 10,000 women) as "the inequity in healthcare provision due to a person's gender" [B. Health 2024]. Noticeably, this does not mention which gender may be disadvantaged, but they later state that the UK "has the largest women's health gap across all G20 countries." The House of Lords published an article prior to a 2021 debate on the topic expressing their concerns about women's poor experiences of the healthcare system (especially compared to men) [Winchester 2021]. As well as concerns about gender biases in clinical trials and less being known about conditions that primarily affect women, the author raises the issue of women's pain (and physical symptoms) being taken less seriously, including a greater rate of misdiagnoses than men. These broader issues are well known, both in academia and in society as a whole. [Mirin 2021] states that:

> *"An issue commonly faced by women is having their physical complaints trivialized or misdiagnosed as psychologically based."*

This is especially true when it comes to pain, as discussed by [Hoffmann and Tarzian 2001], which expresses a similar statement about misdiagnosis albeit with a necessary clarification - women are more likely than men to have their physical pain attributed to a psychological cause, **regardless of whether or not said suggested psychological condition actually causes the pain**. In this paper, the authors review the then-existing literature from a feminist legal perspective to examine differences between how

male and female experiences of pain are treated by clinicians, including that healthcare providers respond differently to different genders' expressions of pain. Their findings include a suggestion that women are initially disbelieved by healthcare providers, based on a prior study that discovered that male chronic pain patients referred to a specialist pain clinic were more likely to have been referred by a general practitioner (GP), while women referred to the same clinic were more likely to have been referred there by a specialist. This is backed up later on in [Hoffmann and Tarzian 2001] when the authors explicitly state that:

> *"Women who seek help are less likely than men to be taken seriously when they report pain and are less likely to have their pain adequately treated"*

Here the suggestion is of differing clinician attitudes to each gender's sensitivity to and tolerance of pain, as well the perceived "validity" of each gender's self-reported pain. Women have been perceived to be "hysterical or emotional", where men may instead be seen as "forceful or aggressive", which can be linked to the historical phenomenon of hysteria [Albanowski 2022].

According to [B. Health 2024] and the corresponding survey (approximate sample size $N = 10,000$), 45% of the women surveyed had struggled to receive a diagnosis, with 31% of survey respondents experiencing delays of over a year before diagnosis. 33% of the respondents who had experienced a poorer health outcome had received some form of misdiagnosis. However, it is unclear what conditions are being referred to here, with only percentages being given, and this survey is from a private health company rather than an academic source. To compare this to PoTS, look at the data from [Kavi et al. 2016] and their sample of 779 PoTS patients (92% female), where the mean time from first medical consultation about PoTS symptoms to receiving a diagnosis was 3.7 years. 48% of respondents were advised that their PoTS symptoms were instead due to psychological or psychiatric conditions instead (75% of female patients and 25% of male patients).

Kesserwani (2020) wrote specifically about a case of PoTS being misdiagnosed as anxiety, which they describe as a common occurrence [Kesserwani 2020]. The author suggests that a potential reason for this is that anxiety often presents as dizziness in young people, but there is another unmentioned reason that is worth considering here,

namely low clinician awareness of both PoTS and its prevalence. Kesserwani considers PoTS 'relatively easily diagnosed' and it generally ultimately is - the issue here is with people not being referred to specialists for that diagnostic testing.

Another issue experienced is people with PoTS being disbelieved about symptoms experienced and their causes, both by clinicians and people around the patients, as well as having their lived experiences invalidated. In their recent paper, [Frye et al. 2023] interviewed six young people with PoTS and eight parents of young people with PoTS (including six parent-child dyads) about their experiences of living with the condition. Five of the adolescents discussed (four interviewed; one deceased) were female. Invalidation was a key theme discussed in this paper, with many families feeling "dismissed by the medical community" as well as the people around them, including other family members, peers, and even school administrators. One adolescent participant expressed concern about this: if a qualified doctor disbelieved them, what chance did they have of being believed and accepted by their friends? (Parents also worried about dismissing the validity of their children's symptoms, although this changed over time.) This invalidation included disbelieving both the existence of and the severity of PoTS, as well as assigning blame to mental health issues. Interviewees felt that more resources and education were needed for both clinicians and families of people with PoTS. Even after receiving a PoTS diagnosis, participants still struggled to find appropriate care providers with knowledge of PoTS-specific treatments. Concern about a lack of understanding was also shown by [Waterman et al. 2021], as well as an underestimation of the impacts of PoTS upon study participants.

One other factor that had an impact on some participants' opinions about and use of wearables was the US Supreme Court's repeal of Roe v Wade in late June 2022 and subsequent changes in American abortion laws [Cao et al. 2024]. This primarily impacted American participants in the third and final study, but remains relevant to this research as wearables can be used for (primarily self-logged) menstrual tracking.

3.3.3 Lived Experience, Co-Production and User-Centered Design

Overall, this thesis sought to understand the lived experiences of people with PoTS. As discussed above, especially in Section 3.3, this research deals with the experiences of a marginalised community with a relatively recently formally recognised condition (first named in 1993, see Section 2.2). Choosing to focus on lived experience led to a focus on participatory and user-centered design methods when constructing the three studies that constitute this research, as it was felt that these methods best allowed the perspectives of people with PoTS to shine. Initially, the researcher also considered contacting clinicians for this research rather than co-designing with people with PoTS, but ultimately decided that focusing on people with PoTS would result in sufficient levels of engagement for this research.

Participatory methods are defined by [Braun and Clarke 2013] as research methods which "involve the participants and/or the community the research is about as active members of the research, even as co-researchers." Within this area of participatory design, co-design is the name given to an iterative process that collaborates with participants throughout research. Previously, [Sanders and Stappers 2008] had referred to a participatory approach as "user as partner" in comparison to the user-centered design approach, which they instead called "user as subject". User-centered design (UCD) is an approach where the researcher aims to focus on creating solutions that meet the needs of the intended user, based upon research into the user group. However, it does not guarantee the involvement of the target user group within studies. Within this thesis all research conducted can be considered to be user-centered design, but the involvement of people with PoTS in pilot testing the survey study and co-designing and pilot testing the co-design workshops means that these can be considered to be participatory design. These design methodologies were chosen as the researcher wished to (where possible) get input from people with PoTS throughout the studies conducted. For the survey study this consisted of pilot testing from the partner charities, especially Dysautonomia International, while the workshop study was both co-designed via survey then pilot tested by people with PoTS. The interview study questions were designed based upon the survey study

responses, but the basic concept of the interviews was known to the partner charities.

Throughout this thesis, the research conducted sought to involve people with PoTS as much as possible, aiming to amplify their voices. The workshop study was co-designed to tailor its structure to participants' comfort and their day-to-day schedule and the collaborative Zoom call element aimed to simulate community discussions. The interviews were designed to be conducted in a manner comfortable to the participants, all of whom were members of this far-flung community. Meetings were scheduled to work around participants' time zones rather than the researcher's time zone.

3.4 Design Choices

Overall this thesis consists of mixed methods research throughout its three constituent studies, more specifically a continual shift in focus from a more quantitatively focused survey to primarily qualitative interviews and co-design workshops. This was an organic shift that took place in order to let the voices of people with PoTS be heard as the focus of this research and one that resulted in longer form recorded and textual responses. These longer form responses led to a reduced number of participants in each study in order to keep the volume of data collected manageable and reasonable in the time available to the researcher. Co-design worked as a way for people with PoTS to help shape the research questions to better fit the desires and concerns of this under-served community, which ultimately led to the final co-design workshop study's structure being itself co-designed by potential participants through a survey and then later pilot testing.

Recruitment throughout took place online via charities, surveys, and emails. The COVID-19 pandemic made this a necessity through reducing the impact of other recruitment methods such as posters, but the plan for this research was always to recruit for and conduct the studies online due to the comparatively rare nature of PoTS. All research was designed to be internationally focused and accessible to participants globally as much as possible, which was tested for by running international pilot testing wherever possible. As one of the charities that distributed the survey study is based in the USA (Dysautonomia International), some language choices were made to adapt to their American English distributive standards (such as using Postural Orthostatic Tachycardia Syndrome and

POTS rather than Postural Tachycardia Syndrome and PoTS). The choice could have been made not to comply with this request, but this would have led to Dysautonomia International being unwilling to distribute the survey, a choice that would have resulted in far fewer responses.

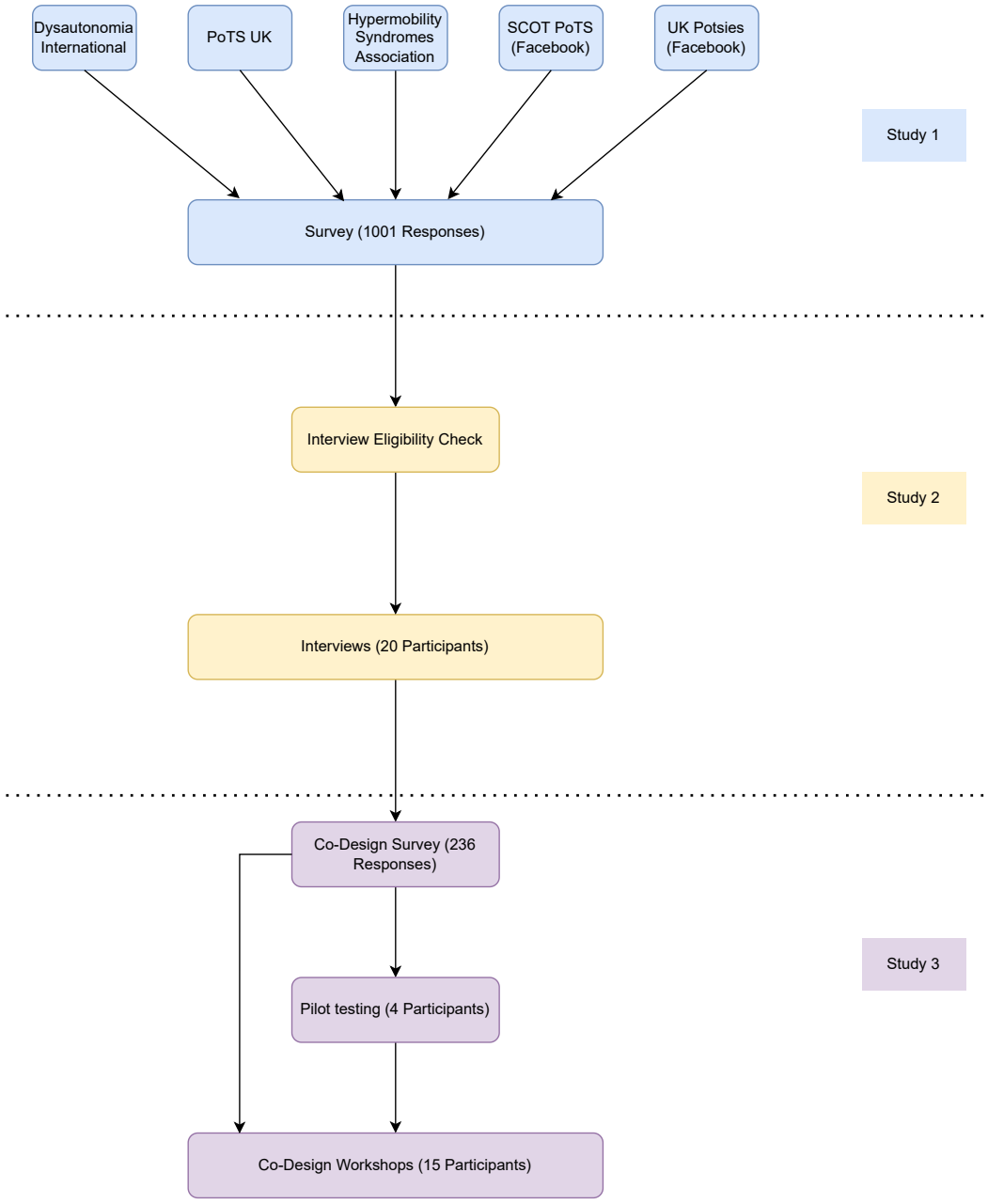

Figure 3.1: A schematic diagram showing the progression of the three studies that comprise this thesis and the recruitment processes for them. This diagram is colour coded by study.

Figure 3.1 informs the reader which order research study tasks were conducted in, with the arrows between lozenges representing a flow of participants. The five smaller lozenges at the top of the diagram represent the three charities and two Facebook groups that assisted with recruitment for Study 1. It should be noted that interviewees were deliberately not selected as workshop participants, although they were able to participate in the co-design survey for Study 3.

3.4.1 Study 1: Survey

The aim of the first study (see Chapter 4) was to gain a broad overview of the PoTS community and the wider chronic illness community's experiences of wearables, day-to-day condition monitoring, and how these two topics interact. The survey also acted as a formal research introduction to the PoTS community and some of their issues in a way that would inform the rest of the thesis going forward, with questions asked to avoid making some potentially distancing presumptions. For instance, participants were asked whether they consider themselves to be disabled, which a majority (roughly two-thirds) did. This question was asked to check if people with PoTS were comfortable being referred to as disabled, with response options asking if they did so due to their condition, a different condition, or were not comfortable with the label. Had the response and reaction to this question been different, this research would have respected community wishes and not referred to them as such unless absolutely necessary. As a result of participants' affirmation of PoTS as a disability, further research was conducted on accessibility and this research as a whole was considered through a disability lens.

A survey was chosen as it was felt that it best married the researcher's initial aims with an accessible research method for a global population of people with PoTS. This method was selected in part due to the comparatively little research on PoTS and wearables at the time and thus the need for more background information on community use of wearables for condition monitoring. However, this specific research method was also the one best suited to gain a broad range of perspectives and responses as it requires relatively little time investment and is a format recognised by and accessible to most people across multiple devices (both on web and on mobile). Due to the relatively small

size of the PoTS community and people tending to have multiple chronic conditions, an international perspective was sought and other conditions were asked about in an attempt to understand how monitoring PoTS specifically overlaps with monitoring other conditions. This survey was conducted in summer 2020, during the COVID-19 pandemic, and it is highly likely that little would have changed in both format and delivery had it been conducted outwith regional, national, and global lockdowns, as few if any alternative methods would successfully gain the breadth of data and views needed to underpin future research without potentially becoming overwhelming in scale.

The pandemic did have an impact upon potential recruitment methods for this study by restricting even further the potential for any in person recruitment - there would have been little point in sending posters to display at clinics, for instance, during a lockdown where people were unlikely to see them. However, the researcher's wish to gain international perspectives rather than just local or UK-based ones meant that, pandemic or not, the decided upon online recruitment method was likely to have been chosen all along. Survey recruitment took place via social media and via email, with the final survey being distributed in two small Facebook groups then by three different charities (two based in the UK, one based in the USA), following a multi-stage pilot testing process.

3.4.2 Study 2: Semi-Structured Interviews

The second study (see Chapter 5) consisted of individual semi-structured interviews which were transcribed then analysed. These served as a chance to gain individual narratives to compare and contrast with the survey findings, as well as giving the researcher chance to go into more depth about individual experiences of PoTS and condition monitoring, as well as issues encountered. This would give the researcher a chance to see how individual opinions compare to the consensus of a broader population. Participants were recruited through the survey, having indicated their interest in taking part in future research.

When selecting the participants for this study, the only survey data of theirs that was considered (aside from the obvious consent to being interviewed) was demographic data (age, gender, country of location) and the predetermined inclusion/exclusion criteria (if they had PoTS, if they used wearables for condition monitoring). Semi-structured

interviews were designed, chosen, and used over structured interviews with a finite and strict number of questions because of the underlying assumption that the interviewee was the expert about their own experiences. Choosing a semi structured interview with a rough structure and a few key questions to be asked allowed for unfamiliar discoveries and discussions about unexpected but still relevant topics to take place. Participants knew the topic of their interview but did not know specific questions in advance as relatively unprepared responses were sought (in contrast to the third study). Individual interviews were conducted to allow participants to discuss topics that they would not be comfortable discussing with strangers (other than the interviewer).

It would have been impossible for the interviews to be conducted in person due to both the COVID-19 pandemic and the global distribution of interviewees. Zoom video calls were ultimately chosen in an attempt to replicate face-to-face conversation using software that had become familiar to people due to the pandemic.

Overall, interviews were chosen as a method for this study that would fit with the already established recruitment methods and research population, giving information that would expand upon the survey whilst adding depth, detail, and some potential context to the survey responses. This choice of method was the one that would best fit those criteria at this point of the research without changing or diluting the focus of the thesis and the researcher's desire to centre the lived experiences of people with PoTS.

3.4.3 Study 3: Co-Design Workshops

Following the interviews, a third and final study (see Chapter 6) was sought that would bring the knowledge gained from the previous two studies together with further insight from people with PoTS to focus the research further onto what this research population would actually want from wearables used for condition monitoring. When designing this third and final study, centring the insights and lived experiences of this group was key, and this shaped the design of and choice of methods for this study. As a result, co-design methods were considered. However, a co-design study designed entirely by a researcher from outside the community being studied would potentially focus less on the needs of said community, as they would not be shaping the questions being asked. Therefore, it

was decided to 'co-design the co-design' for this study - that is, use co-design methods and techniques to involve the community being studied when designing the study, not just when conducting it. This study was then split into two parts (3a and 3b), namely a design survey and a series of workshops. The survey was used to both design the workshops and recruit for them, and was designed to both shape the workshops and increase their usefulness.

Asynchronous workshops with group Zoom calls were chosen as the method for the second part of this study, as an internationally accessible method that would fit around participants' day-to-day lives. Having a range of participants from different countries with a range of international perspectives remained important. A longer, single session workshop could have been conducted via Zoom, but this would have been difficult to schedule between time zones and for a group of participants with potentially busy schedules, so the choice was made to make the prompt responses both individual and asynchronous. Unlike the interviews, participants had time to consider their prompt responses more and potentially link to information that they found to be relevant, so text (e.g. Word document) responses were ideal here. The prompts were deliberately designed to fit around a person's day-to-day life and to take relatively little time to respond to using a "little and often" approach. The group Zoom call was scheduled as close to the middle of each workshop as possible, allowing for participant schedules and time zones.

Remaining interested participants (who were not selected for interview) were considered for the third and final study, in order to give them another chance to have their experiences and opinions heard. In general this method of recruitment for further studies was useful and lower effort than fresh advertising for each study, as well as one that utilised a pool of interested respondents who found the survey engaging enough to complete (the sign up questions for further studies formed the final section of the survey). Participants were chosen to pilot the workshops (the final stage of co-designing the co-design) based upon the free text responses given in the survey.

3.5 Conclusions

The aim of these studies was to conduct inclusive, experiential research that, as much as possible, centred the lived experiences and concerns of an under-served group with a lesser-known chronic condition. The methodology chapter aims to supplement this by providing further useful contextual information about wider social issues that have informed this research, as well as situating it within a broader disability justice and women's health context. This chapter also briefly contextualises the researcher's background and her links to the subject area(s) of this thesis, later discussing methodological choices made when designing the three constituent studies of this thesis. Ultimately, this chapter is about the decisions made by the researcher designing these studies and conducting this research.

Chapter 4

Study 1: Survey Study to Investigate Current Use of Wearables For PoTS Management

4.1 Introduction

As there is little previous research into using wearables to monitor PoTS, this initial research was an exploratory study, both to gain perspectives from people with lived experience of the condition, and to establish parameters for future research. Insight from people who have PoTS was gained to minimise the chance of causing offence or harm with this work, as well as reducing the likelihood of including obvious errors and misconceptions about the condition. As well as this, insight on wearable technology from people with other chronic conditions was also considered, to try and see how universal experiences are across conditions and to see how conditions are monitored, with or without wearables. People often have more than one chronic condition, so it would be naïve to assume otherwise. Including other conditions could also facilitate further research with an expanded scope if needed. For this project the focus was solely on people with chronic conditions (not healthcare professionals) and their usage of wearables, both in and out of a clinical setting. There was a deliberate choice made to only recruit participants aged 18 or over for safeguarding reasons.

4.2 Aims

The main aims of this study have been expressed as three research questions:

1. How widespread is the use of wearables to monitor PoTS?
2. How are wearables currently being used to manage PoTS? Specifically, which data types are currently being tracked?
3. What other types of data could wearables potentially be used to track when monitoring PoTS?

4.3 Methods

4.3.1 Study Design

The initial aim of this study was to gain a wide range of data from as large as sample as possible in an accessible manner. In this case, conducting a survey gave the broadest range of perspectives whilst gaining an introductory data set. This was undertaken using Qualtrics, online survey software with strong data protection and a good range of customisable options and question types.

A balance needed to be struck with the survey questions to ensure that useful information suitable for analysis was gained, whilst not constraining the possible range of answers too much. Open-ended questions can be useful, but do not generate a dataset by themselves, and a whole survey of them would have been comparable to an interview. Therefore, they were used sparingly, namely at the end of the survey to give the participants an opportunity to add any comments or further relevant information. Most of this study instead consisted of multiple-choice questions and Likert scales in order to quantitatively gauge participants' current usage patterns and opinions. The statistics obtained from this portion of the study were primarily descriptive background information that could be used to underpin further research. The exact statistical analysis conducted was decided by the specific questions asked, but age and gender are factors that may be considered to have an effect on the usage of wearables.

4.3.2 Participants

For comparison reasons participants with PoTS and/or other chronic conditions were recruited, with the aim to survey members of both groups who do or do not use wearables for condition monitoring. Doing this gave an idea of the barriers that inhibit the wider use of wearables for condition monitoring, as well as gaining information on the types of data people monitor to track their chronic conditions. Participant recruitment took place online, through two small Facebook groups then three different charities (two UK-based, one US-based). In person recruitment would have been difficult due to the rarity of PoTS, and the COVID-19 pandemic. In addition to this, chronic illness communities are often found online as low prevalence rates mean that people may not be surrounded offline by others who understand what they are going through.

4.3.3 Data Collection

Due to the COVID-19 pandemic, it had been decided that all distribution would take place online, through social media, websites, and email newsletters. However, this was likely to have been the case regardless, due to the low occurrence of PoTS and the need for a broad sample of the community. Initially, nine academics and ten organisations were approached for assistance with distribution. Some of these academics were linked to specific organisations that were contacted separately. Ultimately, five of the organisations were able to help with distribution. An offer of help from an academic linked to a sixth organisation, the American Autonomic Association, was declined, as the organisation represented doctors rather than people with PoTS, and medical professionals were not the target audience of this study. This organisational link could prove useful for future studies if needed, though.

Two of the organisations, both Facebook groups, distributed an early version of the survey, prior to the second (Dysautonomia International) round of pilot testing. The three charities worked with were Dysautonomia International (DI), PoTS UK, and the Hypermobility Syndromes Association (HMSA), and their assistance with distribution resulted in a greater number of responses than expected, which was much appreciated. These charities were chosen for their knowledge, expertise, and prior experience distribut-

ing other academic research, as well as, in Dysautonomia International's case, their global reach. Dysautonomia International is a USA based non-profit that works with individuals living with autonomic nervous system disorders. PoTS UK is, as the name suggests, the preeminent UK based PoTS charity. The Hypermobility Syndromes Association is a UK based charity that works with people with hypermobility disorders. Dysautonomia International distributed the survey via email and via social media (Twitter), and offered assistance with pilot testing beforehand. PoTS UK shared the study on Facebook and via their website, whilst the HMSA posted an advertisement for the study on their website. The researchers conducting the study also shared the study via personal social media, although this is likely to have had a more limited reach.

4.3.4 Data Analysis

The survey data was processed and analysed in multiple ways, depending upon the type(s) of data collected by each question.

Other (please state)

Several multiple-choice questions in the survey allowed respondents to select one or more answers, including an "Other (please state)" option with an accompanying text box, primarily to account for any exclusions of potential useful topics or categories. As part of data cleaning and analysis these written responses were checked using Qualtrics' text mode to see if any of them had duplicated other categories (for instance, a person who selected "Other (please state)" for type of device purchased then typed "Apple Watch", which could be recategorized as an entry for "Smartwatch" instead). To do this each set of responses was checked and answers that could potentially be merged with existing categories were tagged. These tagged responses were then checked against the original spreadsheet. Data was not relabelled if the potential replacement option had already been selected by the initial participant.

When duplicate responses are deleted, some useful findings can emerge. These findings reflect both upon the topic being asked about, and the choice of question wording and response categories. For instance, 14 comments on the brand question (see Figure 4.5)

mention the brand Polar. This is actually over twice as many responses as the brand Google (6), mentioned as a survey option, and a similar number to both Xiaomi (13 responses) and Huawei (15).

Text Processing

As part of the analytics software offered by Qualtrics as standard, there is a tab under Data and Analysis entitled "Text". Text response fields can be added to this tab, with only one question's responses able to be viewed at a time. This then allows the researcher to tag individual text responses with topic labels. These labels are displayed to the side of the text data, along with a simple graphic showing what proportion of comments for each response has had at least one tag assigned. An example of this is given in Figure 4.1.

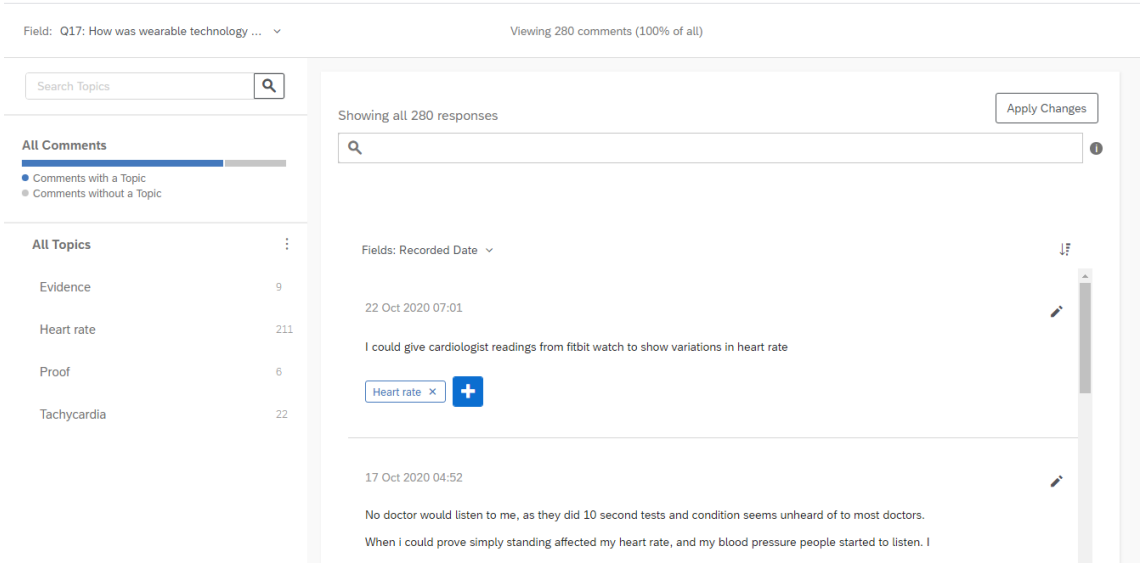

Figure 4.1: A screenshot of responses to a free text question in Qualtrics' text mode, showing tagged topics. The list of topics is displayed on the left hand side.

Topic tags can be assigned to individual responses manually, or a series of responses can be assigned a topic using search formulae. This enables the technology to be used slightly differently for shorter and longer responses, as well as list based versus more narrative responses. For short or list based responses these topic tags can be used to cover items mentioned in the response. If one were to ask, for instance, how many respondents use a wearable made by Polar (a brand not in the original list of multiple choice options),

one could search (and thus tag) every response to the question about brands purchased that mentioned Polar and gain a reasonable initial estimate of the number of people who have bought Polar brand wearables within a sample.

However, this does not account for several potential issues. Firstly, are there any other names the brand is known by, such as any key product names, that may be used instead of the brand name? If so, and these are distinct enough names from other brands' products, the tagger should consider adding them to the search string (preferably with an OR command). This includes abbreviations, something that came to the fore with symptom tagging, where heart rate (also often written as heartrate) often becomes "hr" and blood pressure "bp". Typos are also key to be aware of, as well as alternate forms of words. Often in this case the best option is simply to sort through and tag responses manually, although common ones could be added to the search string.

One must be careful when constructing tagging rules to ensure that they are neither too broad or too narrow: that is, they do not accidentally exclude a subset of responses by narrowing the search criteria too much, or broaden it so much that multiple categories are conflated by mistake. The researcher must also decide if there are any synonyms within the dataset for inclusion in categories, as well as how far each category stretches. Within this dataset this issue manifests when considering tachycardia. Many respondents use wearables to monitor their heart rate, but some also use them to monitor tachycardia (abnormally high heart rate) specifically. Tachycardia monitoring can thus be argued to be a subset of heart rate monitoring, but it deserves mention as its own separate category. When deciding whether tachycardia should be included within the "heart rate" category (as well as its own category) one must also consider whether or not respondents seem to treat it as a separate thing to monitor.

The following examples refer to responses to the short answer free text question "Which symptoms of your condition(s) do you currently monitor?". Here, inclusion of tachycardia within the heart rate category refers to adding the phrase "or tachycardia" to the search string for the heart rate category, hence labelled "Heart rate (inc Tachycardia)" (see Figure 4.2). A separate search using only the search term "tachycardia" can also be performed (see Figure 4.3), but it is notable that the sum of entries in that and the heart rate topic without tachycardia in the search string will be higher than the number of

entries with the heart rate search string including the phrase “or tachycardia” . This is due to the tachycardia only search not deliberately excluding entries that contain one or more of the other heart rate terms (as this would be of little use). Figure 4.2 shows the full search string used to construct the “Heart rate (inc Tachycardia)” topic, which attempts to account for popular shorthand and spelling choices. This search string is significantly longer and more complex than the one used for the “Tachycardia” topic, as shown in Figure 4.3.

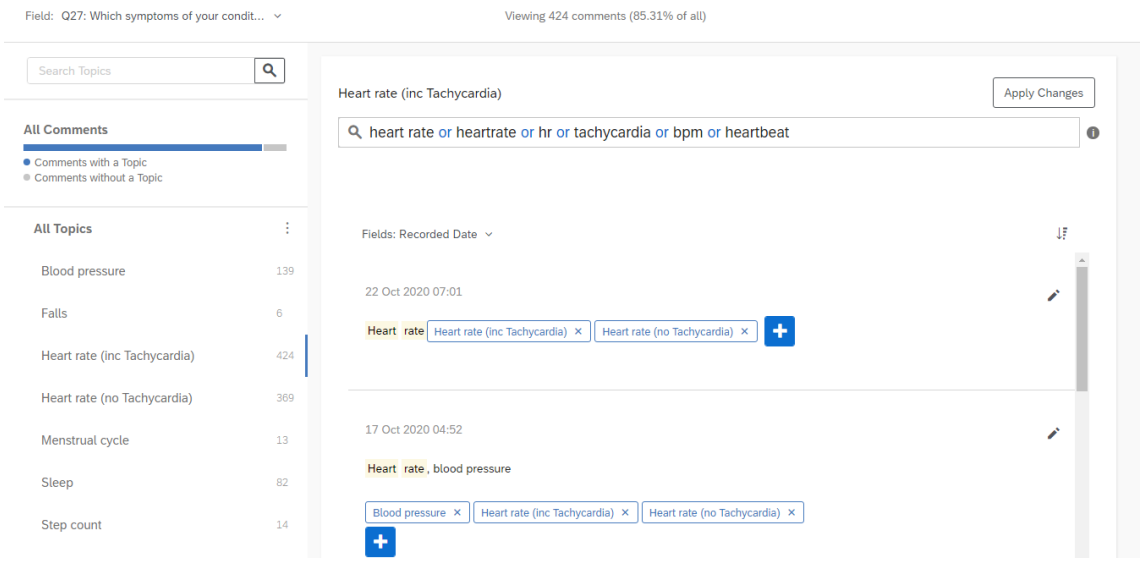

Figure 4.2: A screenshot of Qualtrics’ text mode, showing the full search string used to label responses with the topic “Heart rate (inc Tachycardia)”. Or commands are used to link each individual search term.

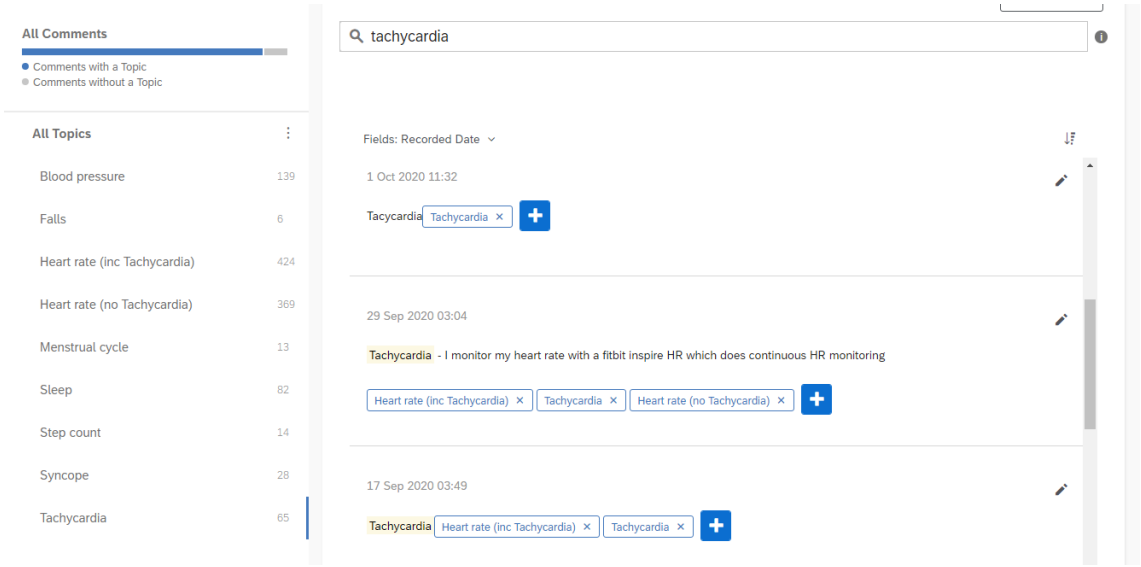

Figure 4.3: A screenshot of Qualtrics' text mode, showing search string used to label responses with the topic "Tachycardia".

Short Answer Questions

The majority of free text questions fall into this category, where responses are typically no more than a sentence or two long, and may well be a list. Again, quantitative analysis could potentially be conducted from the topic tagging, dependent on the question. This is arguably the most sensible option for questions such as "What apps have you used to monitor your chronic condition(s)?", which asks for a list. The three most popular apps mentioned in the 433 responses to the question were Fitbit (96 mentions), Apple Health (85 mentions), and the heart rate monitoring app Cardiogram (70 mentions).

Long Answer Questions

Upon inspection, five of the free text questions were deemed to naturally lead to longer responses. Often these questions ask for an explanation or information about a specific situation. Two of them can be directly compared with each other, as they ask equivalent questions to different audiences: if you could choose to monitor any other symptom of your condition, which would you pick and why? The two distinct audiences were current and former wearable users, and identical data category tagging was used for an initial comparison. The current users question had 364 responses, whilst the former users one had 97. In both cases, the most commonly tagged symptom was the same: blood pressure,

mentioned 143 times by current users and 32 times by former users. Blood pressure is rarely tracked by current wearables [Esposito et al. 2018], with many respondents instead having to own portable monitors with upper arm cuffs and an attachment that may be typically placed on a table.

This survey concludes with a question with the widest range of potential answers, as it simply asks the respondents for any further comments they may have. This question was useful to include as it allowed space for any other observations that participants felt might be relevant.

4.3.5 Ethical Considerations and Approvals

Ultimately, most of the survey participants would not be interacted with face-to-face so it had to be ensured that not only were the questions as unambiguous as possible, but that everything was also conducted to the highest ethical standard. Therefore, a consent form at the start of the survey was essential, as was a debrief at the end with contact information and a chance to register to receive access to the results (see Appendix A for both). Departmental ethics approval (ID number 1197) was gained before conducting the survey.

4.3.6 Pilot Testing

The survey was pilot tested in multiple stages by participants with a wide range of relevant expertise:

1. Local pilot testing - three participants (one academic, one from the PoTS community, one layperson).

2. Dysautonomia International (DI) pilot testing - feedback from two members of the Patient Advisory Board.

The pilot testing process for this study involved both participants chosen by the researcher as well as two members of Dysautonomia International's Patient Advisory Board, to ensure that the survey met their standards for distribution. The first stage of pilot testing was conducted locally with three participants previously known to the researcher:

a fellow academic from the University of Strathclyde, a (British) member of the PoTS community, and a(n American) layperson with no knowledge of the condition. Each person was chosen for their differing perspective and to answer differing questions: was this survey academically rigorous? Was it appropriate for the target group? Was it written accessibly? Was it comprehensible to respondents from outside the UK? The bulk of the feedback received from this group were requests for clarification, such as specifying units when talking about duration of wearable use.

Two members of Dysautonomia International's Patient Advisory Board viewed the survey, and offered a more international pilot testing perspective. The main change resulting from this was a switch in the language used: when referring to the condition internationally, Postural Orthostatic Tachycardia Syndrome (POTS) is the preferred term. DI are very particular about this and refuse to share any research that removes the word "Orthostatic" or uses the other abbreviation.

4.4 Quantitative Findings and Discussion

Gender	Participants	Percentage
Male	43	4.45
Female	908	94.00
Other	14	1.45
Prefer Not to Say	1	0.10
Total	966	100.00

Table 4.1: A table showing participant responses to the compulsory question "What is your gender?" Responses are listed in the order they were given in the question.

Overall, the survey recruitment and number of respondents for this study went well, with 1001 total responses. 752 respondents completed all questions applicable to them about PoTS and wearables, 733 of which also chose to opt in to research updates and/or participation in future studies. Due to the length of the survey, participant attrition, and varying question eligibility, each question has a different number of respondents, which is indicated accordingly when discussing the results of each question.

Exactly 94% of 965 respondents (94.00%, 908 people) identified as female, with 4.45%

identifying as male (43), 1.45% identifying as a gender other than male or female (14), and 0.10% (1 respondent) preferring not to answer (see Table 4.1). Although this sample is very female dominated, this was not unexpected from prior reading, with one prior PoTS UK survey also reporting 4% male participants [McDonald et al. 2014]. However, it should be noted that this other survey had a far smaller sample size (84 participants, only 3 of whom were male). Participants were aged between 18 and 82, with a mean age of 32.67. The survey had a restricted minimum participant age of 18. 29 countries (including both the individual constituent nations of the United Kingdom and Other) were represented in the data set, as was every continent bar Antarctica. 428 participants came from the USA, whilst another 423 came from the UK (353 from England, 41 from Scotland, 20 from Wales, and 9 from Northern Ireland). The high number of US-based participants is likely to be linked to Dysautonomia International's assistance (they are a US-based organisation). (The "Other" response could well have been a participant from a British Crown Dependency but there is no way to know for sure.) Participants were offered a choice of three potential currencies to give their household income in (Pounds Sterling, US Dollars, and Euros). 225 of 921 respondents to this question (just under a quarter) preferred not to answer this question, suggesting that it may be a demographic question that participants are less comfortable with than the others. It may be worth re-evaluating if this question is necessary for future research.

Of the 7 conditions listed in the corresponding survey question and Table 4.2, PoTS was the most common (854 respondents). The second most popular option was "Other (please state)" (382 respondents), followed by Ehlers-Danlos Syndrome (345). Over 200 respondents selected Tachycardia (260), Chronic Fatigue Syndrome (244), and/or Orthostatic Intolerance (233). 189 respondents had Mast Cell Activation Syndrome (MCAS), and 73 Arrhythmia. Overall, 2580 answers were selected by roughly 900 respondents, so the mean number of options selected by a participant was (slightly) greater than 2. This is unsurprising, as many people have multiple chronic illnesses.

Condition	Participants
Postural Orthostatic Tachycardia Syndrome	854
Chronic Fatigue Syndrome	244
Ehlers-Danlos Syndrome	345
Mast Cell Activation Syndrome	189
Arrythmia	73
Orthostatic Intolerance	233
Tachycardia	260
Other (please state)	382
Total	2580

Table 4.2: A table showing participant responses to the compulsory question "What chronic conditions do you have? Please select all that apply.". Responses are listed in the order they were given in the question.

Response	Participants	Percentage
Yes, because of this condition(s) only	305	37.52
Yes, and this condition(s) is one of the reasons why	242	29.77
No, but I consider myself to be disabled for other reasons	8	0.98
No, and I do not consider myself to be disabled	258	31.73
Total	813	100.00

Table 4.3: A table showing participant responses to the compulsory question "Does your chronic condition(s) make you consider yourself to be disabled?" Responses are listed in the order they were given in the question.

Participants were asked if their chronic condition(s) make them consider themselves to be disabled, and whether or not they identify as disabled for other reasons, with the results shown in Table 4.3. Overall, 555 of 813 respondents (68.27%, just over two thirds) consider themselves to be disabled. 8 of them do not consider themselves to be disabled due to their chronic condition(s) discussed in this survey. Of the remaining 547, 305 only consider themselves to be disabled due to the discussed condition(s), whilst the other 242 also consider themselves to be disabled for other reasons. This suggests that there is a mandate for referring to this research as relating to disability, and that it would be suitable to refer to participants with these conditions as disabled.

Number of Devices	Participants	Percentage
0	203	25.15
1	530	65.68
2	52	6.44
3	17	2.11
4	2	0.25
5	1	0.12
6 or more	2	0.25
Total	807	100.00

Table 4.4: A table showing participant responses to the compulsory question "How many wearable technology devices do you currently use for any purpose in your day to day life?" Responses are listed in the order they were given in the question.

The majority of respondents (65.63%, 529 of 806) use one wearable for any purpose in their day-to-day lives, with only 74 respondents using two or more on a day-to-day basis (see Table 4.4). Only 22 used three or more wearables. In total 603 participants use a minimum of 709 wearables for any purpose. The most popular types of device used, as shown in Figure 4.4, were smartwatches (412 respondents) and fitness bands (239 respondents), which were the only categories more popular than "None" (189 respondents) or "Other" (48 respondents). Initially, some specific devices such as Apple Watches were named in the "Other" category, so some of these responses were re-categorised as needed upon further inspection. This also suggests a need for clearer definitions in future research. Over five times as many wearable users used one wearable than used two. This suggests that if people have an electronic system of condition monitoring then it is one that involves a mix of device types and media, rather than relying primarily on multiple wearables. There are a number of potential reasons for this, including cost, but a pressing one may be the difficulty of gaining useful information from a combination of devices from different brands. Many devices do not work well together, especially if they are made by different brands, and any contradictory data could be confusing and stressful. Each brand typically has its preferred app or connected account, and most brands do not produce enough diverse types of wearables to build into a system. Some services such as Google Fit do allow other apps to sync with one central account, but this does require more prior research to determine which devices fit, as well as some digital literacy to link the accounts.

Overall, wrist-worn wearables were overwhelmingly the most popular among survey respondents, with 411 respondents using smartwatches, and another 236 using fitness bands. Smartwatches were significantly more popular than fitness bands, which could be due to their typically greater functionality. The survey did not explicitly define each type of wearable, only wearable technology as whole:

> *"Wearable technology is the name given to electronic devices that are worn attached to the body but unsupported by hands. Types of wearable technology include but are not limited to smartwatches, fitness bands, eyewear (including VR goggles), jewellery, and smart clothing. Mobile phones are not examples of wearable technology."*

There could well be some confusion between types of wearable, especially smartwatches and fitness bands, which may seem very similar to the layman, possibly due to people assuming that most wrist-worn wearables with faces are smartwatches. This is an issue worth revisiting in future, potentially in the interviews. It should be noted that, despite this definition explicitly excluding mobile phones, several participants still listed them in the "Other" category. Any future research must more explicitly exclude these devices. However, when asked later, 461 of 781 respondents (59.03%) stated that they currently use their mobile phones to monitor their chronic condition(s) with a wide range of apps, both those directly linked to or designed to accompany specific wearables (e.g. the Fitbit app) and those not, as well as built in or standard smartphone features such as the notes app and "health" functions such as step counts. According to the survey study, the key wearable data types participants were most interested in tracking were heart rate, blood pressure, sleep, and tachycardia. Of these four, only blood pressure is not a widely available device feature, and it was the most desired feature for future inclusion according to survey respondents.

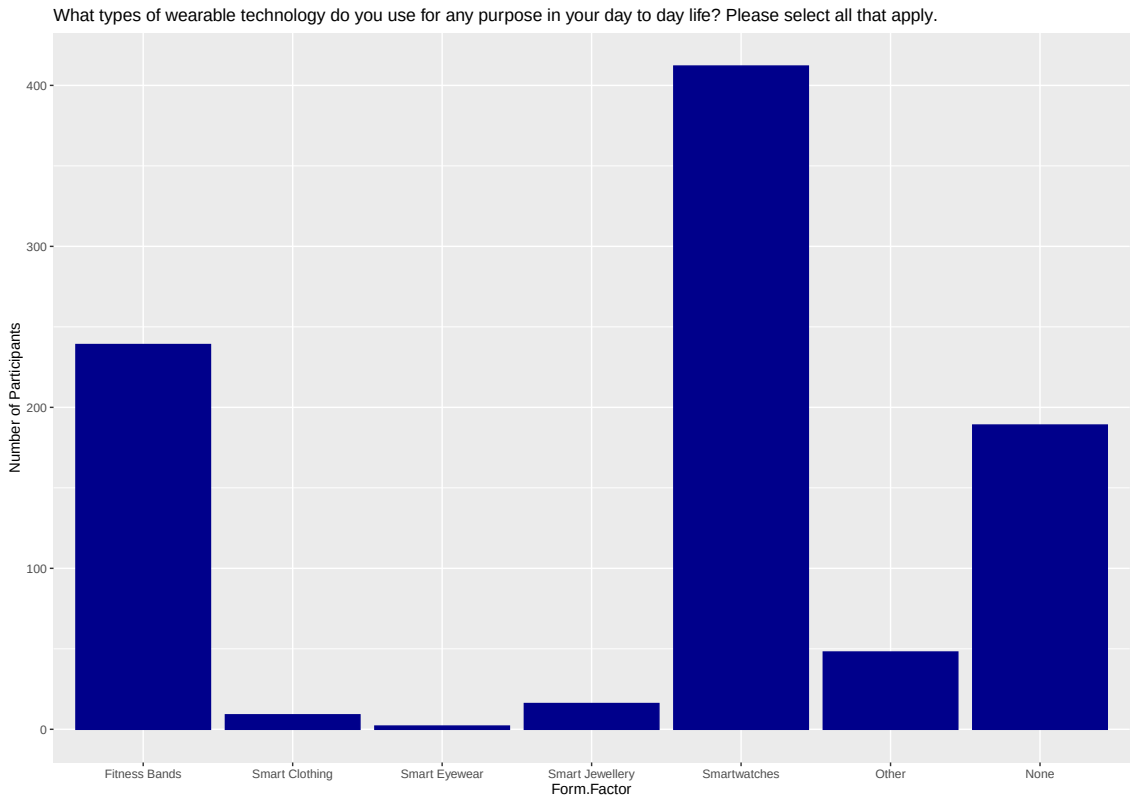

Figure 4.4: A bar chart showing the popularity of different types of wearables (form factors) amongst survey participants. The title of the graph is the survey question being responded to.

Excluding write in answers (of which there were 76), two brands of wearables dominated in popularity, as shown in Figure 4.5. Fitbit was the most popular brand overall, with 324 respondents having purchased at least one of their devices. Apple came in second (268 respondents), and no other option was selected more than the write in group (Garmin came nearest, with wearables purchased by 65 respondents). This is interesting as Fitbit primarily manufactures fitness bands with a few smartwatches, whilst Apple only manufactures smartwatches, and 175 more respondents reported using smartwatches than fitness bands. The other brands chosen could account for the difference between smartwatches and fitness bands, but there could also be some confusion as to what specific types of wearables are.

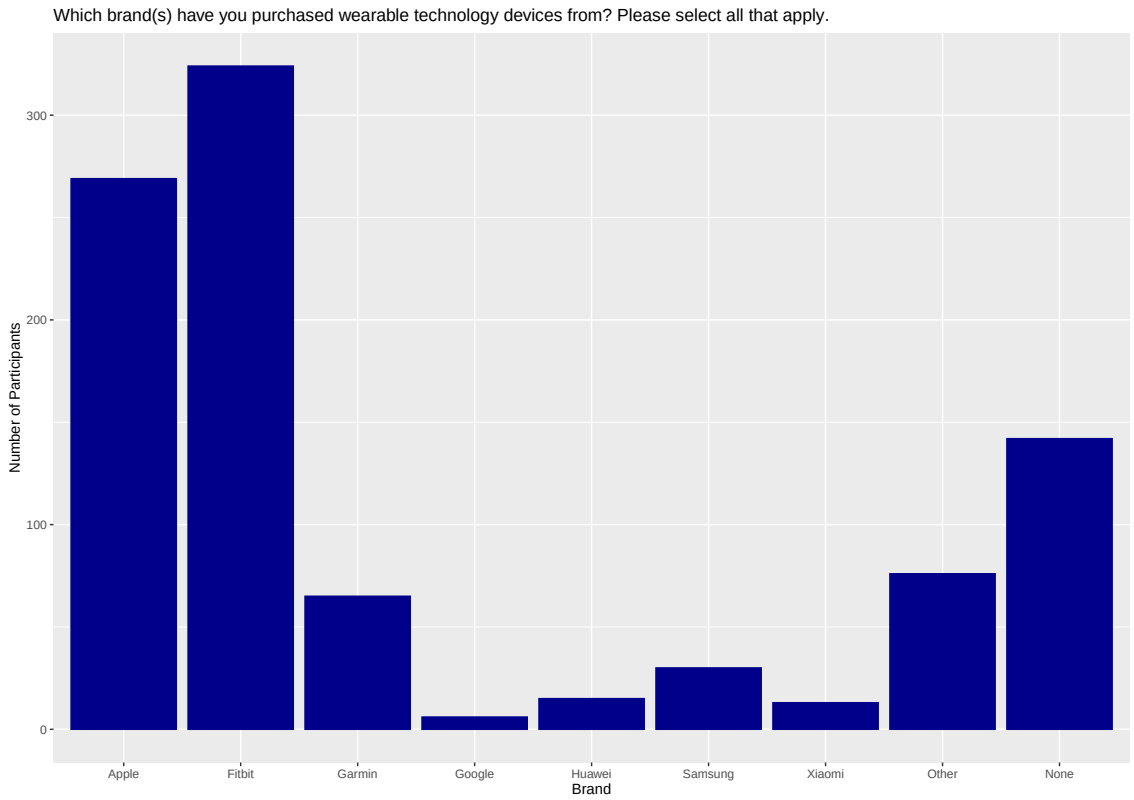

Figure 4.5: A bar chart showing the popularity of different wearable technology brands amongst survey participants. The title of the graph is the survey question being responded to.

519 (of 803) respondents currently use wearables for condition monitoring. 216 of 515 current wearable users used their devices before diagnosis (108 for reasons linked to their suspected health condition, 108 not). 294 of those 515 respondents said that wearables were of use to them during the diagnostic process, and 276 of 508 current wearable users have had their wearable data looked at by medical professionals. 282 of 506 current wearable users (55.73%) use other, non-wearable, devices to monitor their chronic condition(s).

135 of 283 respondents (47.70%) who currently don't use wearables have done so in the past. When asked why they stopped using wearables, the most popular reason given was "Other (please state)" (59 responses), followed by "Devices don't monitor what I need them to" (38 responses). Several further answers were very close together, at around 20 responses. The question asking what reasons prevent wearable use had a far more decisive response: 89 respondents selected "Cost" as the key limiting factor. (For reference, the second most popular answer was "Don't think I need to", at 30 responses.)

However, 259 of 277 respondents said that they would consider using wearable technology for condition monitoring in the future, with affordability (172 responses) and apps suiting the user's needs better (138 responses) being the most popular reasons for potential future adoption of wearables. This suggests that device affordability should be a priority, both as a factor that currently limits wearable use and one that could yet increase future wearable use. This pairs interestingly with the most popular brands mentioned, namely Apple and Fitbit. Fitbit makes more affordable devices than Apple, with the cheapest option (at roughly £50) being just over a quarter of the price of the cheapest Apple Watch (£199), but it should be noted that the cheaper options are fitness bands rather than smartwatches. Any future research involving devices may require balancing form factor with cost, especially considering potential future wearable users who are not part of a study.

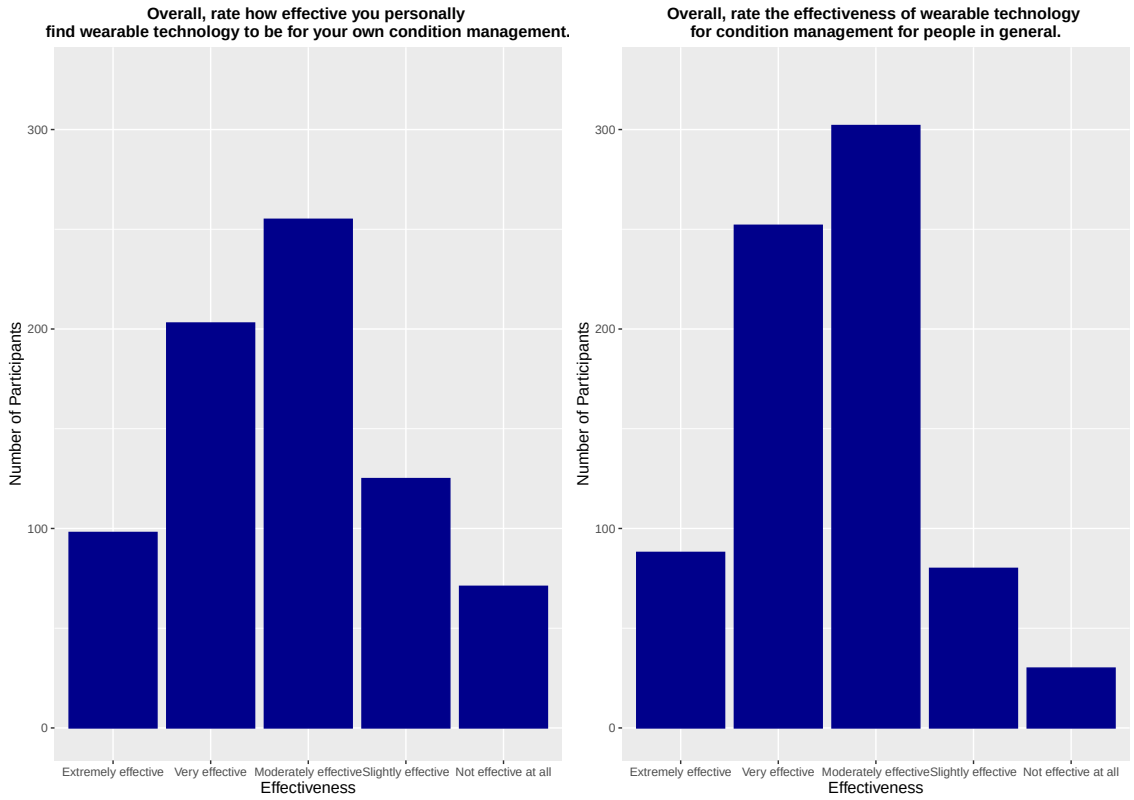

Figure 4.6: Two bar charts showing the perceived effectiveness of wearable technology for condition management, both personally and in general. The titles of the graphs are the survey question being responded to.

Figure 4.6 contains two side by side bar charts showing respondent perceptions of the

effectiveness of wearable technology for condition management, both for their own personal use, and for people in general. The format chosen allows for direct comparison. For both questions, "Moderately effective" is the modal choice, "Very effective" is the second most popular option, and "Not effective at all" (the most negative possible option) is the least popular choice. However, "Extremely effective" (the most positive option) is narrowly more popular than "Slightly effective" for general wearable use, whilst for personal use "Slightly effective" is the more popular option of the two (the difference between the number of "Extremely effective" responses and the number of "Slightly effective" ones is the same as the difference between the number of "Slightly effective" responses and the number of "Not effective at all" ones). Responses to the general effectiveness question were less negative than those to the personal effectiveness question, but also less strongly positive as well. Instead, they were strongly concentrated in two of the middle categories ("Very effective" and "Moderately effective"). Responses to the personal question were more varied, with the most popular response being selected only three more times than the second most popular response to the general question. Overall, people are slightly more moderate about wearables for general use than for their own personal use, and do not seem as willing to express stronger, more polarised opinions.

The design of the effectiveness questions was criticised by multiple respondents at the end of the survey. Their criticisms included that the questions were too broad, and that they were compulsory with no "Not Applicable", "Unsure", or "Don't Know" answer to choose, leading to some respondents guessing or randomly picking an answer. This could have been fixed by adding one of the options mentioned in the last section, or making the questions optional. In these questions, people tended to be slightly more moderate about the general effectiveness of wearables for condition management, and it may have been unfair to expect them to make that generalisation.

4.5 Qualitative Findings and Discussion

There are seven key themes prevalent throughout the survey free text responses, most of which are also reflected in the quantitative data. Unfortunately, it has been impossible to attribute participant IDs to the quotations in this section. This was due to an issue with

the choice of survey and data processing software, with Qualtrics' built in qualitative data tagging functions not visibly attributing free text responses to participant IDs.

4.5.1 Interactions with Medical Professionals

276 of 508 current wearable users had their wearable data looked at by medical professionals (this was a yes/no question) and interactions with medical professionals were very varied. Some experiences were positive, but many more were strongly negative. Some respondents had wearables initially recommended by medical professionals they saw, whilst other respondents initiated wearable use themselves and took their data and concerns to medical professionals they saw. Attitudes towards wearables varied wildly between clinicians (as perceived and reported by people visiting them as patients), with some recommending them to their patients as useful and others refusing to look at or acknowledge any wearable data. 216 of 516 current wearable users used their devices before diagnosis (108 for reasons linked to their suspected health condition, 108 not), but 295 respondents said that wearables were of use to them during the diagnostic process. This increase of 79 is interesting, but we do not know how many of these participants already owned wearables and were using them for a new purpose, or how many started using them for this purpose. Nor do we know who instigated the wearable use in each case, patients or medical professionals, something to potentially be discerned during the interview study in Chapter 5. Overall, if wearable data was taken into account by medical professionals it usually served as a recommendation for further testing (according to patients' reports), such as tilt tests to help diagnose PoTS.

4.5.2 Accuracy

Wearable data provided some evidence that could help with PoTS management, but the exact figures recorded may not be of use, due to data accuracy issues. These accuracy issues are present for all devices, but were especially noted in qualitative responses with regards to Fitbits by many participants. One respondent reported a lack of accuracy from their Fitbit when it was needed most:

"Fitbit and smart watch do not give accurate heart rate readings if there are

unusual spikes or drops in heart rate. These spikes and drops are important when monitoring PoTS."

Here, the lack of accuracy significantly reduces the utility of the mentioned wearable for condition monitoring, as keeping track of sudden heart rate changes is key for people with PoTS. Poor device accuracy can lead to an increase in user stress levels and decreased mental health. Some manufacturers have sought scientific verification for particular device features, such as the Apple Watch's ECG monitor [Turakhia et al. 2018], in an attempt to prove that their wearables' features are accurate. Comparison studies have also taken place to see if specific devices could theoretically replace corresponding items of medical technology, including [Dellgren 2017], which compares Apple Watches to heart pumps.

4.5.3 Device Assumptions

As well as general device inaccuracy, there is another implicit assumption built into many wearables: they measure **steps**. This is an issue for wheelchair users, whose distance travelled is not on foot and who are not accounted for by this able-bodied assumption [Loeppky 2020]. One survey respondent mentions using a "watch" to control their wheelchair, but that it didn't "track HR or connect easily to [their] phone", so they chose to wear a Fitbit at the same time. Step goals do work for some respondents, who may find them "useful" or potentially "encouraging if you're close to hitting your levels", but they can be hard to adjust and they are usually targeted towards abled people who are likely more mobile. A realistic goal for one user may not be the same as one suggested by their device, such as a Polar Vantage V user who complained that "the lowest fitness setting has me preparing for a 5 km run. I cant [sic] walk 50 metres..... [sic]". Overall, wearables are often marketed as health and fitness devices for able-bodied people, and thus do not take chronic illnesses into account. This is commonly shown by the data types available to track, which may not suit a person's condition monitoring needs, and what a device may consider 'normal' data. One respondent discussed their unhappiness about this:

"Most wearable technology is aimed towards fitness, which I can't do much of. It was a constant reminder of me being disabled and there is no way to remove

those aspects from the apps. I found this incredibly frustrating. They are also catered towards 'normal' people and so I'd get weird reports since everything about me is so 'abnormal.' "

As well as this discussion of perceived abnormality, another respondent stated that established presets made a device unwearable for them:

"Could not set my resting heart rate as being high so it buzzed constantly as my resting is over 100bpm so it thought I was always exercising, 24hours a day"

This response, given as an 'Other (please state)' reason for stopping using wearables, shows the most extreme consequence of wearables being designed to fit the norms of 'healthy' people and led to a device becoming uncomfortable and distracting, rather than the relatively unobtrusive ideal desired by manufacturers.

4.5.4 Cost

Another theme that kept recurring throughout both the quantitative and qualitative data was the cost of wearables, primarily as a limiting factor. Cost was the main reason that current wearable non-users said could prevent them from using wearables (89 of 215 responses, from a question where respondents could pick multiple options), and it is also the third most popular reason respondents stopped using wearables (after "Other (please state)" and "Devices don't monitor what I need them to") with 22 out of 183 responses (again, a question where multiple options could be selected). However, cost is not a single issue factor: it has many impacts that can restrict wearable use at all points in a product's life cycle.

Firstly, device cost and thus affordability can provide an obstacle to people considering buying a wearable. They may see others successfully using devices such as Apple Watches, but be unable to afford one themselves, as one respondent reported. If potential users can only afford a cheaper or generic brand device it may be less accurate than a high end one. This cheaper device may be less durable and have a shorter lifespan than a high end device. This may result in potentially higher costs to the user overall due to

the need to buy replacements, despite the lower quality of product and data potentially obtained (see Captain Samuel Vimes' Boots theory of socioeconomic unfairness by Terry Pratchett [Pratchett 1993]). Users may be unable to afford replacement devices or to upgrade to newer ones, regardless of initial device quality, which can result in reduced condition monitoring effectiveness over time. One respondent stated that they had been using the same (now outdated) Fitbit for three years due to being unable to afford a newer, more advanced one, and that this "makes monitoring [their] conditions slightly ineffective."

4.5.5 Digital Literacy

Digital literacy can be an issue for both patients and medical professionals. Wearables and the data they produce are of little use unless the data can be successfully interpreted, which can be difficult. Data interpretation may require said data to be extracted first, which can vary in difficulty between devices. If extraction is not required then people may instead need to interpret graphs, charts, and figures within apps, which can be easier, but relies upon a baseline knowledge of what a user may consider "typical" or "healthy". One respondent (to the final, write-in question) stated:

> *"there's an additional step between "getting the data" on yourself and "managing your illness.""*

Despite this respondent later expressing confidence in their own abilities, this interpretative step can prove to be an issue for many people, who lack the digital literacy to interpret their collected data correctly. As well as this, apps tend to consider data types separately, so digital literacy and data analytical skills are required to analyse multiple data types at a time. A second participant who is a healthcare professional also concurs with this, stating that "wearable monitoring devices are able to provide important data if the patient is able to appropriately interpret these findings." Learning how to do so can take significant time and effort, but could well be worthwhile.

4.5.6 Discovery and Validation

The most strongly positive theme present in the qualitative data is a group of people who would not have been diagnosed with PoTS (or other conditions) without their use of wearables. For them this technology has genuinely been life changing, including one respondent who believes that giving their daughter an Apple Watch led to her being "taken seriously by the Dr for investigation into PoTS" and that without a diagnosis she would not have managed to complete her education. For some of them their wearables detected previously unknown issues, but often people knew something was wrong, just not what exactly.

This can be linked to another prevalent theme throughout qualitative responses: that of validation. Specifically, wearable data confirming and validating what the user thinks they know, usually that something is abnormal, that it is not just "all in [their] head[s]". Some patients had issues with doctors refusing to listen to them until they provided more information from wearable data. One respondent had been trying for seven years to get their consultant to detect their high heart rate 'episodes' when their smartwatch recorded one, finally giving them the evidence they needed to be believed by their consultant. Wearable data by itself isn't typically enough for diagnosis, but it can provide a snapshot of patient health over a longer period of time than a medical appointment which could well be used to support a diagnosis and lead to further testing. For these people, discovery or diagnosis of their condition(s) could act as ultimate proof that they were right; something was wrong and they have a condition(s) that need managing. This may provide a boost to mental health, especially given how long some conditions, especially PoTS, take to be diagnosed. Kavi et al. (2016) conducted a survey of 779 PoTS patients in the UK where the mean time between first consultation with a healthcare professional to diagnosis was 3.7 years [Kavi et al. 2016].

4.5.7 Mental Health Impacts

Wearable use can negatively impact mental health and increase anxiety. People can become fixated upon checking the data being tracked, potentially leading to obsessive behaviour. This may increase anxiety for users, as they may panic over small changes in

their data, even if that data is inaccurate. This is one of many inherent contradictions about wearables present in the survey data, that wearable technology can be effective and helpful for some users, but not for others. Participants showed concern about the idea of data tracking becoming overwhelming and a distracting priority, with one survey participant describing it as a "fixation on results rather than focusing on quality of life and symptom control (those symptoms that you feel/notice, rather than quantitative measured symptoms)". Here, the worry is that no material improvement is actually being made to their health - instead, the priority is improved numbers and conforming to a statistical ideal.

4.5.8 Stopping Using Wearables

A third group of participants is worth considering here, namely people who did use wearables for condition monitoring but now no longer choose to do so. In the survey study, the most popular reason for stopping, excluding 'Other (please state)', was 'Devices don't monitor what I need them to' (38 respondents, 20.77% of 183 responses from a question where participants could select multiple options). This relates to two later points of discussion: participants feeling that they are not the target user group for their devices, and contrasting reality with the idea of an 'ideal wearable' designed to monitor their symptoms.

Another key reason why participants chose to no longer use wearables was reaching a point when their PoTS symptoms appeared to be under control or well-known and understood by them. This may come with a shift in condition monitoring methods, with one survey user stating that "Once I'd learnt the symptoms to look out for, I found it more useful to manage based on symptoms than heart rate figures." Another referred to their symptoms being "well controlled" and thus no longer in need of constant monitoring.

4.6 Conclusions

Overall, the survey results create a portrait of a typical person who uses wearables to monitor their chronic condition(s). They are most likely to use a single wrist-worn device, either a smartwatch or a fitness band, and that device is most likely to have been made

by Apple or Fitbit. The dominance of these form factors and brands was expected, given the categories of wearable discussed in the survey. One device being the most popular also makes sense given that cost was later rated as the most significant factor limiting wearable use for condition management (followed by app suitability). Various other non-wearable condition management options were suggested by respondents, and specific condition monitoring systems and procedures will be interesting to ask about in the interview study.

The key symptoms that respondents are most interested in monitoring using wearables are heart rate, blood pressure, sleep, and tachycardia. Blood pressure is the only one of these that is not typically monitored by most current wearables, and this is something potentially worth looking into further. Instead, portable blood pressure monitors are often used, but these can be bulky. Just over two thirds of respondents consider themselves to be disabled due to their chronic conditions, which means that looking at this topic (of condition monitoring using wearables) through a disability advocacy lens could be both relevant and useful. Considering wearable technology to be assistive technology would be a sensible and appropriate decision going forward.

Over half of the current wearable users state that they started using wearables post diagnosis. However, 295 respondents state that wearables were of use to them during the diagnostic process, whilst only 216 state that they were wearable users before diagnosis. This leads to an interesting question that could be explored further in the interviews: when do people start using wearables and who recommends them? Also, what role do medical professionals play? Participants reported varying experiences with medical professionals, ranging from very positive to very negative, which is something that could be sensitively and compassionately explored further.

The final effectiveness questions should have been optional and could have been improved by including a "Don't Know" option, as several respondents stated that they were off-putting. The recruitment process for this survey went really well, with the online charity assisted recruitment resulting in far more responses than expected. The high American response rate in particular can be linked to Dysautonomia International, the US-based charity that helped distribute the survey. Not only are these methods worth using again in the future, the high response rate and the fact that 494 of the 733 partici-

pants who filled in the interview sign up questions (67.4%) chose to sign up for interviews suggests that this is a topic that people clearly care about and wish to discuss further. As well as this, the high response rate from online distribution provides some proof of an online PoTS (and wider chronic illness) community (as does references to them throughout the write-in responses).

Overall, wearables are very much not a panacea, but there is potential! Some people have very positive experiences with them, others negative. This quotation from the final write-in question summarises everything quite well:

> *"Wearable technology works in conjunction with other symptom management strategies. Ultimately how effective wearable technology is to an individual depends on what chronic illness they have."*

Chapter 5

Study 2: Interview Study to Investigate Opportunities and Challenges for Wearable Use When Managing PoTS

5.1 Introduction

This second study consists of twenty 30-45 minute Zoom interviews about participants' specific experiences of living with PoTS (and other chronic condition(s)) and how those condition(s) are monitored with or without the use of wearable technology. It originally formed the second stage of the initial survey study but was later expanded into its own study due to the amount of survey data gained and the resulting number of potential interviewees. Participants were recruited via an opt-in question at the end of the survey study.

5.2 Aims

The overall aim of this study was to gain individual narratives about condition monitoring and how wearables are and are not currently being used by people with PoTS to monitor their chronic condition(s), as well as the overall condition monitoring systems that these wearables can form part of. These can be compared and contrasted with the survey data from Study 1 (see Chapter 4).

The survey study data from Chapter 4 provided a broad overview of current wearable ownership rates, how wearables are being used to monitor PoTS, data types tracked, and overall attitudes towards this type of technology. Combining the narratives and the survey data should then enable further investigation into ways that wearables could be used in the future, as well as challenges currently faced in this field of study. However, the survey responses have acted as a guide when drafting the interview topic schedule, as they can help realise missed topics. The main aims of this study have been expressed as three research questions:

1. How do people with PoTS monitor their condition(s) on a day-to-day basis?
2. How do wearables fit in to that? (If they do not, what condition monitoring methods do people use instead?)
3. How would people with PoTS like wearables to fit into their day-to-day condition monitoring?

5.3 Methods

5.3.1 Study Design

The study in this chapter involved conducting a series of twenty 30 to 45 minute semi-structured interviews. The interviewees were selected from a pool of survey respondents (see Study 1, Chapter 4) who had indicated their interest in taking part in this process. Initially, it was conceived that interview participants would be loosely divided into 4 groups, those who do or do not have PoTS, and those who do or do not use wearable technology for condition monitoring. However, due to high levels of interest from people with PoTS, it was realised that continuing to include people without PoTS might not lead to meaningful data and thus this was changed to just two groups: people with PoTS who do use wearables to monitor their chronic condition(s), and people with PoTS who do not use wearables to monitor their chronic conditions. There was one significant change made between the creation of the interview study concept and it being carried out, however, specifically a tightening of the inclusion criteria due to the high number

of responses. Initially, respondents who did not have PoTS but did have other similar chronic conditions were to be considered for interview about their experiences choosing or not choosing to use wearables to monitor their chronic conditions, but there were such a significant number of potential interviewees with PoTS that it was felt that including these people would dilute the focus of this research with potentially less relevant information.

These interviews were designed to be semi-structured, to allow for a wide range of experiences to be recorded. The interviews covered a wide range of topics, including but not limited to condition monitoring methods, the diagnostic process, and interactions with medical professionals, with a trio of key questions that every participant will be asked. (The amount of depth each of the topics was discussed in naturally varied between participants as every discussion was different and there were time constraints).

Choosing a semi structured interview with a rough structure and a few key questions to be asked allowed for unfamiliar discoveries and discussions about unexpected but still relevant topics to take place. After all, the researcher does not know everything and to assume that they do would be unhelpful hubris. This did lead to some interviews exceeding the suggested 30-45 minute length guideline, but this was accounted for in advance by sensible scheduling that also allowed the interviewer to decompress between interviews (a safeguard against potential discussion of distressing topics).

5.3.2 Participants and Recruitment

Twenty participants (adults living with PoTS) from 6 different countries and 4 continents (Australia, Brazil, Slovakia, the Netherlands, the UK (England, Scotland, and Wales), and the USA) were interviewed. Seventeen participants were female, two male, and one genderfluid. Interview participants were recruited through the survey, ensuring that all interviewees had some understanding of the research topic. In this case, the survey acted as an introduction to the topic of discussion with a smaller time commitment than an interview. Taking part in a follow-up interview was a chance to further that discussion in more detail and actually converse with the researcher, giving participants more space to discuss topics and details that the survey did not cover. Participating in the survey may have made a possible interview seem less threatening, as participants had a better

idea of the research project's scope before choosing to sign up to be interviewed.

When selecting the participants for this study, the only survey data of theirs that was considered (aside from the obvious consent to being interviewed) was demographic data (age, gender, country of location) and the predetermined inclusion/exclusion criteria (if they had PoTS, if they used wearables for condition monitoring). Participants were selected from a wide range of locations to see how much perceptions varied, and to see how much differing healthcare systems could play a role in how people choose to monitor their conditions. As in Study 1, the UK was considered to be four separate constituent nations due to the devolved nature of the NHS and its governing bodies.

Gender is an important factor to consider, especially in a chronic illness context where patients may have trouble being believed by their doctors [Kavi et al. 2016] [Frye et al. 2023], as women often have difficulty accessing diagnoses due to clinicians believing that 'it's all in their heads' and favouring mental health or psychosomatic explanations for physical health conditions [Mirin 2021] [Opie and Nuttall 2022]. Ninety four percent of survey respondents were female but it was important to interview some non-female people with PoTS as well, to see how experiences differ and how the condition is perceived with regards to gender (e.g. whether or not anyone ever encountered the notion of PoTS as a 'women only condition'). Race was not a factor asked about in Study 1, but it can be an exacerbating factor when it comes to being believed by medical professionals and having access to high quality healthcare (one interviewee was Native American). While participants were asked about household income in Study 1, many chose not to answer this question and it was not considered or viewed when selecting potential interviewees. However, the topic of disability benefits and internationally equivalent systems did come up during some interviews and this will be discussed more later.

Participants were roughly aged between 19 and 58, from university students to retirees, with ages being estimated from survey responses. An issue was encountered with the number of interviewees who used wearables: a snap judgement had been made on that based on their response to one survey question, but the accuracy of that judgement was not borne out by what the interviewees actually said. It was expected that 13 of the 20 interviewees used wearables for condition monitoring, but it turned out that 17 actually did. This issue could be down to more recent wearable use, but it is more likely due to

issues with survey design in Study 1. Overall this split of respondents did still prove to be useful, however, as non-wearable users could be asked why they do not use wearables and how they instead chose to monitor their conditions, but wearable users could also be asked about people around them and why they may or may not choose to use wearables.

5.3.3 Procedure, Ethics, and Consent

The twenty interviews were conducted across a period of five weeks in June and early July 2021. Interview participants were contacted via email in waves throughout June, a group at a time, with interviews themselves scheduled and arranged via email. Survey participants had previously had the chance to register their interest in interviews, receive research updates, and leave a contact email address. Update emails were sent to all potential interviewees and those interested in research updates who had left a valid email address at the end of April 2021. These update emails were sent in batches due to the high number of recipients (621), in an attempt to minimise the chance of the emails going to spam. A link to a second survey was included to give people the chance to update their contact email or opt in or out of the interview selection process as needed. Only seven participants chose to do so; three opted in and four opted out. At this point the decision had not been made to only interview people with PoTS. However, 455 of the 492 potential interviewees had PoTS.

Random number generation in Excel was then used to select participants. Ten sets of random numbers were generated and the one that was judged to give the most suitable initial mix of genders, nationalities, and wearable or non-wearable users was selected. Initially, 20 interview invitations were sent, but two further waves were needed due to previous non-responses. All participants were sent reminders before potential replacements were contacted. Overall, 46 invitations to interview were sent. 23 participants responded, but 3 of them were ultimately unable to be interviewed due to technological issues, ill health, or a lack of availability. Attempts were made to rearrange these interviews at first, but ultimately enough other participants were available to reach the desired sample size of 20. Throughout the interview process (and this thesis) interviewees were referred to using their survey participant ID for administrative purposes and

for anonymity reasons; none of the participants know the ID number used.

Upon agreeing to participate and giving their availability, potential interviewees were sent a list of 3 possible times to choose from. All interviews were arranged in the interviewees' time zones and were both scheduled and conducted via Zoom. Nineteen of the interviews were conducted via video call, with one participant choosing only to be audio recorded. Originally, both the survey and the interview study were considered to be part of one single larger study, with one departmental ethics application (ID 1197) being completed for both, thus the idea to use both these methods was conceived at a similar time. Ultimately a new ethics application was not needed for the interview study, as the scope did not change enough to warrant a new one being submitted. This was due in part to a lack of realisation of the scale of potential survey data submitted.

Interviewees were sent a consent form to fill out and a participant information sheet (see Appendix B) with the scheduled Zoom meeting details, as well as a separate email that acted as a formal meeting invitation for their calendars. The two separate emails were used to reduce confusion, as meeting details stored only in calendar invitations may be hard to find. Participants also gave verbal consent to the questions on the consent form (participation, being audio recorded, and being video recorded) at the start of each interview. When conducting the interviews, appropriate information on data reporting and confidentiality was provided. No more than two interviews were conducted in a day and all interviews were individual, although a few participants brought service animals or other pets. Off-screen family members were occasionally asked questions by the interviewees if needed. Overall, participants from seven time zones were interviewed, which led to occasional confusion by the interviewer when scheduling and a need to be very clear when communicating potential dates and times or scheduling interviews. At the end of each interview each participant was offered a £15 (or equivalent value) Amazon voucher as reimbursement, which 18 accepted - 1 preferred a charity donation, 1 felt that they were happy to participate for free. Interviewee enthusiasm was high and many fruitful discussions were had, with several interviewees thanking the researcher for choosing to conduct this research.

This study was designed to consist of semi structured interviews between 30 and 45 minutes long. All Zoom meeting slots were scheduled to be an hour long, just in case,

which was a sensible decision, as the suggested duration ended up more guidance than reality. Only seven interviews were actually the originally suggested length. Interviews ranged in length between 23:44 and 1:21:00, with the mean length of an interview being 46:25. The total length of the interviews was 15:28:26. Recorded interviews began with a short verbal consent section, and ended with a formal debrief. Video data was collected where possible for the interviews as participants may have wished to "show and tell" their own wearable devices, for instance. As well as this, using video was potentially more reassuring for participants, and being able to see body language was helpful as it conveys more information for the interviewer, both during the interview and when watching footage back. Video could also make it easier to identify harder to hear words than just audio.

The same loose group of topics were discussed in each interview, with the semi-structured nature allowing participants to expand on topics as much or as little as they liked. To ensure that all of the desired topics were covered a key question for each topic was chosen and included in an initial topic schedule document (see Appendix B). If time became limited due to longer discussions of previous questions these questions could be used to refocus the interview and ensure that every desired topic was discussed at least briefly. This initial topic schedule was a useful guide, but several new questions were generated and reused as needed throughout the interview process. Questions included in the original sheet, such as asking how positive or negative interviewee interactions with clinicians during the diagnostic process were, served to illuminate previous survey questions on topics, as it made participants reconsider their prior experiences and divulge standout (primarily negative) interactions that had not previously been discussed. Some topics grew in importance throughout the interview process, such as asking about the COVID-19 pandemic, its impacts on condition monitoring and access to medical care, and people who have been diagnosed with PoTS as a result of Long COVID. Every participant was asked before discussing the pandemic if they were willing to address this topic; none of them declined. As well as the COVID-19 pandemic, the notion of community, especially that found online and through social media, increased in importance from the drafting of the topic schedule to the actual interviews. For many people with PoTS, the internet can provide a far greater community of people who understand the issues they face with

a little-known, comparatively rare condition than they can find in person, and this was true even before the pandemic [Sannon et al. 2019].

One of the most useful and informative wearables questions asked during the interviews does not feature on the topic schedule at all and was instead derived during the interview process. This question involved asking participants what features they would include if they could design a wearable, money and current scientific possibility no object. It proved a successful question as it led to a focus on individual priorities, and what could happen if participants were able to use something perfectly adapted to them, rather than having to do their best with what is currently available.

5.3.4 Recording and Transcriptions

Upon completion of each interview, the recordings and auto-generated transcript were saved on Zoom's cloud storage. Each transcript was then edited using Zoom's easy to use web editor before the files were downloaded and subsequently removed from Zoom. Checking transcripts was very necessary due to inaccuracies by the auto-transcription software, which occasionally resulted in the transcript containing the opposite of what was being said. As well as this, the manual transcript editing helped when reconsidering what was said. When transcribing most "erm" or "um" sounds by either speaker were taken out, unless they were the entirety of an auto-transcribed line, or occasionally due to fit. Commas were inserted between repeated words and at natural breaks in speech - that did not necessitate full stops - for ease of reading. Edited transcripts ranged in length from 3,201 to 12,296 words and the total length of all 20 transcripts was 125,867 words. The mean length of an edited transcript was 6,293.35 words. Edited transcripts were then copied into Word files (from the original .vtt files) and imported into NVivo for coding.

5.3.5 Data Analysis

Data was ultimately coded in NVivo using the code function. Thematic analysis was performed upon the twenty interview transcripts, inspired by [Braun and Clarke 2013]. Notes were kept of potential themes during the interview and transcription editing process

and these were used to devise some of the initial themes. Further themes were devised upon rereading the transcripts and then nodes for each theme were created on NVivo. Some of these nodes were hierarchical in nature, with children and grandchildren nested within the main nodes. The transcripts were then coded using these NVivo nodes, as shown in the three screenshots below (Figures 5.1, 5.2, and 5.3). Examples of the coded data are shown in these figures, including one of the coding nodes (and its children) in Figure 5.1. Figure 5.2 shows a selection of the quotes coded as fitting the selected theme, with further subtheme coding shown by coding stripes. Meanwhile, Figure 5.3 shows what the NVivo coding process looks like for a single transcript, including the coding stripes that show where the themed coding has been applied.

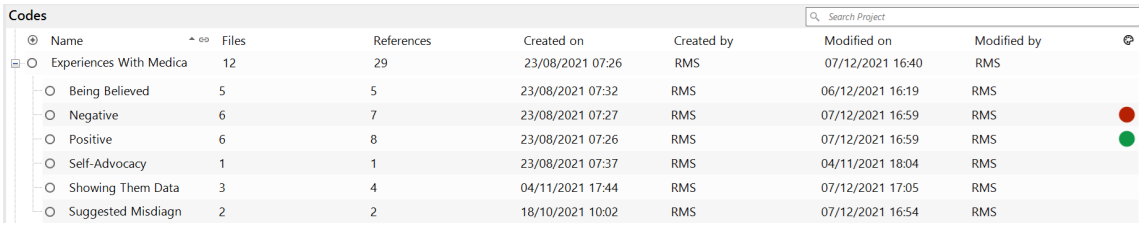

Figure 5.1: A screenshot of NVivo showing the coding node *Experiences With Medical Professionals* and all six of its children. The red and green circles at the right hand side of *Negative* and *Positive* respectively were automatically generated by NVivo to denote the sentiments expressed by the code names.

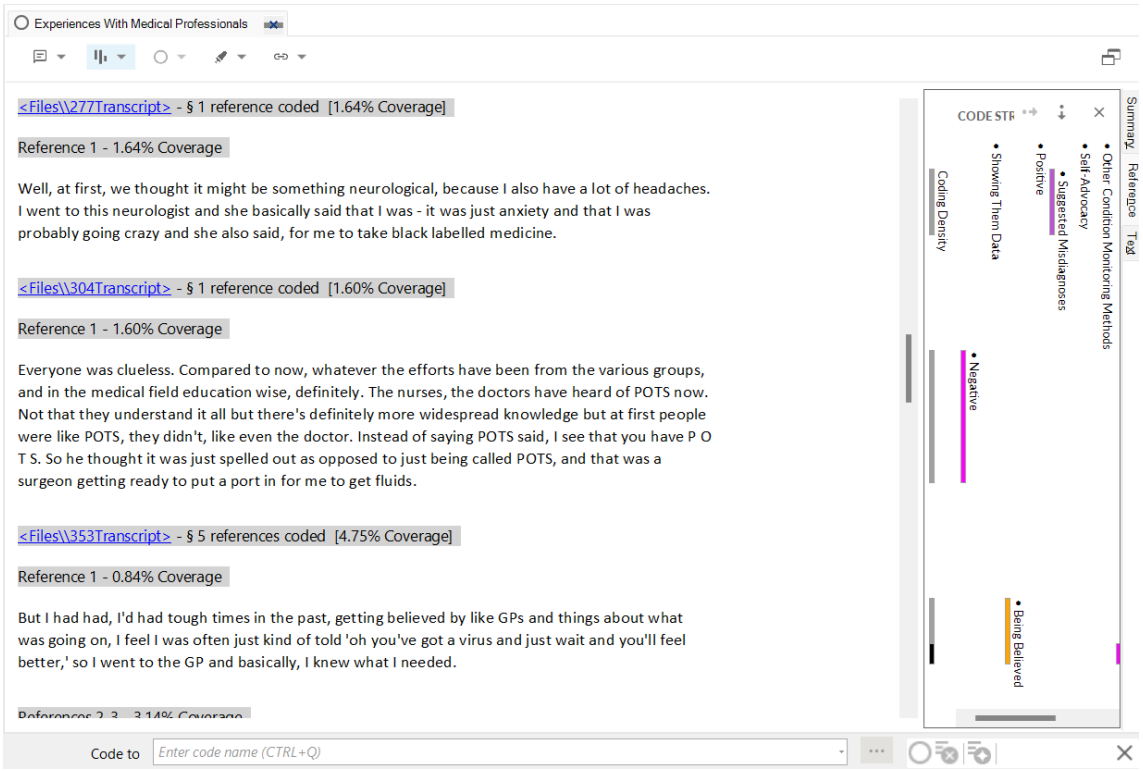

Figure 5.2: A screenshot of NVivo showing the contents of the *Experiences With Medical Professionals* node. The blue hyperlinks denote the file names that each reference came from, and the coding stripes at the right hand side of the screen show which child node(s) each excerpt has also been coded as.

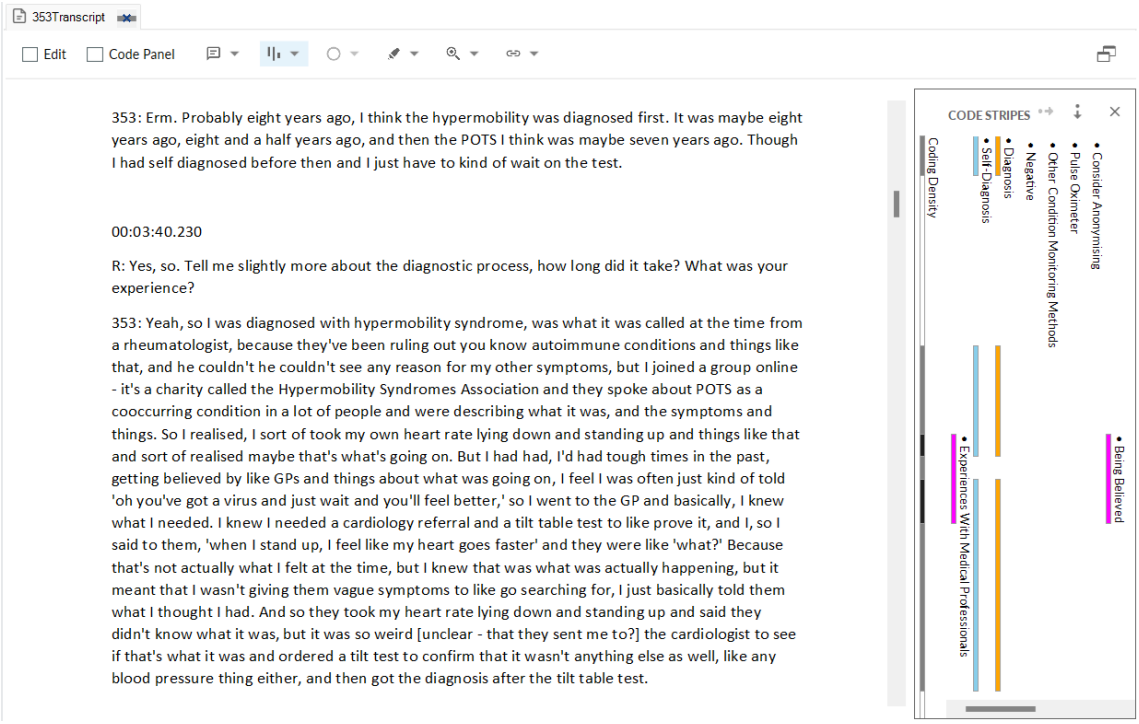

Figure 5.3: A screenshot of NVivo showing an excerpt from Participant 353's interview transcript. A time stamp is given before each new question, for easy reference. The coding stripes at the right hand side of the screen show which theme(s) sections of the text have been coded as.

5.4 Findings and Discussion

Fifteen key themes were identified in the interviews, as shown in Table 5.1.

Category	Theme (Subtheme)	Description
Conditions		The chronic conditions experienced by interviewees.
Diagnosis	Diagnostic Accessibility	Interviewees' experiences accessing a PoTS diagnosis.
	Clinician Knowledge	How (low) clinician knowledge of PoTS has impacted interviewees.
	Misdiagnosis	Interviewees' experience of being misdiagnosed and the types of conditions they were misdiagnosed with prior to being diagnosed with PoTS.

	Self-diagnosis	Interviewees' experiences of discovering PoTS through their own research and how that can sometimes lead to self-diagnosis.
Wearables	Form Factor and Brands	The types and brands of wearables interviewees chose to use and any issues that arose from their choices.
	Marketing	Interviewees' opinions about the marketing of wearables.
	Use of Wearables	What interviewees have used their wearable data for.
	Medical Professionals and Wearables	Interviewees' interactions with medical professionals about wearables.
Not Using Wearables		Condition monitoring by interviewees who do not use wearables.
Designing an Ideal Wearable		What features interviewees would include in their perfect wearable for condition monitoring.
Wider PoTS Community and Social Media		How interviewees have managed to connect with other people with PoTS, including using social media to do so.
COVID-19 Pandemic	Day-to-Day Impacts	How the pandemic has changed interviewees' day-to-day condition monitoring.
	Access To Medical Care (Telehealth)	How interviewees' access to healthcare changed during the pandemic, with a focus on telehealth appointments.
	Long COVID	Interviewees' opinions of Long COVID and people being diagnosed with PoTS as a result.

Table 5.1: A table listing and explaining the key themes of Study 2.

5.4.1 Conditions

As seen in the survey, people with PoTS often have multiple chronic conditions and this is something that continued to be true for the interviewees. Interviewees mentioned also having a wide range of other conditions, including but not limited to Ehlers-Danlos Syndrome (EDS), Mast Cell Activation Syndrome (MCAS), Peripheral Neuropathy, Inappropriate Sinus Tachycardia, chronic migraines, and Pelvic Congestion Syndrome. Special mention should be made of the commonly co-occurring trio of PoTS, EDS, and MCAS [Miranda et al. 2018], which one interviewee (Participant 69) described as being like having "the trifecta of defective genes going on". Therefore, as discussed previously in this thesis, although the primary focus is on PoTS, some of the findings may have broader applicability in other chronic illness contexts. Many interviewees also reported having mental health conditions such as anxiety, depression, or OCD, and some were neurodivergent (typically autistic, either diagnosed or seeking out a diagnosis). Interviewees came from a wide range of backgrounds and were diagnosed at a wide range of ages.

5.4.2 Diagnosis

PoTS is a condition that often takes a long time to be diagnosed from the initial onset of symptoms, as seen previously in the literature [Kavi et al. 2016]). A low level of clinician knowledge below a specialist level has hindered a lot of interviewees, both when seeking diagnoses and interacting with their countries' respective healthcare systems in the time since diagnosis. This hindrance can manifest in several ways, including blocked access to desired or necessary medical procedures, a lack of referrals to specialists with relevant knowledge, patients being disbelieved as to their symptoms, and/or misdiagnosis.

Diagnostic Accessibility

It is key to also emphasise here that the interviewees who were able to access diagnoses more quickly were often able to do so due to prior knowledge (including family with the same condition), fortunate connections, or lucky circumstances. Participant 160 acknowledges their good luck in having knowledgeable medical practitioners with good connections for friends and relatives, although the number of factors that had to fall into

place for her to access a diagnosis make this far from a sustainable recommendation.

Participant 126 also had knowledgeable relatives, but these relatives' knowledge of PoTS and the diagnostic process came from undergoing it as patients. By the time Participant 126 developed PoTS symptoms, multiple siblings of hers had already been diagnosed and had seen a cardiologist, so she knew exactly what process to follow, which tests to conduct at home, and what clinicians she needed to see. As a result, by the time she saw her siblings' cardiologist, she had spent two months conducting at home tests on herself (the 'poor man's tilt table test') and had the data at hand for her initial appointment, which ultimately led to further formal diagnostic testing.

In turn, interviewees could later recognise PoTS in others and pass on support and advice, such as Participant 835:

> *"[I]t's funny because a friend of mine got Long COVID and she got PoTS from it. She- she rang me one day like 'I'm in hospital and I've got chest pains and. And my blood pressure is really low, and my heart's racing.' She says 'they keep telling me I've got a blood clot but they can't find any evidence.' It was like 'oh my God I've heard this all before' but apparently they've had quite a surge of people with PoTS from Long COVID."*

By recognising the commonality of her and her friend's experiences, Participant 835 was ultimately able to offer support and help her friend adjust to living with PoTS.

Clinician Knowledge

Multiple interviewees have reported having to educate medical professionals about their own conditions due to a lack of clinician knowledge, which can make appointments more stressful and require more preparation in advance. Participant 444 described his experiences as such:

> *"None of my GPs knew about it, so it was very much a case of whenever I have a problem, whenever I need a sick note, I have to educate the GPs on what my condition is. Some of them don't believe you, some of them don't really understand it."*

However, attempts at education are not always positively received as they flip the traditional knowledge dynamic in doctor-patient interactions on its head, as reported by Participant 69:

> *"[D]octors do not like to be told that they don't know something... Or don't even like to think that they don't know something... If they don't know something a lot of doctors won't just say I don't know."*

Participants diagnosed several years ago, such as Participant 304, often reported improvements in clinician knowledge over time since diagnosis, but this was not universal, nor did the more recently diagnosed benefit from a wider range of clinicians with greater knowledge during the diagnostic process. Participant 304 described clinicians she encountered at the time of her diagnosis as 'clueless' but felt that, despite wider clinician recognition of the term 'PoTS', understanding is still low to this day.

Misdiagnosis

Interviewees were misdiagnosed with both physical and mental health conditions when seeking a PoTS diagnosis. However, being misdiagnosed with physical health conditions was significantly rarer. Of the two men interviewed in this study, one (Participant 444) was a keen athlete in his 20s who was initially believed to have asthma (he did not) and was sent for physical tests such as ultrasounds on his lungs before ultimately being diagnosed with PoTS following a tilt test. (The only other male interviewee was diagnosed in his mid 50s on a different continent.)

A more typical experience for the interviewees in this study was for clinicians to attempt to misdiagnose their physical chronic health condition(s) as a mental health one(s). Patients were often disbelieved and told 'it's all in your head'. This was something experienced by the majority of interviewees who were female or were perceived to be female by clinicians. It's hard to be certain of this due to the low number of male interviewees, but this may well be a symptom of a larger known issue, namely the treatment of women in modern healthcare, especially when seeking diagnoses for chronic conditions. This misdiagnosis was especially egregious for interviewees with prior experience of mental health conditions who knew that the symptoms they were experiencing were not linked to said

conditions. Overall, this type of misdiagnosis can be invalidating for patients and cause them to query their own experiences, as well as not actually helping them to manage the symptoms of their physical conditions.

Participant 219 developed PoTS symptoms as a teenage girl following back surgery in 2003 and had her symptoms and experiences invalidated by clinicians:

> *"My first week at [children's hospital] after I started passing out. Every doctor who came in was like 'are you depressed, honey? Do you just not want to go to school, do you have friends, are you doing well in school' and. I was a straight A student, I had tons of friends, I was in band, I was all ready to go off to college, I was super excited about it. Like nothing was wrong with my life before that. I was, I was a good, happy kid and it just wasn't an emotional thing. First rattle out of box, when I went to [children's hospital] the nurse who tried to weigh me, she tried to stand me up and get my weight. And I immediately started passing out and she turns to my parents and she goes 'sometimes they just do that, you know, for attention'. I was like 'oh my gosh' so that was my first experience of ever having any kind of medical professional not believe me. I mean I'm 17, I've never been sick in my life, so that was really jarring and there's just like deer in the headlights, I'd no idea what do I do, like what do you do as a 17 year old girl when. The doctors don't believe you. I'm passing out all the time, like obviously I have no control over this, but they're not. Believing me, not doing what they're supposed to be doing, so that was just the first of many, many doctors appointments where they looked at, you know, are you anxious, are you depressed. Maybe this is psychosomatic do you have problems with your parents like it's just on and on."*

It was clear that the interviewee felt that gendered language was being used to dismiss her symptoms and concerns, as well as gendered assumptions being made about her mental health. (She was ultimately diagnosed with PoTS in 2011, eight years later, despite a different clinician first suggesting it as a diagnosis in 2003.) Further to the experience detailed above, Participant 160 was initially diagnosed with a panic disorder and referred

to a psychiatrist, before learning about PoTS from a friend (see Section 5.4.2). She had prior experience of depression and anxiety, which she did think "comes along with dealing with a chronic illness anyway," but seeing a psychiatrist helped her realise that there was a greater underlying issue.

Self-diagnosis

Patients may also choose to seek answers from sources other than clinicians, often choosing to look online. This can sometimes result in self-diagnosis, a complex issue that can be contentious, especially with doctors. However, for interviewees and people they knew, self-diagnosis was typically the result of prior knowledge of the condition and/or significant research. This can also factor into a wider discussion about patients with lived experiences of conditions versus potentially less informed medical professionals. Participant 69 discussed recognising PoTS symptoms in others, ultimately recommending to a few people that they see clinicians. They also had a strong stance on lived experience:

> *"[W]e know a lot about our conditions, you know, like we know more than most doctors about our own conditions and about our own bodies"*

Patients who have experienced repeatedly being disbelieved by clinicians trust the knowledge and experience of those clinicians less, something that was particularly evident in the case of Participant 353. She had been diagnosed with hypermobility syndrome by a rheumatologist, but that diagnosis didn't fully explain the symptoms she was experiencing. She then discovered PoTS as a commonly co-occurring condition from an online support group she joined (linked to a hypermobility charity) and discovered through self-testing that it fit her symptoms. Then in her late teens, Participant 353 had previously struggled to be believed by GPs and knew what testing she needed (a cardiology referral then a tilt table test) for a PoTS diagnosis. She thus chose to describe herself to clinicians as having a textbook case of PoTS, regardless of her true symptoms, in the knowledge that doing so would result in the cardiologist referral that she needed. The cardiologist referral resulted in physical testing, including the tilt table test, and ultimately her (accurate) PoTS diagnosis. It was clear from her actions that she had lost faith in her GPs but maintained trust in specialists and their judgements.

5.4.3 Wearables

Form Factor and Brands

The majority of interviewees (17 out of 20) used wearables for condition monitoring. These wearables were mostly wrist-worn, but some interviewees used halters, also known as chest straps.

Interviewees used wearables made by a wide range of brands including Apple, Fitbit, Garmin, Polar, Samsung, and Kore. Several factors influenced brand choice, including cost, local or regional availability, device design, accuracy, data types tracked, how each wearable worked with the wearer's phone, and brand loyalty. Different brands are perceived in very different ways, such as Garmin, a brand known for its athletic tracking and mapping.

Fitbit specifically is a brand that often has a poor reputation for accuracy, potentially due to how it measures heart rate. This can reduce trust in both the device and the user's perception of themself and their condition(s), as shown by Participant 243:

> *"[M]y heart rate with the Fitbit at least it doesn't do it beat by beat, it does it like an average. So I'd lay down and then I would sit up and it wouldn't change by much so it's like yeah I don't have PoTS. But. Yeah, I do, turns out."*

This inaccuracy can also negatively impact perception of Fitbits among clinicians, with the data collected being seen at best as a stepping stone leading to further, more reputable, methods of tracking. Participant 219 discussed this in more detail:

> *"My electrophysiologist doesn't like Fitbit specifically, he says it's not accurate enough. But it's a, it's like a starting point, I can say 'hey I noticed this on my Fitbit' and he's like 'well I don't really trust Fitbit but here's a halter take this home do your 24 hour halter and then we'll look at what's going on, see if you can repeat it.' "*

Overall, poor accuracy can make specific brands' wearables less desirable, as inaccurate tracking reduces the utility of the device and can even lead to people stopping using wearables for condition monitoring.

Marketing

Marketing may impact brand perception, but often it made participants feel like they were not the target audience for the devices they chose to use, compared to 'healthy' or able-bodied wearable users who do not have chronic conditions.

This research has focused on people with PoTS and their use of wearables for condition monitoring on a day-to-day basis, but these wearables are typically commercially available (off the shelf) as opposed to prescribed medical devices. However, these widely available devices are typically marketed to the general public for lifestyle and exercise monitoring, rather than as a health intervention. (There are obvious liability reasons why features without formal licensed medical approval are not advertised as such.) The typical audience of these devices (and thus the focus of their design) is able-bodied people seeking to exercise more, sleep better, lose weight, or enjoy a "healthier lifestyle" and little consideration is made to people who may not fit that underlying assumption. In the survey study, participants had complained about being unable to set step count targets low enough to be reasonable and/or practical for their day-to-day lives.

This can both reduce the efficacy of wearables as condition monitoring tools for people with PoTS and lead to perceived judgement from people around them. Participant 69 in the interview study describes this concern:

> *"I definitely am not the target market, I used to be an athlete, I was an athlete for 15 years, pretty much straight up until I got sick. [...] So now being where I am now as a sick person, yay. And a college student and also like not somebody who fits the stereotype of like 'the athletic build' or whatever [...] I definitely get some looks of like. Oh, like those watches are made for runners or they're made for cyclists or people who work out or etc., which I can't do that, I can't run. [...] So yeah sometimes it's, it's frustrating if I get that certain look, sometimes of like, why are you wearing that you know."*

This is especially pertinent because Participant 69 uses a Garmin wearable, a brand often specifically associated with athletic training. The tracking features available on their device best suit their needs on a day-to-day basis, but they do not fit the mould of Garmin's assumed user base and thus face judgement.

Use of Wearables

Wearables by themselves are not a panacea; they are not typically the be all and end all of a person's day-to-day condition monitoring. Instead they often form part of a larger triage system, alongside other devices such as pulse oximeters and blood pressure machines that can either verify or supplement wearable data. However, these devices can be less convenient than a regularly worn wearable that could provide near-continuous data tracking (allowing for charging). Participant 84 discusses her wearable use as such:

> *"I tend to use my Fitbit as [a] kind of generalist measure and if I feel like I'm having problems or I feel like. What it's saying on my Fitbit, Fitbit isn't matching what I'm feeling, then I'll follow that up with the pulse oximeter or the blood pressure machine to double check."*

Outside of this potential triage system, wearable data can have a range of uses for condition monitoring. These uses can be medical (e.g. showing clinicians data, trying to assess the impact of a medication change) or non-medical but otherwise useful, such as a way of verifying the impact of chronic condition(s). For instance, Participant 110 was able to submit her heart rate data in an appeal when seeking disability benefits as one of many ways to prove her condition. (The appeal was successful.)

> *"I had submitted [my data] for proof to get approved for the social security disability benefits. Because I was denied several times, and then it got to the judge, and I was able to submit my own evidence per se and I was able to. You know, submit all of those, the heart report app pages that showed all my heart rate data from the watch as well as my doctors, not so much, but it was very important when I was applying for disability benefits. So that may or may not have been the reason why I was able to prove it's really happening to me."*

Again, the notion of using wearables to prove the reality of PoTS is important here.

Medical Professionals and Wearables

This research focused on the lived experiences of people with PoTS, which naturally included their interactions with healthcare systems, especially clinicians from various fields. Medical professionals' reactions to wearables can vary between different types of clinicians, as well as between their individual patients. This may be a matter of a patient's perceived reliability and responsibility in the eyes of their doctor and this may have changed since the start of the pandemic due to a reduced potential for in person visits to clinics.

Interview participants in particular reported issues with clinician knowledge and understanding, leading sometimes to issues with being believed (Participant 444, based in the UK):

> *"None of my GPs knew about it, so it was very much a case of whenever I have a problem, whenever I need a sick note, I have to educate the GPs on what my condition is. Some of them don't believe you, some of them don't really understand it."*

This lack of understanding can increase stress and concern, potentially linked to the ideas discussed later on in Section 5.4.4 about the notion of being a 'difficult patient'.

One positive clinician interaction with wearable data shown in the interview study was experienced by Participant 381:

> *"My cardiologist [...], he's like 'can you send me an EKG from your walk' because you can like you can set it up, so it goes to your doctor. And he's like 'can you send me a really quick EKG I didn't like the arrhythmia that I saw at the ER.' "*

This interviewee uses an Apple Watch, specifically one with an EKG feature (as studied in [Turakhia et al. 2018], discussed further in Section 2.3.3), and clearly her cardiologist trusts both this feature and their patient enough to believe the data she generates using it. It is notable also that she is able to adjust the Apple Watch's settings to easily send this EKG data over to her clinician, making it a convenient way of monitoring any concerns.

However, this clinician trust in wearable data without further verification from other testing is not an experience that other interview participants share. One interviewee describes a generally positive reaction, albeit with understandable scepticism (Participant 69):

> *"They think it's pretty helpful, I mean they, they also are, of course, like take it with a grain of salt, just like I do. But I've - there's been a number of times where I've brought it in, and something has changed with my medicine or something and we can see that reflected very clearly. And she'll, she'll look at that combined with the EKG that I get there, and my ortho tests etc and be like 'OK, it looks like we need a switch we're going to try this' or 'I'm gonna put you on a halter again because that's way too low or that's way too high' or whatever it is, I've had all those things."*

Here, their Garmin wearable data did appropriately reflect symptom changes that they experienced, but the further testing acted to provide reassurance about and verification of this.

Here the clinician expresses concern with the specific brand of their patient's wearable and its purported reputation for inaccuracy. Despite this, he recognises an issue that she reported based upon Fitbit data as something potentially worthy of future investigation - the device may not have correctly identified the specific issue, but a change in data could still mean that there is something worth noting. This is then worthy of testing to see if a monitor he considers to be reliable and accurate (namely a halter) can verify the discrepancy observed in the Fitbit data.

A second interviewee (Participant 84) also discussed their experience identifying a health concern using their Fitbit:

> *"I don't show [the Fitbit data] to [my clinician], but I do discuss it with him. [. . .] I did discuss [a bradycardia issue] with him which he then double checked with. A lie stand test and a blood pressure monitor. And that agreed with the Fitbit data that I've been telling you about."*

In this scenario the interviewee only discussed their observations with the clinician (rather than showing him the data), but again an issue had been correctly identified and was

verified through further testing. The further testing may well have been more extensive due to the lack of actual data being shown, but it appears to have been significantly rigorous. No sense of the clinician's opinion of Fitbits is given when compared to the other case above (with Participant 219), but he clearly trusted his patient's concerns enough to agree to conduct further testing.

One other point made across multiple studies is the notion of wearable data that, through backing up physical symptoms, serves to "prove" that the wearer indeed is disabled and/or has the specific condition they claim. One interviewee felt that this was less necessary after her PoTS diagnosis, as she "stopped needing to prove [herself]" (Participant 110) resulting in her showing her data to clinicians less. However, she did still consider the baseline data she and her physician had collected to be useful reference points when considering medication changes or planning for future condition management. This settling into a routine comes with a potential sense of reassurance, but having the established data can still serve as a useful point of comparison and to temper any concerns should something go wrong.

5.4.4 Barriers to Wearable Use

Not all of the interview participants used wearables, for several reasons, as discussed below. Interviewees who do not use wearables monitor their conditions in several different ways, including via pulse oximeters, blood pressure monitors, mobile phone apps, and symptom diaries.

Cost

Study 2 in particular explored another cost-related key purchasing issue, namely the relative accessibility of specific devices between countries. Some devices were reported by interviewees to be more expensive in some countries than others, namely the Apple Watch, which one interviewee chose to purchase in Canada rather than Brazil due to the lower price (Participant 277). One other participant mentioned that her preferred device was unavailable in her country (Participant 395). Therefore, acquiring this device would be potentially significantly more expensive due to additional purchasing costs (shipping,

import duties) that would not pose an issue for people in countries with a greater variety of wearables available.

As well as the cost of purchasing wearables, users face another potential issue - the cost of replacement should the device become damaged or broken. This may lead to a change in device type or the termination of wearable use for condition monitoring. This is not specific to one device type, with survey participants in particular reporting devices from various brands (including Fitbit) breaking, but there is one specific brand of wearable that warrants a mention here. Between 20 and 30% [N. Gall et al. 2020] of people with PoTS experience syncope as one of their symptoms. This, combined with the Apple Watch's large, glass screen can lead to an additional risk of screen breakage. One interviewee in particular discussed this happening to her (Participant 277) and mentioned that it led to her switching to a Samsung device as a result. Here, the lower cost of this replacement device was explicitly stated as a motivating factor for the switch, with a "pretty low" cost device being preferred to the more expensive and less accessible (to her) Apple Watch.

Anxiety

Throughout the interviews participants discussed distressing experiences of the diagnostic process, particularly those whose symptoms and lived experiences were dismissed or not taken seriously by clinicians. As a result, it is only natural for them to have concerns about being perceived as a burden by clinicians, which can be reinforced by anxiety about potentially minor deviations in wearable data. Participant 906 explained how this led to her having reservations about wearables:

> *"I think that sometimes people are concerned about. Like hypochondria kind of thing, like that's why I didn't have one initially because, like I didn't want to like be one of "those patients" so like that's why I didn't get one before I was diagnosed. Because I didn't want to be the patient that's like 'oh my heart rate's jumped 50 beats when I stand up,' because I knew that, like the GPs, or the doctors would just be like 'oh that's because it's not accurate,' or like 'oh that's because' yeah I was like I'm not going to do that. Because I wanted to be seen as like a relatively level headed patient"*

She later expressed concern about being seen as a "crazy person", which summarises the underlying issue well. People cling to notions of dignity and sanity in difficult situations, such as when experiencing confusing health symptoms that doctors don't seem to be able to understand or treat, and thus being dismissed as troublesome ('one of "those patients"') or mentally unwell ("crazy person") or a hypochondriac can be deeply destabilising to the patient's sense of self.

Stopping Using Wearables

Another key reason why participants chose to no longer use wearables was reaching a point when their PoTS symptoms appeared to be under control or well-known and understood by them. This may come with a shift in condition monitoring methods, with one survey user stating that "Once I'd learnt the symptoms to look out for, I found it more useful to manage based on symptoms than heart rate figures." Another referred to their symptoms being "well controlled" and thus no longer in need of constant monitoring. This is backed up by Participant 505:

> *"I've been with my illness for like 10 years now, so I kind of - I know when I'm not feeling well, I don't need to like check my watch to to know that."*

Here, she discusses having adjusted to living with her symptoms and thus being able to tell when something is wrong without the aid of technology. Overall this is linked to greater experience, confidence in identifying symptoms, and awareness of the body as a whole.

5.4.5 Designing an Ideal Wearable

All interviewees were asked about their ideal wearable design, regardless of whether or not they have ever used wearables for condition monitoring. A wide range of features were named by participants, some of which are currently widely available in devices on the market today, and some of which are not as widely (or at all) available (e.g. blood pressure monitoring, body temperature). The customisability of notifications was very important to many participants, who would prefer alerts customised to their specific needs. Medical alert information was also suggested as something to include, especially

for people who experience syncope. However, some aspects of the design ideas given were contradictory, namely what role a screen should play in an "ideal wearable". Some participants very much favoured a screen (that does not easily shatter) in order to have their data to hand, whilst others preferred an option without a screen so that they would experience less anxiety from overly checking their data.

Blood pressure was also highly desired by interview participants, again becoming the most requested design feature for an ideal wearable. Here what is emphasised is convenience, comfort, and the small size of this proposed ideal blood pressure wearable in comparison to current monitors which involve upper arm cuffs. The integration of alerts when measurements fall above or below user-defined levels is also suggested. However, the potential inclusion of blood pressure monitoring was also described as "not realistic" by Participant 69, with Participant 160 also saying "I don't know how achievable [this feature] would be." Much of the discussion about it was speculative (which was expected with the nature of the question).

Three interviewees in particular emphasised the need for convenience in blood pressure monitoring, with Participant 219 loving the idea of being able to take a blood pressure reading "whenever [she] needed it, that would be so helpful." Participant 505 focused on the design aspect of convenience:

> *"It would be - I don't know if anything can do this, but it would be good to have a thing that you can check your blood pressure on without getting that massive, well it's not even massive, but that big machine out."*

This suggests that she finds the current size and design of at-home blood pressure monitors to be potentially overwhelming. A third interviewee, Participant 126, considers both a preference for comfort when monitoring blood pressure, as well as physical convenience when feeling unwell:

> *"Personally, I would design [...] something that could take your blood pressure, like something small. You know, something that's not going to irritate your skin too much and be able to like set it so like if I wanted to take my blood pressure once every hour or I just hit a little button and it will take my blood pressure for me, so if I'm really dizzy and laying down and my blood*

pressure monitor's across the room I can just hit a little button and it'll take my, take my blood pressure, and I can go 'Oh, I definitely need some more meds.' That would be helpful."

This quotation is especially of interest because it takes the idea of a blood pressure feature one step further by considering the consequences of the readings taken and how to use them to potentially counteract the physical symptoms of PoTS.

Some other potential features were raised by both interview and workshop participants, namely feature integration, data annotation, and a way to track medication. Multiple interview participants discussed their desire for "[e]verything in one thing" (Participant 381), with the idea of a universal app that collates data from multiple devices seeming particularly appealing to Participant 243:

"One app that's free, that syncs to like everything, and displays everything [...]. Just you know just to have everything in one app or that syncs with all the apps."

Here this idea of a universal app would increase cohesion and convenience for the user, something that becomes increasingly relevant when discussing PoTS symptoms, specifically brain fog. This is also especially important in relation to medication management, where taking the incorrect dose (or forgetting to take any) can be harmful. One interviewee, Participant 84, spoke of the importance of medication tracking as a potential feature alongside her desire for a combined all-in-one app for both symptom tracking and management:

"Something that you can include your medication changes into in an app in like a matching app for that wearable piece of technology. [...] Because, certainly, one of the features of PoTS being cognitive dysfunction, it is very, very challenging. To keep track of when you've taken medication, whether you've taken it. Literally within minutes of doing it you can forget."

5.4.6 Wider PoTS Community and Social Media

Interviewees were asked if they knew other people with PoTS who use wearables for condition monitoring and then about their experiences of social media. These questions

about social media use were not just wearable focused but were also a chance to gain information about online PoTS communities. As PoTS is a rare condition, participants did not always know someone else (in person) around them who also has it, so online support networks could prove invaluable, especially those on social media. Online resources could also help people learn more about their condition. A variety of social media platforms were used by participants, including Facebook (groups), Whatsapp, and Instagram. Support groups varied in focus and ranged from locally to internationally focused.

Participant 277 shared her experiences of being from a small country without the infrastructure of the USA or the UK, where support networks were less easily found. Her initial interactions via social media were with internationally focused (English language) online support groups, specifically more general chronic illness Facebook groups. Following her diagnosis, she entered PoTS-specific subgroups, which she described as UK- and US-centric, but which did lead her to finding local contacts and joining a Whatsapp group for people with PoTS from her country. It is noticeable that she felt like she would find more information and support while searching in English rather than in her first language, but she was not alone in doing this as she found other people from her country doing the same. Country-specific support groups can be important as they deal with important location-related issues, such as how the local health service works, or what condition monitoring methods and treatments are available in a specific place (or local alternatives). For instance, not all wearable brands are available (or easily affordable) in all countries, so people may have to figure out the best alternatives to their desired device.

5.4.7 Impact of COVID-19 Pandemic

The current COVID-19 pandemic has had many impacts on interviewees. These can be sorted into several strands: changes in healthcare provision and access, especially a greater utilisation of telehealth; the impact of the pandemic on day-to-day condition management; feelings about Long COVID, specifically people being diagnosed with PoTS as a result of Long COVID. The pandemic has changed how everyone lives their day-to-day lives, but especially people with PoTS, who may be considered clinically vulnerable.

As well as this, some people with PoTS have found it difficult to meet their day-to-day exercise needs.

The pandemic has resulted in a lot of appointments being cancelled, rearranged, or no longer taking place in person. As a result, the relationship between patients and clinicians has shifted slightly due to the lack of physical interaction. Doctors' offices being closed and it not being safe to meet face-to-face has led to an increase in the use of telehealth for appointments. This can increase accessibility, as patients no longer have to travel hours to see consultants. Appointments can also be accessed when patients are in poorer physical health, as they can participate from home rather than having to expend the energy to travel. Participant 767 appreciated the convenience of telehealth appointments for regular check ups and appointments that assessed the effectiveness of her current treatment plan. The lack of travel time needed for virtual appointments accessed from the comfort of her own home meant that these short appointments no longer required hours of travel and waiting at a clinic - she could instead wait at home if there was any delay.

A certain amount of people who develop Long COVID have been diagnosed with PoTS [N. P. Gall et al. 2022] and this is something that participants had mixed feelings about. On the plus side, Long COVID has led to increased recognition of PoTS as a condition, and some interviewees were hopeful about that leading to increased research funding and potential future breakthroughs. In the meantime, however, others worried about potentially overstretched services and reduced access to the already limited number of specialists for other PoTS patients, due to an increase in patient numbers that they felt could potentially overwhelm the system.

5.4.8 Challenges and Opportunities

Challenges for Wearable Use When Managing PoTS

Study participants encountered several challenges when using wearables to manage PoTS. Clinician opinions of and reactions to patient monitoring and data tracking can prove a challenge as they are variable at best between role and specialisation, let alone individual clinicians. Low participant data literacy can also inhibit understanding of symptoms and

data changes and may lead to tracked data seeming overwhelming. Another potential source of overwhelm is the constant checking of data which can result in anxiety, especially if the progress made is not deemed to be positive. The availability of specific desired data types can restrict which brands of wearables are available to participants, such as less widely available ones with blood pressure tracking. As well as this, some of the big name brands (often more widely available to purchase) may not offer more explicitly healthcare focused features. Participants are often using commercial lifestyle devices for personal use and often do not feel like they are the target audience for these wearables.

Opportunities for Wearable Use When Managing PoTS

However, this study also brought to life several opportunities for the future use of wearables when managing PoTS. Interviewees talked at length about their ideal design for wearables, and it could be worth examining in more depth how these ideal design elements compare to what already exists, as well as how they could theoretically be included in future devices. Wearables are being incorporated into some participants' current treatment plans, as well as being used to test the impact of changes to prescriptions and/or treatments. There is scope for this to be more widely discussed and ultimately adopted. As a result of the COVID-19 pandemic and the resultant shift towards telehealth, patients are being increasingly trusted to self-report their own data to their clinicians. Less face-to-face or physical contact with clinicians can lead to more alternative means of exploring symptom change, which could prove to be a further opportunity for wearables. This may also be of use to people who do not live near specialists, and thus are less able to see them in person often. The use of wearables has had positive impacts on participants' lives, including Participant 110, who used her wearable data as a proof of disability to obtain social security benefits. The ability wearables provide to make otherwise 'invisible' conditions visible could help people prove their disability or conditions to others, although this should not become excessively regulated and should remain led by disabled people.

5.5 Conclusions

The interview study initially spun off from the previous survey study, which provided a broad overview of PoTS and wearables, albeit in a granular fashion. Unlike the survey, where responses were analysed on a question by question basis, the interviews sought to dive deeper into individual narratives and experiences across ages, countries, healthcare systems, and genders. This deeper search allowed the researcher to identify patterns and connections between PoTS symptoms experienced, data types tracked, and the form factors and brands of wearable devices used. Participants were also able to express their feelings and opinions in greater detail than a survey allows, with the researcher having the opportunity to ask follow-up questions if needed. Overall, the findings of the interview study contextualise and expand upon the findings of the survey study. Combining the interview narratives and the survey data should then enable further investigation of ways that wearables could be used in the future, as well as challenges currently faced in this field of study.

In comparison to the survey findings, the most popular wearable brands (Apple and Fitbit) and form factors (wrist-worn smartwatches and fitness bands) remained the same, although Garmin devices and halter style (chest strap) wearables were also significantly mentioned in the interviews. The increased accuracy of a chest-worn wearable was particularly praised by participants, in comparison to comments other interviewees made about accuracy issues experienced with their wrist-worn wearables, especially Fitbits. The wider PoTS community was an important theme of the interviews, with some participants seeking wearable recommendations from their network of people with PoTS, primarily online and/or via social media. These digital networks could be local, national, or international, but provided important support nonetheless, including with recommending clinicians. A near-universal constant among interviewees was poor experiences with the healthcare systems encountered prior to diagnosis, sometimes resulting in significant individual trauma. The most valuable positive encounters here were with individual medical professionals who actually believed their patients' symptoms and experiences, often leading to a PoTS diagnosis. The use of wearables and the discussion of wearable data with clinicians depended upon the individual relationship between patient and clinician.

Differences in healthcare systems became more explicit in the interviews than in the survey study, with interviewees discussing issues such as access to clinicians and the cost of both medical appointments and wearables. People living several hours away from their local specialist in a fee paying healthcare system were likely to have different views from a person living near their local specialist under universal healthcare, although long waiting times between appointments could prove to be an issue for both groups.

One key finding from this second study was the notion of an ideal wearable user and issues experienced by participants due to not being part of this expected target audience for the device. Interviewees often found wearables' built in focus on increasing exercise, hitting step counts, and competing with others to do so to be exclusionary as people with PoTS often are not able to do so (or can only do so with significant health consequences from overexertion). Managing step counts for pacing purposes is instead more normal, but this goes against the assumed use case of the device. Participants were asked about the design of their ideal wearable, a question which resulted in a wide range of responses. Customisation and the inclusion of less widely available features such as blood pressure monitoring were popular options, but there were some contradictions, namely whether or not an idealised device should have a screen. Some participants preferred a device with a screen in order to more easily access data, while others preferred a device without a screen in order to reduce anxiety induced by overly checking data. The impact of the COVID-19 pandemic was also a key thread running through the interviews, partially due to the time progression between the start of the pandemic and the interviews and the survey study and the interviews. By the time the interviews were conducted, in Summer 2021, participants had had over a year's worth of experience adjusting to telehealth and other facets of accessing specialist care during the COVID-19 pandemic. As well as this, vaccines were becoming more widely available, and knowledge of Long COVID was increasing.

Following this second study, a decision had to be made as to the design of Study 3, the third and final study which is discussed in full in Chapter 6. Several options were considered, including app design or developing a wearable prototype. App design was dismissed as an option due to the ongoing responsibility and commitment needed for any potential upkeep. A touchstone of this doctoral research was aiming to centre the

lived experiences of people with PoTS where possible, thus choosing a final study centred around something not designed or developed by this group would seem inauthentic. This desire to further the PoTS community's involvement led to co-design, which itself has a rich history in digital health research. Ultimately, the decision made for the design of Study 3 stemmed from the ideal wearables question in the interviews, which was described at the time as 'effectively a mini built-in co-design study'. Expanding the concept of this question into a co-design study producing guidelines proved to be a sensible and achievable concept for the final study.

Chapter 6

Study 3: Workshop Study to Co-Design Future Wearable Technologies to Assist With the Monitoring of PoTS

6.1 Introduction

It was ultimately decided that this third and final study should consist of group co-design workshops to aim to design future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS). The first study uncovered the wider PoTS community's opinions of the use of wearables for condition monitoring and some of the issues involved, while Study 2 drew attention to participants' desires for wearables that would better fit their condition monitoring needs. Study 3 would therefore focus on co-designing acceptable and feasible wearable solutions that better meet the needs of this user group. Co-design was selected to continue to include their lived experience and to ensure that the solution was focused on addressing real world lived problems.

These group co-production workshops consist of a mixture of five asynchronous prompts to guide participants, as well as a group Zoom call to discuss the prompts and give participants from a range of backgrounds and countries the chance to discuss their experiences and opinions with each other. When developing this study, a choice was made to "co-design the co-design" and hence split this study into two phases, the first of which

consisted of a survey that asked potential workshop participants about their workshop design preferences, including length, group size, and technology used. This feedback was then used as co-design input for the workshops themselves, which were pilot tested by participants before launch.

6.2 Aims

The ultimate aim of this phase of research was to co-design guidelines for the creation of future wearable technologies that assist with the monitoring of PoTS (Postural Tachycardia Syndrome) via group co-production workshops. Self-monitoring was the primary focus but clinical monitoring would also be considered if possible. These guidelines were to be generated through a series of co-designed group co-production workshops that consisted of group Zoom calls and individual written responses to text prompts about five different topics (introduction, condition monitoring, issues, solutions, guidance). All participants were people with PoTS, to ensure that the guidelines generated were based on (and centred around those with) lived experience of PoTS and condition monitoring. The aim of the pre workshop co-design phase (conducted via a survey) was to establish good engagement methods for co-designing future wearable technologies to assist with the monitoring of PoTS.

6.3 Methods

6.3.1 Study Design

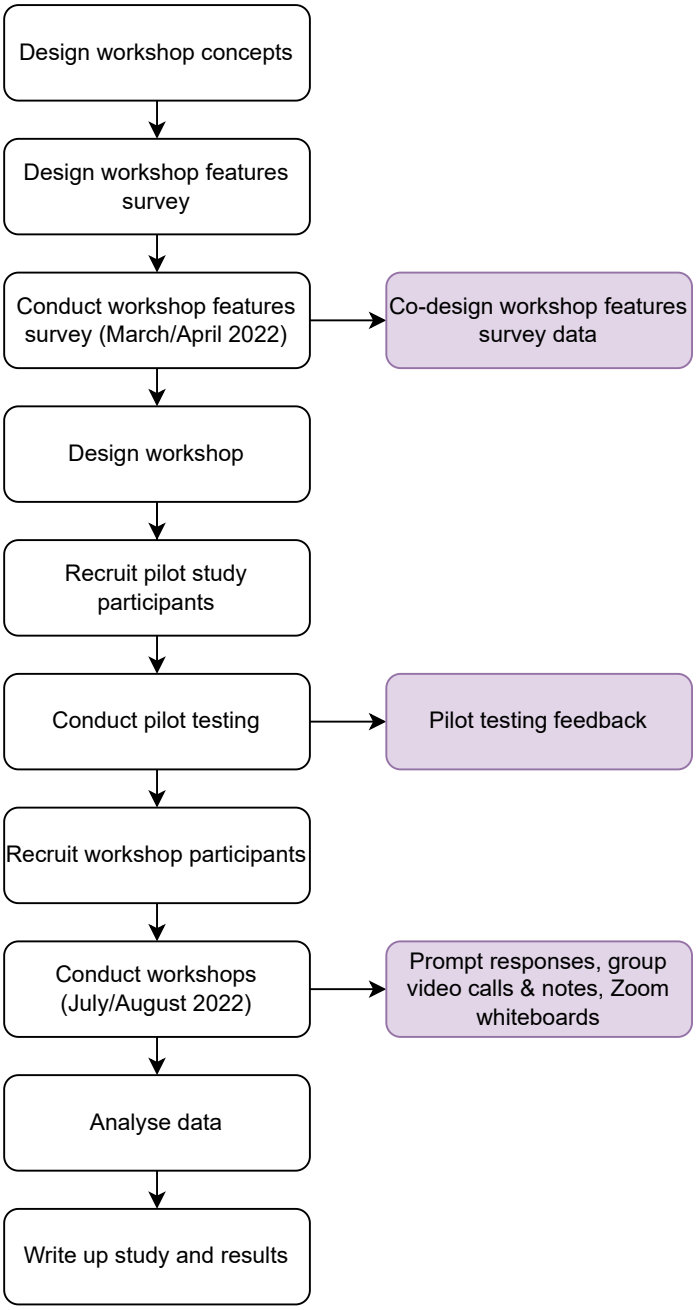

Figure 6.1: A schematic diagram showing the progression of Study 3, with data outputs from participants at each stage given by the purple lozenges.

This third and final study involved online collaborative and qualitative co-design workshops. The final design of the workshops was reached following a careful co-design process

that consisted of a co-design survey conducted between March and April 2022 followed by group pilot testing with 4 participants in June 2022 (see Appendix C). The pilot testing was used to give feedback on and to correct the designed prompts and technology choices. Four participants from three different countries (UK, USA, Australia) took part in the pilot testing in June 2022. The pilot testing consisted of two group Zoom calls (one attended by one participant, the other by three participants) where participants gave feedback on the current study design, including prompts and technology use. There were two primary aims of each pilot testing session: to test the technology used, and to check and refine the prompts and the guidance given with them. Feedback was given on how easily each prompt could be understood, including language use, as well as their usefulness. As a result of the pilot testing, further clarification was added to the prompts, and the language used was streamlined. Like the rest of this doctoral research, this third study continued to centre around lived experiences by only speaking to people with PoTS, in this case those who had experienced using wearables for condition monitoring. The prompts (see Appendix C) mostly focused upon specific wearable user experiences and thus would be significantly more difficult to respond to without that experience. This study was designed to give participants the chance to express their opinions both individually and in groups. This was done to recognise how getting the chance to talk to other people can shape ideas.

Following the pilot testing, each of the five prompts was summarised into a one word heading. The diagram below shows the order of the prompts:

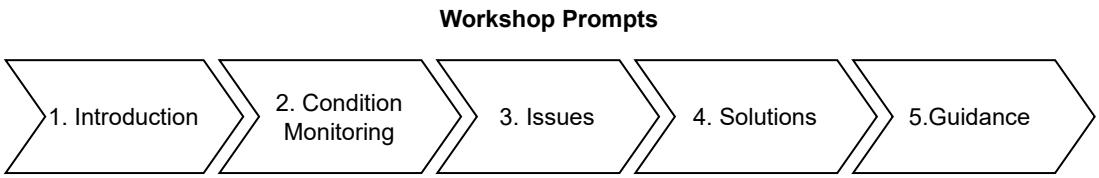

Figure 6.2: A diagram, taken from the Workshop Prompt Guidance document, that shows the number, title, and intended order of progression for the five co-design workshop prompts.

When creating the workshops, the aim was to make them accessible to as many participants as possible, both through using widely available technology and through clarity of prompts. The worst case scenarios for this study would have been people being

unable to use the technology, or worse, having to pay to use specific software. Therefore, prompts were carefully proofread by both researchers and non-academics to ensure a lack of jargon, both within and without the pilot testing process. Additional guidance was provided on the Zoom technology used when needed, and as a result of the pilot testing, it was decided that each workshop should begin with a brief one-to-one Zoom call to give each participant a chance to ask questions, as well as the opportunity for the researcher to troubleshoot any technology problems arising. Each of these calls included ensuring that participants could access their individual OneDrive folders and test the file upload process by uploading their signed consent form.

In general this study was designed to fit in with participants' day-to-day lives for ease of completion, rather than being all-consuming. Each workshop consisted of five prompts that should be able to be responded to using a "little and often" approach, and no essays were expected. A suggested schedule was included (see Appendix C) as part of the study pack but participant could choose to respond to the prompts in their own time as they chose. The only fixed deadline mid study was for uploading the first prompt, which needed to be done by a specific date to ensure knowledge of technology and commitment to participation, else further researcher intervention would be needed.

Unlike the previous studies, the workshop study focused more on ranking, prioritisation, and categorisation. For instance, participants were asked to rank current wearable features by personal importance, enabling prioritisation of generated guidelines. Asking for in depth responses served as a continuation of the previous interview study, namely the chance to dig deeper into wearable usage as part of a system of condition monitoring for PoTS, as opposed to Study 1's establishment of more surface level facts (see Chapter 4). Through these methodological decisions it was possible to discover what is most important about wearables for people with PoTS who use them for condition monitoring, as well as exploring further any contradictions that may exist.

Participants were expected to respond in a manner of their choice to a series of prompts both individually (written) and collaboratively (written and/or spoken) about their opinions of, experiences with, and the design of wearable technology specifically that might help with monitoring or managing PoTS. They were also offered an optional group Zoom video call with other participants in roughly the middle of each workshop to

discuss prompts and responses with both the researchers and other participants and to troubleshoot any issues. This group video call also gave participants a chance to respond collaboratively to prompts, rather than just individually. All written prompt responses were uploaded to OneDrive by participants during the workshop as they were completed. Participants received a £50 retail voucher each upon completion of the workshop to thank them for their participation in the workshop process. (The four pilot study participants, all of whom also participated in the main study, received £75 instead.)

6.3.2 Participants, Recruitment, and Ethics

Recruitment for this study took place in three stages: getting back in touch with prior study participants to recruit them to fill out the co-design survey; recruiting pilot testing participants; then recruiting general participants. Initial recruitment took place through the survey, where participants responded to the question "Please indicate if you are interested in taking part in the co-design workshops" with either "I am interested" or "I am not interested". Following this, pilot testing participants were recruited via email, based on insightful and useful comments they had left on the survey. When the pilot testing process had been completed, further general participants were recruited for the workshops. Separate departmental ethics applications were approved for the co-design survey (ID 1763) and for the group co-production workshops (ID 1811), as the results of the survey shaped the design of the workshops and thus fed into the ethics application created for the workshops as a result.

Workshop participants were selected from a list of 170 co-design survey respondents who had indicated their interest in being recruited for the co-design workshops. However, interview study participants (Study 2, see Chapter 5) were removed from the list of potential workshop participants in order to collect a wider range of viewpoints. It is likely that there would have been some slight overlap between the interview and workshop responses given, especially during the group workshops. All participants had PoTS and were aged 18 or over. Both of these inclusion criteria were screened for in the survey, so all potential participants should have fulfilled both of these criteria already. However, participants were asked to reconfirm that they fulfilled both of these criteria when filling

out the consent form before participating in the workshop. Fifteen (15) participants were ultimately recruited. Fourteen participants were female and one was non-binary. Participants came from four countries (UK (4), USA (9), New Zealand (1), Australia (1)) and five time zones.

6.3.3 Co-Designing the Workshops

Participants from Studies 1 and 2 who had consented to receiving research updates and/or expressed interest in further study participation were each emailed a (general, not individualised) link to the co-design survey in late March 2022. Results were collected until early April 2022. The only responses sought for this survey were those from people with PoTS aged 18 or over, as the subsequent workshops would be for that population. The vast majority of email recruits were already known to have PoTS, and all were known to be over 18 (it was a requirement when they agreed to giving updates). However, survey respondents were asked if they were over 18 at the point of giving consent, and then if they had PoTS and only those who confirmed these things (via selecting the affirmative response to both questions) were able to fill out the rest of the survey.

Phase one of this study consisted of a pre-workshop survey to develop co-design workshops that suited participant preferences. This brief (14 questions, 5-10 minute) survey asked potential workshop participants (people with PoTS) their preferences with regards to group size, study duration, software options, anonymity to other participants in the same group, and workshop synchronicity, specifically with regards to video call discussions. Time zone was also asked about as something to consider when workshop planning. By responding to this survey participants shaped the design and direction of the co-design workshops.

The survey handled practical aspects of the workshop design, but it did not cover more detailed contents aspects such as fine-tuning the prompts, or checking with the study population that the workshop contents would be insightful and useful, or that people could participate in the workshops fully (e.g. ensuring that files could be uploaded). As a result, a second collaborative consultation, namely pilot testing took place to fine tune these elements. All participants in this pilot testing also took part in the workshops.

The co-design survey findings are broken down in detail in Section 6.4. Decisions made as a result of the survey included group size, workshop length, video call length, video call medium, call anonymity, and technology choice. The decision was made to aim for twenty participants split into four groups of five, which would ensure enough participants to cover any who dropped out. A week was chosen as the length of each workshop to allow for flexibility around participants' day-to-day schedule whilst ensuring that participation was not too long a commitment. Face-to-face video calls with video on were preferred to simulate the experience of a face-to-face group workshop taking place across multiple time zones. This in turn led to little or no participant anonymity during the video calls, but participants only saw the display names chosen by other Zoom call participants. Each Zoom call was designed to be roughly an hour long following the survey preference as any shorter would not have covered the depth and breadth of topics desired, but any longer would have made scheduling difficult due to the range of time zones involved (some participants were 8 hours apart), as well as potentially tiring for participants. Zoom was chosen as both the video call and collaborative technology due to participant familiarity, researcher familiarity, and recording functionality. The then new Zoom whiteboard functionality option appeared useful for collaboration (this choice proved to be a mistake). Microsoft SharePoint was chosen for file uploads due to university ethics policies and approved technologies, overruling the participant preference expressed above for practicality and ethics reasons. The comments field gave useful insights and was ultimately used to select pilot testers based on the insightfulness of their questions and feedback.

6.3.4 Data Collection

The four group co-production workshops took place during July and August 2022 and consisted of a series of five prompts, which were designed to break the larger topic down into key points, and two video calls. One of the video calls was a brief (roughly 15 minute long) one-to-one Zoom call with the researcher to begin the workshop and give participants both their prompts and access to their individual OneDrive folder, while the other was the hour long group video call with other participants during the workshop.

Four group video calls and fifteen individual video calls took place, in addition to the two pilot testing video calls. The group video call took place partway through the workshop, on a different day to the onboarding individual video call. If participants decided to change their prompt responses based on the video call, they were asked to upload a second version of the altered response(s) as a separate file and clearly mark which file was the second version. Only one participant, Participant 113, did so.

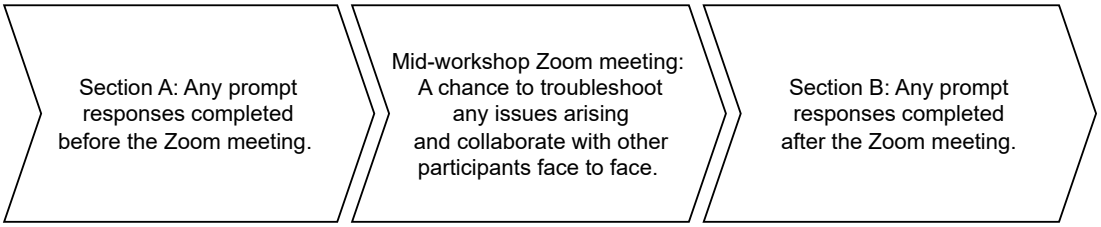

Figure 6.3: A diagram, taken from the Workshop Prompt Guidance document, that shows the intended progression of each workshop and the purpose of the group Zoom call in the middle of the workshop. It splits the prompt responses into two groups, depending on whether they were completed (and submitted) before or after the group Zoom call.

Upon the completion of each of the five prompts, participants uploaded their responses into individual OneDrive folders, one folder per participant. The prompt guidance was provided in a Word document, but participants could choose to submit their responses in another file format if they wished, as long as it was one that the researcher could easily and successfully access. All video calls, both individual and group, took place via Zoom. A Zoom whiteboard was integrated into each group video call with the aim of enabling participants to write thoughts or prompt responses down. This was meant to be supplementary to conversation but could have been used as a replacement if needed. All group video calls were recorded using Zoom's built-in recording features. Notes taken by the researcher during the group video calls can be found in Appendix C in a document entitled *Miscellaneous Workshop Notes (Made During Zoom Calls).*

The five co-design workshop prompts are given in full in the following table, Table 6.1. Each prompt is accompanied by its number and a brief explanation of its purpose. The prompt heading is given in bold text at the top of each prompt.

Number	Prompt	Purpose
1	**Introduction** Rank the four seasons (Spring, Summer, Autumn/Fall, Winter) in order of preference. Why do you like the top one most and the bottom one least? (The aim of this task is to get you comfortable with the file uploading process. It's also a chance to practice ranking and justification, both of which are useful skills for later prompts.)	This prompt acted as an icebreaker and a question that was not necessarily about PoTS, with participants not being explicitly asked about the condition.
2	**Prompt 2: Condition Monitoring** Rank wearable device features (and/or features of an accompanying app) in order of priority to you when monitoring your PoTS (and other chronic condition(s)). It doesn't matter whether these are currently available features or not. Examples of features might include the following: heart rate monitoring (data collected by the device), menstrual tracking (data reported to a device or accompanying app by the user), and alarms (alerts edited by the user related to symptoms or condition management).	Prompt 2 was designed to understand what wearable features people with PoTS most value and/or find to be the most useful.
3	**Prompt 3: Issues** List any issues you have with the use of wearables for your own personal condition monitoring currently, then state the potential consequences of these issues, if known. If possible, rank these issues by importance. If you wish, a mind map or spider diagram may be a suitable way to respond to this prompt. Please don't look at solutions to these problems right now, as you will do so later.	The third prompt was designed to inspire participants to think critically about their wearables, as well as continuing to prioritise by ranking the issues by perceived importance to them as a wearable user.

4	**Prompt 4: Solutions** What do you particularly like about the use of wearables for condition monitoring? What features do you wish could be included in future wearables used for condition monitoring? What solutions do you have to the problems you listed in response to the previous prompt? List your answers to each of these questions. Solutions do not have to be realistic answers that can be implemented straight away.	Prompt 4 was designed to be a more positive flip side to the relative negativity of the third prompt, giving participants the chance to come up with their own solutions for issues experienced with wearables.
5	**Prompt 5: Guidance** Group your solutions from the previous prompt into categories of your own devising. Using these categories, come up with a series of guidelines for the creation of future wearable technologies that assist with the monitoring of PoTS. Come up with at least one guideline for each category. Solutions can fit into more than one category. To define a category, think about the overarching similarities or themes within your lists. For example, uncomfortable material, loose straps, and an easily breakable fastening are all issues that would fit under the potential category device fit. A potential solution for this category would be more adjustable straps in a greater range of materials. Other examples of categories include device accuracy, data types, and customisability (e.g. of alerts and alarms), but you shouldn't limit yourself to just these categories.	This final, fifth prompt served to bring together the findings from the other four prompts, especially Prompt 4 (Solutions), to ultimately co-design guidelines for better wearables for PoTS monitoring.

Table 6.1: A table detailing the five prompts that co-design workshop participants had to respond to, as well as the purpose of each prompt.

Data collected as part of this study included prompt responses, recorded video calls (with participant agreement), and hand-written notes made by the researcher during Zoom calls.

Data Collected	Number of Items	Comments
Co-Design Workshop Features Survey Data	236 survey responses (196 complete, 40 partial) from 236 individuals.	The survey consisted of 15 questions, some of which were optional. (See Appendix C for questions.) A response is defined as complete if the final all-participant compulsory question has been answered.
Pilot testing feedback	2 pages of bullet point notes.	Notes made on verbal discussions typed up by the researcher.
Prompt responses	Prompt 1: 13 Prompt 2: 11 Prompt 3: 8 Prompt 4: 8 Prompt 5: 8	
Group video calls (4 recorded Zoom calls)	1 (15/07/22) 2 (19/07/22) 3 (20/08/22) 4 (26/08/22)	01:03:42, 7 files, 1.07 GB. 00:47:56, 8 files, 733 MB. 00:42:10, 7 files, 1000 MB. 00:56:29, 4 files, 926 MB.
Zoom whiteboards	4 Zoom whiteboards	Minimal data available here, these turned out to be barely usable.
Group video call notes	3 pages of bullet point notes.	Additional notes taken during the video calls typed up by the researcher.

Table 6.2: A table showing the data collected in Study 3. See Appendix C for more details.

6.3.5 Data Analysis

As with Study 2 (see Chapter 5), data was ultimately coded in NVivo using the code function. Responses were separated out on a prompt-by-prompt basis and compiled into five Word documents, one for each prompt. Each prompt response was clearly sectioned off by participant number, again decided by survey response number for thesis-wide consistency. These five documents were then uploaded to NVivo. This method of document compilation was chosen in an attempt to streamline comparison and coding of individual responses, with original formatting being maintained. Thematic analysis (after [Braun and Clarke 2013]) was performed upon the five compiled prompt documents, initially on a prompt by prompt basis, with Prompt 1 (Introduction) being treated differently to the other prompts due to its status as an icebreaker. Prompts 3 and 4 were treated as a pair for purposes of analysis as participants had often considered both prompts as a pair (with some making matching lists) and tended to devise solutions in Prompt 4 to specific problems that they had listed in Prompt 3. The themes generated were then created as nodes in NVivo and each individual document was coded using the list of nodes generated. Initially, Prompt 1 had a separate set of nodes to the rest of the prompts, but these were later combined as it was realised that the themes generated for Prompt 1 also applied to aspects of responses to the other prompts too.

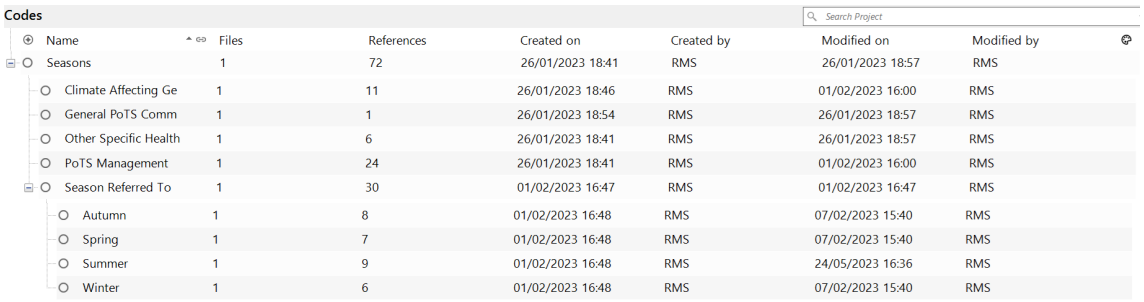

Figure 6.4: A screenshot of NVivo showing the coding node *Seasons* and all five of its children. The child node *Seasons Referred To* has four further children of its own named after the four seasons.

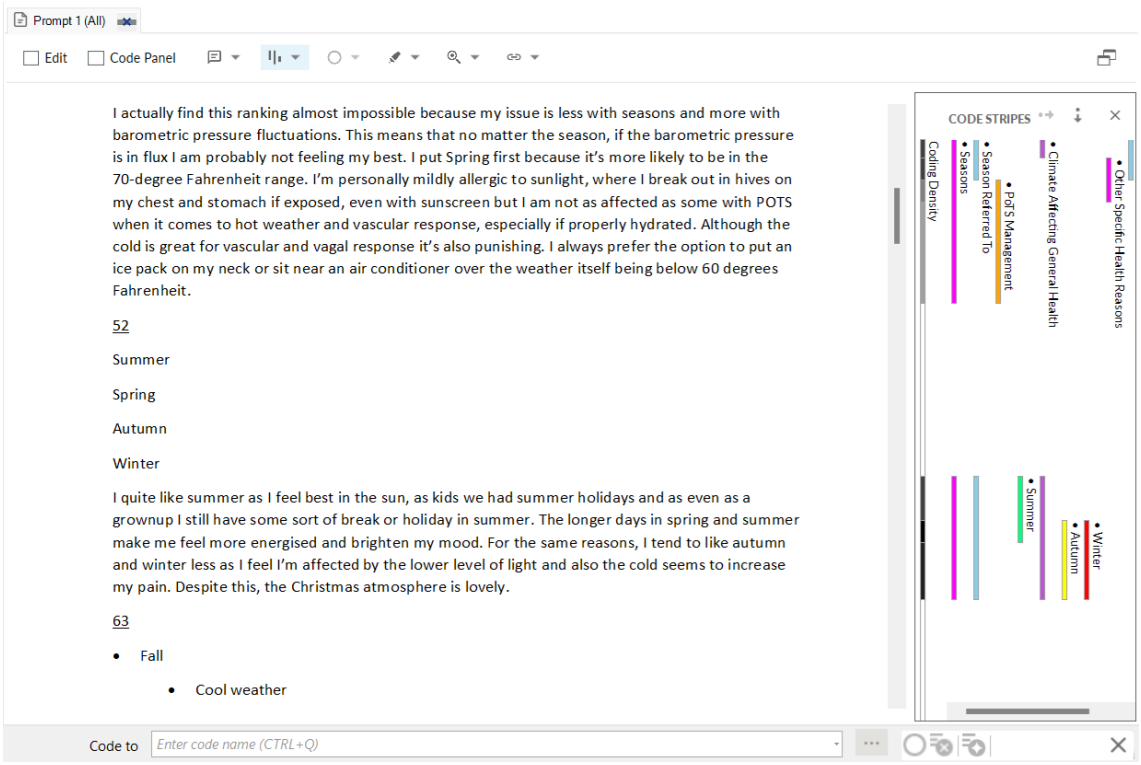

Figure 6.5: A screenshot of NVivo showing an excerpt from the collated responses to Prompt 1. The underlined number shows the start of the corresponding participant's response. The coding stripes at the right hand side of the screen show which theme(s) sections of the text have been coded as.

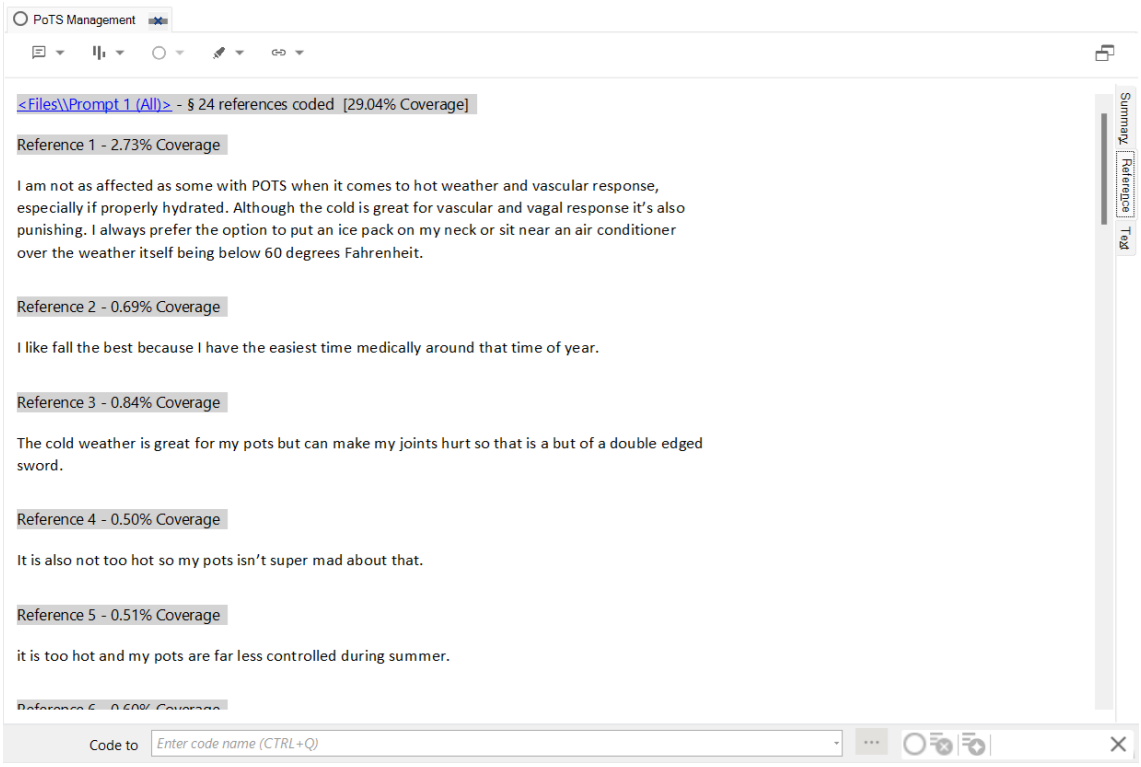

Figure 6.6: A screenshot of NVivo showing the contents of the *PoTS Management* node. The blue hyperlinks denote the file names that each reference came from (but not the participant).

6.4 Co-Design Survey Findings and Discussion

Data from this survey was compiled and used to inform the design of the workshops. The data collected for this part of the study was primarily quantitative, with a small amount of qualitative data. 236 participants responded to the survey, of which 228 were eligible for the workshops.

Firstly, participants were asked what size group they would feel comfortable being part of for a workshop, selecting as many of the six options as they felt suited them. The most popular response was 5-6 people (141 respondents), with 3-4 people not far behind (130 respondents). Figure 6.7 shows the distribution of responses to this question.

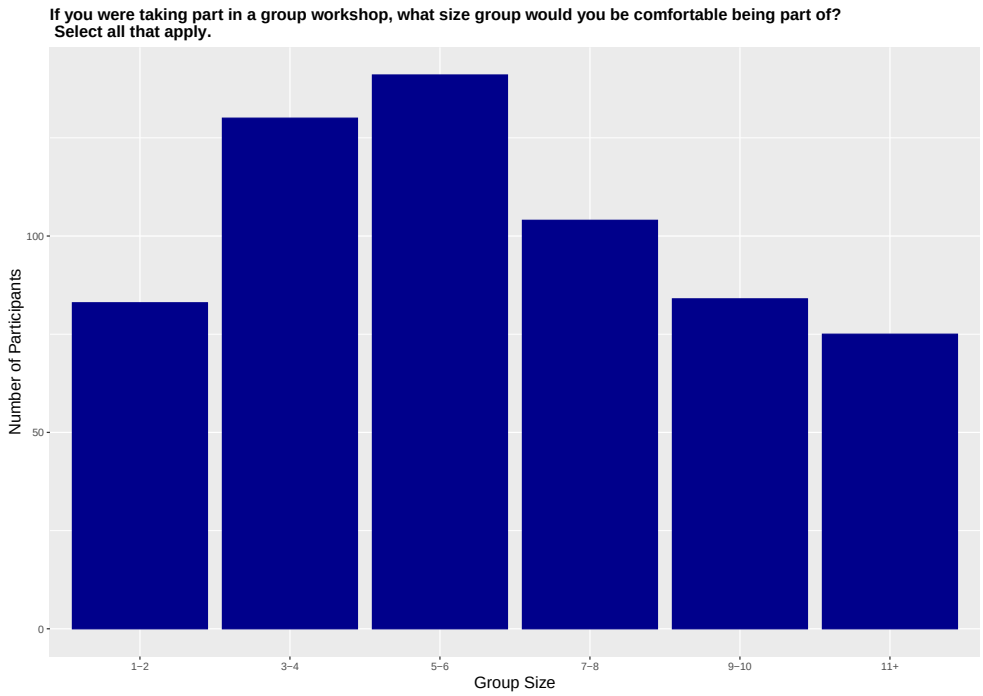

Figure 6.7: A bar chart showing the popularity of different group sizes amongst co-design survey participants. The title of the graph is the survey question being responded to. Participants could select multiple responses.

When asked about their preferred workshop duration (see Figure 6.8), two adjacent lengths emerged as the most popular options. The modal option was 3-5 days (118 respondents), with 6-8 days (106 participants) as a clear second place. These durations are both short enough to avoid dragging and long enough to avoid overwhelm, with the possible exception of the lower end of the modal range, 3 days. (Again, participants were able to select multiple options here.)

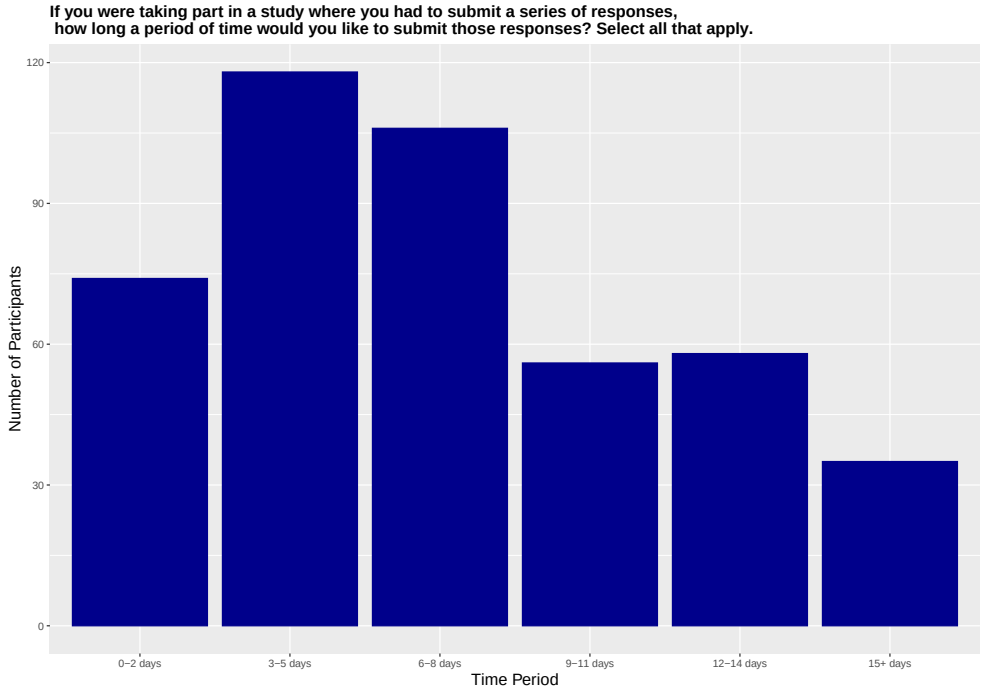

Figure 6.8: A bar chart showing the popularity of different workshop durations amongst co-design survey participants. The title of the graph is the survey question being responded to. Participants could select multiple responses.

The responses to the video call length question (see Figure 6.9) are so skewed towards the lowest two options that it suggests an inappropriate choice of ranges by the researcher. This question may have been improved if fifteen minute intervals had been chosen for durations of up to an hour, rather than thirty minute intervals actually selected. The most popular option selected was 30-60 minutes (152 respondents), followed by 0-30 minutes (141 respondents). On the other hand, the third most popular option, 60-90 minutes, was only selected by 51 respondents. A small number of respondents (14) stated that they would not be comfortable participating in a group video call as part of a workshop, but they were in the minority.

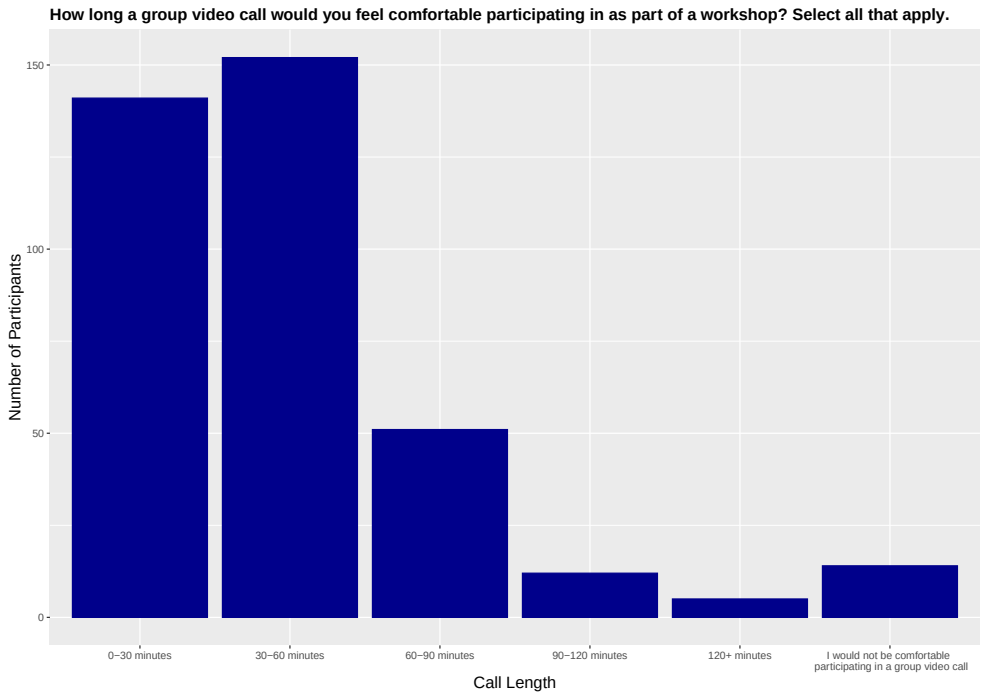

Figure 6.9: A bar chart showing the popularity of different call lengths amongst co-design survey participants. The title of the graph is the survey question being responded to. Participants could select multiple responses.

The overwhelming majority of survey respondents (130 of 212) expressed no preference about whether or not video calls with other participants during the workshops should be face-to-face or not (see Figure 6.10. Of the 82 respondents who did state a preference, no (44 respondents) was slightly preferred to yes (38 respondents).

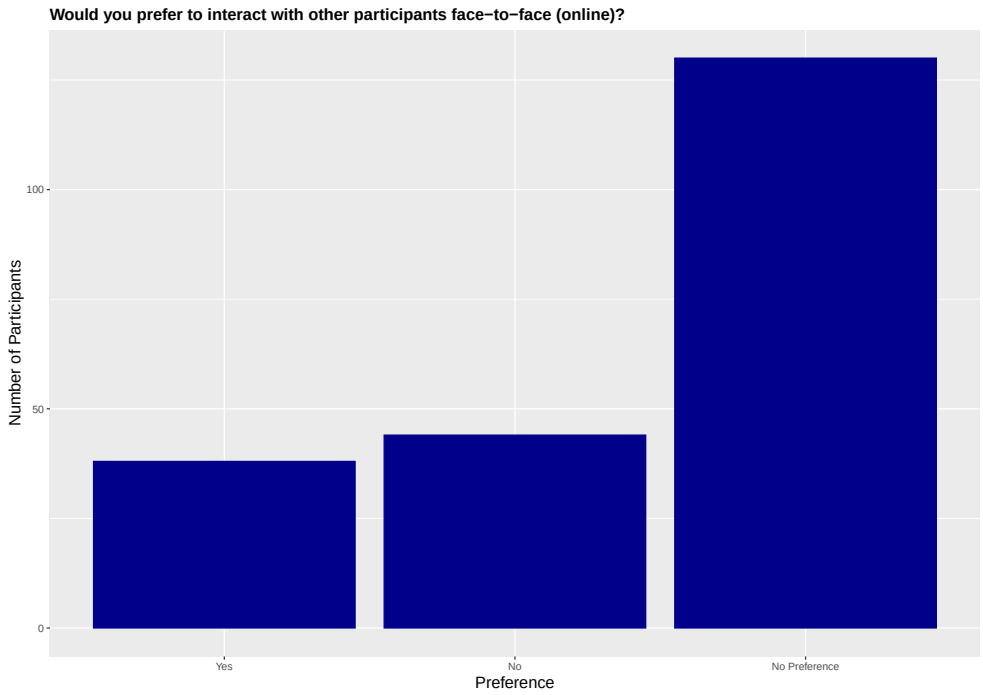

Figure 6.10: A bar chart showing responses to the question "Would you prefer to interact with other participants face to face (online)?" Participants could only select one response.

The 'no strong preference' response was even more emphatic (168 of 212) when co-design survey participants were asked about participant anonymity throughout the workshops. Only 44 participants cared strongly enough about this topic to give a yes or no answer, and 29 of those 44 answered 'yes' to the question. Both this and the responses to the previous question suggest that decisions made as a result of these questions are likely to be a lower priority to participants than others such as group size, workshop length, or technology choice.

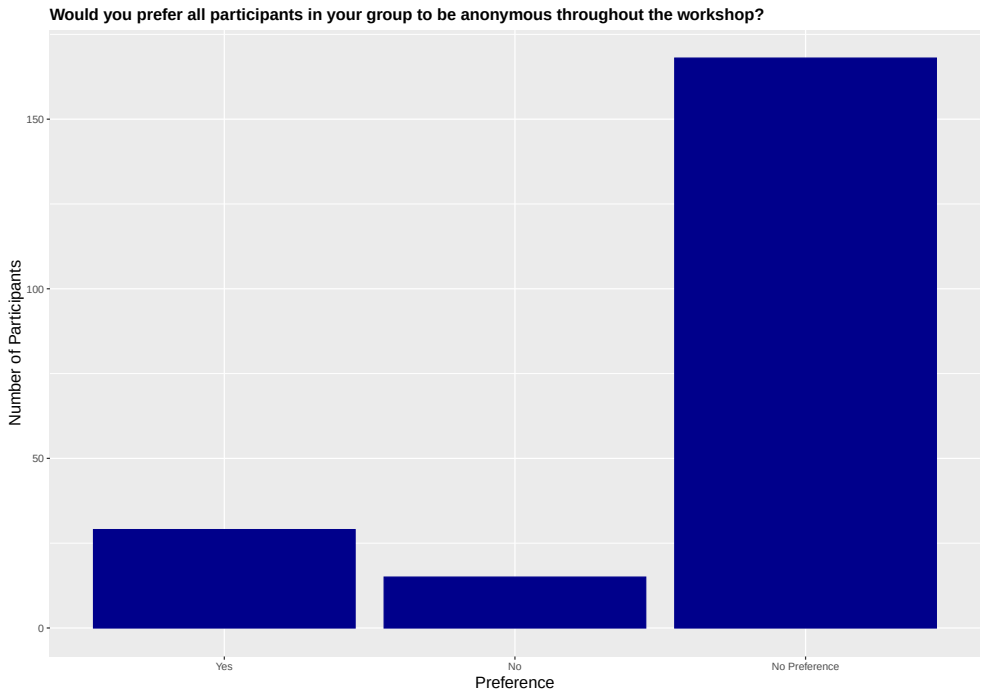

Figure 6.11: A bar chart showing responses to the question "Would you prefer all participants in your group to be anonymous throughout the workshop?" Participants could only select one response.

The final two workshop design multiple choice questions in the co-design survey both asked about familiarity with different types of technology that could be used to facilitate the workshops: video call technology for group discussions, and virtual collaborative technology for document upload and discussion with the researcher and potentially other workshop participants. The video call technology question (see Figure 6.12) had a clear least popular option out of the four named technologies, namely Discord video calls (30 responses), although this was still more popular than the 23 respondents who selected 'Other (please state)'. Zoom (204 responses) was the most known technology by a significant margin, followed by Microsoft Teams (132 responses). This is understandable, as these are two of the most generally known video call technologies.

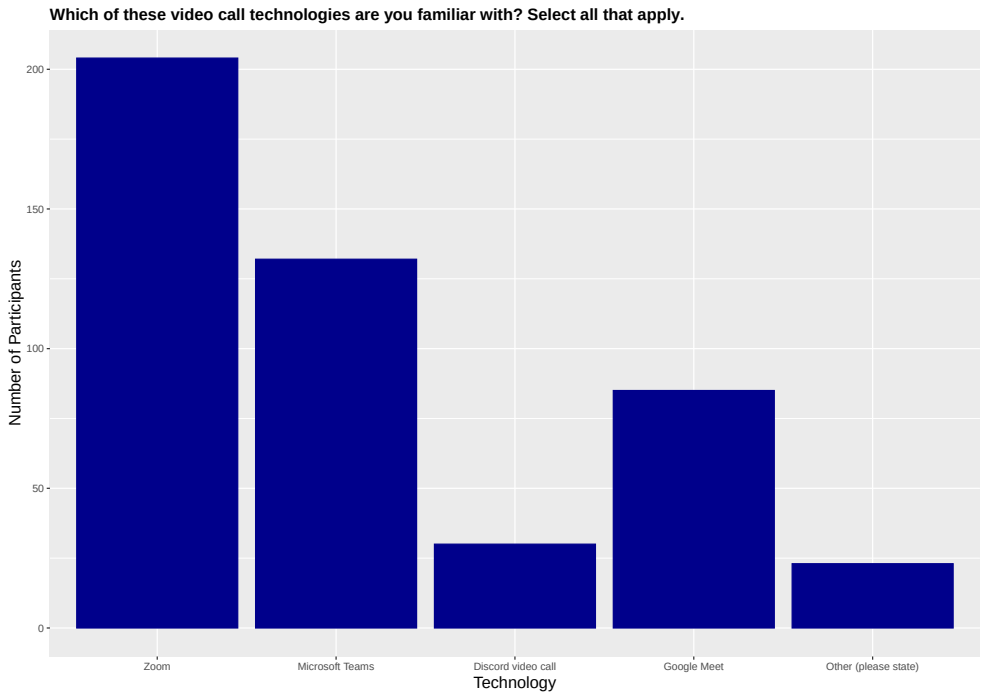

Figure 6.12: A bar chart showing the popularity of different video call technologies amongst co-design survey participants. The title of the graph is the survey question being responded to. Participants could select multiple responses.

The collaborative technology question had the highest number of possible responses for participants to select, with 7 (see Figure 6.13. Here, the two most popular options were made by the same company, namely Google Docs (160 responses) and Google Drive (152 responses). There are also two Microsoft options in this question, which were slightly less well known.

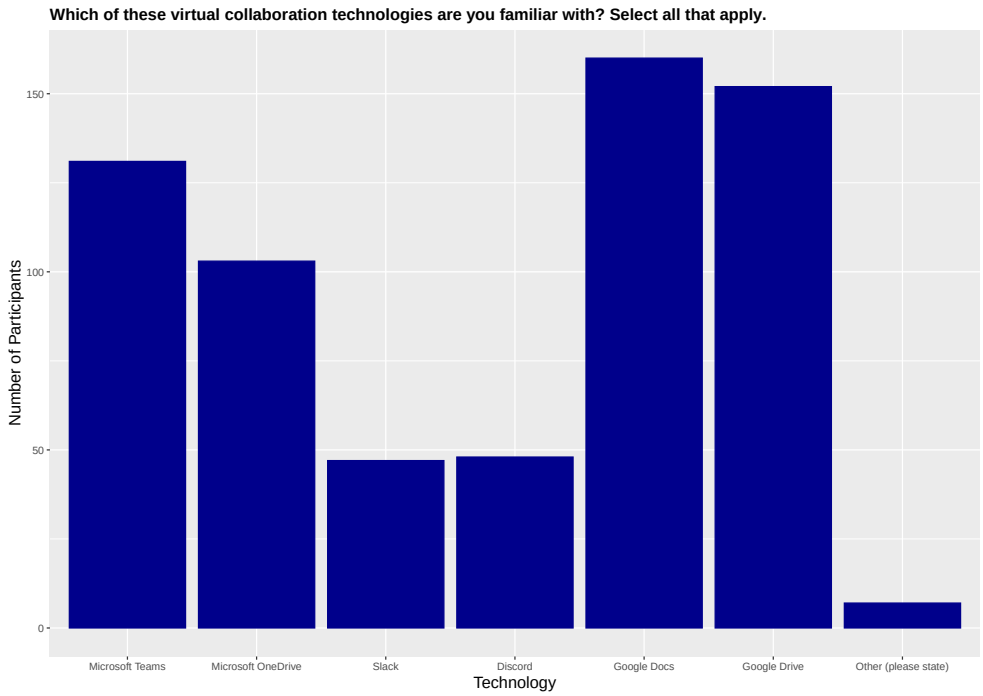

Figure 6.13: A bar chart showing the popularity of different collaborative technologies amongst co-design survey participants. The title of the graph is the survey question being responded to. Participants could select multiple responses.

6.5 Workshop Findings and Discussion

The workshops consisted of five guiding prompts that helped the researcher to do five things. 14 themes were generated, 4 of which had subthemes, with 12 subthemes total.

Theme	Subtheme(s)	Prompts				
		1	2	3	4	5
Symptoms, Seasons, and Climate	PoTS	✓	✓			
	Other Conditions	✓				
Hardware and Device Design	Battery Life			✓	✓	✓
	Fit and Comfort			✓	✓	✓
	Form Factor		✓	✓	✓	✓
Data Types	Heart Rate		✓	✓	✓	✓
	Blood Pressure		✓	✓	✓	
	Sleep Monitoring		✓	✓	✓	✓
	Other		✓	✓	✓	✓
Alarms			✓	✓	✓	✓
Customisation			✓	✓	✓	✓
Cost and Affordability			✓	✓	✓	✓
Accuracy			✓	✓	✓	✓
Anxiety and Over-Reliance				✓	✓	
Convenience					✓	
Ideal User			✓	✓	✓	✓
Clinicians			✓	✓	✓	✓
Other Devices and Apps			✓	✓	✓	✓
Data	Visualisation		✓	✓	✓	✓
	Annotation		✓	✓	✓	✓
	Security and Privacy		✓			
Future Wearables			✓		✓	✓

Table 6.3: A table showing which prompts each of the key themes in the co-design workshops were represented in. The prompts are detailed in full in Section 6.3.4.

6.5.1 Symptoms, Seasons, and Climate

PoTS Management

The first and most important key theme generated from the responses to the first two prompts is PoTS management, specifically the impact of the different and changing seasons on participants' management of their condition(s). Workshop participants had mixed opinions on spring and autumn: some struggled with the transitional nature of these seasons, while others had a better experience with the lack of extreme weather conditions. Participant 84 stated that "[autumn] possesses the physical benefits of spring - no weather typically extreme enough to cause major flares." Participant 95 also prefers these seasons:

"Spring and Autumn offer better temperatures. I no longer like extremes -

despite living in the tropics pre-POTS and loving it! Cooler climes minimise tachycardia, headaches, sleep patterns etc."

Here the mention of sleep patterns implies better sleep patterns, not minimised sleep. These seasons of transition were not regarded this highly by all participants, however, with Participant 135 stating that her love for the season is not reciprocated - autumn "seems to hate" her. Overall, Participant 135 states that:

"Transitional seasons do tend to be bad [for PoTS] but I've gotten very good at doing very little in the Spring."

Here, the change in activity levels is worth noting as the participant adapts to a season she find worse for PoTS management by adopting coping strategies such as reduced activity levels, something that is less possible for her in autumn due to the greater number of holidays.

Summer and winter, as seasons of extremes, can still cause issues for some participants, especially those who live in areas that experience extremes of climates during those seasons, such as Participant 84:

"My least favorite season is the Summer. This is because the heat causes me to feel worse with my PoTS. In addition, where I live is very humid, with little to no breeze and these factors make the heat feel worse."

As a result, it should be expected that PoTS management strategies will change with the seasons, both in methods and difficulty, albeit allowing for differing climates. Medication, activity levels, and each individual's likelihood of flares can change with the changing weather, although the amount each changes varies from person to person. However, not all of the impacts of PoTS suggested in Prompt 1 were due to the season. Participant 84 also described winter, which she ranked last, as thus:

"I used to love ice-skating, but now I can't stand up that long without fainting. I used to love snow tubing and skiing, but now it takes hours to days to warm up after."

Here, the impact of PoTS is not linked to the season, but to the activity of ice skating. While some of the activities mentioned here have temperature related issues, the participant suggests that the primary reason she no longer skates is due to her PoTS and issues standing for a long period of time, rather than anything related to the climate around the rink or any other potentially seasonal factors.

Climate, weather, and seasonal changes also had an impact upon participants' overall health that may not be specifically PoTS related. Some of the issues encountered here may affect one season, while others can affect multiple ("mosquito season" or a humid location) and individual experiences, as stated by Participant 34:

> *"I actually find this ranking almost impossible because my issue is less with seasons and more with barometric pressure fluctuations. This means that no matter the season, if the barometric pressure is in flux I am probably not feeling my best."*

Other Conditions

Another key theme generated from Prompt 1 was other specific health reasons, which covered comments about the effects of different and changing seasons upon health conditions other than PoTS and how this impacts participants' season preferences (6 references). The conditions mentioned here include sunlight allergy, hay fever and pollen allergies, Seasonal Affective Disorder, unspecified joint issues, and Reynaud's Syndrome. Most notably, the season of winter was considered to be "a but [sic] of a double edged sword" by Participant 63, as it was better for two participants' PoTS symptoms than other seasons, but led to the worsening of "some of [their] other conditions" (Participant 77) instead. The main thing to note here would be understanding that, as PoTS tracking needs change with the seasons, so too do additional tracking needs related to other conditions. Additional medications may also be needed on a seasonal basis, such as by Participant 88:

> *"the pollen ruins [spring] after just a few moments outside even if I'm pumped with antihistamines. If I could cure my allergies it would likely take the number two place."*

6.5.2 Hardware and Device Design

Some participants described issues relating to device hardware, namely the physical design and components of wearables. This issue can be split into two key subthemes, namely battery life and charging, and fit and comfort.

Battery Life and Charging

Wearables typically charge in a manner that is not compatible with being worn, and thus data collection with one device cannot be fully continuous, leading to participants needing to "choose what part of my day I don't want to be tracked" (Participant 88) when deciding when to charge their devices. This is inconvenient to begin with, and potentially even more so considering "the need for a specific charger that is compatible with the device" (Participant 88) rather than a universally compatible one. (This also can increase costs if the charger should break.) Devices often have limited battery life, especially when some features are used more intensively, which Participant 113 describes:

> *"Battery lift [sic] limited if heart rate zones are used continuously due to bright colour etc ie I can't get a full day of use out of an apple watch when using the heart rate graph app on it."*

This can lead to a smaller amount of data being collected overall due to an increased frequency of charging being needed.

Issues related to battery life and charging may well be fixed in part by technological advancements, but currently, redesigning features such as the Apple Watch's heart rate zone feature to be less battery intensive could help. According to Participant 113, this could be done by not showing all aspects of the feature (namely "HR averaging and max min") constantly and by viewing the zones in black and white rather than in colour. The majority of the other issues are design related and could be fixed by changing the design of the typical wearable and its charger. These potential fixes, according to Participant 88, include changing the type of battery, potentially to "a solar or kinetic battery that continues to charge while you are wearing it or a switchable battery where you have two and one is charging while you wear the other and you flip them as needed." A simple

yet potentially effective solution to the charger issues is compatibility with a universal charger, such as the European Union's move to standardise chargers for many portable electronic devices (not including wearables) [European Union 2022].

Fit and Comfort

The second subtheme of hardware related issues with wearables experienced by study participants are those related to device fit and comfort. This is an issue that is not limited to wrist-worn wearables, with one participant reporting issues with the fit of their chest strap wearable. Some of the issues reported are specific to particular brands or devices, while others are more general. Participant 79 mentioned that their "Fitbit can sometimes leave a small mark on my wrist after wearing it for a long period of time. It does not cause pain but sometimes my wrist needs a break from wearing the Fitbit." This is something that has been experienced by the researcher, who is also a Fitbit wearer.

Participant 133 describes general issues with wrist-worn wearables that are also specifically applicable to her Fitbit, namely device bulkiness and rubbery, uncomfortable straps that make her hyper-aware of the device on her wrist. As well as this, she works in a corporate environment where the rubbery, athletic design of her Fitbit's wrist strap may be sartorially inappropriate. She would prefer a softer, more comfortable fabric wristband, but those are not available for her current model of Fitbit and in her opinion discomfort is not a strong enough reason to upgrade devices. Other models of Fitbits and brands of wearables such as the Apple Watch have alternative straps in materials that may be more comfortable, but this would be at an additional cost. As well as this, the bulk of a chosen device may be a necessary sacrifice for a higher quality heart rate tracking feature.

However, wrist-worn wearables are not the only form factor of wearable with comfort issues. Participant 135 chooses to wear a device with a chest strap for reasons of increased accuracy (particularly related to heart rate readings) when exercising but this is not sustainable for long periods of time due to comfort issues. This can result in "shortened workouts" as well as "[s]kin redness, itchiness/irritation" and ultimately "[n]ot using a heart rate monitor during times when it would be beneficial" leading to a smaller amount of potentially useful data for condition monitoring being tracked.

Taking more breaks from wearing a Fitbit to avoid a small mark and potential dis-

comfort was suggested as a solution by Participant 79, but this reduces the utility of the device and makes it a less cost-effective method of condition monitoring as less data is being collected overall for the price of purchase. The other solutions suggested by all participants included changes of design to avoid the specific issues raised, including creating "[w]rist bands that are designed for 24/7 use" in more comfortable materials than the current rubber by Participant 133. One additional suggestion was for wristband designs to include medical information or even double as medical alert bracelets, rather than wearing an additional bracelet (Participant 133, who currently does not wear a medical alert bracelet but has considered doing so). Participant 135 had some suggestions for dealing with or potentially replacing the chest strap:

> *"If the chest strap no longer just went around the body horizontally but over the shoulders like a bra strap? Or was addable to a sports bra? The wrist piece is more comfortable. The indicator and the sensor don't have to be in the same place to me. I'd even wear a tight glove for it to read off of my finger if that were key for accuracy and comfort."*

It is not fully certain whether they mean that the strap should be added to a sports bra, or whether the sensor portion should be detachable and able to clip on to the bra instead (more likely, in the researcher's opinion).

Form Factor

One participant's top priority was the device's form factor, specifically a wearable worn on the wrist rather than one using a chest strap. In their opinion, "chest straps are more accurate and lack the inherent lag in recording HR seen in wrist watches however most people find them uncomfortable to wear all day long" (Participant 113, second version of Prompt 2). When considering comfort and practicality, they were prepared to sacrifice the increased heart rate recording accuracy gained from the use of a chest strap for a wrist based wearable that could be worn unobtrusively all day long.

6.5.3 Data Types

Heart Rate

The most prioritised wearable feature was heart rate monitoring (ranked first six times in the responses to Prompt 2), which has been shown throughout the literature and through all three studies to be key when monitoring PoTS on a day-to-day basis. Having access to this heart rate monitoring data gives participants the chance to both monitor their symptoms in the moment and pace themselves for later, as well as being able to spot trends in their data and present said data to their doctors and other medical professionals. Participant 63 stated that

> *"the heart rate monitoring is the most important because that is what I use my watch for the most. Beingable [sic] to get a heads up on if I am going tachycardic is really important to me."*

This statement was concurred with by Participant 133, who uses their Fitbit to check the same thing when undertaking household tasks, as they "won't feel the symptoms until it's too late" otherwise. Overall, they summarised this use of heart rate monitoring best by stating that it allows them "to pace myself and SLOW DOWN BEFORE I GO DOWN!" This knowledge is important for patients to have as it prevents longer term consequences - choosing to take a short break when their heart rate is visibly rising can protect against potential collapse later. Participant 133 was also the only one of the six participants who ranked heart rate monitoring first to specify that the monitoring needs to be continuous, although this was agreed with by Participant 113, who ranked this feature third in their response to Prompt 2 and wanted continuous graphing. The continuous nature of the monitoring is vital as "[s]pot HR data doesn't provide the "instantaneous" feedback needed" to allow for necessary changes in activity and behaviour. However, this knowledge is not just useful for PoTS, with one participant using the heart rate tracking feature to differentiate between their PoTS and supraventricular tachycardia (SVT). More specifically, the heart rate that their wearable displays enables them to tell if the symptoms they are experiencing are due to PoTS or SVT, as their SVT "runs" in a very specific heart rate range.

Blood Pressure

Blood pressure was considered to be a reasonably high priority feature to track, albeit one considered less realistic as a current wearable feature (in the previous studies participants often owned separate at home blood pressure monitors, but this was not asked about here). Three participants ranked it second in Prompt 2, below only heart rate monitoring (twice) and data security (once). Blood pressure medication was mentioned as a treatment to help with one participant's PoTS, when detailing their use of built in alarms (and indeed this sort of medication is commonly used). After heart rate monitoring, blood pressure monitoring has been consistently referred to as a top priority to track when monitoring PoTS, with Participant 88 referring to both as "greatly important" as "monitoring them could tell me when I need more salt, medication, rest, etc.". Knowing this allows participants to adjust their behaviour and application of treatments as needed in order to cope on a day-to-day basis. However, blood pressure monitoring is less of a staple feature of wearable devices than heart rate monitoring, and its recurrence on these lists may be due at least in part to the prompt specifying that ideal features can be included. Participant 34, who ranked blood pressure monitoring 8th of 24 features, explained its importance to them:

> *"Although POTS criteria does not involve blood pressure many of us do suffer from blood pressure variations. In my case, I particular suffer from narrow pulse pressure and sometimes low blood pressure."*

Sleep Monitoring

In general, participants had mixed opinions on sleep monitoring, which was the only feature to be ranked both top and bottom in the written responses to Prompt 2. Even Participant 79, who called sleep monitoring one of their "favourite features", acknowledged potential concerns with the feature, referring to it as "not totally accurate" sometimes. However, it was considered to be especially helpful by one participant (Participant 133, ranked 2nd of 3, only ranked "helpful" features), as they can use the sleep tracking feature to "compare it against how my POTS is doing. It allows me to track whether my sleep quality is affecting my pots [sic] symptoms."

Overall it seems that participants considered the sleep tracking feature to be interesting but not essential, with Participant 31 ranking it 7th of 7 and describing it as "interesting to have occasionally but not something I'd want to look at every day". It can provide useful contextual information, albeit with some limitations, as discussed by Participant 88 (ranked 5th of 6):

> *"Sleep monitoring doesn't really help me do anything about my chronic illnesses in a way I can see a direct connection, but it does show if I had a lack of REM or deep sleep which can help me understand why I am extra tired or need more sleep."*

6.5.4 Alarms

This is a broad category which covers multiple types of alerts, namely those programmed by participants that do not rely on any data (such as medicine timers) and those triggered by changes in the data currently being recorded (such as heart rate data). Participant 79 (Prompt 2) utilises their Fitbit's self-programmable alarms for subtle and convenient medication alerts in order to increase their medication adherence:

> *"I use a Fitbit and I really enjoy the silent alarm feature because I need to take medication for my blood pressure to help treat my PoTS every four hours. The silent alarm vibrates instead of making a noise so it is very discreet. It is also very easy to set an alarm from the Fitbit watch."*

To them, these alarms are reliable and consistent, as well as quiet enough to not be distracting to others. Participant 133 (Prompt 3) is not as fortunate, as their Fitbit does not offer the alarm types they need for condition monitoring purposes:

> ***"I cannot set alarms to notify me when my HR gets too low.*** *My device does not have an alarm for when my HR gets too high, but I know that feature is available on similar models. This is a great feature that I would use if I had it, but I'm OK without it, because if my HR is too high I would already be symptomatic and don't need an alarm to tell me that. What I do*

need, however, which my device does not have, is an alarm that goes off when my HR is too low."

This is less of an issue when it comes to high heart rates, but they are currently on a medication that can cause their heart rate to drop, so being able to be woken up by a low heart rate alarm would be very beneficial to them.

6.5.5 Customisation

Several participants' issues with customisation formed part of a key, wider issue, namely that these wearables being used for day-to-day monitoring of PoTS (and other chronic conditions) were not designed for this purpose and thus have built-in assumptions based on a "normal" person, such as typical heart rate issues and what heart rate change is detected as an indicator of exercise. Participant 31 summarised this as "[d]ata not tailored to PoTS, e.g. registering as exercise based on HR rises of a normal person". This is an issue for multiple, almost opposing reasons. Devices may not respond with alerts quickly enough when needed, as described by Participant 63, who finds that this issue impedes the device's usefulness for condition monitoring:

"[I] can't change how fast [I] get an alert about changes in my heart rate so if [I] am relying on those alerts they come to [sic] late to be helpful. Such as [I] only get an alert if my heart rate goes above and stays above a certain BPM for 5 min."

They also mentioned separately, both in their response and in the Zoom call, that there are recurring built-in alerts that are unable to be removed for standardised large exercise goals that are often unrealistic for people with PoTS. However, devices may also over-compensate with what is perceived as wrong or unhelpful, as described by Participant 88:

"Lack of customizability is an issue because my data is not the same as a person that doesn't have PoTS. Because of this, it is reading my heart rate like there is always something wrong or as if I am exercising far more often than I do."

Overall this is best summarised by Participant 88, when they state that "my data is not the same as a person that doesn't have PoTS" and this is something that should be remembered throughout this research.

This issue is one participants considered to be a relatively easy fix and one where the solutions are known and simply need implementing, with Participant 63 saying that "the hardwear [sic] is there already. The UI would just have to be tweaked to allow for more customization on when and how the device alerts to certain things." Other participants were less specific from a technical perspective, instead stating what else they found important in terms of features that would fix the issue, namely manual customisation of baselines, ability to set own alerts, manually stating when exercise is taking place, and even potentially adding in "various conditions and chronic illnesses" (Participant 88). This last feature could take more work as it would potentially involve creating sets of baseline alert profiles to include in shipped devices rather than manual tweaks of this one.

6.5.6 Cost and Affordability

Issues and concerns related to wearable cost and affordability persisted throughout the workshop study. These were primarily discussed by two participants, Participant 133 and Participant 135. Participant 133 (Prompt 3) uses many apps to manage her condition (no one app fits all of her needs) and thus is unwilling to pay for subscriptions to any of them, which reduces her access to specific features deemed to be "premium" and thus locked behind a paywall. Her ideal wearable would continue to keep the "core features" of data tracking apps "free of cost for all users" (Participant 133, Prompt 5). Doing so would make apps more accessible to all, especially people on low incomes.

Both Participants 133 and 135 discuss ways to make wearables more affordable to disabled people. Participant 135 (Prompt 2, ranked 4th of 4) states that:

> *"I would love to see insurance pay for [a wearable]. Having a disability is expensive- transportation, cost of help, loss of work hours, special diet, prescriptions, etc. Any bit helps."*

There are many disability-related expenses, and the cost of buying a wearable is counted

here alongside others. Managing to reduce these costs in any way possible would help people with PoTS to more easily make ends meet. It is notable, however, that the mention of "insurance" marks this out as a more location-specific solution, namely one from a country without universal healthcare (specifically the USA). Similar concepts could be applied in the UK, though, with an equivalent proposal being to make devices available on the NHS. Participant 133 (Prompt 5), also an American, expressed a similar desire for a discount programme for wearables for people who "require wearables to manage a medical condition," alongside making the devices "FSA-approved" with a prescription or a letter of medical necessity.

6.5.7 Accuracy

Participants had concerns about the accuracy of the data being collected by their wearables, most often when it pertained to heart rate monitoring or sleep tracking. This can lead to a lack of useful data and thus knowledge. Participant 135 ranked accuracy, including data granularity, as their top priority for wearables:

> *"Top priority for me is accuracy. I'd like to see some kind of verifiable accuracy. I also mean how frequently it calculates a reading. Some calculate every 10 seconds or more. I have gotten very used to recognizing arrhythmia or adrenaline surges and the correlating heart rate response."*

Despite the (implied) inaccuracy of devices they've used, Participant 135 successfully worked out what patterns of data depict arrhythmia and adrenaline surges through tracked heart rate data. This is useful, but can require both data literacy and significant self-awareness of bodily responses if a device is inaccurate.

One cause discussed by Participant 113 (Prompt 3) suggests that incorrect device calibration or inappropriate design assumptions, both by manufacturers, can lead to issues such as a high resting heart rate being interpreted as something that must result from running or other exercise causing a high level of exertion, rather than simply "lying in bed" at rest. This inaccuracy may be consistent and thus still potentially useful for the participant's personal day-to-day use.

Accuracy also becomes a key issue when attempting to show clinicians collected data, as clinically inaccurate data may not only be of less use, but also may be taken less seriously when trying to report issues experienced. It is understandable that clinicians may be sceptical of patient claims based on clinically inaccurate data and may dismiss concerns or request further verification through testing with clinically verified methods, techniques, and devices. Issues experienced may be assumed to be due to device inaccuracy or it malfunctioning and not due to a patient's health concerns.

When asked how they would choose to solve accuracy issues, participants wished for greater research, testing, and technological advancements. One participant in particular, Participant 88, wished to be able to update or "bring your wearable in for recalibration" which could prove more time consuming and expensive than remotely delivered software updates but could work to increase device longevity. However, any such service that would require devices to be sent away rather than fixed or re-calibrated in person or by a user would result in a period of time where a participant would be unable to use their device for condition monitoring (unless a temporary replacement is provided). Medical grade certification of devices (and their features, see [Turakhia et al. 2018]) and thus the theoretically improved accuracy of their features could potentially lead to tracked data and any resulting concerns being taken more seriously by clinicians. This is not certain (as some clinicians may be sceptical regardless [West et al. 2016]) and could increase device costs, but the increased accuracy would save users recalculation time and reduce concerns about device inaccuracy.

6.5.8 Anxiety and Over-Reliance

Anxiety is another key factor affecting wearable use, specifically the "obsessive" checking of devices and data (Participant 31, Prompt 3, point 3). It can both prevent the commencement of and stop the use of wearables for condition monitoring, due to perceived stigma and suggestions of hypochondria. Participants showed concern about these issues and the idea of the data tracking becoming overwhelming and a distracting priority. Participant 31 ultimately stopped using her wearable as a result of both anxiety and an unfocused choice of which data types to track. More specifically, she felt an over-reliance

on her wearable led to her becoming "very anxious when things weren't looking "right", eventually lead[ing] to [her] stopping using it" (Prompt 3 point 3). Here, the concept of 'looking "right"' is linked to an underlying two-fold concern: worry about her own health, and worry about how she will be perceived by those around her, especially clinicians.

6.5.9 Convenience

Participants praised the convenience and unobtrusiveness of wearables for condition monitoring, especially Participant 88 (Prompt 4):

> *"The convenience of a wearable is great for condition monitoring. No one wants to get out a device or multiple devices to assess what's going on with your body, especially for conditions that cause low energy levels. Having it in a small wearable form is very helpful and allows much more tracking of symptoms and levels to be done."*

As fatigue is a symptom of PoTS, having a wearable device to hand can be the most useful and convenient option for condition monitoring, especially to provide instantaneous snapshots of the wearer's current condition. A small device such as a wearable is less cumbersome than larger medical devices, as well as more easily allowing for tracking while on-the-go. Participant 63 (Prompt 4) also praised wearables' abilities to blend in, describing them as "more subtle than medical devices." This participant also appreciated the interaction between wearables and smartwatches, allowing them to view information across multiple devices as needed.

6.5.10 Ideal User

When discussing the integration of wearable technology with physical therapy, Participant 133 (Prompt 4 point 5) contrasted healthy people with people with PoTS, specifically regarding what counts as an improvement in fitness (or just a good day). For healthy, able-bodied people, watching metrics continue to improve is a sign of improving fitness, while for people with PoTS being able to use heavier weights one week compared to another shows a good day or a good consequence of a prior action (e.g. starting a new

medication, getting enough sleep, or avoiding gluten). This relates to the next key issue that is prevalent throughout this research, the notion of an 'ideal wearable', by discussing potential improvements in wearable design to better suit devices for the monitoring of PoTS. Often, wearable designers assume able-bodied metrics of progress for the users of their devices. Participant 113 discussed this:

> *"Many of the issues are software [programming] issues that can be readily fixed. The major obstacle is that the wearable manufacturers often do NOT want the devices to be labelled/seen as medical devices. If a device is considered a medical device then it must be approved as such and there are stringent/expensive certification requirements."*

The ultimate solution in this case is a shift in attitude from designers of wearables, which would then hopefully lead to the desired software changes. In order for this to happen, the medical certification of wearable devices and their features would need to become more financially viable to manufacturers of all sizes.

6.5.11 Clinicians

Participants in both Studies 2 and 3 discussed the specific interactions that they had with clinicians about wearables and any consequences of them. In the workshop study, one participant gives an example of how their use of wearable data led to a change in prescription, albeit reluctantly on the part of the specialist (Participant 113, Prompt 4 point 5):

> *"I took HR data to my appointment with a cardiologist that showed that when I stopped exercising my resting heart rate decreased i.e. I became healthier. I also took a continuous graph of HR data recorded whilst I did the stand test (NASA lean test) along with photos of my feet at rest (wh[i]te) and after standing for 2 minutes (purple blood filled). My cardiologist was sceptical of the data and suspected a faulty HRM but I did manage to convince him to prescribe a beta blocker."*

Here, the participant attempted to record what tests they were conducting to cause the change in the heart rate data (as well as presenting the data). Although this did not fully reduce clinician concern, it did appear to lead to a change in prescription without any follow up testing.

One other point made across multiple studies is the notion of wearable data that, through backing up physical symptoms, serves to "prove" that the wearer indeed is disabled and/or has the specific condition they claim. One workshop participant continues to use her wearable as a way to contrast her disabled self with her able-bodied peers (Participant 113, Prompt 4, point 3):

> *"The HRM [(heart rate monitor)] is also a really good way for friends and family to "see" my level of disability which is frustratingly invisible. Many of my health professionals, family and friends, disbelieving my HR data, have tried wearing the HRM to check that it is working. They have been surprised when they have been unable to get the high HR's [sic] that I have which has convinced them that it is my body that is faulty and not the wearable."*

Here the wearable technology serves to validate both her disability and her lived experiences of her physical (specifically cardiovascular) symptoms when faced with doubting observers. Ultimately, it serves to make an invisible disability visible through recorded heart rate data when in comparison to readings from able-bodied peers.

6.5.12 Data

Visualisation

Integrated data visualisation was ranked highly by one participant, while others prioritised specific graphs instead, mostly those related to heart rate monitoring. Ideally these graphs would be available both in real time or on demand as needed. Being able to compare factors was important, however, albeit not necessarily through combined or side by side visualisation. The participant who ranked this highest (Participant 31, ranked 2nd) was in favour of "[v]isualisation of all data in one page, so you can compare different factors (e.g. periods, exercise) with symptoms and spot trends", which could potentially

be overwhelming but would enable easy access to select data types and work on improving condition monitoring strategies as a result. Another participant who suggested this (Participant 113, version 2) was aware that backups on other devices would be needed for large amounts of data and for the ability to annotate data, specifically to "overlay the record of activities, medications, sleep, activity etc over the continuous heart rate graph."

Annotation

Annotation of heart rate and other data is never ranked first by itself in responses to Prompt 2, typically being ranked lower down longer lists (the Cardiogram app is mentioned as having these features by one participant). It is mentioned once alongside heart rate monitoring when that feature is ranked first, however, in a context linked to the reporting of data to a participant's medical team. In this case it is mentioned that it "[w]ould be useful to have [a] feature to add notes, e.g. what activity caused specific spike/drop in HR" (Participant 31), which would seek to enhance the usefulness of the collected heart rate data and could even save the medical professionals time by highlighting potential areas of interest.

When asked about desired features for future wearables, Participant 113 (Prompt 4) discussed the concept of annotation in detail:

> *"Ability to take notes on top of the various things the wearable is measuring. Whether that's a calendar inside of the app or the ability to annotate my HR chart, I would like to be able to make notes that will help me explain / remember the circumstances from that day and what might be behind some of the HR readings."*

To this participant, improved annotation allows for improved contextualisation, which in turn makes it easier to deduce the reasons behind specific readings or any issues encountered. The ability to annotate directly onto the data (rather than in a different app) reduces the potential for ambiguity and allows clinicians to see what the wearable user was thinking at or around the time the data was logged.

Security and Privacy

Data security and consumer privacy proved to be a significant concern for some participants, with Participant 135 (ranking this feature 3rd of 4) stating that:

> *"Privacy is also key. I don't know if I could value the factors if I didn't trust the app/device. I'd pay the extra fee to trust the product more."*

A lack of trust in device data security here is linked to a lack of trust in the device and its readings as a whole. Concerns about a lack of data security are also linked to participant concerns about the use of wearables and their accompanying apps for menstrual tracking. These workshops took place shortly after the repeal of the Supreme Court judgement Roe v Wade in the USA and the resulting fear about menstrual tracking data being used to criminalise pregnant people seeking abortions, especially when living in U.S. states where it is now longer legal to do so [Cao et al. 2024]. Ultimately, this led to one American participant, Participant 63, saying that the menstrual tracking feature "is something that I actively avoid using due to the current events. I honestly would rather it be gone." This is a concern that does not apply to all countries, however, due to differing abortion laws, and thus not all participants who listed menstrual tracking as a feature regarded it with such concern.

Participant 88, who has endometriosis and irregular periods, mentioned that their "PoTS symptoms flare up from ovulation through [their] period" so menstrual tracking is of use to help notice, understand, and manage these flares. As well as this, Participant 113 (ranked 20th) suggested that:

> *"Hormonal changes directly affect POTS and an overlay of this data is needed when attempting to interpret trends and the effect of medications/activity/symptoms etc."*

Here, the inclusion of menstrual tracking data would help to contextualise other data types and understand patterns and trends, as a potential confounding factor.

6.5.13 Future Wearables

Participants desired a wide range of interesting features for hypothetical future wearables. These included the addition of new sensors in order to monitor additional data types; refinements to current features including improved customisation of what data is displayed and data annotation; the ability to manually log other types of data such as salt input; democratised access to features such as respiratory rate tracking that can be locked behind additional, "premium" paywalls; hardware design changes both for comfort and potentially to assist with temperature regulation.

Blood pressure was mentioned less as a potential feature in Study 3, but it was still suggested by workshop participants, with Participant 88 (Prompt 4) stating that "if it doesn't exist already, [it] would be a great addition" when considering features for inclusion in potential future wearables.

Alternatives to a built-in medication tracking feature include keeping notes, setting alarms, or using other medication trackers across a range of apps (or even pen and paper), but the user has to remember to access each separate one in order to reset them after taking the medication as opposed to simply checking just the one app. Participant 133 (Prompt 4 point 2) suggested medication management as a desired future wearable feature:

> *"Integrating medication management, particularly being able to set alarms to remind me to take my meds AND the ability to "check off" when I've taken a certain medicine within the app. (I need the reminder / notification to stay visible until I indicate that I've taken the medicine.)"*

In this case, marking off medicines that have been taken is a sensible suggestion for multiple reasons: it can provide short-term reassurance that prescriptions and drug schedules are being adhered to for an uncertain user, and it also creates a potentially longer-term record for the user and their clinicians to look back at when tracking symptom changes related to differences in condition management.

6.6 Guidelines

How can people with PoTS be best served when designing wearables (for condition monitoring)? To answer that question, first consider this one: what assumptions do people with PoTS make when using wearables for condition monitoring? That the wearables are part of a **system**, rather than a panacea by themselves (and not the be-all-and-end-all of condition monitoring). This awareness of how wearables fit into a broader condition monitoring system is key when attempting to design for this under-served population. The raw data collected may be relatively little use by itself for condition monitoring - what makes it useful is the links and connections made between data types and devices. As well as this, the ability to annotate and thus contextualise the data is key to understanding and interpreting it.

The last of the five prompts that workshop participants had to respond to asked them to group their solutions from the previous prompt into categories then use those categories to develop guidelines for the creation of future wearables designed to monitor PoTS. From the prompt responses submitted by participants the researcher then compiled a list of guidelines. This list was manually collated by close examination and comparison of the responses to Prompt 5, undertaken in order to draw out the threads of commonality between the participant suggested categories. Knowledge gained from conducting previous studies was also taken into account. Participants' submitted category headings were checked side-by-side, to look at both name frequency and the degree of overlap between the submitted ideas. Individual guidelines within each category were then considered to further contextualise the headings and to add more depth and specificity to the generated guidelines. Ultimately, this comparison process resulted in the generation of nine guidelines, as shown below:

- Dismantle underlying assumptions related to user health and fitness goals. Not every user is trying to increase how much they exercise.
- Allow for greater customisation of alarms, alerts, data types being tracked, and typical heart rate ranges.
- Consider device comfort and fit, as well as form factor. Devices should be comfort-

able and ideally unobtrusive for longer term wear.

- Include desired features and data types to best suit condition monitoring needs.
- Enable data annotation to contextualise the data being tracked and potentially link to other elements of a condition monitoring system.
- Integrate wearables with a broader condition management system (including third party apps), recognising that a wearable (or one linked to a phone) is not a full monitoring system by itself.
- Increase data accuracy, leading to greater legitimacy (to both clinicians and wearable users) and making devices more desirable.
- Create affordable devices that enable people to participate in self-tracking for condition monitoring in a meaningful fashion.
- Recognise how monitoring needs vary between individuals and support user choice.

These guidelines are suggestions and not all of them may be followed, but it is hoped that they show what people with PoTS value in the design of wearables. There is also a certain degree of crossover between the categories represented by these guidelines. For instance, a lot of the desired device customisation includes the ability to choose which data types are being recorded.

6.6.1 Dismantle Underlying Assumptions

Currently, the primary underlying assumption made about wearable users is that they wish to increase their activity levels and the amount they exercise, hopefully meeting set goals. However, the goals set are often too high for people with PoTS, and they care more about tracking for health rather than for fitness. This group's use of tracking for health is often from an activity pacing perspective, rather than a sport or fitness-based activity maximisation perspective (see [Homewood 2023] for more on activity pacing for chronic condition management). Participant 31 was particularly keen on ensuring the communication of this change of assumption:

"Remove the assumption that all wearables users are tracking for sport/fitness and reflect this in messaging both in the wearable/app and in general advertising/messaging for the company"

As well as this, Participant 113 found the current design assumptions unrealistic:

"The lowest "exercise" setting and goals are typically way above the ability of many POTsies using the HRM's."

6.6.2 Customisation

The most suggested category by workshop participants was customisation, namely the ability to customise a wide range of device features, including alarms, alerts, the data types being tracked, and what heart rate values constitute a typical range for the user. Again, these requests all consider the wearable user as an individual with their own norms and goals, rather than the existing 'one size fits all' approach that does not allow the user to state what counts as a typically low or high heart rate. This is especially key with PoTS, where what is considered a typical heart rate can very much vary from the norm, potentially making any standardised high heart rate notifications useless. The customisation of tracked data types can also be a case of exclusion rather than inclusion, as shown by Participant 31 (Prompt 5):

"Allowing for the complete removal of specific data tracking (either the whole category – sleep tracking – or a part of a category – calories on food tracking)"

The removal of unnecessary data tracking can be of use to people with PoTS as it increases the efficiency and usability of their condition monitoring system by discounting extraneous information that could confuse people or distract them from more essential data.

6.6.3 Comfort (and Fit)

A key factor that can affect the long-term adoption of wearables is their comfort and fit, with unobtrusive devices being preferred by participants. Devices used for long-term wear

need to be comfortable and unobtrusive to the wearer in order to reduce stress levels that could impact the data being tracked. As well as this, many wearables, especially wrist-worn ones, are designed to blend in and be perceived as (akin to) jewellery rather than medical devices, both to reduce stigma [Rukasha et al. 2020] and to fit the environment the wearer is in. This may not always be feasible with a person's chosen device depending on price and availability (see Section 6.5.2 for an example) but could factor in when choosing a replacement.

The physical comfort of a wearable device is important to users as they are likely to be wearing it near-constantly for an extended period of time. Participant 113 discussed strap-related issues in their response to Prompt 5:

> *"The plastic straps on some wearables can result in rashes under the strap due to not breathing too well. The adjustability and breathability of the chain metal strap on the apple watch is much more comfortable and a good solution for people wearing HRM's continuously."*

Negative physical consequences of wearable use can negate the benefits of wearing device(s) for continuous data tracking as the device itself can become an irritant, both mentally and physically. It should be noted that the Apple Watch straps described to be more comfortable are those that cost more, adding a further financial barrier to wearable use.

6.6.4 Features and Data Types

Participants wished for a greater amount of control over which features and data types were available to them, in order to best suit their condition monitoring needs. Greater customisation of activity and exercise tracking was desired, as shown by Participant 133:

> *"Ability to create activity categories of your choice so you can track progress on an individualized fitness-related goal. (Current options include traditional sports like biking and swimming, but I want to be track[ing] things like showering and cleaning – those are my 'exercise')"*

Here, the respondent's desire is for wearables to allow greater customisation of self-logged

activities, as opposed to auto-detected ones, with a greater range of categories and labelling available. Rather than an activity being a form of sport (or an action e.g. hill walking) that would traditionally be considered to be exercise, they instead seek for it to be any task with tracked movement and other data (e.g. heart rate) collected between two chosen points in time. It can be helpful to see how performing household tasks such as showering or cleaning have an impact upon users' heart rates and fatigue levels, for instance, as it can help people with PoTS to monitor their exertion levels and develop more manageable schedules to reduce exhaustion where possible.

6.6.5 Data Annotation

Data annotation is of use to wearable users as it allows them to log further information that a device does not track in order to add context to their data. This information may be logged at the time of recording or later on, when looking back, and can include details such as how a person felt (including illness), any medication changes, or any lifestyle changes. These details, when included, can serve to help understand the impact of the wearer's day-to-day experiences and condition monitoring systems upon themselves and thus the data being tracked. Integration of this annotation into a wearable device or its accompanying app would be desired, with Participant 156 (Prompt 5) explaining their prior experiences of a similar system:

> *"When you are provided with a cardiac monitoring device you are asked to record information in a daily diary which is a way of tracking which event/activity may have caused a variation in the data. A way of creating the same type of daily activity diary which users could record relevant information on in conjunction with the recording of physiological changes would be useful."*

Participant 156 shows that there is already a set precedent for this type of annotation and contextualisation within a medical context, specifically when aiming to present data to clinicians. For wearable users who would like to discuss their data with clinicians, built in annotations would streamline this process and enable easier interpretation of data.

6.6.6 Integration

Integration overlaps with the notion of annotation, as both of these guidelines agree that wearable data by itself is not necessarily sufficient for condition management. However, this guideline has a broader focus, namely that a wearable device (and its linked phone) by itself does not a condition monitoring system make. Condition monitoring and interventions for PoTS may also include medication and/or compression stockings, as well as other devices such as blood pressure monitors and pulse oximeters. Keeping track of data from these devices as well as wearables requires organisation, and ideally there would be some form of cross-compatibility or a way to log all tracked data in the same place.

Participant 133 (Prompt 5) explained their ideal system:

> *"Ability to integrate ALL data into one CALENDAR that tracks overall wellness. Each data category the app collects (HR, sleep, exercise, period tracking, mood) could appear on each calendar day. All of the various data points would be overlaid onto each day. This would help us better recognize when things correlate."*

Their point about correlation is especially key here, as spotting links between different types of data becomes easier when the data is presented side by side. A higher level of data literacy is required to navigate disparate devices and their differing methods of displaying data.

6.6.7 Accuracy

Inaccurate data is an issue with wearables that has been encountered across all three studies in this thesis. A lack of accuracy can reduce device utility and legitimacy, especially when discussing tracked data with clinicians, and inaccurate data may lead to unnecessary stress for the wearable user. This inaccuracy may be due to poor quality sensors or issues with data tracking or device design, including inaccurate design assumptions. Participant 113 (Prompt 5) discusses this:

> *"The software algorithms need to be refined to recognise that there is a range of chronically ill people using the devices and that a high HR does not always*

mean a person is running/standing or walking; they may be resting with a high HR due to previous overexertion/overtraining. Note that the symptoms of overtraining syndrome and post exertional exacerbation of symptoms due to overexertion in people with POTS/ME/CFS are similar. For a wearable manufacturer a focus on recognising over training may be more palatable as it may not trigger questions about whether or not the device is a medical device."

Here, the accuracy issues raised relate to assumptions made during the design of a wearable. Specifically, the notion that a high heart rate must mean a person is exercising is actively unhelpful to people with PoTS, whose heart rate spikes when standing up. Participant 113 focuses on the issue of overexertion, which they consider symptomatically comparable to overtraining. Many available wearables are designed to increase exercise and exertion levels, so the notion of allowing rest to counteract overexertion or overtraining goes against this use case. Overall, increasing accuracy would make wearables more desirable and reputable, with the preferred goal being rigorous and accurate data tracking that can be annotated as needed and have custom parameters applied to it.

6.6.8 Affordability

The cost of wearable devices presents a significant barrier to their use by people with PoTS, especially in countries without universal healthcare. When [K. Bourne et al. 2021] surveyed 5,556 people with PoTS, primarily from the USA, 70.5% of respondents had lost income due to their condition, and 95% of respondents reported spending money on PoTS-related out of pocket medical expenses since their diagnosis. This reduced income could make high-quality wearables unaffordable, unless such devices could be considered a medical expense. Participant 133 (Prompt 5) suggested two ways to make wearables more affordable for people with PoTS:

"Discount programs for people who require wearables to manage a medical condition

Continuing to keep core features of the app free of cost for all users"

Wearable manufacturers such as Fitbit offer premium subscription models to their customers in order to track an increased amount of data types and offer more features to

customers willing to pay more. These companies may also suddenly remove device features in software updates, such as Fitbit removing the Floors Climbed feature. The loss of access to features and types of tracking (through removal or locking behind a paywall) can disrupt condition monitoring methods and reduce the utility of wearables for people who may not be able to afford a subscription as well as their device (or choose not to pay for one). Wearable manufacturers committing to keeping important features free would be valuable to people using these devices for condition monitoring.

Introducing discounts for people using wearables for condition monitoring would recognise the financial burden of chronic conditions and seek to lessen it slightly. However, devices need to be reputable and accurate in order to be subsidised for medical reasons. Participant 135 (Prompt 5) suggests one way that this could be done:

> *"Medical Grade: Being medical grade would cover accuracy and certification. This would also increase the odds of the product being covered by insurance and/or medical savings accounts."*

Working to have a wearable certified as medical grade would show commitment to the chronically ill portion of the device's user base. Unfortunately, doing so would be expensive and time-consuming, as well as requiring more rigorous testing of features. It would be a noble goal to aim for.

6.6.9 Flexibility and Individuality

The previous guidelines discuss people with PoTS as a user group, but this group is not a monolith. Every individual person has different condition monitoring needs and uses wearables in a different way. Device design should take this into account and allow for greater flexibility, no longer assuming homogeneity. Participant 88 (Prompt 5) gives guidelines for this:

> *"Expanding User Friendliness Guidelines:*
> *1. Always keep in mind the people who are using the devi[c]e [sic] and how it can serve them*
> *2. Have people who are from a variety of lifestyles and health situations weigh in on the best and worst parts of the wearable"*

Here, Participant 88 suggests that wearable developers should consider a broader potential user group when designing devices, in order to gain a better understanding of the ways in which their devices could be used rather than the ways they expect.

6.7 Conclusions

Overall, the design and contents of Study 3 were informed by the discussions had in the previous interview study (Chapter 5), a study which was itself shaped by the findings of the initial survey study (Chapter 4). Knowledge gained from both studies was used to design appropriate prompts for the workshop participants and instigate discussions during the group Zoom calls. In particular, co-designing this co-design workshop study was a good way to shape the study to both increase its appeal to participants and make it more useful for them, as well as hopefully more accessible in both technology and format. The design choices made as a result of the co-design survey were selected for both participant convenience and accessibility, in order to run a study using technology that would hopefully be familiar to participants. The duration of the study was designed to fit around participants' day-to-day lives. As well as this, conducting a survey was a good way to keep former and then potential future participants engaged with the research, as well as giving a research update. These participants gave their details as part of Study 1 and consented to receiving further research updates.

Workshop participants favoured design features that would integrate wearables into part of a wider condition monitoring system. Data by itself is of little use without additional context, such as any changes in medication or how a person felt on a given day. This contextualisation can be provided by allowing wearable data to be annotated, either on the device itself or on a companion app such as the Fitbit app. Annotated data can be more useful to present to clinicians to show the impact of PoTS, recommended medications and/or lifestyle changes upon a patient's health. Participants had often had issues with having their PoTS symptoms believed by clinicians, and thus wearable data showing the impact of PoTS was deemed to be important as it proved their symptoms. Participant 113 (Prompt 3, point 11) summed this up well:

"The invisibility of POTS is a major problem and wearables make the invisible

both visible and objective."

Therefore the purpose of using wearables to monitor PoTS can be argued to be twofold: helping people with PoTS keep track of their conditions, and acting as a proof of their condition to people who don't have PoTS (people without PoTS were sometimes able to compare their data to that of people with PoTS using the same type of device to see the difference). A wide range of issues encountered with current wearables were discussed in the workshop study, including the range of data types currently trackable (sometimes insufficient for participants' needs), device accuracy, a lack of customisation, and issues related to anxiety and an over-reliance on the technology. However, the nature of this study allowed participants to suggest their own solutions to these issues, as well as how these solutions could influence the design of future wearables that would better serve themselves and the broader PoTS community.

Ultimately, a series of nine guidelines for the design and development of future wearables to monitor PoTS were generated from participant responses, supported by knowledge gained from the previous two studies. These guidelines sought to encourage the creation of wearables that would better suit the needs of the PoTS community and reduce current barriers to wearable use for condition monitoring, based upon the wants and needs of the PoTS community. Workshop participants wished for wearable designers and developers to dismantle their underlying assumptions about how their devices will be used, specifically the assumption that wearable users wish to increase their activity levels. For people with PoTS these devices are often used for activity pacing instead, and thus hitting a specific built-in target (e.g. step count) may be a hallmark of over-exertion rather than a cause for celebration. Other guidelines referred to improving device comfort and fit, accuracy, affordability, the availability of features and data types, and device customisation. Two guidelines recommended the inclusion of data annotation, as well as ensuring that future wearables can be integrated into broader condition monitoring systems. Finally, the guidelines seek to remind designers and developers of flexibility and individuality when designing for this specific (or indeed any) user base, as every wearable user utilises their device(s) in a different way.

The set of generated guidelines serves as a final output of this research, ultimately bringing together knowledge gained from all three studies contained in this thesis. This

sense of joining continues in the remaining chapter of this thesis, the Discussion and Conclusions chapter (Chapter 7), which brings the findings of all three studies together with the context provided from the Background and Methodology chapters (Chapters 2 and 3). The discussion portion of that chapter will compare and contrast all three studies and the existing literature, then this doctoral research will conclude by exploring the limitations of this research and giving recommendations for future work.

Chapter 7

Discussion and Conclusions

7.1 Introduction

The purpose of this final chapter is to discuss the findings of this research and how they relate to the existing literature and methods discussed previously in this thesis, especially as featured in the Background (Chapter 2) and Methodology (Chapter 3) chapters. It will briefly recap the three studies then synthesise findings that reoccur across the studies and link them together.

7.2 Research Questions

The overall aim of this thesis was to understand both how and why people with PoTS choose to use wearables on a day-to-day basis for condition monitoring, as well as how this could be improved, ultimately making recommendations on how to do so. Several smaller aims were created to approach the subject of this thesis in greater depth.

1. How popular is wearable use among people with PoTS, and how do wearables fit into wider individual condition monitoring systems on a day-to-day basis?

2. Why may people choose not to use wearables for condition monitoring and what are their reasons for that choice?

3. What issues are encountered by people with PoTS when using wearables for condition monitoring?

4. What potential solutions are there that could mitigate any issues encountered when using wearables to monitor PoTS?

5. What guidance do wearable designers and manufacturers need in order to best serve this under-acknowledged user group?

7.3 Summary of Study Findings

7.3.1 Study 1: Survey

Study 1 (Chapter 4) consisted of an introductory survey that acted as an exploratory study. It sought to gain a broad range of perspectives through a combination of multiple choice, short answer, and longer answer write-in questions. Participants were people with PoTS and other chronic conditions and this survey focused on their experiences of their conditions and their usage of wearables (or choice not to do so). Their usage of wearables was discussed as part of a wider condition monitoring system, both in and out of a clinical setting. According to the survey study, the modal user of wearables for condition monitoring uses one wearable: a wrist-worn smartwatch or fitness band, most likely made by Apple or Fitbit. The data types that most participants were interested in monitoring were heart rate, blood pressure, sleep, and tachycardia.

7.3.2 Study 2: Interviews

Study 2 (Chapter 5) consisted of twenty individual interviews with participants from across the globe. These participants were people with PoTS who were recruited through the survey study. Each of the interviews sought to discover participants' individual experiences of living with chronic condition(s) including PoTS and how they chose to monitor those conditions on a day-to-day basis, with or without wearables. More specifically, the interviews discussed participants' experiences with wearables both as a tool for condition monitoring and as part of a wider condition monitoring system. The majority of participants used wearables and those who did still favoured wrist-worn wearables, although more accurate chest-worn wearables were used by some participants. People with PoTS

not fitting the model of an ideal wearable user was a key discussion point in the interviews, which led to a discussion of what participants would want from a wearable that would better suit them. Desired features included blood pressure monitoring, medication tracking, and increased customisation for the wearable as a whole, such as which data types are tracked.

7.3.3 Study 3: Co-Design Workshops

Study 3 (Chapter 6) consisted of four asynchronous co-designed co-design workshops. Participants (people with PoTS) completed responses to five individual prompts and participated in a group Zoom call to discuss the topics that the prompts were about. This co-design study was itself co-designed, with a survey being sent to Study 1 participants interested in research updates that asked about their workshop design preferences. The factors asked about included group size, workshop length, and familiarity with potential workshop technology options. Workshop participants were also recruited through this survey. Co-designing the workshops increased participant convenience and accessibility, creating a study using familiar technology and one which would fit around participants' day-to-day lives. A wide range of issues experienced with current wearable use were discussed in the workshops, including device accuracy, the range and availability of currently trackable data types, and anxiety and over-reliance on wearables. Overall, when designing their ideal wearable, workshop participants preferred design features that would enable greater integration of wearables into a broader condition monitoring system, allowing for greater contextualisation. Finally, a series of nine guidelines for the design and development of future wearables to monitor PoTS were developed that sought to reduce barriers to wearable use for condition monitoring and encourage the creation of wearables that would better suit the needs of this underserved community.

7.4 Discussion

The doctoral research contained in this thesis aims to thread the needle between PoTS research and wearable technology research and through doing so consolidates prior research in both of these fields. It validates the findings of prior PoTS studies, as well as

showing how the findings from other research about the use of wearables for condition monitoring hold when PoTS is a condition being monitored. Very few papers found discussed PoTS and wearables, and the research that did had either a single mention of the possibility (Canadian Cardiovascular Society guidelines [S. R. Raj, Guzman, et al. 2020]) or dismissed wearables' suitability for PoTS monitoring (in favour of apps) based upon issues with using wearables to monitor Chronic Fatigue Syndrome (ME/CFS, in a paper by [Mead 2022a]).

7.4.1 Current Wearable Use

This research aimed to investigate the popularity of wearable use among people with PoTS, understanding how wearables fit into wider individual condition monitoring systems on a day-to-day basis. The popularity of wearable use is addressed in a more limited fashion through the first study. It is hard to estimate overall popularity but it is possible to express the proportion of Study 1 participants that used wearables due to the large sample size. Also, there may be potential bias issues due to the nature of the study title which may have encouraged more wearable users and/or people with a keen interest in wearables to take part. However, this research has shown that people across the globe do use wearables for condition monitoring and do find it important to do so. The second part is addressed through all three studies at different scales and with varying degrees of individuality and detail.

The critiques [Mead 2022a] raised, albeit valid, have not ultimately deterred people with PoTS from using wearables and adapting their own individual condition monitoring systems to fit the features offered by their devices. In particular, some workshop participants wished to change which activities could be tracked as exercise, replacing cycling or swimming with household tasks such as cleaning or showering in an attempt to measure exertion. This links into the broader concept of activity pacing, as expressed by [Homewood 2023]. Homewood conducted an autoethnographic study about her use of a Fitbit to monitor her exertion levels as a person with Long COVID, specifically conducting data tracking in order to minimise activity levels where possible. She is aware of how far she is from a typical Fitbit user, an underlying concept shared by both interview and

workshop study participants in this thesis. Here too the same wearable design assumptions reoccur and are discussed: the typical wearable is designed for a user who is in good health, specifically a level of health that can only be improved by increased physical activity. This assumption is untrue for many chronic conditions, including PoTS, with workshop participants in this thesis discussing the impacts of over-exertion. One workshop participant builds on this to discuss another assumption not raised in the discussed papers, which is the notion that a high heart rate does not mean that a person is actively exercising - they may be at rest following prior overexertion (Participant 113, Prompt 5).

Another observation in [Homewood 2023] that resonates with this thesis, albeit not a PoTS specific one, is their discussion of people with ME/CFS independently using commercially available wearables for condition monitoring purposes (especially to monitor exertion), in a very similar manner to the way people with PoTS do. Specifically, this tracking uses the data gathered from a wrist-worn wearable to inform the level of activity they could participate in in order to manage their symptoms. Kavi (2022) explicitly links PoTS and Long COVID through their shared symptom of exercise intolerance resulting in prolonged post-exercise fatigue, implying that similar management strategies for both conditions may be of assistance here and thus potentially similar uses of wearables for self-management [Kavi 2022]. Strassheim et al. (2018) also discusses activity management for people with PoTS in order to reduce fatigue, which can also be linked to pacing and the activity management by workshop participants discussed above [Strassheim et al. 2018]. As well as this, [Strassheim et al. 2018] discuss the impact of environmental demand on PoTS and its management, specifically related to weather and climate. Notably, this topic was discussed during the workshops due to the first icebreaker prompt, which asked participants to rank the four seasons in order of preference. Here, participants discussed the impacts each season had upon their symptoms and condition management strategies.

Interviewees shared their experiences of having their PoTS symptoms disbelieved by clinicians prior to diagnosis and how distressing this was to them, something also encountered in previous qualitative research by [Frye et al. 2023] and [Waterman et al. 2021]. In particular, the teenagers discussed by [Frye et al. 2023] reported very similar experiences to participants in the interview study who had experienced PoTS symptoms as teenagers, specifically the insistence that 'it's all in your head' and that any symptoms experienced

were either psychosomatic or related to anxiety. This misdiagnosis as anxiety was discussed also by [Waterman et al. 2021] and [Kavi 2022], who linked it to a broader pattern of low clinician understanding of PoTS, which is a theme that emerges through all three studies in this thesis (especially the interview study) as a concern for participants and something that has negatively impacted their lives and health.

7.4.2 Barriers to Wearable Use

The aim here was to seek to understand why people may choose not to use wearables for condition monitoring and their reasons for that choice. This is addressed primarily in Study 1 with questions targeted towards this group. It was also originally intended to be addressed in Study 2 by interviewing non-users, but incredibly high number of sign ups led to a change of plans. However, the reasons given by [Mead 2022a] for the potential unsuitability of wearables to monitor ME/CFS are still relevant to people with PoTS, albeit generally not significant enough to deter broad use of the technology. The critiques raised in this paper are that wearables are "designed for people without a health condition" and that features encouraging users to reach exercise targets are inappropriate for people with ME/CFS.

These critiques are both accurate and relevant for people with PoTS, having both also been encountered in this thesis. In particular, the built in design assumptions about wearable users have been corroborated, discussed, and challenged throughout this thesis through the notion of the 'ideal user'. One of the guidelines ultimately generated at the end of the final, workshop study invites designers and developers of wearable technology to dismantle these underlying assumptions. Participants across all three studies lamented currently available step count targets as being too high for people with PoTS, although some survey respondents did find use in the feature despite how unrealistic it can be.

7.4.3 Wearable Issues Encountered and Potential Solutions

Throughout this research issues encountered with the use of wearables for condition monitoring by people with PoTS were investigated across all three studies, including how these issues changed over time. In turn, interview and workshop participants sought to

generate solutions that would mitigate these issues where possible.

Workshop participants were concerned about device comfort when considering the design of wearables to monitor PoTS, which was considered to be an important usability factor by both [Chiauzzi et al. 2015] and [Zeagler 2017]. Ometov et al. (2021) share the concern expressed by interviewees and workshop participants about limited battery life as a hindrance to wearable use, albeit one that is diminishing as batteries improve [Ometov et al. 2021]. Accuracy of wearable data was a concern for [Ancker et al. 2015] and [Chiauzzi et al. 2015] as well as participants across all three studies in this thesis. However, this was a two-fold concern for study participants with only one of their concerns shared by each paper, with [Chiauzzi et al. 2015] showing a more general concern for reliability and validity of data and [Ancker et al. 2015] discussing clinician concerns about unreliable data. The clinicians [Ancker et al. 2015] spoke to trusted lab data significantly more than wearable data, which is a similar sentiment to that expressed by interviewees' clinicians, who tended to prefer their own tests and tracker data (e.g. a 24 hour ECG) to wearable data collected outside a clinical setting.

7.4.4 Guidance for the Development of Future Wearables

Finally, this research sought to generate guidance for wearable designers and manufacturers for how to best serve people with PoTS, an under-acknowledged user group, when designing and developing future wearables. This formed the ultimate outcome of the workshop study, the third and final study conducted, where participant feedback was collated into a series of nine guidelines.

Although [Mead 2022a] conducted research primarily focusing on app development to assist with the monitoring of PoTS, they did also encounter one other link to wearables in their (published) research, with six respondents (of 80) writing in to express a desire to link a monitoring app to wearable technology in order to enable automatic data tracking. This was a topic of discussion during the survey study, where participants detailed which apps they used to monitor their chronic conditions as well as if and how those apps connected to their wearables.

Some of the wearable issues encountered throughout this thesis have also been encoun-

tered in previous literature. Albaghli and Anderson (2016) interviewed medical practitioners about heart rate monitoring using wearables [Albaghli and Anderson 2016]. These practitioners favoured letting individuals record when they were experiencing concerning symptoms then correlating that data with recorded heart rate data. This is similar to the workshop study, where participants favoured the idea of being able to annotate their data in order to contextualise it, such as with how they were feeling at the time. Welhausen (2018) showed a prototype suggesting how annotation could be integrated into a mobile phone app that would work with a wearable device [Welhausen 2018].

7.5 Significance of this Research

This research aimed to bring together two topical areas of research, Postural Tachycardia Syndrome and wearables, and through doing so provided several novel contributions to both fields. Previously, there were very few mentions of the use of wearable technology to monitor PoTS in the literature, with any acknowledgements of this being comparatively recent and not covered in much depth (the 2018 Canadian Cardiovascular Society statement [S. R. Raj, Guzman, et al. 2020] and [Mead 2022a]), let alone as the focus of the research. However, this usage of wearables for condition monitoring was well-known within the PoTS community and openly discussed online. Thus, the focus on the use of wearables to monitor PoTS specifically can be considered to be novel.

Throughout all three studies, this research aimed to centre the lived experiences of people with PoTS while discussing how wearable technology was, is, and could best be used to monitor their symptoms. These questions had not been previously been asked of this under-served population. All research was conducted with a consciously international focus, especially during the interviews and co-design workshops, in order to see the impacts of different healthcare systems (e.g. variations in cost, access to specialists) upon participants' perceptions of the use of wearables, healthcare technology typically not provided by clinicians. As well as this, this perspective took into account how international online PoTS support groups can be, especially relationships created and maintained through social media. This research fills a known gap in the literature and offers a new academic perspective on this under-researched condition. Specifically, it

examines the idea of wearables as part of a broader condition monitoring system for PoTS and through doing so brings together these potentially disparate research areas. It also hopes to show important individual perspectives throughout a changing time, specifically the global COVID-19 pandemic.

The interview study sought to ask participants about the impacts of the COVID-19 pandemic upon their lives, conditions, and condition monitoring strategies, as well as their thoughts about Long COVID. Specifically, interviewees were asked about people with Long COVID also being diagnosed with PoTS. This line of questioning proved to be novel, as it asked participants during the pandemic about the resultant increased public knowledge of their condition, as well as their feelings about the newly diagnosed. At the time Long COVID research was inevitably in its infancy, and stories about PoTS and Long COVID focused on the newly diagnosed, who often had little prior knowledge of PoTS. Few questions were being asked of the pre-existing PoTS community, which was being brought into the spotlight amid the changes and uncertainty of the pandemic (such as medical appointments moving from in-person to telehealth), and understandably this community had a lot to say about this, both positive and negative. Interviewees welcomed the higher level of awareness and a potential increase in research funding, but they also expressed concern about access to specialists and clinicians, who were limited in number and potentially overstretched even before the pandemic and this new wave of diagnoses.

The findings of this research can be used for many purposes. Firstly, the findings of all three studies challenge assumptions made when designing wearables, including the characteristics of default wearable users (presumed to be primarily able-bodied people aiming to improve their health) and that said wearable users would be aiming to exercise **more** and/or increase their step count, rather than using wearables for pacing and activity management reasons to avoid overexertion. The final aim of the co-design workshop study was to generate guidelines for the development of future wearables and those guidelines could form the basis of future work with wearable designers and manufacturers to hopefully lead to the design of devices that better suit this under-served user group's needs. Alternatively, the points raised by this research could be funnelled into broader policy making around self-management for PoTS (and other chronic conditions), including recommendations for at-home technology use in healthcare and ultimately wearable

design.

This research matters because PoTS is a condition that is comparatively little understood by both the general public and non-specialist healthcare professionals, causing diagnostic delays (or even misdiagnosis), undue stress, and potentially leading to inadequate care [Kavi et al. 2016] [Waterman et al. 2021]. As well as this, people with PoTS are often disbelieved by peers, family, and clinicians about their symptoms and condition, especially when seeking a diagnosis [Frye et al. 2023]. Wearables are an emerging and accessible area of technology primarily designed for fitness and lifestyle purposes that contain features suitable for medical tracking (e.g. heart rate monitoring features and the Apple Watch's ECG feature) and are increasingly being used to self-manage chronic conditions such as PoTS. Prior to this research the use of PoTS for condition monitoring was known among this community but not well reported in the literature or considered within the broader context of research about the use of wearables to monitor chronic conditions.

This interdisciplinary research is potentially important to a wide range of stakeholders, including people with PoTS, clinicians, academics, and those in the wearable technology industry. For people with PoTS, this thesis provides an international collection of varied perspectives that will hopefully give them a sense of community experiences on this topic, as well as helping them to feel seen. As well as this, this thesis is of interest to people interested in learning more about PoTS and/or wearables for healthcare, regardless of their level of prior knowledge, especially those who have used wearables to monitor other health conditions (especially chronic ones). Meanwhile, this research is of interest to clinicians as it gives them a chance to explore patient perspectives alongside discussion of other medical professionals' reactions to (and sometimes integration of) wearable technology for condition monitoring purposes. This research is also of interest to people working in the wearable technology industry, especially those working to design and develop wearables, because it provides important examples of how their (or similar) technology is currently being used by a potentially unexpected user group and the issues they have experienced while doing so. Hopefully it will encourage industry professionals to reconsider their design assumptions in the face of a user base (and available market) that desires assistance.

As an example of medical humanities research, this thesis has appeal to clinicians and academics from varying research areas. For PoTS researchers, it provides a necessary digital health perspective on the condition by providing information on how specific types of data are tracked and used on a day-to-day basis as part of individuals' integration of wearable technology into their condition monitoring systems and procedures. On the other hand, this thesis is also of interest to Digital Health and broader Human-Computer Interaction (HCI) researchers as it shows an innovative adaptation of technology by an under-served population who were not previously its target audience, who are also a willing and interested study population with a lot to contribute. The self-management strategies detailed in this thesis could be of interest and potential use to people seeking a diagnosis and looking for self-management measures to try before obtaining anything formal. Finally, this research theoretically matters to everyone, as anyone could get PoTS and the knowledge of adapting technology use for self-management could be relevant regardless.

7.6 Limitations

This doctoral research was limited in several ways, both due to research decisions made and by factors beyond the researcher's control. A key factor that had to be considered throughout this research was that participants often had multiple conditions rather than just PoTS. Care had to be taken to ensure that these other conditions were accounted for where possible in order to ascertain which findings and condition monitoring methods were actually related to PoTS, rather than other chronic conditions. Failing to consider and account for race as a potential variable meant that this research lacked another dimension, one that can have a significant impact upon discrimination faced in a medical setting and how likely patients are to be believed by their clinicians. The global COVID-19 pandemic had an extensive impact upon this research, as shown by the inclusion of a positional paragraph, Section 3.2.2. The pandemic began during the design phase of the first study, which meant that adjustments could take place to ensure that the research could still be conducted. However, it took time for the researcher to adapt to working during lockdowns in a vastly changed academic environment.

The workshop study experienced technology issues due to the usage of Zoom whiteboards, a then newly-introduced feature, which did not work as expected or planned, despite working satisfactorily during the pilot testing sessions. Initially, the aim was for the whiteboards to be usable during and after the workshops to enable participant communication, but significant issues were encountered when the whiteboards failed to display pre-prepared prompt texts during the Zoom calls. Participants then also experienced issues attempting to add text to the whiteboards, and it was ultimately decided that they were only hindering the discussions taking place.

7.7 Recommendations and Future Work

There is very little prior literature on the subject of PoTS and wearables. This PhD collects information on the use of wearables for condition monitoring from a global study population, discussing topics that have not been written about before for this condition. Overall, it has proved to be an exploration of both the current and potential use of wearables for condition monitoring for this unexplored user group. Throughout this thesis, the research conducted aimed to centre people with PoTS and their experiences of wearables (rather than a clinical perspective), using novel research methods when engaging with this population, such as co-designing a co-design workshop.

Several recommendations for best practice in future research and wearable technology development can be made. Firstly, all future research on wearables and chronic conditions must recognise that this research population (people with PoTS) both exists and uses these wearable technologies, and why they choose to do so. This should be accounted for when designing apps and wearables for health tracking. A separate recommendation is given for clinicians, namely to consider how wearables and data tracking could complement the patient/clinician relationship and help to sustain effective condition monitoring between appointments in a way that encourages patient self-sufficiency.

The PoTS community is a very active and engaged population who are very keen to participate in research and have their stories and experiences heard. There are many potential future research topics that could stem from this thesis, many of which feature this community. The first (and most traditional) of these is to use the findings of this

research to prototype a PoTS-specific wearable (a process that would require technological knowledge that this researcher lacks). Further exploration of the use of wearables for activity pacing by people with PoTS would also be valuable in order to explore in greater depth how activity pacing fits into PoTS monitoring. This could also be compared and contrasted with the use of wearables as pacing technology in order to monitor other chronic conditions, such as ME/CFS (see [Davies et al. 2019]) or Long COVID (see [Homewood 2023]), potentially in a literature review.

Long COVID and people developing PoTS as a result of the COVID-19 virus is also a topic that deserves to be considered in more depth than was possible in this thesis in a manner that explores impacts of the COVID-19 pandemic upon specialists, clinicians, and people with PoTS. How has the pandemic changed this community, and how much of that impact is due to Long COVID? PoTS could also be considered as part of a wider group of female-predominant chronic conditions in a study of gendered healthcare experiences, looking at how female-predominance affects condition awareness, accessibility of care, and the diagnostic process, especially for lesser-known conditions such as PoTS. Social media focused research would also be an interesting possibility, namely investigating further how these communities support and affect people with PoTS, especially those seeking a diagnosis and/or going through the diagnostic process. Linked to this, a sensitive and compassionate exploration of self-diagnosis of PoTS could take place, exploring the motivation and rationale for doing so, as well as outcomes for people who choose to do so.

7.8 Conclusions

Overall, there are many recurring themes across the three studies that comprise this thesis. As a whole, participants were concerned about how they were being perceived, both by clinicians and by other wearable users, and worried about being judged as a result. Another key issue is the constant availability of data, which forms part of the wider problems of digital literacy and societal adjustment to this technology, which is still relatively new. This adjustment also has an impact upon clinicians, who are also adapting to technological developments and may gain increasing knowledge and acceptance of

wearables over time. However, many participants, especially interviewees, remained very dependent on individual clinicians recognising their symptoms when seeking a diagnosis, which is far from ideal. There is also a general need for greater device customisability and for wearable device developers to reconsider their underlying assumptions of who their user base will be.

> *"Wearable technology works in conjunction with other symptom management strategies. Ultimately how effective wearable technology is to an individual depends on what chronic illness they have."*

This quotation, from a survey study participant, reminds us that wearables are part of a broader whole, but nevertheless a part that remains worth investigating. In summary, people with PoTS who use wearables for condition monitoring do the best they can with what is currently available, despite potential overwhelm, but dream of better.

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Appendix A

Survey Study Documents and Data

A.1 Study 1 Participation Information Sheet and Consent Form

Participant Information Sheet for Interview Participants

[FOR USE WITH STANDARD PRIVACY NOTICE FOR RESEARCH PARTICIPANTS]

Name of department: Computer & Information Sciences.
Title of the study: Investigating the Use of Wearable Technology to Monitor Postural Tachycardia Syndrome.

Introduction

My name is Rachel Sales and I'm a doctoral student in the Department of Computer and Information Sciences at the University of Strathclyde. This research is funded by the Engineering and Physical Sciences Research Council (EPSRC).

What is the purpose of this research?

This survey and the subsequent interviews together form an initial investigation into the use of wearable technology to monitor chronic conditions, especially Postural Tachycardia Syndrome, specifically how this technology is currently used and how widespread that use is.

Do you have to take part?

No, participation is voluntary. All participants have the right to withdraw from this research at any point without detriment.

What will you do in the project?

This project consists of two stages. You may complete either or both stages. The first stage is a survey about wearable technology and chronic conditions and should take roughly 10-15 minutes to complete. There is no reimbursement for taking part in the survey. The second stage is a 30-45 minute interview about your specific experiences of living with chronic condition(s) and how you monitor your condition(s) with or without wearable technology. This interview will be conducted either by telephone or by video on a virtual online platform and will be recorded. Before participating in the interview you will sign and return a separate consent form that I will email over in advance. I will also verbally ask for consent to be recorded at the start of the interview, before beginning the recording. (Consent to participate in the survey will be given at the very beginning of the survey questions.) Interviewees will receive a £15 retail voucher each to thank them for their participation in the interview process.

You are under no obligation to respond to any parts of the investigation that you feel uncomfortable with.

Why have you been invited to take part?

You have been invited to take part in this study as you have a chronic condition(s) that could potentially be monitored using wearable technology. You may already use wearable technology to monitor your condition, but this is not a requirement for participation.

What are the potential risks to you in taking part?

There is no physical risk to taking part in this study and care will be taken to reduce emotional distress where needed. This study is about lifestyle, but if the topics discussed cause you to feel worse about your condition(s) please talk to your family, support network, or doctor. We hope that this research will ultimately benefit your community.

What information is being collected in the project?

The survey data being collected includes demographic data, as well as data about participants' chronic conditions and experience of wearable technology. This will include personal data. All of the interviews will have audio recordings taken, and video recordings will be made where possible. Both survey and interview data will be anonymised to reduce identifiability, and we will ensure this where possible by checking any specific quotes used with their authors.

Who will have access to the information?

Only my supervisors and I will have access to the survey data. An external transcription service may be used to transcribe some of the interviews, but I will transcribe the rest myself.

Where will the information be stored and how long will it be kept for?

The data collected in this study will initially be stored on secure internal university systems. At the end of the study the anonymised data will be moved to Pure, the University of Strathclyde's research information portal. However, only a summary of the final data will be made publicly available on that data repository. All physical notes will be stored securely and later digitised. I will be following EPSRC guidelines which state that the data must be stored for at least 10 years.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998 and all data will be processed in accordance with this.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Please also read our Privacy Notice for Research Participants.

What happens next?

This project will be written up and submitted for publication. It will also form part of my PhD thesis, and the results may be presented at seminars and academic conferences. I will inform participants upon the publication of this work.

If you do not wish to take part in this study, thank you for your time and attention.

After the study, participants can leave contact details to request project updates and final results.

Researcher contact details:

If you have any further questions about this study, feel free to contact any of the people below:

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Chief Investigator details:

This research was granted ethical approval by the University of Strathclyde Department of Computer and Information Sciences Ethics Committee, with ID number 1197.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the Departmental Ethics Committee
Department of Computer and Information Sciences,
Livingstone Tower
Richmond Street
Glasgow
G1 1XH
email: ethics@cis.strath.ac.uk

Note: The Livingstone Tower is currently closed indefinitely due to COVID-19, so please contact the committee by email if needed.

Consent Form for Interview Participants

Name of department: Computer & Information Sciences
Title of the study: Investigating the Use of Wearable Technology to Monitor Postural Tachycardia Syndrome.

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that I can request the withdrawal from the study of some personal information and that whenever possible researchers will comply with my request. This includes the following personal data:
    - video recordings of interviews that identify me;
    - audio recordings of interviews that identify me;
    - my personal information from survey transcripts.
- I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project. Yes / No
- I consent to being audio recorded as part of the project. Yes / No
- I consent to being video recorded as part of the project. Yes / No

(PRINT NAME)	
Signature of Participant:	Date:

A.2 Study 1 Survey

Investigating the Use of Wearable Technology to Monitor Postural Orthostatic Tachycardia Syndrome.

Start of Block: Consent

My name is Rachel Sales and I'm a doctoral student in the Department of Computer and Information Sciences at the University of Strathclyde.

This research project is an initial investigation into the use of wearable technology to monitor chronic conditions, especially Postural Orthostatic Tachycardia Syndrome (POTS), specifically how this technology is currently used and how widespread that use is.

It consists of two stages and you may complete either or both stages. This survey is the first stage and should take approximately 10-15 minutes to complete. The second stage is a 30-45 minute interview (conducted via video call and recorded) about your specific experiences of (living with) chronic condition(s) and how you monitor your condition(s) with or without wearable technology. You will be able to opt into the second stage at the end of this survey by providing a contact email address. Consent to participate in this survey is given below. If you participate in the interview stage you will sign a separate consent form beforehand.

You have been invited to take part in this study as you have a chronic condition(s) such as Postural Orthostatic Tachycardia Syndrome that could potentially be tracked using wearable technology. You may already use wearable technology to monitor your condition, but this is not a requirement. You are also aged 18 or over. Participation in this research is voluntary. All participants have the right to withdraw at any point without detriment and you are under no obligation to respond to any parts of the investigation that you feel uncomfortable with.

Data from this survey will be written up and submitted for publication, as well as forming part of my PhD thesis. All survey data will be and remain anonymous throughout this process. The data collected in this study will initially be stored on secure internal university systems. At the end of the study the anonymised data will be moved to the University of Strathclyde's research information portal. However, only a summary of the final data will be made publicly available there. All data will be kept for 10 years according to EPSRC (Engineering and Physical Sciences Research Council) expectations. Please also read our Privacy Notice for Research Participants. This research has been approved by the Departmental Ethics Board, ID number

1197.

If you've got any questions about this study, feel free to contact me at rachel.sales@strath.ac.uk
My supervisors can also be contacted with any concerns:
Marilyn Lennon marilyn.lennon@strath.ac.uk
Martin Halvey martin.halvey@strath.ac.uk

Throughout this survey mandatory questions will be marked with an asterisk (*).

Are you 18 or over and do you consent to taking part in this study?*

- ○ Yes (1)
- ○ No (2)

Skip To: End of Survey If Are you 18 or over and do you consent to taking part in this study? = No*

End of Block: Consent

Start of Block: Demographics

What is your gender?*

- ○ Male (1)
- ○ Female (2)
- ○ Other (3)
- ○ Prefer not to say (4)

How old are you?*

_____

End of Block: Demographics

Start of Block: Demographics (Part 2)

Which country do you currently live in?*

▼ England (1) ... Other (584)

The next question is a multiple choice question that asks you for your household income. Which currency would you prefer to answer this question in?*

- Pounds Sterling (GBP) (1)
- US Dollars (USD) (2)
- Euros (EUR) (3)
- I would prefer not to answer the household income question. (4)

Display This Question:

If The next question is a multiple choice question that asks you for your household income. Which cu... = Pounds Sterling (GBP)

What is your household income?*

- Less than £10,000 (1)
- £10,000 - £19,999 (2)
- £20,000 - £29,999 (3)
- £30,000 - £39,999 (4)
- £40,000 - £49,999 (5)
- £50,000 - £59,999 (6)
- £60,000 - £69,999 (7)
- £70,000 - £79,999 (8)
- £80,000 - £89,999 (9)
- £90,000 - £99,999 (10)
- £100,000 - £149,999 (11)
- More than £150,000 (13)

Display This Question:

If The next question is a multiple choice question that asks you for your household income. Which cu... = US Dollars (USD)

What is your household income?*

- Less than $10,000 (1)
- $10,000 - $19,999 (2)
- $20,000 - $29,999 (3)
- $30,000 - $39,999 (4)
- $40,000 - $49,999 (5)
- $50,000 - $59,999 (6)
- $60,000 - $69,999 (7)
- $70,000 - $79,999 (8)
- $80,000 - $89,999 (9)
- $90,000 - $99,999 (10)
- $100,000 - $149,999 (11)
- More than $150,000 (12)

Display This Question:

If The next question is a multiple choice question that asks you for your household income. Which cu... = Euros (EUR)

What is your household income?*

- ○ Less than €10,000 (1)
- ○ €10,000 - €19,999 (2)
- ○ €20,000 - €29,999 (3)
- ○ €30,000 - €39,999 (4)
- ○ €40,000 - €49,999 (5)
- ○ €50,000 - €59,999 (6)
- ○ €60,000 - €69,999 (7)
- ○ €70,000 - €79,999 (8)
- ○ €80,000 - €89,999 (9)
- ○ €90,000 - €99,999 (10)
- ○ €100,000 - €149,999 (11)
- ○ More than €150,000 (12)

End of Block: Demographics (Part 2)

Start of Block: Conditions (Part 1)

What chronic conditions do you have? Please select all that apply.*

- [ ] Postural Orthostatic Tachycardia Syndrome (1)
- [ ] Chronic Fatigue Syndrome (2)
- [ ] Ehlers-Danlos Syndrome (3)
- [ ] Mast Cell Activation Syndrome (4)
- [ ] Arrythmia (5)
- [ ] Orthostatic Intolerance (7)
- [ ] Tachycardia (8)
- [ ] Other (please state) (9) _____

End of Block: Conditions (Part 1)

Start of Block: Conditions (Part 2)

Approximately how many years ago did you first experience symptoms of each of the conditions stated below? Please indicate to the nearest year.*

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Postural Orthostatic Tachycardia Syndrome*

Postural Orthostatic Tachycardia Syndrome* _____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Chronic Fatigue Syndrome*

Chronic Fatigue Syndrome*

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Ehlers-Danlos Syndrome*

Ehlers-Danlos Syndrome*

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Mast Cell Activation Syndrome*

Mast Cell Activation Syndrome*

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Arrythmia*

Arrythmia*

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Orthostatic Intolerance*

Orthostatic Intolerance*

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Tachycardia*

Tachycardia*

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Other (please state)*

Any other chronic conditions*

_____

_____

_____

_____

_____

End of Block: Conditions (Part 2)

Start of Block: Diagnosis

When and where were you diagnosed with each of the conditions stated below?

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Postural Orthostatic Tachycardia Syndrome*

Postural Orthostatic Tachycardia Syndrome

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Chronic Fatigue Syndrome*

Chronic Fatigue Syndrome

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Ehlers-Danlos Syndrome*

Ehlers-Danlos Syndrome

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Mast Cell Activation Syndrome*

Mast Cell Activation Syndrome

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Arrythmia*

Arrythmia

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Orthostatic Intolerance*

Orthostatic Intolerance

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Tachycardia*

Tachycardia

_____

Display This Question:

If What chronic conditions do you have? Please select all that apply. = Other (please state)*

Any other chronic conditions

_____

_____

_____

_____

_____

End of Block: Diagnosis

Start of Block: Disability

Does your chronic condition(s) make you consider yourself to be disabled?

- ○ Yes, because of this condition(s) only (1)
- ○ Yes, and this condition(s) is one of the reasons why (2)
- ○ No, but I consider myself to be disabled for other reasons (3)
- ○ No, and I do not consider myself to be disabled (4)

End of Block: Disability

Start of Block: Tracker Types

Wearable technology is the name given to electronic devices that are worn attached to the body but unsupported by hands. Types of wearable technology include but are not limited to

smartwatches, fitness bands, eyewear (including VR goggles), jewellery, and smart clothing. Mobile phones are not examples of wearable technology.

How many wearable technology devices do you currently use for any purpose in your day to day life?*

- ○ 0 (1)
- ○ 1 (2)
- ○ 2 (3)
- ○ 3 (4)
- ○ 4 (5)
- ○ 5 (6)
- ○ 6 or more (7)

What types of wearable technology do you use for any purpose in your day to day life? Please select all that apply.*

- [ ] Fitness Bands (2)
- [ ] Smart Clothing (4)
- [ ] Smart Eyewear (1)
- [ ] Smart Jewellery (3)
- [ ] Smartwatches (5)
- [ ] Other (please state) (6) _____
- [ ] None (7)

Which brand(s) have you purchased wearable technology devices from? Please select all that apply.*

- ☐ Apple (1)
- ☐ Fitbit (2)
- ☐ Garmin (4)
- ☐ Google (9)
- ☐ Huawei (5)
- ☐ Samsung (3)
- ☐ Xiaomi (7)
- ☐ Other (please state) (6) _____
- ☐ None (8)

End of Block: Tracker Types

Start of Block: Wearable (Filter Question)

Do you **currently** use wearable technology to monitor your chronic condition(s)?*

- ○ Yes (1)
- ○ No (2)

End of Block: Wearable (Filter Question)

Start of Block: Duration of Wearable Use

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Approximately how many years have you been using wearable technology to monitor each of the conditions stated below? Please indicate to the nearest year.*

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Postural Orthostatic Tachycardia Syndrome*

Postural Orthostatic Tachycardia Syndrome*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Chronic Fatigue Syndrome*

Chronic Fatigue Syndrome*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Ehlers-Danlos Syndrome*

Ehlers-Danlos Syndrome*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Mast Cell Activation Syndrome*

Mast Cell Activation Syndrome*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Arrythmia*

Arrythmia*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Orthostatic Intolerance*

Orthostatic Intolerance*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Tachycardia*

Tachycardia*

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

And What chronic conditions do you have? Please select all that apply. = Other (please state)*

Any other chronic conditions*

_____

_____

_____

_____

_____

End of Block: Duration of Wearable Use

Start of Block: Current Wearable Use

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Did you use wearable technology before being diagnosed with your chronic condition(s)? *

- ○ Yes, for reasons linked to my suspected health condition (1)
- ○ Yes, for unrelated reasons (2)
- ○ No (3)
- ○ I have not yet been diagnosed (4)

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Was wearable technology of any use to you during the diagnostic process?*

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Was wearable technology of any use to you during the diagnostic process? = Yes*

How was wearable technology of use to you during the diagnostic process?

_____

_____

_____

_____

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Has data you have collected using wearable technology ever been looked at by a medical professional you have visited?*

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Has data you have collected using wearable technology ever been looked at by a medical profession... = Yes

What did the medical professional(s) you visited use your data for?

_____

_____

_____

_____

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Do you use any other devices (not wearable technology) to monitor your condition(s)? *

- ○ Yes (1)
- ○ No (2)

Display This Question:

*If Do you use any other devices (not wearable technology) to monitor your condition(s)? * = Yes*

If any of the devices are not mobile phones, please give details.

_____

_____

_____

_____

_____

End of Block: Current Wearable Use

Start of Block: Not Using Wearables

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = No*

Have you previously used wearable technology to monitor your chronic condition(s)? *

- ○ Yes (1)
- ○ No (2)

Display This Question:

*If Have you previously used wearable technology to monitor your chronic condition(s)? * = Yes*

Why did you stop using wearable technology to monitor your chronic condition(s)? Please select all that apply.*

- [ ] Cannot wear the device (1)
- [ ] Complexity of technology (2)
- [ ] Cost (3)
- [ ] Devices don't monitor what I need them to (4)
- [ ] Was uncomfortable with the degree of tracking (9)
- [ ] Lack of appropriate apps (5)
- [ ] Lack of availability (6)
- [ ] No longer needed to (8)
- [ ] Other (please state) (7) _____

Display This Question:

*If Have you previously used wearable technology to monitor your chronic condition(s)? * = No*

Which of these reasons may prevent you from using wearable technology to monitor your chronic condition(s)? Please select all that apply.*

- [ ] Cannot wear the device (1)
- [ ] Complexity of technology (2)
- [ ] Cost (3)
- [ ] Devices don't monitor what I need them to (4)
- [ ] Don't think I need to (8)
- [ ] Lack of appropriate apps (5)
- [ ] Lack of availability (6)
- [ ] Other (please state) (7) _____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = No*

How else do you monitor your condition(s) without wearable technology?*

_____

_____

_____

_____

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = No*

Would you consider using wearable technology in the future to monitor your condition(s)? *

- ○ Yes (1)
- ○ No (2)

Display This Question:

*If Would you consider using wearable technology in the future to monitor your condition(s)? * = Yes*

What could make you (re)start using wearable technology to monitor your condition(s)? Please select all that apply.

- ☐ App that fits my needs better (1)
- ☐ Different ways to wear a device (2)
- ☐ More affordable technology (3)
- ☐ More user friendly technology (4)
- ☐ Other (please state) (5) _____

End of Block: Not Using Wearables

Start of Block: Mobile phones

Do you use your mobile phone to monitor your chronic condition(s)?*

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Do you use your mobile phone to monitor your chronic condition(s)? = Yes*

What apps have you used to monitor your chronic condition(s)? Please give a list if possible.

_____

_____

_____

_____

_____

Display This Question:

If Do you use your mobile phone to monitor your chronic condition(s)? = Yes*

Which monitoring app is your favourite?

_____

End of Block: Mobile phones

Start of Block: Symptoms/Data Types

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Which symptoms of your condition(s) do you currently monitor?*

_____

_____

_____

_____

_____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

Which data types do you currently track? Please select all that apply.

- [ ] Calories (1)
- [ ] Distance (2)
- [ ] Electrocardiogram (ECG) (3)
- [ ] Exercise (4)
- [ ] Fall Detection (5)
- [ ] GPS (6)
- [ ] Heart Rate (7)
- [ ] Heart Rate Variability (HRV) (13)
- [ ] Menstrual Cycle (12)
- [ ] Sleep (8)
- [ ] Step Count (9)
- [ ] VO2 Max (Aerobic Fitness Level) (10)
- [ ] Other (please state) (11) _____

Display This Question:

If Do you currently use wearable technology to monitor your chronic condition(s)? = Yes*

If you could use your device(s) to monitor any other symptom of your condition(s), which symptom would you pick and why?

_____

_____

_____

_____

_____

End of Block: Symptoms/Data Types

Start of Block: Past Symptoms/Data Types

Display This Question:

*If Have you previously used wearable technology to monitor your chronic condition(s)? * = Yes*

Which symptoms of your condition(s) did you monitor?*

_____

_____

_____

_____

_____

Display This Question:

*If Have you previously used wearable technology to monitor your chronic condition(s)? * = Yes*

Which data types did you track? Please select all that apply.

- [ ] Calories (1)
- [ ] Distance (2)
- [ ] Electrocardiogram (ECG) (3)
- [ ] Exercise (4)
- [ ] Fall Detection (5)
- [ ] GPS (6)
- [ ] Heart rate (7)
- [ ] Menstrual Cycle (12)
- [ ] Sleep (8)
- [ ] Step Count (9)
- [ ] VO2 max (aerobic fitness level) (10)
- [ ] Other (please state) (11) _____

Display This Question:

*If Have you previously used wearable technology to monitor your chronic condition(s)? * = Yes*

If you could have use your device(s) to monitor any other symptom of your condition(s), which symptom would you pick and why?

_____

_____

_____

_____

_____

End of Block: Past Symptoms/Data Types

Start of Block: Other

Overall, rate how effective you personally find wearable technology to be for your own condition management.*

- Extremely effective (1)
- Very effective (2)
- Moderately effective (3)
- Slightly effective (4)
- Not effective at all (5)

Overall, rate the effectiveness of wearable technology for condition management for people in general.*

- Extremely effective (1)
- Very effective (2)
- Moderately effective (3)
- Slightly effective (4)
- Not effective at all (5)

Do you have any further comments?

_____

_____

_____

_____

_____

End of Block: Other

Start of Block: Contact

You have now completed the first stage of this project.

The second stage is a 30-45 minute interview about your specific experiences of living with chronic condition(s) and how you monitor your condition(s) with or without wearable technology. This interview will be conducted either by telephone or virtually via video call and will be recorded. Before participating in the interview you will sign a separate consent form.

The questions below only serve to register your interest in the interview section. It is not a firm commitment to being interviewed. Further information via email will be provided to all who are interested shortly, and you will be able to confirm your interest then. If I have too many people interested in being interviewed, final participants will be selected at random.

Please indicate if you are interested in taking part in the interview section of this research.*

- ○ I am interested (1)
- ○ I am not interested (2)

Please indicate if you would like to receive updates and the final results of this research.*

- ○ Yes, I would like to receive updates (1)
- ○ No, I would not like to receive updates (2)

Display This Question:

If Please indicate if you are interested in taking part in the interview section of this research. = I am interested*

Or Please indicate if you would like to receive updates and the final results of this research. = Yes, I would like to receive updates*

Please provide a contact email if you are interested in participating further in this research or to receive updates, including final results.

_____

Thank you for your participation!

If you've registered interest in taking part in the interview process, you will receive further details from the research team via email.

If this survey has affected you in any way related to your life or your health condition(s) please speak to your family or GP.

If you have any queries about this research, feel free to contact any of the following:

Rachel Sales
PhD student
Department of Computer and Information Sciences
University of Strathclyde
rachel.sales@strath.ac.uk

Dr Marilyn Lennon
Reader
Department of Computer and Information Sciences
University of Strathclyde
marilyn.lennon@strath.ac.uk

Dr Martin Halvey
Senior Lecturer
Department of Computer and Information Sciences
University of Strathclyde
martin.halvey@strath.ac.uk

End of Block: Contact

Appendix B

Interview Study Documents and Data

B.1 Study 2 Updates Survey

Interview Study Updates - Wearable Technology and Postural Orthostatic Tachycardia Syndrome

Start of Block: Intro

My name is Rachel Sales and I'm a doctoral student in the Department of Computer and Information Sciences at the University of Strathclyde.

Thank you for your interest in and assistance with my research on wearable technology and Postural Orthostatic Tachycardia Syndrome (POTS) so far.

This form is for any changes you wish to make to your contact details and current registration.

Please fill it out by 23:59 BST on 7th May 2021 if you wish to sign up as a potential interviewee or remove yourself from the list of potential interviewees.

Please provide the contact email that you used to fill out the survey. This is the same email address that you were last contacted on about this study.

_____

Are you currently registered as a potential interviewee?

- ○ Yes (1)
- ○ No (2)

End of Block: Intro

Start of Block: Block 1

Display This Question:

If Are you currently registered as a potential interviewee? = No

Which of the following applies to you?

- ☐ I would like to register as a potential interviewee. (1)
- ☐ I would like to change my contact email address. (2)
- ☐ I no longer wish to receive updates about this research. (3)

Display This Question:

If Are you currently registered as a potential interviewee? = Yes

Which of the following applies to you?

- ☐ I would like to change my contact email address. (1)
- ☐ I no longer wish to be registered as a potential interviewee. (2)
- ☐ I no longer wish to receive updates about this research. (3)

End of Block: Block 1

Start of Block: Change of email

Display This Question:

If Which of the following applies to you? = I would like to change my contact email address.

Or Which of the following applies to you? = I would like to change my contact email address.

*

What is your new preferred email address?

_____

End of Block: Change of email

Start of Block: Block 4

Display This Question:

If Which of the following applies to you? = I would like to register as a potential interviewee.

Thank you for signing up as a potential interviewee!

Please fill out these questions to tell me a little more about yourself.

Display This Question:

If Which of the following applies to you? = I would like to register as a potential interviewee.

Do you have Postural Orthostatic Tachycardia Syndrome?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Which of the following applies to you? = I would like to register as a potential interviewee.

Do you currently use wearable technology to monitor your chronic condition(s)?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Which of the following applies to you? = I would like to register as a potential interviewee.

What is your gender?

- ○ Male (1)
- ○ Female (2)
- ○ Other (3)
- ○ Prefer not to say (4)

Display This Question:

If Which of the following applies to you? = I would like to register as a potential interviewee.

How old are you?

_____

End of Block: Block 4

Start of Block: Goodbye

Thank you again for your assistance with my research.

Please get in touch with me at rachel.sales@strath.ac.uk if you have any further questions.

End of Block: Goodbye

B.2 Interview Schedule

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
		1st	2nd	3rd	4th	5th	6th
	June					136 9am EST 2pm BST	395 3pm CET 2pm BST
	7th	8th	9th	10th	11th	12th	13th
		243 11am EST 4pm BST	353 1pm BST				
		893 2pm PST 10pm BST					
	14th	15th	16th	17th	18th	19th	20th
	835 7pm BST	505 2pm BST	219 5pm CST 11pm BST				
	21st	22nd	23rd	24th	25th	26th	27th
	69 4pm EST 9pm BST	538 6pm EST 11pm BST	304 3pm EST 8pm BST	160 4pm EST 9pm BST			110 2pm EST 7pm BST
	28th	29th	30th	July 1st	2nd	3rd	4th
	84 3pm CEST 2pm BST	906 8pm AEST 11am BST	444 1pm BST				
	5th	6th	7th	8th	9th	10th	11th
		126 2pm EST 7pm BST	277 1pm BRT 5pm BST		767 4pm CST 10pm BST		
		381 6pm CST 12am BST					

Scheduled	0
Done:	20
Total:	20
To sort:	0

Figure B.1: A screenshot of an Excel spreadsheet, showing the schedule for the Study 2 interviews. Each interview is labelled with the participant number, the time in the participant's time zone, and (if needed) the time in the researcher's time zone.

B.3 Interview Topic Schedule

Interview Topic Schedule.

Introductory Text.

Hi *[name]*, thank you for agreeing to take part in this interview. My name is Rachel Sales and I'm a PhD student in the Department of Computer and Information Sciences at the University of Strathclyde. This interview forms the second part of an initial study about the use of wearable technology to monitor chronic conditions, especially Postural Tachycardia Syndrome (PoTS) and should take approximately 30 to 45 minutes of your time. At the end of this interview you will be sent a £15 retail voucher to thank you for your participation.

Today I'm going to ask questions about your experiences as someone living with chronic conditions and how you choose to monitor those conditions. I'm also going to ask you about your experiences of wearable technology, then if and/or how those relate to healthcare.

This interview will be recorded via Zoom's built in recording software. This recording has not been started yet and will not be until I have your consent to do so. If at any point during the survey you wish to say anything "off the record" or temporarily pause the recording for any other reason, please let me know and I will do so. I will always inform you before restarting the recording. Do you have any questions or concerns about the recording?

Do you give consent to me starting the recording?

[Space for participant to give consent.]

I have started the recording.

Topic List.

These are the topics I will ask about. There are three key questions I will aim to ask every interviewee, and these are highlighted in red. My overarching intention is to find out the interviewee's personal narrative about condition monitoring and wearable technology.

- Demographics/Introduction:
    - Tell me a little bit about yourself, so I can understand the different people I'm talking to.
- How did you find out about this study?
- Conditions (two potential loose categories, PoTS and not PoTS?):
    - Symptoms and duration
    - Diagnosis
- Methods of condition monitoring *(two loose categories – wearable tech/no wearable tech)*:
    - How do you monitor your condition currently?
    - Mobile phones and their use in condition monitoring
- Chronology:
    - How have people changed the way they monitor their condition(s) over time?
        - Has technology had any input?
    - Have you ever used wearable technology (for any reason)?
- Introduction of technology into individual condition monitoring:
    - Do you use wearable technology for condition monitoring?
    - How did people hear about tech they ended up using?
    - What made them take the leap?
        - *(potential themes of community to consider here)*

Rachel Sales

- Device use over time:
    - Have people used many different devices?
    - Brand loyalty?
    - Technological advancements?
        - Built in obsolescence?
- Data collected & links between data and symptoms:
    - *Chance to make the link between data collected and the corresponding symptoms monitored more explicit.*
    - What data types does your device track?
    - What data types have you been observing? *(i.e. Which ones do you actually care about?)*
- Not using wearable tech:
    - *Condition monitoring is covered earlier*
    - What is your current opinion of wearable technology?
    - Have you ever considered using wearable technology for condition monitoring?
    - What would make you choose to use wearable technology for condition monitoring?
- Community/People around you
    - Does anyone (else) you know use wearable technology?
        - If so, do any of them use it for condition monitoring?
    - What barriers are there that you think restrict the wider use of wearable technology for condition monitoring?
- Other experiences of wearable technology (not health related):
    - Opinions on wearable technology as a whole
- What else can be done?
    - What do you feel is missing when it comes to using wearable technology for condition monitoring?
    - What improvements would you like to see?
- *Follow up/What next research-wise (extra topic, only to be covered if there's enough time):*
    - *Would people be interested in app-based studies?*
- Is there anything else you'd like to say?

<u>Scripted debrief.</u>

Thank you for participating in this interview. It is now complete. I'll email you the retail voucher within a week. If you have any further questions, please contact me via the email address given on the Participant Information Sheet.

I am now ending the recording.

<u>Note:</u> These questions will be finalised when I have the survey results.

B.4 Anonymised Interview Crib Sheets

Anonymised Interview Crib Sheets.

The following is a digitised version of my handwritten interview crib sheets from Study 2, which I filled out during the interviews to keep track of key participant details. All ages are approximate and were taken from their survey data so may be inaccurate (participants were not asked their current age at time of interview). Genders were also taken from the survey identity (but generally discussed too.)

Interview 1: Participant 136.

Male, 58, USA.

* Does use wearables, does have PoTS.

Conditions & When Diagnosed: PoTS, Orthostatic Hypotension, Type II Diabetic. Peripheral Neuropathy.

Condition Monitoring Methods Used: Blood pressure monitor, O2 sensor, wrist worn wearable.

Does use wearables.

*= Not expected category. (Had him down as someone who doesn't.)

Kore(?) Track.

Interview 2: Participant 395.

Female, 40, Slovakia.

Current wearable user, has PoTS.

Conditions & When Diagnosed: PoTS, fatigue. Vision issues (blue light?). Heart valve issues. Chronic mononucleosis?

Condition Monitoring Methods Used: App, home blood pressure monitor, oximeter.

Omron – could not get. Cheap version?

App – Omron.

Interview 3: Participant 243.

Female, 20, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: EDS, PoTS, Mast Cell (symptoms since birth), lung issues (including sleep apnoea).

Condition Monitoring Methods Used: Polar H10 strap, Fitbit (sleep primarily), c tab, blood pressure monitor, apps.

Owning a tilt table does not a diagnosis make.

Fitbit – trends and averages rather than pure HR readings.

Interview 4: Participant 893.

Female, 50, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: Fibro (2004), ME/CFS (2014), PoTS (2015/16?).

Condition Monitoring Methods Used: Fitbit Charge, Apple Watch, Oximeter (for air hunger), heart graph app (Apple Watch) (battery drainer), well tory(?) (finger scan, BP cuff connection), BP cuff.

Wants voucher donated to animal shelter.

Interview 5: Participant 353.

Female, 27, Scotland.

Doesn't use wearables, has PoTS.

Conditions and When Diagnosed: Hypermobility (diagnosed first), PoTS (diagnosed a year after), Pelvic.

Condition Monitoring Methods Used: Pulse oximeter, HR app.

Interview 6: Participant 835.

Female, 42, England.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, MCAS, E-D (Ehlers-Danlos), inappropriate sinus tachycardia.

Condition Monitoring Methods Used: Apple Watch (various since Gen 1), Heart Rate Free app, beta blockers, home BP monitor, heart meds.

Rachel Sales

Hot and humid day.

Interview 7: Participant 505.

Female, 33, England.

Doesn't use wearables, has PoTS.

Conditions and When Diagnosed: PoTS (10-12 years ago), hypermobile EDS, MCAS.

Condition Monitoring Methods Used: BP monitor, Fitbit (past).

Interview 8: Participant 219.

Female, 35, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, EDS, Sjögren's, Hashimoto's, MCAS symptoms (undiagnosed). [Misdiagnosed with Addison's.]

Condition Monitoring Methods Used: Fitbit, BP Cuff. Past Polar.

Interview 9: Participant 69.

Genderqueer, 20, USA (gave gender as `Other' on the survey).

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS (~6/7 years ago), EDS, MCAS (not formally diagnosed, but being treated for).

Condition Monitoring Methods Used: Garmin Vivo 4 (and 3), medication, water & salt, phone alarms, BP cuff, pulse ox.

AFAB genderqueer, she/they pronouns.

Interview 10: Participant 538.

Female, 18 (probably 19 now), USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, h-EDS, GI dysmotility (?).

Rachel Sales

Condition Monitoring Methods Used: Apple Watch, previously Fitbit, apps, at home BP, meds.

Slight audio and some video issues.

Interview 11: Participant 304.

Female, 45, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: immune deficiencies, auto-immune, PoTS, neurocardiogenic syncope, hemiplegic migraines, dysautonomia, osteoarthritis, fibro.

Condition Monitoring Methods Used: service dog (Golden Retriever) (for syncope), Garmin HR+, family, meds, Noom app. Fitbit previously. BP cuff.

Send voucher to second email address.

Interview 12: Participant 160.

Female, 28, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS*, chronic pain, convulsive syncope, small fibre neuropathy*. *=formal.

Blood condition.

Condition Monitoring Methods Used: service dog, Apple Watch (non ECG). HR monitor implant, journal, assume BP cuff.

Interview 13: Participant 110.

Female, 29, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, IST, dysautonomia, chronic migraines, anxiety, OCD, depression, iron deficiency, SVT.

Condition Monitoring Methods Used: Apple Watch, pulse ox, app (Heart Report), BP cuff.

Mentioned Cardiogram app.

Rachel Sales

Interview 14: Participant 84.

Female, 30, The Netherlands (Scottish).

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, fibro ('up in the air'), suspected CFS.

Condition Monitoring Methods Used: pulse ox on back of Samsung S10, Samsung Health app, Fitbit (watch and app), home BP machine, Cardiogram app, Bearable(?) app.

Audio only.

Interview 15: Participant 906.

Female, 21, Australia.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, IBS, migraines, all under dysautonomia umbrella.

Condition Monitoring Methods Used: Garmin HR (Garmin Connect app).

Interview 16: Participant 444.

Male, 29, Wales.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS (2012, symptoms from 2010), suspected MCAS.

Condition Monitoring Methods Used: diary (past?), Fitbit, compression socks, watch with apps (could be the same thing as Fitbit?).

Interview 17: Participant 126.

Female, 28, USA.

Doesn't use wearables, has PoTS.

Conditions and When Diagnosed: mitochondrial disorder, complication → PoTS (diagnosed 5 years ago), neuropathy. (3rd sister to be diagnosed.)

Condition Monitoring Methods Used: BP monitor, medication, pulse ox (on occasion), electrolyte tablets, hyperbaric oxygen chamber.

Has used a Fitbit.

Rachel Sales

Spreadsheet.

Notif if pulse ox is off that says to check BP.

Interview 18: Participant 381.

Female, 35, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, PTSD, EDS, inappropriate sinus tachycardia (prior diagnosis), MCAS trademarks but no diagnosis.

Family with dysautonomia, potential PoTS. Autism – to be diagnosed.

Condition Monitoring Methods Used: CBD & cannabis, service dog, my ID liquid IV (drink containing salt), Apple Watch (iWatch), Weather X app (for barometric pressure info), wearable fan, bed (sleepnumber?). Pressure cuff massagers.

Past Fitbit user.

CW: mentions of rape, child molestation, suicide, cancer for interview 18.

Interview 19: Participant 277.

Female, 18, Brazil.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS, congenital hyperplasia, hypermobility (not h-EDS).

Condition Monitoring Methods Used: Apple Watch s3 (now broken), Samsung Galaxy (Fitbit-esque), oximeter, medication.

Interview 20: Participant 767.

Female, 38, USA.

Does use wearables, has PoTS.

Conditions and When Diagnosed: PoTS (2008, took 2 years), narcolepsy or idiopathic hypersomnia (between the two), endo, lupus/Sjögren's, coeliac, hyperthyroidism (no longer), neurally mediated syncope (same as sister).

Condition Monitoring Methods Used: Fitbit, achievement app (collects Fitbit data). Used to have Jawbone Charge 2. Pulse Ox.

Rachel Sales

Suggestion.

Diagnostic process: halter. Appears ‘normal’. Is there a way to catch [spot/notice] PoTS from halter monitors? Contextualise when heart rate is high.

Appendix C

Workshop Study Documents and Data

C.1 Study 3 Co-Design Survey

Co-Design Workshop Features Survey

Start of Block: Consent

My name is Rachel Sales and I'm a doctoral student in the Department of Computer and Information Sciences at the University of Strathclyde.

This is a brief preliminary survey to establish good engagement methods for co-designing future wearable technologies to assist with the monitoring of Postural Orthostatic Tachycardia Syndrome (POTS). You will fill out a short (5-10 minute) survey about your preferences for workshop design. The responses will be used to shape the design of an upcoming series of group co-design workshops about your specific experiences of living with POTS and how wearables are and could be used to monitor Postural Orthostatic Tachycardia Syndrome (POTS).

You have been invited to take part in this study as you have a chronic condition(s) that could potentially be monitored using wearable technology. You may already use wearable technology to monitor your condition, but this is not a requirement for participation. You are also aged 18 or over. Participation is voluntary. You are under no obligation to respond to any parts of the investigation that you feel uncomfortable with and all participants have the right to withdraw from this research at any point without detriment.

There is no physical risk to taking part in this study and care will be taken to reduce emotional distress where needed. This study is about lifestyle, but if the topics discussed cause you to feel worse about your condition(s) please talk to your family, support network, or doctor. We hope that this research will ultimately benefit your community.

Data from this survey will inform the design of the workshops, which will be conducted within the next few months. It will also be written up and submitted for publication, as well as ultimately forming part of my PhD thesis. All survey data will be and remain anonymous throughout this process. The data collected in this study will initially be stored on secure internal university systems. At the end of the study the anonymised data will be moved to the University of Strathclyde's research information portal, but only a summary of the final data will be made publicly available there. All data will be kept for 10 years according to EPSRC (Engineering and Physical Sciences Research Council) expectations. Please also read our Privacy Notice for

Research Participants. This research has been approved by the Departmental Ethics Board, ID number 1763.

If you've got any questions about this study, feel free to contact me at rachel.sales@strath.ac.uk
My supervisors can also be contacted with any concerns:
Marilyn Lennon marilyn.lennon@strath.ac.uk
Martin Halvey martin.halvey@strath.ac.uk

Throughout this survey mandatory questions will be marked with an asterisk (*).

I confirm that I have read and understood the above information and have had the opportunity to ask questions which the researcher has answered to my satisfaction. I understand what is being asked of me if I choose to take part in this study. I am aged 18 or over and I consent to taking part in this study.*

- ○ Yes (1)
- ○ No (2)

Skip To: End of Survey If I confirm that I have read and understood the above information and have had the opportunity to a... = No

End of Block: Consent

Start of Block: POTS Confirmation

Do you have Postural Orthostatic Tachycardia Syndrome (POTS)?*

- ○ Yes (24)
- ○ No (23)

Skip To: End of Survey If Do you have Postural Orthostatic Tachycardia Syndrome (POTS)? = No*

End of Block: POTS Confirmation

Start of Block: Duration and Participants

If you were taking part in a group workshop, what size group would you be comfortable being part of? Select all that apply.

- [ ] 1-2 (1)
- [ ] 3-4 (2)
- [ ] 5-6 (3)
- [ ] 7-8 (4)
- [ ] 9-10 (5)
- [ ] 11+ (6)

Page Break

The workshops are intended to include a series of prompts (no more than 5 or so) for you to respond to in your own free time (within a set time period), as well as a short (potentially optional) video call element. This video element may be open to all participants at the same time.

If you were taking part in a study where you had to submit a series of responses, how long a period of time would you like to submit those responses? Select all that apply.

- [ ] 0-2 days (1)
- [ ] 3-5 days (2)
- [ ] 6-8 days (3)
- [ ] 9-11 days (4)
- [ ] 12-14 days (5)
- [ ] 15+ days (6)

How long a group video call would you feel comfortable participating in as part of a workshop? Select all that apply.

- [ ] 0-30 minutes (1)
- [ ] 30-60 minutes (2)
- [ ] 60-90 minutes (3)
- [ ] 90-120 minutes (4)
- [ ] 120+ minutes (5)
- [ ] I would not be comfortable participating in a group video call (6)

Would you prefer to interact with other participants face to face (online)?

- ○ Yes (1)
- ○ No (2)
- ○ No Preference (3)

Would you prefer all participants in your group to be anonymous throughout the workshop?

- ○ Yes (1)
- ○ No (2)
- ○ No Preference (3)

End of Block: Duration and Participants

Start of Block: Technology

Which of these video call technologies are you familiar with? Select all that apply.

- [ ] Zoom (1)
- [ ] Microsoft Teams (2)
- [ ] Discord video call (3)
- [ ] Google Meet (4)
- [ ] Other (please state) (5) _____

Which of these virtual collaboration technologies are you familiar with? Select all that apply.

- [ ] Microsoft Teams (1)
- [ ] Microsoft OneDrive (2)
- [ ] Slack (3)
- [ ] Discord (4)
- [ ] Google Docs (5)
- [ ] Google Drive (6)
- [ ] Other (please state) (7) _____

Page Break

Do you have anything else you'd like to say about this topic?

_____

_____

_____

_____

_____

End of Block: Technology

Start of Block: Contact

Thank you for completing this survey.

The next stage of this project is a series of group co-design workshops that will take place within the next few months.

The aim of these workshops is to codesign future wearable technologies for assisting in the monitoring of Postural Tachycardia Syndrome (PoTS), via the creation of a set of design guidelines. These guidelines could be used to assess suitability of current devices and/or guide the development of future ones.

Before participating in a workshop you will sign a separate consent form.

The questions below only serve to register your interest in the workshops. Answering them is not a firm commitment to taking part. Further information via email will be provided to all who are interested shortly, and you will be able to confirm your interest then. If I have too many people interested in the workshops, final participants will be selected at random.

Please indicate if you are interested in taking part in the co-design workshops.*

- ○ I am interested (1)
- ○ I am not interested (2)

Display This Question:

If Please indicate if you are interested in taking part in the co-design workshops. = I am interested*

What time zone are you in?

_____

Please indicate if you would like to receive updates and the final results of this research.*

- ○ Yes, I would like to receive updates (1)
- ○ No, I would not like to receive updates (2)

Display This Question:

If Please indicate if you are interested in taking part in the co-design workshops. = I am interested*

Or Please indicate if you would like to receive updates and the final results of this research. = Yes, I would like to receive updates*

Please provide a contact email if you are interested in participating further in this research or to receive updates, including final results.*

_____

Thank you for your participation!

If you've registered interest in taking part in the workshops, you will receive further details from the research team via email.

If you have any queries about this research, feel free to contact any of the following:

Rachel Sales
PhD student
Department of Computer and Information Sciences
University of Strathclyde
rachel.sales@strath.ac.uk

Dr Marilyn Lennon
Reader
Department of Computer and Information Sciences
University of Strathclyde
marilyn.lennon@strath.ac.uk

Dr Martin Halvey
Reader
Department of Computer and Information Sciences
University of Strathclyde
martin.halvey@strath.ac.uk

End of Block: Contact

C.2 Study 3 Co-Design Survey Consent Form

Participant Information Sheet for Participants

[FOR USE WITH STANDARD PRIVACY NOTICE FOR RESEARCH PARTICIPANTS]

Name of department: Computer & Information Sciences.
Title of the study: *A series of co-design workshops to design future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS).*

Introduction

My name is Rachel Sales and I'm a doctoral student in the Department of Computer and Information Sciences at the University of Strathclyde. This research is funded by the Engineering and Physical Sciences Research Council (EPSRC).

What is the purpose of this research?

You will take part in a group workshop in order to ultimately design a series of guidelines for the design of wearables used to monitor Postural Tachycardia Syndrome (PoTS).

Do you have to take part?

No, participation is voluntary. All participants have the right to withdraw from this research at any point without detriment.

What will you do in the project?

You will be expected to respond to a series of individual and collaborative prompts about *your opinions of, experiences with, and the design of wearable technology*, both individually and collaboratively. There will also be an optional Zoom video call for *you* to discuss prompts *with both the researchers and other participants* and to troubleshoot any issues. All responses will be uploaded to OneDrive.

You are under no obligation to respond to any parts of the investigation that you feel uncomfortable with.

Why have you been invited to take part?

You have been invited to take part in this study as you are aged 18 or over and have Postural Tachycardia Syndrome (PoTS). You may already use wearable technology to monitor your condition, but this is not a requirement for participation.

What are the potential risks to you in taking part?

There is no physical risk to taking part in this study and care will be taken to reduce emotional distress where needed. This study is about lifestyle, but if the topics discussed cause you to feel worse about your condition(s) please talk to your family, support network, or doctor. We hope that this research will ultimately benefit your community.

What information is being collected in the project?

These workshops will ask participants about their opinions of, experiences with, and the design of wearable technology. This will lead to a focus on how they would refine and improve this technology to better suit their condition monitoring needs and those of other people with PoTS.

Who will have access to the information?

Only my supervisors and I will have access to the data generated through this study.

Where will the information be stored and how long will it be kept for?

The data collected in this study will initially be stored on secure internal university systems (OneDrive). At the end of the study the anonymised data will be moved to Pure, the University of Strathclyde's research information portal. However, only a summary of the final data will be made publicly available on that data repository. All physical notes will be stored securely and later digitised. I will be following EPSRC guidelines which state that the data must be stored for at least 10 years.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998 and all data will be processed in accordance with this.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Please also read our Privacy Notice for Research Participants.

What happens next?

This project will be written up and submitted for publication. It will also form part of my PhD thesis, and the results may be presented at seminars and academic conferences. I will inform participants upon the publication of this work.

If you do not wish to take part in this study, thank you for your time and attention.

After the study, participants can leave contact details to request project updates and final results.

Researcher contact details:

If you have any further questions about this study, feel free to contact any of the people below:

Rachel Sales
PhD student
Department of Computer and Information Sciences
University of Strathclyde
rachel.sales@strath.ac.uk

Dr Marilyn Lennon
Reader
Department of Computer and Information Sciences
University of Strathclyde
marilyn.lennon@strath.ac.uk

Dr Martin Halvey
Reader
Department of Computer and Information Sciences
University of Strathclyde
martin.halvey@strath.ac.uk

Chief Investigator details:

This research was granted ethical approval by the University of Strathclyde Department of Computer and Information Sciences Ethics Committee, with ID number 1763.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the Departmental Ethics Committee
Department of Computer and Information Sciences,
Livingstone Tower
Richmond Street
Glasgow
G1 1XH
email: ethics@cis.strath.ac.uk

Note: The Livingstone Tower is currently not receiving post indefinitely due to COVID-19, so please contact the committee by email if needed.

Consent Form for Interview Participants

Name of department: Computer & Information Sciences
Title of the study: A preliminary survey to establish good engagement methods for co-designing future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS).

I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.

- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that I can request the withdrawal from the study of some personal information and that whenever possible researchers will comply with my request. This includes the following personal data:
    - survey responses that may contain personal information
- I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project. Yes / No

(PRINT NAME)	
Signature of Participant:	Date:

C.3 Study 3 Workshop Consent Form

Participant Information Sheet for Participants

[FOR USE WITH STANDARD PRIVACY NOTICE FOR RESEARCH PARTICIPANTS]

Name of department: Computer & Information Sciences.
Title of the study: A series of co-design workshops to design future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS).

Introduction

My name is Rachel Sales and I'm a doctoral student in the Department of Computer and Information Sciences at the University of Strathclyde. This research is funded by the Engineering and Physical Sciences Research Council (EPSRC).

What is the purpose of this research?

You will take part in a group workshop (some online via zoom and some in your own time digitally) in order to help identify guidelines for the design of future wearables used to monitor Postural Tachycardia Syndrome (PoTS).

Do you have to take part?

No, participation is voluntary. All participants have the right to withdraw from this research at any point without detriment.

What will you do in the project?

You will be expected to respond to a series of prompts (like questions or ideas) both individually (on your own) and collaboratively (with other participants) about your opinions of, experiences with, and the design of wearable technology specifically that might help with monitoring or managing PoTS. There will also be an optional Zoom video call (like an online workshop) for you to discuss prompts and responses with both the researchers and other participants and to troubleshoot any issues. All responses will be uploaded to OneDrive (a secure cloud based computer storage system which only the researcher has access to). Participants will receive a £50 retail voucher each upon completion of the workshop to thank them for their participation in the workshop process.

You are under no obligation to respond to any parts of the investigation that you feel uncomfortable with (you can answer some questions and leave others).

Why have you been invited to take part?

You have been invited to take part in this study as you are aged 18 or over and have Postural Tachycardia Syndrome (PoTS). You may already use wearable technology to monitor your condition, but this is not a requirement for participation.

What are the potential risks to you in taking part?

There is no physical risk to taking part in this study and care will be taken to reduce emotional distress where needed. This study is about lifestyle, but if the topics discussed cause you to feel worse about your condition(s) please talk to your family, support network, or doctor. We hope that this research will ultimately benefit your community.

What information is being collected in the project?

These workshops will ask participants about their opinions of, experiences with, and the design of wearable technology. There are no right or wrong answers. This will lead to a focus on how people might refine and improve this technology to better suit their condition monitoring needs and those of other people with PoTS.

Who will have access to the information?

Only my supervisors and I will have access to the data generated through this study.

Where will the information be stored and how long will it be kept for?

The data collected in this study will initially be stored on secure internal university systems (OneDrive). At the end of the study the anonymised data will be moved to Pure, the University of Strathclyde's research information portal. However, only a summary of the final data will be made publicly available on that data repository. All physical notes will be stored securely and later digitised. I will be following EPSRC guidelines which state that the data must be stored for at least 10 years.

The University of Strathclyde is registered with the Information Commissioner's Office who implements the Data Protection Act 1998 and all data will be processed in accordance with this.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Please also read our Privacy Notice for Research Participants.

What happens next?

This project will be written up and submitted for publication. It will also form part of my PhD thesis, and the results may be presented at seminars and academic conferences. I will inform participants upon the publication of this work.

If you do not wish to take part in this study, thank you for your time and attention.

After the study, participants can leave contact details to request project updates and final results.

Researcher contact details:

If you have any further questions about this study, feel free to contact any of the people below:

Rachel Sales
PhD student
Department of Computer and Information Sciences
University of Strathclyde
rachel.sales@strath.ac.uk

Dr Marilyn Lennon
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This research was granted ethical approval by the University of Strathclyde Department of Computer and Information Sciences Ethics Committee, with ID number 1811.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the Departmental Ethics Committee
Department of Computer and Information Sciences,
Livingstone Tower
Richmond Street
Glasgow
G1 1XH
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Consent Form for Interview Participants

Name of department: Computer & Information Sciences
Title of the study: A series of co-design workshops to design future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS).

I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e. how it will be stored and for how long).
- I confirm that I am aged 18 or over and that I have Postural Tachycardia Syndrome.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences. Data collected up until that point will be retained.
- By agreeing to take part I understand that the video and audio responses will be included in the analysis phase of the study only.
- All submitted data will be retained and stored privately and confidentially.
- I understand that anonymised data (i.e. data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project. Yes / No
- I consent to being audio recorded as part of the project. Yes / No
- I consent to being video recorded as part of the project. Yes / No

(PRINT NAME)	
Signature of Participant:	Date:

C.4 Study 3 Workshop Prompt Guidance

A series of co-design workshops to design future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS).

Prompts and Guidance.

General Guidance.

You will be expected to respond to a series of five prompts, both individually and collaboratively. There will also be an optional Zoom video call on day 4 of the study for you to discuss the prompts with the other participants face to face and to troubleshoot any issues arising. The collaborative elements of this study will take place on collaborative whiteboard software, either Zoom Whiteboard or Mural, which can also be integrated into the mid-workshop Zoom call.

Example prompt:

> *"List issues you have with the use of wearables for your own personal condition monitoring currently, then state the potential consequences of these issues. If possible, rank these issues by importance.*
>
> *If you wish, a mind map may be a suitable way to respond to this prompt."*

You can respond to these prompts in any way that suits you, as long as what you choose to upload is legible and a recognisable file type that the researcher can both download and open (please ask if you are unsure about a specific file type). Please upload an individual response for each prompt, whilst trying to also engage with the collaborative whiteboard.

(Potential response types include but are not limited to writing, drawings, diagrams, videos, audio recordings, photographs.) Each of the five prompt responses should take no more than 2 hours of your time, but preferably less than an hour.

These prompts have been designed so that they follow a specific and logical progression, but you can respond to them in any order that you wish. You will have access to all five prompts at once.

However, there is one strict deadline – please have submitted your individual response to prompt 1 by 23:59 BST on day 2 of the workshop. Submitting this prompt response aims to get you comfortable with the file uploading process, as well as practicing analytical skills that will be useful when responding to later prompts.

You will be uploading your individual responses to the prompts to a OneDrive folder. Please upload each prompt response as a separate file, file name format *ParticipantIDPromptNumberSection*.

As well as submitting individual responses, you will have the chance to share ideas and collaborate with other participants throughout this workshop via a Zoom Whiteboard (or equivalent software such as Mural). There will be a page on the whiteboard for responses to each prompt, as well as a page explaining how the whiteboard works.

Please engage with the whiteboard and any submissions on it in good faith and don't delete others' submissions. If you have any concerns or if you accidentally delete another's contributions, please contact the researcher as soon as possible.

As part of this workshop there will be a short Zoom call on the fourth day of the workshop, giving you a chance to troubleshoot any issues that you may have (e.g. with file types/file uploading), as well as a chance to talk to other participants about the prompts face to face, rather than just via the whiteboards. With your consent, this video call will be recorded.

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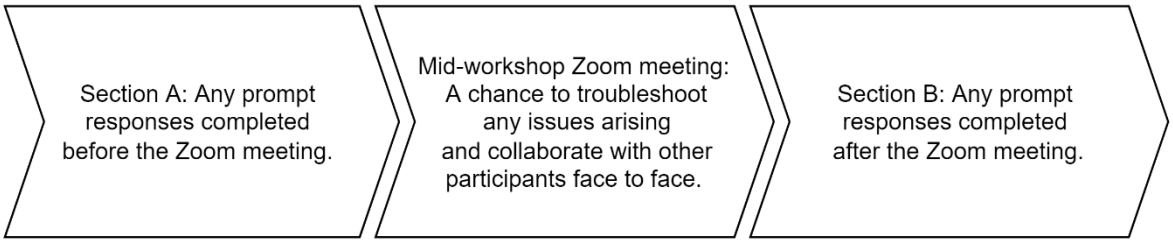
If you have chosen to upload a response to a prompt before the Zoom call and decide to edit it after based on the discussion had, please upload it as a separate file.

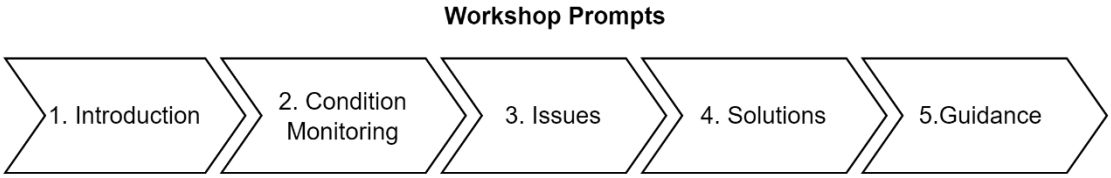


Study Timeline.

The suggested submission dates for individual responses to prompts 2-5 are for guidance only.

Day of Workshop	Suggested tasks
1	Workshop begins
2	Submit prompt 1 by 23:59 BST - **Compulsory**
3	Submit prompt 2
4	Zoom call
5	Submit prompt 3
6	
7	Submit prompt 4
8	Submit prompt 5, end of workshop

Prompts.



Prompt 1.

Rank the four seasons (Spring, Summer, Autumn/Fall, Winter) in order of preference. Why do you like the top one most and the bottom one least?

(The aim of this task is to get you comfortable with the file uploading process. It's also a chance to practice ranking and justification, both of which are useful skills for later prompts.)

Prompt 2.

Rank wearable device features (and/or features of an accompanying app) in order of priority to you when monitoring your PoTS (and other chronic condition(s)).

Examples of features include heart rate monitoring (data collected by the device), menstrual tracking (self-logged data), and alarms (alerts edited by the user).

Prompt 3.

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List issues you have with the use of wearables for your own personal condition monitoring currently, then state the potential consequences of these issues. If possible, rank these issues by importance.

If you wish, a mind map may be a suitable way to respond to this prompt.

Prompt 4.

What do you like about the use of wearables for condition monitoring?

What do you wish would be included in future wearables used for condition monitoring?

What solutions do you have to the problems you listed in response to the previous prompt?

List your answers to each of these questions.

Prompt 5.

Group your solutions from the previous prompt into categories.

Using these categories, come up with a series of guidelines for the creation of future wearable technologies that assist with the monitoring of PoTS. Come up with at least one guideline for each category.

For example, if you had a series of issues with device fit (e.g. uncomfortable straps, too loose etc.), a potential solution would be more adjustable straps in a greater range of materials.

C.5 Study 3 Workshop Support Toolkit

A series of co-design workshops to design future wearable technologies to assist with the monitoring of Postural Tachycardia Syndrome (PoTS).

User Guide/Toolkit.

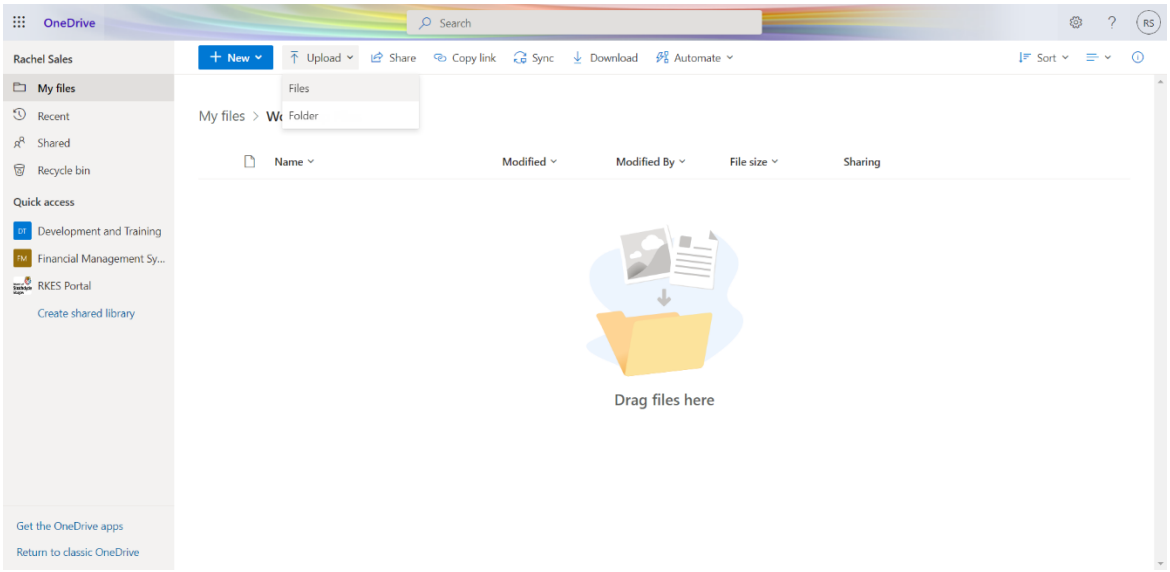
File Types.

You can upload any file type of your choice to OneDrive. If you choose to handwrite a response, please upload either a scanned pdf of the response, or a clear photograph, ensuring that all text is legible.

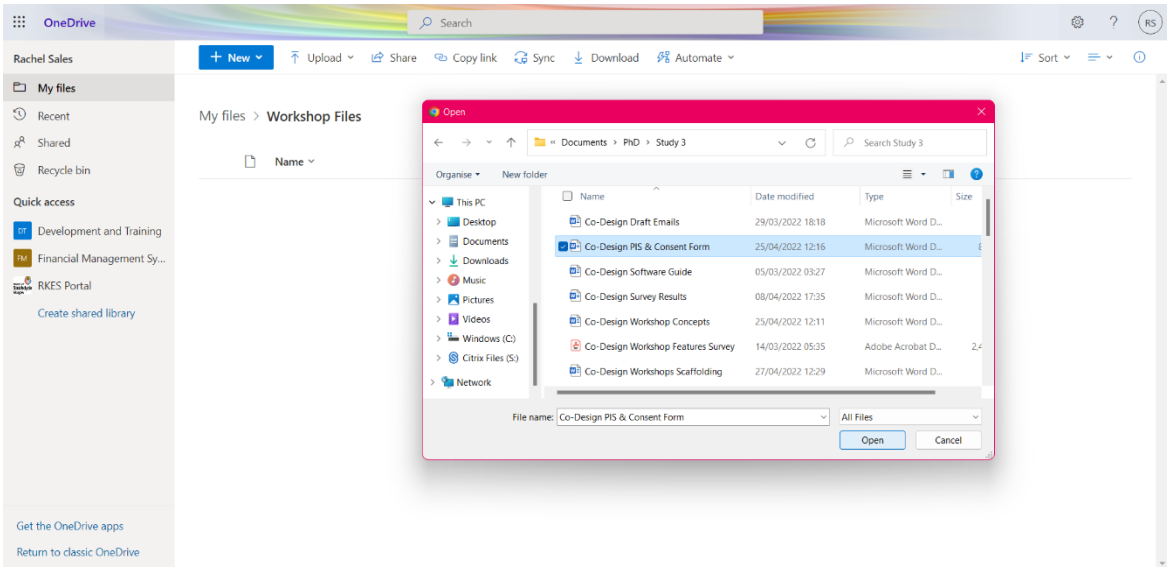
Uploading Files to OneDrive.

You will have been sent a link to a OneDrive folder where you can upload your prompt responses.

Click the button at the top of the folder that says “Upload” then select “Files” from the dropdown option that appears.



You can then select a file from your computer to upload.



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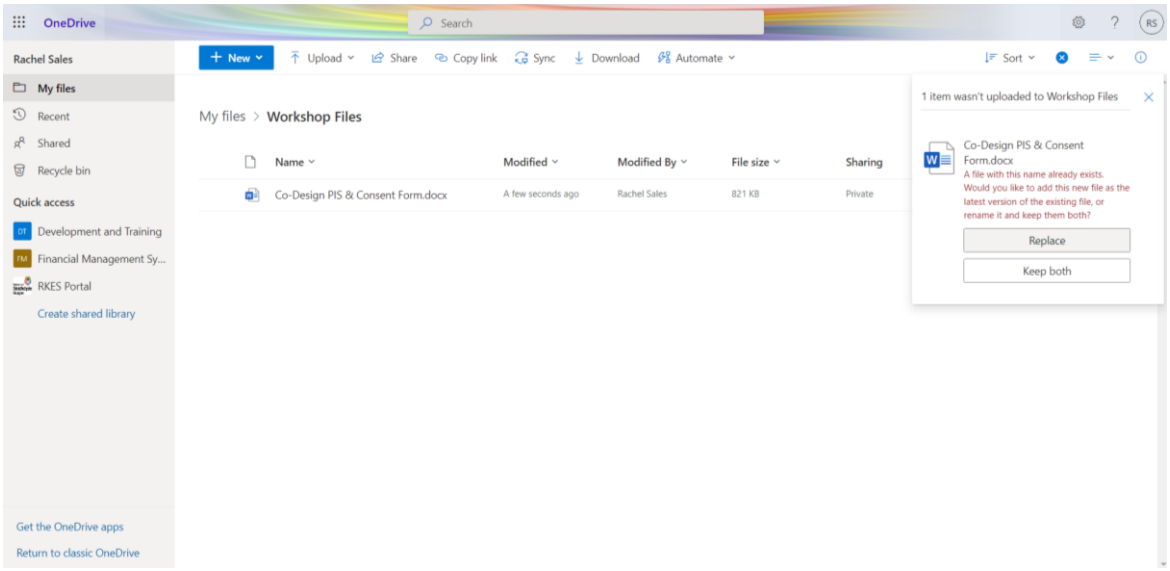
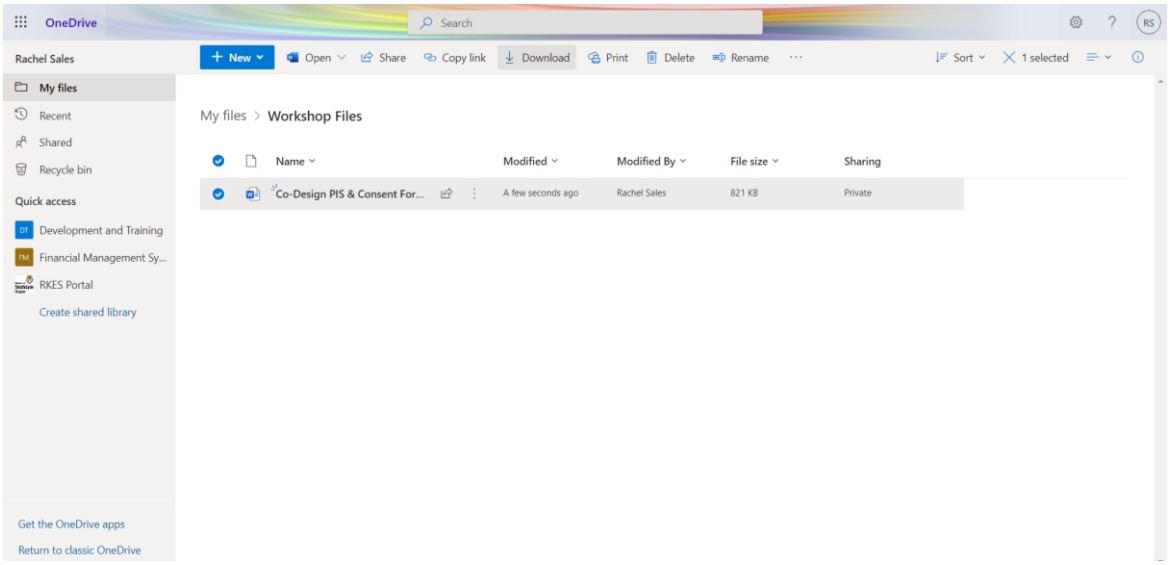
If you are uploading a file with an identical name to one previously uploaded, this will be flagged and the file will not initially be uploaded. You will need to click the alert on the right hand side of the window to confirm that you wish to replace the old file.



Downloading Files from OneDrive.

To download a file from OneDrive, first select it with the tick box to the left. Then click the button in the top bar that says “Download” and the file will begin downloading.



Using *[Whiteboard]* Software.

Throughout this workshop *whiteboard* software will be used to collaborate with other participants.

A guide to Zoom whiteboard controls can be found here: https://support.zoom.us/hc/en-us/articles/5304058491405-Zoom-Whiteboard-User-Guide#h_01G0140GBDZ688CT8TMQHXS9R5

An introductory guide to Mural: https://www.mural.co/blog/5-essential-skills-get-started-mural

An introduction to Zoom: https://support.zoom.us/hc/en-us/articles/4420426401037-What-is-Zoom-Video-Conferencing-

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C.6 Study 3 Workshop Zoom Call Notes

Miscellaneous Workshop Notes (Made During Zoom Calls).

Notes currently transcribed as is, clarity/dates to be added. Text in italics is added for context. Check against transcripts. These notes supplement the contents of the Zoom calls.

Sheet 1 – Group A Video Call.

- A – by end of Tuesday *(refers to group end date)*.
- It *(the Zoom whiteboard)* doesn't change pages with you!
- Annotating graphs – good.
- Annotation and contextualisation – good.
- Don't care about calories with diet tracking.
- Next time – get people to write more down?
- R take more notes?
- Customisability – own limits, below others'.

- Invite S to B's meeting? *(Comment on participant, potentially remove this.)*

- Change background assumptions. *(By companies?)*
- Accounting for broad range of experiences.
- Able-bodied assumptions of fitness.
- What would you like to achieve today?

- Introduce whiteboard and leave it for people to use after?
- Participant-centred discussions.
- Battery: brand-specific issue.
- Audience inclusivity while remaining up to date technologically.
- Not just athletes.
- Cohesiveness, power.
- Send whiteboard.

- Use prompts for discussion.
- Different overlays.
- Customisation – recognising that everyone is different.

- Apple Watch orthostatic tolerance test.
- Issue – requires standing for 2 mins.

Set 2 – Video Call B, titled "Group Workshop B".

- Zoom whiteboard – wee bit of a nightmare in my humble opinion.
- Medication systems can be complex.
- Variety of opinions on alarms – can use other devices.
- Mention Roe v Wade repeal as a factor – US menstrual tracking accuracy issues.
- Add guide to standard wearable features in thesis.
    - Categorisation (see prompt).
    - Who defines what is standard?
- *Brands participants have experience with:* Samsung, Xiaomi (app updates reset settings), Fitbit.

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- Allergies/Allergens.
- Mention materials.
    - Band switching helps.
- What is a standard wearable?
- Assumptions of standard user groups for wearables?
- Desire to try the ring from one participant – doesn't rub.
- What is 'good' battery life?
- Charging when heartbeat is most regular/when you know you're doing nothing.
- Customisability. *Pretty sure this section refers to desired features.*
- Fast charging!
- Universal charging? Greater charging compatibility.
- Accuracy.
- Fitbit underestimating HR?
- Cost – not an issue for one person but she chooses to be cheap.
- List of mentioned clinicians – add sleep doctor.

Set 3 - Video call C.2 (4th and final video call).

- 2 participants.
- Chest strap discussion.
- HR x2. *Priority/most used?*
- Fitbit users – kinda convoluted.
- Profession based wearing *(nurse)* – bare below the elbow.
    - Chest strap could work.
- *Low priority/Less important:* ↓ stress monitor – not much use.
- Chest based Kardia?
- Comprehensive recording v attitude change.
- What data can you afford to lose? *Refers to when participants choose to charge devices.*
- Charging v. water resistance?
- Keen on prescribed medical device.
- Both favour screen. *Wider theme/discussion on screen v no screen in ideal device.*
- Maintenance of condition while exercising.
- Would like to strip settings down to optimise battery life.
- Fitbit – thought more suitable for PoTS.
- Calorie logging – can be useful.
- Can help with establishing a routine.
- Hydration + sodium + water.
- Cardiogram/Kardia?
- Routine.
- Pip – stress management device (Kickstarter, obsolete).
- Flowly.
- PoTS journal – Amazon.
- Digital v paper tracking.
- Not expecting consistent input logging because brain fog, which is why having the tracking done for you can be good.
- Spacing between appointments.
- Long Covid *potentially* reducing diagnostic times? ← Check this.

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- Dysautonomia International funding ↑↑ because Covid.
- Cost of wearables v. cost of appointment?
- Hope for market and cater to needs.

- Who was away?
- K whiteboard.