



Identify, Adapt, Persist: The Journey of Blind Individuals with Personal Health Technologies

JARRETT G.W. LEE, University of Maryland, College Park, USA

BONGSHIN LEE*, Yonsei University, Republic of Korea

SOYOUNG CHOI, University of Illinois Urbana-Champaign, USA

JOOYOUNG SEO, University of Illinois Urbana-Champaign, USA

EUN KYOUNG CHOE*, University of Maryland, College Park, USA

Personal health technologies (PHTs) often do not consider the accessibility needs of blind individuals, preventing access to their capabilities and data. However, despite the accessibility barriers, some blind individuals persistently use such systems and even express satisfaction with them. To obtain a deeper understanding of blind users' prolonged experiences in PHTs, we interviewed 11 individuals who continue to use such technologies, discussing and observing their past and current interactions with their systems. We report on usability issues blind users encounter and how they adapt to these situations, and theories for the persistent use of PHTs in the face of poor accessibility. We reflect on strategies to improve the accessibility and usability of PHTs for blind users, as well as ideas to aid the normalization of accessible features within these systems.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**; **Empirical studies in accessibility**; *Smartphones*; *Mobile devices*; Auditory feedback; • **Applied computing** → **Health informatics**.

Additional Key Words and Phrases: Personal Health Technologies, Blindness, Low Vision, Accessibility, mHealth, Screen Reader, Personal Health Data, Vision Impairment

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1 INTRODUCTION

Over the last decade, personal health technologies (PHTs) have become an increasingly important health management tool [2, 62]. These technologies—including mobile health (mHealth) apps and exercise and medical devices—have made it easier for people to collect health data, such as physical activity, sleep, diet, blood pressure, and glucose levels. The adoption rate of smartphones is 85% [52], and nearly two-thirds of US adults have used mHealth apps [35]. Meanwhile, about 35% of Americans have adopted wearables [74]. Substantial research has shown the effectiveness of these PHTs for monitoring health status, managing chronic diseases, and promoting a healthy lifestyle (e.g., [20, 47, 49]).

*Co-corresponding authors.

Authors' addresses: Jarrett G.W. Lee, jgw1@umd.edu, University of Maryland, College Park, College Park, Maryland, USA, 20740; Bongshin Lee, b.lee@yonsei.ac.kr, Yonsei University, Seoul, Republic of Korea; Soyoung Choi, soyoung@illinois.edu, University of Illinois Urbana-Champaign, Urbana, Illinois, USA; JooYoung Seo, jseo1005@illinois.edu, University of Illinois Urbana-Champaign, Urbana, Illinois, USA; Eun Kyoung Choe, choe@umd.edu, University of Maryland, College Park, College Park, Maryland, USA.

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However, PHTs meant to empower people and democratize healthcare inadvertently created more barriers for people with disabilities, widening the health disparity gap [70]. These technologies are predominantly created with sighted individuals in mind, leveraging graphical user interfaces and visual feedback for data collection and reflection. This restricts the accessibility and usability of PHTs for blind users¹, potentially compromising their equitable access to personal health data and healthcare services.

The prevalence of smartphones led research communities to examine challenges and solutions related to overall mobile app accessibility (e.g., [22, 54, 65, 66]). However, PHTs present distinct characteristics that are different from other mobile apps. Many PHTs are “personal informatics systems” wherein users go through several phases—preparation, data collection, data integration, reflection, and action—each posing unique challenges that cascade to the next phase [37]. Unlike other mobile apps, they usually require frequent interactions for the input and review of data on a daily basis. The data PHTs collect and handle are inherently personal and private. In addition, users are commonly expected to configure and use both hardware and software functionalities together.

Researchers have started to investigate the accessibility barriers of mHealth apps for blind users through app analyses [28, 42] and survey [32]. From the analyses of nine iPhone mHealth apps, Milne et al. found that none of them met the basic guidelines provided by Apple and Section 508² for being accessible to blind users [42]. Based on the four principles of the Web Content Accessibility Guidelines (WCAG) 2.1—perceivable, operable, understandable, and robust—Kim identified several accessibility problems of five mainstream self-care apps [28]. Our research group recently performed a survey with 156 blind users to learn about their personal health data tracking experiences, reporting a broad range of barriers to tracking personal health data primarily due to the tools’ vision-centric designs [32]. It is noteworthy that, despite many reported challenges, some blind respondents showed a high level of satisfaction with their tracking systems. Due to the close-ended nature of the survey study, it remains unclear why some blind users find personal health data tracking “satisfactory,” what workarounds they employ, what challenges and barriers persist, and how they identify accessible tools. To gain a deeper understanding of blind users’ full experience with these and other forms of PHTs, we conducted an interview study with 11 screen reader users who have been using PHTs for an extended period of six months or longer. Specifically, we aimed to answer the following three research questions:

- **RQ1. How do blind individuals find accessible personal health technologies?** We are interested in how our participants began tracking their health data—exploring both the factors influencing their decision to track and how they initially found the devices and apps that made up the system they found accessible and usable. We aimed to examine how new technology is discovered and what usability & accessibility factors are considered by blind individuals when choosing a system.
- **RQ2. How does the existence or lack of PHTs’ accessibility features influence blind users’ experience in terms of data collection, reflection, and sharing?** To obtain insights into actual usage, we asked participants to share their mobile screens and demonstrate their routine interactions with PHTs. From our observations and the participant’s own stories, we sought to learn about subtle accessibility challenges and real-world usages that are hard to obtain from app analyses.
- **RQ3. What aspects of personal health technologies affect blind users’ continued use?** With the goal of aiding blind users to continue using PHTs and subsequently gaining their benefits, we investigated factors that help sustain usage despite such technology often overlooking their specific needs.

¹The term “blind users” here represents individuals whose “sight is bad enough—even with corrective lenses—that they must use alternative methods to engage in any activity that people with normal vision would do using their eyes” [45]. Throughout this paper, we use this identity-first language (i.e., blind users) instead of person-first language (i.e., people who are blind) because both our community partner, the National Federation of the Blind, and the blind author of this paper view blindness as identity rather than any negative characteristic that defines one or one’s future.

²U.S. government requirement for electronic and information technology to be accessible to people with disabilities.

The key contributions of this paper are twofold. First, we report on blind users' lived experiences of using PHTs for extended periods of time, including their techniques in identifying accessible technology, accessibility issues they encounter and how they adapt to these situations, and theories on why blind users persist to use PHTs in the face of poor experiences with accessibility. Second, we provide design considerations to improve the experiences of blind users using PHTs as well as strategies that may help designers and developers create PHTs with a greater level of accessibility.

2 RELATED WORK

2.1 Personal Health Technologies' Impact on Health Disparities

Personal health technologies (PHTs) can play a significant role in bridging health gaps and enhancing health outcomes among marginalized populations. Numerous studies point to the success of mHealth strategies in expediting access to healthcare and bolstering the availability to services for chronic illnesses [23]. Moreover, these strategies promote preventive measures and health literacy in communities facing health inequities [1]. While mHealth technologies hold potential for healthcare advancement, they may inadvertently widen disparities, especially between individuals with and without disabilities [25]. Despite its advantages, this digital innovation frequently has design limitations that hinder accessibility for those within marginalized populations, including people with disabilities, exacerbating health and healthcare disparities [71].

Within the spectrum of disabilities, the visual disability community including blind individuals remains notably under-researched. Globally, over 2 billion people live with low vision and blindness [63] and they are 1.5 to 2 times more likely to suffer from chronic conditions such as hypertension, heart disease, high cholesterol, stroke, arthritis, asthma, cancer, kidney disease, diabetes, hepatitis, depression, hearing impairment, and chronic obstructive pulmonary disease compared to those without visual disabilities [13, 30, 41]. The prevalence of low vision and blindness increases with age, indicating that these conditions will become more common as the global population ages [9]. Despite the evident health disparities affecting this minority group, advancements in personal health technologies frequently fail to accommodate their specific needs, underscoring a critical gap in accessibility and inclusivity in health technology development.

2.2 Blind Individuals' Use of Personal Health Technologies

PHTs can be viewed as a subset of personal informatics (PI) systems that aim to assist people in collecting and reflecting on their data. Within HCI, extensive research has examined how individuals use these PI systems [18, 43]. In 2020, Epstein et al. surveyed over 500 PI articles that have been published since 2010, but the majority of their target audience were the general public [18] (several systems and studies targeted older adults; we do not consider older adults as people with disability [29] unless the research with older adults is focused on a specific disability). Topics intersecting PI and disability did not surface frequently in this review, with only a handful of papers on people with motor disabilities being captured (e.g., [6–8, 39]). In 2022, Motahar and Wiese conducted a subsequent mapping review, emphasizing PI research that catered to individuals with motor disabilities stemming from a variety of conditions, including spinal cord injury, multiple sclerosis, stroke, and Parkinson's disease [43]. This work highlights research gaps in PI and offers design guidelines for more inclusive PI systems based on Universal Design principles.

In particular, blind users face significant accessibility challenges with PI systems, primarily due to the technology's deeply ingrained vision-centric features. Although HCI research focusing on blind users' use of PI systems remains sparse, notable studies have been published from the assistive technology (e.g., [16, 28, 38, 42, 68]) and health informatics (e.g., [25, 32, 50, 69]) communities. These studies examined blind users' interaction with PHTs, including mHealth apps and medical devices. Radcliffe et al. conducted a pilot evaluation of mHealth app accessibility for weight management in three disability groups (i.e., vision, dexterity, cognitive impairment) [50].

Their findings indicate that participants with visual impairments consistently provided the most unfavorable accessibility ratings, reflecting the substantial challenges blind users face in interacting with mHealth apps.

To gauge the state of app accessibility, researchers have conducted app analyses [15, 28, 42], often evaluating a small number of representative health apps using accessibility frameworks and guidelines such as Section 508 and WCAG. Both Milne et al. and Kim's work highlight significant accessibility violations, indicating a lack of attention in making mHealth apps accessible to blind users. Lee et al. recently surveyed 156 blind users to understand their personal health data tracking experiences, uncovering a broad range of barriers to tracking this data, stemming from the technologies' vision-centric designs [32]. While such app analyses and surveys shed light on accessibility issues, they do not fully capture the lived experiences and challenges that blind users face when collecting and reflecting on personal health data, owing to methodological limitations. Furthermore, despite many reported challenges, some blind respondents expressed a high level of satisfaction with their PHTs, indicating long-term usage and successful adoption of PHTs. Previous research in PI [12] suggests that expert users' experiences can offer valuable design insights. Their workarounds can serve as potential avenues for innovations, and the challenges they face are more daunting for non-expert, 'mainstream' users. This led us to conduct an interview study targeting seasoned blind users of PHTs to delve deeper into their experiences.

2.3 Mobile App Accessibility

As mobile phones are becoming an integral part of people's lives, research communities have examined the accessibility of mobile apps and explored innovative ways to improve them. A survey conducted in 2017 provides a comprehensive review of the touchscreen accessibility for people with visual impairments (PVI) [22]. The survey presents various solutions that have been explored and highlights many remaining issues with touchscreen interaction that hinder full inclusion. More recently, a scoping review on smartphone use by and for PVI points out the value of smartphones as an effective and affordable assistive technology for PVI while emphasizing the lack of training and learning support of their use [66].

As manual accessibility evaluations are laborious and difficult to scale, researchers sought automated accessibility testing approaches [60, 61]. For example, the MATE tool automatically generates and performs tests to check the accessibility of mobile apps related to visual impairments [17]. Researchers also conducted large-scale studies examining many apps to explore the accessibility issues at a population level [21, 55–57]. Drawing inspiration from epidemiology, Ross et al. presented a conceptual framework for assessing mobile app accessibility [55]. Through a preliminary application of their framework to 100 popular Android apps using Google's Accessibility Scanner, they reveal common accessibility errors and their co-occurrences, suggesting potential interactions or underlying influences between the errors. Ross et al. also assessed three classes of image-based buttons for label-based accessibility barriers in 5,753 apps [56]. Then they extended the work by examining about 14K classes of screen elements of nearly 10K apps for seven accessibility barriers [57]. Following this line of research, Fok et al. performed a large-scale longitudinal analysis of the missing label issue with the data collected by crawling 312 Android apps on a monthly basis over 16 months [21].

To understand blind individuals' experiences and needs, past research employed surveys, interviews, diary studies, etc. [27, 53, 54], complementing large-scale app analysis. For example, Kane et al. conducted an interview study with 20 participants with visual and motor disabilities, followed by a week-long diary study with 19 participants to examine how people with visual and motor impairments select, adapt, and use mobile devices in their daily lives [27]. Rodrigues et al. presented an in-depth discussion on the challenges blind people face when using smartphones, focusing on touchscreen access [54], which extends their earlier investigation on the challenges, needs, and coping strategies conducted with five visually impaired novice users over eight weeks [53]. They employed multiple research methods in three studies conducted with both novice and expert blind users. Following these footsteps, our work complements the analysis of mHealth apps [15, 28, 42] and survey [32]

with the interviews of seasoned blind users of PHTs. Going beyond conventional interview methods that rely on memory recall or focus groups based on reactions to unfamiliar apps, we strove to learn blind users' lived experiences [51] with PHTs. We observed via screen sharing how experienced users interacted with PHTs they have been using for an extended period.

3 METHODS

To speak with a broad group of users, our study design focused on using internet videoconferencing to hold our semi-structured interviews with our participants. In this section, we describe the recruitment process, the interview procedure, and the data analysis for this study. This study received approval from the Institutional Review Board of the University of Maryland, College Park (#1929357), ensuring all research procedures adhered to ethical standards and guidelines.

3.1 Recruitment and Included Participants

We employed a convenience sampling strategy from an existing participant pool originating from a prior survey study with blind users (recruited from Facebook groups and the National Federation of the Blind). The survey focused on people's interests and barriers related to PHTs, and a subset of individuals indicated interest in being contacted for future research studies. Given the differences in study methods and a substantial time gap between the two studies, we anticipate minimal, if any, carryover effect or bias.

We recruited interview candidates by email, introducing our study focus, listing inclusion criteria, and briefly explaining the study procedure. Any individuals who responded in interest were directed to a Qualtrics screening questionnaire designed to ascertain their eligibility based on the inclusion criteria. Our study's inclusion criteria were as follows: (1) Engagement with a technology-based system for tracking personal health data for at least three months, ensuring participants had meaningful experience with PHTs. Ultimately, all of our participants had at least six months of engagement; (2) Possession of the necessary equipment for a video conference, including a computer with a stable internet connection, webcam, microphone, and Zoom software, and a willingness to use video, audio, and screen-sharing functionalities. This requirement was crucial to enable us to observe their PHT interactions; (3) Consent to have both audio and video recorded during the interview; and (4) Capability to capture photographs or videos of devices used for health tracking, offering deeper insight into their PHT configurations. After a pilot session with a low-vision individual, we were reminded of how individuals who use different forms of adaptive technologies have different experiences and needs. Wishing to not co-mingle the experiences of all blind users, we chose to add an additional inclusion criterion to focus our research: (5) Use of screen reader as main assistive technology.

We curated a subset of participants from the pool, taking into account their gender, age, educational attainment, degree of visual impairment, and variety of PHTs. Qualified participants were formally invited to join the study and were presented with a comprehensive consent form delineating the research protocols. Both the screening tool and the consent form were validated for accessibility by a blind member of our team, who relies on screen readers. As all respondents had already self-identified as having low vision or being blind in the earlier study, this aspect was not reiterated in our recruitment efforts. Besides our pilot participant, 11 participants (Table 1) completed the interviews, ranging in age from 32 to 65 (average: 48.2), and with use of their personal health technology from 6 months to 11 years (average: 3.6 years). All participants except one (P3 from Australia) were based in the United States.

3.2 Interview Design

Our research interests included both obstacles when accessibility was not considered and benefits when such considerations resulted in accessible tools. We worded our interview questions to be open to either scenario,

Table 1. Details of participants interviewed for study.

	Gender	Age	Highest Education	Visual Impairment	Personal Health Technologies	Motivation	Use Duration
P1	Female	56	Master's degree	Blindness with light perception	Weight: Smart scale Activity: Fitbit and its synced app, Apple Watch and Apple Health Oxygen saturation: Digital oximeter	Health improvement	5 years
P2	Male	43	Master's degree	Blindness	Physical activity: Fitbit and its synced app Body weight: Talking scale	Continuation badges & milestones	6 months
P3	Female	65	Highschool graduate	Blindness with light perception	Physical activity: Runkeeper, Apple Watch and Apple Health, Sole Treadmill	Preventative health monitoring	11 years
P4	Female	43	Master's degree	Low vision	General health/Physical activity: Fitbit and its synced app (no longer in use) Body weight: Smart scale Sleep apnea: CPAP machine and: MyAir Medical records: MyChart	Health monitoring & self diagnosis of symptoms	9 years
P5	Male	59	Master's degree	Low vision	Food: MyFitnessPal (no longer in use) Mental health: AbleTo (no longer in use) Blood glucose level: Accu-Check Exercise: Seconds	Health tracking & improvement	> 1 year
P6	Non-binary	40	Bachelor's degree	Low vision	Water intake: Water Minder Physical activity: Fitbit and its synced app (no longer in use), Apple Watch and Apple Health Body posture: Upright (no longer in use) Daily goals: Habitica Health: Apple Health	Health monitoring & improvement	> 2 years
P7	Female	60	Doctorate or professional degree	Low vision	Physical activity, vital signs: Apple Watch and Apple Health Food: MyFitnessPal (no longer in use)	Preventative health improvement	6 months
P8	Male	50	Master's degree	Low vision	Blood glucose level: Abbott Libre Physical activity: Google Fit	Health monitoring & improvement	1 year
P9	Female	37	Highschool graduate	Blindness	Menstrual cycle: Apple Health (no longer in use), Apple Notes Physical activity: Apple Health	Health recordkeeping	2 years
P10	Male	32	Bachelor's degree	Low vision	Physical activity: Fitbit (no longer in use), Strava (social), Apple Watch	Team sports & continuation milestones	6 years
P11	Female	45	Bachelor's degree	Low vision	Exercise, sleep: Apple Watch and Apple Health Body weight: Talking scale, MyFitnessPal Food: MyFitnessPal	General activity tracking & curiosity	1.5 years

allowing the participants to freely share how their experiences with PHTs had been. The interview's question topics were: (1) Why did I decide to track? (2) How did I learn how to use my system? (3) How did I capture data? and (4) How did I review the data and what did I learn?

3.3 Setup and Procedure

Before the scheduled interviews, we asked participants to provide images of personal health devices and apps they employed, along with the names of the apps in use. This allowed us to familiarize ourselves with the devices and apps in advance, ensuring that our interview could focus on participants' experiences rather than the specific features of each system. We held 90-minute semi-structured interviews with each participant, scheduled at their convenience. At the beginning of each session, we asked the participants to connect to our interview session both from a computer for their audio and video, and from their phone for sharing its screen so that we could observe their use of their mobile apps. Because audio from a mobile phone's screen reader does not transmit

to videoconference software, we asked our participants to turn on screen reader captioning to follow along on screen. With the participants' consent, we recorded the Zoom session for subsequent analysis.

We began the interview by learning about the participant's background, including their tech proficiency and vision status. We then explored what influenced them to use PHTs, how they learned about the components in their system, and what factors led to those components being chosen over others. From there, we asked the participant to share the use of their PHTs, using screen sharing for apps and the video camera to demonstrate their devices. When relevant, this included apps they had stopped using, if still installed on their phone. During this time, we asked questions about their use of the tracked data, their level of satisfaction with their system, and their suggestions for improving the usability of each component. After the completion of the interview, participants were given a \$50 gift card as a token of appreciation for their participation.

3.4 Data Analysis

We chose to use a Reflexive Thematic Analysis approach [4], with our belief that its promotion towards richness of data rather than coding reliability, and its recursive process of generating and revising themes would provide a deeper analysis of our interviews. To begin, we transcribed the recordings of all interviews, only filtering out vocalized pauses and duplicated words. Three researchers independently coded the first two interview scripts inductively, and we met as a group to discuss our codes and explore initial candidate themes. We ran an iterative process of continuing to inductively code newer interviews and to hold regular meetings to discuss the different ways themes could be generated. We also used smartphone screen recordings from participants' app usage in our interview script analysis. To assist our analysis of how our codes could connect, we drew a thematic map [5] to explore related observations. Finally, after consensus towards an outline of themes generated from our coding, we proceeded to write up our findings while continuing to work and adjust these themes in response to our group discussions.

4 FINDINGS

Aligned with our study motivation and research questions focusing on blind users' use of PHTs, we prioritize reporting accessibility issues specific to the PHT context. However, our participants also reported many well-documented accessibility issues found in prior work, including our prior survey study. We confirmed the existence of general mobile app accessibility issues in PHTs, including inaccessible graphics or graphical components [28, 42], silent display change caused by unintentional selection [54], accessibility breakdown by app updates [54], missing or incorrect labels/descriptions [28, 42, 54, 55], difficulty discerning whether information is inaccessible or not present [3], and information overload [28]. Our selective reporting approach, focusing on pronounced issues in PHT use, in no way diminishes the significance or prevalence of other general accessibility issues.

4.1 RQ1: Finding and Evaluating Accessible Systems

Before being able to use PHTs, blind individuals need to find a system that meets both their health needs and their accessibility requirements—part of the *preparation* stage in the Stage-Based Model of Personal Informatics Systems [37]. To expand upon the *Knowledge Void* challenge reported by Rodrigues et al. [54] and to build on initial findings around researching and acquiring mobile devices [27], we present our findings on how our participants found suitable systems and performed their testing.

4.1.1 Identifying Candidate Systems. Here, we present sources used for finding accessible systems, and what details blind individuals pay attention to when making their decisions.

Shared Knowledge within the Blind Community. The blind community often shares information about accessible systems with each other (e.g., blind organizations' recommendations, personal advice from blind peers). Many of our participants mentioned learning about PHTs through information from organizations focused on

the needs of blind individuals, such as nationally distributed podcasts and blogs, conference sessions, companies dedicated to selling accessible items, and in-person help from local groups like The Lighthouse for the Blind. In some cases, the introduction of an accessible system becomes the origin of the decision to use PHTs to track their health data. For example, four participants mentioned how their tracking routines originated from a program sponsored by the US Association of Blind Athletes, which had given away free Fitbit devices to promote activity in blind individuals.

Both traditional and newer forms of media can be a source of information where users learn about accessible technology. P9 discovered screen reader technology through a segment on television, which led her to find a training center to learn about more accessibility tools. Four participants mentioned learning about their accessible PHTs from blind social media influencers' content.

Additionally, blind peers who have already tested a system and are willing to vouch for its effectiveness share their experiences directly with each other. This can be over the internet, such as on listservs like the National Federation of the Blind's "SportsandRec" list, Discord servers, and subreddits, or in-person for those with a local group of peers. Shared experiences can make a difference, as P4 contrasts between her blind friend's recommendation and a prior introduction from her doctor's office: "...when [medical staff] said, 'Oh this MyChart is gonna be so much better.' I thought you know, eh, maybe it will, maybe it won't. But until my friend really told me, 'Oh my gosh, these are the things I can do with it, and this is why I like it,' I don't know that I would have tried that on my own."

Researching Options on Their Own. Some individuals do not have access to the advice of others in choosing a suitable PHT or prefer a personalized decision. In these situations, blind individuals conduct independent research to find possible solutions for their tracking desires. Some begin with a search query, whether through a general-purpose search engine, an online merchant's search bar, or one for their device's app store. Our participants mentioned searching for functionality first, rather than accessibility.

Once a product's feature set meets their tracking needs, the user can examine if the product listing describes its accessibility. For some categories, accessibility is inherent in the type of product itself, such as talking scales. But for many other products not designed with blind individuals in mind, accessibility is not directly mentioned in a system's store listing or marketing. Blind individuals need to read between the lines, seeking clues to accessibility to circumvent the lack of direct information in product descriptions and reviews. For physical systems, this may be references to a companion app or Bluetooth capabilities, which hint at compatibility with a mobile OS screen reader. Other indicators are product traits that individuals anticipate being incompatible with their disability.

However, sometimes discovery of a tool is incidental and not the result of a planned search; a third of our participants discovered PHTs simply by exploring the base applications pre-installed on their phone, such as P8: "[Google Fit] was default. It was sitting on the phone... I might as well just use what's on the phone." The finding and exploration of such apps became the initial motivation that encouraged a few participants to begin using PHTs.

Medical Guidance without Accessibility Considerations. Results from a medical visit might influence a blind individual to personally seek out a PHT system, but doctors, therapists, and other medical staff may also directly recommend specific systems that aid given health needs. Unfortunately, this recommendation might be given without an understanding of the systems' accessibility, and our participants reported needing to figure out on their own whether these recommended systems were accessible and usable by them. Health insurance can also be an early filter when determining which systems are up for consideration, as many individuals are limited to systems that are covered financially. Regrettably, these choices can also be ignorant of accessibility needs—surprisingly, even for Medicare, the U.S. government health insurance program covering those with disabilities. P5 shares his frustration with AbleTo, a mental wellness app he found completely inaccessible: "But it was approved by Medicare. Now, there you go. Here's a product and service that the U.S. government is endorsing that is not accessible. So it doesn't comply with its own Section 508 requirements."

4.1.2 Testing Systems for Accessibility. Once a product candidate is identified, blind individuals generally perform a ‘testing’ phase, determining if the product provides accessible methods for the PHT features advertised by manufacturers. We share various strategies that are used to make this assessment, along with scenarios that hinder this effort.

Taking Advantage of Trials. While trialing [33] is a reported technique for many users of personal informatics, this holds special importance for blind individuals who may not know the accessibility levels of the product before purchasing. However, some apps do not offer a trial, and physical items usually require purchase before use. When blind individuals have guessed on the product’s accessibility features, this can be a disappointing, albeit expected, event. P1 shares her experience: “...a lot of the time it’s hit and miss. Like with the oximeter, even though it had Bluetooth capabilities and an app, because I couldn’t download the app prior to the purchase. I just thought, well I had good luck, you know, so I took a gamble...eh, it wasn’t a great gamble.” In response, some blind individuals have developed a policy of only using apps that provide a free trial.

Relying on Conventions and Conformality. User interface (UI) conventions allow people to apply their prior knowledge of navigation and data entry towards new apps. Blind individuals benefit from the use of such conventions, as they reduce the task of conceptualizing the content of an app, which can be difficult without visual affordances. Many participants mentioned testing for standard design pattern expectations when using an app for the first time, such as exploring for tabs at the bottom of the screen or starting with a menu-opening gesture to test for its existence. If available, these contents could then be reviewed to understand the general structure of the app.

Another convention used in accessibility testing is attempting to use features designed for the distinctive mechanisms of the accessibility tools themselves. For instance, P10 attempts VoiceOver rotor commands with new apps, where success becomes a “tip-off” to gauge if the development team is familiar with designing software compatible with Apple’s accessibility tools.

Ascertaining Understandability. Although screen readers have been invaluable in enabling computing resources to blind users, they are reliant on being fed correct information, which may or may not be present for a given app. Blind users thus assess if the description of buttons, tabs, and other controls makes sense. Beyond the comprehension of individual items in an app, blind users need to determine if they can understand the general output of a screen reader’s interpretation of an app. This might be a quick test if output is garbled and obviously incomprehensible, but partially comprehensible screens are a judgment call, especially when a screen reader’s output is the sole source of truth for the user.

There are times when comprehension difficulty is not due to screen reader errors but unfamiliar terminology. PHTs might use health and athletic jargon, e.g., exercise-specific acronyms such as a swim app using an unfamiliar swimming “SWOLF” metric, or tracking concepts new to the user, such when our participants did not understand Apple Health’s rings concepts being portrayed as “moving 1%.” Therefore, when blind users explore an app, each unknown word becomes an ambiguous judgment as to whether their confusion is due to accessibility issues or merely the clarity in which the PHT concepts are portrayed.

4.1.3 Deciding on a System. For systems that can be tested beforehand, accessibility obviously plays a factor in deciding to choose a system for use. A system’s compatibility with other health factors is considered, such as a talking scale needing a longer stepping-onto grace period for someone using a walker, or apps being calm enough for P6’s ADHD.

Blind users may find themselves having successfully tested two similar systems for accessibility, or they may need to decide between two systems with physical aspects that cannot be trialed. Our participants mentioned considering common concerns such as privacy, feature sets, and simplicity when deciding between multiple apps.

However, the reputation of the system's parent company's accessibility also helps form an opinion. Several of our participants chose Apple products due to their expectation of Apple's accessibility over others.

PHTs are not only compared against other systems designed for the same purposes but also against the tried and tested solutions that blind users have already validated in the past. Some participants weighed the difficulties of the specialized PHT systems they tested over the benefits such specialization provided and decided to find other means of accomplishing their goals. P3 turned to using her Google Home voice assistant for food nutritional information rather than using an app, P5 resorted to mentally tracking his food intake after being frustrated by attempts to enter information into MyFitnessPal, and P9 chose to track her menstrual cycle with a text-based notes app that she already used, due to her poor experiences with apps designed specifically for that purpose.

4.2 RQ2: Unique Interactions with PHT Data

Once PHT systems have been selected by a user, the iterative stages of *collecting* and *reflecting* on one's data begin [37]. In some cases, the user *shares* the collected data with other stakeholders such as clinicians [10, 46]. In this section, we share how these stages and other unique interactions with PHT data are affected for blind users when accessibility with a screen reader is considered or ignored.

4.2.1 Affecting Data Collection Accuracy. The accessibility of data collection can affect the accuracy and utility of the data, or it might impact the *reactivity* of the overall self-tracking—the extent to which the frequency of the target behavior changes as a result of self-tracking efforts [44]. Our participants shared instances where accessibility problems negatively affected various aspects of their data, at times disrupting the very purpose of tracking altogether.

The Importance of Timely Recordings. When PHT data is collected is an important factor; prior literature has discussed how users may not have the time or schedule to collect data on a timely basis and how data quality is negatively affected [26, 37]. However, our participants shared incidents where they were ready to collect data but were delayed by issues in their PHT setup. A timing delay of even minutes can threaten data integrity: bodily measurements like blood pressure can vary throughout the day [64], or the user may want to capture a specific episode. While some PHTs support accessibility, i.e., exposing all elements on a screen, *efficiency barriers* [54] delay or inhibit blind users' ability to reach specific functionality. This in turn could prevent timely data collection from occurring, with a variety of repercussions.

Our participants shared how they used PHTs as a tool to better understand one's body, using measurements from biofeedback sensors. For instance, P3 was cognizant of her heart's health due to a recent health issue and used her Apple Watch's cardiac monitoring features to check on her measurables when she was feeling unwell. However, reaching this functionality in a timely manner may be challenging, as illustrated by another participant's difficulties in using his screen reader to reach his ECG functionality. Due to *dynamic content* and *update barriers* [54], in the form of disorienting popup messages and presumably updated UI, he was unable to review his ECG data. Similar obstacles could result in missing the capture of a specific episode, or even a delay in asking for medical care, which could result in serious consequences.

While PHTs are primarily used for personal data, some activities are done in a group (e.g., an athletic team). P10 used Strava to record his running times to share with his teammates in Achilles International, an organization that supports people with disabilities in athletic programs. While his Apple Watch is generally accessible, it did not support a timely way to start and stop a recording—especially when coordinating with a guide runner or other teammates. His team chose to start their activity tracking before the actual activity to avoid delaying each other, resulting in lull periods that distorted the attributed time for a course run. Because only the desktop version of Strava was accessible to P10 for editing, this delayed the sharing of the accomplishment with others.

When the data recording ability of activity tracking apps is hindered altogether, it can reduce the healthy activity they were meant to encourage, as P5 shares: “It’s really frustrating and discouraging, and it raises my

freaking blood pressure, honestly, when I'm geared up to get exercising and I go to record something and the app doesn't load, or something's not loading correctly, or the button doesn't work." As such, embedding personal data tracking as part of a user's routine can be counterproductive if accessibility is not considered, as users can be discouraged from beginning their activity when knowing they will not obtain the data they wish to capture.

Losing Credit for One's Activity. Merely beginning an activity tracking session is not enough to record accurate data. While some PHTs can record data without user interaction, many follow the semi-automated tracking approach [11], relying on some form of user input. As a result, accessibility issues can cause users to forfeit any "credit" they would have received for their efforts. For some users, including two of our participants, PHTs' unique feature of receiving credit for activity is a large reason for their use, and such expenditures of physical efforts without proper records can be demoralizing.

Some PHTs require being told when specific activities are occurring (e.g., setting the start and end of a run). This action might trigger the use of a different algorithm in computing the data, or could credit users against a fitness goal. However, incomplete levels of accessibility in such requirements can lead to losses of data, such as P3 who found she erred in her fitness app's activity selection after her workout, resulting in only receiving credit for a quarter of her output. Although thinking she had selected "walking" as her activity type, she mistakenly chose "cycling," and the system's lack of feedback or confirmation left her unaware that her system only monitored movements expected from a person riding a bike. P1 completely lost data at the end of her workout due to the inability to finalize her session: *"I finished the workout, but I can't close and finish the data because an ad has popped up, and there's no button to stop the ads. I have to close the entire app, losing all the data, losing all the information."* Again, blind users may not benefit from their device when obstacles such as *dynamic content barriers* [54] prevent the entry or finalization of data. Thus, while similar in tone to user concerns over data accuracy and quality reported in prior literature [19, 24], these situations differ as our participants did not distrust the devices' ability to track, but rather their ability to access the desired functionality.

4.2.2 Lessened Value from Data Reflection. In the reflection stage, users review their data both to monitor their current state and to reflect on their progress over a longer term of data collection. The reflection stage holds significance in paving the way for subsequent actions and behavior change. Feedback, conveyed through various visualizations and numerical representations, plays a pivotal role in aiding self-reflection, providing meanings to the collected data. However, accessibility again can be a barrier when a blind user wishes to review their data, delaying or even preventing users from acting upon this information.

Delayed From Knowing Your Current State. With personal health data, "reflection in action" [48], or the review of data during or immediately after recording, provides context about what bodily factors could be contributing to how they currently feel. Prompt data access creates opportunities for users to take informed and timely actions in response to their insights. Similar to P3's account of monitoring one's heart health when feeling ill, P4 appreciates the ability to confirm how she is feeling with data from her CPAP machine, noting how the recorded apnea events per hour correlate with how she feels when she wakes up. However, for physical systems where accessibility is obtained via a companion app, access to this data can be delayed if **synchronization barriers** are encountered, i.e., problems with the transfer of data to the corresponding accessibility tool. P4's CPAP machine sometimes fails to sync data to the companion app, forcing her to: *"close the app, reopen it... sometimes I have to unplug the machine."* Unfortunately, the app is the only accessible portion of her system, delaying her from understanding her body and acting upon its data. Although not limited to interactions with PHTs, this barrier causes stronger issues with personal health data, due to the blockage of the benefits from timely reflection.

Some cases of delayed feedback come when one's activity prevents accessible use of technology. P3, a swimmer, found that exercising in water conflicted with the use of her smartwatch, as it used "water lock" mode to prevent phantom touches from being detected on the watch. This prevents the user from interacting with the watch through touch, and unfortunately for blind users, this means accessibility is lost, an example of **activity**

interference—where requirements of an activity disrupt the means to interact with one’s accessibility tool. Thus, P3 only has access to her data after her swimming is over, so her watch loses the ability to provide feedback during her exercise. This in turn means she loses the opportunity to adjust her activity during her workout or to reflect on her data. The common use case of activity tracking results in a higher presence of this barrier in PHTs, although not limited to that area.

Overloaded with Feedback. The data presentation style can be the barrier to a user effectively reviewing aggregated data over time, or “reflection-on-action” [48]. If auditory cognitive load is not considered, the content can be overwhelming and unusable. For instance, P1 benefited from insights via her smart scale’s historical data, but this practice was abandoned once inaccessibility frustrations became too large. Her smart scale app measured seven additional data points beyond weight, such as BMI and body fat percentages, but all these data points were presented as an uninterrupted mass of content when used with a screen reader. In addition, this app also suffered from contextual issues, as it would read seven data headers first, then read seven data points, making it nearly impossible to comprehend. P1 decided to avoid the functionality, losing the ability to obtain more insight towards her weight goals.

Another difficulty with large amounts of data is the added time it takes to review via a screen reader, especially when information is not of interest to the user. P9 attempted to use Apple Health to track and predict her menstrual cycle, but found much of the information irrelevant to her lifestyle, e.g., fertility tracking. Regardless of her interest, P9’s practice is to read the entirety of content on an app screen and explained why too many data fields became burdensome: *“I mean it’s seconds. But any little time (is) just extra for a blind person to go through the whole app, see if I don’t miss something, maybe, that I did want to enter and I didn’t know. You could’ve just scanned through it and missed something.”* Thus, any bit of unneeded information presented on the screen can become a burden for blind users because extraneous content must continually be re-reviewed to ensure nothing is missed or changed from an update. Beyond the information overload reported in prior PHT studies [28, 67], P9 experienced a disinterest overload, with the expectations of repetitively needing to consume personally insignificant matter. As a result, she discontinued use of the app.

4.2.3 Knowing What Data is Shared. Data collected by PHTs can be shared with third-parties for a variety of reasons. Medical staff may want to review historical data, insurance companies may want to monitor usage compliance, or users may want to share fitness data with friends. What data is shared and who is privy to the data are both factors that are affected when accessibility is not provided.

Added accessibility gives blind users more agency in deciding with whom to share their health information—a form of data whose privacy is important enough to be protected by laws. P4 mentioned how paper-based patient information sheets required for doctor visits meant she needed someone to aid her in filling out the form, which sometimes meant uncomfortably sharing personal information with a friend. Other times, this was done in the waiting room, where her spoken personal data could be revealed to other patients nearby. In contrast, she mentions how the accessibility of MyChart was *“very empowering and really made that situation just much, much better for me.”* The ability for P4 to have an accessible way to enter health information not only improved her health privacy but also reduced her stress before seeing a doctor. This allowed her to be comprehensive in recounting her health history, a situation that likely would result in a more accurate diagnosis.

Even if one’s health data is only reviewed by medical staff, there is still some discomfort when not knowing what exactly about oneself is being shared. P1 recounts earlier experiences with tracking apps: *“When I first started bringing my phone to my doctors and showing them exercise and body fat, I really had no idea of what was being shown on the scale, on the graphs and all that. I didn’t even get the average.”* This situation also applied to CPAP users, whose health insurance required certain levels of usage compliance before financially covering the costs, and thus had machines that automatically sent data. An accessible CPAP machine would mean a difference in knowing what data was being gathered and being able to confirm its accuracy to avoid financial repercussions.

4.3 RQ3: Rationales for Continuation

Despite the numerous barriers and burdens encountered by blind users when using PHTs, many continue, including our participants who have used aspects of their system for many years. Previous sections have already identified various ways that our participants have found workaround strategies to allow continued use. In this section, we look at additional dimensions that may help explain the continuation of PHT usage in the face of these challenges.

4.3.1 Experiencing and Expecting Progress. A commonality we recognized in our interviews was each participant sharing how they personally experienced accessibility technology improvement. This ranged from such formative experiences during the introduction of accessible features on computers and devices to simply an app incrementally widening its accessibility. Such experiences have given blind users a positive outlook on the future advancement of accessible technology, such as P10 noting how *“VoiceOver is just getting better at kind of compensating for apps that are not accessible.”* Similarly, P4 uses these developments to support expanding her use of PHTs, stating, *“So I guess now that I’ve had good experiences, I’m much more willing to try on my own.”* Our participants’ tolerance to some accessibility issues could be higher due to their continued experiences in the growing development of accessible technology.

However, the knowledge that technology is progressing simultaneously informs the user that technology also exists in a state with room for improvement. Similar to how some blind users workaround accessibility problems by simply constraining their use, others set their expectations lower due to past experiences, like P8 who states, *“It is what it is. So I just make use of what technology I do have to access to right now.”* Likewise, P6 notes that they *“tend to just download stuff expecting it’s not going to work for me,”* so finding something simply navigable with accessible data can make an app worthwhile enough to keep, as such functionality is already considered better than other inaccessible apps tried in the past.

At times, progress is something an individual expects of themselves, rather than their system. P2 portrays a related scenario: *“...if there’s something generally working, maybe I’m just not using it properly. I might talk to my friends about it, and see if they can give me some pointers and I can figure out, you know? So sometimes it’s just being patient.”* Because of success in other areas of an app, P2 deduces that his usability problem might not be an accessibility problem, but instead something he can teach himself to use. He finds that a strategy of patience has eventually allowed him to expand the use of his systems, and so he is willing to continue usage and research further, in an attempt to increase the functionality he has access to.

4.3.2 Expanding One’s Independence. Maintaining and increasing independence is an important aim for blind individuals, as P7 expresses regarding why exercising at the gym without help is so important: *“As visually impaired people, you fight for whatever independence you can keep. And I know it’s like a stupid thing to say because it’s not a critical life function to be able to know how fast you’re going on the bike or how far, but it’s just something that you can control and you can get better at, which helps your mental status.”* Although P7 successfully uses equipment at her gym with the help of her friends and the use of Be My Eyes (<https://www.bemyeyes.com>), she wishes for built-in accessibility in these machines to gain independence. A third of our participants shared this wish for greater autonomy specifically while exercising. PHTs improve success in this area, especially when accessibility to exercise machines is often blocked by touchscreen interfaces.

4.3.3 Augmenting Systems for Accessibility. Whether due to cost, availability, errant purchases, or simply the inexistence of accessible variants, blind individuals end up needing to interact with non-accessible systems. During our interviews, we learned how several of our participants overcame this situation by augmenting non-accessible systems through accessible portions of their PHTs, expanding their own access by way of assemblage.

Treadmills and similar exercise equipment are regularly outfitted with fitness data tracking features that generate activity data of its usage along with the output from biofeedback monitors. Currently, this information

is generally not offered in an accessible manner. However, the availability of tracking devices and other accessible apps have allowed blind users to use these inaccessible machines by providing **accessibility-by-proxy**, or, the ability to supply surrogate accessibility for a separate inaccessible item. For instance, many of our participants have treadmills that only display workout data on a screen that normally would be unreadable. To overcome this, many use activity tracking technology as a proxy for the data collection that would normally be reported by the treadmill itself, giving them access to duration, heart rate information, and overall progress.

In another example, P5 uses Seconds, an interval timer app compatible with his screen reader, to configure a workout routine in advance for his treadmill and elliptical use, e.g., a five-minute warm-up period followed by a high activity interval of 10 seconds and a 30 minute walk period. This session is programmed to speak aloud when a new interval starts, as well as which interval is upcoming. In conjunction with the biometric data gathered by his smartwatch, P5 is able to *“still get the information but effectively circumvent what’s provided through those two machines,”* fundamentally bypassing the inaccessibility of his exercise machines. Similarly, P11 designs music playlists on her phone to compensate for exercise machines’ inaccessible timer displays, judging her workout time by which song is currently being played.

Using an accessibility-by-proxy approach is not limited to physical devices. P8 uses the app paired with his Abbott CGM, and although much of its functionality is accessible, the app does not expose the data within its graphs to screen readers. After researching via online diabetes forums, he learned how to access his device’s data on a website, where he exported his data to text and imported it in Excel—an accessible application he is familiar with. Thus, a complicated but successful process enables him access to the data he originally wished to review.

4.3.4 Satisfying Important Tracking Needs. Naturally, being able to track important items can provide enough benefits to compensate for usability and accessibility issues. Our participants shared their specific tracking needs that help explain their continued use.

Eyesight-Adjacent Needs. Our interviews uncovered situations where changes in individuals’ vision status led to new needs for tracking to emerge. P7 wished to track her sleep because her sleep quality had degraded when her eyesight began changing, a common problem for blind individuals [34, 58]. P4’s CPAP machine reported that her measured mask seal had unexpectedly degraded, allowing her to discover that her cat had chewed on her tubing, causing a leak. P6’s occupational therapist recommended a posture correction tracker, as their low-vision led to thoracic outlet syndrome from their posture, as explained: *“We don’t really have a reason to just look up at stuff even with limited vision, that’s just not a thing that I think to do. So we have a tendency to just slouch forward... I have injured myself to the point of needing physical therapy because of just how much I have to curl my arms in and sort of smash my phone into my face in order to see it.”*

P9’s blindness arrived later in life, and she discovered a new need for menstrual tracking. *“When I was sighted I didn’t really need to track anything, it was kind of visual. But when I’m blind, I do want to kind of track and see (when) my next cycle would be.”*

Medical and Health Reasons. Our participants often mentioned medical and health reasons as the motivation for using PHTs. Some wished to prevent relapse of an earlier medical problem, and others mentioned desires for preventative measures. Participants mentioned how the COVID-19 pandemic introduced new PHT needs, such as blood oxygen saturation tracking and tools to motivate activity during lockdown.

Some participants already have a history of benefiting from the data generated by their PHTs. P4 noticed her sleep apnea counts rising while reviewing her data, which led to her contacting her doctor and subsequently finding an additional diagnosis for her apnea. These health diagnostic benefits can extend to others, as she explains additional reasons for wanting to keep health records: *“Because if I do have something unusual that I could pass along to [my children] or if they start having issues that are that are similar to things that I’ve had happened, I want to be able to say, oh, that’s interesting. I had that happen too, all those things.”*

Such medical and health benefits can override the need for total accessibility, such as how P8 describes his glucose monitoring system: *“This has made life much simpler, much [more] convenient. There are aspects of the app that aren’t accessible, but eh, what can you do?”* These important advantages in using PHTs allow some leeway in usability, but also underscore how important these systems are for blind users.

5 DISCUSSION AND FUTURE EXPLORATION

The manner in which accessibility is considered affects blind users throughout multiple stages of use in PHTs: *preparation, collection, reflection, and sharing*. In this section, we consider further why accessibility in PHTs results in unique interactions, and offer design implications and future avenues of research.

5.1 Supporting the Preparation Stage for Blind Individuals

Blind individuals use a variety of techniques to discover suitable PHTs for use, but often this process converges to a manual effort in trialing an app, with an added task of testing for accessibility delaying the actual test for desired functionality. While trialing is common in other mobile app contexts, the challenges become more pronounced with PHTs [33]. This is because part of the trial involves attempting to configure apps and devices, and collecting and accessing actual data, which may demand additional dedicated efforts and time than merely installing an app. Because our research focus dealt with technology already in use by seasoned PHT users, we did not study their exploration of product listings and trialing of apps and devices, and could not directly observe the initial onboarding process of exploring new systems. However, our participants reported encountering diverse challenges in the initial phase of trialing various systems and faced difficulties understanding new functionalities and establishing a complete mental model [54], especially after major updates (reported in Section 4.1).

An important future research avenue is to explore how we can make this stage for blind individuals more efficient. Future studies could observe these processes directly to further investigate how blind individuals consume product information, how their expectations compare to their actual use, and what forms of information can best support the system discovery process for blind individuals. Furthermore, what forms of instruction do blind individuals prefer when using systems for the first time? Do more experienced users of accessibility tools prefer different content than newer users? Exploring these questions and investigating these aspects could harness the recent advancements in Large Language Models (LLMs) and their powerful capabilities in understanding and generating natural language and codes. Recent studies leveraging LLMs have demonstrated their potential in summarizing UIs [73], engaging in conversations with humans about different UI functionalities [72], and supporting user-driven customization of UIs [36]. Similarly, we envision that LLMs could enhance the onboarding process for blind users by generating summaries that facilitate the rapid development of an accurate mental model for new systems or updated features, thereby enabling them to achieve their goals efficiently.

Additionally, there may be cases where reported accessibility barriers could be eluded using existing technology, had the user been informed. Technology that is accessible, but not taught to users, remains inaccessible technology. Continued research into suitable ways to disseminate information on systems’ accessibility features is warranted.

5.2 Improving Data Collection

Our interviews uncovered multiple scenarios where data was erroneously recorded or lost, both frustrating experiences in PHT usage. However, preventing these problems would not necessarily be tied to accessibility, and would benefit all users of the same technology. Two participants lost their tracking data due to input issues: P1 being unable to “close out” their session due to navigational issues, and P4 who had mistakenly chosen the wrong workout type. Both scenarios would be helped by data recovery strategies similar to those in content creation software: auto-save functionality to recover from crashes, real and user-forced; and the ability to recalculate

one's raw data towards another activity, the same way that WYSIWYG editors can automatically reformat its output when given new parameters.

Others had difficulties adjusting their systems for real-time use: P4 whose swimming activity prevented her from interacting with her watch due to a necessary water lock, and P8 who found the procedure for starting a run too cumbersome when running with a team. Both cases would benefit from preloaded actions and context-aware interaction. For instance, a smartwatch could automatically read swimming statistics after every four laps, or map physical button interactions to feedback requests at such markers within one's workout. With P8's measured activity, where accurate start and stop times are important, he and his friends created a workaround by preparing a workout session beforehand and pausing it long before starting the actual activity. Likewise, a built-in ability to prepare personalized workout templates with quick-start options would do well in preventing the friction of PHT usage and activity. This too can be context-aware, preloading in the vicinity of a calculated start point—something that could benefit all users, e.g., a phone triggering a watch to begin precise GPS satellite triangulation when the user is close to their calculated start point.

5.3 Examining Deeper Interactions with PHTs

Although our participants used PHT systems for extended periods, in many cases we found their use was limited to a subset of the features available in their technology. While complete usage would not be expected for any group of PHT users, our participants noted avoiding accessibility problems as reasons for some of their constrained use. One commonly reported issue continues to be inaccessible graphs, matching the interest in the research community towards making data visualization accessible to blind users (e.g., [31, 40]).

In other cases, we also witnessed real-time occurrences of “Not Knowing What You Don't Know,” a phenomenon in which blind users grapple with discerning whether information is inaccessible or simply not presented at all [3]. When our participants navigated feedback pages featuring graphical representations of captured data with poor accessibility, their screen readers skipped over the graph, leaving our participants unaware of what had not been represented. Although we refrained from intervening in such instances, it became evident that participants were underreporting accessibility issues related to feedback, confirming findings from web accessibility contexts [3].

However, the technology to make graphs and other forms of data reviewable by blind users is seemingly becoming more mainstream, as many of our participants discovered newly accessible portions of their PHTs for the first time during our interview. Since it is likely that we are at the cusp of a new phase of use, future research is warranted to investigate how this population reacts to a deeper consumption of their data, and what barriers, burdens, and benefits arise from these new use patterns. Given that our study captures a moment in time for an evolving technology sector, future long-term studies may be useful to examine how individuals change their usage techniques as their experience with their systems grows longer and as they are exposed to different forms of feedback. Nevertheless, given that technology changes are not only non-homogeneous across systems but sometimes an erasure of prior progress, our findings are likely to have continued relevance.

Additionally, now that these additional areas of PHTs are becoming more accessible, the health technology community should learn how best to promote the further use of such technologies to blind individuals. Because of their poor accessibility experiences in the past, merely explaining these benefits may not encourage blind individuals to explore what benefits may be obtained from further reflection on their data.

5.4 Additional Benefits of Accessibility Proxies

Our participants demonstrated multiple examples of **accessibility-by-proxy**, using accessible PHTs to interface with inaccessible devices. However, their role as a proxy does not limit their use to simply a bridging mechanism, and it is possible that users could inadvertently receive some of the original benefits of the technology. For instance, a blind user using a fitness tracker to compensate for an inaccessible treadmill may automatically be

exposed to feedback and advice that alters their healthy behaviors for the better. However, what happens when the original accessibility need is removed? If exercise machines widely become accessible and individuals no longer need PHTs as an accessibility proxy, will blind users discontinue their use and possibly lose some benefits? Thus, the use of accessibility proxies holds a unique predicament, where added accessibility could result in a net negative for users—if these existing workarounds are not considered. To allow individuals to fully benefit from progress in accessibility, future work should catalog cases of accessibility-by-proxy across all sectors of technology and discover the best ways to minimize any possible repercussions from their future discontinuation.

5.5 Making Accessibility Accessible to Non-Users

When we observed our participants interacting with their screen reader, we asked them to turn on captioning, as screen reader audio is not transmitted over Zoom. Having a blind screen reader user & researcher in our research team was pivotal in creating an accessible and inclusive remote interview environment for both the blind participant and other sighted interviewers. We noted how well these captions helped us follow along, and this ended up being an invaluable tool for us during the interview. Using a screen reader is not immediately intuitive to non-users, as noted in the discussions around *Sighted Assistance* in Rodrigues et al. [54] and supported by P9's described actions when family uses her phone: *"I have to always turn off the VoiceOver for [my family] to use it as a normal phone... they don't know how to use it with VoiceOver, it's just different."* Accessibility tools are something that must be learned, and many receive specific training on the subject.

While we promote involving blind individuals in the entire process of system development, we also think that improving tooling for non-blind individuals to understand screen reader output will improve the end result for blind individuals, even if just to eliminate obvious flaws. While tools to aid sighted users in visualizing screen reader order do exist [59], we suggest supplementing this with tooling that exposes all screen reader content, to add detection for other errant areas. For instance, a simple text transcription of how a screen reader describes screen elements could quickly point out mislabeled controls, incorrect orderings, and missing content. Transcriptions of screen reader output can also provide data that automated testing software libraries can consume, which could help prevent accessibility degradation. These screen transcriptions would also be useful as an accompaniment to app store listings, allowing blind individuals to quickly judge the accessibility and usability of an app with the same ease that a sighted user can judge an app from the screenshots on its listing. While some work has begun to transcribe screen reader output at the desktop level [14], we do not know of a means to do so on mobile phones, which are widely used by blind individuals and are the sole source of technology for some of our participants.

5.6 Reflection on Study Design

Our interview setup affected how our participants used their devices, as videoconferencing interfered with voice-based interaction (i.e., voice control and screen reader output). For instance, Zoom blocked the use of voice control, and some participants needed to navigate to apps differently due to Siri not being available. One participant had issues with their audio setup for the interview, as the earpiece transmitted a slightly delayed echo of their voice, causing difficulties when responding to our questions and hearing VoiceOver audio. Finally, the delays in internet-based videoconferencing meant that the interviewers sometimes spoke at the same time as the participants' screen readers. Interviewers attempted to be cognizant of such issues and welcomed our participants' full disclosure when things went awry.

Our participant pool ranged from 32 to 65, so this work may not capture how younger individuals use personal health technology. Our participants were also generally experienced in their use of screen readers, all considered themselves proficient in using technology, and our videoconference interview requirements likely prevented less tech-savvy individuals from participating. Therefore, this work does not capture the journey of individuals

new to screen readers or technology in general. This may over-represent the successes in how blind users find workarounds for the problems they face but also may underscore how accessibility issues can be encountered regardless of one's experience with technology. Nevertheless, further research with diverse age groups and varying expertise in accessibility tools could uncover different behaviors, needs, and experiences.

Although our participants have shared why they discontinued using specific apps and devices, they are still individuals who continued to use some aspect of PHTs. How do they differ from those who decided to stop using PHTs completely? What could change to reverse such complete abandonment, and how central to this decision is the accessibility of the technology? A counterstudy that investigates blind individuals who have ended any use of PHTs may be useful to compare against this set of individuals to learn deeper about the choices for PHT users both for blind individuals and for the wider community.

Additionally, our work focused on users who rely on screen readers, but as mentioned earlier, users who use other accessibility aids will have different needs and experiences. Future research is also needed to capture the experiences of these users, perhaps in comparison and contrast to the findings in our work.

6 CONCLUSION

In this paper, we investigated the prolonged use of personal health technologies by blind users via an interview study with 11 blind participants who used such technologies for a minimum of six months. By reviewing their experiences and watching how they used various PHT apps, we aimed to discover how different stages and interactions with PHT data are influenced for blind users, and reasons why they persist in using technology that might not cater to their specific accessibility needs. Through consideration of our findings, we discuss strategies for improving the experiences of blind users with PHTs, both in the design of the systems themselves, and by the suggestions of new tools for the teams that design and build the systems.

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