Chronic Access: Understanding the Accessible Technology Practices of People with Chronic Health Disabilities

Emma J. McDonnell
emma.mcdonnell@tuwien.ac.at
TU Wien
Vienna, Austria

Tae E. Jones
taejones@cs.washington.edu
University of Washington
Seattle, WA, USA

Wanda Pratt
wpratt@uw.edu
University of Washington
Seattle, WA, USA

Abstract

Billions of people worldwide work to balance the impacts of their chronic health conditions with the demands of their everyday lives. While accessibility research has begun to work with people with chronic health disabilities, we lack a baseline understanding of how people with chronic health conditions use technology to increase access in their day-to-day lives. To establish this baseline, we conducted interviews and photo elicitation activities with 15 people who identify as disabled due to their chronic health conditions. Participants described a diversity of often everyday tools that increased access in their lives. We find that participants leveraged a set of strategies we call *chronic access* to use everyday technologies as accessibility support and to rescope what it means to make something accessible for people experiencing pain, fatigue, or other distressing symptoms. We conclude by imagining a future for chronic access, where more access technology explicitly supports people with chronic health conditions, health and accessibility researchers collaborate productively, and all disabled people are better-served by accessibility support that aligns with their everyday lives.

CCS Concepts

• **Human-centered computing → Empirical studies in accessibility**.

Keywords

Chronic Health Conditions, Accessibility, Assistive Technology

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1 Introduction

Billions of people around the world live with at least one chronic health condition [42], which is to say, billions of people worldwide experience symptoms that their health care providers do not expect to go away. While health informatics researchers have invested significant focus into health management for people with chronic health conditions (e.g., [14, 21, 24, 95, 107]), accessible technology research is just beginning to integrate chronic health into our conception of disability [28, 51, 55, 69, 86]. Yet, accessible technology research has much to offer people with chronic health conditions. While health management is, of course, crucial for people with chronic health conditions, its goal is fundamentally entangled with a medicalized belief that to live a sick life is to live a less full life [104]. Disability communities have spent decades articulating the rich, full, whole lives that are possible for people whose bodies and minds fall outside the norm [54, 62, 65] and pushing accessibility technology designers to build for this worldview [44, 73, 105]. Accessibility tools can offer a new way to approach everyday life with a chronic health condition — the goal shifts from getting better, an often elusive target, to making everyday life richer, given the circumstances.

Some accessibility research has begun to outline the gaps between current accessibility practice and the needs of people with chronic health disabilities. Mack and McDonnell et al. [69] identified tenets to help guide accessibility research into the chronic health space, balancing the need to address undesirable symptoms while centering on access, not cure. Recent accessibility research demonstrates, with a small subset of chronic health conditions (e.g., people with energy-limiting conditions [37, 50–52, 55, 56]) and with regard to specific tools (e.g., videoconferencing [28, 66]), the revelatory potential of accessibility support for people with chronic health conditions. Further, recent work by Mack et al. [67] names types of access barriers that are particularly relevant to people with chronic health conditions: bodymind barriers, or access needs that arise because an individual's bodymind[1] is dysregulated, and future impact barriers, or access needs that arise from the future consequences (e.g., nausea, fatigue) of completing an activity. While this work, taken together, shows the importance of accessibility tools for people with chronic health conditions and identifies ways to understand symptom regulation within the framework of accessibility, we lack a broad understanding of people with chronic health disabilities' current accessibility practices. Despite the tendency to research conditions in isolation, chronic health conditions frequently co-occur [15], making cross-population research vital. Furthermore, despite a historical lack of dedicated access support, people with chronic health conditions have appropriated tools for access across a wide range of contexts (e.g., [49, 50, 69])– better understanding current practices can inform future supports that improve the daily lives of people with chronic health conditions.

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[1] Bodymind is a term developed by disability studies scholars and activists [54, 90] to underscore that the body and mind are fundamentally intertwined

To build an understanding of a diverse group of individuals' current access practices, we conducted interviews and photo elicitation activities with 15 participants who identify as disabled due to chronic health conditions, guided by the following research questions:

(1) How do people with chronic health disabilities leverage disparate technologies to increase access in their daily lives?
(2) How does the assistive technology use of people with chronic health disabilities challenge dominant assumptions in accessibility research?

We sought participants who identify as disabled due to their chronic health conditions — people we hypothesized would be likely to have explored accessibility supports. We conducted semi-structured interviews and photo elicitation activities with fifteen participants with a wide range of chronic health conditions. These sessions focused on understanding participants' journeys with chronic health disabilities and their current approaches to accessibility.

We found that participants incorporated a diverse array of technologies into their access practices, using strategies to find assistive purposes for everyday objects and rescoping what it means to make something accessible. The majority of tools our participants described using were not purpose-built accessibility tools, but everyday and medical technologies they described as increasing access in their day-to-day lives. Participants made everyday tools assistive in three main ways: by optimizing for accessible tool properties, identifying indispensable tools, and finding creative use cases for everyday technologies. These strategies helped illuminate participants' water bottles, loofahs, and post-it notes as assistive tools. In addition, participants redefined what it meant for technology to help them achieve access. When dealing with draining, painful, and unpleasant symptoms, participants often rescoped tasks into a more manageable version that they could access. Participants rescoped the goal for access by changing timelines, constraining tasks, altering environments, and involving others. For instance, several participants described how doing a task from bed, rather than an office, classroom, or coffee shop, was the difference between that task being accessible and inaccessible. We call these strategies *chronic access,* an accessibility practice that is attuned to the realities of chronically ill bodyminds and dominated by the creative use of everyday objects, rather than designed accessibility tools.

Our research contributes (1) empirical understandings of people's access practices across a diverse group of people with chronic health disabilities, (2) chronic access, a way to describe the strategies and tools that support the unique accessibility concerns of people with chronic health disabilities, and (3) opportunities to alter accessibility research practice to better serve both people with chronic health disabilities and broader disability communities.

2 Related Work

Our research is in conversation with accessibility research conducted with people with chronic health conditions and disability studies and activist theorizing around chronic health. In our framing of chronic health conditions, we align with feminist disability studies scholar Susan Wendell's argument that *"any practical concept of chronic illness has to be patient-centered ... because many diseases cannot be reliably categorized into chronic and non-chronic"* [104]. Therefore, when we discuss chronic health conditions, we broadly refer to the set of health experiences that require people living with these conditions to adapt their daily lives to accommodate them.

2.1 Accessibility Research With People With Chronic Health Conditions

While, historically, chronic health conditions have received very little attention in accessibility research [68], recent work has generated conceptual frameworks to change this trend. To facilitate more accessibility research with people with chronic health conditions, Mack and McDonnell et al. [69] identified tenets outlining how accessibility research must change to better support this population. Specifically, they highlight the need to see people with chronic health conditions as experts on their lived experience, emphasize the unique access needs that arise from variable conditions, and call for a focus on both physiological and sociopolitical access barriers. Building on this understanding, Mack et al. [67] articulated two types of access barriers technology can address that are particularly relevant for people with chronic health disabilities: bodymind barriers and future impact barriers. These barrier types frame dysregulation in someone's bodymind or health consequences from completing an activity as manifestations of disability that can be supported by accessibility technology, not only symptoms that must be managed with medical care. McDonnell and Pratt [76] emphasize that experiencing accessibility support can be revelatory for people with chronic health conditions, helping them to build a disability identity and more positive self-conception, underscoring the necessity of work that integrates chronic health into accessibility.

Chronic health conditions have been increasingly integrated into some subsets of accessibility research, particularly research that takes an intersectional approach to accessibility. Chronic health conditions disproportionately occur in marginalized communities, making intersectionality critical to research with this group [8]. Understandings of chronic health conditions have informed research on many topics, including disability activist practices [7, 16, 64], bias in generative AI tools [57, 70], intersections between disability and sex work [92], LGBTQIA+ people's experiences with assistive technology [5, 26], the experiences of disabled refugees [43], and frameworks to better integrate considerations of race and disability when designing technology [45]. Chronic health disabilities have also been included in workshops focused on integrating critical perspectives from disability studies and disability justice into accessibility research [9, 98, 99]. Increasingly, as accessibility researchers study disability communities broadly, they include people with chronic health disabilities in research on topics including online dating [88], work place access [36, 66], video game accessibility [74], and participation in online communities [17, 48]. While it is crucial to include chronic health disabilities in research with broad, intersectional disability communities, there remains disproportionately little research specifically focused on the experiences of people with chronic health conditions.

The research that has focused on people with chronic health conditions has been limited to specific conditions or technologies. A growing body of research investigates how to better support people with energy-limiting conditions (e.g., ME/CFS, long COVID, chronic Lyme disease) in finding accessible public places [55, 56], hacking fitness trackers [51, 52], self-managing ME/CFS [31] and using telepresence robots to access social interaction [37]. Paymal and Homewood [86] explored the ways people with ME/CFS use technology in their everyday lives, introducing 'trajectories of technology use', highlighting how technology needs change rapidly in response to symptoms. Working with diverse groups of people with chronic health conditions, researchers have studied the accessibility benefits and barriers from videoconferencing [10, 28] and explored ways that physical therapy could be made more accessible [106]. Autoethnography has also emerged as an popular method for studying chronic health conditions within accessibility research (e.g., [38, 49, 50, 55, 66, 69, 71]). This research contributes valuable insights into support for specific, narrowly scoped populations and tools, but we lack an understanding of accessibility needs across a wide range of chronic health conditions, a gap our work fills.

2.2 Disability Studies and Activist Perspectives on Chronic Health Conditions

Disability studies and activist thinking on chronic health conditions deeply inform the sensibility of this work.

Disability studies has long been animated by a desire to overthrow the medical model of disability, but this often fails to capture the complexity of chronic health disabilities. First defined by Micheal Oliver in the 1980s [82], the medical model describes the dominant understanding of medical providers and researchers at the time that disability is an unalloyed bad that ought to be eliminated. Scholars and activists articulated their ideal alternative: the social model of disability. Under the social model, disability is seen as a natural aspect of human diversity that becomes limiting due to discriminatory social attitudes and design practices [83, 96]. The social model has become the standard for progressive approaches to disability, including within HCI [73]. However, as disability studies scholar Alison Kafer [58] articulates, *"the social model can marginalize those disabled people who are interested in medical interventions or cures."* Wendell [104] takes up the question of what it could look like to build a scholarly and activist practice that includes those who *"experience physical or psychological burdens that no amount of social justice can eliminate"* [104]. Drawing from Kafer and Wendell, our work neither valorizes cure nor negates the desire for relief from unpleasant and disabling symptoms.

We also draw on understandings of chronic health conditions developed by activist communities. Activism by people with chronic health conditions has long shaped medical practice, including ACT UP's efforts to establish a standard of care for people living with HIV/AIDS [81], people with ME/CFS's successful efforts to eliminate harmful therapies [101], and patient-driven recognition of long-COVID as a syndrome in need of pressing attention [22]. In this tradition, we see people with chronic health disabilities as the leading authority on what supports they need. In recent years, activists such as Brianne Benness [11], Leah Lakshmi Piepzna Samarasinha [87], Mia Mingus [77], the collective Sins Invalid [54], and many more have been instrumental in building new vocabularies and resources to support people with chronic health conditions in developing a disability identity. These generations of activists guide our attention toward the accessibility practices of people with chronic health conditions, and we are indebted to their theorizing.

3 Methods

Our 15 participants, who identify as disabled due to chronic health conditions, completed a photo elicitation activity prior to joining the lead researcher for a 90 minute research session on Zoom. All participants were compensated $75 for their time. These sessions had a broad scope, and for the purposes of this paper, we focus only on the first hour of these interviews. All protocols for this study were reviewed by the University of Washington's Institutional Review Board and deemed exempt, meaning they were determined to pose minimal risk to participants and therefore require correspondingly less continual review[2].

3.1 Participants

We required that participants in this study be 18 years or older and identify as disabled due to one or more chronic health conditions. We recruited participants via accessibility-related mailing lists, researchers' established research recruiting pools, and personal networks. All study sessions took place on Zoom and all participants were US-based at the time of the research study.

Our participants reported a large range and number of chronic health conditions. All conditions were self-reported and we did not require that participants had a formal diagnosis. Participants reported between one and eleven conditions, and had, on average, 5.5 chronic health conditions (SD = 3.9). Only three participants reported only one condition. Participants reported 54 unique conditions, most commonly asthma (4), allergies (3), dysautonomia[3] (3), migraines (3), and chronic fatigue/ME[4] (3). While their designation as a chronic health condition is often debated, eight participants discussed neurodivergence and mental health diagnoses as part of their experiences with chronic health conditions, including ADHD (6), autism (3), anxiety and depression (2), and cPTSD[5] (2). This wide range of conditions often meant that participants' access needs derived from the interplay of multiple conditions, not single diagnoses in isolation.

Our participant group was also very diverse on other axes of identities. Participants skewed young overall — three participants were between 18 and 25 years old, seven were 26-35, four participants were 36-45, and one participant was between 66 and 75 years old. Participants had a range of racial and ethnic backgrounds and many held multiple racial identities. Nine participants identified as white (six only identified as white without other racial or ethnic identity), four reported being Asian, four identified as Latinx/Hispanic, one as Middle Eastern, one as Indigenous, one participant identified as Black, and one participant identified as mixed. With regard to

[2] https://www.washington.edu/research/hsd/guidance/exempt/2

[3] An umbrella term referring to dysregulation of the autonomic nervous system, often resulting in conditions such as POTS or orthostatic hypotension [2]

[4] Chronic Fatigue Syndrome/Myalgic Encephalomyelitis is a type of chronic, severe fatigue that is not alleviated by rest [3]

[5] Complex Post-Traumatic Stress Disorder is a mental health condition that develops following long-term trauma [1]

gender, six participants identified as women, six as non-binary or genderqueer, and three as men.

3.2 Photo Elicitation Activity

Prior to the study session, we instructed participants to complete a photo elicitation activity. We requested that participants take three pictures of ways that they *"have set up different aspects of your day-to-day life to take care of your health and make daily activities more doable."* Participants shared between three and eleven images (Mean=4.1, SD=2.3). We provided participants with nine prompts[6] to guide their photography, as well as the option to include images that did not correspond with prompts but they felt were relevant. Example prompts include:

- What do you have on your bedside table to make getting up or going to bed easier?
- When you're leaving the house, what needs to be in your bag or car to manage symptoms or handle any emergencies?
- Do you change any settings on your phone, tablet, computer, TV or other digital device to make it more usable for you?

3.3 Synchronous Study Session

Participants joined the lead researcher for a 90-minute, remote session, facilitated via Zoom. Prior to the session, we invited participants to share their access needs so that we could make the study session accessible to them. Most commonly, we sent participants the study protocol in advance, turned on automatic captioning, and added additional breaks. The full study protocol can be found in Supplementary Materials.

The first half hour of the study session was a semi-structured interview. The researcher asked participants about their experiences with chronic health conditions and how they came to identify as disabled.

In the second half hour of the session, we discussed the images participants generated during the photo elicitation activity. The researcher screen shared a slideshow of that participant's images and began by asking the participant to describe what was in each image and how it made their life more accessible. The researcher then asked follow-up questions, centered on how participants came to acquire these tools, how they use them in different contexts, and the impact of using these tools on their day-to-day lives.

We do not analyze data from the final half hour of this study session in this paper, as its focus on future tools does not match this paper's goal of understanding current practices.

3.4 Analysis and Positionality

All interviews were recorded via Zoom and initially transcribed using Zoom's automatic transcription. To account for inaccuracies in automatic transcription, we listened to interview audio while coding.

We drew from Braun and Clark's reflexive thematic analysis [18, 19] to code our data. We took a primarily inductive, semantic, and critical realist approach to data. Two researchers collaborated to first develop a codebook[7]. We each took notes on a subset of interviews – the lead researcher reviewed six transcripts and a research assistant reviewed four. We then developed candidate codes from our notes and met to develop a codebook. Researchers then independently applied that codebook to a single interview transcript, and met to discuss differences. Having improved our shared understanding of the codebook, we then both independently coded another transcript. We met and resolved all differences in preparation for independent coding. The coders divided up the remaining transcripts among themselves and each coded their half. Upon completion of the initial coding pass, researchers reviewed each others' work, marking places where they would revise the other's coding. The lead author reviewed all transcripts and merged reviews and initial coding into a final coding of all data.

The two coding authors also wrote summaries about each participant as they coded. Upon completion of coding, all paper authors met to affinity diagram those summaries across different axes (e.g., degree of motivation to find accessible technologies). This step allowed us to involve the whole research team and begin thinking across participants. We then followed Braun and Clark's process of reflecting on how codes contribute to larger themes in the data. During our theme development, we identified a strong focus among participants on how tools extended access in their everyday lives, aligning with our interests as accessibility research and driving us to focus our themes around accessibility rather than, for example, health management. Section 4 provides a summary of which tools our participants used and how they came to use them while Section 5 identifies the strategies our participants used to achieve access using those tools.

The identities and backgrounds of authors had a significant impact on how data was gathered and analyzed. Multiple authors identify as disabled due to chronic health conditions. The lead author, who conducted all interviews, disclosed this identity to participants at the beginning of all study sessions. This shared lived experience informed how the study was framed, what questions we asked participants, how participants interacted during the study sessions, and how we analyzed the data. The research team has significant expertise in accessibility, health, and HCI.

4 Results: Patterns in Accessible Technology Use

In our first results section, we describe the wide suite of technologies that our participants used to make their daily lives accessible, highlighting which tools participants used and identifying barriers to accessible tool use. Note that we intentionally broadly define "technology," understanding both explicitly digital tools and analog designed objects as technologies [84]. This breadth in definition also follows from the tools our participants chose to describe – their conception of tools that made their everyday lives more accessible was broad and varied. Notably, participants used many tools in conjunction with each other, a phenomenon Mack et al. [67] describe as an *assistive repertoire*. Individual tools alone may not secure full access, but each tool was an important part of a person's repertoire.

4.1 Tools Used

First, we describe the tools that participants used for accessibility purposes and the motivations for using them. See Table 1 for a summary of the types of tools our participants employed.

[6] A full list of prompts is available in Appendix A
[7] See Supplementary Materials for the full codebook

Table 1: Participants used a large diversity of tools to make different aspects of their lives accessible. Within a larger goal, such as creating a supportive environment, tools could function to achieve that goal in different ways, such as enabling environmental regulation, selecting specific furniture, configuring spaces, and acquiring supportive gadgets.

Reason For Tool Use	Tool Function	Tool Examples
Creating a Supportive Environment	Environmental Regulation	Remote controlled light bulbs, aromatherapy scent diffuser, air conditioner
	Specific Furniture	Height-adjustable desk, adjustable bed, power-lift recliner, ergonomic desk chair
	Space Configurations	Raised garden beds, one-level house, lifted litter box, couch-based workspace
	Supportive gadgets	Vibrating alarm clock, pillows, heating pad, ergonomic standing mat, weighted blanket
Enabling Digital Tool Use	Specific Peripherals	Roller pad mouse, adjustable monitor riser, microphone, keyboard
	On-device assistive supports	Voice-to-text, dark mode, speak selection, laptop brightness settings
	Selecting appropriate devices	Lightweight Macbook Air, iPad, cellphone, Amazon Alexa
Caring for Self	Shower support	Shower chair, grab bars, loofah, handheld shower head
	Preparing for health risks	Emesis bags, face mask
	Sensory Regulation	Earplugs, eye mask, meditation app, portable fan, fidget toys
	On-body support	Compression garments, braces, hiking boots, hat and gloves
Managing Health	Prescription medications	Insulin pens, anti-nausea medication, inhaler, beta blockers
	Over-the-counter medications	Cough drops, Advil, eye drops
	Keeping track of medication	Pill organizer, digital bottle cap, medication tracking app
	Health tracking	Blood pressure monitor, smart scale, health tracking apps
Leaving the House	Mobility aids	Wheelchair, forearm crutches, portable camping stools
	Built-environment access	Accessible parking permit, automatic door opener, wheelchair lift
Supporting Executive Function and Memory	Digital reminder systems	Finch App, iPhone reminder app, notes app, digital calendar
	Physical reminder systems	Sticky notes, refrigerator whiteboard, pen and paper
Eating and Drinking	Beverages to support symptom management	Electrolyte drink mixes, juice boxes, caffeine drink mixes
	Food to support symptom management	Protein bars, sugary snacks
	Cooking tools	Garlic press, Ninja Creamy ice cream maker, mandoline

Our participants described how focusing on increasing accessibility, rather than solely on medical management, substantially increased their quality of life. Technology increased access for our participants by creating a supportive environment, enabling digital tool use, facilitating hygiene and self-care, allowing for health management, navigating the broader world, supporting memory and executive function, and accessing food and drink (see Table 1). During the course of their chronic health journeys, many participants experienced periods where they lost the ability to do both instrumental tasks and the things that brought them joy. In addition to medical care to stabilize their health where possible, turning to technology and accessibility services was often participants' path back toward the lives they desired. For example, P15 reflected that for *"five years I thought that I needed my headache to go away before I could start school again, as opposed to seeing if I can make school more accessible in other ways, then I can live with a headache."* For P2, the early years living with her chronic health condition were dominated by the assumption that *"oh, a lot of the things I enjoyed doing are hard now, I'll just kind of give up."* Since coming to identify as disabled she has begun seeking *"what accessible alternatives there might be"* to return to beloved hobbies.

Some technologies that participants described as integral to increasing access in their lives were explicitly medical tools. Participants discussed their medical care as part of what increased their access to everyday lives. Having medication to, for example, control a racing heart rate (P13), decrease nausea (P6), or prevent an asthma attack (P10, P7) regulated participants' bodies such that they could participate in daily life as they desired. These medications are traditionally separate from conceptions of accessible technologies, but we highlight that our participants discussed medication management as a key part of being able to access more activities throughout their everyday lives. Participants also leveraged medical supplies such as adjustable beds (P6, P7, P11, P12), shower stools (P3, P4, P6, P8, P11, P14), and braces (P3, P6, P11, P12, P14) to make their lives accessible. Notably, while these are tools that are often marketed for medical management, our participants' described them in terms

of how they increased access. For example, P3 found that now that they have a shower stool *"it's nice just knowing that if I'm feeling a bit unsteady on my feet or I'm feeling lightheaded, I have this here so that I don't have to worry about potentially falling in the shower."* P3 had worried that their symptoms were not severe enough to need a shower stool, but reflected *"I think it was more the internalized ableism talking ... if [a tool] helps you be more functional, by all means have it!"* While many of these tools were inextricably tied up in ongoing medical care and symptom management, participants understood them as related to their disability identities and as part of the larger project of increasing access in their lives.

Another small subset of the tools that participants leveraged were explicitly accessibility supports. Mobility aids such as wheelchairs (P4, P6, P11, P12, P14), canes (P14), and portable chairs (P6, P12) enabled our participants to be more mobile and take part in the activities they enjoy. Participants also used accessibility services, such as accessible parking permits (P2, P6, P11) and paratransit (P7) to access the broader world. Digital accessibility was a consideration for a subset of participants. Some used on-device accessibility settings, such as voice-to-text (P2, P11), laptop brightness settings (P1, P2, P8) and speak-selection features (P15). Other participants relied upon peripherals such as ergonomic mice (P2, P9), headsets (P2, P11), keyboards (P9, P11, P14), and adjustable height monitors (P14). Often, participants relied on medical providers or accessibility professionals to learn about or acquire these tools, limiting the participants who knew to seek them out.

However, the majority of the tools that participants described were everyday objects that they had leveraged to increase access in their daily lives (see Table 1). Tools such as supportive furniture, heating and cooling systems, and in-home gadgets (e.g., alarm clocks, Amazon Alexa) increased access in participants' daily environments. Participants also used everyday items to facilitate sensory regulation (e.g., iPad, portable fan), support their body through fluctuating symptoms (e.g., hiking boots, hat and gloves), and keep their bodies comfortable (e.g., pillows, weighted blanket). Participants turned to iPhone apps, whiteboards, and sticky notes to support their executive function and memory. To make hygiene and self-care more accessible, participants leaned on loofahs, well-organized bathroom cabinets, and items like floss picks that made self-care tasks simpler. In Section 5.1 we highlight the strategies participants employed to turn everyday items into an assistive repertoire.

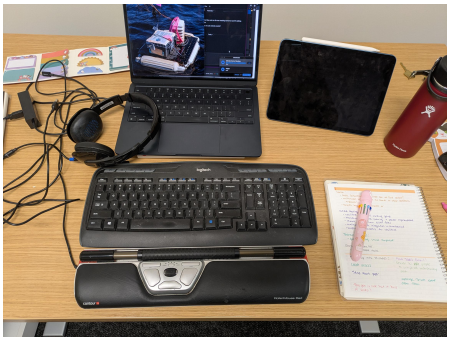
4.2 Paths To Tool Use

While participants were able to find a range of tools to increase access for themselves, they often did so with limited support or information from health care providers. Therefore, many people initially missed opportunities for accessibility support. For those students who were attending university while managing their chronic illnesses (P2, P7, P8, P9, P14), disability services operated as one exception to an overall lack of support. For example, P2 has *"a lot of hand pain and issues with dexterity. Using a mouse was really difficult ... the accessibility office ... really helped me find this [roller pad mouse]."* Many more participants stumbled upon accessibility tools, using their research skills or community forums to identify technology that may be useful to them. P6 articulated their experiences: *"as far as making my own life accessible, that has been all me. I haven't really gotten any help from medical professionals."* Our participants also called for medical providers to have more knowledge and information resources around accessible tools. Participants described often having guide their medical providers toward assistive tools, such as P14 who approached his providers saying *"I did a bunch of research, and here are all the things I think could help me."* It was his initiative and knowledge that ensured access to prescriptions for otherwise-prohibitively-expensive tools such as wheelchairs. Other participants described how providers' lack of resources translated into inadequate practical support. When trying to find more accessible diets with the support of nutritionists, P3's providers did not *"really understand some of the histamine stuff"*, P7's nutritionists failed to account for her sensitive stomach, and P10 found that recommended diets were neither culturally sensitive nor budget-aware. Currently, the formal paths to assistive technology support for people with chronic health disabilities are profoundly underdeveloped, leaving participants to develop their own solutions.

Participants' paths to accessibility technology support often drew on community knowledge and diverse resources. Particularly when buying more expensive tools, P2 depended on Reddit to learn what others recommended, which was complicated without a diagnosis: *"there's not great places, especially when you don't have a name for what you have .. when all you could say is like 'oh pain something.'"* P5 has found that ChatGPT increasingly fills a niche he used to fill with Google: *"sometimes it's gonna tell me really practical ways that I haven't thought about before. Sometimes it's just generic information, but it's also helpful, because that encourages me to ask it more."* Participants often filtered their searches for accessible tools through their own expertise. P11 utilized her own experience as a nurse in conjunction with community Facebook pages to determine which specific tool best met her needs. P6 consolidated disparate information resources, including searching for *"indigenous stuff, mostly going back to the roots of my people: turmeric, cinnamon, all of those things that are natural anti-inflammatories."*, paying attention to *"how people treat sports injuries."*, and researching *"what do they help old people with."* Participants' use of nontraditional information resources led them to many tools that were instrumental to everyday access, but they were constrained by the limits of their knowledge in isolation.

5 Results: Strategies for Chronic Access

In this results section, we report on the adaptive strategies our participants employed to make their everyday lives more accessible, including extensive use of technology. These tools and practices often differed from traditional expectations around accessibility. In this section we, first, articulate the unique ways our participants made everyday tools fit their accessibility needs and, second, rescoped what it meant to make tasks accessible. In doing so, we outline what it looks like to secure *chronic access,* or an accessibility practice that anticipates changing bodily realities [69, 86], ingeniously leverages everyday tools to fill a gap in purpose-built access technology, and engages with the messy bodily limitations that characterize chronic health disabilities [85].



(a) P2 uses an ergonomic mouse and voice to text software to navigate her laptop. She also keeps a lightweight water bottle at her desk to manage dry mouth from voice-to-text use.

(b) P12 needs to keep her legs elevated over her heart and found that an adjustable bed configured as a couch was the best option to allow her to spend time with family and friends while managing symptoms.

(c) P13 keeps a wide range of tools to support her in managing chronic symptoms in her purse. Many are used to creative ends, such as cough drops to control asthma symptoms.

Figure 1: Participants found ways to make everyday tools assistive

5.1 Making Everyday Tools Assistive

As demonstrated in Section 4.1, our participants relied heavily on everyday tools to make their lives more accessible. These tools were not designed as accessible technology, but participants leveraged them to successfully increase access in their lives. We identify three ways that participants made everyday tools assistive; (1) by optimizing for accessible tool properties, (2) by identifying indispensable tools, and (3) by finding creative use cases for everyday tools.

5.1.1 Optimizing For Accessible Tool Properties. Often, rather than seeking out a purpose-built assistive tool, participants were careful consumers, selecting versions of everyday tools that optimized for properties that well-aligned with their accessibility needs. Most consumers have many choices when selecting everyday items – for example, which brand of soap, what kind of water bottle, and which speaker to buy. Our participants were able to build accessibility considerations into those choices, selecting versions of everyday items that had properties that could prevent symptoms from occurring, make it more bearable to live with symptoms, or act directly as assistive technology.

Often, participants worked to optimize for ool properties that avoided triggering symptoms in the first place. Tools often provided access by allowing participants to avoid the symptom flares that increased their access needs. For instance, P10 has allergic reactions to many skin care products so they seek out fragrance-free shampoos and soaps to avoid triggering an eczema flare in the first place. P2 experiences pain in her hands and therefore uses voice-to-text software instead of typing on her computer. When using voice-to-text all day she needs water nearby, and picking the right water bottle has been critical to avoid hurting her hands further: *"I've slowly gotten smaller and smaller [water bottles]. I used to have the massive one, but that became way too heavy"* (see Figure 1a). Both voice-to-text and a just-right-sized water bottle allowed P2 to avoid pain in her hands, rendering them as assistive technology. Whether for soap, software, or a water bottle, the same process of carefully selecting from available consumer options led participants to access supports.

Other participants optimized for accessible tool properties that make experiencing distressing symptoms more bearable. Doing dishes for P9 is always a painful task, which they have mitigated by using a padded floor mat and storing their trash can in a cabinet that slides out. As they explain, *"when something is more easy to access and move, every single thing that's like that helps so much."* For P4, listening to music and audiobooks helps minimize tinnitus if and only if P4 has the right tool: *"the computer speaker or my phone speaker made the tinnitus worse, so at last I got a nice Bose [speaker]."* Optimizing for accessible tool properties allowed our participants a non-medical way to manage distressing, unpreventable symptoms and continue accessing the joyful and banal parts of everyday life.

For others, optimizing for accessible tool properties allowed them to use everyday items directly as assistive technology. P11's disability progressed to a point where she was struggling to get on and off the toilet. As a nurse, she was well-acquainted with rehabilitation solutions, such as a toilet lifter. However, she prioritized being able to continue using her muscles, and carefully shopped, purchasing the *"highest toilet you can buy."* This specific, commercially-available toilet met her access needs in a way that any random toilet would not. P12 also has a chronic health condition that impacts her mobility, and optimizing the shoes she wears allows them to act as assistive tools. P12 has been prescribed leg braces, and when she wears them, a specific pair of knee-high boots *"are the only pair of shoes that work with them ... it covers [the braces] visually but it also helps hold it in place."* However, P12 often skips wearing leg braces, which constrain her range of movement and wears *"hiking boots as regular shoes, [they] give more ankle support and more traction."* When carefully optimized for, everyday items could function as assistive technology directly, giving participants cheaper, readily available options that aligned with their goals for technology use.

5.1.2 Identifying Indispensable Tools. Another reason that everyday items became accessibility supports for our participants was because of how relatively important they were for our participants'

daily lives. These tools were not obviously assistive until participants highlighted what would happen if they did not have them. Tools such as a space heater, garlic press, or nice mattress are useful to most people. However, these tools became a part of our participants' assistive repertoires because, unlike people without chronic health disabilities, they experienced significant access barriers without these tools. Everyday tools could become critical infrastructure in our participants' lives by allowing them to manage or prevent symptoms, by becoming the only way to do an instrumental task, or by addressing access needs that arise frequently in their lives.

One way everyday tools became indispensable accessibility tools was when they allowed participants to more directly manage or prevent symptoms. For some participants, temperature regulation was a matter of symptom regulation, not just comfort. P1 relied on a space heater to minimize her migraines in her dorm room, P9 used air conditioning and foam sheets in their bedroom windows to keep cool, and P3 carries a cheap portable fan in her bag at all times. P3 explains: *"I find that helpful for if it's really hot and I feel like I'm overheating a bit and sometimes I get hot flashes just out of nowhere, even when it's cold."* P5 coordinated with his workplace to get a standing desk because *"if I sit down for too long and if I stand up it gives me lightheaded[ness] for like ten minutes"* These tools are all used for their mass-market purpose, but become accessibility support because of their indispensable role in reducing or preventing participants' chronic health symptoms.

For others, tools became indispensable because, rather than operating as a luxury or novelty, they became the only way by which participants could complete a task. P2, who experiences pain and weakness in her hands relies on a mandoline to cut vegetables, scissors to cut herbs and a garlic press that works on unpeeled garlic so that she can cook the meals she loves. For P4, P6, and P11, long sponges or loofahs enable them to scrub their whole bodies, given their limited range of motion. Though many people use loofahs to clean hard-to-reach areas, for participants whose disabilities made it hard to shower regularly, it was critical they got fully clean when showering. P6 found their go-to tool through curious browsing: *"I was at the Dollar Store and I found this thing that said 'exfoliating towel scrub' and I was like 'what the fuck is that?' and so I took it out of the package, and it was just this long scrubby ... I was able to [scrub] places that I couldn't get before without hurting myself and I just never went back."* These everyday tools offered our participants access to tasks that were otherwise not possible, becoming indispensable.

Lastly, participants described instances when an everyday tool became indispensable because it met a pronounced access need. P14, who experiences hypersomnia, searched Amazon for alarm clocks designed for heavy sleepers, and found one that *"vibrates and makes noises, so I put that right next to/partially under my pillow – [it] helps me wake up because ... I sleep like the dead and I will sleep for up to 20 hours if you let me."* The overlap between 'heavy sleepers' and people with sleep-related health conditions creates a market for P14 to find indispensable access tools among everyday items. Similarly, P4 finds that a good night sleep is critical to being able to manage symptoms and prioritized buying *" grown up pillows, grown up sheets, [and a] grown up bed, it makes a huge difference ... because sleep is at a premium."* Though P4 may not usually shop for more luxurious goods, the 'grown up' versions of bedding meet P4's pronounced need for good sleep. For P15, severe traumatic brain injuries mean that he is always cold. He adapts to this reality by *"wear[ing] extra layers. I bring gloves and my hat with me all, you know, eight months out of the year ... and I've learned to get over the social thing of having a lot of thick clothes on."* Hats and gloves are intended for people to stay warm in the cold, but for P15 they become an integral part of managing a disability that makes him cold more often than most. Chronic health disabilities frequently meant that our participants experienced a more extreme version of everyday needs, allowing everyday tools to become accessibility tools.

5.1.3 Finding Creative Use Cases For Everyday Tools. The final strategy we observed our participants using to make everyday tools assistive was finding unusual use cases for everyday items. Participants became skilled at identifying ways that using an everyday tool for a different purpose than it was designed for could increase the accessibility of their day-to-day lives. In these cases, it wasn't a matter of picking the perfect water bottle or coming to rely upon a loofah, but seeing the potential for a scent diffuser to prevent migraines or for post-it notes to augment short-term memory. Seeking out alternate use cases of everyday items allowed participants to decrease the likelihood of symptom flares, manage symptoms as they arose, and continue with day-to-day life while symptomatic.

Some participants found that creatively using everyday tools could decrease the likelihood of their symptom flares. P1's aromatherapy scent diffuser on her bedside table may not immediately register as an accessibility tool, but she explains: *"when the room smells a certain way ... it is helpful with my migraines."* P12's access solution is more immediately obvious – instead of a couch in her living room, she has an adjustable bed. It took significant iteration to find a solution that allowed P12 to keep her feet, heart, and hands at the same level, as is required for her health condition: *"we couldn't find anything comfortable enough that was sold as a sofa, so we broke down and were like, fuck it, we're getting a bed in the living room."* She has styled her adjustable bed (see Figure 1b) to look as much like a couch as possible, explaining that *"it's what we could come up with for comfort and accessibility."* P6 has cats and bending down to scoop out their litter box had been making them dizzy. One day they realized that their *"cats be jumping on shit, if I just lift their litter box, they should be fucking fine."* The cats' litter box now rests on a storage bin that is *"lifted to a spot where I can get in without hurting myself"* and has been no problem for the cats. Adding new tools, substituting, or modifying the use of everyday tools allowed our participants to creatively increase access for themselves.

For some participants, using everyday tools creatively enables them to deal with symptoms as they arise. P3, P6, and P13 carry purses that are full of things that *"people wouldn't think are disability related"* (P13), but nonetheless enable them to manage or mitigate potential health crises when not at home. P13's purse contains, among many other things, cough drops to manage asthma symptoms, snacks to manage her blood sugar, and lotion to address the dry skin that accompanies her diabetes (see Figure 1c). For P5, the ability to pick his seat on an airplane is critical. He always chooses an aisle seat because he has to go to the bathroom frequently and relying on others to access the bathroom is *"the kind of uncertainty that makes me think twice about going out or*

traveling." P11's progressive muscle condition makes it difficult to get in and out of bed. Besides having an adjustable bed, she uses a well-placed sheet that allows her care provider to help adjust her when she's in bed, a DIY bed cage to prevent her from being trapped under the covers, and a scarf tied to her bed frame that helps her pull herself out of bed independently in the morning. Creatively finding the access application of everyday tools allowed participants to manage symptoms as they arise without expensive or hard-to-acquire formal assistive tools.

For others, using everyday tools creatively allows them to continue with everyday life while managing symptoms. If P11 falls, she needs to call emergency services for help. To ensure that she can always call for help, P11 has placed Amazon Alexa devices throughout her house. Although Alexa is restricted from calling 911 directly, P11 created *"'call for help' as a contact, and it's to 911."* P11's creative Alexa-based emergency line allows her to go about her daily routine without fear, because she knows she can always access help. For P12, having access to a range of medications and daily care tools is important if she is stuck in bed for long, symptomatic stretches. She has found a storage solution that works particularly well for her: a lazy susan that allows her to keep needed items *"not in the drawer and having the spinability to be able to reach everything."* P15's working memory *"is just totally shot post TBI"*, so he uses both analog and digital memory supports to work on his college degree. He keeps pen and paper by his bed, particularly because bedtime is *"when I remember like, oh, I have a homework due tomorrow."* P15 also adds myriad reminders to an app and uses his MacBook's built-in speak selection tool to have the system *"speak the announcement out loud–it's a little bit of an annoying voice, so it gets my attention and it helps me pivot a little bit to whatever it's saying."* Participants use everyday, available tools creatively to be able to continue with their day-to-day lives while managing chronic symptoms.

5.2 Rescoping 'Access'

Our participants with chronic health disabilities often conceptualized 'accessibility' differently than it is often framed or discussed within accessibility research and practice. Rather than gaining full access to an activity using alternate means (e.g., a ramp, captions, braille), our participants often achieved access by rescoping the activity they were trying to access. Many of our participants' disability experiences were defined by fatigue, pain, or other forms of discomfort that could be triggered or exacerbated by the activity they were trying to access. Therefore, to access a given activity, they altered it, recognizing that completing the activity as a nondisabled person would was not feasible given their chronic health conditions. Rescoping brought our participants both joy and sorrow – at times they celebrated the creativity and unexpected benefits of rescoping, and at others they mourned the limitations that governed their day-to-day lives. Understanding how rescoping functioned for our participants can help illuminate the different needs and goals involved in meeting bodymind and future impact access barriers[67]. Participants described four major types of rescoping they employed: changing timelines, constraining tasks, altering environments, and involving others.

5.2.1 Changing Timelines. A common way that participants rescoped activities was by changing the timelines on which they completed a given task. Participants altered timelines both by changing how long they spent on a task directly and by choosing when to complete a task to better align with their fluctuating symptoms. Changing timelines is a strategy that fits under the larger umbrella of crip time [58, 90, 94], a concept named by disability studies scholars to articulate the ways that disability moves people off of normative timelines.

Some activities became accessible to participants when they adjusted their expectations around when they would occur and how long they would take. Many participants experienced episodic symptoms and spontaneous flare-ups, which made managing responsibilities more difficult. P1 described working ahead for homework deadlines so that *"if I were to get a migraine later on, then my homework is already done, so I don't have to worry about the fact that I just physically am unable to work on it right now."* Participants also prioritized planning around activities that are likely to cause flare-ups. When P2 travels for work, she *"will always change my flight to land a day– at least an extra day, if not two days, earlier ... I need that extra time to sleep after a long flight."* P3 is heat sensitive and needs to be *"extremely careful"* during the summer heat, and tries to *"take advantage"* of opportunities to be outside during her area's mild winters. When people's disabilities meant certain activities were accessible at some times and incredibly difficult at others, they planned to complete them on more accessible, less normative timelines.

5.2.2 Constraining Tasks. Another type of rescoping our participants performed was constraining tasks to the essential pieces that they were able to access. This strategy was often employed when the activity they were trying to access was broadly defined – for instance, cooking dinner or socializing with friends. Participants identified what, within the broader umbrella of a task, they could complete, and by placing constraints on the task, were able to rescope it into something accessible to them.

Sometimes, constraining a task was unsatisfying for participants – they desired better options, but made do with a limited version of the task. Both P2 and P4 found that cooking became significantly more difficult after they developed chronic health conditions. P2 explained *"I used to cook a lot, and that became really difficult, the chopping especially, but even stirring can be pretty hard, to be honest."* Now, her husband does a lot of the cooking and she changes the kinds of dishes she cooks: *"instead of cutting a bunch of chicken into bite sized cubes, finding a dish where, instead, I could just put chicken thighs and roughly cut vegetables on a roasting pan."* While P2 would prefer to be able to cook like she used to, by constraining the task of cooking she finds ways to continue doing something she loves and ensures she is fed. P9 finds that there is no way around dish washing being painful, but has streamlined their process: *"I actually use very hot water [to wash dishes], because I really want it to be as effective as possible in the least amount of time."* While rescoping tasks is an essential strategy for maintaining necessary activities, it is not always an appropriate end goal for access.

For other participants, rescoping and constraining the task at hand resulted in satisfying options. P6 is a photographer and brings a foldable stool to shoots and builds breaks into their shooting schedule — they have found that *"when I have to take a couple of minute breaks it also is good for the model to take a couple of minute*

(a) A large recliner allows P4 to be comfortably positioned to manage both dysautonomia and surgery recovery. P4 ensures that remotes, beverages, devices, and more are always on the side table to allow P4 to preserve energy

(b) P14 keeps the braces he might need first thing in the morning within easy reach of his bed and his cane always stays in the same place in his room so that his service dog can retrieve it when he needs it.

(c) P11 has a lift in the back of her minivan to allow her son, who has inherited her genetic condition, to get her wheelchair into the van.

Figure 2: Participants leveraged specific properties of their tools to increase access in their daily lives.

breaks." For P6, altering their approach to their job also benefits the people they work with. P7 uses paratransit to get around her city, but finds that it is cumbersome to use. She is still able to see friends by asking that they come to her, constraining the things she does with friends to ensure that she is able to enjoy time with them. For P10, navigating their dietary restrictions while eating at restaurants is a difficult task, so instead they *"eat at home pretty regularly ... I have figured out what works for me."* For these participants, rescoping allowed them to continue doing everyday activities with less friction, preserving the essence of the task.

5.2.3 Altering Environments. Participants were able to complete some tasks if and only if they were in a supportive environment. These tasks became accessible when participants rescoped where they could be done. Some participants altered environments to better match their sensory needs and avoid a symptom flare and others built supportive environments to allow them to continue a task when symptoms flared.

Some participants focused on ensuring that their environment matched their sensory needs. For instance, P10 advocated to move their workspace from a basement to a room with windows, knowing that their depression would be triggered by lack of light. P1 found that living in a dorm room with a roommate who has different sensory preferences has underscored how much her environment impacts her migraines. P1 and her roommate have worked to compromise on noise, temperature, and light, agreeing to use headphones when watching TV, ensuring that she sleeps on the side of the room closer to the heater, and setting up a curtain between their sides of the room. When participants were able to spend time in environments that met their sensory needs, fewer access needs arose throughout their days.

Participants also worked to alter their environments to accommodate themselves during symptom flare-ups. P3, P6, P7, and P13 ensure that they are able to work from bed on days when symptoms flare. P3 has days when they can't *"leave bed all day"* and other days when they nap in the middle of the workday, which helps them maintain their ability to work. They set up their bedroom up so that *"I had my water bottle there [on the night stand] and my work computer next to it. If I need to access anything, it's all right there, and it's just reassuring."* For P7, mornings are the most likely time for her symptoms to flare, so she ensures that there are always two protein bars and a drink on her bedside table when she goes to bed. This arrangement makes it possible to *"start the day slower and still eat,"* while also being able to keep up with her job. To leverage these environmental supports, several participants actively sought jobs and educational opportunities that allow them to work from home. Getting ready for the day is a frequent trigger for P6's symptoms, so they set all of their toiletries within reach of the toilet. They explain: *"I get dizzy getting back up, back and forth. I've noticed that if I put everything within reach while I'm sitting down, it is easier."* While these environmental configurations do not themselves prevent symptom flares, they make it possible for participants to continue with their days while symptomatic.

Other participants planned for days when they would struggle to get up or need to be minimally mobile. For example, P14 lives with chronic pain and has a box next to his bed containing *"basically any sort of brace under the sun that you can think of ... so that if I wake up in the morning and I'm like 'ow!' [they're] right there"* (see Figure 2b). When P4 experiences a flare, a large recliner is the most comfortable option (see Figure 2a). P4 has a side table next to the recliner that is deliberately stocked with everything P4 may need: *"it's all within reach, because I'm probably not getting up for a while."* Though the range of activities participants can do often shrinks during a flare, altered environments preserve as much functionality as possible.

5.2.4 Involving Others. A final strategy participants used to rescope tasks into an accessible version was to involve others. Often, our participants highly valued technology that allowed them to be more independent. However, they also found value in turning toward tools that enabled *interdependence*, or the ability to work to meet their access needs with others [13, 54]. Interdependence was

a particularly useful strategy when a task remained inaccessible independently.

Our participants often involved their loved ones, friends, and service animals to increase access. P11 has a Joey lift in the back of her minivan to load her wheelchair into the car (see Figure 2c), but she cannot walk from the trunk to her seat. Her son helps her transfer from her wheelchair into the car and then he *"rides the wheelchair onto the Joey lift and then uses the controls to get it into the back of the van."* P11's son has inherited her genetic condition, so she plans her assistive technology purchases to ensure that his access needs are met while supporting her. For P12, a lightweight, foldable camping stool allows her to rest in between locations, furthering the distances she can walk and extending the time she can spend at fun events. However, she has found that it is critical she has not one, but two stools, so that whoever she is with can also use one. P12 explains: *"if everyone is standing and I'm sitting, I'm sitting at people's feet. It feels really shitty, [it's] really important to have two so we can sit together."* For P14, it is his service dog, rather than another human, who most often supports his access needs. P14 makes sure his cane is always stored in his bedroom so that his dog *"knows exactly where it is, so he can go upstairs and get it and run back downstairs and give it to me"* (see Figure 2b). For many people, technology alone would not provide full access, but it provided access when used interdependently with others.

6 Discussion

From the experiences of 15 people who identify as disabled due to their chronic health conditions, we identified patterns in accessible technology use and strategies to create chronic access. We now envision a future for accessible technology research that includes people with chronic health disabilities. Specifically, we outline design directions for chronic access, identify opportunities for health and accessibility collaboration, and reflect on how chronic access could change conceptions of access across the field.

6.1 Design Directions For Chronic Access

Articulating chronic access illuminates many opportunities for future accessible technology research to better support the large and growing group of people with chronic health disabilities.

First, accessibility designers and researchers could create tools to help people build everyday assistive repertoires. While many needs may be better met by assistive technology designed for chronic health disabilities, everyday tools have a real and lasting role in people's day-to-day lives. Everyday tools are often cheap, do not necessarily carry an assistive stigma [91, 97], and, as our participants demonstrated, can be used in ingenious ways to secure access. Designer Sara Hendren has long argued that all technology is fundamentally assistive [46] and our participants demonstrate the potential for tools not perceived of as *for* disability to increase access. Right now, participants describe experiences building an everyday assistive repertoire in isolation, or perhaps with the intermittent support of Reddit communities or other online resources. However, identifying and creating that repertoire took great time and effort, which many people with chronic health disabilities lack. Thus, more research is needed to understand the assistive potential of everyday tools and to create information resources that could support people with chronic health disabilities in brainstorming and creating their repertoires. Notably, we deliberately conducted this research with people who already had developed a disability identity related to their chronic health conditions, a niche subset of a globally diverse group. Tools to assist people in developing the creativity and ingenuity our participants displayed could be particularly useful to people with new diagnoses or who are new to seeking to accommodate, rather than only treat, their chronic health disability.

Another key place for designers to leverage chronic access is in maximizing the realms of possibility within participants' rescoping practices. Rescoping calls our attention to the fact that a direct one-to-one replication of experiences is often not the most appropriate goal for chronic access. However, there is still need for design to maximize the proportion of a task participants can access. Consider the example of P2's experiences cooking – due to pain in her hands, she has stopped cooking the more complex dishes she loves to make in favor of dishes that put less stress on her hands. She already has some everyday assistive tools to expand her capacity (scissors, mandolin, garlic press) but there are many opportunities for accessible technology designers to make cooking less painful on the hands of people like P2. New accessible technology design for chronic health disabilities could be guided by attending to places where rescoping is unsatisfactory.

Finally, accessible technology researchers and designers should begin to build purposeful chronic access technologies. There is a burgeoning market for chronic-health-specific tools, such as the Visible armband [63], designed to help people limit energy expenditure. Yet, few dedicated accessibility tools have been designed for people with chronic health disabilities. Implementation-focused accessibility research and practice could make a significant difference for a community that has frequently been targeted with technology to understand and manage their illness (e.g., [4, 33, 95]), but rarely with tools to support their day-to-day lives.

6.2 Opportunities for Health and Accessibility Collaboration

Chronic health disabilities sit at a unique intersection between health and accessibility research communities, challenging the common practice of both fields and highlighting opportunities for collaboration. Health researchers have long-invested in building tools to support people with chronic health conditions in managing and understanding symptoms and navigating health care systems (e.g, [14, 53, 59]). However, as our participants demonstrate, people with chronic health disabilities are often failed by health care systems. A solely medicalized understanding of chronic health is necessarily incomplete. Accessibility and disability perspectives offer an epistemic intervention – rather than relying upon a medical authority, accessibility research can center people with chronic health conditions as experts on their bodies and needs [69] and can offer support that is not fundamentally focused on curing or improving someone's bodymind. But, accessibility research has not historically focused on chronic health disabilities [68] and is just beginning to build the capacity to design for access needs that are deeply connected to bodily realities [67, 69]. Furthermore, current infrastructure ensures that people with chronic health conditions

are far more likely to interact with medical providers than accessibility supports. Health researchers hold deep expertise in designing interventions that can reach patients. To best serve people with chronic health disabilities, we need trauma-informed collaboration between health and accessibility research communities.

There are myriad opportunities for health and accessibility collaboration to better support people with chronic conditions. First and foremost, we lack an understanding of how existing accessibility technologies and everyday tools could support people with chronic health conditions. To begin to bridge this gap researchers must be well-acquainted with how chronic health conditions manifest and what access needs accessibility technologies can currently meet. Collaboration between health and accessibility research could build this foundational knowledge and lead to design interventions that enable medical providers to connect their patients to appropriate accessibility technologies. This research should depend highly on community-engaged methods, as people with chronic health disabilities, such as our participants, are currently leading innovation in applying accessibility technology to chronic health-related access needs. Following explorations of current tools, health and accessibility researchers could then collaborate to discover how tools could be better customized and developed to match chronic health related access needs. Furthermore, many of our participants highlighted that their providers' lack of knowledge and stigma around disability limited their access to technology, a trend that is echoed across conversations about chronic health disabilities [12, 34, 41, 79]. Interventions that target medical providers' understandings of disability and chronic health could increase quality of care and access to resources for people with chronic health conditions. Ongoing collaboration between health and accessibility research could also help make these fields more legible to each other, enabling greater sharing of information and eroding current barriers in practice, reporting, and understanding.

6.3 Chronic Access Influencing Accessibility Practice

While our participants found significant value in chronic access in their everyday lives, their experiences also highlight the need for accessibility practice to evolve.

Our findings highlight the need to design more accessibility support for everyday care tasks. Our participants described many ways they leveraged accessibility tools to make the minutiae of everyday life more accessible. Yet, while health researchers are often highly focused on supporting what they term 'activities of daily living' [78], the ASSETS community has rarely focused on technology to support people in tasks such as going to the bathroom, getting out of bed, or feeding themselves. HCI Accessibility research has long-focused on providing critical support for disabled people to access work (e.g., [30, 100]), public life (e.g., [40, 56]), online discourse (e.g.,[7, 39]), and education (e.g., [20, 61]), but relatively little work supports domestic access (e.g., [23, 25]). Our participants stressed that none of their efforts at school or work could happen without the ability to accessibly care for themselves. Furthermore, like many disabled people [80], several of our participants are on social security disability or are otherwise unable to work. Fields, such as occupational therapy [27, 93, 103, 108] and rehabilitative medicine [6, 60, 72, 75], focus on using assistive technology to support people in accessing activities of daily living. ASSETS researchers have much to learn from these fields but remain a valuable and unique perspective in this space – ASSETS researchers are not fundamentally intertwined with medical practice, creating the potential to provide much-needed support to the many people with chronic health disabilities who are traumatized and ignored by medical systems. When HCI accessibility research primarily designs for public, not domestic life, we fail to serve many people, particularly those with chronic health disabilities.

The features of chronic access we describe are derived from the experiences of chronic health disabilities, but future research should explore whether these dynamics play out across broader disability communities. Our participants experienced far more bodymind and future impact barriers than often addressed in accessibility research, but Mack et al. [67] emphasize that these barriers are not solely the domain of chronic health disabilities. Further, prior work has incidentally documented everyday assistive technology use among blind people [13, 49], d/Deaf and hard of hearing people [32, 35], AAC users [29, 102], and people with upper limb mobility disabilities [47, 89]. Furthermore, it is very likely that rescoping is a strategy employed by disabled people without chronic health conditions: perhaps in the absence of full access, because the cognitive drain of persistently advocating for access is exhausting, or because access strategies use up limited resources (i.e., energy, money, time). Chronic access becomes highly notable in the absence of purposefully designed assistive tools and when situated within the realities of pain, fatigue, and other chronic symptoms. However, future work should investigate whether these strategies are more prevalent across other disability groups and seek opportunities to support the less-obvious assistive strategies all disabled people use to navigate complex and dynamic inaccessible worlds.

6.4 Limitations and Future Work

This paper has some key limitations. First, this research was done with a small number of uniquely situated people: those who currently identify their chronic health condition as a disability. We chose to conduct this research with participants who were more likely to have existing accessibility practices we could learn from, but this is not a representative sample. Future work should investigate accessible technology use among people with chronic health conditions who do not identify as disabled. Next, while we were able to learn about large swaths of participants' accessibility tools, they were shaped and guided by participants' responses to photo elicitation prompts and limited by time and method. Future work could systematically document chronic access across all aspects of individuals' lives. Finally, our participants are all currently based in the United States and their experiences are deeply shaped by the structure and function of the United States' health care systems.

7 Conclusion

By discussing accessible technology use with 15 participants with chronic health disabilities, we identified unique patterns in tool use and access strategies. Participants leveraged a diverse set of medical, assistive, and everyday technology to increase access in their day-to-day lives. The strategies they used to secure access, which we

name *chronic access*, focused on finding the assistive potential in everyday technologies and rescoping access to reflect the limitations of chronic symptoms. We envision a future for accessibility research that attends to the access needs of this group of disabled people who have, for too long, only been offered health management and treatment. In so doing, we also see the potential for the practice of accessibility writ large to innovate in response to chronic access.

8 AI Disclosure

No generative AI tools were used in data analysis or the writing and editing of this paper.

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A Appendix - Photo Elicitation Activity

The following text is the content of the photo elicitation activity sent to participants in this study:

A.1 Photo Elicitation Activity Description

We're excited to have you join this study! During the study session we will discuss your experiences with chronic health and disability, the kinds of tools, technologies, and strategies you use to make your day-to-day life more accessible to you, and brainstorm what kinds of future tools you would be interested in. To anchor our conversation, we request that you take pictures of the way you currently have set up different aspects of your day-to-day life to take care of your health and make daily activities more doable. Please take three pictures, guided by the following prompts - pick the ones that feel most relevant to your life:

- What do you have on your bedside table to make getting up or going to bed easier?
- What items do you have next to you on the couch or in bed if you're riding out a symptom flare?
- If you work (either professionally or on projects of your own), how have you set up your workspace to best support you?
- When you're leaving the house, what needs to be in your bag or car to manage symptoms or handle any emergencies?
- If you use a mobility aid, like a wheelchair, cane, or rollator, what specific tool do you use, and have you modified it at all?
- Do you change any settings on your phone, tablet, computer, TV or other digital device to make it more usable for you?
- Often activities like cooking or getting ready in the morning can cause symptoms for people with chronic health conditions – have you set up your bathroom, kitchen, or other part of your home to specifically support your needs?
- If you're going on a trip or doing an activity that you know will be hard, what is in your bag or suitcase to prepare for that?
- If you take medication, what kind of tools do you use to keep on top of your meds?

If you have any other set up we haven't asked about but you'd love to share, please do! Please take and send these photos to <RESEARCHER EMAIL> at least 24 hours before your scheduled study session. The overall study compensation of $75 is designed to compensate you for both the time it takes to photograph your space and the 90 minute study session. Please reach out if you face access barriers to this task and we will work with you to make your study participation accessible.