Between Control and Uncertainty: Understanding Self-Tracking Practices in Enigmatic Disease Management

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Abstract

Self-tracking tools are often built around the assumption that tracking the "right" health variables will lead to actionable insights and greater control over one's health. Yet, it remains unclear how these assumptions hold up in contexts marked by uncertainty, unpredictability, and frequent fluctuations in health needs. We explore this question in the management of enigmatic diseases—conditions such as fibromyalgia, Crohn's disease, and endometriosis that are poorly understood and highly individualized. Through interviews with 23 participants living with disparate enigmatic conditions, we examine goals, motivations, and how tracking practices evolve across different disease states. Our findings show that tracking was strongly shaped by shifting needs, with goals emerging, evolving, or being abandoned in response to health fluctuations. Tracking was often double-edged: at times empowering, fostering a sense of control, but also frustrating, leading to self-blame and negative views of everyday activities being tracked.

CCS Concepts

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

Keywords

Self-Tracking, Enigmatic Diseases, Disease stages, Health

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1 INTRODUCTION

The desire to monitor and keep track of aspects of daily life has always been present in human societies since ancient times. Individuals have long used tools like scales, thermometers, and journals to record physical and mental states [54]. According to Lupton [32], self-tracking *"involves practices in which people knowingly and purposively collect information about themselves, which they then review and consider applying in their lives."* Driven by technological advancements, self-tracking has gained popularity and is now a common practice among individuals seeking a healthier lifestyle. Research has shown that 69% of U.S. adults monitor at least one health-related indicator (e.g., weight, diet, exercise routine, or symptoms) [22], for reasons ranging from behavior change to sense-making and simple curiosity [14, 33].

A population with particularly complex and ongoing self-tracking motivations is that of individuals living with chronic conditions. This group tends to engage more actively in self-tracking practices [22], as persistent health challenges make it valuable to document symptoms, identify correlations, or preserve healthy stories for care. For many chronic conditions, tracking can be oriented around well-established conditions [5, 38, 59]; for example, dietary choices and blood glucose are strongly associated with diabetes management [23, 28, 53].

In contrast, for conditions such as inflammatory bowel diseases, endometriosis, and fibromyalgia, it is far less clear which metrics are helpful for meaningful tracking. These conditions have been referred to as *enigmatic diseases*, and are characterized by limited biomedical understanding regarding their chronic and multifactorial nature, often compounded by unknown triggers [42]. Additionally, these conditions can manifest uniquely in each patient, presenting a diverse array of symptom clusters that can fluctuate unpredictably [40]. Their unpredictability complicates the establishment of clear tracking objectives, raising questions about how tracking can effectively support this population.

Prior work in HCI has begun to address this challenge. McKillop et al. investigated how to design self-tracking tools for endometriosis, identifying dimensions and variables of disease experience [38]. Their work sought to standardize patient-generated data to advance both individual self-management and collective disease knowledge, surfacing tensions between personalization and large-scale analysis. Schroeder et al. explored the potential of goal-directed self-tracking for migraine management to support patients articulate, configure, and pursue personalized tracking goals [49]. Their study demonstrated how goal-oriented designs can bridge gaps between patients' condition management objectives and the capabilities of current self-tracking tools. Similarly, other studies of enigmatic conditions (e.g., endometriosis, IBS) have explored how individuals engage in self-experimentation or hypothesis-testing to uncover personal triggers, identify symptom patterns, and test management strategies [42]. These efforts emphasize *what* to track and *how* such data might inform a broader understanding of a particular enigmatic disease.

In this paper, we shift the focus to *when* and *why* people track. We explore how individuals with enigmatic diseases engage with tracking across fluctuating states of illness, and how their goals emerge, evolve, or lapse over time. While prior work has largely approached

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enigmatic diseases by studying a single condition, we study multiple diseases collectively. Although single-condition studies offer valuable insights into how self-tracking tools might be tailored to the particular need of a specific condition, such as endometriosis or IBS, this framing may overlook opportunities to design for the broader characteristics that many enigmatic diseases share. Enigmatic diseases are often marked by unpredictability, limited clinical guidance, fluctuating symptoms [42]. These commonalities suggest that challenges like deciding what is "worth" tracking, managing uncertainty, and interpreting inconclusive data may extend beyond any one condition. Studying multiple enigmatic diseases together enables us to foreground shared experiences rather than limiting our understanding to the contours of a single condition. By treating each condition in isolation, existing research risks reproducing a fragmented design landscape in which only certain diagnoses receive tailored support, while others - especially rare, stigmatized, or comorbid conditions - remain underserved.

With this in mind, we aim to address the following questions: (1) How do people with different enigmatic diseases engage in self-tracking across fluctuating states of illness, and what common needs and challenges arise as their goals shift over time?; and (2) What opportunities and considerations do these shared experiences highlight for designing self-tracking tools that support people living with enigmatic conditions.

Our work contributes to HCI and personal informatics literature in three key ways:

1. We broaden research on health tracking by examining how people with enigmatic diseases navigate **shifting needs and evolving goals** across different conditions. Our findings reveal shared tracking experiences shaped by uncertainty, shifting priorities, and fluctuating symptoms.
2. We offer a nuanced account of the double-edged role of tracking: while it can foster agency, it can also amplify uncertainty, frustration, and self-blame when expected insights fail to materialize, underscoring the need for non-judgmental designs.
3. We advance design knowledge for adaptive, inclusive self-tracking tools by identifying opportunities for systems that support shifting goals and adapt to fluctuations, extending disease-specific insights into a broader, cross-condition design space.

2 BACKGROUND AND RELATED WORK

We provide background on enigmatic diseases and our view of the term. Although not unique to our work, this concept has been discussed in various academic papers, which typically share a similar understanding, one that we will uphold, with a particular emphasis on the shared experiences of those living with these conditions. We also review literature on self-tracking in the context of disease management and the impact of its fluctuating nature.

2.1 Enigmatic Diseases

Enigmatic diseases have been defined as chronic conditions that remain not fully understood due to their multifactorial nature, unknown pathology, and undetermined etiological agents [42]. Examples include inflammatory bowel disease (IBD), which encompasses ulcerative colitis and Crohn's disease; endometriosis [6, 38]; and axial spondyloarthritis (axSpA), a rheumatologic condition characterized by chronic spinal pain, stiffness, and fatigue [27, 52].

Although prevalent, these conditions lack clear biomarkers or standardized pathways for management [39]. They are permanent, meaning they do not resolve over time [8], and require ongoing medical attention. In addition, enigmatic diseases often manifest in a highly individual way for each patient, meaning that they vary from person to person, making each patient's experience unique [42]. Additional variations may include differences in the severity of the disease, the degree of disability, medication adherence and effectiveness, side effects of medications, and the presence of comorbid conditions that may interact with or complicate the disease.

Symptoms fluctuate in intensity and form, with individuals frequently experiencing *good days* and *bad days* as symptoms vary in intensity [40]. This variability may be triggered by a range of possible factors, such as diet, stress [1], however, definitive causal links and influences are at large poorly understood [56]. This underlying uncertainty often leads to emotional strains, feelings of isolation, and diminished sense of control [57]. For many, cultivating self-awareness and "expert patient" knowledge becomes a key survival strategy [42].

2.2 Self-tracking and Enigmatic Disease Management

Prior HCI literature has examined how self-tracking can support the management of conditions that are less well understood, where it is not obvious what should be tracked or how such data might inform treatment.

One line of research has examined self-tracking as a practice of *documentation and communication with clinicians*. This line of research has explored how self-tracked health data can help bridge the gap between brief, episodic medical appointments and the lived reality of fluctuating illness. Research shows that tracked health data can help legitimize patients' experiences, preserve the episodic nature of symptoms, and advocate for recognition of severity in contexts where institutional records are incomplete or dismissive [42]. Pichon et al. [42] conducted ethnographic fieldwork with women with endometriosis and their clinicians, showing how self-tracking supported clinical encounters. Patients kept detailed records of pain episodes, treatments, and daily disruptions to assert the validity of their experiences, especially in situations where medical records or clinical measures failed to reflect the realities of their illness. Similarly, Queirós et al. [43] described how patients with chronic conditions produced extensive personal documentation of symptoms and life events, which they mobilized during clinical consultations. These practices were not only instrumental for recall and communication but also worked as strategies of legitimacy, countering skepticism from professionals and family members about the reality or severity of their illness. Although these studies focus on different conditions, they reveal a shared pattern: people use tracking to fill gaps in clinical recognition and legitimacy across a wide range of enigmatic conditions.

A second line of work has focused on self-discovery and experimentation. These studies have examined how people use self-tracking to move beyond documentation, engaging in practices of reflection and hypothesis-testing to make sense of complex or fluctuating symptoms. A common thread in this literature is self-experimentation, where individuals run small-scale personal trials, adjusting variables such as diet, medication, or lifestyle factors to observe possible effects on their condition [11]. Unlike formal clinical studies, these efforts are initiated and managed by patients themselves, often with minimal methodological guidance, and are deeply entangled with the uncertainty of everyday life. Schroeder et al. [47] showed that people with migraines track not only to record migraine instances but also to anticipate flare-ups and conduct informal self-experiments, such as testing whether changes in diet, sleep, or stress management could reduce frequency or severity. Chopra et al. [11] investigated practices among people with polycystic ovary syndrome (PCOS), showing that self-experimentation was not a rare occurrence but a routine part of navigating the condition. Participants tried different diets, supplements, and exercise regimens to test what might alleviate symptoms, drawing on both personal tracking and peer advice from online communities.

A third, growing body of work has explored how to *design* tracking tools that better support the management of conditions marked by uncertainty and enigma. Sefidgar et al.'s MigraineTracker [50] examined how goal-directed tracking supports migraine management across self-tracking stages. The study shows that this approach enhances patients' understanding of their condition, fosters self-care, and underscores the need for personal informatics models that address multiple, concurrent goals in long-term tracking. For endometriosis, McKillop et al.'s work on identifying meaningful dimensions of endometriosis tracking informed the design of *Phendo*, a large-scale platform that allows individuals to record daily experiences across pain, menstruation, treatments, emotions, and other personally relevant dimensions [38]. A key finding of their study was that emotions played a significant role in how patients tracked their disease, an aspect typically overlooked in clinical phenotyping of endometriosis. *Phendo* was designed to bridge individual and collective goals: people with endometriosis could use it for day-to-day reflection, while researchers and clinicians could aggregate thousands of records to enrich clinical documentation. This focus on the patient's emotional experience and need for personalized forecasting was further explored by Pichon et al. [41], who conducted a speculative design study investigating the voice as a potential, low-burden modality for capturing disease experiences. The primary aim of their study was to explore how the analysis of voice could facilitate the forecasting of symptom flare-ups, thereby guiding health actions and reducing disease uncertainty. Participants showed enthusiasm for the forecasting potential and highlighted imagined emotional benefits from the voice logs, such as providing a nonjudgemental outlet for venting and a means of feeling validated in their day-to-day illness experience. These findings reinforce how profoundly emotions shape both the acceptance of health technology and individuals' perceptions of their own disease management.

For IBS, Karkar et al.'s *TummyTrials* translated self-experimentation into a structured, app-based protocol, helping people test potential dietary triggers to IBS [29]. While promising, the study also illustrated the risks of formalizing experimentation without adequate support: isolating triggers required strict adherence and yielded mixed success, underscoring the challenge of balancing scientific rigor with everyday feasibility. Similarly, Chung et al.'s *Foodprint* explored lightweight food diaries to help people with IBS capture diet–symptom relationships in ways that could be meaningfully shared with providers [12].

Taken together, these lines of work seem to show that although enigmatic diseases differ clinically, people often self-track with similar aims across conditions: to document fluctuating symptoms, search for patterns, experiment with management strategies, and navigate the emotional realities of uncertain illness. Our work builds on this foundation by examining how these dynamics unfold across different enigmatic diseases, and highlights how a multi-condition perspective can guide the design of tools that are not limited to a single diagnoses but support patterns shared across enigmatic diseases.

2.3 Self-tracking in the Context of Change

Self-tracking is not a static practice but one that ebbs and flows with people's circumstances, identities, and goals. Personal informatics research has long argued that tracking must be understood as a *lived* practice, intertwined with everyday routines and shifting priorities rather than a linear march toward behavior change [20, 45].

Building on this perspective, subsequent work has shown that goals and practices evolve over time [18], that lapses and resumptions in self-tracking are common, and that these dynamics are not failures but expected parts of engagement [19]. A large body of this work has studied how significant life events and transitions impact digital practices. Studies of retirement, for example, show how digital personhood and online routines are reconstructed as people adapt technologies to new identities and rhythms [16]. Technology however often falls short during such periods: they neglect shifting needs, expose users to additional stress, or fail to offer meaningful support [10]. Haimson and colleagues developed a taxonomy of major life events, emphasizing how transitions involve intense social readjustment and how digital systems mediate disclosure and identity work in these periods [26]. Related work illustrates how digital footprints complicate identity transitions, such as during gender transition, where past data and networks collide with emerging selves [25]. Together, these studies argue that that moments of change are critical events where technologies can scaffold or undermine continuity and agency.

In health contexts, the challenges of change are particularly acute. Figueiredo et al. [15] show that fertility apps rarely support transitions across different reproductive goals such as conception, contraception, or menopause, resulting in mismatches between evolving needs and rigid system framings. Feron et al. [21] studied pregnancy as a transformative life event, finding that motivations and goals for tracking evolved across different stages. Women often experienced misalignments between data collected prior to pregnancy and the realities of their changing bodies, which led them to reinterpret or abandon tracking altogether. In the context of chronic disease, Keys et al. [31], focusing on atrial fibrillation (AF), found that as the condition progressed, tracking devices became less useful and often failed to keep up with more complex arrhythmias. Those who developed atrial flutter, ventricular arrhythmias, or entered permanent AF received increasingly inaccurate or inconclusive readings, and the technology offered little guidance during recovery, adding uncertainty about whether data changes signaled progress or concern. This led to confusion, frustration, and a gradual loss of trust in the technology, even though many continued using it out of habit or relied on unsustainable workarounds. Similarly, Paymal and Homewood [40] explored how the *"ever-changing nature of symptoms"* shapes technology use for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Participants described conflicting tendencies: on "better days," many reduced reliance on technology to preserve energy for social or outdoor activities, while during flare-ups, technology was either used more intensively to maintain a sense of productivity or abandoned altogether due to overwhelming fatigue. These findings resonate with studies of mental health: Matthews et al. [36] show how self-tracking among people with bipolar disorder is fragmented as identity and mood fluctuate in unpredictable ways. Schroeder et al. [49] examined goal-directed self-tracking for migraine management, noting that existing tools often fail to support lapsing and resumption. Their study found that participants not only anticipated needing temporary breaks (e.g., during busy periods like finals week) but also developed strategies for a non-binary lapsing approach. This meant reducing tracking to a manageable subset of critical data rather than complete discontinuation, thereby allowing them to prioritize tracking severe symptoms even when time constraints would otherwise force abandonment.

Finally, work on online health communities points to the importance of social scaffolding during times of changes. Massimi et al. [34] examined how people adopt, use, and disengage from online health communities at different life stages, showing that disengagement is not a failure but a logical response to changing needs. These insights underscore that tracking and technology use are rarely stable. Yet most systems still frame lapses, discontinuity, or change as problems to be avoided rather than expected dynamics to be supported. By focusing on enigmatic diseases, our work contributes to this literature by examining transitions that are not occasional but recurrent and unpredictable. We show how fluctuating symptoms drive the emergence, adaptation, and abandonment of tracking goals, and argue for systems that normalize discontinuity while supporting reflection and agency across transitions.

At the same time, the simple act of documenting data can lead to recalling previous moments when one's illness was less debilitating, evoking a range of emotional responses. For some, this may lead to discouragement and hopelessness, as they perceive a regression in their condition and lose a sense of control over their body [36]. In chronic and fluctuating conditions such as migraines or IBS, this tension is further amplified by the difficulty of establishing clear causal relationships, making sense-making with personal data both effortful and emotionally charged [29, 47]. In this sense, the chronic nature of these illnesses further emphasizes the frequent and distressing changes that shape the lives of those affected.

Individuals living with enigmatic illnesses face similar challenges, as these conditions are characterized by fluctuating symptoms that may shift gradually or, at times, abruptly [47]. Together, this body of research highlights the need to support the evolving tracking needs of people with enigmatic diseases, while also surfacing unresolved tensions. Prior work has concentrated on identifying which variables to track, how to scaffold self-experimentation, or how to reconcile individual relevance with population-level insight. Yet, less attention has been paid to the *temporal dynamics* of tracking: when patients decide to track or stop, how goals evolve over time, and how experiences of ambiguity, frustration, or self-blame shape long-term engagement. Our work extends this literature by examining these dynamics across multiple enigmatic conditions, highlighting how fluctuating states of illness give rise to shifting, and sometimes abandoned, tracking goals.

3 METHODOLOGY

We report on a qualitative study conducted with individuals living with enigmatic diseases, designed to capture the lived experiences of self-tracking and examine how goals, practices, and perceptions evolve across different disease states. We conducted semi-structured interviews to explore these dimensions in depth and analyzed the resulting qualitative data to identify key patterns and insights. The study was approved by our institution's Institutional Review Board (IRB), and all participants provided informed consent.

3.1 Recruitment

Recruitment was carried out through multiple complementary channels. We posted targeted study invitations in disease-focused Facebook groups and Reddit communities, and worked with local patient associations, who disseminated our call through mailing lists, WhatsApp groups, and online networks. Importantly, we did not cast a wide net across all chronic conditions, but instead targeted specific diseases where (1) there was a local patient association in our country that could circulate our call, and/or (2) there existed online communities where study invitations could be posted. This strategy focused our recruitment on enigmatic diseases with active support infrastructures and people already engaged in these networks.

Invitations were shared through local associations for fibromyalgia, Crohn's disease, ulcerative colitis, endometriosis, and psoriasis. In parallel, calls were posted in online communities on Facebook and Reddit. On Facebook, invitations were shared in a Crohn's, a lupus, and axial spondyloarthritis groups. On Reddit, we posted in the following communities: r/fibromyalgia, r/ankylosingspondylitis (axial spondyloarthritis), r/Autoimmune (autoimmune diseases), r/lupus (systemic lupus erythematosus), r/rheumatoid, r/psoriasis and r/rheumatoidarthritis (rheumatoid arthritis).

Invitations were explicitly framed around the sharing of tracking experiences. Calls described the study as an opportunity to share everyday practices as: *"We'd love to hear about your experiences with tracking—what worked, what didn't, and how your approach may have changed over time."*

Eligibility criteria required that participants (1) had been formally diagnosed for at least one enigmatic condition, and (2) had experience with any form of tracking, whether digital (e.g., apps, wearables, spreadsheets) or analogue (e.g., journals, paper notes). In some cases, participants were still undergoing diagnostic evaluations for additional conditions at the time of the interview, although each had already received at least one formal diagnosis. Details clarifying which conditions were formally diagnosed are provided in Table 1.

All participants completed a consent form and an accompanying demographic questionnaire, which asked about age, gender, nationality, occupation, diagnosed conditions and age of diagnosis, main symptoms, and perceived severity of their health state on a 5-point Likert scale (1 = mild, 5 = very severe). This scale was not intended as a clinical measure but rather to capture participants' subjective perceptions of severity. Participants also reported which tracking tools they had used and for how long.

3.2 Participants

23 participants were interviewed for this study. Fourteen were recruited through Reddit, five through Facebook groups, and four through local associations. Ages ranged from 24 to 49 years old (M = 35, SD = 8). The majority identified as female (n = 20), with three identifying as male. Most participants were employed or students. Five were unemployed, with their unemployment due to illness-related impairment. The sample included 11 participants from Europe, 11 from North America, and 1 from South America. Table 1 presents an overview of the participant information.

The female predominance in the sample aligns with the epidemiology of most conditions represented. Endometriosis and adenomyosis occur in individuals with a uterus, and several other diagnoses show higher prevalence in females, including fibromyalgia (ratio of 9:1) [7, 46], Hashimoto's thyroiditis (between 7:1 and 10:1) [9], systemic lupus erythematosus (between 2:1 and 15:1) [2, 44], rheumatoid arthritis (ratio of 3:1) [58] and functional neurological disorder (between 2:1 and 3:1) [35].

All participants reported having been formally diagnosed with at least one enigmatic disease. fibromyalgia was the most prevalent (n = 9), followed by ulcerative colitis, rheumatoid arthritis and endometriosis (n = 4 each). Other conditions included Crohn's disease, Hashimoto's thyroiditis, and migraine (n = 2 each), and single cases of lupus, axial spondyloarthritis, adenomyosis, Behçet's Disease, functional neurological disorder, and psoriasis. Several participants were also undergoing investigations for additional diagnoses, including endometriosis, rheumatoid arthritis, axial spondyloarthritis, and an autoimmune neurological disorder. Comorbidities were common and spanned a wide range of conditions, including hypothyroidism, osteopenia, thalassemia (see full list in Table 1). These comorbidities often interacted with primary conditions and contributed to additional symptom burden. Most described their symptoms as moderate to severe: 10 participants (43%) rated severity as 3 ("moderate"), nine (39%) as 4 ("severe"), and three (13%) as 5 ("very severe"). One participant (4%) reported severity of 2 ("mild to moderate").

3.3 Data Collection

Semi-structured interviews were conducted remotely via Zoom, lasting on average 48 minutes (SD = 12.9; range: 25–75 minutes). All interviews were recorded and transcribed using Zoom's transcription feature. Interviews were conducted in English, and participants received a €10 voucher as compensation for their time. The interview guide was organized around three main themes, aligned with our research focus. First, participants were asked about their **disease journey**, with attention to their diagnostic experiences and early tracking practices. Second, they reflected on the **role of self-tracking during good and bad days**, exploring how practices shifted with changes in disease state. Third, participants were invited to discuss how they **reviewed past data**, including whether and how they revisited their data. To support recall and elicit concrete experiences, participants were encouraged to show us their tracking tools (e.g., apps, journals, spreadsheets) and share any examples of data they considered illustrative of fluctuations or of *good* and *bad days*. Rather than defining these terms in advance, we intentionally left *good* and *bad days* open to participants' interpretation, allowing them to select examples that were personally meaningful and relevant to their lived experiences.

3.4 Data Analysis

All interviews were recorded, transcribed, and checked for accuracy by the first author, who also anonymized identifiable details (names, locations). Transcripts were imported into ATLAS.ti for coding [1].

We used a codebook thematic analysis approach, combining deductive and inductive coding. We began with a deductive framework derived from the interview guide and research questions, while remaining attentive to inductive codes emerging from the data. The first author conducted initial line-by-line coding, and the coding scheme was iteratively refined in weekly discussions with the research team. To ensure rigor, coding decisions and theme development were discussed within the team. Differences in interpretation were examined collaboratively, leading to refinements of codes and, in some cases, the creation of new codes to accommodate divergent perspectives.

Through iterative clustering and abstraction, codes were organized into broader themes that represented key dimensions of the analysis:

- **Tracking goals**: codes relating to the different aims participants associated with their tracking practices.
- **Transitions between goals**: codes capturing how and when participants described shifts in their tracking aims.
- **Impact of fluctuations**: codes concerning the role of symptom variability in shaping tracking engagement and practices.
- **Experiences of control, frustration, and uncertainty**: codes reflecting the emotional and experiential aspects of tracking.

4 FINDINGS

In this section, we highlight the key results of our interview thematic analysis. We describe which tools participants used to support tracking, what the intended goals were, how those goals shifted over time, and how disease constraints influenced their tracking practices.

4.1 Tracking Tools

All participants reported using multiple tools to track their health, with 4 tools on average being mentioned by each participant. These tools spanned across digital apps (used by all participants), wearable devices (5 participants), and paper-based formats, such as journals (7 participants). Every participant mentioned currently using at least one app, with 28 unique apps being mentioned across participants. While some of these apps (n=5) were tailored to a single condition or symptom (e.g. *Poopify*, a bowl movement tracking app for IBD

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[1] Software for Qualitative Data Analysis - ATLAS.ti

Id	Age	Gender	Occupation	Country Origin	Enigmatic Diseases and Age of Diagnosis	Other Conditions Mentioned
P1	30	F	Student	Portugal	ulcerative colitis (28); axial spondyloarthritis (axSpA) (28), migraine (Childhood)	–
P2	31	F	Unemployed	Portugal	Crohn's disease (18); endometriosis (under investigation)	–
P3	40	F	Freelancer	Portugal	endometriosis (39)	–
P4	24	F	Receptionist	Canada	fibromyalgia (16)	–
P5	35	F	Unemployed	Portugal	ulcerative colitis (23); Hashimoto's thyroiditis (23)	hypothyroidism; osteopenia; thalassemia
P6	48	F	Unemployed	Portugal	ulcerative colitis (19); lupus (21)	–
P7	27	F	Student	Portugal	Crohn's disease (22)	–
P8	40	F	Association President	Portugal	endometriosis / adenomyosis (23)	–
P9	30	F	Company Employee	Portugal	endometriosis (27), Behçet's disease (27), autoimmune neurological disease (under investigation)	–
P10	30	F	Real Estate Manager	Portugal	ulcerative colitis (15)	–
P11	44	F	Administrator	USA	fibromyalgia (35); rheumatoid arthritis (under investigation)	postural orthostatic tachycardia syndrome (POTS); myofascial pain syndrome (MPS); May-Thurner syndrome (MTS); Ehlers-Danlos syndrome (EDS); autonomic dysfunction; gastroparesis
P12	48	F	Professor	USA	fibromyalgia (14)	brucellosis; osteoarthritis
P13	29	F	Researcher	Canada	fibromyalgia (20)	postural orthostatic tachycardia syndrome (POTS); premenstrual dysphoric disorder (PDD)
P14	38	M	Senior Manager	Canada	fibromyalgia (38)	agoraphobia
P15	33	F	Cloud Security Engineer	USA	fibromyalgia (32); endometriosis	–
P16	49	F	Writer	USA	Hashimoto's thyroiditis (47), fibromyalgia (47)	hypothyroidism
P17	39	M	Marketing	USA	fibromyalgia (15), vestibular migraine (37)	post-traumatic stress disorder (PTSD); attention deficit hyperactivity disorder (ADHD)
P18	29	F	Unemployed	UK	fibromyalgia (22); functional neurological disorder (FND) (26)	–
P19	24	M	IT Developer	UK	psoriasis (12)	–
P20	31	F	Teacher	Brazil	rheumatoid arthritis (30)	polycystic ovary syndrome (PCOS)
P21	45	F	Civil Rights Coordinator	USA	rheumatoid arthritis (39)	long covid
P22	36	F	Unemployed	USA	rheumatoid arthritis (8)	–
P23	30	F	Dentist	USA	rheumatoid arthritis (27), axial spondyloarthritis (axSpA) (under investigation)	Ehlers Danlos syndrome (EDS); postural orthostatic tachycardia syndrome (POTS)

Table 1: Participants' Demographic Information (Age, Gender, Occupation, Country of Origin), Enigmatic Conditions Reported including Age of Diagnosis, and other Conditions Mentioned.

and gut health), the large majority (n=14) were general health and wellness apps, designed to support a broader range of tracked metrics and aspects related to everyday health (e.g. *Apple Health's* app). General-use apps (n=7) were also commonly used - including productivity or utility apps not specifically designed for health (e.g., Notes, Excel, Weather App). While most of these tools, such as the "Weather App," did not track symptoms directly, some participants reported using its data to support disease management, or to help them document their conditions.

4.2 Tracking Goals

We identified five tracking goals across participants: Attributing Fluctuations and Symptoms, Anticipating or Preventing Flare-Ups, Ensuring Recognition and Continuity in Care, Establishing a Diagnosis, and Documenting. Although we present these goals separately, participants rarely pursued them in isolation. As we later show in section 4.3, people often moved between these goals, with goals emerging, being lapsed, and multiple being pursued in parallel. In this sense, the goals described below should be understood less as discrete categories and more as dynamic states that participants moved in and out of depending on their circumstances.

4.2.1 *Attributing Fluctuations and Symptoms.*

Participants tracked to attribute fluctuations and symptoms to potential causes. Since enigmatic diseases are highly individualized and poorly understood, participants often felt compelled to identify what might be driving changes in their symptoms. This included understanding how different behaviors (such as diet and sleep) and environmental factors might exacerbate or attenuate symptom. This goal was particularly salient during periods of uncertainty, such as after medication changes, the onset of new symptoms, or unexpected flare-ups. As P3 explained: *"I think whenever there are changes, it's really good to consult the records. That's why I think of it as detective work… sometimes there's no link, but sometimes there is."*

We observed two main approaches to attribution. The first, more common, involved recognizing patterns and trends in data. Participants looked back at their data to identify possible triggers, such as diet, weather, or activity. P17 noted a recurring link between flare-ups and barometric pressure: *"I was able to find correlation between the days that I felt the worst and the bigger changes in barometric pressure."* Similarly, P6 tracked food to confirm or rule out suspected triggers. Some, like P10, even used records to advocate for treatment changes: *"If I hadn't had the records and hadn't pushed for the connections I had seen, I might still be on the wrong dosage."* However, it is important to acknowledge that such cases were uncommon, as they required a certain level of clinical understanding from the patient. In this case, P10's professional background in the healthcare sector contributed to their ability to interpret the data and engage in decision-making.

The second approach was prospective, using tracking to test the effects of specific behaviors or treatments. P12, for example, monitored supplements to judge whether they were worth the cost: *"I wanted to know, is this supplement doing any good or not, so that I wouldn't be paying for more than I needed to."*

4.2.2 *Anticipating and Preventing Flare-Ups.*

Participants also tracked to anticipate flare-ups and take preventive action. In some cases this meant reacting more quickly in the moment by recognizing early warning signs that might otherwise go unnoticed. P1 tracked pain episodes to avoid delaying medication until symptoms became severe: *"At first, I'd let the pain reach an almost unbearable point… that's why I started keeping records."* Similarly, P8 monitored bowel movements to decide when to intervene: *"If I see I haven't gone in three days, I use that info to take action."* Tracking in these ways supported moment-to-moment decisions and helped participants respond before symptoms escalated. P22 described how this became a continuous effort: *"I did a ton of stuff yesterday. And I don't feel good today… I'm going to do low-key stuff at home to make sure I don't keep pushing myself too much, so I don't have a flare. It's an ongoing thing."*

For others, anticipation often involved planning around predictable vulnerabilities. P3 used a menstrual calendar to avoid scheduling demanding work during periods of increased symptoms. P11 and P17 adapted travel or work schedules around weather forecasts. These were often lifelong efforts, with participants like P19 describing how tracking his skin responses to surrounding environmental factors helped him strategically time medication applications before social events: *"Seeing some consistency in how my skin is… helped me plan ahead."* These practices highlight how participants built on patterns identified over time, using records not only to react in the moment but also to prepare for the future.

4.2.3 *Ensuring Recognition and Continuity in Care.*

Tracking was used to support medical consultations, which participants often described as short and infrequent, making it difficult to convey the episodic nature of their conditions. To bridge this gap, participants used their records to show doctors what happened outside the consultation room. As P4 noted: *"I'm tracking it more so that I can show my doctor like, this is what's going on when I'm not right in front of you."* Participants relied on tracking to preserve details that might otherwise be lost, particularly during flares when information was overwhelming. P5 explained: *"When it's a flare-up, it's pages and pages… I'm not going to memorize when it started or how long each bathroom visit lasted."* Long gaps between appointments compounded this challenge, as P4 admitted: *"Because we have such a long wait for the doctors right now... I forget why I'm there."* Incomplete institutional records added another layer of insecurity, prompting some to keep their own medical histories. For example, P1 explained the value of tracking corticosteroid use: *"Now I always have the data here I can see when I started cortisone, what dose I took, when I tapered, and when I stopped. This becomes important for follow-up appointments, because the doctor doesn't always have this record. And even in other medical specialties, it's useful to be able to say: I took cortisone, for this amount of time, I tapered, and I stopped, now I've been however long without it."*

For some, tracking became a tool of self-advocacy. Dissatisfied with their care, they used data to validate concerns or push for changes. P21 explained: *"I felt like the doctor was missing part of the story, and I was trying to validate it with numbers."* Similarly, P10, drawing on nursing experience, emphasized the need to take responsibility: *"People with more complex conditions end up having to take on that responsibility and autonomy, otherwise you just get lost."* This responsibility was often coupled with frustration and the need to "prove" severity. Participants feared that without evidence, their symptoms might be dismissed. P19 described photographing skin flare-ups: *"If I show them at like day one after using topicals… they'll be like, okay, it's not even that bad. And then there's a chance they may not take it seriously."* As P21 put it: *"They didn't ask me to do it, but I felt like it was important to get somebody to believe me."*

Tracking also provided proof in contexts where patients felt doubted. Because these illnesses are episodic, symptoms were not always visible during medical visits. Records helped participants present a more accurate picture of their condition over time, demonstrating its impact and legitimizing their concerns. As P13 explained: *"For some illnesses you're really treated as a liar until proven innocent. And so it was just a daily reminder that like, oh, I need to prove myself. And if I don't prove myself via this data, I won't get any resources, medication."*

Tracking also helped participants communicate their experiences more clearly. Rather than relying on vague accounts, records supported specificity and nuance. For P1, quantifying was essential because what feels frequent to a patient may not be perceived the same way by a doctor. P7 described how data replaced general impressions with concrete detail: *"Instead of saying I felt worse this week, I can say on this day, this happened… it helped me not feel lost."* For P14, records made it possible to convey the complexity of fibromyalgia symptoms: *"It was really hard to explain pain as a linear scale… I could pull up the chart and say, this is kind of where I'm at."*

4.2.4 Establishing a Diagnosis. One tracking goal that emerged in participants' early experiences with their conditions was diagnostic tracking. Participants often described the diagnostic process as slow and uncertain, with multiple tests required before a condition could be identified. To support this process, they used tracking to document symptoms and provide evidence that something was wrong, and in some cases to suggest possible diagnoses themselves. P3 described how they combined their records with online research: *"I started reviewing my notes and connecting the dots. I'd see a symptom here, another there, but when I read other women's stories and doctors' explanations, I went back to my records to match the symptoms. That's when I realized it had to be that [endometriosis]."* Similarly, P6, initially diagnosed with lupus, suspected a separate condition after noticing inconsistencies. Using their own records and book research, they identified patterns consistent with ulcerative colitis: *"I was always keeping records… and at the time, the symptoms I had didn't match lupus… based on the research I did, it matched ulcerative colitis."*

4.2.5 Documenting. Another common tracking goal was documenting tracking. In these cases, participants tracked to simply keep a record of their condition - such as their symptoms, test results or treatments, without a immediate intention to use that data. One purpose was to preserve a timeline of illness, capturing details that might otherwise be forgotten. As P3 explained: *"If I didn't write things down, there were things I wouldn't remember … "* and P6 added: *"For me, it was important to have it recorded to know that it really happened and that it was what actually occurred."* Another participant had been keeping years of daily symptom logs - hoping this data might be useful in the future to support care or research.

Documenting helped some participants recalibrate their perspective by providing a broader view of their condition. P23 noted how records countered a tendency to remember only negative experiences: *"I wanted to make sure the way I was remembering things was the way they actually happened… I actually did have more good days!"* There were also examples of people using their data to share their experiences with others. P6 described documenting so that family members could understand their medical history: *"I think it's important to keep a record so that, in the future, a family member can know what happened to me."* They also emphasized its potential value if they became incapacitated: *"I wanted a record in case I became incapacitated, so whoever cares for me would have my symptoms and hospital records to share with doctors."*

4.3 Transition Between Goals

While the previous section identified five distinct tracking goals, participants rarely engaged in tracking with a single, fixed goal. Instead, goals emerged, evolved, were lapsed and sometimes abandoned in response to shifting needs, changes in health and new understandings of their conditions. Early tracking was often driven by uncertainty, diagnostic efforts, or doctor requests. Several participants (n=7) began tracking to support a diagnosis, which they discontinued once a formal diagnosis was made. Yet diagnosis itself often sparked new tracking goals, such as identifying symptom triggers or exploring treatment effects. Similarly, four participants who began tracking at the suggestion of a doctor reported continuing beyond that initial request, having discovered its broader utility. As P5 explained: *"The doctor explained the tapering plan and I got used to following it, also writing it down on paper... And from then on, I always kept doing it because those records make sense. I think they're really important."*

Goals were often described as temporary, re-emerging or disappearing in line with fluctuations in the condition. For example, identifying triggers was a common but episodic tracking goal (n=20), that would re-emerge in response to disease fluctuations. When successful, participants shifted to applying their discoveries in daily life—for example, by reducing exposure to triggers or preventing flares. For example, P14 initially tracked to understand pain trends, but later shifted toward monitoring activity and energy expenditure after identifying a correlation: *"The pain trend overlaid with my activity trend... I wanted to see that inverse correlation... It's evolved from a conversation tool with pain management all the way into this lifestyle management tool."* Others, like P17, tracked less once they identified their condition triggers, focusing instead on predicting flare-ups.

Other accounts illustrated how tracking practices expanded gradually over time, evolving into more active and layered goals as people recognized their value. As P11 described: *"So that's kind of what I started with was the baseline. And then as my symptoms started to progress I was like, well, I may as well track this... And then I realized how much it gives me information on how I should feel. So I'll track anything new."* P11 also described how changes in health directly shaped their tracking. After surgery, when triggers shifted and the disease became more unstable, they adjusted what and how they recorded: *"As my circumstances have changed, my tracking has changed a little bit... I'm just trying to kind of find my new normal and what those symptoms are."*

Similarly, P8 described how changing life circumstances drove changing self-tracking goals. Initially, she tracked her menstrual cycle to support conception within a limited timeframe. Later, after entering menopause, she reoriented her tracking toward understanding digestive issues: *"When my focus was getting pregnant, that was all I wanted to focus on... Now my focus is understanding how my digestive system works, and I don't feel the need to track anything else."*

4.4 How Fluctuations Shape Tracking

Fluctuations in symptoms played a central role in shaping how, when, and what participants tracked. Across all participants, tracking was rarely described as a steady or regular practice but instead ebbed and flowed with the ups and downs of their condition.

Participants explained that when specific symptoms became routine and persisted over a long period, they began to see them as constants in their lives and felt little need to track them. Tracking only felt relevant when there were noticeable changes—whether an improvement, a worsening, or the appearance of a new symptom. As P9 described, *"Imagine that a new symptom appears, one I don't even know what it's associated with, like a pain in a finger. I'm more likely to record that than if I have a bad night of sweating a lot."* Positive changes could also feel important to document, particularly when they disrupted expectations. P3 explained, *"When I'm on my period, I normally wouldn't be able to do anything. But I've actually managed to go to the gym, to feel okay. Sometimes even to the point of having no pain at all. I usually write that down too."*

Tracking frequency was especially heightened during moments of instability, such as medication changes or flare-ups, when participants felt a stronger need to monitor their condition closely. P3 described how stopping birth control made them track daily: *"At this stage, I'm tracking every day. Since stopping the pill is something new for me after being diagnosed, I've been tracking everything daily."* By contrast, periods of stability often led participants to reduce or stop logging. Some explained that if they could easily remember a change to share with their doctor, there was no need to track it in detail. As P1 put it, *"At the moment, things are more or less stable. And when one of these situations happens, since it's out of the ordinary, I can remember it and report it . . . at the next appointment."*

Participants described tracking during *bad days* more frequently and in greater extent as compared to *good days*. As P3 explained, *"When it's bad, you go into more detail, because I think that's really the purpose of tracking, to see what's not going well."* Similarly, P8 noted that tracking was mostly focused on the negative: *"On good days, there's not as much of a need. But if I'm having cramps or pain, I'm more careful with what I log. I think more about what I ate, for example."* P4 reinforced this narrative, reflecting that *"We tend to look at the bad better than the good. I think that's just a human nature thing,"* and described how blank entries in their pain diary often implied *good days*: *"It's like a monthly thing, a bunch of bad ones, some okay ones, and if they're blank, they're mostly good."*

However, some participants recognized that tracking mostly *bad days* created a distorted picture of their condition: *"Tracking the good days helps me when I want to say 'everything sucks and nothing ever helps.' Seeing that something actually does help can pull me out of that mindset"* (P13). Despite this, many admitted that when feeling well they preferred to avoid focusing on illness, either forgetting to track or deliberately distancing themselves from data as it commonly portrayed the condition as part of their identity. As P10 explained, *"If I'm feeling reasonably well, it's very rare that I write anything... When I'm well, I don't even want to remember I'm sick."* Similarly, P6 emphasized, *"I never kept a daily journal because the disease doesn't define me. I've always tried to make sure that, despite everything, I'm not just ulcerative colitis. We're two separate entities, I'm more than this disease."*

These patterns were tied to how participants themselves understood *good* and *bad days*. Most described a *good day* as one where symptoms were reduced or manageable, allowing them to go about their day without the illness taking center stage. While the intensity and type of symptoms varied, the common thread was the sense of relief and restored normality. As P4 shared, *"On a good day, I wake up with no pain... something I can manage with either no medication or over-the-counter medication. Those are the better days."* Similarly, P23 noted, *"Even just a decrease in symptoms can be a good day." Good days* were often defined by the ability to function normally—going to work, running errands, or spending time with family—sometimes even forgetting about the illness altogether. P8 expressed this clearly: *"It's a day when I have no symptoms and I forget I have a disease."*

By contrast, *bad days* were described as overwhelming and exhausting, characterized by severe pain or fatigue and an inability to carry out normal tasks. P8 noted, *"It's a day when I have a schedule to follow and I have to completely change it... That, for me, is a bad day. It's a day when the illness interferes with what I want to do."* For others, these were moments where frustration and a loss of autonomy were felt most strongly. As P14 put it: *"On days like that there's very little room for personal joy. It's mentally draining, and it's probably the point where I'm on edge because it's generally not a good day, since I'm not able to do even the things that I want to do!"*

For some, *bad days* made it harder to track at all, either because of fatigue or because tracking felt like an additional burden. P23 described, *"I definitely struggle to track on the worst days, mostly just because I hurt and I don't want to do anything, including tracking, which can sometimes feel like a chore."* Conversely, a small group of participants developed stable routines, tracking consistently regardless of fluctuations. P12 explained, *"I just track every day because to me the information is valuable . . . It's just part of my morning routine"* - further emphasizing that while they tried to maintain a consistent tracking routine, *bad days* were often when that was challenged: *"I try to do it every day because that's the only way to have consistent data. But it doesn't always work out, and the worst days are usually the ones where I fail to."*

4.5 Tracking as an Attempt to Regain Control

Tracking was often described as a double-edged sword, on the one hand, offering a sense of control over the unpredictability of enigmatic conditions, while on the other, serving as a persistent reminder of their lack of control over the underlying uncertainty of their conditions.

Some participants described how tracking helped them feel more attuned to their bodies, and how this increased awareness fostered a sense of agency in otherwise uncontrollable circumstances. As P11 explained, *"I'm not sure what I'm learning here because I'm not a scientist, but it makes me feel better to know that I'm making an effort to understand what's going on with me."* Similarly, P21 described the *"illusion of control"* that helped them cope on difficult days: *"If I just try hard enough, I can figure something out and fix it."* In these cases, tracking did not necessarily change the course of the illness, but allowed participants to feel more engaged in their own care. As one participant put it, *"I think the biggest bonus for me is just feeling like I'm infecting my disease by tracking. The most important thing is you have to feel like you're doing something. As someone with a chronic illness, I feel like I'm making a difference in my life"* (P11).

Others linked control more directly to concrete action. Tracking helped participants stay accountable to choices that alleviated symptoms, such as diet, medication routines, or energy management. P14, for example, used tracking to focus their efforts: *"The tracking is most certainly connected to my need for control. And these are the things that I can control... Most of these are in service of where I can direct my energy."* P7 similarly found that tracking offered a practical tool for managing stress, which they had identified as a major trigger for flare-ups. For them, the act of logging was not only about data collection but also about calming down: *"I track my emotions when I'm in pain or going through a situation, like a surgery. I always try to think clearly."* They elaborated that tracking itself helped them breathe, slow down, and reduce stress-induced symptoms: *"It helps positively because I end up understanding myself better... Tracking helps me slow down and positively impacts me."*

Despite these differences, both perspectives converged on the idea that tracking reframed illness as something that could be acted upon rather than simply endured. P12 captured this shift, describing how tracking provided a sense of agency: *"It's a positive thing to feel like I have some agency on what's going on… It turns it into a puzzle rather than just this ordeal. It's not a puzzle I would have chosen, but it makes it into a challenge rather than just this ordeal that I'm going through."*

4.6 Tracking as a Source of Frustration and Self-Blame

While participants described tracking as a way to regain control, many others experienced the opposite when pursuing it: tracking heightened frustration, guilt, or even obsession when it underscored the limits of what could be managed. In these cases, the promise of control backfired, turning tracking into a reminder of how unpredictable their conditions could be, particularly when the insights gained through tracking could not be acted upon. P16 expressed this frustration: *"What's interesting is that I feel a little angry because, in spite of all of this, I feel like a lot of it is out of my control. So a lot of it is watching the data, monitoring the data... I don't feel like I can really apply it, if that makes sense."* Similarly, P15 described how flare-ups still occurred despite their efforts, making reflection on data feel futile: *"You're working out, you're not drinking... And then you get a flare-up. If you try to find a reason, you're going to drive yourself insane."* For them, the hope of finding answers often turned into disappointment and self-blame. For P15, tracking itself wasn't inherently negative, but the reflection on the data, and the hope to find clear answers, often led to disappointment and self-blame. They explained how tracking reinforced negativity: *"I think it doesn't take away from listening to your body but I think it takes away from your confidence in yourself. I think because fibromyalgia symptoms are not predictable that when you do track you're just reinforcing the idea that you don't have any control… So I think it's just reinforcing the negativity of the disease rather than anything."*

Tracking also fostered optimism that setbacks quickly undermined. As P15 further explained, *"I'll go back to thinking maybe it's gone... and then I'll have a really bad flare-up. I've done all the right things, and it just happens."* Here, the data gave the impression that progress was possible, but unpredictable symptoms made flare-ups feel like personal failure. P9 further echoed this, noting how tracking itself can imply blame: *"I think tracking gives you the idea that there's something in that data, there's something in the activity that you're doing that is resulting in the fact that you have a flare up. And I think there's an idea and blame with tracking."*

For others, repeated attempts to identify triggers became obsessive and emotionally harmful. P15 described being caught in cycles of self-blame: *"There has to be something I'm personally doing that is causing this."* They eventually abandoned tracking altogether. P19 similarly explained how the absence of consistent correlations eroded their motivation: *"Over a long period of time there hasn't really appeared to be any consistent correlation, which really demotivated me from wanting to track."*

Together, these accounts highlight the fragile balance between tracking as empowerment and tracking as harm. When insights could not be translated into meaningful action, tracking risked reinforcing self-blame, amplifying uncertainty, and eroding confidence in one's ability to manage an enigmatic condition.

4.7 Living With and Tracking Through Uncertainty

Beyond control, participants also spoke about the uncertainty associated with living with enigmatic conditions and how this shaped their tracking practices. Tracking was often driven by the hope that it might provide clarity, yet participants frequently confronted the challenges of making sense of their data in the context of highly fluctuating conditions. Rather than immediate answers, tracking required an ongoing effort, and at times became a source of frustration rather than insight. As one participant explained, their early expectations with tracking did not match the reality: *"I think I was a little naive in the beginning and like I'm going to track and I'm going to find the thing that makes things worse and I just won't do it anymore... But that didn't become super clear"* (P13). Others similarly described how keeping detailed logs became burdensome and emotionally draining, as the effort of recording often outweighed the clarity it provided. One noted that while activity tracking was intended to help with pacing, the shifting nature of their illness meant that the same action could have very different impacts from day to day, making interpretation *"like predicting the weather"* (P3). In such cases, tracking not only failed to produce useful correlations but also amplified feelings of stress, disappointment, and desperation for answers.

Uncertainty also strongly influenced what participants chose to track. Living with conditions characterized by fluctuating and ambiguous symptoms meant that people often struggled to know which data and metrics were relevant. New or unfamiliar symptoms, for example, raised doubts about whether they were disease-related or simply part of everyday life. P3 highlighted this difficulty: *"Sometimes I don't know if a pain is from the gym, an injury, or the disease itself. We have no way of knowing, and that's the most distressing part."* For many, the ability to distinguish between normal discomfort and illness-related symptoms was crucial for protecting their mental health. If soreness after exercise could be recognized as ordinary, it prevented unnecessary worry about disease progression. On the other hand, when it came to differentiating between multiple coexisting diseases, participants generally did not feel the need to make such distinctions. P11 explained that they tracked symptoms collectively, focusing on their overall impact rather than distinguishing between specific diseases: *"I just kind of track symptoms because that's the most relevant to me like it doesn't even matter what names or numbers the doctors have given me. What matters to me is the symptoms that I'm experiencing and how they affect my daily life. So obviously diagnoses are helpful in the office, but it doesn't really matter what those words are day to day."*

5 DISCUSSION

In the following section, we discuss how self-tracking shapes expectations and self-blame, how tracking practices vary with symptom fluctuations and shifting goals, and how more inclusive, flexible tool designs can better support people living with enigmatic conditions. Each subsection concludes with design recommendations grounded in our findings.

5.1 The Weight of Expectations when Self-Tracking Enigmatic Conditions

Our findings highlight how self-tracking can be double-edged. On the one hand, tracking helped some participants feel more engaged in managing their health conditions and offered a sense of agency and control that many felt they had lost after diagnosis. On the other hand, it often fostered unrealistic expectations: that if enough data was collected, an explanation would emerge and symptoms could be controlled. When this failed to materialize, participants frequently experienced guilt or self-blame.

These negative feelings stemmed from a mismatch between participants' expectations and the fluctuating, unpredictable nature of enigmatic conditions. Many hoped that self-tracking would help them identify patterns or triggers. Instead, they were confronted with data that reflected inconsistency: the same behavior or symptom could lead to very different outcomes from one day to the next. In this context, the absence of clarity was not interpreted as a feature of the illness, but as a shortcoming of their own effort. Even when participants did not set explicit tracking goals, the very act of documenting and logging data created an implicit expectation of progress or improvement. As participants explained, keeping records suggested that they were working towards something, which made the lack of tangible results feel like a personal failure.

These dynamics are reinforced by broader narratives of responsibility in chronic illness. Enigmatic diseases already place a heavy burden on individuals to manage uncertainty and communicate legitimacy in clinical encounters. Self-tracking intensified this responsibility by making participants the central agents of sense-making. When their records failed to yield answers, they did not only perceive tracking as unhelpful, but also judged themselves for failing to manage the illness. This mirrors prior work showing that patients with chronic conditions often overanalyze their behaviors and blame themselves when symptoms persist despite their efforts [3], and aligns with research on self-regulation showing that unmet goals can evoke shame and negative affect [37]. Just as medical providers should not promise a cure to those living with chronic illness [42], technologies should also avoid creating unrealistic hopes.

Our findings also point to the double-edged role of past data. While revisiting records was sometimes seen as a way to restore awareness when progress felt absent, participants often described past data as reminders of goals they had not achieved. In this sense, looking back could reinforce disappointment rather than alleviate it, echoing observations from prior work [21]. Similar challenges have been observed in clinical contexts. For example, patients in physiotherapy reported guilt when unable to meet prescribed goals, feeling accountable to their therapists [24].

We argue that self-tracking tools for enigmatic conditions should be designed with the understanding that these diseases are inherently unpredictable. Tools should normalize the idea that failing to uncover clear patterns is expected rather than exceptional. This aligns with calls for non-judgmental interfaces, which emphasize avoiding punitive framings and normalizing lapses in engagement [55]. More broadly, technology should prioritize fostering a sense of agency and emotional control by promoting awareness and organization as primary goals. Exploratory objectives, such as identifying potential triggers, can be supported as secondary aims but framed with caution. Crucially, this should include guidance rather than leaving individuals to determine what and how to track entirely on their own. Work on scaffolding goals in personal informatics shows that structured guidance can help people set more realistic expectations and sustain engagement [17, 47]. In the context of enigmatic conditions, scaffolding could mean suggesting a spectrum of goals—ranging from documentation and reflection to cautious exploration—while explicitly acknowledging the limitations of what tracking can reveal.

Recommendation: Designs should help users interpret unpredictable or inconsistent data without assuming that clear patterns will always emerge. Tools can normalize uncertainty, for example, by showing ranges instead of definitive conclusions or by offering several plausible interpretations when data is inconclusive. Prior work shows that such uncertainty-aware framing can help people avoid overconfidence or self-blame when patterns do not appear [48]. Tools might guide people toward focusing on goals that remain valuable even when patterns are inconsistent, such as documentation, while framing exploratory aims (like identifying triggers) as tentative.

5.2 When the Data Skews: Asymmetric Logging and Lapsing

Our study revealed a asymmetry in how people tracked their experiences with enigmatic diseases. Participants tended to track more actively during moments of instability, such as flare-ups, unusual symptoms, and treatment changes, while stable periods and *good days* were often normalized and ignored, and many participants reduced or abandoned tracking to step back from the "patient role" and focus on other aspects of life. These insights resonate with prior work on episodic use of health technologies [27, 51] and with the concept of *happy abandonment* [4, 13], in which disengagement reflects positive shifts in circumstances rather than failure. Yet our findings add nuance by showing that tracking was not simply abandoned, but often strategically modulated in intensity depending on whether symptoms felt disruptive, unusual, or worthy of attention.

This dynamic produced a form of asymmetry: *bad days* and flares were logged in detail, while *good days* and stability were far less visible in people's records, creating datasets dominated by negative states. This observation extends prior work on episodic engagement [27, 51] by surfacing how fluctuations not only change whether people track but also shape the kinds of data that gets tracked. This asymmetry sometimes produced a distorted sense of the illness and contributed to discouragement when revisiting records.

Equally, lapses in tracking were not signs of disengagement but often protective choices. Participants stepped back during stability to preserve their mood or distance themselves from illness. Yet most self-tracking tools still frame lapses as failure, pushing people back through reminders or streaks. Our findings suggest instead that pauses should be legitimized as part of healthy engagement.

Importantly, goals themselves shifted alongside these practices. Changes in needs, priorities, and overall well-being influenced how individuals perceived the value of tracking at a given moment. For instance, participants spoke of being motivated to identify triggers during unstable periods, but prioritizing organization or distancing themselves from illness during stability. In this sense, goals and engagement were interconnected: fluctuations in symptoms prompted changes in goals, and shifting goals influenced how and when people engaged in tracking.

Recommendation: Designs should acknowledge that tracking naturally varies with symptom fluctuations and support users as their goals shift. Tools could offer gentle prompts to revisit or adjust goals—for example, switching between "understanding triggers," "documenting symptoms," or "minimal check-ins," so that tracking remains aligned with what a person needs at a given moment rather than treating goal changes as inconsistency (as suggested in [18]).

Designs should also have lightweight daily check-ins or one-tap summaries that let users quickly mark a day as stable, improving, or difficult. This helps create continuity in tracking records so data does not become dominated by bad days alone. Additionally, tools should also provide low-effort ways to log flare-ups, such as quick prompts or short tags, for people who find tracking too burdensome during difficult days.

5.3 From Single-Disease Tools to Inclusive Designs

Much self-tracking research on disease management has focused on single conditions, designing tools tailored to the needs of patients with a particular diagnosis [29, 38, 40, 47]. This approach is valuable for addressing disease-specific requirements, yet it risks overlooking broader dynamics that cut across conditions. Our study took a different approach by bringing together individuals with a wide range of enigmatic diseases in a single investigation.

We found that people's tracking experiences were not defined solely by the specificity of their condition but also more general factors, experienced by all participants - irrespectively of their condition, such as fluctuations, shifting goals, and evolving needs. These shared dynamics point to design considerations that extend beyond disease-focused silos. They also suggest opportunities for cross-condition knowledge-sharing and community support, where patients can learn from each other's strategies regardless of the specifics of conditions.

However, as expected, differences emerged in people's tracking experiences. Symptoms varied considerably, shaping what participants wanted to track and how they were able to do so. Some conditions lent themselves to quantitative monitoring through wearables, while others required qualitative descriptions of pain, fatigue, or mood. In some cases, symptoms even limited participants' ability to interact with tracking tools, underscoring how condition-specific features directly influence tracking practices. These observations echo prior single-disease studies showing that type and severity of symptoms often dictate both the content and form of tracking [40, 47].

Taken together, these findings suggest that while disease-specific tailoring remains valuable, there is also an opportunity for more inclusive approaches. Designing from commonalities such as fluctuations and evolving goals would allow technologies to support patients with less common conditions, which may lack dedicated tools, while also accommodating high prevalence of comorbidities - which were highly prevalent in our participant sample. Flexibility has been highlighted as an essential strategy when designing for chronic conditions [47], enabling tools to adapt to the diverse constellations of symptoms and goals that individuals bring.

One promising direction is a layered approach to tracking, in which a general layer supports shared experiences of fluctuation, shifting goals, and uncertainty, while condition-specific modules can be flexibly enabled as needed. Such a design would not only address common needs across enigmatic diseases but also provide the depth required to capture condition-specific symptoms. Importantly, this structure would accommodate comorbidities by allowing individuals to combine modules that reflect their range of conditions, rather than being constrained by a single-disease framing. Designing with both commonalities and differences in mind may lead to tools that are inclusive yet sensitive to the particularities of specific conditions.

A key advantage of a multi-condition perspective is its relevance for people managing multiple conditions, a group that was strongly represented in our sample. Twelve of our twenty-three participants were living with at least two enigmatic conditions, and many more managed two or more additional conditions concurrently. Tracking across multiple conditions introduces added challenges documented in prior work, such as increased cognitive burden, conflicting data streams, and difficulty interpreting symptoms that may stem from overlapping diagnoses [3]. Rather than tracking each disease separately, as most single-condition tools implicitly expect, participants described needing a unified way to monitor symptoms whose causes were unclear or intertwined. Our findings echo prior multi-morbidity research showing that people often think in terms of their overall state, not discrete conditions. A layered, multi-module design therefore offers particular value for this population: the shared core supports cross-cutting experiences, while optional modules allow people to selectively add condition-specific detail without fragmenting their records across tools.

Recommendation: Tracking tools for enigmatic diseases should follow a layered design. Designs should provide a shared core that helps with common challenges, such as logging symptoms during flare-ups, and making sense of data when symptoms feel unpredictable. On top of this, tools should offer optional condition-specific modules that people can add when relevant. For example, someone with endometriosis could enable a module for tracking cycle-linked pelvic pain, while someone with migraines could turn on a module for capturing sensory triggers. This approach keeps tools usable for people whose conditions are comorbid, or not well represented in existing apps, while still offering depth where needed. Future work could explore how people combine multiple modules in practice - especially those with comorbid or changing diagnoses- and how community-generated or co-designed module templates might help these tools evolve based on real lived experiences (as in [30]).

6 LIMITATIONS

There were a number of limitations to our study. First, our participant pool may not be representative of the wider population living with enigmatic diseases. While many of these conditions disproportionately affect women, the strong gender imbalance in our sample nevertheless limits the generalizability of our findings. Moreover, most participants were based in Europe and North America, leaving cultural and structural differences in healthcare systems elsewhere underrepresented. Second, our recruitment strategy may have introduced bias. Because many participants were recruited through online communities such as Reddit and Facebook, the sample likely overrepresents individuals who are digitally literate, proactive in managing their condition, and engaged in online support networks. This provides valuable insights into technology use but may offer fewer perspectives from those who engage less with digital tools or who are less connected to patient communities. Recruitment also posed practical challenges. Engagement varied across conditions: for example, participant recruitment rates for psoriasis were lower than for fibromyalgia or Crohn's disease. This may reflect differences in how common symptom tracking is within patient groups, the relatively small size of some online communities, or simply the limited reach of our recruitment posts. In some cases, community members expressed hesitancy to participate. Such reactions likely reflect broader patterns of mistrust within these communities, shaped by repeated experiences of dismissal or misunderstanding of conditions.

7 CONCLUSION

This work shifts attention to when and why people with enigmatic diseases track, showing how their engagement unfolds across fluctuating states of illness as goals emerge, evolve, or lapse over time. By focusing on diverse conditions rather than a single diagnosis, we uncovered shared patterns of uncertainty, shifting needs, and emotional challenges. Our findings show that while tracking can foster a sense of control, it can also intensify frustration and self-blame when expectations fail to align with reality. Looking forward, our study points to future directions for researchers and designers to move beyond static and disease-specific approaches. It emphasizes the need for flexible, adaptive, and non-judgmental designs that can support users through changing illness states, evolving goals, and emotionally complex experiences. More broadly, our findings highlight the importance of inclusive designs that can serve both common needs across conditions and the specificities of individual symptoms or comorbidities.

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References

[1] Rebecca L Acabchuk, Jayesh Kamath, John D Salamone, and Blair T Johnson. 2017. Stress and chronic illness: The inflammatory pathway. *Social Science & Medicine* 185 (2017), 166–170.

[2] Katinka Albrecht, Wiebke Troll, Johanna Callhoff, Anja Strangfeld, Sarah Ohrndorf, and Johanna Mucke. 2025. Sex-and gender-related differences in systemic lupus erythematosus: a scoping review. *Rheumatology International* 45, 7 (2025), 1–13.

[3] Jessica S Ancker, Holly O Witteman, Baria Hafeez, Thierry Provencher, Mary Van de Graaf, and Esther Wei. 2015. "You Get Reminded You're a Sick Person": Personal Data Tracking and Patients With Multiple Chronic Conditions. *J Med Internet Res* 17, 8 (19 Aug 2015), e202. doi:10.2196/jmir.4209

[4] Christiane Attig and Thomas Franke. 2020. Abandonment of personal quantification: A review and empirical study investigating reasons for wearable activity tracking attrition. *Computers in Human Behavior* 102 (2020), 223–237. doi:10.1016/j.chb.2019.08.025

[5] Matthew Bietz, Cinnamon Bloss, Scout Calvert, Job Godino, Judith Gregory, Michael Claffey, Jerry Sheehan, and Kevin Patrick. 2015. Opportunities and challenges in the use of personal health data for health research. *Journal of the American Medical Informatics Association : JAMIA* 23 (09 2015). doi:10.1093/jamia/ocv118

[6] Julie Brown and Cindy Farquhar. 2014. Endometriosis: an overview of Cochrane Reviews. *Cochrane Database of Systematic Reviews* 3 (2014), CD009590. doi:10.1002/14651858.CD009590.pub2

[7] Asensi Cabo-Meseguer, Germán Cerdá-Olmedo, and José Luis Trillo-Mata. 2017. Fibromialgia: prevalencia, perfiles epidemiológicos y costes económicos. *Medicina Clínica* 149, 10 (2017), 441–448. doi:10.1016/j.medcli.2017.06.008

[8] Linda D. Cameron and Christopher M. Wally. 2015. Chronic Illness, Psychosocial Coping with. In *International Encyclopedia of the Social & Behavioral Sciences (Second Edition)* (second edition ed.), James D. Wright (Ed.). Elsevier, Oxford, 549–554. doi:10.1016/B978-0-08-097086-8.14068-1

[9] Patrizio Caturegli, Alessandra De Remigis, Kelly Chuang, Marieme Dembele, Akiko Iwama, and Shintaro Iwama. 2013. Hashimoto's Thyroiditis: Celebrating the Centennial Through the Lens of the Johns Hopkins Hospital Surgical Pathology Records. *Thyroid®* 23, 2 (2013), 142–150. arXiv:https://doi.org/10.1089/thy.2012.0554 doi:10.1089/thy.2012.0554 PMID: 23151083.

[10] Mauro Cherubini, Luca Reut, James Tyler, and Martin Ortlieb. 2021. Inattentive, imprudent and inapt: discovering inadequacies of ICT during life-changing events through the lens of non-users. *Behaviour & Information Technology* 40, 15 (2021), 1643–1670. arXiv:https://doi.org/10.1080/0144929X.2020.1772879 doi:10.1080/0144929X.2020.1772879

[11] Shaan Chopra, Rachael Zehrung, Tamil Arasu Shanmugam, and Eun Kyoung Choe. 2021. Living with Uncertainty and Stigma: Self-Experimentation and Support-Seeking around Polycystic Ovary Syndrome. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* (Yokohama, Japan) *(CHI '21)*. Association for Computing Machinery, New York, NY, USA, Article 202, 18 pages. doi:10.1145/3411764.3445706

[12] Chia-Fang Chung, Qiaosi Wang, Jessica Schroeder, Allison Cole, Jasmine Zia, James Fogarty, and Sean A. Munson. 2019. Identifying and Planning for Individualized Change: Patient-Provider Collaboration Using Lightweight Food Diaries in Healthy Eating and Irritable Bowel Syndrome. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 3, 1, Article 7 (March 2019), 27 pages. doi:10.1145/3314394

[13] James Clawson, Jessica A. Pater, Andrew D. Miller, Elizabeth D. Mynatt, and Lena Mamykina. 2015. No longer wearing: investigating the abandonment of personal health-tracking technologies on craigslist. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (Osaka, Japan) *(UbiComp '15)*. Association for Computing Machinery, New York, NY, USA, 647–658. doi:10.1145/2750858.2807554

[14] Dan Cosley, Elizabeth Churchill, Jodi Forlizzi, and Sean A. Munson. 2017. Introduction to This Special Issue on the Lived Experience of Personal Informatics. *Human–Computer Interaction* 32, 5-6 (2017), 197–207. arXiv:https://doi.org/10.1080/07370024.2017.1324787 doi:10.1080/07370024.2017.1324787

[15] Mayara Costa Figueiredo, Thu Huynh, Anna Takei, Daniel A Epstein, and Yunan Chen. 2021. Goals, life events, and transitions: examining fertility apps for holistic health tracking. *JAMIA Open* 4, 1 (03 2021), ooab013. arXiv:https://academic.oup.com/jamiaopen/article-pdf/4/1/ooab013/36453929/ooab013.pdf doi:10.1093/jamiaopen/ooab013

[16] Abigail Durrant, David Kirk, Diego Trujillo Pisanty, Wendy Moncur, Kathryn Orzech, Tom Schofield, Chris Elsden, David Chatting, and Andrew Monk. 2017. Transitions in Digital Personhood: Online Activity in Early Retirement. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 6398–6411. doi:10.1145/3025453.3025913

[17] Tina Ekhtiar, Armağan Karahanoğlu, Rúben Gouveia, and Geke Ludden. 2023. Goals for goal setting: a scoping review on personal informatics. In *Proceedings of the 2023 ACM Designing Interactive Systems Conference*. 2625–2641.

[18] Tina Ekhtiar, Armağan Karahanoğlu, Ruben Gouveia, and Geke D.S. Ludden. 2025. Changing Health Goals with Personal Informatics. In *Proceedings of the 2025 ACM Designing Interactive Systems Conference (DIS '25)*. Association for Computing Machinery, New York, NY, USA, 2867–2883. doi:10.1145/3715336.3735813

[19] Daniel A. Epstein, Jennifer H. Kang, Laura R. Pina, James Fogarty, and Sean A. Munson. 2016. Reconsidering the device in the drawer: lapses as a design opportunity in personal informatics. In *Proceedings of the 2016 ACM International Joint*

Conference on Pervasive and Ubiquitous Computing (Heidelberg, Germany) *(UbiComp '16)*. Association for Computing Machinery, New York, NY, USA, 829–840. doi:10.1145/2971648.2971656

[20] Daniel A. Epstein, An Ping, James Fogarty, and Sean A. Munson. 2015. A lived informatics model of personal informatics. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (Osaka, Japan) *(UbiComp '15)*. Association for Computing Machinery, New York, NY, USA, 731–742. doi:10.1145/2750858.2804250

[21] Catrin Feron, Tina Ekhtiar, and Ruben Gouveia. 2022. Transitions in Personal Informatics: Investigating Self-Tracking During Moments of Change. In *Adjunct Proceedings of the 2022 Nordic Human-Computer Interaction Conference* (Aarhus, Denmark) *(NordiCHI '22 Adjunct)*. Association for Computing Machinery, New York, NY, USA, Article 43, 5 pages. doi:10.1145/3547522.3547686

[22] Susannah Fox and Maeve Duggan. 2013. Tracking for Health. http://www.pewinternet.org/2013/01/28/tracking-for-health/

[23] Marie Glasemann, Anne Marie Kanstrup, and Thomas Ryberg. 2010. Making chocolate-covered broccoli: designing a mobile learning game about food for young people with diabetes. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems* (Aarhus, Denmark) *(DIS '10)*. Association for Computing Machinery, New York, NY, USA, 262–271. doi:10.1145/1858171.1858219

[24] Ankit Gupta, Tim Heng, Chris Shaw, Diane Gromala, Jenny Leese, and Linda Li. 2021. Oh, I didn't do a good job: How objective data affects physiotherapist-patient conversations for arthritis patients. In *Proceedings of the 14th EAI International Conference on Pervasive Computing Technologies for Healthcare* (Atlanta, GA, USA) *(PervasiveHealth '20)*. Association for Computing Machinery, New York, NY, USA, 156–165. doi:10.1145/3421937.3421991

[25] Oliver L. Haimson, Jed R. Brubaker, Lynn Dombrowski, and Gillian R. Hayes. 2016. Digital Footprints and Changing Networks During Online Identity Transitions. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (San Jose, California, USA) *(CHI '16)*. Association for Computing Machinery, New York, NY, USA, 2895–2907. doi:10.1145/2858036.2858136

[26] Oliver L. Haimson, Albert J. Carter, Shanley Corvite, Brookelyn Wheeler, Lingbo Wang, Tianxiao Liu, and Alexxus Lige. 2021. The major life events taxonomy: Social readjustment, social media information sharing, and online network separation during times of life transition. *J. Assoc. Inf. Sci. Technol.* 72, 7 (June 2021), 933–947. doi:10.1002/asi.24455

[27] Simon L. Jones, William Hue, Ryan M. Kelly, Rosemarie Barnett, Violet Henderson, and Raj Sengupta. 2021. Determinants of Longitudinal Adherence in Smartphone-Based Self-Tracking for Chronic Health Conditions: Evidence from Axial Spondyloarthritis. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 5, 1, Article 16 (March 2021), 24 pages. doi:10.1145/3448093

[28] Anne Marie Kanstrup, Pernille Bertelsen, Marie Glasemann, and Niels Boye. 2008. Design for more: an ambient perspective on diabetes. In *Proceedings of the Tenth Anniversary Conference on Participatory Design 2008* (Bloomington, Indiana) *(PDC '08)*. Indiana University, USA, 118–127.

[29] Ravi Karkar, Jessica Schroeder, Daniel A. Epstein, Laura R. Pina, Jeffrey Scofield, James Fogarty, Julie A. Kientz, Sean A. Munson, Roger Vilardaga, and Jasmine Zia. 2017. TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 6850–6863. doi:10.1145/3025453.3025480

[30] Ravi Karkar, Jasmine Zia, Roger Vilardaga, Sonali Mishra, James Fogarty, Sean Munson, and Julie Kientz. 2015. A framework for self-experimentation in personalized health. *Journal of the American Medical Informatics Association* 23 (12 2015). doi:10.1093/jamia/ocv150

[31] Rachel Keys, Paul Marshall, Graham Stuart, and Aisling Ann O'Kane. 2025. Rethinking Lived Experience in Chronic Illness: Navigating Bodily Doubt with Consumer Technology in Atrial Fibrillation Self-Care. In *Proceedings of the 2025 CHI Conference on Human Factors in Computing Systems (CHI '25)*. Association for Computing Machinery, New York, NY, USA, Article 355, 19 pages. doi:10.1145/3706598.3713326

[32] Deborah Lupton. 2016. *The Quantified Self: A Sociology of Self-Tracking* (first ed.). Polity Press.

[33] Haley MacLeod, Anthony Tang, and Sheelagh Carpendale. 2013. Personal informatics in chronic illness management. In *GI '13: Proceedings of Graphics Interface 2013*. Canadian Information Processing Society, Regina, Saskatchewan, Canada, 149–156. https://ink.library.smu.edu.sg/sis_research/7995

[34] Michael Massimi, Jackie L. Bender, Holly O. Witteman, and Osman H. Ahmed. 2014. Life transitions and online health communities: reflecting on adoption, use, and disengagement. In *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing* (Baltimore, Maryland, USA) *(CSCW '14)*. Association for Computing Machinery, New York, NY, USA, 1491–1501. doi:10.1145/2531602.2531622

[35] Nassim Matin, Sigrid S Young, Benjamin Williams, W Curt LaFrance Jr, Julie N King, David Caplan, Zeina Chemali, Jeffery B Weilburg, Bradford C Dickerson, and David L Perez. 2017. Neuropsychiatric associations with gender, illness duration, work disability, and motor subtype in a US functional neurological disorders clinic population. *The Journal of neuropsychiatry and clinical neurosciences* 29, 4 (2017), 375–382.

[36] Mark Matthews, Elizabeth Murnane, and Jaime Snyder. 2017. Quantifying the Changeable Self: The Role of Self-Tracking in Coming to Terms With and Managing Bipolar Disorder. *Human–Computer Interaction* 32, 5-6 (2017), 413–446. arXiv:https://doi.org/10.1080/07370024.2017.1294983 doi:10.1080/07370024.2017.1294983

[37] Holly A. McGregor and Andrew J. Elliot. 2005. The Shame of Failure: Examining the Link Between Fear of Failure and Shame. *Personality and Social Psychology Bulletin* 31, 2 (2005), 218–231. arXiv:https://doi.org/10.1177/0146167204271420 doi:10.1177/0146167204271420 PMID: 15619594.

[38] Mollie McKillop, Lena Mamykina, and Noémie Elhadad. 2018. Designing in the Dark: Eliciting Self-tracking Dimensions for Understanding Enigmatic Disease. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (Montreal QC, Canada) *(CHI '18)*. Association for Computing Machinery, New York, NY, USA, 1–15. doi:10.1145/3173574.3174139

[39] Jahangir Moini, Oyindamola Akinso, Katia Ferdowsi, and Morvarid Moini. 2023. Chapter 12 - Chronic diseases and risks. In *Health Care Today in the United States*, Jahangir Moini, Oyindamola Akinso, Katia Ferdowsi, and Morvarid Moini (Eds.). Academic Press, San Diego, CA, USA, 283–322. doi:10.1016/B978-0-323-99038-7.00022-9

[40] Léa Paymal and Sarah Homewood. 2024. Good Days, Bad Days: Understanding the Trajectories of Technology Use During Chronic Fatigue Syndrome. In *Proceedings of the 2024 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) *(CHI '24)*. Association for Computing Machinery, New York, NY, USA, Article 128, 10 pages. doi:10.1145/3613904.3642553

[41] Adrienne Pichon, Jessica R Blumberg, Lena Mamykina, and Noemie Elhadad. 2025. The Voice of Endo: Leveraging Speech for an Intelligent System That Can Forecast Illness Flare-ups. In *Proceedings of the 2025 CHI Conference on Human Factors in Computing Systems (CHI '25)*. Association for Computing Machinery, New York, NY, USA, Article 519, 15 pages. doi:10.1145/3706598.3714040

[42] Adrienne Pichon, Kayla Schiffer, Emma Horan, Bria Massey, Suzanne Bakken, Lena Mamykina, and Noemie Elhadad. 2021. Divided We Stand: The Collaborative Work of Patients and Providers in an Enigmatic Chronic Disease. *Proc. ACM Hum.-Comput. Interact.* 4, CSCW3, Article 261 (Jan. 2021), 24 pages. doi:10.1145/3434170

[43] Filipa Queirós, Liliana Gil Sousa, João Arriscado Nunes, Rita Serra, and Carlos Barradas. 2014. A relevância das narrativas de experiência da doença: desafios concetuais e metodológicos. *Sociologia On Line* 7 (February 2014), 81–97. https://hdl.handle.net/10316/40950

[44] Frances Rees, Michael Doherty, Matthew J Grainge, Peter Lanyon, and Weiya Zhang. 2017. The worldwide incidence and prevalence of systemic lupus erythematosus: a systematic review of epidemiological studies. *Rheumatology* 56, 11 (08 2017), 1945–1961. arXiv:https://academic.oup.com/rheumatology/article-pdf/56/11/1945/21365328/kex260.pdf doi:10.1093/rheumatology/kex260

[45] John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers. 2014. Personal tracking as lived informatics. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Toronto, Ontario, Canada) *(CHI '14)*. Association for Computing Machinery, New York, NY, USA, 1163–1172. doi:10.1145/2556288.2557039

[46] Ilga Ruschak, Pilar Montesó-Curto, Lluís Rosselló, Carina Aguilar Martín, Laura Sánchez-Montesó, and Loren Toussaint. 2023. Fibromyalgia Syndrome Pain in Men and Women: A Scoping Review. *Healthcare* 11, 2 (2023). doi:10.3390/healthcare11020223

[47] Jessica Schroeder, Chia-Fang Chung, Daniel A. Epstein, Ravi Karkar, Adele Parsons, Natalia Murinova, James Fogarty, and Sean A. Munson. 2018. Examining Self-Tracking by People with Migraine: Goals, Needs, and Opportunities in a Chronic Health Condition. In *Proceedings of the 2018 Designing Interactive Systems Conference* (Hong Kong, China) *(DIS '18)*. Association for Computing Machinery, New York, NY, USA, 135–148. doi:10.1145/3196709.3196738

[48] Jessica Schroeder, Ravi Karkar, James Fogarty, Julie A Kientz, Sean A Munson, and Matthew Kay. 2019. A patient-centered proposal for bayesian analysis of self-experiments for health. *Journal of healthcare informatics research* 3, 1 (2019), 124–155.

[49] Jessica Schroeder, Ravi Karkar, Natalia Murinova, James Fogarty, and Sean A. Munson. 2020. Examining Opportunities for Goal-Directed Self-Tracking to Support Chronic Condition Management. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 3, 4, Article 151 (Sept. 2020), 26 pages. doi:10.1145/3369809

[50] Yasaman S. Sefidgar, Carla L. Castillo, Shaan Chopra, Liwei Jiang, Tae Jones, Anant Mittal, Hyeyoung Ryu, Jessica Schroeder, Allison Cole, Natalia Murinova, Sean A. Munson, and James Fogarty. 2024. MigraineTracker: Examining Patient Experiences with Goal-Directed Self-Tracking for a Chronic Health Condition. In *Proceedings of the 2024 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) *(CHI '24)*. Association for Computing Machinery, New York, NY, USA, Article 129, 19 pages. doi:10.1145/3613904.3642075

[51] Bart F Seppen, Jimmy Wiegel, Merel J L'ami, Sharon Duarte dos Santos Rico, Fabio S Catarinella, Franktien Turkstra, Maarten Boers, and Wouter H Bos. 2020. Feasibility of Self-Monitoring Rheumatoid Arthritis With a Smartphone App: Results of Two Mixed-Methods Pilot Studies. *JMIR Form Res* 4, 9 (21 Sep 2020),

e20165. doi:10.2196/20165

[52] Joachim Sieper and Denis Poddubnyy. 2017. Axial spondyloarthritis. *The Lancet* 390, 10089 (2017), 73–84. doi:10.1016/S0140-6736(16)31591-4

[53] Irene Strychar, Belinda Elisha, and Norbert Schmitz. 2012. Type 2 Diabetes Self-Management: Role of Diet Self-Efficacy. *Canadian Journal of Diabetes* 36, 6 (2012), 337–344. doi:10.1016/j.jcjd.2012.10.005

[54] Fenneke Sysling. 2020. Measurement, self-tracking and the history of science: An introduction. *History of Science* 58, 2 (2020), 103–116. arXiv:https://doi.org/10.1177/0073275319865830 doi:10.1177/0073275319865830 PMID: 31726878.

[55] Romain Toebosch, Arne Berger, and Carine Lallemand. 2024. Non-judgmental Interfaces: A New Design Space for Personal Informatics. In *Companion Publication of the 2024 ACM Designing Interactive Systems Conference* (IT University of Copenhagen, Denmark) *(DIS '24 Companion)*. Association for Computing Machinery, New York, NY, USA, 166–170. doi:10.1145/3656156.3663706

[56] Itishree Trivedi, Erin Darguzas, Salva Balbale, Alyse Bedell, Shilpa Reddy, Joel Rosh, and Laurie Keefer. 2019. Patient Understanding of "Flare" and "Remission" of Inflammatory Bowel Disease. *Gastroenterology Nursing* 42 (07 2019), 375–385. doi:10.1097/SGA.0000000000000373

[57] Jane Turner and Brian Kelly. 2000. Emotional dimensions of chronic disease. *The Western journal of medicine* 172 (03 2000), 124–8. doi:10.1136/ewjm.172.2.124

[58] Ronald F van Vollenhoven. 2009. Sex differences in rheumatoid arthritis: more than meets the eye... *BMC medicine* 7, 1 (2009), 12.

[59] Griffin M. Weber, Kenneth D. Mandl, and Isaac S. Kohane. 2014. Finding the Missing Link for Big Biomedical Data. *JAMA* 311, 24 (06 2014), 2479–2480. arXiv:https://jamanetwork.com/journals/jama/articlepdf/1883026/jvp140057.pdf doi:10.1001/jama.2014.4228