

Towards Hormone Health: An Autoethnography of Long-Term Holistic Tracking to Manage PCOS

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Abstract

Polycystic ovary syndrome (PCOS) is a common hormonal disorder affecting 11-13% of women of reproductive age, characterized by a wide range of symptoms (e.g., menstrual irregularity, acne, and obesity) that varies among individuals. While self-tracking tools help PCOS patients to monitor their symptoms and find personalized treatment, they often focus on regular periods of healthy women with inadequate support for the 1) personalization and 2) long-term holistic tracking necessary for managing complex chronic conditions like PCOS. To bridge this gap, the first author (who has PCOS) conducted an autoethnographic study of holistic self-tracking over a period of ten months in an effort to manage her condition. Our results highlight the challenges of personalized, holistic, long-term tracking in medical, socio-cultural, temporal, technical, and spatial contexts. Based on these insights, we provide design implications for tracking tools that are more inclusive and sustainable.

CCS Concepts

• **Human-centered computing** → **Human computer interaction (HCI)**.

Keywords

PCOS, self-tracking, autoethnography, women's health, hormone health

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1 Introduction

Polycystic ovary syndrome (PCOS) is a chronic condition affecting 11–13% of women (and more broadly individuals who have ovaries) of reproductive age globally [96, 119, 119]. PCOS is a complex condition related to metabolic disturbance and hormonal imbalance [79]. This syndrome causes symptoms like anovulatory cycles (menstrual cycle that occurs when an egg does not release from the ovaries) and irregular menstruation while also increasing the risk of other health issues, such as cardiovascular diseases and type 2 diabetes [108]. PCOS can also significantly impact women's emotional well-being as well. For example, physical symptoms like weight gain and unwanted hair growth due to hormone imbalance may challenge their sense of femininity [130, 141].

PCOS is an enigmatic condition whose root causes remain unknown [119]. It is an understudied disorder [55, 119], which, in turn, leads to challenges in improving health, finding treatment, and managing lifestyle. Given that PCOS is a poorly understood and highly individualized condition [135], professional medical help is often limited, leaving many patients dissatisfied with their treatment [30, 64, 130]. Although managing PCOS requires a *personalized* approach, it is often challenging for patients to identify what works best for them [30]. Thus, patients often largely rely on self-tracking technology (e.g., menstrual tracking app) to monitor their symptoms and find management strategies that work for them [10, 22, 51, 64].

Mobile health applications such as menstruation cycle tracking apps have been found useful for improving PCOS patients' health [124, 149]. However, these applications are limited in fully supporting the needs of PCOS patients due to insufficient support for personalization and a lack of inclusivity [10, 22, 26, 51]. For example, menstruation cycle tracking apps (e.g., Flo, Clue) focus on monitoring periods and PMS (premenstrual syndrome) symptoms for healthy women, but often overlook important variables for PCOS patients like hormonal acne and hirsutism (excessive body and facial hair growth). These symptoms, associated with irregular periods or anovulatory cycles, can be valuable indicators for monitoring the severity of PCOS [22, 119]. Moreover, personalization is crucial in managing PCOS due to the high variability of symptoms between individuals driven by factors like genetics, hormones, and lifestyle [95].

Furthermore, menstrual cycle tracking apps mainly focus on symptoms relevant to the period, while the management of PCOS requires monitoring broader aspects of a patient’s health and wellness. Since PCOS is a complex *chronic* condition coupled with *metabolic health* issues, the primary recommended treatment is lifestyle modifications: diet, exercise, and behavioral interventions [128, 139]. This complexity necessitates ongoing comprehensive monitoring of PCOS symptoms *plus* various lifestyle factors such as diet, exercise, weight, sleep, and daily steps [29, 128]. As all these factors can play an intertwined influence on PCOS, its management requires a *holistic* approach, addressing multiple interconnected aspects of health. Furthermore, since PCOS is a chronic condition that can affect one’s health for life, even after menopause, it requires *long-term* management.

To summarize, PCOS management requires *personalized, holistic, long-term tracking* to effectively manage a wide range of symptoms. While this approach is crucial for PCOS patients, our understanding of the specific challenges and strategies involved in implementing such tracking remains limited [22]. To bridge this gap, we ask the following research question in this study: **What are the challenges and strategies involved in personalized, holistic, long-term tracking for managing PCOS?** Then, we answer the research question by conducting an autoethnography study of the first author, a PCOS patient, who documented, recorded, and reflected on her long-term experience of tracking various variables related to PCOS, general health, and lifestyle. Over ten months, the first author tracked fifty-five variables (appendix A) using different tools (e.g., wearable devices, mobile applications, spreadsheets, paper, hormone test kits) while collaborating with her healthcare provider.

After reflection on the autoethnography data using a hybrid coding approach, we develop five themes highlighting the challenges the first author encountered while tracking and the strategies she employed in managing them across five areas:

- 1 **Medical challenge:** Ovulation tracking tools that are primarily designed for healthy women with a goal of conceiving pose a risk of false positive predictions for PCOS patients, and interpreting abnormal hormonal data is challenging without adequate in-app support.
- 2 **Socio-cultural challenge:** Diet tracking using photos is challenging when collaborating with a nutritionist from a different cultural background. Also, differing socio-cultural norms can impede accurate tracking.
- 3 **Temporal challenge:** Occasional events like traveling disrupt tracking, which leads to multiple devices and tracking methods to unexpected challenges like timezone change.
- 4 **Technical challenge:** Flexible tools and tracking methods that may seem convenient at the time often lead to manual effort and unstructured data.
- 5 **Spatial challenge:** Consistent tracking could be challenging, and physical cues in living spaces could be effective for building a tracking routine.

Our work makes two key contributions to HCI and Personal Informatics research. First, we utilize autoethnography to gather in-depth, longitudinal data to shed light on self-tracking by an often-overlooked population. The autoethnographic study encompassed

a variety of *everyday and uncommon activities* (e.g., eating and traveling), *stakeholders* (e.g., nutritionist, primary care provider), and *technologies* (e.g., smartwatch, spreadsheet, mobile apps), providing a rich qualitative account for analysis and reflections. Second, we propose design implications based on our findings to encourage the development of more inclusive tracking tools. We believe there is an opportunity to improve inclusivity by 1) extending beyond fertility by incorporating metabolic health, 2) offering granular tracking for hormones and diet, 3) providing flexible tracking modalities and data consolidation for long-term holistic PCOS management, and 4) supporting data-driven behavior change in living spaces for consistent and personalized tracking.

2 Related work

2.1 Polycystic ovary syndrome (PCOS)

Studies suggest that PCOS may have affected women for tens of thousands of years [6, 41, 106, 136]. Despite its long history and prevalence, PCOS is still an overlooked and understudied health issue for women [119]. While medical research has identified that hyperandrogenism (high levels of male hormones) and insulin resistance (cells that do not respond well to insulin) are highly associated with PCOS [32, 94, 119, 138], and hyperandrogenism and insulin resistance reinforce each other [94], the root causes of PCOS are not yet fully understood [55].

In PCOS, abnormal hormone levels disrupt ovulation. Normally, ovaries grow follicles (sacs in the ovary that each contain one immature egg), one of which matures and releases an egg during ovulation. In PCOS, this process is disrupted, preventing follicles from maturing, which leads to anovulation or irregular periods [116]. These immature follicles accumulate in the ovaries, and produce excess androgen [119], which may lead to symptoms such as acne, hirsutism (increased hair growth in androgen-dependent areas, e.g., face, lower abdomen), and hair loss [46, 88]. PCOS is the most common cause of irregular menstrual cycles and difficulty getting pregnant in individuals of reproductive age [129].

PCOS is not just a reproductive disorder; it is also characterized by significant metabolic disturbances, including insulin resistance [32, 127, 138] that can persist even after menopause [92]. Prevalent in 85% of PCOS patients [120], insulin resistance can progress over time to obesity or type 2 diabetes [45, 53]. Beyond physical health, PCOS also impacts emotional and mental well-being, with chronic health challenges and long-term risks contributing to emotional distress [130, 141]. Therefore, managing PCOS requires a holistic approach that addresses both physical and mental health through lifestyle interventions, such as diet, exercise, and behavioral changes [128, 139].

Recent international guidelines for PCOS diagnosis specify at least two of the following criteria must be met: irregular or absent ovulation, elevated androgen levels, or polycystic ovaries with multiple small immature follicles [129]. However, how PCOS appears varies greatly across individuals, due to the interplay between multiple factors, including genetics, hormones, and lifestyle [95], requiring personalized approaches to care. For example, while weight loss is often the first-line treatment for patients who suffer from weight gain, a small yet notable subset of PCOS patients with a

normal BMI (body mass index) exhibits similar symptoms and requires different lifestyle modifications [131]. Other studies found ethnic differences in clinical, hormonal, and metabolic characteristics of PCOS, such as more severe hirsutism in East Mediterranean regions [129] and lower BMI and milder hyperandrogenism-related symptoms in Asian populations [69, 142, 148]. The complexity of PCOS may contribute to delayed diagnosis [49] and challenges in providing tailored treatment [129].

2.2 Women's health and self-tracking in HCI

Dissatisfaction with delayed diagnosis and inadequate information received from health care providers [49] can motivate PCOS patients to start monitoring their symptoms and manage their own health using various tracking apps [10].

Considering women's health more broadly, in recent years, HCI research has highlighted the significance of creating technologies that support and empower women in areas such as physical, mental, and reproductive health [2, 68]. This arises from the enduring systemic discrimination that has limited women's access to healthcare and education, leading to the frequent neglect of their health and wellness needs [1, 38].

In an attempt to support women's health, prior HCI work in this domain has covered a wide range of topics such as menstruation [16–18, 42, 43, 56, 117, 132, 133], pregnancy [54, 100], new motherhood [33, 102], menopause [73], menstrual pain [99], and endometriosis [89, 101]. The majority of this HCI research focuses on personal informatics, specifically, understanding the role of self-tracking applications to monitor menstruation cycle [36, 59, 134] and fertility [26, 27, 40, 83].

While recent works have aimed to support women with various health conditions, such as menopause [73] and endometriosis [89, 101], research suggests there is still room to design more inclusive technology [10, 28] and highlights the limitations of menstruation tracking apps designed based on homogeneous experience (e.g., regular 28-day cycle) rather than accommodating the diversity of menstrual cycles [28, 36, 44, 68, 80]. For instance, menstruation or fertility tracking apps are often designed for healthy women with regular menstruation, but individuals with health conditions like PCOS may experience a different norm. For them, irregular periods, anovulation, and missed periods—conditions typically considered *abnormal*—may be the norm [28, 44]. Our understanding of how individuals with endocrine disorders (e.g., PCOS) use mainstream fertility tracking tools and their experiences with them is limited. A survey of PCOS patients revealed that due to the limitations of existing menstruation cycle tracking tools—such as the lack of evidence-based information on PCOS—91% of respondents indicated they would prefer to use a PCOS-specific app if one were available [10].

While the challenge of living with PCOS is discussed in the medical field [23, 24, 30], in HCI, there is very limited research about PCOS and PCOS patients' usage of technology to monitor their health. A recent HCI research started to shed light on PCOS patients, arguing for the importance of supporting personalized, contextual, and long-term tracking [22]. Our research contributes to the existing literature by providing insights into self-tracking technologies and the challenges of personalized, holistic, long-term tracking,

using the autoethnography method through the perspective of the first author, who has PCOS.

3 Method

Previous HCI research has applied interviews to understand the experiences and challenges of PCOS patients, highlighting the need for long-term, holistic monitoring [22]. However, the long-term lived experience of tracking and managing PCOS is difficult to capture through conventional research methods since the user group is marginalized, and finding participants for long-term tracking is challenging. To fill this gap, we adopted autoethnography, leveraging the first author's deep and personal experiences to provide a unique perspective on tracking and managing PCOS, which complements existing research, differentiating itself through its autoethnographic approach.

3.1 Autoethnography

Autoethnography is a first-person research approach in which researchers become participants in an ethnographic study to get a first-hand understanding of users' everyday lived experiences [65]. Autoethnography has become increasingly popular in HCI research in the past decade [57, 58, 63, 76, 86, 97, 144], due to its uniqueness in embracing and acknowledging the subjectivity, emotionality, and influence of the researchers, *"rather than hiding from these matters or assuming they don't exist"* [35].

Autoethnography also has the unique benefit of obtaining an intimate and long-term understanding of nuanced experiences when the user group is marginalized and hard to reach (e.g., people who stutter [144], hard-of-hearing individuals [63]), and in situations where asking participants to engage in regular studies would be impractical [76, 97]. For example, Jain's 2.5-year autoethnographic study on his travel experience as a hard-of-hearing traveler provided deep and valuable insights into designing accessible travel technologies [63]. Li and Guo's three-month autoethnographic study, where the researchers participated as audience in live-stream meditation sessions, provided a deep exploration of how live meditation can serve as a resource for mental well-being [76].

At the intersection of women's health and self-tracking, HCI researchers have adopted autoethnography to provide rich and first-hand insights into their experiences of long-covid [47, 57], menstruation [58], and pregnancy [47]. For example, Gamboa's autoethnographic exploration of her experiences during her third pregnancy and childbirth provided profound insights into the interplay between her body, the unborn child, and technologies during the pregnancy [47].

Given that the first author is both diagnosed with PCOS and has a background in HCI, design, and data visualization, this autoethnographic account also offers a perspective that is both deeply personal and analytically informed [4]. Despite the various benefits, we also recognize the challenges associated with autoethnography, such as balancing personal and analytical voices, managing emotional intensity, and navigating the inherent subjectivity and bias in the research process [65]. To address these challenges, this study employs detailed documentation of the first author's experiences in tracking and managing PCOS, along with reflexive practices supported by co-authors.

3.2 Biography and positionality

Diagnosed with PCOS during mid-adolescence, the first author initially received limited guidance from her healthcare provider about PCOS and how to manage it. Informed that PCOS could primarily pose challenges in conceiving, with oral contraceptives recommended as a management strategy, she chose not to pursue this treatment, viewing it as a temporary measure rather than a fundamental solution. In the early stages of her PCOS journey, she experienced mild hirsutism, irregular menstrual cycles, and severe hormonal acne, the latter being the most distressing symptom in her early twenties. At that time, she did not pay much attention to her irregular periods or the possibility of anovulation, as these symptoms were not outwardly visible like acne. It is also important to note that the first author is classified as having lean PCOS (associated with a normal BMI) [131], unlike the common weight gain associated with PCOS [119].

While lifestyle changes, including a healthy diet and regular exercise, helped alleviate the acne to some degree, factors such as high stress from her academic and professional career led to symptom fluctuations and challenges in managing PCOS. Through years of managing PCOS, and now in her early thirties, she realized that PCOS is not just a fertility issue and it does not affect just a single body part (e.g., ovaries), but a complex metabolic condition affecting overall hormone balance. She learned that maintaining overall health and harmony is essential for effectively managing her condition, aligning with recommendations from medical research [29, 128].

Initially, the first author did not track her health to manage PCOS because of the unpredictable nature of her symptoms. For example, she might go months without periods, only to experience sudden, short cycles, making it feel pointless to track something with no discernible patterns. Three primary reasons motivated her to begin tracking. First, she decided to adopt a more data-driven approach to better understand and manage her PCOS instead of trying to rely on guesswork, which led in the past to symptom fluctuations and frustrations. Second, as an HCI researcher, she was interested in exploring how technology could support gaining deeper insights into her condition and identifying potential avenues for improvement. Third, she hoped to contribute to more data-driven discussions surrounding women's health, particularly PCOS. By using her own data, she aimed to enhance the understanding of PCOS within the HCI field and inspire other designers, healthcare providers, and women experiencing PCOS.

In addition to her PCOS journey, the first author is an international PhD student in the United States, with a research focus on HCI, human-AI interaction, and data visualization. Raised in South Korea, she has an academic background in design and UI/UX design work experience. Given her technical skills, data literacy, and access to healthcare, the first author's experience, while unique, may not represent all individuals with PCOS.

The other co-authors, who do not have PCOS, joined the first author to support reflection, data analysis, and presentation of this autoethnographic research. The second author, with expertise in autoethnographic research, technology for mindfulness and mental well-being, supported the first author in reflecting on her experiences. The third author, an expert in qualitative research and

technology design, assisted with data synthesis and reporting. The fourth author with expertise in data visualization and interactive systems, contributed to reflections on tracking tools. The last author, an expert in women's health and personal health informatics research, contributed by situating the findings within the broader context of personal health informatics. Their involvement provides a more diverse perspective to the data analysis and reflexivity practice, situating this autoethnography with related HCI work while maintaining the authenticity of the first author's personal narrative.

3.3 Autoethnographic data collection

Over 10 months, from November 2023 to the end of August 2024, the first author used a variety of tracking tools to document her PCOS experience and journaled reflections on the process. The full list of tracked variables with data collection methods and dates is described in Appendix A, and the data collection journey is visualized in Figure 1. Additionally, examples of data collected using an Apple watch and a smartphone are shown in Figure 2.

3.3.1 Initial tracking (Nov 2023 - Jan 2024): developing tools and getting into a tracking routine. In November 2023, the first author started tracking seven categories (Figure 1 - 1) based on a combination of the known impacts of PCOS on health [119, 129] and her personal experience with the condition: 1) PCOS symptoms: Acne and Mood, 2) Menstrual cycle, 3) Diet, 4) Weight, 5) Physical activity, 6) Sleep, and 7) Others: sleepiness and fatigue.

To track most of these categories (PCOS symptoms, menstrual cycle, diet, and others), the first author created a Google Sheet because of its flexibility to allow detailed tracking. While other menstruation tracking apps (e.g., Flo, Clue) log symptoms like acne, the first author wanted to capture more specific details, such as the location of acne (e.g., right chin, left chin) and qualitative symptom descriptions. She avoided flexible health tracking apps like Bearable [7] to maintain complete freedom in customizing her tracking without the constraints of pre-defined interfaces. For instance, Bearable lacked desktop compatibility, which she preferred while working on her desktop. Further, given the high number of different tracked variables, she found inputting data into a Google Sheet more convenient than using multiple applications since it allowed her to efficiently record everything in one place without switching between applications. Finally, with the potential for later analysis, the ability to export a CSV file made future data analysis more straightforward.

In addition to the Google Sheet, the first author used an Apple Watch (Series 9) to track her physical activity, given the practicality in gym settings where accessing a laptop was difficult. She also monitored her heart rate using the watch to track workout intensity and to monitor sleep patterns given these built-in watch functionalities.

Finally, for variables such as acne and food, the first author used her phone's camera (iPhone 12 mini) to visually document daily food consumption and track changes in acne over time. She decided not to use food tracking apps, which were either inaccurate (e.g., MyFitnessPal), or when relying on photo recognition (e.g., Foodvisor) struggled to recognize non-Western foods like Korean dishes. Instead, the first author decided to take photos and manually label the ingredients in the Google Sheet. Additionally, she found

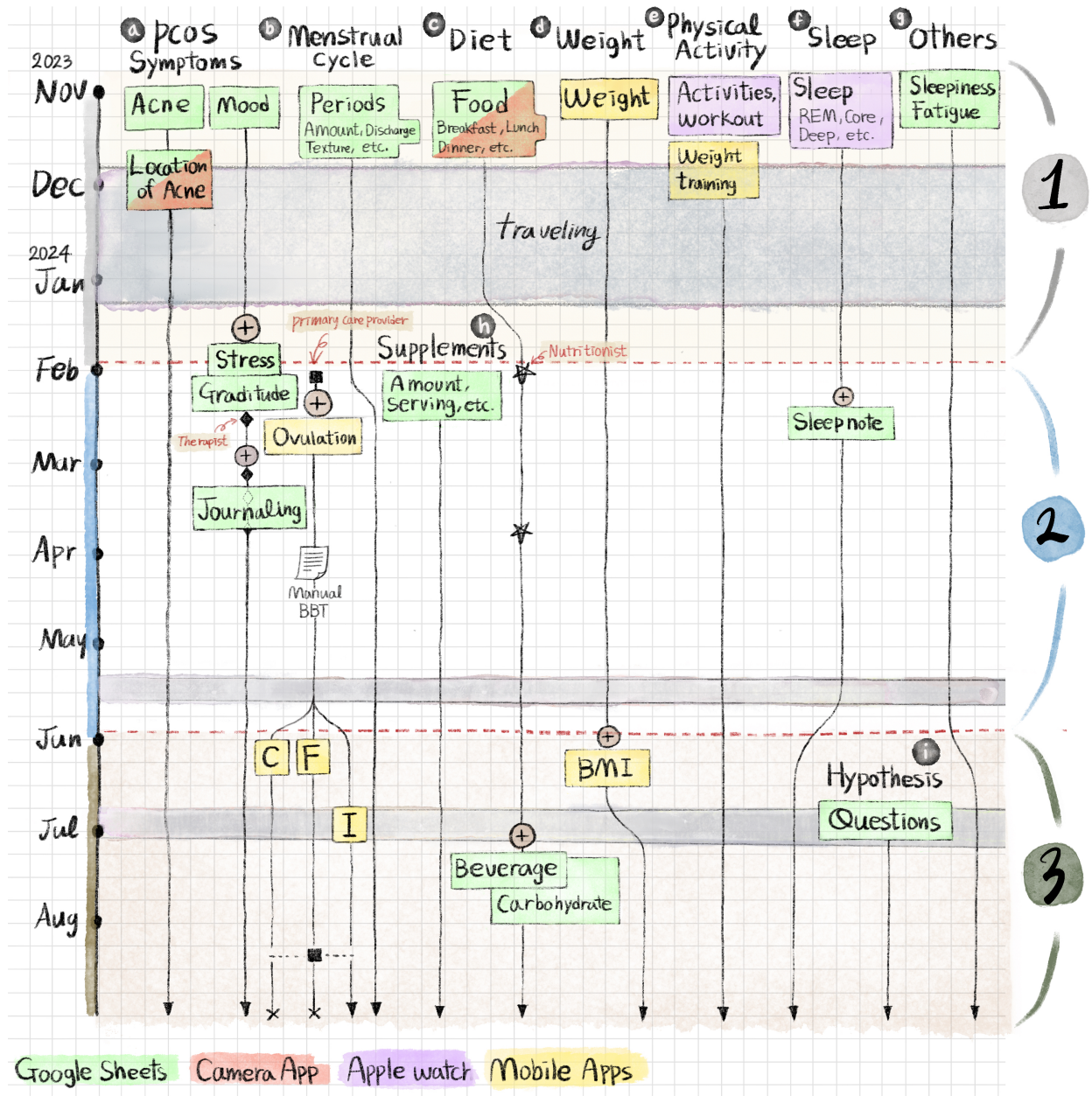


Figure 1: Tracking journey This graph illustrates the ten-month tracking journey of the first author. The vertical axis represents the timeline from November 2023 to August 2024, while the horizontal axis displays the nine categories of data tracked by the first author (a, b, c, d, e, f, g, h, i). The colors denote the tools used for tracking. The journey is divided into three stages: the initial stage 1, where tracking began; the turning point 2 when the first author met various health providers (◆: therapist, ■: primary care provider, ★: nutritionist) and made adjustments to the tracking strategy; and the later stage 3, where new technical apps were adopted (C: Clue, F: Femometer, I: Inito) to monitor ovulation. The first author eventually adopted Inito for ovulation tracking, discontinuing the use of manual BBT, Clue, and Femometer (marked by x). Limitations of discontinued tools are discussed in section 3.3.3 and section 4.1.1. Grey areas in the graph indicate periods of travel.

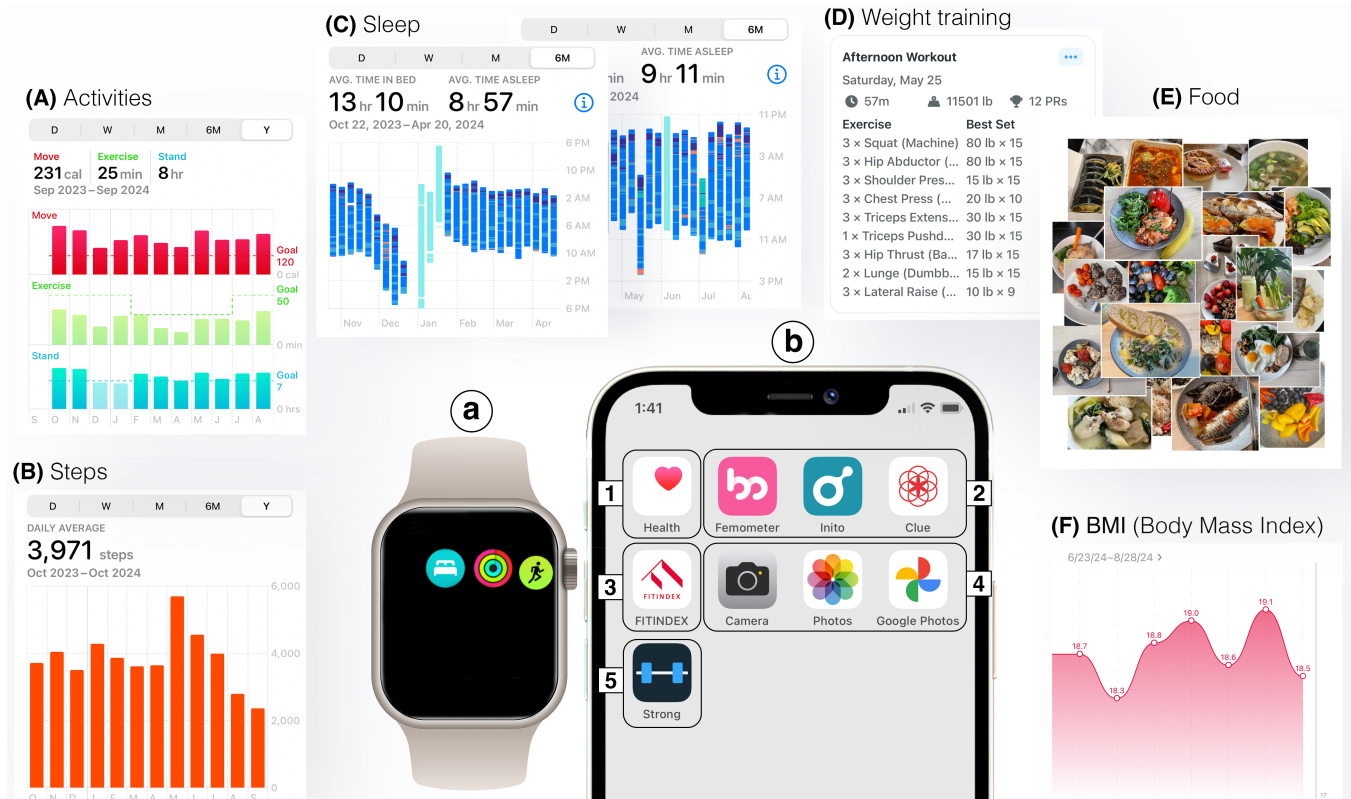


Figure 2: Tracked data and applications used for tracking on Apple watch and iPhone Apple watch (a) and apple Health app [1] was used to track physical activities (A, B) and sleep (C). The iPhone (b) was utilized to monitor diet (E) via the camera and photo app [4], track weight training (D) with the Strong app [5], and log weights (F) using the FITINDEX app [3]. Ovulation tracking was managed through the Femometer, Inito, and Clue apps [2].

the photo metadata, which records the time each picture was taken, helpful for accurately tracking when food was consumed.

As she started self-tracking, the first author sought to deepen her understanding of PCOS by gathering information from various sources, including social media, books, podcasts (e.g., The PCOS girls podcast [50], A cyster & her mister podcast [140]), online communities (e.g., PCOS subreddit [107]) and journals. However, the sheer volume of information was overwhelming, making it difficult to determine what was most relevant and trustworthy. She soon realized that professional feedback was necessary to fine-tune her self-treatment. This realization led her to consider co-managing her health with healthcare providers, which marked the beginning of the next phase of tracking.

3.3.2 Turning point (Feb - May 2024): Involving healthcare providers. After a couple of months of tracking, at the end of January 2024, the first author decided to involve health professionals in her journey: a nutritionist to get advice on her diet, a therapist to support her mental well-being, and a primary care provider for assistance with managing PCOS (Figure 1 - (2)).

The first author met with the nutritionist twice between January and March 2024. During these meetings, the first author shared photos from her phone of her daily meals. The nutritionist appreciated

the photos, considering they provided a clear picture of the diet compared to a verbal description alone. She did not recommend additional food tracking, noting that focusing on calorie counting might lead to an eating disorder. Therefore, the first author continued recording food by taking photos and labeling them in the Google Sheet.

The first author also met with a mental health therapist four times between February and March 2024 to receive advice on mindfulness practice. The therapist recommended keeping a daily journal to monitor her mood. Based on this suggestion, the first author started journaling her mood more regularly.

Finally, the first author met a nurse practitioner who provides primary care at the university healthcare center with a particular interest in reproductive health for the first time in February 2024. During the initial meeting, the primary care provider recommended some lab work to assess the first author’s current health status and suggested tracking ovulation due to the possibility of anovulatory cycles. Based on these suggestions, the first author decided to start tracking ovulation. After researching various ovulation tracking methods, she decided to start with basal body temperature (BBT) tracking, as it seemed easier than other methods like ovulation urine tests. BBT is the lowest temperature a person’s body reaches

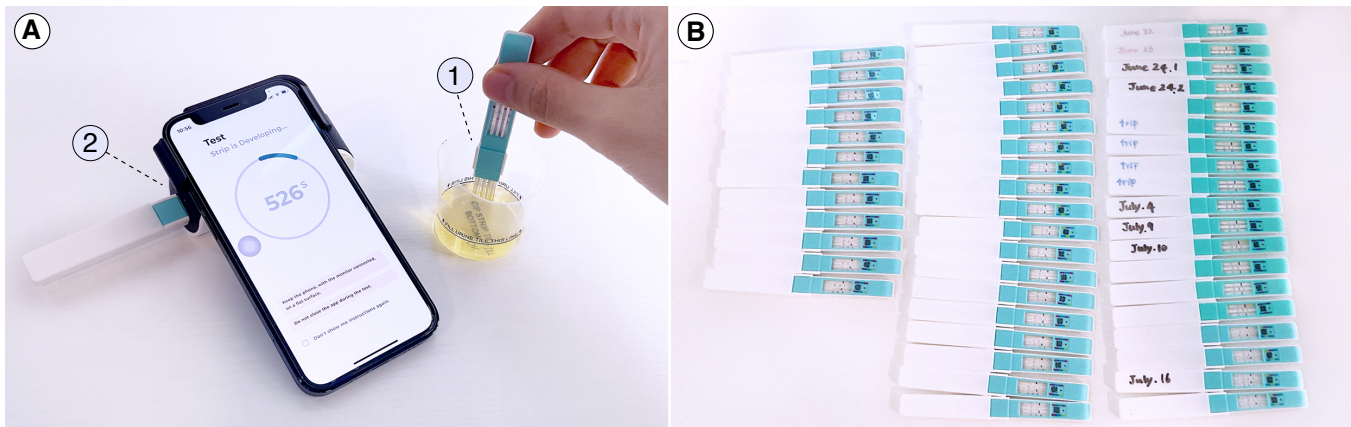


Figure 3: Hormone tracking using Inito The left picture (A) illustrates an example of hormone tracking using a urine test kit. After dipping the test strip in urine for 15 seconds (1), users attach the Inito fertility monitor to their phone and insert the test strip into the device (2). After a 600-second (10-minute) wait, the result will be displayed. The right picture (B) shows the test strips used by the first author to track her hormone levels from June to August 2024.

while at rest, usually first thing in the morning, and an increase in BBT is a sign of ovulation [121]. The first author purchased a thermometer and began recording her body temperature each morning in a paper notebook.

3.3.3 Later stage (June - Aug 2024): tracking ovulation using specialized apps and devices. In June 2024, after manually tracking BBT for a few months without noticing any significant trends, the first author decided to explore other methods to track ovulation more accurately (Figure 1 - 3).

While searching online for ovulation tracking methods, she found Femometer, a digital thermometer linked to a mobile app, which specializes in ovulation and fertility tracking. It measures BBT and automatically records it in the app, visualizing the results in a graph. She purchased and started using Femometer. She also downloaded and started using the Clue mobile app, designed for regular period tracking, due to its ovulation prediction feature.

In addition to BBT tracking, the first author decided to try ovulation urine test kits that measure hormone levels. She initially considered using a typical ovulation urine test kit that measures only LH (luteinizing hormone) levels. These tests provide a binary result, indicating whether or not ovulation is likely when a high level of LH is detected, and need to be used around the expected ovulation day to confirm ovulation. However, due to having an irregular menstrual cycle, the first author was uncertain about estimating the expected ovulation day for using the test kit. Since these test kits are designed for healthy individuals with regular menstrual cycles, the first author believed that the affordances of these tools are not well-suited for the context of PCOS, where irregular periods are common [119]. Furthermore, the single binary results did not allow her to understand how her hormones change over time throughout the cycle.

To examine ongoing trends in her hormone levels, the first author therefore purchased Inito, a device that comes with a test kit and strips that connect to an app to track four hormones: Estrogen,

LH (luteinizing hormone), PdG (the urine metabolite of progesterone), and FSH (follicle-stimulating hormone) [61]. Inito provides real numerical values with a trend graph, offering a clearer understanding of hormonal changes throughout each cycle. Using the first urine of the day (as guided by the app), she tracked hormones using Inito since June 22, 2024 (Figure 3). After tracking ovulation from February to July, the first author met the provider for the second time in August 2024 to share her tracked data.

3.4 Data analysis

After removing any sensitive information she did not want to share, the first author shared the Google Sheet and her reflection notes with the co-authors. Each of them read the raw data and reflection notes multiple times. We used a hybrid coding approach [110] to analyze the autoethnographic data. The first author initially applied inductive coding. Then, drawing from her reflections and the data, the first author developed initial themes by grouping codes according to their meanings. During weekly meetings, the co-authors asked the first author probing questions and suggested additional codes and themes, which helped to integrate the inductive insights with broader theoretical concepts. We iterated on this process several times to co-develop themes and ensure that the developed themes were in-depth reflective of the first author's personal experiences and contextualized within the existing literature.

4 Findings

This section is written in the first person singular to present our findings from the first author's perspective, offering a more personal and close voice [63]. The quotes are taken from the first author's notes and have been lightly edited for grammar. Our findings focus on the *challenges* the first author faced (Table 1).

Table 1: Summary of findings

RQ: What are the challenges and strategies of personalized, holistic, long-term tracking to manage PCOS?	
§ 4.1: Medical challenges: tracking ovulation	
Section	Summary
§ 4.1.1	False positive ovulation prediction: The tools used to track ovulation—Clue, Femometer, and Inito—gave conflicting results, with only Inito providing an accurate ovulation prediction. This discrepancy led the first author to realize she might have been experiencing anovulatory cycles, mistaking them for menstruation.
§ 4.1.2	Interpreting hormonal data: Reading the hormone chart in the Inito app was challenging due to the lack of support for understanding abnormal patterns. This forced the first author to rely on external research. Additionally, the app's lack of integration with other health tools, such as diet tracking, further hindered a comprehensive view of hormone health.
§ 4.2: Socio-cultural challenges: food tracking	
	Using food photos for diet tracking is challenging when working with a nutritionist from a different cultural background. Social norms and communal dining in non-Western cultures make it difficult to track meals accurately through photos.
§ 4.3: Temporal challenges: routine disruptions while traveling	
	Occasional event like traveling can disrupt usual tracking routines. The first author had to adapt by using alternative tools like manual logs and notes to cope with events like time zone changes or packed schedules.
§ 4.4: Technical challenges: data integration across unstructured tools	
	Despite using flexible and adaptable tracking methods (e.g., Google Sheets), managing data across different platforms becomes challenging, leading to disorganization and difficulty in keeping consistent records.
§ 4.5: Spatial challenges: establishing a tracking routine in the home	
	Health tracking is also about behavior change. Transitioning from disruptive digital notifications to a smart home system with an AI speaker and ambient light created a more seamless, supportive routine that felt like shared care, relieving the mental burden of managing health.

4.1 Medical challenges: tracking ovulation

In this subsection, I share my ovulation tracking experience as an example of the complexities involved in tracking and understanding the medical aspects of PCOS.

4.1.1 False positive ovulation prediction. Using three different apps—Clue, Femometer, and Inito—to track ovulation, meant that I had to cross-validate ovulation predictions due to conflicting results between the apps, with inaccurate and false positive predictions from Clue and Femometer, while Inito provided true negative results. For instance, during the cycles I tracked from June to August 2024, both Clue and Femometer apps predicted ovulation each month. However, hormone tracking with Inito indicated that I did not ovulate anytime during this timeframe, and by physically examining my discharge I did not observe any signs of ovulation. On June 29th, I wrote in my journal, "...it [Femometer] said my ovulation was on June 26... I didn't notice any egg white-like discharge [which indicates ovulation] at all." Figure 4 shows an example of ovulation prediction from these three apps for my June 2024 cycle.

The conflicting ovulation predictions from these apps and false positive results made me feel confused, stressed, and anxious because I did not ovulate as Clue and Femometer predicted. It made me question if my body was not normal, and left me wondering why I had not ovulated as predicted by these apps.

As a result of this confusion, I learned to rely on Inito to track my hormone levels and ovulation, due to the hormone imbalances in PCOS. Unlike Clue and Femometer, Inito did not confirm my ovulation immediately. Instead, it recommended continued tracking hormones to detect a progesterone surge after the expected ovulation day. I did some research and learned about the importance of specifically tracking progesterone given its role in indicating ovulation: progesterone levels rise after ovulation, and chronically low progesterone is common in women with PCOS [11, 77]. In my case, no progesterone rise was observed, and Inito confirmed that ovulation did not occur for that cycle.

The results from Inito made me realize that what I had thought were periods might have actually been anovulatory cycles (periods without ovulation). After two consecutive cycles of receiving the anovulatory cycle results from Inito, I wasn't too surprised, as I had already suspected something was off due to my extremely light periods. At that point I realized that I might have been experiencing anovulatory bleeding for years, mistakenly believing I was menstruating lightly. I knew that anovulation was possible due to my PCOS, but I had never considered it seriously because I still experienced period-like bleeding, even though it was irregular. Reflecting on my menstrual history of last year, I remembered only two to three instances with clear signs of ovulation, such as egg

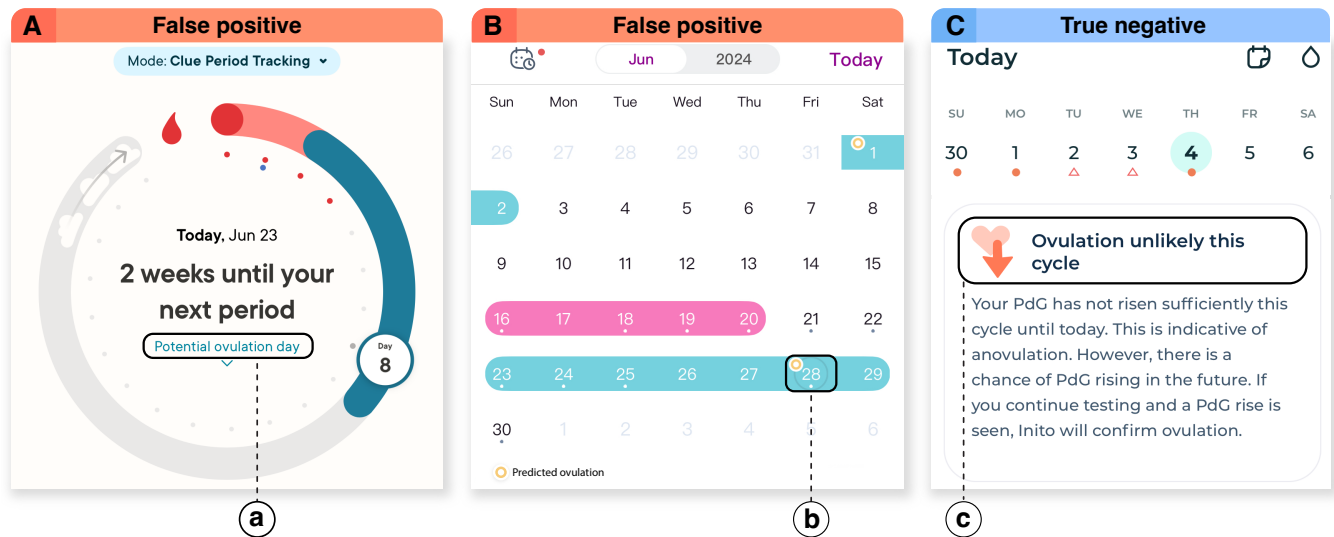


Figure 4: Ovulation Prediction App Screenshots For the June 2024 cycle, (A) Clue, a menstruation cycle tracking app, and (B) Femometer, a basal body temperature (BBT) tracking app, both produced false positives (a, b). (C) Inito, a hormone tracking app, monitored the progesterone surge until early July and correctly detected anovulation (c).

white-like discharge, and concluded that I may have only had three ovulatory cycles last year.

My experience highlights the lack of inclusivity in designing ovulation prediction apps by ignoring populations such as those with PCOS. The false positive predictions from Clue and Femometer confirmed my already false belief that my bleeding was an irregular period, unaware that one could still bleed without ovulating. I suspect that Clue and Femometer based their predictions on the period history data I entered, assuming regular healthy ovulatory menstrual cycles. The result may be that many women with PCOS might mistakenly believe they are ovulating based on standard period or BBT tracking tools when, in reality, they may be experiencing anovulatory bleeding [78].

4.1.2 Interpreting hormonal data. Hormone self-tracking can be empowering. Before starting to use the Inito app to track my hormones, tracking hormones required a doctor's visit for blood tests, which offered only a snapshot. I appreciated the practical testing guidance offered by the app and was fascinated to see my hormone levels change daily. Also, having access to my hormone chart prompted me to ask questions I had never asked before, such as: "I don't know why my estrogen can fluctuate [so much]. Why I don't have much estrogen today? (10-June-24)", "Why is my estrogen elevated when I expect it to be low, considering PCOS is associated with high testosterone? (30-June-24)" "Why isn't my progesterone increasing? (30-June-24)" "Why is there a higher level of LH in the third month compared to previous months, and is this a positive or negative indicator? (24-Aug-24)" "What does a normal hormonal pattern look like, and how does my data compare? (25-Aug-24)"

Despite feeling empowered by and aware of my data, I found that interpreting hormone charts without sufficient guidance was extremely difficult. Being unfamiliar with hormones and their roles

in the menstrual cycle, I needed some explanations to comprehend the graph. However, my graph did not show the regular patterns typically seen in a healthy menstrual cycle. After tracking for three cycles, I could not find a clear trend in my graph (Figure 5B). My graph deviated significantly from examples of typical hormonal patterns that I found online and on the Inito website (Figure 5A). The Inito app provides a hormone trend chart with fertility window predictions, but does not provide guidance for detecting abnormal trends, comparisons to normal menstrual cycles, or other hormone trend interpretations.

After noticing elevated LH levels in my August graph, I decided to research the topic, and found through reading medical journal publications that this is common in PCOS, where a higher LH/FSH ratio is typical [109]. This required significant effort to get through unfamiliar medical jargon, and I wished for curated, science-based resources in plain language. Later, I discovered that Inito has a blog with explanations about the LH ratio and PCOS [62], and I wished the app made the relevant information more readily available where the graphs are presented. In contrast, the Femometer app offers videos with doctors talking about PCOS on its main page, making the information accessible and helpful for understanding my condition better, but again, not linking it to the tracked data visualizations.

Another challenge I encountered was the disconnect between Inito and other variables I was tracking, which made it difficult to interpret the hormone chart from a holistic perspective. Inito allows logging additional variables like mood, pain, discharge, and physical activity, but does not support tracking diet or sleep. As PCOS is a multi-faceted condition influenced by many aspects of life (e.g., diet, stress, sleep), I found myself considering the effects of other hormones, such as insulin and cortisol, on the hormone data. Since PCOS is related to insulin, I have generally been sticking to a

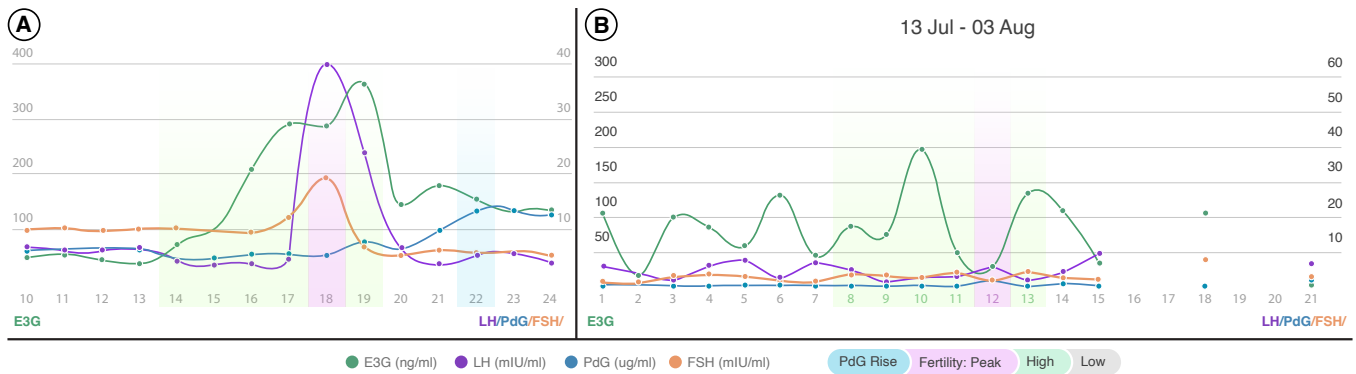


Figure 5: Tracked hormone Hormone chart (A) illustrates a normal menstrual cycle, as shown on Inito’s blog [60]. The X-axis represents the cycle days. The chart highlights a noticeable rise in E3G (estrogen), LH (luteinizing hormone), and FSH (follicle-stimulating hormone) around the fertility peak day (pink area), indicating a high likelihood of ovulation. Following this peak, the chart shows a rise in PdG (progesterone) a few days later, which confirms ovulation. In contrast, chart (B) displays the hormone chart of the first author’s July cycle (exported from the Inito app), spanning from July 13th to August 3rd, 2024. This chart shows a relatively high level of E3G compared to other hormones with high fluctuations. There is no clear surge in LH and FSH on the fertility peak day. Additionally, PdG remains low throughout the entire cycle, with no significant rise.

low-carb diet, and in August, I experimented with a Keto diet (high-fat, adequate-protein, low-carbohydrate). However, I still observed higher LH levels, which are associated with high insulin levels [87], which did not align with what I expected from the extremely low-carb diet. I was wondering if my diet might be stressing my body, raising cortisol levels and potentially contributing to elevated blood glucose [66]. But, since the data were separately located, with my diet in a spreadsheet and hormones in an app, it was challenging to make sense of the potential effects of eating certain foods on my hormones on a daily basis. It made me question the capacity of specialized tracking tools that focus on a single aspect of health, such as hormones, to provide a complete picture of one’s health.

4.2 Socio-cultural challenges: food tracking

In this section, I share the challenge of tracking from a cultural perspective, using food tracking as an example. This example highlights the difficulty of communicating with a nutritionist through food photos when there are cultural differences. It also underscores the challenge of using photos as a method for collecting dietary data on certain occasions in non-Western cultures.

When meeting with a nutritionist, she expressed an appreciation for my food photos and thought they were helpful for her to understand my diet better. Upon reviewing the photos, she suggested that I eat more carbohydrates and include snacks between meals, expressing a concern that I might be under-fueling my body. However, I thought I was eating enough carbohydrates, and suspected that the photos alone were not sufficient for the nutritionist to make accurate interpretations and recommendations, due to a difference in our cultural backgrounds. My diet consists of a mix of Western and Asian cuisines, while my nutritionist is more familiar with a Western diet. My food photos often included multi-grain rice, which appeared purple due to the inclusion of black rice. This might not look like typical Western carbohydrates such as pasta, noodles, potatoes, or white rice. Additionally, I frequently eat rice bowls

topped with vegetables and protein, so in the photos, the rice was often hidden under the other ingredients, causing the nutritionist to be unaware of some of my nutrients.

Korean dining culture played another contributing factor to the complexity of my food tracking using photos. In December 2023, I traveled to South Korea to visit friends and family. In Korean culture, taking photos while dining with seniors or elderly people could be considered impolite, which disrupted my usual habit of tracking my meals with photos during my visit. Another challenge related to Korean dining culture was that, unlike in Western culture, where individuals eat from their own plates, Korean food is typically shared. A key feature of Korean meals is banchan, small side dishes that are spread across the table for everyone to share, making meals naturally more communal. When taking photos of these shared meals, it was difficult to accurately gauge the portions of food I personally ate. Overall, I realized that food photos as the only tool for food tracking could be misleading, being short of accurately representing my diet and lacking nuance given my cultural background.

4.3 Temporal challenges: routine disruptions while traveling

Tracking can be challenging to maintain when life brings unexpected events that disrupt lifestyle routines. Here, I share an example of a challenge I faced due to long-distance travel. During the ten-month period of tracking, I had several long-distance travels, and each trip brought new difficulties in maintaining my tracking habits. For instance, during a 16-hour flight, I lost all sense of day and night due to the changing time zones, making it challenging to track my hormone levels, which required my first morning urine samples. I fell asleep multiple times on the flight and was not sure when is morning for my body, so I eventually gave up on tracking that day, but it left me feeling anxious because the Inito app indicated that the daily test was *required*.

Additionally, the time difference between the U.S. and South Korea further complicated my sleep tracking. In the U.S., I set my sleep schedule on my iPhone and Apple Watch based on Eastern Standard Time, and when I arrived in Korea, it was automatically updated to Korean Standard Time, but my body did not sync as easily. I could have manually set a new schedule, but experienced unpredictable sleep patterns during the adjustment period. It took more than two weeks for my body to fully adapt. During this time, instead of using my Apple watch to track sleep, I decided to manually log my sleep times daily on the spreadsheet.

Besides affecting my sleep, the change in routine when traveling disrupted other parts of my tracking. I noted in my journal, "I realized my logging is messed up because during traveling [Arizona before coming to South Korea], it was difficult to exercise, log, and reflect on my health. (03-Dec-23)" Similar to how I switched to using the spreadsheet to track sleep, I found myself switching to different tools to track other variables while traveling. Especially in situations where I had packed schedules filled with activities and visits to tourist attractions, I often relied on my phone's Notes app to jot down my mood, symptoms, or to take photos of what I ate, with the intention of transferring the data to my spreadsheet later.

4.4 Technical challenges: data integration across unstructured tools

While using multiple tracking devices and tools like Google Sheets helped me adapt my tracking to my own personal needs that were dynamically changing, this ended up with a source of technical challenges of dealing with messy, unstructured data across multiple devices and in multiple formats: a Google Sheet, my Apple Watch, voice memos, and various mobile apps.

In my daily life, although I spend much of my time working at a desk in front of a computer, I would lose access to my Google Sheet when I moved around, sometimes without my phone. As a result, I have developed a reliance on my watch, wearing it as much as possible to maximize data collection. The convenience of always having it on me allowed me to record data even when my laptop or phone was not immediately accessible. For example, I found myself often walking to the kitchen to take my dietary supplements, using the voice recording feature on my watch to immediately log what I consumed. For instance, I might record, "I took Omega-3 1000mg, Vitamin C 1000mg, and Vitamin D 1000IU." This helped me accurately and consistently track my supplement intake, as otherwise I would sometimes get distracted and forget exactly what I took by the time I returned to my desk and attempted to log it in the spreadsheet. However, while convenient at the moment, voice memos became a hassle later on. Finding the right memo and transferring the voice data into the spreadsheet turned out to be a lot of work. Compared to written notes that could be glanced over, I had to listen to multiple memos to identify the right one buried in a mixture of other recordings and verify its content.

In addition to the challenge of mixing multiple devices and formats for tracking, sometimes flexible tools turned out to be too unstructured to easily manage. Initially, I chose Google Sheets as my primary tracking tool because of its flexibility and ease of customization. However, as the number of variables I tracked increased, the spreadsheet became messy and long. For example, when I stopped

tracking a certain variable, such as specific supplements I stopped taking, I could not simply delete these rows, as that would erase the previous data I already tracked. The result was disorganized records in a sparse spreadsheet. Additionally, the open-ended nature of Google Sheets was a source of inconsistency in how I logged my data, sometimes finding myself recording data in fields not originally designated for that purpose. For example, I created a timeline in the spreadsheet from morning to night in 30-minute intervals to track my daily meal intake, noting when and what I ate. However, I occasionally used this timeline also to record my feelings or my energy levels at a particular time, such as noting, "8:00 pm - I drank one big bottle of spearmint tea with oat, and it made me calm. I was stressed before this. (20-Feb-24)", "6:30 pm - I was extremely sleepy. (21-Aug-24)" This open-endedness and lack of structure made me concerned about how to clean and organize the data for later analysis. To sum up, the flexibility and customization I initially valued in using Google Sheets turned out to be a source of frustration and anxiety about managing my tracking.

4.5 Spatial challenges: establishing a tracking routine in my home

One key lesson I have learned from health tracking is that tracking is not just about recording data; it is also deeply connected to behavior change and habit formation [37, 82]. For habits I already had, tracking was easy. For example, before I started my tracking journey, I already had the habit of taking photos of my food, making it easy to integrate it into my tracking routine. On the other hand, new activities such as daily hormone testing using urine tests or tracking my basal body temperature (BBT) required more conscious effort and adjustments to my environment.

To support new tracking behaviors, I made changes to my physical environment to serve as embodied reminders to take action [125, 126]. For instance, when tracking BBT, I placed a thermometer, a pen, and paper beside my bed so I could record it as soon as I woke up. Similarly, for hormone testing, I kept the plastic urine cup in the bathroom by the toilet to remind me to use it every morning. To exercise, I bought a stationary bike and positioned it at home by my standing desk, to put my computer in front of it. Instead of spending an hour going to the gym, I would take quick 20-30 minute rides on days I was working from home, and I could now work and exercise simultaneously, making it easier to fit exercise into my busy schedule. However, there were times when small disruptions affected my routines. For instance, on days when I misplaced my thermometer or slept on the other side of the bed, I was more likely to forget to track my BBT. Similarly, when my standing desk broke and I could not fit the stationary bike under it, my daily biking routine was put on hold until I replaced the desk. These experiences made me realize how crucial physical and spatial affordances are in nudging me to track consistently and maintain healthy habits like exercising.

Another example of the effectiveness of spatial affordances is how my supplement intake and tracking were influenced by the physical placement of embodied reminders in my home. I initially set timed reminders on my phone and watch to take supplements, but they often interrupted my focus and became more of an annoyance than a helpful prompt and I found myself ignoring them.

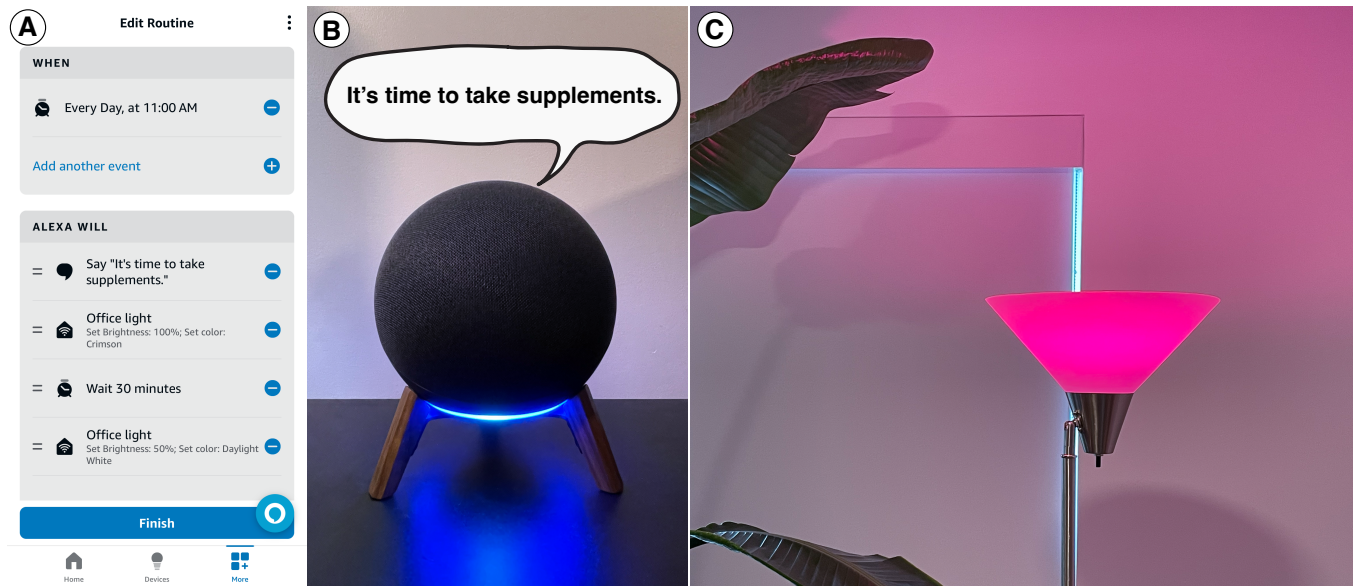


Figure 6: Smart home IoT Image (A) displays a screenshot of the Amazon Alexa app, which the first author used to set up a daily routine for supplement intake reminders. Every morning at 11 a.m., the Amazon Echo Dot (B) reminds her to take the supplement, and the floor light in her office changes to crimson (deep red color) for 30 minutes (C).

Then, in July 2024 when "my partner somehow got super interested in turning the house into the smart home," I sought a different approach. With my partner, we integrated an Amazon Echo Dot and a smart light to replace the digital notifications from my phone and watch. Now, every morning at 11 a.m., the Echo Dot verbally reminded me to take my supplements, and the floor light in my home office changed to a deep red color for 30 minutes. Figure 6 shows the setup. Having my partner involved in setting up this smart home system made my health journey feel less like a solo effort and more like a communal path toward better well-being in our household.

Unlike the digital reminders that I found intrusive, I had a different reaction to this smart home setup. Previously, managing my health within a busy schedule felt overwhelming, as I was striving to juggle work-life balance by handling everything on my own. The Echo dot, though just programmed, felt like a reliable butler at home—someone gently nudging me to stay healthy and making me feel cared for. Its consistency and reliability were reassuring, relieving me from having to constantly pay attention to dings and vibrations coming from my phone and watch. The ambient light was another valuable addition. Because it stayed on for 30 minutes, even if I was busy when it first lit up, I could still find time within that window to take my supplements. Its subtle presence kept me reminded in a non-intrusive way, and prompted me to think about delegating more tasks to my smart home setup. On August 1st, I wrote in my journal, "I think it's a shame that Alexa can't access my other healthcare apps and remind me of things to do. For instance, it could remind me to track my hormones on testing day," imagining a home that offers tracking assistance more dynamically, responding to my changing life and health needs.

5 Discussion

Our findings shed light on the first author's challenges and strategies for personalized holistic long-term tracking to manage PCOS. In this section, we first discuss the first author's final reflections on her tracking process to offer a more intimate and self-reflective perspective [63]. Then, we provide potential design implications for future health-tracking tools that support (1) integrating metabolic health beyond fertility, (2) granular data tracking, (3) flexible input modalities, and (4) data-driven behavior change in living spaces. While the design implications are initially derived from the first author's experiences, we complement them with prior research on PCOS and women's health to expand their reach. We present these implications as initial design proposals to serve as a foundation for further exploration and evaluation with a broader population of PCOS patients.

5.1 Final reflection: a journey of understanding and self-management of PCOS via tracking

Before, when I was not tracking my health, I often forgot about my period, ovulation, or PCOS symptoms unless they were particularly severe. This allowed me to channel my energy into other activities. Holistic, long-term tracking required me to consider many aspects of my life on a daily basis, which at times left me feeling mentally and emotionally exhausted. This aligns with prior work that while self-tracking can enhance awareness, it can be cognitively and emotionally burdensome [75, 104]. Section 5.4 discusses potential ways to ease the tracking process for managing PCOS.

Despite these challenges, tracking has deepened my understanding of my body. Having almost no prior knowledge about tracking ovulation or how hormones change throughout the menstrual cycle,

I found ovulation tracking, and especially hormone tracking, to be highly educational. Seeing my hormones on a graph felt like finally putting a face to PCOS, something I could not visualize before. This insight has convinced me of the value of tracking hormones as part of managing my condition. Section 5.2 discusses how this could benefit a broader group. Holistic tracking has also encouraged me to prioritize a more balanced, healthier lifestyle. By tracking various aspects of my health, I have developed a new perspective on the interconnection of sleep, nutrition, physical exercise, and mental well-being with my overall wellness, rather than viewing each aspect separately.

Reflecting on my experience, I wish I had the knowledge about my health and PCOS that I learned through tracking earlier in life, perhaps in my teens or early 20s. When I was diagnosed, I received very limited information about PCOS and did not know it was related to metabolic health. Understanding the link between PCOS, metabolic health, and insulin resistance would have significantly improved my condition management. For example, I had a period of eating sugary fruits, thinking they were healthy, but felt more fatigued and my symptoms worsened—likely due to elevated blood glucose, which I could have avoided with the knowledge I have now. My experience resonates with many other women with PCOS who get frustrated because of not being informed enough by medical providers [24, 30, 130].

Additionally, the data I have tracked has helped both my healthcare provider and me to ask more specific questions and adjust my treatment plan accordingly. Although my condition remains enigmatic and complex, this data has provided us with clearer insights, facilitated more informed conversations, and improved our decision-making process. My provider even asked me to upload the hormone graphs to the portal so she could review them in more detail later.

In summary, my experience with tracking has underscored both the challenges and benefits of long-term, personalized tracking for managing my PCOS. Despite the burden of tracking, the detailed data has enhanced my understanding of my condition and motivated me to keep self-experimenting by building hypotheses and testing as other heavy self-trackers do [21]. This highlights future opportunities to better support this process, which I discuss below. The design implications are summarized in Table 2.

5.2 Beyond fertility: integrate metabolic health for inclusive ovulation tracking

5.2.1 Expand the purpose of ovulation tracking. In section 4.1.1, we shared the challenges of using ovulation tracking tools with PCOS. Receiving conflicting ovulation predictions from different apps highlights the need to make ovulation tracking tools more inclusive, broadening their scope to support a wider audience, beyond people trying to conceive.

Examples of the focus on conception in ovulation apps include sending notifications to "make time for sex" during predicted ovulation (Femometer), and baby-themed packaging (Inito). These design choices could deter potential users (e.g., teenagers, PCOS patients, and women using birth control) who may wish to use these tracking tools to *understand their bodies and health*, instead of trying to conceive. Such users may perceive that these tools are solely intended

for individuals preparing for pregnancy and may not attempt to use them, and miss out on the educational benefits these tools offer. A more *inclusive design* could allow users to select their primary goal, with tailored designs based on their chosen focus.

For individuals using ovulation tracking tools for health monitoring, ovulation can be seen as an indicator of a woman's overall metabolic health, not just a means for conception. Factors such as diet, physical activity, and sleep all affect hormone levels, and metabolic dysfunction in PCOS can lead to chronic anovulation [29]. Even for women without PCOS, anovulation can happen due to high stress or an unbalanced diet [8]. When anovulation is detected, ovulation tracking apps that monitor other aspects of life (e.g., diet, sleep) can provide interventions to *pay attention to metabolic health*, such as diet. This way, anovulation could be viewed as an opportunity for intervention to improve metabolic health rather than a missed opportunity to conceive.

5.2.2 Be aware of false positive ovulation prediction. Anovulation is common in women with PCOS, as well as those taking oral contraceptive pills (many birth control pills prevent monthly ovulation but bleeding still happens [113]). By providing false positive ovulation predictions, regular anovulatory bleeding may mistakenly be perceived as a normal menstrual cycle. For PCOS patients, this may delay the initiation of treatment. Studies suggest that early treatment is essential to prevent the development of new comorbidities, such as diabetes, in PCOS patients [52]. A more inclusive tracking tool should therefore consider factors such as individuals' medical conditions and medication use in ovulation predictions, rather than assuming that all women ovulate. Ovulation tracking apps that are prone to high false positives could potentially inform users with medical conditions like PCOS about more accurate alternative tracking methods, such as hormone monitoring.

Providing uncertainty can also help users assess the reliability of the AI prediction. Assessing reliability is important, as research has shown that users tend to over-rely on AI assistance [12, 48]. Yet, one must consider the users' data literacy skills. For everyday users, studies suggest that presenting model confidence as a percentage (e.g., 70%) has a limited impact on user reliance on AI [13, 105]. Instead, presenting model confidence as a frequency (e.g., 70 out of 100 samples) helps users calibrate their trust in AI [147] and make better decisions [19]. Therefore, providing uncertainty in frequency may help the decision-making of PCOS patients.

5.3 Support granular data tracking

5.3.1 Granular reproductive hormones tracking. In section 4.1.2, we presented the challenges of interpreting the hormone charts in the Inito app, particularly when the data showed complicated or abnormal trends. At the same time, our findings suggest that *tracking hormones granularly offers significant benefits to finding an individualized treatment plan*. The first author's experience is just one example of the high variability of PCOS. PCOS has various subtypes, each characterized by different hormonal profiles, for instance, type I PCOS shows high androgen (male hormone) while type IV shows normal androgen levels but elevated levels of LH and a higher LH/FSH ratio [91]. Research suggests that treatment approaches should vary depending on the specific PCOS subtype [91]. These subtypes are not static and may evolve as women age [91].

Table 2: Summary of design implications

Section	Design Implication(s)
§ 5.2: Beyond fertility: integrating metabolic health for inclusive ovulation tracking	
§ 5.2.1	Consider supporting users' goals—whether for conception or general health—by adjusting design elements, such as minimizing baby-themed visuals for non-conception users. Additionally, consider using anovulation detection as an opportunity for metabolic health intervention rather than solely viewing it as a missed conception.
§ 5.2.2	Ovulation tracking designs could consider users' medical conditions, such as the use of birth control pills or PCOS, in ovulation predictions. Communicate the model's uncertainty to prevent over-reliance on potentially inaccurate predictions.
§ 5.3: Support granular data tracking	
§ 5.3.1	Menstruation tracking designs could consider supporting granular reproductive hormone tracking to enable personalized PCOS treatment by identifying evolving subtypes.
§ 5.3.2	Diet tracking designs for PCOS management could consider exploring the effect of continuous glucose monitoring and support culturally tailored diet monitoring by enabling users to customize the granularity of tracking, such as through manual input of ingredients, or adjusting image recognition technology.
§ 5.3.3	Future tracking designs could consider providing science-based sensemaking support for granular data interpretation in visualizations or natural language to help PCOS patients better understand complex health metrics, including abnormal patterns.
§ 5.4: Support flexible tracking modalities and data consolidation	
	Holistic and long-term tracking for PCOS could consider leveraging flexible voice input (e.g., voice agent) and natural language processing to streamline data consolidation and reduce manual effort in tracking for chronic condition, though balancing input flexibility with data quality remains essential.
§ 5.5: Towards data-driven behavior change in living spaces	
	For holistic and long-term PCOS management, voice agents integrated with smart home devices could leverage users' health data to deliver personalized, data-driven support for behavior change within living spaces. Yet, it is also important to consider environmental factors and address privacy concerns.

Similar to the first author's experience of better understanding her PCOS, providing access to detailed hormone data and long-term hormone changes can help PCOS patients and their healthcare providers understand which PCOS subtype they have and plan treatment accordingly. Furthermore, home tracking tools like Inito, which track key sex hormones (estrogen, LH, FSH, progesterone), can be empowering for PCOS patients by providing direct access to their health data without the need for frequent hospital visits.

5.3.2 Culturally-sensitive granular diet tracking. Section 4.2 demonstrated the impact of the first author's *cultural background* on diet tracking using food photography. She experienced difficulty communicating with a nutritionist who was unfamiliar with Korean food regarding her carbohydrate intake, and found it challenging to estimate portions given the shared nature of Korean dishes. *Image recognition systems should account for these cultural differences when calculating proportions and nutritional content.* In other situations, diets such as the ketogenic diet can alter the composition of seemingly identical foods; for example, a ketogenic green smoothie may include more oil, significantly increasing its caloric value. These nuanced differences are difficult to capture only using image-recognition based tracking. Users should be able to *adjust the results or train the AI model within the system to better*

fit their specific diet and cultural practices by using methods such as machine teaching [93]. While improving training datasets to better represent cultures and cuisines must be our ultimate goal, this could help users to make up for underrepresentation in model training datasets as a stopgap.

Another potential avenue to address shortcomings in cultural food image recognition, as well as sociocultural norms related to taking food photos (e.g., in situations where it might be impolite in South Korea), is more discreet and private tracking options. For example, *continuous glucose monitoring (CGM) devices may be used to supplement diet tracking, especially for PCOS patients with insulin resistance, to manage blood sugar levels.* Originally designed to manage diabetes, CGMs are now available over the counter in the U.S. for anyone over 18 who wants to track how diet and exercise affect blood sugar [39]. Research has shown that CGMs can improve the quality of life for people with diabetes [20, 146], but it is unclear how non-diabetic individuals use CGMs to manage their health. Food tracking apps like Veri [137] integrate CGMs with AI-enabled food image recognition and manual input for diet tracking. The manual input within the app allows users to adjust the results of image recognition when it fails to accurately capture cultural context. This supports more accurate diet logging within cultural contexts, while allowing users to see the immediate effects

of their diet on glucose levels, thus reducing the guesswork about whether their diet improves or worsens metabolic health. To further expand cultural sensitivity, diet tracking apps could consider going beyond nutritional value and calories by incorporating factors such as eating speed and cooking methods (e.g., raw, steamed, fried, fermented) that vary across cultures [9, 112, 118] and affect blood glucose [15, 98, 114].

5.3.3 Data interpretation support for granular data and abnormal patterns. The first author overcame challenges in making sense of detailed hormonal data by reading medical journals (section 4.1.2). Given her lack of medical knowledge, and the complex jargon in these publications, this process was time consuming and required high cognitive effort, resources that are not readily available to all PCOS patients. The implication is to *provide science-based yet comprehensive data sensemaking support within the tool*. While self-tracking can empower users by equipping them with valuable health insights [82], many self-trackers lack the data literacy to interpret metrics like correlations or variations [25]. To support such users, *visual data representations* could support data interpretation [25], accompanied by *guided sensemaking support* by explaining the meaning of numbers or identifying the correlations between different patterns [25, 67, 81].

Further, it is important to provide layperson explanations for PCOS patients who regularly experience *abnormal* patterns such as irregular periods or chronic anovulation. *One possible solution is large language models (LLMs) to deliver personalized, easy-to-understand interpretations of hormone data by translating medical jargon into simple language*. For example, a recent study found that LLM-supported data interpretation fostered more reflective engagement with step count than data visualization alone [123]. In the context of PCOS management, interpreting complex data, such as abnormal hormone levels and interdependent factors like glucose and androgen levels, presents greater challenges compared to simpler metrics like step count. This underscores the potential value of using LLMs to support interpretation and enhance reflection on intricate data. However, LLMs present challenges such as privacy concerns and hallucinations. To address these, methods like data anonymization should be implemented before using sensitive health data. Since previous research on LLM-supported data interpretation relied on one-time surveys [123], future studies are needed to explore the impact of LLM-supported data interpretation on the long-term management of chronic conditions like PCOS. One avenue is to explore how LLMs can uniquely provide emotional support together with data interpretation, potentially reducing emotional distress (e.g., sadness, frustration, disappointment) associated with the long-term management of PCOS [3, 22].

5.4 Support flexible tracking modalities and data consolidation

Section 4.3 described the first author's practice of using multiple devices to manage routine disruptions. For instance, she used a spreadsheet to supplement her smartwatch while jet-lagged from traveling and the smartwatch voice memos to log supplements when her phone was left at the office. This aligns with prior findings that people rely on multiple devices for brief, real-time recording as a placeholder before entering detailed information later [115].

This calls for the implication to offer *flexibility in input modalities for tracking* given dynamic life events and routine interruptions.

However, the first author found that the manual consolidation of the data collected in various input modalities in the spreadsheet led to data inconsistencies, disorganization, and sparsity (section 4.4). *A system that automatically consolidates the data on behalf of users would significantly reduce this burden*. One potential solution is to use voice input for recording data, and then apply natural language processing (NLP) to extract the data to be inputted into the self-tracking application. Luo et al. demonstrated this with specific keywords for easier information extraction [84], and future work could explore unstructured natural speech for greater flexibility.

Voice input can also be in the form of voice agents, found useful in monitoring health for older adults [31, 145], and future research could explore *voice agents for tracking and managing chronic conditions like PCOS* [14]. Older adults and PCOS patients differ in health needs and interaction preferences [150]. Therefore, future work could explore the unique needs of PCOS patients for voice agents and how their usage patterns differ compared to older adults.

5.5 Towards data-driven behavior change in living spaces

In section 4.5, we discussed how the first author identified the connection between tracking and behavior change, emphasizing how physical cues can aid in the tracking process. This observation aligns with personal health informatics literature, which highlights that acting (e.g., behavior change) is an integral component of tracking [37]. Building on the idea of flexible tracking and data consolidation with a voice agent mentioned in section 5.4, we envision a future where voice agents are integrated with smart home devices. These devices could provide data-driven, proactive nudges based on consolidated health data, fostering consistent tracking and behavior change.

For instance, in the Amazon Alexa app used by the first author, users must manually set routines, which remain static and do not adapt based on user data. If the voice agent had access to users' tracking data, it could offer dynamic support such as reminding users about unfinished tasks, nudging them to exercise, or adjusting lighting to promote better sleep, aligning with their health goals. Yet, off-the-shelf smart home devices often do not fulfill diverse user needs, leading users to adopt do-it-yourself (DIY) approaches [70]. For individualized conditions like PCOS, DIY kits (e.g., detachable sensors) could help customize home spaces to support their personalized tracking and behavioral change. While prior research examined the user experience of customizing smart home devices [70, 143], these customizations were not intended for healthcare purposes. Future studies could investigate how PCOS patients customize their smart home devices with health-related goals in mind.

While it presents an opportunity, environmental factors, such as whether the voice agent is placed in a private or public area of the home where guests may have access, may influence the usage of the AI agent [34, 103]. Furthermore, contextual factors like family members' health needs or their prioritized use cases for the AI agent [74, 122], as well as privacy concerns regarding the use of smart home devices [72], should be carefully considered.

6 Limitation and future work

We acknowledge the inherent limitations of using autoethnography, as it may not fully capture the diverse experiences and challenges faced by others who have PCOS. Additionally, the first author's use of specific technologies and tools does not represent all tracking tools available. Moreover, the design implications proposed in this study may not universally apply to all PCOS patients. To address this, future research should involve more people with PCOS and diverse tracking tools, employing methods such as participatory design [111] to offer a more comprehensive understanding of inclusive tracking technologies. Furthermore, future work could expand the scope of this autoethnography beyond a single-person narrative. Incorporating approaches such as group autoethnography [71, 85] could offer diverse perspectives from different researchers with PCOS and more insights on community support. Lastly, the first author's socioeconomic and cultural backgrounds—having received higher education, access to medical care, academic resources, and expertise in designing technologies—may not reflect the experience of PCOS patients from other socioeconomic backgrounds. In many developing countries, women who menstruate may still rely on traditional paper or notebooks to journal their menstruation rather than digital technology, as they may lack access to resources such as smartphones, laptops, or wearable devices [5, 90]. Additionally, the first author's cultural background in South Korea does not represent all the challenges that may arise from different cultural norms. Future work should investigate PCOS patients from diverse cultural backgrounds to design more inclusive technology.

Despite its limitations, our study demonstrates the value and richness of first-person accounts of personalized, holistic, long-term tracking to manage PCOS, offering novel insights for designing more inclusive technologies. We hope our work can help other women with PCOS in choosing the right tools and managing their health. Additionally, we hope it provides the medical community with insights into the challenges of managing PCOS from a patient's perspective. Lastly, we hope our work informs the HCI community in designing more inclusive tools that support women with PCOS, while considering the complexities and challenges of long-term holistic tracking in their designs.

7 Conclusion

In conclusion, this autoethnographic study, conducted over ten months by the first author, highlights the complexities of holistic long-term self-tracking for managing PCOS. We identified significant challenges across medical, socio-cultural, temporal, technical, and spatial dimensions. Specifically, medical tools designed primarily for fertility often lead to misinterpretations for those with PCOS, while socio-cultural differences complicate diet tracking. Temporal disruptions such as travel introduce further difficulties in tracking, while flexible yet fragmented tracking methods create technical and organizational hurdles. Additionally, spatial challenges in maintaining a consistent tracking routine were observed.

Drawing from these insights, we propose several design implications for more inclusive and sustainable tracking tools. These include expanding beyond fertility tracking to incorporate metabolic health, offering more granular tracking, supporting flexible tracking modalities and data consolidation, and promoting data-driven

behavior change in living spaces. Addressing these challenges can lead to more inclusive and accessible tools for individuals managing complex chronic conditions like PCOS.

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A List of tracked categories, variables and tools

Category	Sub category	variable(s)	data type	Tracking tools	Added date
PCOS symptoms	Acne	1 Acne	binary (0: no, 1: yes)	Google Sheets	11/6/2023
		2 New	binary (0: no, 1: yes)	Google Sheets	11/6/2023
		3 Qualitative data	text	Google Sheets	11/18/2023
		4 Total number of acne	numeric	Google Sheets	11/23/2023
		5 Forhead	numeric, image	Google Sheets, Camera app	11/23/2023
		6 Right cheek	numeric, image	Google Sheets, Camera app	11/23/2023
		7 Right chin	numeric, image	Google Sheets, Camera app	11/23/2023
		8 Left cheek	numeric, image	Google Sheets, Camera app	11/23/2023
		9 Left chin	numeric, image	Google Sheets, Camera app	11/23/2023
	Mood	10 Mood	Likert-scale (1:Extremely bad, 5: Extremely good)	Google Sheets	11/6/2023
		11 Mood reason	text	Google Sheets	11/6/2023
		12 Stress level	Likert-scale (1:Extremely low, 5: Extremely high)	Google Sheets	1/22/2024
		13 Stress reason	text	Google Sheets	1/22/2024
		14 Thank you diary	text	Google Sheets	1/22/2024
	Ovulation	15 Journaling	text	Google Sheets	03/06/2024
		16 Basal body temperature	numeric	Notes, Femometer app	02/15/2024, 06/01/2024
		17 Ovulation	numeric	Clue app	06/01/2024
		18 Hormones (E3G, LH, PdG, FSH)	numeric	Inito app	06/22/2024
Menstrual cycle	Periods	1 Quantiative	binary (0: no, 1: yes)	Google Sheets	11/6/2023
		2 Amount	text, image	Google Sheets, Camera app	11/6/2023
		3 Amount scale	Likert-scale (1:Extremely low, 5: Extremely high)	Google Sheets	11/6/2023
		4 Texture	text	Google Sheets	11/6/2023
		5 Discharge	text	Google Sheets	11/6/2023
Diet	Food	1 Breakfast	time, text, image	Google Sheets, Camera app	11/6/2023
		2 Lunch	time, text, image	Google Sheets, Camera app	11/6/2023
		3 Dinner	time, text, image	Google Sheets, Camera app	11/6/2023
		4 Snack	time, text, image	Google Sheets, Camera app	11/6/2023
	Beverage	5 Tea/Juice	text	Google Sheets	7/7/2024
	Carbohydrate	6 Sources and amount	text, numeric	Google Sheets	7/11/2024
		7 Sources and amount	text, numeric	Google Sheets	7/11/2024
		8 Sources and amount	text, numeric	Google Sheets	7/11/2024
Weight		1 Weight	numeric	Digital scale, FITINDEX app	11/6/2023
		2 BMI	numeric	Digital scale, FITINDEX app	6/23/2023
Physical activity	Activities	1 Step count	numeric	Apple watch	11/6/2023
		2 Move	numeric	Apple watch	11/6/2023
		3 Stand	numeric	Apple watch	11/6/2023
	All workout	4 Workout type	categorical data	Apple watch	11/6/2023
		5 Workout hours	numeric	Apple watch	11/6/2023
		6 Heart rate	numeric	Apple watch	11/6/2023
	Weight training	7 Type of exercise	categorical data	Strong app	11/6/2023
		8 Repetitions	numeric	Strong app	11/6/2023
		9 Lbs	numeric	Strong app	11/6/2023
Supplements		1 Brand	text	Google Sheets	1/16/2024
		2 Ingrdient	text	Google Sheets	1/16/2024
		3 Amount	numeric	Google Sheets	1/16/2024
		4 Serving	numeric	Google Sheets	1/16/2024
Sleep		1 Awake hours	numeric	Apple watch	1/16/2024
		2 REM sleep hours	numeric	Apple watch	1/16/2024
		3 Core sleep hours	numeric	Apple watch	1/16/2024
		4 Deep sleep hours	numeric	Apple watch	1/16/2024
		5 Sleep note	text	Google Sheets	2/10/2024
Hypothesis		1 Hypothesis	text	Google Sheets	6/21/2024
		2 Questions	text	Google Sheets	6/21/2024
Others		1 Sleepiness	text	Google Sheets	11/6/2023
		2 Fatigue	text	Google Sheets	11/6/2023