MigraineTracker: Examining Patient Experiences with Goal-Directed Self-Tracking for a Chronic Health Condition

Yasaman S. Sefidgar
einsian@cs.washington.edu
University of Washington
Seattle, Washington, USA

Carla L. Castillo
carla23@uw.edu
University of Washington
Seattle, Washington, USA

Shaan Chopra
schopra7@cs.washington.edu
University of Washington
Seattle, Washington, USA

Liwei Jiang
lwjiang@cs.washington.edu
University of Washington
Seattle, Washington, USA

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

Anant Mittal
anmittal@cs.washington.edu
University of Washington
Seattle, Washington, USA

Hyeyoung Ryu
hyryu115@uw.edu
University of Washington
Seattle, Washington, USA

Jessica Schroeder
jesscs@cs.washington.edu
University of Washington
Seattle, Washington, USA

Allison Cole
acole2@uw.edu
University of Washington
Seattle, Washington, USA

Natalia Murinova
nataliam@uw.edu
UW Headache Clinic
Seattle, Washington, USA

Sean A. Munson
smunson@uw.edu
University of Washington
Seattle, Washington, USA

James Fogarty
jfogarty@cs.washington.edu
University of Washington
Seattle, Washington, USA

ABSTRACT

Self-tracking and personal informatics offer important potential in chronic condition management, but such potential is often undermined by difficulty in aligning self-tracking tools to an individual's goals. Informed by prior proposals of goal-directed tracking, we designed and developed MigraineTracker, a prototype app that emphasizes explicit expression of goals for migraine-related self-tracking. We then examined migraine patient experiences in a deployment study for an average of 12+ months, including a total of 50 interview sessions with 10 patients working with 3 different clinicians. Patients were able to express multiple types of goals, evolve their goals over time, align tracking to their goals, personalize their tracking, reflect in the context of their goals, and gain insights that enabled understanding, communication, and action. We discuss how these results highlight the importance of accounting for distinct and concurrent goals in personal informatics together with implications for the design of future goal-directed personal informatics tools.

CCS CONCEPTS

• **Human-centered computing → Human computer interaction (HCI)**; **Interactive systems and tools**; **Empirical studies in HCI**.

CHI '24, May 11–16, 2024, Honolulu, HI, USA

ACM ISBN 979-8-4007-0330-0/24/05
https://doi.org/10.1145/3613904.3642075

KEYWORDS

Goal-Directed Tracking, Long-Term Tracking, Goal Evolution, Self-Tracking, Chronic Conditions, Personal Informatics, Migraine

ACM Reference Format:
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 CHI Conference on Human Factors in Computing Systems (CHI '24), May 11–16, 2024, Honolulu, HI, USA.* ACM, New York, NY, USA, 19 pages. https://doi.org/10.1145/3613904.3642075

1 INTRODUCTION

Management of chronic conditions often involves examining one's health and making adjustments in behavior or treatment [29], commonly based on measures of symptoms, contributors, or treatments. Self-tracking of such measures is thus common in managing conditions such as migraine [56], where intermittent symptoms over time limit utility of clinical testing. However, self-tracking for chronic conditions like migraine is challenging, in part because existing tools embed assumptions about what people want to gain from tracking (i.e., their *goals* for tracking [63]). Deciding what to track, adjusting tracking over time, and using tracked data is thus poorly supported [65]. This gap in tracking support is particularly problematic given high idiosyncrasies among migraine patients and the complexity of potential contributors [63]. Schroeder et al. [65] thus proposed *goal-directed self-tracking* as a framework to address this gap. They suggested that designs centered around an individual's goals can support tracking *exactly* and *only* the data that individual needs. More concretely, tools designed within this framework aim to elicit goals and scaffold a process of defining *what*, *when*, and *how* to track toward those goals. Goal-directed tools can also use knowledge of individual goals in determining what data to present and how to better facilitate interpretation. In their work, Schroeder et al. [65] offered evidence that this approach improved preparation for tracking. However, they were unable to examine if the improvements extended to data collection, reflection, and action.

We designed and developed the *MigraineTracker* app to understand the lived experience of goal-directed self-tracking and to examine whether and how tracking routines configured within a goal-directed tool can support patients in managing their migraines across stages of tracking [24, 43]. Our study engaged 10 patients, each working with a clinician and using the app for average of 12+ months, totalling 50 interview sessions. We contribute the following:

- We demonstrate goal-directed data collection and reflection supports patients in (1) deciding what to track and how to align their tracking to their needs, (2) obtaining relevant and useful knowledge from tracking, (3) recognizing when and how to adjust their tracking, (4) feeling prepared to discuss their care with their clinicians, and (5) seeking expertise where they most need it.
- We provide evidence that goal-directed tracking led patients to further understand their condition and to feel they were better caring for themselves.
- We highlight the need for adapting personal informatics models to consider distinct and concurrent goals that are each at a different stage of tracking. We also articulate distinctions and relations among goals as an analytical lens for understanding needs and challenges in long-term self-tracking of chronic conditions.

We next position our research within health tracking literature (Section 2), present our design of MigraineTracker (Section 3), and describe our deployment study and analysis (Section 4). We then share key observations around goals, their evolution, and the benefits of goal expressions for patients (Section 5). We conclude by discussing implications for future research in personal informatics and the design of self-tracking tools (Section 6).

2 BACKGROUND AND RELATED WORK

We first review related work on self-tracking and self-tracking tools, focusing on chronic condition management. We also highlight key requirements along with existing challenges and how our work aims to address them. We then introduce background on personal informatics models that we draw upon to understand experiences with goal-directed self-tracking, and on migraine and the needs it poses for self-tracking.

2.1 Self-Tracking for Chronic Conditions

Self-tracking has long been considered as a strategy to improve care and self-management of chronic health conditions [18, 29, 45]. Research has examined self-tracking for conditions with relatively well-understood symptom-contributor relations (e.g., asthma [34], diabetes [15, 25, 37, 45, 46, 58], hypertension [8, 28, 32]), conditions with enigmatic and intermittent symptoms (e.g., irritable bowel syndrome [35, 64], migraine [63, 65], multiple sclerosis [3, 69], polycystic ovary syndrome [12]), or progressive conditions (e.g., Parkinson's disease[50]). Such research has shown self-tracking can improve care and self-management through identifying factors which contribute to symptoms [35, 36, 64], control of symptoms [3, 69], and more effective collaboration with clinicians [13, 49].

Prior research suggests key features for self-tracking tools to support, including goal expression [9, 54], guided and collaborative reflection [9, 18], customization [9, 18, 31, 55], and continuous learning [18, 54]. In their absence, self-tracking tools may nudge people toward unwanted behaviors (e.g., an emphasis on calorie tracking promoting unhealthy eating [17]) and restrict data exploration and reflection [9, 10]. Tools may also promote unsustainably burdensome tracking routines [52] and undirected data representations that overwhelm people without answering their questions [38]. A struggle to find value in self-tracking [11] can in turn lead to abandonment [16, 23, 42].

Despite calls for supporting goal expression, particularly for qualitative and subjective goals [23, 54], it remains uncommon in current tools [9]. A notable exception is Schroeder et al. [65]'s goal-directed self-tracking framework, which proposes designs where explicit goal expressions drive *what*, *when*, and *how* an individual tracks. The framework aims to enable custom data collection and a need for goal evolution, which is integral to long-term tracking [54]. Although prior research has focused on increasing the amount or diversity of data people can collect (e.g., [40]), flexible tracking is not by itself sufficient when people are unable to connect data to their core needs [38, 54]. Goal-directed self-tracking therefore combines flexible tracking with a principle of reduction and focus [52] to emphasize tracking *exactly* and *only* data supporting an individual's goals. Our work realizes this framework in MigraineTracker and examines its speculations in a field deployment.

2.2 Models of Personal Informatics

Personal informatics models provide a lens for designing self-tracking tools and for understanding people's experiences. We applied both Li et al. [43]'s stage-based model and Epstein et al. [24]'s lived informatics model in designing MigraineTracker. The former characterizes distinct stages of preparation, collection, integration, reflection, and action, highlighting how later stages depend on earlier stages. The latter additionally highlights lapsing and resumption in everyday experiences with tracking [60], which is particularly important in long-term tracking as with chronic conditions. We also considered recommendations stipulated by Niess and Woźniak [54]'s Tracker Goal Evolution Model, which contextualizes goals within the lived informatics model. It highlights that needs (e.g., 'feeling well') manifest in qualitative goals (e.g., 'losing weight') which are translated into quantitative goals (e.g., 'taking 12K steps'). These quantitative goals can be linked to data in self-tracking tools (e.g., 'step counts'). The model thus highlights the importance of considering qualitative goals and supporting their translation into quantitative goals as part of meaningful long-term engagement with tracking.

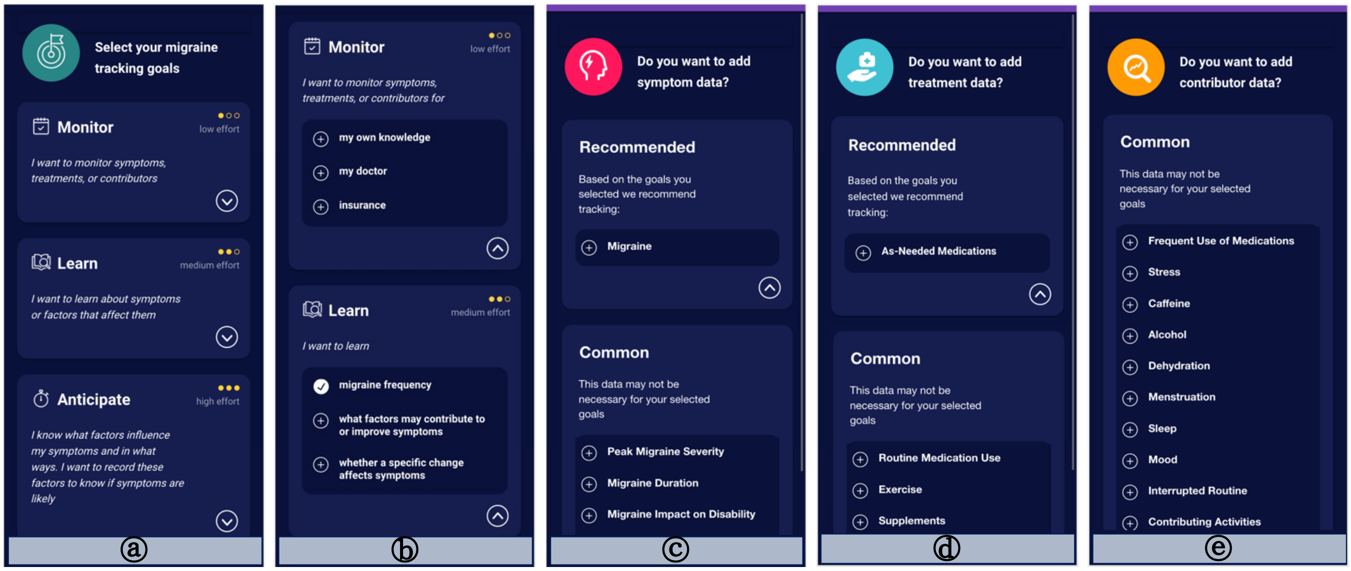

Figure 1: MigraineTracker configuration. (a) Individuals can express goals in three categories: monitoring, learning, and anticipation. (b) There are sub-goals under each category. For example, monitoring for 'my own knowledge' or 'my doctor' and learning about 'migraine frequency' or 'what factors may contribute to or improve symptoms'. Recommended tracking items based on an individual's configured goals (e.g., learning about migraine frequency) appear under categories of (c) symptoms, (d) treatments, or (e) contributors.

2.3 Migraine as a Context for Examining Goal-Directed Self-Tracking

Migraine is a debilitating chronic condition that can result in reduced quality of life [67], occupational impairment [47], constrained social and family functioning [66], economic burden [26], and diminished emotional health [19]. There is high idiosyncrasy in migraine symptoms [56], which are often simultaneously affected by multiple and accumulating factors [39]. Managing migraine relies on medication and behavior changes to limit contributing factors and to encourage preventive and abortive measures [20]. However, there is high variability in response to medication [48] or behavior change [2]. These characteristics make self-tracking particularly useful for managing migraines [63].

Despite the potential, self-tracking in migraine is challenging as current tools are generally not well-aligned with an individual's evolving needs. Tools commonly force individuals to record irrelevant information or fail to support recording needed information. Individuals therefore struggle in preparing or in adjusting what they track and often fail to obtain useful information [63]. Addressing these challenges, Schroeder et al. [65] proposed goal-directed self-tracking, a design framework wherein explicit scaffolding for goal expression guides individuals to (1) track *exactly* and *only* the data they need and to (2) review data in the context of goals. Examining this approach with a paper prototype, they found improved tracking preparation and anticipated benefits for all stages of self-tracking. We expand this work with a functional prototype to examine whether and how goal expressions facilitate data collection, reflection, and action.

3 MIGRAINETRACKER SYSTEM

We built upon the formative work of Schroeder et al. [63, 65] to design and develop MigraineTracker in a user-centered design process. Design was iterative and involved cycles of paper prototyping, development, feedback from the research team (e.g., co-authors with lived experience and/or clinical expertise in migraine), and revision. There are three major components to MigraineTracker: configuration (Figure 1 and 2), data entry (Figure 3), and data review (Figure 4). Configuration is available at the onset of tracking and is modifiable afterwards. Data entry is defined by configuration and provides the interface individuals regularly use to record information. Review is available as a calendar visualization within the app and is complemented by more sophisticated summaries and visualizations outside the app. We provide additional details on each component below.

3.1 Tracking Configuration

Goals are at the center of MigraineTracker configuration. As such, configuration starts with *goal expression* through selecting goals from three categories: monitoring, learning, and anticipation (Figure 1, a-b). Next is constructing a *tracking routine* (i.e., selecting *what* and *how* to track) in three categories: symptoms, treatments, and contributors (Figure 1, c-e). Items are recommended based on an individual's selected goals. There are also common items that may or may not be relevant to an individual. These items are separately listed to discourage tracking more than necessary. Custom items allow recording information that does not appear in the 'Recommended' or 'Common' lists. For example, MigraineTracker recommends recording 'Migraine' when

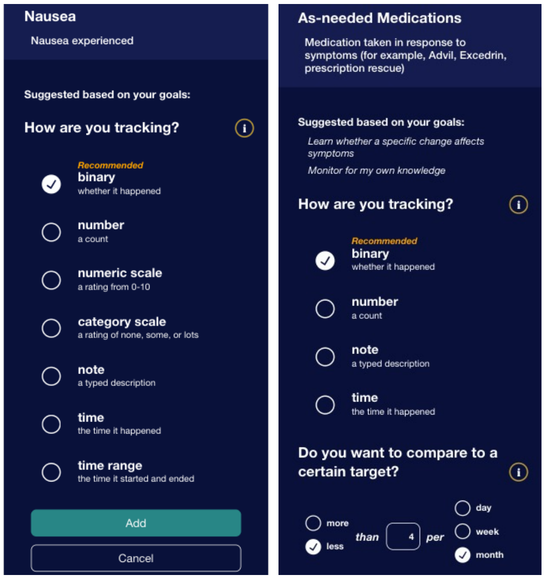

Figure 2: MigraineTracker configuration of tracking routine. The left shows nausea can be recorded in a number of ways. For example, whether it happened (binary) or its level (category scale). The right illustrates setting targets for as-needed medication (a count of less than four per month).

an individual has a goal of learning about migraine frequency. It is also possible to record 'Peak Migraine Severity', which is commonly considered along with frequency. After selecting what to track, an individual decides *how* to record each selected item. For example, if they choose to record nausea, they can decide to record whether they experienced nausea or they can rate the levels of their nausea (Figure 2, left). There are recommendations for such data types based on an individual's goals. An individual configuring treatment and contributor items can also specify targets to get indications of behaviors relative to the targets. For example, setting a target for the dosage of as-needed medication (Figure 2, right) provides an indication of status relative to the target (Figure 3, b).

Configuration also supports reminders. The app offers up to two daily reminders and/or followup reminders. Followup reminders alert within a specified period of time (e.g., a day later), allowing individuals to initially report symptoms and then fill in other details at a later time when they have recovered.

3.2 Data Entry

With a configuration in place, individuals can record data for their selected items. Certain items (e.g., 'Migraine') appear on the landing page for quick entry (Figure 3, a). Others are listed by category (e.g., symptoms, treatments, contributors) so an individual can navigate to them as needed (Figure 3, c-d). MigraineTracker provides a per day data model where information is recorded against each calendar date. Although it is possible to support semi-automated tracking within the app, the version used in our study only supported manual entry. MigraineTracker also

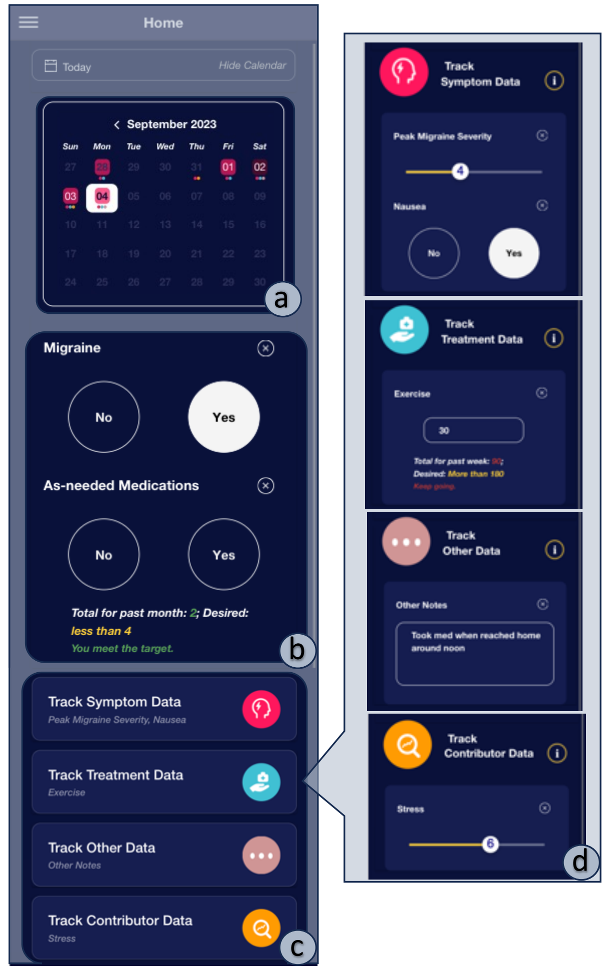

Figure 3: MigraineTracker data entry and review. (a) Calendar view with migraine days in bright pink and days with other symptoms in dark purple. Colored dots indicate tracking of information from that category. (b) Quick tracking items appear on the landing page, including their status relative to relevant targets (e.g., for as-needed medication). (c) Tracking items are organized under categories for symptoms, treatments, contributors, and other. (d) Opening a category presents configured tracking items.

offers a lapsing feature which pauses all notifications (e.g., for a vacation) with a configurable reminder to resume tracking at a specified date.

3.3 Data Review

A landing page calendar provides a simple view of tracked data (Figure 3, a). Migraine days appear with a bright pink background (e.g., Sep 03 in Figure 3, a), whereas days with other symptoms have a dark purple background (e.g., Sep 02 in Figure 3, a). Small colored dots indicate information has been tracked within a category. For example, a light orange dot indicates information was recorded under the 'Contributor' category (e.g., Aug 31 in Figure 3, a). The research team also prepared static data summaries and visualizations, personalized according to each participant's tracking goals and preferences (Figure 4), as needed throughout the study (e.g., when patients were meeting with the research team, when patients requested them for appointments with clinicians). These were not available at other times. We opted for this approach to enable iterative and exploratory preparation of a set of goal-based visualizations, which was not feasible within the app.

4 DEPLOYMENT STUDY

We used MigraineTracker as a technology probe [33] in a deployment study to examine the lived experience of self-tracking with tools designed according to a goal-directed framework. This study builds on Schroeder et al. [65]'s investigation of whether patients can successfully use a tracking tool explicitly configured for their goals and further examines needs and considerations in designing goal-directed self-tracking tools for different stages of tracking [24, 43]. Examining goal-directed informatics in the context of migraine, our primary research questions are:

RQ1 How does tracking based in explicit expression of goals support patients in managing their migraine?

RQ2 How do patient goals and tracking change as they use MigraineTracker over time?

4.1 Recruitment and Participants

We advertised the study to migraine patients on mailing lists and via flyers, then reached out to their clinicians to join the study. If a patient's clinician was unavailable for the study, we offered to match the patient to a clinician already participating in the study. We also separately recruited clinicians through clinical collaborators and asked them to refer patients to the study. This approach of reaching clinicians through patients and vice versa increased our chances of recruitment during the pandemic. We asked clinicians to refer patients who experience migraine. Although we did not require a formal diagnosis of migraine, we also did not recruit patients who had a different specific diagnosis (e.g., cluster headaches). Patients who enrolled without clinician referral self-identified as experiencing migraines. Patients were in the United States, over 18 years old, and owned an Android or iOS phone to run MigraineTracker. Both headache specialists and primary care physicians were recruited, as both commonly work with migraine patients and not all patients have access to specialty care.

We initially recruited 17 migraine patients and five clinicians, of which 10 patients (eight women) and three clinicians (all women) completed the study (Table 1). We removed four patients we identified as inauthentic, an increasingly common challenge in remote research [59]. Three patients left the study after the initial interview and before starting tracking: one because their clinician did not join the study and two because their schedules changed. Two clinicians withdrew due to the demands of the ongoing pandemic. We observed both established patient-clinician pairs (9 pairs) and a newly formed pair. All participants were new to MigraineTracker (i.e., they had not participated in prior activities that informed the design of MigraineTracker).

Table 1: Patient demographics and length of study tracking. Gender was self-reported, consistent with recommended practices [62]. Length of study tracking is from the day they configured the app to their final day of recording. Patients either worked with their own clinician ('Y' under 'Established?') or a clinician they were matched with for the study. PR01 and PR02 were headache specialists and PR03 was a primary care clinician.

	Age	Self-Reported Gender	Study Tracking Days	Clinician	Established?
PT01	49-64	Woman	420	PR02	Yes
PT02	34-48	Woman	471	PR02	Yes
PT03	34-48	Woman	422	PR01	Yes
PT04	34-48	Man	420	PR01	Yes
PT05	18-33	Man	355	PR03	No
PT06	18-33	Woman	373	PR01	Yes
PT07	34-48	Woman	398	PR02	Yes
PT08	18-33	Woman	269	PR02	Yes
PT09	18-33	Woman	367	PR01	Yes
PT10	49-64	Woman	335	PR02	Yes

4.2 Procedure

Figure 5 provides an overview of our study protocol. After screening for inclusion, we interviewed patients about their self-tracking needs and prior experiences. We also introduced patients to goal-directed self-tracking and installed MigraineTracker on their phones. After demonstrating its basic functionality and use, we asked patients to think aloud as they configured their tracking routine.

After configuring the app, patients started tracking. After an average of two and half months of tracking (range: 27-153 days), they met their clinician, discussed their tracking setup, and made modifications if desired. This process ensured both patient and clinician goals were considered in tracking. In preparation for this session and to ease patient-clinician interactions, we briefly presented MigraineTracker to clinicians and created summaries of each patient's tracking setup. We were also available to answer questions as we observed these interactions. We did not, however, provide any formal training or guidance to patients or clinicians, in order to avoid overly influencing study results. We asked patients to track consistent with their goals and informed them if their tracking was inconsistent (e.g., if they had configured goals that required everyday tracking but only tracked when having symptoms). We documented these incidents as probe-surfaced needs and requirements for future support.

We met with each patient twice after their setup review with the clinician. The first meeting, a mid tracking interview, was scheduled an average of three months after the setup review (range: 46-144 days), when patients had collected a reasonable amount of data with respect to their goals. The second meeting, an end of tracking interview, was scheduled before a second meeting with the clinician. The main purpose of these sessions was to learn about patient day-to-day tracking experiences and any changes they made in their tracking. We also obtained feedback on goal-appropriate summaries and visualizations we had prepared based on patient and clinician comments in earlier sessions. This material was not available at other times unless patients requested it (e.g., for clinical

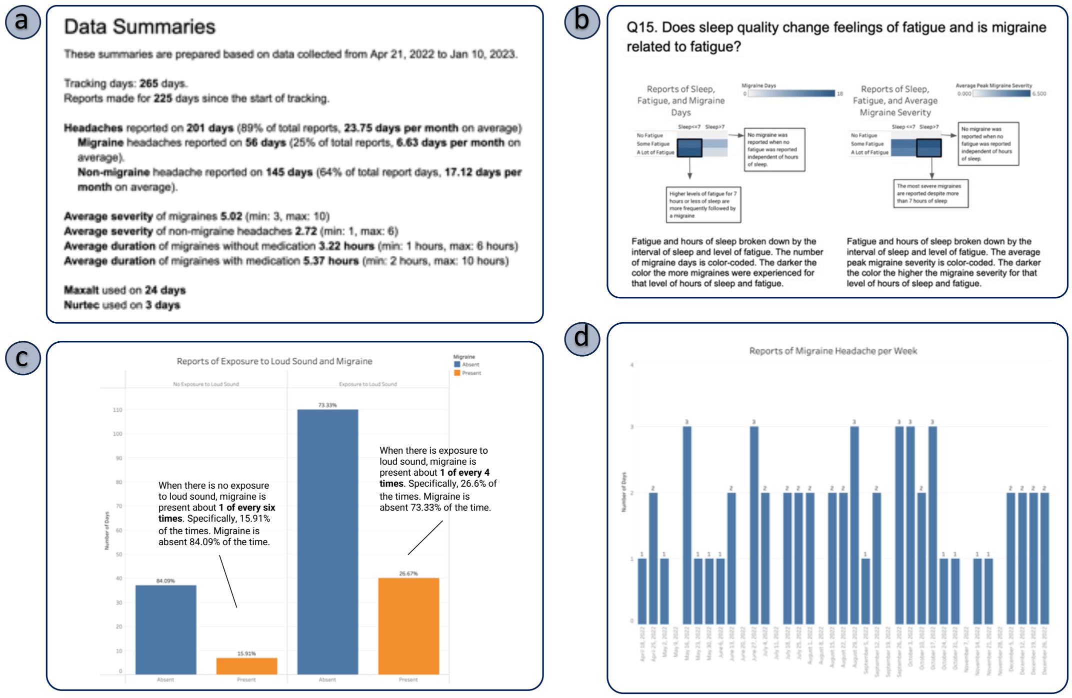

Figure 4: PT06's (a) data summary and sample visualizations: (b) inter-relations of sleep, fatigue, and migraine based on the occurrence and severity of migraines at different levels of fatigue and sleep, (c) frequency of the presence and absence of migraines with vs. without exposure to loud sound, (d) number of migraine days per week over time. Summaries and visualizations were separately prepared for each patient as needed throughout the study (e.g., when patients met with the research team or their clinician).

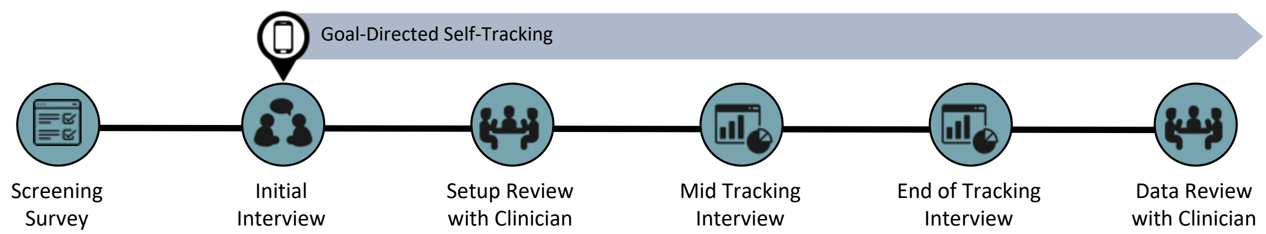

Figure 5: Plan for longitudinal study of migraine. We recruited patients who met the recruitment criteria in their screening responses. We learned about their needs and self-tracking experience in the initial interview and helped them configure MigraineTracker. Patients next reviewed their setup with their clinician. We learned about patient experience using the app in mid tracking and end of tracking sessions and obtained their feedback on goal-appropriate data summaries and visualizations. Patients then met with their clinician to review their data and material. Patients recorded information using MigraineTracker as soon as configuring it. Some patients continued tracking even after the second meeting with the clinician which concluded their participation.

visits outside the study). Following the end of tracking interview, each patient met their clinician to review goal-appropriate material, interpret patient-generated data, and make decisions about patient care. We conducted a short follow-up interview with clinicians after each session with a patient. Patients and clinicians reviewed materials in the same static formats used in mid tracking and end of tracking sessions, sometimes updated according to patient feedback from those sessions.

Patients completed weekly check-in surveys throughout tracking to report their self-tracking experiences, difficulties, care status (e.g., any scheduled appointments with their clinician), and changes in their tracking goals or routine. We addressed any critical usability issues that were raised in these reports. In addition to weekly surveys, patients completed surveys about their experience each time they met with the clinician as a part of the study. If patients requested their data for a non-study visit with their clinician, we followed up on their experience during that clinical visit.

Patient tracking data was continuously synchronized to our database with daily backups. We shared an exported copy of the data with each patient at the end of the study. We could directly access and review data to prepare study material and to help with any technical difficulties. Our analysis and presentation of patient data was performed in collaboration with patients and according to their goals for that data.

We performed most initial interview sessions remotely due to pandemic constraints. We were later able to conduct most mid tracking and end of tracking sessions in-person while adhering to safety protocols. All meetings involving clinicians were in-person and subject to the same safety protocols. In-person patient sessions occurred on our university campus to ensure these feedback sessions were distinguished from clinical practice. Patient-clinician sessions generally occurred in the same clinic that a patient and their clinician typically met. This increased external validity and simplified logistics for patients and clinicians.

The initial, mid tracking, and end of tracking interviews took an average of about 90 minutes. Setup review and data review sessions lasted for an average of about 45 and 60 minutes respectively. We compensated patients at a rate of $10 for each 10 minutes of their time in sessions with the research team or their clinician. Patients also received $5 for each weekly survey they completed and $10 for responding to surveys after meeting their clinician. Clinicians were compensated at the rate of $20 for each 10 minutes of their time, unless they chose not to be compensated. This study was reviewed and approved by our institutional review board.

4.3 Analysis

We analyzed data in multiple ways for different needs of the study. Early sessions (i.e., initial interview, setup review with clinicians, mid tracking interview) were analyzed to prepare for later sessions (particularly the end of tracking interview). For example, we analyzed the initial interview to understand patient goals and the mid tracking interview to understand whether and how patient goals evolved. The research team regularly met and discussed observations and our interpretations in preparing for upcoming sessions. At the conclusion of the study, we used interview transcripts, session notes, survey responses, tracking setup, and tracking data to summarize patient experiences in vignettes. Vignettes provided an overview of key observations in each patient's experience and familiarized the entire research team with each patient across study sessions. Lastly, we performed reflexive thematic analysis [6, 7], focused on the end of tracking interviews, to develop themes around patient experiences with goal-directed tracking. We decided to focus on end of tracking interview sessions for formal analysis as these provided the most comprehensive account of patient experiences, and the protocol for each end of tracking interview was informed by our analysis of multiple earlier sessions. In this process, we drew on our expectations and questions as personal informatics researchers and on our positions as designers of MigraineTracker within the goal-directed self-tracking framework. The first and second authors used a combination of inductive and deductive coding to analyze end of tracking sessions. Deductive coding was informed by models of personal informatics (e.g., stages of tracking) and the goal-directed tracking framework (e.g., goal-centered configuration, goal evolution). Inductive coding occurred iteratively as we constructed new themes. Although we focused coding on the end of tracking interviews, the first and second authors referred to other sessions, survey responses, and tracking data as needed to support further understanding or provide key details. The first and second authors double-coded four of the 10 sessions, compared analysis, and discussed themes throughout analysis. Each wrote memos as they reviewed data. The research team developed inductive codes through the coding process as well as discussions and memos about key observations. Initial themes were based on patterns in the data (e.g., 'new or refined goals', 'adjustments in data entry process') and were grouped to form higher level themes (e.g., 'distinct goal types', 'tracking models', 'alignment between goals and tracking models') through research group discussions.

5 RESULTS

We observed that patients successfully used self-tracking for managing migraine with a tracking tool that explicitly accounted for goal expressions. This section starts by showcasing key observations (Section 5.1). As we unpack these observations, we define terminology (Section 5.2), show patients concurrently moved across different stages of tracking for different goals, and share examples of goal evolution (Section 5.3). We then present ways patients built upon goal expressions not only to decide what to track in alignment with their goals, but also to recognize when and how to adjust tracking in response to goal evolution (Section 5.4). We demonstrate the culmination of these capabilities as highly personalized tracking (Section 5.5). We next show patients gained valuable insights and identified where to seek expertise (Section 5.6). As a result, they achieved improved understanding and care and were empowered in communication and action (Section 5.7).

5.1 Goal-Directed Self-Tracking Experience at a Glance

We observed ways that goal-directed self-tracking supported patients as they configured MigraineTracker for a variety of needs and used it over the course of 383 days on average (min = 269, max = 471). We briefly describe the value this experience brought to patients and demonstrate it through case studies. We then detail themes underlying these case studies in subsequent sections.

All patients found MigraineTracker easy to use, pleasant, customizable, and flexible. They appreciated its unique features, such as medication targets and retrospective reminders. For example, PT08 said: *"the app's customizability also really helped, because I could add whatever fields I wanted to, and it really felt like the only limit was how burdensome I wanted tracking to be. I definitely made some changes to my tracking based on that throughout the tracking period - it was so helpful that I wasn't* *locked into tracking any particular field and could alter what I was tracking whenever something occurred to me."* Moreover, patients felt goal-appropriate summaries and visualizations presented the information they needed. They felt empowered in interpreting data, recognizing trends, reflecting on time-bound events, figuring out if medications had an impact, and identifying actions to take. For example, PT03 appreciated the *"crazy charts, reports"*, noting *"It's like I know my head better"*. All patients wanted to continue using the app after the study and preferred the app over their prior tracking experiences. Several wanted to know if the app would be commercially available.

PT02 Aligned Tracking of Different Goals to Her Needs. PT02 started experiencing episodic migraines three years ago. As she was at the early stages of her migraine journey, she set up the app to understand why migraines happened and how to control them. To the former, she included contributors she suspected (e.g., stress, menstruation). To the latter, she recorded if she took rescue medications early enough and how well they worked. She also included items in her tracking routine to reinforce health behaviors that were broadly beneficial (e.g., exercising). PT02 gained insights in relation to some of her goals after collecting data for a few months and reflecting on it. For example, she learned of a relationship between alcohol consumption and her migraines. She continued tracking toward other goals she was still figuring out (e.g., impact of stress) and new goals formed during tracking (e.g., whether a biofeedback device helped).

PT04 Obtained Insights and Adjusted Tracking. PT04 managed migraines along with other chronic conditions such as diabetes. With constraints on side effects and availability of medications, he prioritized learning about contributing activities and the efficacy of his preventive medication. He recorded presence and severity of headaches along with their context (e.g., levels of stress, amount of sleep, sugar intake). Examining the monthly frequency of his migraines in relation to changes in his preventive medication, he learned the medication did not make much difference. In consultation with his clinician, and considering its negative side effects, he concluded to not continue it. He also learned that stress and lack of sleep were more frequent when his migraines significantly increased in number and severity. He wondered about the potential relation between stress, sleep, and migraines and decided to record stress and sleep on headache-free days in addition to headache days to more fully examine the relation.

PT06 Gained Improved Understanding and Care and Her Goals Evolved. PT06 had no successful prior migraine tracking experience. At the beginning of the study, she recorded her migraines along with various associated symptoms, potential contributors, and treatment information. Consistently tracking for several months, PT06 got better at distinguishing migraines from her everyday chronic headaches as she learned when and how associated symptoms (e.g., light and sound sensitivity) preceded her migraines. Better recognizing migraines led her to take rescue medication sooner, which prevented the migraines from getting worse. Moreover, daily reporting on whether she used different treatment options brought the unexpected benefit of having those options in mind when migraines occurred. PT06 felt her migraines limited her cognitive resources, but greater awareness of treatment options allowed her to apply more when migraines happened. As a result, the average severity of her migraines decreased over the course of the study. Having learned about symptoms and treatments, PT06 was no longer interested in the informational value of tracking them. Nonetheless, she kept the items in her tracking routine as she had other goals: the list of symptoms worked as a checklist for deciding if a daily headache was a migraine. The list of treatment options reminded her of things to do to reduce symptoms.

PT09 Felt Empowered and Sought Clinician's Help. Initially misdiagnosed with cluster headaches, PT09 tracked her symptoms (e.g., their timing and duration) to ensure her clinician had an accurate account of her condition. Tracking information empowered PT09's communication of migraines and helped her feel prepared to discuss care with the clinician. Tracking surfaced areas where PT09 most needed her clinician's input and expertise. For example, tracking data highlighted the high impact of migraines on her ability to function which prompted a conversation about changes in treatments. Moreover, PT09 noticed specific and repeating patterns of monthly frequency and severity of migraines and sought her clinician's input to tease apart different explanations, especially in relation to her preventive medication. Sharing tracking information also led the clinician to learn about PT09's alternative treatments (e.g., marijuana) and to educate her about the potential risks of those treatments (e.g., rebound headaches).

5.2 Management, Information, and Tracking Goals

Patients used MigraineTracker for a myriad of reasons, which we organize into management, information, and tracking goals (Figure 6). This categorization was inspired by Schroeder et al. [65]'s categorization of goals, but refines it to capture the range of patient goals we observed in our longitudinal study. We define these goal categories and describe relations among them that shape and drive tracking.

Distinct Classes of Goals. ***Tracking goals*** were goals a specific tracking setup would achieve. For example, 'recording presence or absence of migraines' or 'recording hours of sleep'. ***Information goals*** were knowledge to obtain and questions to answer about one's migraine experiences. For example, 'monthly frequency of migraines' or 'does lack of sleep make migraines more likely?' ***Management goals*** were desired health states to achieve (e.g., 'improved symptoms'), constraints to meet (e.g., 'medication availability'), or needs and values to support (e.g., 'control and agency'). We also observed self-regulating behaviors (e.g., 'holding oneself accountable to exercise') as management goals.

Tracking Goals Support Information and Management Goals. Tracking goals typically supported an information goal that subsequently supported a management goal. For example, the tracking goal of 'recording presence and absence of migraines' supported the information goal of 'monthly frequency of migraines'. Knowledge of the monthly frequency helped patients

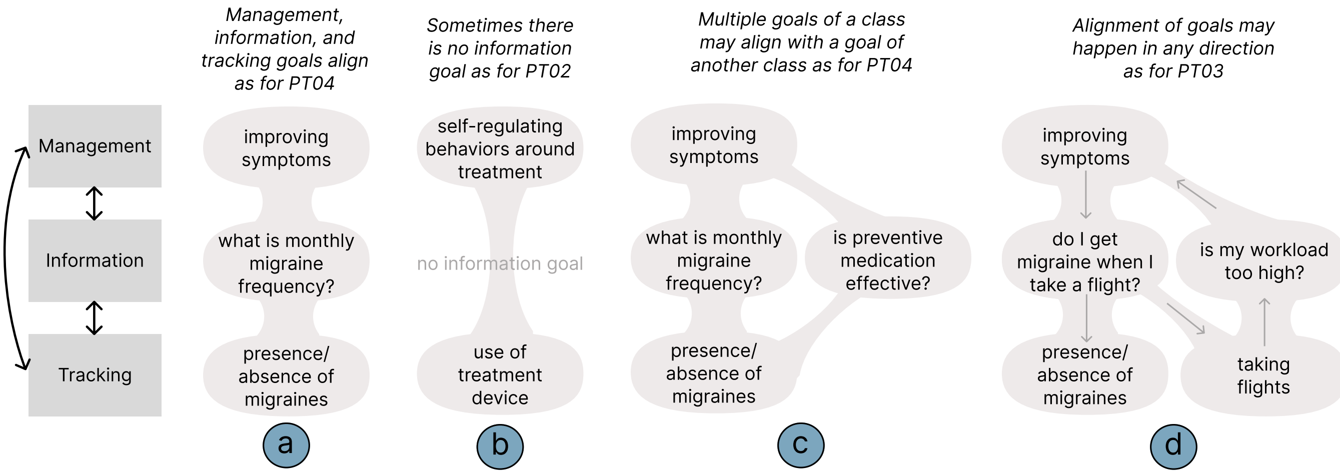

Figure 6: Participants described distinct classes of management goals, information goals, and tracking goals as well as different forms of relationship among such goals. An abstract representation of the inter-relation of these goals is illustrated with four specific examples in (a-d). Specifically, tracking goals support management goals (a) with or (b) without information goals. (c) Goals may overlap, such that a goal of one class may relate to multiple goals of another class. (d) There is no strict sequencing in how goals of different classes are related. This characterization of goals is consistent with qualitative and quantitative goals as introduced by Niess and Woźniak [54] and surfaces additional nuance in the inter-relation of goals (e.g., overlapping and dynamic alignments). It also extends Schroeder et al. [65]'s goal types and highlights more complex relations (e.g., goals that concurrently align or evolve).

such as PT04 make adjustments to treatments or behaviors and eventually achieve the management goal of 'improving symptoms' (described in Section 5.1). Another example was using the tracking goals of 'recording migraine severity and duration' to support the information goal of 'how much time is lost to migraine?'. This information goal served patients such as PT09 in their management goal of 'quantifying and communicating' their health state, which might be dismissed because of the invisibility of migraine. All patients used the app to achieve at least one sequence of tracking, information, and management goals. In these cases, data recorded against a tracking goal was of value as it supported the related information and then management goals.

Tracking Goals Support Management Goals without Information Goals. Although tracking goals typically supported management goals through information goals, there were also cases where no information goal was involved. This was most evident when patients had a self-regulation goal, such as exercising, and used a tracking goal to remind and reinforce the relevant behavior (e.g., as with PT02, Section 5.1). We observed similar reasoning around other behaviors (e.g., dehydration for PT06 and PT09, stress management for PT02 and PT01). Section 5.1's description of PT06 using tracking goals around symptoms to decide if headaches were migraines and her use of tracking goals around treatment options are also examples where tracking goals supported management goals without tracked data enabling an information goal.

Overlapping Inter-Relations among Goals. It was not uncommon for tracking goals to simultaneously support multiple information and management goals. For example, the tracking goal of 'recording the presence or absence of migraine' supported such information goals as 'monthly migraine frequency' and 'how effective are preventive treatments?', which supported the overall management goal of 'improving symptoms'. As another example, PT08 pursued parallel management goals with the same tracking goal. She included a tracking goal for whether she used Cefaly, a neurostimulation device, both to reinforce its regular use (i.e., a self-regulation management goal) and to learn if it improved her symptoms or impacted the efficacy of other treatments (i.e., a management goal of improving symptoms).

Dynamic Inter-Relations among Goals. Classes of goals were not always linked top-down (thus the double arrows in Figure 6). There is no hierarchy to imply a strict sequencing of goal types down from management goals, and tracking goals were not always explicitly set toward a specific information or management goal. Similarly, information goals were not necessarily planned according to specific management goals, and tracking goals sometimes inspired new information or management goals. For example, PT02's record of alcohol consumption, tracked as a potential migraine contributor, led her to learn that she consumed more alcohol than expected and highlighted a need for moderation. Neither monitoring alcohol consumption nor its moderation were part of her initial reasons for tracking. Such a pattern where tracking leads to additional awareness was not uncommon. As another example, PT03 inferred from her records of air travel (i.e., tracked as a potential contributor) that her work had become more demanding, but obtaining information on workload was not initially a goal. The emergence of such new goals is a part of our broader observation of changes in goals within and between classes of goals, as we detail in the next section.

5.3 Goal Evolution

Patients had multiple and evolving goals in their use of MigraineTracker, and they could simultaneously be at different stages for each goal. For example, a patient might lapse in one goal while still actively tracking for another, or they might achieve one goal even as they need to continue tracking for others. Although this may seem obvious in hindsight, it is not clearly indicated by current models of personal informatics [24, 43] or goal evolution [54], which tend to consider a single goal for the tracking experience. Designs based on a model of single, separable goals are ill-suited for tracking in chronic conditions in which patients have multiple tracking, information, and management goals, each of which may decrease or increase in priority or resolve at different times, but may share some underlying tracking. In the remainder of this section, we detail participant experiences and some of the complexities associated with multiple evolving goals.

Progression of Individual Goals Across Stages of Tracking. Patients sometimes achieved one goal but needed to continue working toward other goals. This was the case with PT02, who achieved their information goal concerning alcohol but needed to continue investigating the relation between stress and migraines. It was also common to refine a goal or follow up with a new information or management goal. In the latter, patients could abandon tracking the original goal as they started tracking anew for another goal or could concurrently track toward both goals. We observed evolution of information goals for all patients when they reviewed their tracking after several months. Examples include when PT10 refined her information goal from learning about the average length of migraines to learning about the average length of treated migraines (i.e., how long migraines lasted after taking abortives), when PT06 learned that alcohol was not a strong contributor and moved to investigating 'feeling chilled' as a contributor, or when PT04 followed up on observations of migraine severity by wondering about their daily activities during months with higher severity. New management goals also sometimes emerged after the resolution of information goals. For example, PT01 wanted to prioritize her health over other commitments after learning of her stress-migraine relationship.

Evolution Across Classes of Goals. Changes in tracking goals sometimes followed resolution, refinement, or emergence of information or management goals. Resolution of an information goal usually led to implicit or explicit abandonment of associated tracking goals, especially when those tracking goals did not support any other information or management goals. PT06's removal of alcohol tracking, which was found not to be a contributor, was an explicit change. PT03's lapsing in reporting of brain fog, a symptom she no longer wondered about, was an implicit change. Abandonment did not happen when tracking goals supported new management goals independent of the resolved information goals. For example, PT02 continued tracking her menstruation, even after learning about its connection to migraines, because she wanted to stay aware of that context around migraines near her cycles.

Refinements in information goals often led to changes in tracking goals. For example, PT10 started recording the timing of treated migraines in addition to the total length of migraines. However, there were also cases where no change in tracking goal was needed to support a refined information goal. For example, PT07 wanted a monthly average duration of migraines, after learning about her overall average duration. Although additional processing was needed, she did not need to track differently. Emergence of new information goals sometimes involved new tracking goals, as with PT06's learning about 'feeling chilled'. In other cases, existing tracking goals could adequately support new information goals. For example, PT09's records of migraine presence vs. absence were enough to examine inter-migraine intervals.

Patients sometimes changed their tracking goals without changing the associated information or management goals, often through improvements in their tracking process. For example, PT04 changed his tracking goal of noting the location of pain to recording the presence or absence of pain in frequent locations, a change which simplified his recording. PT07 similarly simplified her recording of sleep from a time range to length of time in hours. The precision of a time range was more burdensome and seemed unnecessary for her information goal of examining the potential link between inadequate sleep and migraines.

Evolution in Goal Priorities. In addition to changes in specific goals, goals became more or less important even as they remained relevant. For example, PT08's migraine severity improved and she then cared more about information goals regarding non-migraine headaches. PT06 cared less about learning if loud sounds contributed to her migraines, as she felt she could do little regarding the source of the loud sounds (i.e., her young dogs) even if there was a relation. Both PT03 and PT09 cared more about goals that implicated a behavior change in day to day life. In addition to actionability, new or unexpected variations made patients more interested in certain information, whereas lack of variation led them to lose interest. For example, PT08 started caring more about migraine duration after noticing increased average duration, whereas PT10 lost interest in the relation of migraines and lightheadedness as it rarely happened.

Changes in what goals were pursued and at what priority often prompted additional changes beyond the classes of goals. The next section details such changes through our observations of tracking and data models.

5.4 Expression of Goals Facilitates Alignment of Tracking to Patient Needs

Patients configured MigraineTracker by selecting goals and describing what each tracking item helped them achieve. In doing so, they aligned different management, information, and tracking goals. How patients recorded data during tracking, which we characterize through *tracking models* and *data models*, then complemented alignment of goal types. As goals evolved, goal-centered review additionally facilitated adjustment and re-alignment of goals, tracking models, and data models. We detail these observations by first presenting the tracking and data models patients used and then providing examples of different forms of alignment and re-alignment. We also point out challenges we observed in the process. Considering the tracking experience in terms of distinct goals, tracking models, and data models, along with the alignment of these elements, offers insights into how goal-directed tracking enabled patients in deciding what to track over time and subsequently highlights support that is relevant to long-term tracking of chronic conditions.

Data Models. We define data models as *units of recording*. Patients used three distinct data models: a ***day-based model*** where recording happens for each calendar day (e.g., presence of migraine or its peak severity for each calendar day), an ***episode model*** where recording happens for each episode of migraine, which may extend beyond a single day (e.g., duration or peak severity for each episode), and an ***interval model*** where recording happens for a window of time, typically since the previous recording (e.g., number of days of migraine within each interval). Although MigraineTracker's default model was day-based, patients adjusted it to other models and sometimes combined multiple data models. For example, PT04 recorded presence or absence of migraines for each *day* but preferred to record migraine duration for each *episode*.

Tracking Models. We characterize *when recording happened* under four types of tracking models: a ***daily model*** where patients recorded every day, an ***event model*** where recording was initiated by an event, often the start of a migraine, a ***divergence model*** where certain changes prompted recording, and a ***hoarding model*** where recording happened occasionally when an opportunity arose (e.g., a break in routine activities every few days). Patients commonly combined these different tracking models. Many patients who reported presence of migraines on a *daily* basis reported associated symptoms (e.g., light and sound sensitivity) in the *event* of a migraine. It was also common for patients to report preventive medication dosage only if they were *diverging* from the previous levels. Recording upon *divergence* from typical levels was also common for stress levels and stressors because of the associated negative affect. PT08 described this: *"I don't want to have to dwell on that, dwell on particular stressors by mentioning them day after day because I don't think that, that would be good for my mental state."*

Aligning Goals, Tracking Models, and Data Models. Patients often used tracking and data models consistent with their goals. PT01 provides an example of *aligning tracking models to goals*, as she used different tracking models for different goals. She recorded symptoms such as brain fog only on migraine days because she only cared about learning how frequent these symptoms were with migraines. On the other hand, she recorded excessive stress on a daily basis to investigate if she got let-down headaches (i.e., a type of headache that happens when a few days of high stress are followed by release from stress). PT10's recording of alcohol provides an example of *aligning data models to goals.* She wanted to learn if her migraines happened the day after drinking alcohol. Although most of her tracking was interval-based, she used a day-based model for her specific tracking goal of tracking migraines along with prior-day alcohol consumption.

Patients were also able to adjust tracking models as their goals evolved. For example, PT04 switched from event-based recording of stress and sleep to daily tracking in order to more fully understand how stress impacted sleep and how both influenced migraines. Goal priorities also informed tracking models. Some patients had a 'minimum recording set' corresponding to their highest priority goals. This typically included migraine presence, migraine duration, and rescue medication, which patients prioritized recording even when extremely busy.

Mismatches sometimes occurred in aligning goals, tracking models, and data models. The most common mismatch between goals and tracking models was using an event-based model for goals that required daily tracking. For example, PT07 recorded her menstruation only on migraine days, which was inadequate for learning whether and how menstruation affected her migraines. In an example of difficulty aligning certain data models with tracking models, PT01 and PT07 were confused about daily recording of preventive shots they received every one or three months. The influence of each shot extended to other days, so answering 'no' to whether they used that medication felt inaccurate on those other days. The app's default day-based data model also sometimes did not match a patient's data model. For example, PT04 could not directly record the start and end of a multi-day migraine episode. After consulting the research team, he worked around this by adding a custom item 'same as yesterday' to his tracking.

As goals evolved, patients commonly recognized a need for more rigorous tracking models (e.g., from event-based to daily recording). They were less cognizant when goal evolution meant they could adjust their tracking to be less burdensome. For example, PT06 reached a point where the presence of migraines was the only information she needed to record on a daily basis. Despite acknowledging that she had no need for the data, she wanted to keep recording all information every day and felt doing otherwise was a "user error".

Aligning Classes of Goals. The configuration process for MigraineTracker involved choosing relevant goals and configuring a tracking routine in relation to those goals. In the course of adding and configuring tracking items, patients articulated tracking, information, and management goals and described how they aligned. For example, PT08 included a time of day entry for migraine start time and a text entry for her location when a migraine started (tracking goal). This allowed her to learn when and where migraines were more likely (information goal) to then decide where was safer for her to be (management goal). We similarly observed other patients translating management goals to information or tracking goals and operationalizing the tracking goals into specific settings within the app (see Section 5.2 for other examples). Every part of a patient's tracking thus spoke to an explicit need they had.

As patient goals evolved, they repeated the same process to make adjustments to their tracking and re-align it to their needs. For example, after mixed insights on the relationship between sleep and migraines (the information goal), PT06 decided to record sleep in terms of its quality (new tracking goal) and not its length (prior tracking goal). Similarly, PT02 decided to use higher granularity in rating stress levels (tracking goal) after data was inconclusive with respect to the relation between migraine and stress (information goal) at higher levels of stress.

Challenges could arise at various stages of the process from articulating goals, to aligning and realigning them, to retaining the established alignments. Patients sometimes struggled with articulating their goals. For example, PT07 did not initially express interest in knowing which rescue medication worked. As a result, she primarily recorded a list of medications she took and if the overall combination worked for her (which did not allow her to understand the separate impact of the various medications). PT10 did not initially differentiate migraine length before and after taking rescue medication. Encouragingly, this challenge was remediated through goal refinement and re-alignment of tracking with the refined goals as part of patients reviewing their goals during sessions with the research team.

There were also challenges in alignment of tracking with goals or among distinct goal types. PT10 did not include any items in her tracking routine for the tracking goal of recording persistence of migraines. This meant she lacked data needed to support her information goal regarding efficacy of rescue medication. Review of goals during interview sessions helped surface and address this type of misalignment. In another example, PT03 could not define a tracking goal to support the information goal of determining whether migraines returned because a rescue medication effect wore off or because the medication led to rebound. Given goal expressions highlighted this specific challenge, she was able to seek clinician expertise and analytic support from the research team. Her clinician educated her with general information about the medication, and the research team transformed and restructured her existing data into a goal-appropriate visualization.

There were times when realignment of tracking or goal types to evolved goals could similarly be challenging. With little variation in categorical levels of fatigue (typically 'some' on the scale of 'none'/'some'/'lots'), PT04 could not fully examine the relationship between fatigue and his symptoms. He also did not re-align his tracking through finer-grain recording of fatigue. Existing tracking goals and setup sometimes fell short of supporting new or refined information goals. For example, PT09's new goal was to know times she felt desperate in managing migraines, and she thought the number of rescue medication taken could be a good indicator. Her original tracking, however, could not support this new question because she only recorded whether she took medication and not the dosage. Although goal expression alone was inadequate in both PT04's and PT09's cases, it highlighted what change was needed.

We observed the importance of recording patient rationale for their future use as they articulated and aligned goals, given this may be otherwise lost over long periods of tracking. Information goals were particularly prone to loss. PT08 forgot she chose to record fatigue to understand its variations during migraines. Such loss of an information goal sometimes led patients to lapse in recording. For example, PT07 stopped recording their migraine impact on disability, which she had originally planned to record to learn functional severity of her migraines.

5.5 Goal-Directed Configuration of Tracking Is Meaningfully Personalized

The ability to express different goals and align tracking to them led patients to highly personalized tracking. Additional examples in this section complement those in earlier subsections to illustrate the importance of the explicit scaffolding of goal expression and the alignment process in facilitating personalization.

Patients customized MigraineTracker's recommended and common tracking items and defined custom items to capture information that mattered most to them. Customization of the app's provided items happened through selecting *how* information was recorded to be more conducive to goals and preferences. For example, patients customized the recording of stress through whether it happened or not (PT01), its qualitative severity (e.g., 'none' vs. 'some' vs. 'lots' for PT02), or a note of what the stressor was (PT08). Patients recorded sleep by its start and end (PT07), as a number of hours (PT06), or as notes of any inconsistency (PT09). Custom items enabled further personalization through defining concepts of interest. Many patients created custom items for specific medications (e.g., ajovy, botox) and alternative treatments (e.g., acupuncture, massage). Custom items were also used to capture person-specific symptoms and contributors. For example, 'clumsiness' mattered to PT08, while PT01 tracked 'numbness'.

Although valuable, customization led to challenges. Patients sometimes forgot how they planned to record information. PT05 forgot he wanted to record his typical rescue medication under 'as-needed medication' and other rescue medication under 'new as-needed medication'. Providing rich support was also particularly challenging for custom items. Patients wanted specific features for the entry and visualization of medication items. For example, PT06 wanted reports of a particular medication to appear with a unique icon on the app calendar view.

5.6 Goal Expression Drives Reflection; Reflection Drives Goal Evolution

Reflection happened at the time of recording and when reviewing data summaries and visualizations. In both cases, goal expressions played an integral role. In this section, we first show the connection between goal expression and reflection at the time of recording. Next, we demonstrate that data review around explicit goal expressions enabled reflection. We do so using examples that indicate patients successfully engaged in the processes that Fleck and Fitzpatrick [27]'s and Baumer [4]'s models articulate for reflection. As additional evidence for successful reflection, we show the overall process led patients to gain valuable insights. We then note how the very processes characterized in [4, 27] can also be considered through the lens of goal evolution, and thus advance understanding of the role of reflection in goal evolution [54]. We conclude by presenting challenges patients encountered throughout the reflective process.

Reflection Happened at the Time of Recording. Information goals associated with a tracking goal prompted patients to think about the information they were seeking in the moment of tracking. For example, the act of recording led PT02 to conclude her migraines were related to the amount of alcohol she drank. She had configured her tracking to record whether or not she consumed alcohol, but she did not record alcohol quantity. The insight into relevance of quantity *"was in concert with being really diligent about tracking on the app, but also just having my awareness and my life be very* *open to what are possible triggers, what are things that are going to potentially lead to a migraine that are within my control?"* Learning from immediate experience while recording also led PT08 to quickly determine that any intense smell could trigger her migraines. For both PT08 and PT02, goal-focused attention at the time of tracking facilitated reflection, which happened either within a short period of tracking or without explicit data entry.

Patients Navigated Levels of Reflection. Patients frequently chose to reflect on information goals that they anticipated would lead to changes in behavior or treatment. As patients reviewed goal-appropriate summaries and visualizations, we commonly observed the first three of Fleck and Fitzpatrick [27]'s levels of reflection: description (R0), description with reflection (R1), and dialogic reflection (R2). Patients commonly attended to patterns that stood out to them (R0), including minimum or maximum values, consecutive migraine or migraine-free days, and variations over weeks or months. This was often followed by attempts at explaining the patterns (R1), typically in relation to treatments or context including day of week, events, and habits. Patients sometimes considered multiple explanations or tried connecting multiple patterns and explanations (R2). For example, PT04 noticed months with higher frequency and severity of migraines (R0). He then examined the monthly breakdown of contributors to explain the differences and saw higher frequency of stress and inadequate sleep in those months with higher migraine frequency and severity. Connecting the two insights, he next asked if he got worse headaches on days with inadequate sleep, or when he was more stressed, and if inadequate sleep days followed high stress days (R2). PT04's full engagement in the reflective process occurred despite limited experience working with data and even though cognitive load could exhaust him due to his medications.

Breakdown and Inquiry Were Key to Navigating Levels of Reflection. Patient navigation from lower to higher levels of reflection was closely linked to *breakdown* and *inquiry* aspects of reflection [4]. Salient or surprising patterns at R0 signaled a breakdown between patient understanding and data. The inquiry process always ensued to describe and explain the breakdowns, thus patients went to R1 and R2. The process sometimes started with verification. For example, observation of higher likelihood of migraines within three days of taking a medication (the breakdown) led PT03 to first verify how days were counted for 'the number of migraines within three days' of the medication. After the clarifications, she tried explaining the pattern and considered multiple explanations: *"whether it's a rebound headache and that [the medication] caused the headache or if it just wore off and those headaches days are still there."* Hypothesis formation was integral to the inquiry process, and sometimes relied on defining new concepts. For example, PT09 noticed patterns of migraine and migraine-free days and wondered if there was a fixed 'inter-migraine interval': the number of consecutive migraine-free days between consecutive migraine days. The process of noticing breakdowns, defining concepts, and forming hypotheses led patients to form complex information goals they had not previously considered.

Reflection Brought Value. Goal-appropriate summaries and visualizations addressed some of the most pressing information goals that were initially set or arose from the inquiry process. All patients found insights that addressed needs (e.g., around symptom patterns during the week; medication efficacy; or key contributors such as sleep, stress, or alcohol). Moreover, patients identified when they needed additional data or expertise. For example, PT04 learned he needed to record sleep and stress on both headache and headache-free days to fully establish a hypothesized relation that increased stress caused decreased sleep which led to migraines. PT05 decided to integrate diet tracking data to cross-check the specifics of his diet and headache patterns. Insights from reflection also guided patients in seeking expertise, particularly from their clinician. PT08 wanted her clinician's advice for dealing with multi-day migraine episodes she learned were common for her. PT03 wanted her clinician's input on alternative hypotheses about a medication (if it caused rebound headaches vs. its effectiveness ran out). Patients also sometimes looked to online resources to follow up on or augment insights from reflection. PT09 wanted to know how typical her migraine duration and frequency were.

Elements of Reflection Are Mechanisms for Goal Evolution. Patient goals evolved as they went through levels of reflection, defined concepts, formed hypotheses, and gained insights. Defining concepts and forming hypotheses led to new or refined information goals, as with PT03, PT04, and PT09's above. Gaining insights addressed existing information goals and was sometimes followed by new goals, as with PT05's above. Patients then aligned tracking goals, tracking models, and data models with evolved information goals (Section 5.4). Resolution of information goals was sometimes followed by new management goals, as in PT06's use of light and sound sensitivity to make sense of her everyday headaches and whether or not they were migraines.

Challenges. There were pain points in the reflection process. Patients sometimes struggled to form hypotheses. PT04 was unable to explain the weekday differences in migraine frequency. Clinicians were often a good resource. Brainstorming with their clinician led PT04 to consider increased social interactions during weekends as a potential explanation. Closely related to the challenge of forming hypotheses was the challenge of developing hypotheses. MigraineTracker's emphasis on expressing goals and aligning tracking with goals meant developing hypotheses, where goals were yet to be well-defined, did not receive much support. As PT06 learned about week of month differences in migraine frequency, she said *"food for thought, is what this is. This now makes me want to start paying attention to what else is going on, …I don't know yet what I would want to record to go along with this, but it just makes me curious, and I'll probably have to sit and think about it, and maybe even take a month or two to observe on my own before I go, "Okay, here's something I want to start watching," and then stick it into the app."* Patients sometimes forgot insights they gained from their reflection. For example, PT08 paused a preventive medication mid-way in her tracking, learned of increased migraine frequency, and resumed the medication. However, she could not explain the sudden increase then decrease of migraine frequency when she considered her data at the end of tracking. Another challenge was in identifying complex patterns.

For example, PT08's data showed higher everyday headache severity followed within a few days of higher stress, but neither PT08 nor her clinician were able to identify this relationship with the available visualizations. Patients also misinterpreted data. PT10 interpreted higher likelihood of migraines when not drinking alcohol to indicate that alcohol helped. She was surprised but did not consider alternative explanations or additional factors (e.g., that alcohol consumption typically happened on good days and in the absence of other contributors).

5.7 Goal-Centered Insights Enable Understanding, Communication, and Action

Goal-directed tracking led to practical insights, informed behavior, and facilitated help-seeking and communication. We observed these benefits as well as challenges and additional considerations in effectively supporting them.

Insights from the tracking experience led patients to better understand and manage their condition. For example, commenting on improved migraine severity over the course of the study, PT06 said *"I think I'm getting better at nipping them in the bud. The app has helped me… It's helping me recognize when I have one sooner, and helping me just go ahead and take the damn drugs. So they're not getting up to six, seven, eights and nines… I am actually glad to see that. I'm glad to see that I'm taking better care of myself. I'm not suffering."* Patients identified whether changes they had made helped or if they needed to make further adjustments in daily behavior or medications. For example, upon seeing improved migraine frequency, PT01 decided to continue her new preventive medication. Comparing the efficacy of different rescue treatments convinced PT09 to take naproxen less and rizatriptan more. Patients sometimes identified needs they had not otherwise considered, as with PT01's realization of a need for prioritizing stress management.

Added understanding of their condition facilitated improved patient communication with clinicians. For example, PT05 felt the information helped *"accurately express things that I've wanted to express to a doctor"*. PT09 similarly found that reviewing goal-appropriate material helped her *"feel more prepared to see my provider"*. Clinicians also described how tracking and a focus on goals prepared patients to take the lead in conversations, making more effective use of their sessions. PR02 described that ideally *"we'll have a conversation, and then that conversation will lead to, "What can we do about it?""*. This ideal vision was realized in her interactions with patients through goal-directed tracking. Commenting on the session with PT08, PR02 noted *"having her tracking, she already had it in her head, what might be contributing? And so then, we could have this full on conversation about, "Okay, how do we change this?""*. In leading conversations with clinicians, patients sought expertise where they needed it the most (e.g., in the challenging task of translating insights to actions). For example, PT04 was able to get advice on reducing migraines on weekends by taking breaks from social interactions. PT08 worked with her clinician toward a concrete plan for ensuring adequate sleep (i.e., having dinner earlier).

PT09 also saw opportunities to use data and analysis from her tracking to communicate with others: *"I just wish people could see this in my academic and professional life, and also in my personal life. You have to disappoint a lot of people when you have migraine by canceling, not being available, calling out… I do wish that I could show them, I can't be there and I failed to be there because of this, what we're seeing here."* She felt the insights helped her better advocate for herself.

Not all insights led to action. Patients were more likely to act if they felt the underlying relationships were strong enough relative to the cost and feasibility of taking action. For example, the relationship between migraines and loud sound in PT06's view *"is not huge. 26% is not a big number. And with the house that I live in… It's just noisy."* (Figure 4, c). Perceived necessity of action also influenced how patients reacted to insights. An example is PT08 who did not feel a need for further changing treatments because of already-achieved improvements in her condition. Backed by PT08's data, which still showed high migraine frequency, her clinician was able to talk with her about additional change.

Despite gains in communication and action from goal expressions and subsequent insights, patients needed further support. Although they were empowered to seek clinician expertise for action planning, they were mostly on their own in following through with actions. For example, both PT01 and PT02 included their use of a biofeedback app recommended by the clinician as part of their tracking routine. Despite sincere intentions, neither followed through with actually using that app, as being reminded of it while tracking was not sufficient.

6 DISCUSSION

We studied the lived experience of goal-directed self-tracking. Patients described distinct and evolving goals for self-tracking related to their migraines and concurrently pursued those goals across distinct stages of tracking. Our observations extend prior work on goals and goal evolution [54, 65] in detail and scope. Goal-based support in MigraineTracker and accompanying visualizations facilitated awareness of and progress toward qualitative goals. Moreover, we concretely illustrated results past work speculated and anticipated (e.g., goal evolution) and uncovered how these are achieved (e.g., reflection and realignment). Specifically, we observed the importance of scaffolding around expression of patient goals to ensure goals were aligned to each other and to other aspects of tracking, including tracking models and data models. This led to a highly personalized tracking experience. Goal expressions also facilitated reflection, which improved understanding, communication, and action. Reflection in turn drove goal evolution. Overall, expression of goals enabled patients to externalize their needs and values and situate tracking accordingly. As predicted by prior work [5, 61], this led to improved sense-making and condition management. Below, we discuss how identifying distinct goals provides an analytical lens for analyzing and designing personal informatics systems (Section 6.1). We also note the importance of goal-specific adaptations of existing models of personal informatics (Section 6.2). We then share design implications of our observations (Section 6.3) and reflect on our methods and their limitations (Section 6.4).

6.1 Classes of Goals as Analytical Tools

We identified distinct classes of goals in patient use of MigraineTracker. This distinction between management goals, information goals, and tracking goals provides a novel perspective for understanding self-tracking in chronic condition management and for designing effective support. Not accounting for these goal types and their interconnections leads to design gaps. For example, the need for aligning different goal types cannot be recognized without first distinguishing goal types. Goals such as self-regulation are unlikely to receive adequate support if we overlook tracking goals that may exist without an information goal. Our observations suggest no goal-directed tracking tool can be expressive enough unless it supports an interconnected subset of management goals, information goals, and tracking goals. Related to and in consideration of the range of goals we observed in each class, it is reasonable to expect that any design may be incomplete in what goals it anticipates. It is highly likely to encounter unknown management goals, advanced information goals that rely on unsupported analysis, or unconventional tracking goals for recording information in new ways. Considering distinct classes of goals can guide development of specialized designs that should be in place for a successful tracking experience. It can also inform the flexibility we should aim for in designs to enable people to adapt their tools to their evolving goals.

Considering distinct classes of goals also provides an analytical lens to understand the failures and shortcomings of existing tools. For example, a design that only supports an event-based tracking model will fall short in supporting people in achieving goals that rely on a daily tracking model. People may still be able to appropriate tools if a design does not undermine their ability to do so. For example, a tool with an event-based tracking model that allows certain entries to be left blank might be appropriated for daily recording.

We emphasize that we are not the first to note different goal types. We complement prior work, such as [54, 65], by bringing new and more detailed understanding of goal types and how they relate to other aspects of tracking. By elaborating upon goal distinctions and inter-relations we draw attention to areas to which designers and researchers should attend.

6.2 Accounting for Multiple Goals in Models of Personal Informatics

Existing models of personal informatics [24, 43] and goal evolution [54] describe the self-tracking experience with the unstated assumption that stages and concepts apply to a person's entire tracking experience. Existing models do not strongly distinguish among the various interrelated goals a person may be pursuing through tracking nor depict how those goals may change or resolve at different times. Our observations demonstrate that people are simultaneously at different parts of these models for different goals. For example, because a tracking goal may support multiple information goals, confusion can arise when an information goal resolves or changes but other information goals continue, or similarly when a patient lapses in one information goal but continues with others. It can be unclear what the person needs to continue tracking or what might they stop tracking or change to tracking using less burdensome models.

Considering goal-specific versions of existing models of tracking can inform future system design and analysis. For example, consider the preparation stage of tracking, where people decide what and how to track. A goal-specific design could support different tracking models for each goal rather than assuming a fixed model for all goals. Another example is lapsing. A goal-specific design could better support different forms of lapsing [65] with goal-specific support (e.g., goal-specific vacation-lapsing, informed in part by limitations of MigraineTracker's support for vacation-lapsing across all tracking). MigraineTracker's design for intentional lapsing in tracking was based on insights from prior models of personal informatics [24]), but was ultimately inconsistent with patient experience (e.g., there was a minimum set of tracking goals that patients maintained even during vacation). Considering models of personal informatics at the level of goals also highlights the need for accounting for how evolution of one goal is related to other goals. For example, reflecting on one goal may influence the preparation, collection, and interpretation of another goal. Tools that account for such inter-relations and facilitate people in adapting their tracking as goals resolve or evolve can provide a better tracking experience.

6.3 Implications for Designing Goal-Directed Tracking Tools

Explicit scaffolding around expressing distinct goals and aligning them to each other played a key role in personalization of tracking and gaining value from it. Prior work had highlighted the importance of explicitly supporting the initial articulation of goals [65]. Our observations of goals over an extended period of tracking underscore the importance of open design problems in supporting not only an initial articulation of goals but also their alignment and re-alignment. Our prototype supported initial goal articulation by offering a list of options from which people could select. However, there were cases where patients did not accurately articulate goals (e.g., PT07's and PT10's struggles in initial articulation; Section 5.4). Well-designed goal-setting practices involve feedback loops and opportunities to adjust goals [44], and our results add to literature calling for the HCI community to develop design practices that support reflecting on and revising goals over time [1, 22] (e.g., using techniques for scaffolding the process and targeting opportune times for reflection so as to avoid rumination, a potential unintended consequence of self-tracking in which people dwell on negatives and blame themselves rather than finding potential solutions and experiencing progress [21]). As noted in prior work [14] and as we observed in our study, reviewing and updating goals before a clinical encounter is one such opportune time. It can focus the visit and make the most of a clinician's expertise (e.g., rather than retreading things the patient already knows). Updating goals during a clinical visit can also incorporate clinician expertise into goals going forward. We further note that as people gain experience with tracking and their priorities change, they may also wish to revisit and tune their goals and associated tracking routines, a process that designs should explicitly prompt and support. Additionally, goal expression alone was not always sufficient for aligning goals, tracking models, and data models (e.g., PT03's, PT04's, and PT10's challenges in goal alignment; Section 5.4). Reviewing goals, especially after some tracking data had been collected, and with clinical expertise or tracking and analytics expertise (often provided by the research team in this study), could help detect and correct misalignments. As our study relied on human resources that may not be available to everyone engaging in tracking (clinicians and researchers), future work should develop design strategies for supporting this review process. This might include structured walkthroughs (e.g., through conversational agents [41]) or review interfaces (e.g., dashboards or visualizations that can highlight misalignments between expressed goals and data being tracked).

Our results also highlight opportunities for specialized support of different management, information, or tracking goals related to similar data or activities. For example, consider recording exercise to self-regulate vs. to learn of its relation to migraines. In the rare event that similar tracking and data models apply to both cases, other aspects of their support could be different: goal realization techniques such as implementation intentions [30] would be more appropriate to integrate in reminders for a self-regulation goal and less so for a learning goal. Visualizations for a self-regulation vs. learning goal could also vary in complexity. Enabling specialized support depends not only on eliciting goal expression but also accounting for nuanced inter-relations and evolution. Tracking tools can adapt support to such specifics of the goals and can capture this information instead of relying on an individual's memory, where we saw it was prone to loss over time.

Reflection is integral to goal evolution. Goal-directed self-tracking tools should therefore address difficulties that impede the reflection process, including forming or developing hypotheses, identifying complex patterns, and misinterpreting information. Designs can leverage clinician expertise, new interactions, and computational techniques to better support these tasks. For example, tools could enable brainstorming with clinicians for hypothesis formation or could use mixed-initiative pattern discovery techniques to surface complex patterns that might otherwise be missed, similar to [14, 64].

6.4 Reflections on Methods and Limitations

We used MigraineTracker as a technology probe to understand patient experience with goal-directed tracking in the wild. The benefits that it brought to patients should however be considered in the full context of our study. For example, we asked patients to think aloud as they configured MigraineTracker and to explain why they made various selections. This aspect of our method led them to describe different goals and ensure they had a setup consistent with those goals. We also had patients repeatedly review and comment on their goals as well as whether and how their data supported those goals. Although primarily intended to elicit feedback, these aspects of our method substantially influenced patient experience and suggest opportunities for future designs.

We intentionally offered data review via simple static visualizations. Consistent with Moore et al. [51]'s insights, this approach is both more cost-effective than building a custom exploratory data analysis tool in a poorly understood design space and more conducive to generating truthful design requirements. Keeping the data presentation simple and static focused our sessions with patients on *what they want* to achieve, instead of being distracted by comments on the usability of visual elements.

We analyzed our data primarily from a patient perspective, to center their goals and ways in which MigraineTracker did or did not support them. Future analysis should more deeply examine the patient-clinician interactions in our study as well as clinician experiences to identify ways in which the design supported collaborations and clinician needs and to surface additional opportunities for better support. Although models of personal informatics that were centered on the individual [24, 43, 54] facilitated a patient-centric and goal-centric analysis, examination of the collaboration might also draw upon other lenses, such as patient-generated data as a boundary negotiating artifact [13]. As prior research has emphasized that tracking to manage a chronic illness is a process with many interested parties (e.g., clinicians, family members, informal carers, workplace and community members) [53, 57, 68], future research might also examine the ways that goal-directed self-tracking technologies can support communication and coordination across a broader range of parties.

7 CONCLUSION

Self-tracking plays an important role in managing chronic conditions such as migraine, yet it remains challenging. Tracking tools generally leave patients unsupported in deciding what and how to track, how to adjust tracking, or how to interpret data. We designed, developed, and deployed MigraineTracker, a prototype app based in a goal-directed self-tracking framework, to examine whether and how scaffolding around explicit expression of goals can support migraine management. We observed expression of goals facilitated externalization of distinct goal types and alignment of these goals to each other and to the specifics of when and how recording occurred. Patient tracking was highly personalized to their needs as a result. Goal expressions also supported reflection through goal-appropriate material, and reflection in turn led to goal evolution and enabled improved understanding, communication, and action. We discussed the importance of accounting for distinct goal types in the design and analysis of self-tracking tools and highlighted the need for goal-specific adaptations of personal informatics models. We also noted the importance of further research to better enable goal articulation and alignment, to provide specialized support (e.g., for management goals with no associated information goal), and to facilitate reflection through verification, concept definition, hypothesis development or formation, and pattern identification.

AUTHOR CONTRIBUTION STATEMENTS

Manuscript Preparation: YS led; CC, SC, SM, and JF contributed. **MigraineTracker Design, Development, and Maintenance:** JS, LJ, and YS led in succession. AM, NM, SM, and JF contributed. **Study Design, Material Design, and Material Preparation:** YS led overall study design, material design, and material preparation; CC led material design and material preparation for specific study components; HR, JS, SM, and JF contributed. **Participant Recruitment and Clinical Facilitation:** YS, CC, HR, JS, AC,

and NM jointly contributed. **Planning, Coordinating, and Conducting Sessions:** YS led overall planning and coordination; YS, CC, and HR led conducting specific sessions; SC and TJ contributed to conducting specific sessions. **Data Analysis:** YS led overall analysis; CC and SC led analysis of data from specific sessions; TJ, JS, SM, and JF contributed.

ACKNOWLEDGMENTS

We thank the patient and clinician participants in this research. We also thank Melissa Schorn, Frances Vallejos, and the staff of participating clinics in facilitating this research. We thank Natra Zeryihun for assistance with visual design in MigraineTracker. This work was supported by the National Institutes of Health through awards R01LM012810, UL1TR002319, and UL1TR000423 and by the National Science Foundation through awards IIS-1813675 and IIS-1553167. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the National Science Foundation.

REFERENCES

[1] Elena Agapie, Patricia A. Areán, Gary Hsieh, and Sean A. Munson. 2022. A Longitudinal Goal Setting Model for Addressing Complex Personal Problems in Mental Health. *Proc. ACM Hum.-Comput. Interact.* 6, CSCW2, Article 270 (nov 2022), 28 pages. https://doi.org/10.1145/3555160

[2] Mendinatou Agbetou and Thierry Adoukonou. 2022. Lifestyle modifications for migraine management. *Frontiers in Neurology* 13 (2022), 719467. https://doi.org/10.3389/fneur.2022.719467

[3] Amid Ayobi, Paul Marshall, Anna L. Cox, and Yunan Chen. 2017. Quantifying the Body and Caring for the Mind: Self-Tracking in Multiple Sclerosis. 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, 6889–6901. https://doi.org/10.1145/3025453.3025869

[4] Eric P.S. Baumer. 2015. Reflective Informatics: Conceptual Dimensions for Designing Technologies of Reflection. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (Seoul, Republic of Korea) *(CHI '15)*. Association for Computing Machinery, New York, NY, USA, 585–594. https://doi.org/10.1145/2702123.2702234

[5] Andrew B.L. Berry, Catherine Y. Lim, Calvin A. Liang, Andrea L. Hartzler, Tad Hirsch, Dawn M. Ferguson, Zoë A. Bermet, and James D. Ralston. 2021. Supporting Collaborative Reflection on Personal Values and Health. *Proc. ACM Hum.-Comput. Interact.* 5, CSCW2, Article 299 (oct 2021), 39 pages. https://doi.org/10.1145/3476040

[6] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77–101. https://doi.org/10.1191/1478088706qp063oa

[7] Virginia Braun and Victoria Clarke. 2019. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 11, 4 (2019), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

[8] James Earl Carnahan. 1973. *The effects of self-monitoring by patients on the control of hypertension.* The University of Arizona, USA. https://doi.org/10.1097/00000441-197501000-00008

[9] Janghee Cho, Tian Xu, Abigail Zimmermann-Niefield, and Stephen Voida. 2022. Reflection in Theory and Reflection in Practice: An Exploration of the Gaps in Reflection Support among Personal Informatics Apps. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems* (New Orleans, LA, USA) *(CHI '22)*. Association for Computing Machinery, New York, NY, USA, Article 142, 23 pages. https://doi.org/10.1145/3491102.3501991

[10] Eun Kyoung Choe, Bongshin Lee, Haining Zhu, Nathalie Henry Riche, and Dominikus Baur. 2017. Understanding Self-Reflection: How People Reflect on Personal Data through Visual Data Exploration. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare* (Barcelona, Spain) *(PervasiveHealth '17)*. Association for Computing Machinery, New York, NY, USA, 173–182. https://doi.org/10.1145/3154862.3154881

[11] Eun Kyoung Choe, Nicole B. Lee, Bongshin Lee, Wanda Pratt, and Julie A. Kientz. 2014. Understanding Quantified-Selfers' Practices in Collecting and Exploring Personal Data. 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, 1143–1152. https://doi.org/10.1145/2556288.2557372

[12] 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. https://doi.org/10.1145/3411764.3445706

[13] Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A. Kientz, and Sean A. Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (San Francisco, California, USA) *(CSCW '16)*. Association for Computing Machinery, New York, NY, USA, 770–786. https://doi.org/10.1145/2818048.2819926

[14] 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 (mar 2019), 27 pages. https://doi.org/10.1145/3314394

[15] Christine Clar, Katharine D Barnard, Ewen Cummins, Pamela Royle, and Norman Waugh. 2010. Self-monitoring of blood glucose in type 2 diabetes: systematic review. *Health Technology Assessment* 14, 12 (2010), 1–140. https://doi.org/10.3310/hta14120

[16] 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. https://doi.org/10.1145/2750858.2807554

[17] Felicia Cordeiro, Daniel A. Epstein, Edison Thomaz, Elizabeth Bales, Arvind K. Jagannathan, Gregory D. Abowd, and James Fogarty. 2015. Barriers and Negative Nudges: Exploring Challenges in Food Journaling. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (Seoul, Republic of Korea) *(CHI '15)*. Association for Computing Machinery, New York, NY, USA, 1159–1162. https://doi.org/10.1145/2702123.2702155

[18] Aykut Coşkun and Armağan Karahanoğlu. 2023. Data Sensemaking in Self-Tracking: Towards a New Generation of Self-Tracking Tools. *International Journal of Human–Computer Interaction* 39, 12 (2023), 2339–2360. https://doi.org/10.1080/10447318.2022.2075637 arXiv:https://doi.org/10.1080/10447318.2022.2075637

[19] I Ruiz de Velasco, N González, Y Etxeberria, and JC Garcia-Monco. 2003. Quality of Life in Migraine Patients: A Qualitative Study. *Cephalalgia* 23, 9 (2003), 892–900. https://doi.org/10.1046/j.1468-2982.2003.00599.x PMID: 14616931.

[20] Domenico D'Amico and Stewart J Tepper. 2008. Prophylaxis of migraine: general principles and patient acceptance. *Neuropsychiatric disease and treatment* 4, 6 (2008), 1155–1167. https://doi.org/10.2147/ndt.s3497

[21] Elizabeth Victoria Eikey, Clara Marques Caldeira, Mayara Costa Figueiredo, Yunan Chen, Jessica L Borelli, Melissa Mazmanian, and Kai Zheng. 2021. Beyond self-reflection: introducing the concept of rumination in personal informatics. *Personal and Ubiquitous Computing* 25, 3 (2021), 601–616. https://doi.org/10.1007/s00779-021-01573-w

[22] 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* (Pittsburgh, PA, USA) *(DIS '23)*. Association for Computing Machinery, New York, NY, USA, 2625–2641. https://doi.org/10.1145/3563657.3596087

[23] Daniel A. Epstein, Monica Caraway, Chuck Johnston, An Ping, James Fogarty, and Sean A. Munson. 2016. Beyond Abandonment to Next Steps: Understanding and Designing for Life after Personal Informatics Tool Use. 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, 1109–1113. https://doi.org/10.1145/2858036.2858045

[24] 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. https://doi.org/10.1145/2750858.2804250

[25] A. Farmer, O. J. Gibson, L. Tarassenko, and A. Neil. 2005. A systematic review of telemedicine interventions to support blood glucose self-monitoring in diabetes. *Diabetic Medicine* 22, 10 (2005), 1372–1378. https://doi.org/10.1111/j.1464-5491.2005.01627.x

[26] Michel D Ferrari. 1998. The economic burden of migraine to society. *Pharmacoeconomics* 13 (1998), 667–676. https://doi.org/10.2165/00019053-199813060-00003

[27] Rowanne Fleck and Geraldine Fitzpatrick. 2010. Reflecting on Reflection: Framing a Design Landscape. In *Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction* (Brisbane, Australia) *(OZCHI '10)*. Association for Computing Machinery, New

York, NY, USA, 216–223. https://doi.org/10.1145/1952222.1952269
[28] Robert H Friedman, Lewis E Kazis, Alan Jette, Mary Beth Smith, John Stollerman, Jeanne Torgerson, and Kathleen Carey. 1996. A telecommunications system for monitoring and counseling patients with hypertension: impact on medication adherence and blood pressure control. *American journal of hypertension* 9, 4 (1996), 285–292. https://doi.org/10.1016/0895-7061(95)00353-3
[29] Paul Glasziou, Les Irwig, and David Mant. 2005. Monitoring in chronic disease: a rational approach. *Bmj* 330, 7492 (2005), 644–648. https://doi.org/10.1136/bmj.330.7492.644
[30] Peter M. Gollwitzer and Paschal Sheeran. 2006. Implementation Intentions and Goal Achievement: A Meta-analysis of Effects and Processes. 38 (2006), 69–119. https://doi.org/10.1016/S0065-2601(06)38002-1
[31] Rúben Gouveia and Daniel A. Epstein. 2023. This Watchface Fits with my Tattoos: Investigating Customisation Needs and Preferences in Personal Tracking. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems* (Hamburg, Germany) *(CHI '23)*. Association for Computing Machinery, New York, NY, USA, Article 327, 15 pages. https://doi.org/10.1145/3544548.3580955
[32] Erik Grönvall and Nervo Verdezoto. 2013. Understanding challenges and opportunities of preventive blood pressure self-monitoring at home. In *Proceedings of the 31st European Conference on Cognitive Ergonomics* (Toulouse, France) *(ECCE '13)*. Association for Computing Machinery, New York, NY, USA, Article 31, 10 pages. https://doi.org/10.1145/2501907.2501962
[33] Hilary Hutchinson, Wendy Mackay, Bo Westerlund, Benjamin B. Bederson, Allison Druin, Catherine Plaisant, Michel Beaudouin-Lafon, Stéphane Conversy, Helen Evans, Heiko Hansen, Nicolas Roussel, and Björn Eiderbäck. 2003. Technology Probes: Inspiring Design for and with Families. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Ft. Lauderdale, Florida, USA) *(CHI '03)*. Association for Computing Machinery, New York, NY, USA, 17–24. https://doi.org/10.1145/642611.642616
[34] Susan L. Janson, Kelly Wong McGrath, Jack K. Covington, Su-Chun Cheng, and Homer A. Boushey. 2009. Individualized asthma self-management improves medication adherence and markers of asthma control. *Journal of Allergy and Clinical Immunology* 123, 4 (2009), 840–846. https://doi.org/10.1016/j.jaci.2009.01.053
[35] 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. https://doi.org/10.1145/3025453.3025480
[36] Ravi Karkar, Jasmine Zia, Roger Vilardaga, Sonali R Mishra, James Fogarty, Sean A Munson, and Julie A Kientz. 2016. A framework for self-experimentation in personalized health. *Journal of the American Medical Informatics Association* 23, 3 (2016), 440–448. https://doi.org/10.1093/jamia/ocv150
[37] Dmitri S. Katz, Blaine A. Price, Simon Holland, and Nicholas Sheep Dalton. 2018. Data, Data Everywhere, and Still Too Hard to Link: Insights from User Interactions with Diabetes Apps. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (Montreal, Quebec, Canada) *(CHI '18)*. Association for Computing Machinery, New York, NY, USA, 1–12. https://doi.org/10.1145/3173574.3174077
[38] Matthew Kay. 2014. Challenges in personal health tracking: the data isn't enough. *XRDS* 21, 2 (dec 2014), 32–37. https://doi.org/10.1145/2678024
[39] L Kelman. 2007. The Triggers or Precipitants of the Acute Migraine Attack. *Cephalalgia* 27, 5 (2007), 394–402. https://doi.org/10.1111/j.1468-2982.2007.01303.x PMID: 17403039.
[40] Young-Ho Kim, Jae Ho Jeon, Bongshin Lee, Eun Kyoung Choe, and Jinwook Seo. 2017. OmniTrack: A Flexible Self-Tracking Approach Leveraging Semi-Automated Tracking. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 1, 3, Article 67 (sep 2017), 28 pages. https://doi.org/10.1145/3130930
[41] Rafal Kocielnik, Lillian Xiao, Daniel Avrahami, and Gary Hsieh. 2018. Reflection Companion: A Conversational System for Engaging Users in Reflection on Physical Activity. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 2, 2, Article 70 (jul 2018), 26 pages. https://doi.org/10.1145/3214273
[42] Amanda Lazar, Christian Koehler, Theresa Jean Tanenbaum, and David H. Nguyen. 2015. Why We Use and Abandon Smart Devices. 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, 635–646. https://doi.org/10.1145/2750858.2804288
[43] Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A Stage-Based Model of Personal Informatics Systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Atlanta, Georgia, USA) *(CHI '10)*. Association for Computing Machinery, New York, NY, USA, 557–566. https://doi.org/10.1145/1753326.1753409
[44] Edwin A Locke and Gary P Latham. 2013. Goal setting theory: The current state. (2013), 623–630. https://doi.org/10.4324/9780203082744
[45] Lena Mamykina, Elizabeth M. Heitkemper, Arlene M. Smaldone, Rita Kukafka, Heather J. Cole-Lewis, Patricia G. Davidson, Elizabeth D. Mynatt, Andrea Cassells, Jonathan N. Tobin, and George Hripcsak. 2017. Personal discovery in diabetes self-management: Discovering cause and effect using self-monitoring data. *Journal of Biomedical Informatics* 76 (2017), 1–8. https://doi.org/10.1016/j.jbi.2017.09.013
[46] Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: investigation of social scaffolding for reflective thinking in diabetes management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Florence, Italy) *(CHI '08)*. Association for Computing Machinery, New York, NY, USA, 477–486. https://doi.org/10.1145/1357054.1357131
[47] Aubrey N Manack, Dawn C Buse, and Richard B Lipton. 2011. Chronic migraine: epidemiology and disease burden. *Current pain and headache reports* 15 (2011), 70–78. https://doi.org/10.1007/s11916-010-0157-z
[48] Michael J. Marmura, Stephen D. Silberstein, and Todd J. Schwedt. 2015. The Acute Treatment of Migraine in Adults: The American Headache Society Evidence Assessment of Migraine Pharmacotherapies. *Headache: The Journal of Head and Face Pain* 55, 1 (2015), 3–20. https://doi.org/10.1111/head.12499
[49] Helena M. Mentis, Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough, and Lisa Shulman. 2017. Crafting a View of Self-Tracking Data in the Clinical Visit. 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, 5800–5812. https://doi.org/10.1145/3025453.3025589
[50] Sonali R. Mishra, Predrag Klasnja, John MacDuffie Woodburn, Eric B. Hekler, Larsson Omberg, Michael Kellen, and Lara Mangravite. 2019. Supporting Coping with Parkinson's Disease Through Self Tracking. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland Uk) *(CHI '19)*. Association for Computing Machinery, New York, NY, USA, 1–16. https://doi.org/10.1145/3290605.3300337
[51] Jimmy Moore, Pascal Goffin, Jason Wiese, and Miriah Meyer. 2022. An Interview Method for Engaging Personal Data. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 5, 4, Article 173 (dec 2022), 28 pages. https://doi.org/10.1145/3494964
[52] Sean A. Munson. 2017. Rethinking assumptions in the design of health and wellness tracking tools. *Interactions* 25, 1 (dec 2017), 62–65. https://doi.org/10.1145/3168738
[53] Elizabeth L. Murnane, Tara G. Walker, Beck Tench, Stephen Voida, and Jaime Snyder. 2018. Personal Informatics in Interpersonal Contexts: Towards the Design of Technology that Supports the Social Ecologies of Long-Term Mental Health Management. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW, Article 127 (nov 2018), 27 pages. https://doi.org/10.1145/3274396
[54] Jasmin Niess and Paweł W. Woźniak. 2018. Supporting Meaningful Personal Fitness: The Tracker Goal Evolution Model. 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, 1–12. https://doi.org/10.1145/3173574.3173745
[55] Aisling Ann O'kane, Sun Young Park, Helena Mentis, Ann Blandford, and Yunan Chen. 2016. Turning to peers: integrating understanding of the self, the condition, and others' experiences in making sense of complex chronic conditions. *Computer Supported Cooperative Work (CSCW)* 25 (2016), 477–501. https://doi.org/10.1007/s10606-016-9260-y
[56] Sun Young Park and Yunan Chen. 2015. Individual and Social Recognition: Challenges and Opportunities in Migraine Management. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing* (Vancouver, BC, Canada) *(CSCW '15)*. Association for Computing Machinery, New York, NY, USA, 1540–1551. https://doi.org/10.1145/2675133.2675248
[57] Laura R. Pina, Sang-Wha Sien, Teresa Ward, Jason C. Yip, Sean A. Munson, James Fogarty, and Julie A. Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (Portland, Oregon, USA) *(CSCW '17)*. Association for Computing Machinery, New York, NY, USA, 2300–2315. https://doi.org/10.1145/2998181.2998362
[58] Shriti Raj, Toshi Gupta, Joyce Lee, Matthew Kay, and Mark W Newman. 2023. "It can bring you in the right direction": Episode-Driven Data Narratives to Help Patients Navigate Multidimensional Diabetes Data to Make Care Decisions. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems* (HamburgGermany) *(CHI '23)*. Association for Computing Machinery, New York, NY, USA, Article 470, 16 pages. https://doi.org/10.1145/3544548.3581073
[59] Damien Ridge, Laurna Bullock, Hilary Causer, Tamsin Fisher, Samantha Hider, Tom Kingstone, Lauren Gray, Ruth Riley, Nina Smyth, Victoria Silverwood, Johanna Spiers, and Jane Southam. 2023. 'Imposter participants' in online qualitative research, a new and increasing threat to data integrity? *Health Expectations* 26, 3 (2023), 941–944. https://doi.org/10.1111/hex.13724
[60] 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. https://doi.org/10.1145/2556288.2557039

[61] Hyeyoung Ryu, Andrew B.L. Berry, Catherine Y Lim, Andrea Hartzler, Tad Hirsch, Juanita I Trejo, Zoë Abigail Bermet, Brandi Crawford-Gallagher, Vi Tran, Dawn Ferguson, David J Cronkite, Brooks Tiffany, John Weeks, and James Ralston. 2023. "You Can See the Connections": Facilitating Visualization of Care Priorities in People Living with Multiple Chronic Health Conditions. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems* (Hamburg, Germany) *(CHI '23)*. Association for Computing Machinery, New York, NY, USA, Article 473, 17 pages. https://doi.org/10.1145/3544548.3580908

[62] Morgan Klaus Scheuerman, Katta Spiel, Oliver L. Haimson, Foad Hamidi, and Stacy M. Branham. 2020. *HCI Guidelines for Gender Equity and Inclusivity*. https://www.morgan-klaus.com/gender-guidelines.html

[63] 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. https://doi.org/10.1145/3196709.3196738

[64] Jessica Schroeder, Jane Hoffswell, Chia-Fang Chung, James Fogarty, Sean Munson, and Jasmine Zia. 2017. Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food and Symptom Journals. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (Portland, Oregon, USA) *(CSCW '17)*. Association for Computing Machinery, New York, NY, USA, 1726–1739. https://doi.org/10.1145/2998181.2998276

[65] 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 (sep 2020), 26 pages. https://doi.org/10.1145/3369809

[66] Robert Smith. 1998. Impact of Migraine on the Family. *Headache: The Journal of Head and Face Pain* 38, 6 (1998), 423–426. https://doi.org/10.1046/j.1526-4610.1998.3806423.x

[67] Glen D Solomon and KL Price. 1997. Burden of migraine: a review of its socioeconomic impact. *Pharmacoeconomics* 11 (1997), 1–10. https://doi.org/10.2165/00019053-199700111-00003

[68] Lisa M Vizer, Jordan Eschler, Bon Mi Koo, James Ralston, Wanda Pratt, and Sean Munson. 2019. "It's Not Just Technology, It's People": Constructing a Conceptual Model of Shared Health Informatics for Tracking in Chronic Illness Management. *J Med Internet Res* 21, 4 (29 Apr 2019), e10830. https://doi.org/10.2196/10830

[69] Kathryn Yorkston, Kurt Johnson, Estelle Klasner, Dagmar Amtmann, Carrie Kuehn, and Brian Dudgeon. 2003. Getting the work done: a qualitative study of individuals with multiple sclerosis. *Disability and Rehabilitation* 25, 8 (2003), 369–379. https://doi.org/10.1080/0963828031000090506 PMID: 12745946.