Personalizing Health Technologies to Support Patient and Provider Goals

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Abstract
Many people and health providers are excited by the prospect of using patient-generated data to better understand and manage their health. Unfortunately, current tools generally fail to support the goals people have for their health. In this position paper, we discuss challenges and opportunities in using personal data and artificial intelligence to support personalized health. We first describe our prior research in supporting the collection and collaborative interpretation of patient-generated data to support personalized health goals. We then present open challenges we hope to discuss in incorporating artificial intelligence into health technologies.

Introduction and Context
Many patients and healthcare providers believe self-tracked data has the potential to capture a more complete understanding of patient health [4, 5, 19]. Unfortunately, self-tracking tools often leave the goals people have for their data unstated and lacking explicit support. For example, people with chronic conditions often want to better understand how habits and behaviors affect their symptoms [2, 11], but tools tend to emphasize the data itself without providing such insights (e.g., in charts and timelines that primarily show the magnitude of data) [6]. Providers also struggle with their goals for patient-tracked data, as they often lack time to analyze the data or feel unequipped to interpret it [4, 19].

Due to these disconnects between the goals people have and the designs of the tools they use, people often: 1) find self-tracking overwhelming and without purpose (i.e., *struggle to define tracking goals*) [7]; 2) find self-tracked data does not support their questions (i.e., *struggle to align data with their goals*) [3]; 3) find tools fail to support their goals over time (i.e., *struggle to adapt tracking to evolving goals*) [8]; and 4) find collaboration with providers difficult (i.e., *struggle with the multiple goals of patients and providers*) [5].

To help people and health providers overcome these challenges, our research has focused on investigating novel methods and tools to better support personalized health goals. Our systems have generally used heuristics and expert knowledge to support people and health providers in collecting and collaboratively interpreting patient-generated data to help them better understand and manage their health. In our evaluations of these systems, our patient and provider participants have reported that these systems contribute both tracking and medical expertise, helping them communicate and collaborate with each other and form a more personalized understanding of their health. In our current work, we are beginning to investigate how patient-provider collaboration and personal data interpretation might extend to tools that incorporate artificial intelligence (AI) techniques.

In this position paper, we discuss challenges and opportunities in using artificial intelligence to support personalized health goals. We first review our prior research in three health contexts characterized by complex, chronic symptoms that require personalized interventions to address: mental health disorders, irritable bowel syndrome, and migraine. For each context, we propose opportunities we see to augment our systems with artificial intelligence. We then present open challenges we hope to discuss in attempting to incorporate artificial intelligence in health technologies.

Emphasizing Goals in Condition Management

Our research has examined designing for personalized health goals across three different health contexts.

Supporting DBT for Mental Health Management

Approximately 18% of US adults suffer from a mental illness in a given year [12]. Dialectical behavioral therapy (DBT) is an evidence-based treatment designed to help people develop concrete skills to solve problems, maintain relationships, and navigate negative situations. We investigated fostering DBT engagement with Pocket Skills, a multimedia mobile app designed to provide holistic support for DBT, including goal setting, educational components, skill practice, and self-tracking of positive and negative moods and behavior [17]. We conducted a 4-week field study with 73 participants to assess the feasibility of Pocket Skills. After the study, participants reported statistically and clinically significant improvements (i.e., 50.0% of participants were "recovered" or "improved" in terms of anxiety, 26.4% in terms of depression, and 19.4% in terms of DBT skills use, with details of these scales and definitions in [17]). We also contributed a model of how participants felt Pocket Skills supported DBT, finding that the app helped them *engage* with their DBT and *learn* and *practice* skills that worked for them, which enabled them to *implement* those skills in their daily lives, see *concrete results* of using the skills, and increase their *self efficacy* to manage their mental illness.

However, although participants reported progress towards their personal goals, the app did not explicitly support those goals: skills were taken directly from traditional DBT, and not tailored or suggested based on the individual using the app. We ultimately envision an app intelligently recommending feasible, effective, and contextually appropriate skills for an individual to use in times of distress. We are therefore examining how technology-delivered mental health interventions could use machine learning techniques to tailor skill suggestions given an individual's past app use, in-the-moment emotions and environment, personal characteristics, and goals for their therapy [16].

Supporting Trigger Identification for IBS Management
Irritable Bowel Syndrome (IBS) symptoms can often be triggered by certain foods, but different people have different triggers. Providers often recommend patients keep food and symptom journals to identify personal symptom triggers [2], but patients and providers struggle to interpret the resulting data (e.g., describing data as overwhelming, making biased and inconsistent recommendations). We investigated how to support people and providers in identifying personalized IBS triggers using food and symptom journals. We first developed analyses using food and symptom data to identify correlations between specific food nutrients an individual consumed and their subsequent IBS symptoms [20]. We then designed and developed interactive visualizations to help people explore relationships between the foods they eat, the nutrients those foods contain, and the symptoms that correlate with those nutrients [14]. We evaluated those visualizations in a feasibility study with 10 pairs of patients with IBS and health providers, finding that collaboratively reviewing the visualizations helped patients and providers interpret the data, communicate and apply their knowledge and expertise, and build mutual trust. Finally, we designed, developed, and evaluated a system that supports hypothesis testing by guiding people through personalized self-experiments to examine whether a particular nutrient causes symptoms [9].

The systems we developed can support people people as they *form* and *test* hypotheses about what foods trigger their IBS symptoms. However, in evaluating our systems, we found nuanced and personalized goals people often want to pursue beyond simply identifying whether a certain food can trigger IBS symptoms (e.g., cost-benefit analyses to determine whether to avoid a potential trigger in a particular context). In a follow-up study investigating personalized health goals [15], we therefore proposed Bayesian methods to analyze self-tracked data and produce representations that better support these additional goals. These analyses could incorporate both individual *and* population-based knowledge and help patients and providers answer specific questions they have about their health.

Supporting Goal-Directed Tracking for Migraine Management
Similar to IBS, migraines can be caused by personalized factors [1, 10]. However, potential migraine contributors span a wide range of possible domains (e.g., sleep, diet, mood and stress, environmental factors). In addition, multiple factors often must accumulate before precipitating symptoms [10, 18]. Due to these challenges, collecting and interpreting migraine-related data can be particularly difficult. In a formative study with people with migraine and health providers, we identified four distinct goals people often have for migraine tracking [13]. Based on these findings, we developed *goal-directed self-tracking*, a new method that aims to support people and providers in: 1) understanding each other's goals; 2) tracking *exactly* and *only* what they need to track to achieve those goals; and 3) collaboratively interpreting resulting data relative to those goals.

We are currently developing a system to support goal-directed self-tracking for migraine management. Our preliminary findings indicate potential for such a system to: 1) help people define and develop tracking and management goals; 2) encourage people to consider and prepare for all stages of self tracking; and 3) contribute additional expertise in patient-provider collaboration. We have also identified pitfalls people may encounter when relying on a system's expertise, attempting to define and navigate appropriate tracking goals, and configuring infeasibly broad tracking routines. Machine learning could help people avoid some of these pitfalls by recommending goals and configurations and dynamically adjusting tracking routines to minimize tracking burdens on a day-to-day basis (e.g., narrowing a routine to focus on symptoms during particularly stressful time periods).

Challenges in Using AI in Health Technologies

We see a number of parallels between challenges we encountered in attempting to support people's personalized health goals and pitfalls we anticipate in systems attempting to incorporate artificial intelligence into health technologies. In this section, we argue that any insights provided by artificial intelligence in health technologies must be *actionable*, *personalized*, and *interpretable* to ensure the resulting systems are feasible, ethical, and useful.

First, for a machine learning algorithm to be feasible and useful, it needs to generate *actionable* insights. Exactly what "actionable" means will depend on the specific health context; in the mental health space, we might want our DBT system to detect when a person is distressed and suggest a skill to help reduce distress. Without a human-centered perspective that emphasizes actionability within a specific health context, insights generated by machine learning algorithms are unlikely to support people and providers in that context in practice.

However, actionability within a given context cannot provide sufficient support; an insight also has to be *personalized* (i.e., tailored to an individual's preferences, characteristics, and in-the-moment context) to be both feasible and ethical. For example, a DBT system that detects distress and suggests an actionable skill will be helpful in theory. However, if a model recommends "taking a cold shower" and the person is at work, the suggestion is not feasible, even if that skill is typically effective. Recommendations therefore must be personalized to the individual's routine and context. Similarly, some people may not want an app to automatically sense distress, so the interface should also be personalizable to instead elicit self-report of distress. Systems including population-level aggregations therefore must take this wide range of personal and contextual data into account, both in the models they use and the interfaces they present.

Another requirement for artificial intelligence in health technologies is *interpretability*. Interpretable AI is an open area of research in general, as interpretability can help people both understand how an algorithm came to its conclusion and verify that the conclusion is a reasonable one. However, interpretability is particularly important in health, because we generally do not want to just tell people what to do; we want to teach them how to identify and implement strategies that can help them start to independently manage their health. Without interpretability, a system might also exacerbate pitfalls we have seen in which participants rely *too* much on our system to contribute necessary expertise and end up making decisions that might not actually be ideal for them personally. Although a system that does not support interpretability could help people navigate a subset of scenarios in which they have access to that system, that system is unlikely to help people understand and implement beneficial choices in any scenario they might encounter.

Overall, intelligent systems have the potential to be transformative in supporting personalized health, because they could help people in collect and interpret data and identify patterns they may otherwise have overlooked. But for these systems to be feasible, ethical, and useful, they cannot be "one size fits all", assuming what everyone in a given context wants, consents to, and needs. Instead, we need our tools to acknowledge and adjust to the multiple, distinct, and evolving goals people and health providers may have.

Acknowledgments

We thank all of the additional co-authors on our reviewed work. This work was supported in part by the National Science Foundation under grant numbers DGE-1256082, IIS-1553167, and IIS-1813675 and the National Institutes of Health under grant number P50MH115837.

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