# Patient Perspectives on AI-Driven Predictions of Schizophrenia Relapses: Understanding Concerns and Opportunities for Self-Care and Treatment

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## Abstract

Early detection and intervention for relapse is important in the treatment of schizophrenia spectrum disorders. Researchers have developed AI models to predict relapse from patient-contributed data like social media. However, these models face challenges, including misalignment with practice and ethical issues related to transparency, accountability, and potential harm. Furthermore, how patients who have recovered from schizophrenia view these AI models has been underexplored. To address this gap, we first conducted semi-structured interviews with 28 patients and reflexive thematic analysis, which revealed a disconnect between AI predictions and patient experience, and the importance of the social aspect of relapse detection. In response, we developed a prototype that used patients' Facebook data to predict relapse. Feedback from seven

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patients highlighted the potential for AI to foster collaboration between patients and their support systems, and to encourage self-reflection. Our work provides insights into human-AI interaction and suggests ways to empower people with schizophrenia.

## Keywords

artificial intelligence; mental health; patient perspectives; schizophrenia relapse

## 1 INTRODUCTION

Schizophrenia spectrum disorders (or schizophrenia) are among the most severe persistent psychotic disorders, affecting nearly 24 million people, or about 1 in 300 people worldwide [113]. They are characterized by hallucinations, delusions, and disorganized thinking and speech [59]. There is no known cure for these illnesses; however, recent pharmaceutical and behavioral research has found that some treatments can help patients manage their symptoms [92], allowing them to maintain their daily lives. However, over 80% of patients experience symptom worsening or relapse leading to challenges such as hospitalization, job loss, and even suicide [4, 19, 59]. Therefore, it is critical for clinicians and patients to identify early signals of potential relapse and intervene quickly. To this end, clinicians rely on patient self-reports and family observations during consultations [19, 59]. Unfortunately, both the accuracy and timeliness of this information are limited by recall bias and the typically low frequency of consultations [97].

To address the limitations of traditional approaches to relapse detection, computing and clinical researchers have developed artificial intelligence (AI) models capable of predicting schizophrenia relapse [11, 18, 19, 55, 96, 110]. Among various types of input data, such as electronic health records, smartphone data, and social media, social media data are considered promising due to their written text (already utilized in psychoanalysis) and social behaviors, such as interactions with others [50]. More broadly, human–computer interaction (HCI) researchers have created AI models that leverage social media data to predict a variety of mental health conditions, including depression [17], suicidal ideation [66], psychotic disorders [19], and schizophrenia relapse [11, 56]. Despite concerns about privacy [15], appropriation of non-health data, and data ownership [85], experts recognize the potential of AI models using social media data to address pressing challenges in mental health treatment. The potential lies in the ability of such AI models to overcome the inherent subjectivity in the mental health diagnostic process and disparities in treatment decisions [27]. Specifically, AI models for predicting schizophrenia relapse are expected to enable clinicians and patients to identify and intervene as early as possible, while mitigating gaps in clinical judgment and patient self-awareness [56].

Similar to AI models in other domains, such as the public sector [75], education [62], and human resources [91], AI models in mental health —including those that predict relapse in schizophrenia—face numerous challenges in implementation [23]. For example, the insights provided by these AI models often diverge from clinicians' clinical language and conceptualizations of treatment, undermining their practical utility[102]. In addition,

patients tend to be unfamiliar with these AI models, and many feel sidelined during their development [27]. This lack of patient perspective can lead to technologies that are misaligned with the patient experience. In extreme cases, patients may place unwarranted trust [68] in AI technologies, influenced by the AI hype prevalent in mainstream narratives. This raises ethical dilemmas around transparency, accountability, patient autonomy, and potential harm [45, 77]. Given that mental health patients have historically been marginalized and their values often downplayed, there is a risk of deepening their distrust and disengagement from healthcare systems [107]. AI-driven models could exacerbate this marginalization and hinder patients' quest for appropriate and timely care [89]. By addressing their concerns and insights, we aim to identify how mental health AI technologies could better support patients in their treatment and recovery. In this paper, we address the following research questions:

- RQ1: How do patients perceive AI-based predictions in the context of schizophrenia relapse?

- RQ2: What is the potential role and impact of AI-based predictions on the self-care strategies of patients with schizophrenia?

To answer these research questions, we conducted a three-phase study: first, we conducted interviews; second, we developed a prototype based on the findings from the interviews; finally, we elicited feedback on the prototype. For Phase 1, the exploratory interview study, we recruited 28 patient participants via schizophrenia peer support online communities on Reddit and Facebook. The exploratory interviews revealed that relapse detection involves social behaviors in which patients rely on their support systems. Therefore, better incorporation of existing support systems into AI models is the most critical social requirement. In Phase 2, based on the findings from Phase 1, we built a prototype using real Facebook data, which was voluntarily provided by 7 patient participants. Subsequently, in Phase 3, we collected feedback on this prototype from the same 7 participants. These feedback-gathering sessions revealed a new role for AI-driven predictions in facilitating conversations between patients and support systems, as well as the potential for self-refection using social media-based AI models. Summarily, we offer the following contributions:

- This study found that patients with schizophrenia rely on their support systems —including family, friends, and caregivers—to detect relapse signals. Current research efforts to develop AI models overlook this aspect. We propose a new role for AI in mental health: initiating conversations between patients and their support systems.

- We explored patient concerns about the accuracy, utility, and ethics of AI-driven relapse prediction in schizophrenia. By amplifying patient voices, we aim to inform future HCI research on AI models for schizophrenia treatment.

- We developed a prototype based on patient concerns. Feedback showed that presenting predictive information alongside raw social media data encouraged refection, a vital part of self-care and treatment.

- Our approach of soliciting input from individuals diagnosed with schizophrenia distinguishes our study from existing HCI literature. This focus addresses a gap in HCI research and societal attention where this population is often overlooked, and reinforces the importance of our findings in the context of inclusive and patient-centered AI development.

## 2   RELATED WORK

In this section, we situate the research presented in this paper by pulling together findings and insights from three areas or topics: first, how data, computing, and AI-driven approaches have been developed to address challenges in mental health; second, how human-AI interactions and collaborations have been examined and implemented in various health technologies; and third, investigations that have sought to assess the risk of relapse among patients with schizophrenia.

### 2.1   Data, Computing, and AI-driven Technologies for Mental Health

Data, computing, and AI-driven technologies are enabling researchers to analyze vast amounts of data to uncover clinically significant patterns [54]. In fields such as radiology, oncology, and ophthalmology, AI-driven technologies have been touted to outperform experienced professionals in detecting abnormalities in images [65, 98]. AI has also been touted to improve clinical diagnostic workflows by extracting relevant information from electronic health records (EHRs) [76]. However, its adoption in psychiatry has lagged due to the inherent subjectivity of the field [27]. Despite this, many believe that AI could transform diagnostic systems, predict disease trajectories, and tailor treatment plans by harnessing large amounts of clinical and non-clinical data [24, 32, 99]. This role of AI is often noted to be critical in the mental health domain, because of the alarming shortage of trained professionals and the increasing mental health needs of individuals as both the prevalence of these conditions and adverse events such as suicide increase [73].

However, incorporating such models into clinical practice is challenging, and ethical concerns are paramount [13, 33, 86]. A gap exists between insights derived from AI models and established mental health practices, which can render these insights less interpretable and actionable. Mental health professionals, including researchers and clinicians, are still exploring ways to translate these insights into actionable information [43, 90]. There is also a risk that mental health patients will either avoid or misuse AI models if the insights do not resonate with their language and practices. This can lead to compromised patient autonomy in the clinical decision-making process [23, 108]. Furthermore, the promise of AI-driven personalized care [73] challenged by a lack of understanding of patient practices and preferences. Many AI initiatives overlook the unique needs and desires of patients. To truly achieve personalized care, we need to amplify patients' voices and understand their interactions with their environment [93]. In this paper, we explore patient practices, concerns, and needs related to AI-driven predictions of schizophrenia relapse.

Graham et al. highlighted five types of data for AI-driven mental health technologies: electronic health records (EHRs), mood scales, brain imaging, passive sensing, and social media [50]. Each has unique benefits and challenges. Brain imaging data, enriched by

computer vision, still offers limited understanding in the context of mental illness [114]. EHRs provide rich clinical data, but may miss nuances of daily life outside of clinical encounters. Passive sensor data, such as from smartphones, capture daily behaviors but may miss cognitive and social details [87]. Social media data reveal patients' online behaviors, including linguistic markers of mental illness [37]. However, researchers have identified moral tensions in using social media data for mental health research and potential interventions [29]. In this paper, we focus on social media data as a representative example of mental health AI technologies. Based on the known ethical tensions of inferring mental health states from social media, we advocate that any collection of this data should only be undertaken by trusted entities, such as healthcare providers, with explicit consent, and that the data should always be handled with the utmost care and transparency [29]. We neither encourage nor discourage the use of social media by people with mental health issues. We chose to explore the potential and concerns of this data source because many individuals with mental health challenges actively use social media [70], and there is a growing interest in leveraging this data in the field of digital mental health and HCI [50, 116]. Our work contributes to HCI researchers seeking to harness social media data to understand and support mental health [30, 38], and more broadly to those investigating AI solutions for digital mental health [87, 106].

In summary, we explore the potential of AI-driven technologies in mental health, particularly using social media data, and address the ethical challenges involved. Studies have shown that AI using social media data can predict risk for conditions such as major depression, psychosis, and suicidal tendencies with accuracy comparable to traditional methods such as self-reports on validated psychometric and clinical instruments [19, 21, 66]. Our goal is to ensure that such advances are safe and beneficial for patients, emphasizing the importance of integrating patient insights for an ethical and effective AI mental health framework [27, 48].

We note that in this paper we use the term "artificial intelligence (AI)" in a broad sense to encompass data-driven and machine learning-based technologies [51, 79]. With deep roots in traditional statistical and computational analysis, these modern AI approaches often inherit the transparency and trust issues associated with these traditional methods [83, 103]. It is important to understand this connection as we explore the implications of AI-driven technologies in our work.

## 2.2 Human-AI Interaction in Healthcare

Recently, HCI researchers have been extensively investigating how to improve human-AI collaboration in real-world healthcare contexts. This includes exploring how AI can be incorporated into pathologists' workflows [25, 26, 52], treatment recommendations [23, 102, 115], and clinicians' coping strategies [7, 108]. These studies show that clinicians have their own mechanisms for 'negotiating [102]' with AI technologies, rather than fully following or rejecting AI decisions. While these studies offer insightful implications for future AI in healthcare, the current research trajectory is heavily skewed toward the perspectives of healthcare providers, often overlooking the voices of patients. We hypothesize that this is in part because clinicians and providers, such as pathologists, are typically the primary users

of AI technologies. However, we emphasize the importance of including patient voices in human-AI interactions, as they are the ones most affected by the resulting technologies.

There have been several studies that have explored patient perspectives on human-AI interaction. For instance, Ayobi et al. utilized computational notebooks such as Jupyter to facilitate interactions between young adults with type 1 diabetes, their caregivers, and clinicians [6]. This approach highlighted the value of interactive data visualizations for both understanding personal health data and the functionality of AI models. In a different context, Corvite et al. analyzed employees' views on emotion AI in the workplace through open-ended survey questions [36]. Their results were mixed, with one-third of participants questioning the benefits of AI-driven emotion inference in the workplace, while others noted both potential harms and benefits. This study underscores the ethical considerations of using AI to interpret emotional states in professional settings. These early investigations align with our belief that future research should strive to align AI models with real-world experiences [6, 36]. In the field of mental health AI, delving into the depth and breadth of patients' lived experiences is paramount given the unique nature of each individual's illness journey [16, 50]. Our research aims to expand the scope of human-AI interaction in healthcare by focusing on "patient-AI interaction," ensuring our models are attuned to the nuanced experiences of those they serve.

It is crucial to recognize that early efforts to understand patient perspectives, including those of data subjects, may not be directly applicable to the context of schizophrenia. The unique symptoms of schizophrenia, such as paranoia, hallucinations, and delusions, represent experiences that are largely unfamiliar to the general population. For instance, individuals experiencing paranoia may avoid technology due to heightened concerns associated with their symptoms [14]. Additionally, cognitive dysfunction such as impaired working memory might prevent individuals with schizophrenia from engaging in complex data tasks, such as using a Jupyter Notebook, as discussed by Ayobi et al [6]. On a more optimistic note, patients with schizophrenia who have established strong relationships with clinicians and support systems may be more inclined to share AI-inferred information, in contrast to the workplace contexts examined by Corvite et al [36]. Therefore, it's essential to tailor the design process to these specific conditions and experiences of individuals with schizophrenia. Including patient voices in this process is vital to ensure the feasibility, acceptability, and usability of health technologies, all of which are key to their successful implementation [84].

In our work, we continually advocate for the concept of "patient-AI interaction," which emphasizes the importance of not only the direct relationship between patients and AI technologies, but also the role of support systems. These systems include family members, friends, loved ones, healthcare providers, and other trusted individuals involved in the patient's self-care and treatment journey [101]. Previous research has extensively explored design opportunities to enhance collaboration between patients and their support systems across a range of health conditions, including adolescent cancer patients [1, 64], clients of occupational therapists [47], children with special needs [100], people with dementia [42, 53, 88], children with type 1 diabetes [28], and people with serious mental illness [101]. This body of work highlights the challenges and needs of support systems in

assisting patients. Our research contributes to these ongoing HCI efforts by focusing on improving collaboration between individuals with schizophrenia and their support systems. We identify design opportunities for mental health AI technologies based on our participants' willingness to engage with their support systems. Furthermore, we extend these design insights to address the preservation and prioritization of patient autonomy in the sharing process. Finally, we propose a new role for mental health AI technologies in facilitating dialogue between patients and their support systems.

### 2.3   Relapse Prediction in Schizophrenia

Schizophrenia is characterized by both positive and negative symptoms [3]. Positive symptoms include exaggerated or distorted functioning, such as hallucinations, delusions, and disorganized thinking. In contrast, negative symptoms are characterized by a reduction or loss of normal functioning, including poverty of speech, inability to experience pleasure, and lack of motivation. These symptoms significantly disrupt the daily lives of people with schizophrenia, often leading to a significant decrease in quality of life and difficulty maintaining employment or education [111]. While the biological causes of schizophrenia are not fully understood and a definitive cure remains elusive, a combination of pharmaceutical treatments and psychotherapy has proven effective in managing symptoms and supporting daily functioning. However, more than 80% of patients who experience a first episode of schizophrenia will experience a relapse, defined by a worsening of symptoms that often requires intensive care including hospitalization [49]. These relapses may result in drug-resistant or residual symptoms [78] which may contribute to more complex future treatment pathways [112]. Therefore, preventing relapse, detecting early signs of impending relapse, and intervening as early as possible are critical aspects of schizophrenia management [49]. Clinicians typically rely on patient self-report and clinician observation to detect early signs of relapse [58]. However, the complex and individualized nature of schizophrenia symptoms makes relapse prevention difficult. Even among those who adhere to their treatment plans, including medication, 40% experience a relapse during their course of treatment [44].

To address the challenges of relapse prevention, researchers have explored diverse ways to predict potential relapse. Early work utilized statistical approaches (e.g., multivariate logistic regression) based on clinician assessments of prodromal symptoms, such as difficulty concentrating or loss of interest [49], and hospital administrative information, such as the number of emergency admissions and unplanned discharges [109]. These early efforts failed to achieve significant predictive value, in part because clinician assessments and hospital administrative information lack sufficient granularity to identify nuanced changes in patient symptoms [104]. To address this sparsity issue, a recent effort used ecological momentary assessment (EMA) to leverage patients' self-reported symptoms in their daily lives [22]. This study found small to medium effects on negative mood, anxiety, persecutory ideation, and hallucinations prior to relapse.

Recently, researchers have applied advanced machine learning methods to diverse data types such as smartphone passive sensing [12, 118] and social media [19]. Zhou et al. used clustering models (Gaussian mixture model and partition around medoids) and

balanced random forest [118] to analyze a year's worth of six types of mobile sensing data (ambient light, sound, conversation, acceleration, etc.) from 63 patients, achieving an F2 score of 0.23 for relapse prediction. Barnett et al. conducted a three-month pilot study using passive sensor data such as GPS, accelerometer, anonymized calls and texts, screen on/of time, and phone charging status from 17 patients [12]. Their anomaly detection indicated that the rate of anomalies detected in the two weeks prior to relapse was 71% higher than in other periods, suggesting the potential of passive sensing data for early relapse signals. Birnbaum et al. performed anomaly detection on 52,815 Facebook posts from 51 patients and developed a one-class classification model to identify months leading to hospitalization [19]. They analyzed linguistic features, including word usage and psycholinguistic attributes (using LIWC [105]), related to emotion, behavior, and mental health states. In their structural linguistic analysis of Facebook posts, they focused on readability, word repetition, and length. Additionally, they examined the frequency, timing, and types of Facebook activities, such as check-ins, co-tagging, and app usage, to gain insight into social functioning and patterns. Their classifier achieved a specificity of 0.71.

In this study, we utilize Birnbaum et al.'s model [19] as an exemplary technology because of its demonstrated higher performance compared to other models. However, it is important to note that relapse prediction algorithms are still in their infancy and require more rigorous evaluation, including external validation and randomized trials. While many HCI and digital mental health researchers are working to refine these algorithms and develop deployable solutions, our study aims to gather insights from patients with schizophrenia. The objective is to provide actionable implications for future research in relapse prediction and human-AI interaction.

## 3   PHASE 1: INTERVIEW STUDY

The purpose of this interview study is to understand patients' current relapse detection practices and their opinions on existing relapse prediction technology. This exploratory interview study aims to deepen our understanding of the concept of AI-based relapse prediction and inform our prototypes, which will be described in Section 4.

### 3.1   Interview Study Methods

**3.1.1   Recruitment.—**To gather patient perspectives, we recruited participants who had been diagnosed with schizophrenia, were 18 years of age or older, and lived in the United States. We chose to focus on U.S. participants to align our study with the unique medical and legal context of the U.S. healthcare system.

To recruit individuals with schizophrenia who are active on social media, we posted recruitment advertisements on relevant support groups on Facebook and Reddit. On Reddit, we posted the ad on two schizophrenia support group subreddits. On Facebook, we selected eight groups with more than a thousand members each and followed the community rules for posting materials. Interested individuals completed an online survey detailing their diagnosis, age, and location. They were then phone-screened to confirm their understanding of the study and to address any concerns. This also helped to establish an initial rapport and verify the legitimacy of the researcher.

Ultimately, 28 participants (15 female, 9 male, 3 transgender, and 1 non-binary) between the ages of 18 and 52 (average age 29) participated in the study. The majority of participants identified as White (18), followed by four who identified as Hispanic or Latino, four as Asian, one as Middle Eastern, and one as multiracial. 14 participants had a bachelor's degree or higher. Table 1 shows the demographic information of the participants. The study protocol was approved by the authors' institutional review board (IRB). Interviews ranged from 35 to 75 minutes, and participants were compensated with a $25 gift card.

**3.1.2 Participant Safety Measures.—**To ensure the safety and wellbeing of the participants, we implemented several safety measures. These began with a preliminary telephone screening in which we explained the study and assessed participants' comfort level. This step was instrumental in building trust, as several participants expressed increased comfort after the call.

Prior to the interviews, we informed participants about available support resources, such as 7 Cups of Tea[1], the Crisis Text Line[2], and the National Suicide Prevention Lifeline[3]. We also worked with a medical professional to assist in the event of intense distress during the sessions.

During the interviews, participants were encouraged to express their discomfort and reassured of their autonomy to decline uncomfortable questions. On one occasion, a brief pause was necessary for a participant who was overwhelmed with emotion; however, she chose to continue after recovering. No participants reported any distress after the interview. However, they were reminded of their ability to contact us or the mental health resources mentioned if any problems arose after the interview.

**3.1.3 Interview Procedure.—**We conducted semi-structured online interviews with participants. Upon entering the Zoom meeting, we explained the purpose of the research and addressed their questions. Participants then provided consent by entering their name on an online form.

The first part of the interview explored the participant's experiences with mental illness and relapse. This included their diagnosis, hospitalizations for schizophrenia, and their relationship with their care providers. Most participants had seen both a psychiatrist and a therapist. We explored their views of their clinicians, how they defined relapse, recent relapse events, and prevention measures.

The second part of the interview focused on their views on AI in mental health. We began by discussing their general experiences with AI technologies. We then presented an example based on Birnbaum et al.'s AI model, as shown in Figure 1. This model predicts schizophrenia relapses that result in hospitalization, using hospitalization as a measurable proxy for relapse. Additional details about the example model can be found in section 3.1.4.

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[1] https://www.7cups.com
[2] http://www.crisistextline.org/
[3] 1-800-273-8255

After participants reviewed the example, we gathered their impressions and concerns, and concluded with any remaining questions they had about the research.

### 3.1.4 An Example AI Model Used in Interviews.—In this subsection, we discuss the AI model used as an example during the interviews, shown in Figure 1. This model, developed by Birnbaum et al.[19], was chosen for its pioneering use of patient social media data and stringent patient safety measures. Birnbaum's team recruited 51 participants (ages: 15–35) with primary psychotic disorders from the northeastern United States and collected their Facebook data after obtaining informed consent. Hospitalization dates and diagnoses were obtained from their medical records. They ensured participant safety through follow-up interviews and had a system in place to address any concerns raised. If any issues were identified, the researcher was able to contact the patient's treatment team immediately. Note that these participants are separate from those in our study.

The data consists primarily of textual content from Facebook posts and metadata such as date, time, and location. Images, videos, and direct messages are not used in the data analysis due to privacy concerns. A total of 52,815 Facebook posts from 51 participants (mean=71.08) were used for model development. Birnbaum et al. utilized linguistic features such as word usage (n-gram language model) and psycholinguistic attributes (LIWC) [105]. They also analyzed structural aspects of language, including readability, repeatability, and word length. Additionally, they examined behavioral aspects of Facebook usage, such as the volume and timing of posts, as well as specific Facebook activities (e.g., check-ins, co-tagging, liking, and sharing content).

Using the data and features, Birnbaum et al. developed one-class support vector machine (SVM) models [35] to classify a one-month period of Facebook data as either a healthy period or an unhealthy/relapse period [19]. The "unhealthy/relapse period" is defined as a one-month period that ends with a relapse hospitalization. They employed an ensemble support vector machine (SVM) method, training the model on 90% of the healthy periods and testing it on the remaining 10% of the healthy periods as well as all unhealthy/relapse periods. The model achieved a specificity of 0.71 and a sensitivity of 0.38. This means that the model was accurate about 71% of the time in identifying an unhealthy/relapse period. However, it was accurate only 38% of the time in identifying a healthy period. Given the serious consequences of relapse and the ongoing nature of schizophrenia treatment, higher specificity would be more desirable. The positive predictive value of the model is 0.66, which means that when the model classifies a period as unhealthy/relapse, it is correct 66% of the time.

Figure 1 presents information about this model in plain language. The information specifies the types of data (the language patterns, volume, and timing of the posts) as well as the definitions of relapse (worsening of symptoms leading to hospitalization). It also provides the positive predictive value of the model in plain language: "If the algorithm says someone is at high risk, it is right about two-thirds of the time." Participants in the interviews were shown this figure and asked to comment on it. During the interviews, the interviewers provided additional information when participants expressed interest in learning more about

the example technology. We note that all participants indicated that they had no prior experience or knowledge of predictive algorithms.

**3.1.5    Data Analysis.—**All interview sessions were recorded with the consent of the participants. These recordings were transcribed using Otter.ai[4], and the first author reviewed the transcripts for accuracy. We used the reflexive thematic analysis to analyze the written interview transcripts [20]. The first and second authors familiarized themselves with the data by reading it thoroughly several times. They each coded the five interviews independently and met to discuss differences. Through iterative meetings, the authors discussed diferences until a consensus was reached. The first author then coded the remaining interviews, meeting periodically with the second author to discuss new codes and potential initial themes. The initial analysis identified seven themes across the transcripts such as "patient perspectives on accuracy", "patient perspectives on utility of AI models", "ethical concerns", "patient social media use", "social media and relapse detection", "social aspects of relapse detection", and "including AI into support systems". After iterative discussion within the research team, we refined these to four main themes. These final themes are discussed in the following section. For our data analysis, we used Atlas.ti[5], a computer-assisted qualitative data analysis tool.

As Braun and Clarke have explained [20], we utilized both inductive and deductive approaches simultaneously in our analysis. We paid close attention to the individual context and flow of each transcript while also attempting to contextualize the meanings within the existing literature on human-AI interaction and relapse prediction in schizophrenia, as detailed in the related work section (Section 2). As outlined in our positionality statement (Section 3.1.6), we acknowledge that our perspectives and prior knowledge influenced the data analysis. Therefore, we advise readers to interpret our findings and design implications with caution.

**3.1.6    Positionality.—**In our study, we take a constructionist approach, acknowledging our inherent biases and the subjective nature of our interpretations. We do not claim to be detached "scientists" uncovering unaltered truths, but rather acknowledge that our real-world perspectives influence our research [8, 9]. Our research group consists of eight professionals from the HCI and mental health fields who bring diverse demographic and cultural experiences to the table. This diversity includes individuals from ethnic minorities, members of the LGBTQ+ community, and immigrants. Importantly, some team members have personal experience living with mood disorders and caregiving experience supporting family members or friends with psychotic disorders.

Two authors conducted the interviews and initial thematic analysis of the transcribed data. Those authors have personal experiences with mental health related to a patient and a caregiver. While this personal connection enriches our professional understanding, we acknowledge that these lived experiences could potentially bias the interpretation of the data, possibly leaning more toward patient advocacy perspectives. To mitigate this, the final stages of thematic analysis, which included discussion of themes and iteration of

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[4] https://otter.ai
[5] https://atlasti.com

data analysis, were conducted collaboratively by all eight team members. This collective approach, drawing on our diverse individual and shared experiences, was critical to ensuring a balanced representation of patient perspectives and mental health care considerations.

## 3.2 Interview Study Findings

### 3.2.1 Disconnects Between Patient Experience and AI Models' Definition of Relapse.—From a clinical perspective, a schizophrenia relapse is defined as an acute psychotic exacerbation [44]. Similar to other mental disorders and symptoms [5], the definition of relapse in schizophrenia remains subjective, as there are no objective criteria for terms such as "acute" or "exacerbation". Because of this ambiguity, clinical research has often resorted to operationalizing the definition by using hospitalizations or medical records as markers [4]. Such operational definitions have been incorporated into recent AI models that refer to hospitalizations [19], medical records [11], and changes in medical scales (e.g., the Positive and Negative Syndrome Scale, PANSS [71]) [56]. Consequently, the definition of relapse in predictive models and its detection may not match patients' own perceptions of relapse or their methods of detecting it.

Participants in our study had different definitions of relapse. Some simply described it as the return of psychotic symptoms (e.g., "I just went into psychosis" (P3) and "I would define it as psychotic symptoms coming back, like delusions?" (P25)). Participants who defined it this way were generally more stable and did not experience psychotic symptoms on a daily basis. Others described relapse as a worsening of their symptoms, which is more consistent with the clinical definition of an acute psychotic exacerbation. A few participants used the phrase "losing touch with reality" to characterize their relapses:

> "At first I would start hearing voices, then I would start talking to the voices and then it feeds me delusions, and then I would just completely lose touch with reality. That's happened probably two or three times now. It's just a cycle, pretty much of what happens."
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> –P15

> "I think for relapse, I would have to completely lose touch with reality. when I was in a psychotic episode, I thought dead people were talking to me. I was looking for ghost, I was talking back to them. I was writing to them. I was looking for their obituaries in the newspaper. I think managing persecutory delusions and auditory hallucinations, while still being fairly in touch with reality and in control of my actions. I don't see that as relapsing. Although I could see someone arguing that it is, I think that's just a daily aspect of living with schizophrenia."
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> –P4

While the previous definitions focused more on symptoms, some participants approached the definition of relapse in terms of the consequences of relapse. They explained some of the changes in their daily activities due to their symptoms, such as "not being able to take care of my things" (P21) and "I slowly stopped doing laundry" (P14). P9 also elaborated on her relapse experience and anchored it in hygiene.

> "Usually, when I have a psychotic episode, or when I start when the paranoia gets too much, and I don't go out, and things like that, or don't interact, and my house becomes a mess, because I'm not cleaning it up. This stuff like that, and everything becomes… I have hard times you know, thinking straight and clearly and difficulty doing the things I need to do every day you know, taking a shower, that kind of stuff."

> –P9

The gap between patients' own perceptions of relapse and AI models' definitions of relapse implies that resulting technologies based on AI models may not be able to support patients in their treatment and recovery journeys. We further discuss design implications based on this finding in Section 6.1.

**3.2.2   Social Aspects of Relapse Detection.**—Although participants could easily define relapse in their own terms, they mentioned that recognizing it can be elusive. In stable conditions, they recognized hallucinations and delusional thoughts as unreal, but during psychotic episodes or relapses, it was difficult for them to recognize that they were experiencing psychotic symptoms, as P14 explained.

> "Relapse, as in I became unable to take care for myself, in general, I feel like relapses, usually, consist of psychosis and stuff like that. If I become, like, lose insight into some of the thinking or behavior that, you know, I'm not really sure to how to explain it because usually during these episodes, I don't really know what's going on and I don't really remember them too well. If I'm actively, like, having, like, delusions and hallucinations, and I'm not aware that they are delusions and hallucinations, and they're impacting how I'm interacting with people, and, you know, if I'm not able to carry out my day to day tasks, that's when I go to the hospital."

> –P14

Note that when P14 mentions "losing insight", he is referring to the medical term that means "acknowledging having a mental disorder or symptoms of a mental disorder [2]". We can reasonably assume that all of our participants have insight into their psychosis because they consider themselves to be patients with schizophrenia. As P2 specifically mentioned, *"I have a lot of what we call insight. People with schizophrenia often don't have insight, or what's called anosognosia, which basically means they think they're normal and everybody else is crazy."* However, even people with insight lose awareness of their psychosis, making it difficult to detect relapses.

Because it is difficult for patients to recognize a relapse, they rely on their support systems: significant others, family members, and friends. For example, P4's husband is very supportive and well informed about P4's psychotic symptoms. P4 often checks in with her husband when she feels anxious about things that might be related to possible relapses.

> "Lately, I've been going to restaurants, and I don't think people are talking about me at other tables. But if I were to go to a restaurant and think that people were talking about me, like, I would become suspicious of myself and my thoughts, I

also have I'm married, so I can rely on my husband's perception of situations and ask him like, Is this happening? So that's regarding like auditory hallucinations, I'll often ask like, did you hear that? And so often, the answer is no."

–P4

Similarly, P22 discusses his delusional thoughts with others as a coping mechanism.

"My biggest symptom that I usually have is paranoid delusions, somewhere I'll be wholeheartedly convinced that some very outrageous thing is going to happen. It feels more like a premonition than anything and it's unshakeable. And I'll start talking about it and, and saying, I feel like this is going to happen. And worst-case scenario, someone confirms that saying, 'Yep, it's gonna happen.' And then best case scenario, they're like, 'No, that's not going to happen.' You need to take a step back and just relax."

–P22

The social dimension of relapse detection suggests that AI models could benefit from incorporating these interpersonal processes. Most likely, patients who receive an alert from AI models will need to check in with others to confirm their relapses. How to initiate or facilitate this social process of relapse detection has not been considered in the literature to date and will be a key to developing useful AI models for patients with schizophrenia. We will explore this aspect further in the following section.

**3.2.3  Including AI into Support Systems.**—As we discussed in the previous section (Section 3.2.2), patients consistently turned to their support systems, consisting of family, friends, peers, and sometimes clinicians, when faced with potential relapses or worsening symptoms. They would reach out to their support systems to check in on them, something like, "Have you noticed that I've been acting different? (P25)" P28 elaborated on this symptom check-in with their support systems, focusing on having an excuse to reach out to them:

"Sometimes, just speaking for myself, it's sometimes hard to get taken seriously. Or I don't even think to tell them about a delusion or, paranoia because it's so common for me, so maybe having this information [AI-based prediction] to bring to them might, you know, get their attention or would remind me to tell them about how I'm feeling when I would otherwise forget."

–P28

In the quote above, P28 pointed out two different aspects. The first is that AI-based predictions can help them get the attention of their support systems. The other is that AI-based predictions can remind them to communicate with their support systems, especially when they have mild daily symptoms. Both of these aspects can facilitate symptom management and communication with support systems. P22 even mentioned that he would ask his support systems to monitor him: "Could you guys just keep an eye on me and make sure that I don't start acting out or saying things that, you know, hurt people or hurt myself in any way?"

Some participants included their clinicians in their support systems. They want to tell their clinicians that an AI model has alerted them, and they want to be evaluated for symptoms and possible relapses. For both caregivers and clinicians, it is imperative that participants already have a good relationship with and trust them. Some participants explained that there are different levels of trust and types of relationships within support systems, and they would like to reach out to those they trust the most. It is also apparent that they would like to reach out to those who are already providing them with good care and attention. This point was made even clearer when P5 said that he would rather tell his therapist than his psychiatrist because of their existing relationship:

> "My psychiatrist, he's a little harder to communicate with. He's a lot more stern, like an authoritarian figure. My therapist she's a lot easier to talk to, you can pretty much say anything, and she'll just roll with it. So I'd be more inclined to mention it to my therapist rather than my psychiatrist personally."

–P5

Support systems are essential not only for relapse detection, but also for most aspects of treatment and daily life. However, due to the devastating nature of these disorders, tensions can arise between patients and their support systems. For example, P18, who has a very supportive husband who attends psychiatric appointments with her, mentioned that there were disagreements about relapse detection and symptom assessment, especially when she was symptomatic.

> "It makes me feel kind of wary of him. Like, why is he not accepting my experience as fact, because I think it's a fact. And then we changed my meds and I'm like, Okay, I was not doing too great."

–P18

P5 also noted that he has a very supportive girlfriend, although he is sometimes reluctant to burden her with the responsibility of managing his symptoms. Similarly, P1 said that she sometimes did not want to talk to her support system because she often had difficulty expressing herself when she was symptomatic. These implicit and explicit tensions between patients and their support systems imply that future technologies should facilitate constructive conversations between the two parties in terms of collaborative relapse detection and symptom management.

Another aspect of collaboration between patients and support systems is that participants would make an effort to seek help from support systems even if they didn't agree with the predictions or in the case of false positives. Participants conveyed that recognizing relapses or symptoms alone is challenging, so it would be wise to seek support systems even if the predictions differ from their self-assessments or turn out to be false alarms. As a result, they have a greater tolerance for inaccuracy. They appreciate the importance of regularly checking in with their support systems, even in the case of false alarms, as explained by P7.

> "I just think that no matter what, it would be useful for your loved ones to be notified by this technology, whether or not it really indicated a risk of relapse. I think it's good to draw attention to those things […] And then, for it to turn out to be not as a huge risk, still a very valuable thing as long as you're not scaring or

frightening your loved ones, then I think it's fine. And truthfully, at the end of the day, your loved ones shouldn't be frightened by that, like they should be supportive and they should be there for you no matter what."

–P7

In summary, our participants reported that while AI models provide valuable support in relapse prevention, they should not operate in isolation. Participants expressed a desire to work with their existing support systems when AI models alert them to potential relapse risks.

**3.2.4 Ethical Concerns.—**Participants expressed ethical concerns regarding the AI mental health technology example in Figure 1. The primary concern is **surveillance**, as the use of these AI models could lead to monitoring and profiling of individuals. This concern dovetails with recent studies showing harm and discrimination against marginalized communities [39, 80, 82]. P16 shared his concerns about potential surveillance and profiling as follows:

"It sounds like Facebook might have access to this data. And then, you know, is Facebook going to be targeted? I don't know. I just don't think a company should have data about that sort of thing. Guess what, if it alerts the police, that's pretty terrifying."

–P16

The algorithm in the example technology was developed by a university-affiliated team, establishing its independence from Facebook and making clear that Facebook does not own it. This distinction is important given Facebook's past involvement in controversies, such as the misuse of data in the Cambridge Analytica scandal [67] and ethical questions surrounding its suicide prevention efforts [10]. These incidents have contributed to Facebook's complicated public image and raised legitimate concerns about its privacy and ethical practices.

Participants' concerns about Facebook reflected the nuanced perceptions. Some were influenced by negative media portrayals and folk theories [40] about the company's data practices. For example, P20 expressed a general distrust, saying, "I don't trust Facebook all that much. […] I'm sure you've heard horror stories like Facebook accessing your camera." In contrast, others drew on personal experience. P1, with a background in criminal justice, provided insight into the practical implications of data surveillance, noting, "I've worked for the government in the legal system and criminal justice. So they monitor our accounts, obviously if I had a Facebook account linked to my email, they could easily find that, like we find that information on our defendants all the time." This blending of external perceptions with individual experiences creates a multifaceted understanding of why participants might be anxious about technologies associated with Facebook, despite the algorithm's independent development.

Regarding issues of surveillance and privacy, participants raised concerns specific to one psychotic symptom — paranoia. Paranoia refers to an excessive and distressing sense of alarm about the intentions of others that can interfere with one's ability to function

normally [14]. Patients with paranoid ideation tend to believe that other people have harmful intentions behind their behavior. Because of this tendency, researchers believe that paranoia precedes persecutory delusions [14]. Both paranoia and persecutory delusions are common symptoms in people with schizophrenia. Therefore, many participants mentioned their concerns about paranoia, as P23 and P16 explained:

> "Let's say the algorithm is correct and it's spotting a time when someone is feeling delusional or paranoid. If you get an email or a popup telling you this information, I know for me that might make me even more paranoid because my mind would start to think I'm being watched."
>
> –P16

> "From my own perspective, as I live with the paranoia, I don't like letting people in my head. And yeah, it would kind of creep me out. I feel like it might improperly profile me, like, I might get offended. It might tell me I'm going into an episode when I'm not. I feel like there could be a lot of it could be abused."
>
> –P23

We are not suggesting that participants distrust AI models solely because of their paranoia symptoms. As we noted above, their concerns about surveillance and privacy are indeed valid, and are also echoed in non-mental health contexts [31]. The important point here is that these AI models could pose additional risks to these individuals because of their paranoid ideation. The potential for surveillance and profiling could exacerbate the symptoms of those with paranoid ideation and persecutory delusions, as explained by P20.

> "Mainly I, my main concern is again, being watched, being monitored. It might exacerbate symptoms in people with psychotic disorders because that's a common delusion is just, oh, I'm being watched. And I feel like that might take some fears into overdrive for people with psychosis."
>
> –P20

P25 made a constructive suggestion in this regard:

> "If I wasn't stable, if I was having a relapse of symptoms, it might be a little scary for me. Feeling like someone's watching me. I think it might be something that you have to really talk through with them, and really explain what it is. Or even have like a therapist explain what it is to them. Because when you are paranoid, you do think that computers and televisions and things like that are watching you. And like tracking your every move and like AI can be really scary. So I think you really need to be very gentle. And, like, really explain what it is and explain how it's not harmful. And explain how it's, like, has the potential to be a helpful tool to you. I know that's not going to work for everyone. But I think that that is a good way to start."
>
> –P25

At the very least, as mental health AI researchers, we need to be aware of these patient concerns, as the existence of AI models could exacerbate some symptoms of schizophrenia. We envision that future mental health AI research should include patient representatives

on research teams or invite patient auditors to ensure that AI models are not used against patients. Building trust with patients will be as important as improving model performance in mental health AI research.

Participants also mentioned their concerns about their **autonomy**. They were worried about situations in which they might be hospitalized based solely on the output of these AI models. They clearly mentioned that they wanted these AI models to serve as additional sources of assessment to support human clinicians' decisions. If clinicians are going to use these AI models to evaluate patients, participants mentioned that patients need to have ways to interact with their clinicians, especially for advanced care such as hospitalization, as P16 and P12 explained.

> "But for me, if that thing, sent that information to my psychiatrist without audit, if it did it automatically, oh, I would be furious and paranoid so much. I would feel like I have no power, which is very triggering. I would feel like things are working behind my back, which is very triggering, I would be extremely paranoid about not being able to give my psychiatrists context and being worried that he was just going to, like, commit me to a hospital."
>
> –P16

> "Potentially the risk of being 1013ed and being involuntarily admitted to a psychiatric hospital by my therapist. That's my only concern, but I do feel that my therapist works with me generally, to make sure that like I'm agreeing to it."
>
> –P12

Finally, it is worth noting that participants mentioned the need for **data security** for these mental health AI models. P9 mentioned that even hospital records are stolen and used against patients, so he might be concerned about data security. P1 raised concerns about social media platforms selling data to others, such as insurance companies. We believe these are all valid concerns, and mental health AI researchers should be cautious when developing new AI models and AI-based interventions in light of these patient concerns. We further discuss the implications of these ethical concerns from patient voices in Section 6.2.

### 3.2.5 Patient Perspectives on Social Media and Relapse Prediction.—Many participants believed that the content and frequency of their social media posts could serve as indicators of their mental health conditions. For instance:

> "I think my symptoms were apparent through my Facebook post."
>
> –P21

> "I remember, like, one episode I had, I was just on Twitter, like, all night long, tweeting about random things that made no sense. And it was very indicative that I was having an episode."
>
> –P1

Some participants who were active in online support groups reported noticing other people with schizophrenia engaging in symptomatic behaviors in their posts ("I've noticed from people [other users in Facebook support groups] if they're going into mania or depression

or something like that, based on their Facebook posts." (P28)). P5 had an incident where another Reddit user messaged him saying that his posts were symptomatic:

> "I remember a few years ago, um, I don't even remember what I was making posts about. But I made a post on one thing. Somebody had commented underneath, like, "hey, OP [original poster], I've been going through your posts and comments. And are you okay, it sounds like something's not right." I deleted that account. But yeah. Posts on social media can be reflective of what's going on inside you, around you."

–P5

Although participants mentioned that their social media posts could be indicative of their symptoms, they questioned the ability of AI models to identify symptoms from their posts. Some participants believed that AI or machines could not understand a person's mental health experience, because it is complicated, contextual, and highly personalized.

> "I would just be concerned because everyone's so different. And everyone's gonna have diferent indicators. But I guess that's the point of the algorithm to like, learn. That's just what I would keep in mind, because what works for someone else? Or what indicates an episode for someone doesn't work for others. A lot of people are just eccentric."

–P23

In summary, participants shared experiences in which their use of social media reflected worsening symptoms. They also expressed concern about the ability of AI models to predict mental health states based on social media data. We discuss this concern and the tension of appropriating social media data for mental health purposes, further in Section 6.3.

## 4 PHASE 2: PROTOTYPE DEVELOPMENT

To develop patient-centered AI-based tools and gather iterative feedback, we created a prototype as shown in Figure 2. Figure 3 shows how the Phase 1 findings shaped the design considerations of the prototype. The prototype uses the AI model discussed in the interviews (detailed in Section 3.1.4), which predicts imminent schizophrenia relapse with a predictive value of 0.66 [19]. In the prototype, we explain the model's predictive value and key features (such as LIWC [105], n-gram [19], sentence readability and complexity, word repetition, and post frequency and timing) in plain language (see Figure 2).

Below, we detail how the findings from the Phase 1 interviews influenced the design of the prototype in three areas: Using More Patient-Centered Language in Place of 'Relapse', Nudging Users to Reach Out to Support Systems, and Using Caring and Suggestive Language and Allowing Users to Review Raw Data.

### 4.1 Disconnect in Definition of Relapse: Using More Patient-Centered Language in Place of 'Relapse'

As we discussed in Section 3.2.1, the concept of relapse in schizophrenia is diverse and unique to patient status and experience. Consequently, the operationalized definitions of relapse in AI models may or may not translate to the specific contexts of potential patient

users. Therefore, we decided not to use the term relapse in our prototype to minimize any misunderstanding or disconnect between AI models and the daily routines of patient users. This is also based on participant input that the term relapse and hospitalization can trigger. The language in the prototype is more reflective of everyday language and uses fewer trigger words. Specifically, this prototype says, "You may be experiencing some mental health issues."

### 4.2   Relapse Detection as a Social Process: Nudging Users to Reach Out to Support Systems

In Sections 3.2.2 and 3.2.3, we discuss how our participants rely heavily on their support systems for early detection of potential relapses, and express the need to incorporate these systems when using algorithmic predictions of relapse. Therefore, we design our prototype to nudge the user to reach out to their support systems. It has a prompt asking "Would you like to share this information with your support system?" accompanied by "No" and "Yes" buttons. These buttons are not functional in the prototype; however, we envisioned that a user could register their support systems in this application and it would reach out to their support systems via text or email.

### 4.3   Alleviating Ethical Concerns: Using Caring and Suggestive Language and Allowing Users to Review Raw Data

In Section 3.2.4, we discuss the ethical concerns expressed by our participants about the use of AI-driven information for relapse prediction. They were concerned that such information might infringe on their autonomy and create a sense that their actions were being dictated by AI technologies. To address these concerns, our prototype is designed to provide gentle suggestions rather than definitive directives, focusing on medication, sleep, and hygiene reminders, which emerged as the most common symptom management strategies among our participants.

Additionally, our participants expressed concerns about potential surveillance issues that could exacerbate paranoid thinking. To address this, our system offers a transparency feature that allows users to review social media posts analyzed by the AI model. On the "Review Your FB Information" page, users can see all the posts that informed the prediction. This review process not only helps users understand how the AI model reached its conclusions but also allows them to agree or disagree with the predictions, fostering a sense of contestability [61, 81].

## 5   PHASE 3: FEEDBACK GATHERING STUDY

Using the prototype shown in Figure 2, we gathered feedback from patients with schizophrenia to conduct a formative evaluation. This evaluation aimed to understand the potential role and impact of the prototype in relation to our second research question: "*What is the potential role and impact of AI-based predictions on the self-care strategies of patients with schizophrenia?*" We describe the study methods and the findings in following subsections.

### 5.1 Feedback Gathering Study Methods

**5.1.1 Recruitment.—**We sought feedback on our prototype from the participants in the Phase 1 interviews (Table 1). All had previously agreed to participate in future research. Of those contacted by email, ten agreed to participate in Phase 2 and seven completed it. Their demographics are shown in Table 2.

**5.1.2 Procedure.—**Participants were informed of the purpose of the study and how the data would be handled. After signing an online consent form, they downloaded their Facebook data from the designated website[6] and uploaded it to our secure server. Only designated researchers had access to the data, and only for the purposes of this study. The data was deleted after feedback was received.

With the uploaded data, we populated the prototype (Figure 2), excluding the last three months to avoid potential anxiety from future predictions. From the remaining nine months, we selected their most active month. All seven had no high-risk predictions.

During the remote sessions, participants viewed the prototype populated with their own data. We then walked them through each page of the prototype (as shown in Figure 2), allowing them to explore each page for a few minutes. We then asked with questions about their interpretation of the page, actions they might take based on the information, any confusion or missing information, and any concerns they had. Participants were also encouraged to ask questions. On the "Your Mental Health" page (the middle image in Figure 2), we asked about their thoughts on the self-care suggestions and the prompt to reach out to support systems, including whether they found these features helpful and would act on them. On the "Review Your FB Information" page, we asked participants to confirm their recognition of the posts and to evaluate these posts in terms of their symptom exacerbation. We also compared their evaluation of the posts to the prediction provided on the previous page. Finally, we asked for their overall impression of the prototype and any remaining thoughts or concerns.

After the session, participants confirmed that they felt comfortable, and we highlighted available mental health resources. They were also encouraged to report any subsequent discomfort from the interview.

This process, including the use of Facebook data, was approved by institutional review board (IRB). Participants received a $50 Amazon gift card for their participation.

**5.1.3 Data Analysis.—**All feedback-gathering sessions were recorded and transcribed. We used reflexive thematic analysis to analyze the transcripts [20]. Since the goal of this feedback-gathering was to obtain iterative feedback based on the results of Phase 1, those results and the structure of the prototype informed our analysis. The first author conducted the initial coding, which included the familiarization process. This initial coding and the five emerging themes were discussed by the entire team. Following these discussions, we

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6 www.facebook.com/dyi

narrowed these down to the two themes discussed in the following subsection: "Sharing Predictions with Support Systems" and "Opportunity for Refection."

## 5.2   Feedback Gathering Study Findings

### 5.2.1   Sharing Predictions with Support Systems.—In our prototypes, after receiving predictions (e.g., "You may be experiencing some mental health problems"), participants were prompted with the question: "Would you like to share this information with your support system?" All participants indicated that they would like to share this information with their respective support systems. P9 was particularly positive about this feature, commenting, "I like that you can share it with your support system. […] I was going to suggest 'contact support system,' but you already have that." P27 mentioned that she would share the information with her father because she "made a promise that if it ever happened again, I would let him know so he could help me." P14 gave a more detailed response, stating that he would share with his support system (mother, aunt, and partner) if he received warning signals. His reasoning was, "I don't want to relapse again," and his support system consists of people who "won't let him go to a dark place." P4 mentioned that sharing with her husband would help with decision making:

> "It would be helpful in talking about, like next steps and planning, you know, what to do? I think from there, it would just be a helpful tool to start making decisions. So I would share it with him."
>
> –P4

All participants indicated that they would not share results from the prototype if it showed that they were doing well. They were only willing to share information with their support systems if the results were concerning. However, opinions about sharing worrisome results varied. Some participants (P3, P12) indicated that they would only share if they agreed with the assessment, while others (P8, P14, and P27) were willing to share any worrisome results, reasoning that an additional check with support systems could be beneficial in situations that they might not perceive as worrisome. In summary, while one group prefers to share results only when they agree with the AI model's predictions, the other group is inclined to share any concerning alerts for further validation.

As expected, participants defined their support systems in a variety of ways. Some participants mentioned both their loved ones and clinicians (P3, P4, P27), while others mentioned only loved ones (P14) or only clinicians (P8 and P12). P9 highlighted peer support specialists he had met through a peer support group. It appears that their preference for a support group depends on their existing relationship with their caregivers. This suggests that future technologies should allow patients to customize their support systems.

In particular, P4 suggested the value of being connected to support systems. She was currently away from her husband and had recently experienced auditory hallucinations, which had increased her interest in technology such as the prototype:

> "I'm going to be living on my own for a while. It's going to be the first time in a really long time that I'm going to be doing that. Recently, I heard my auditory hallucination and I haven't experienced that in a long time. I also felt someone

poking me, but no one was there. So I think I would be very interested in having a tool like this available. Because I'm not going to have a person around to help with those things. I think that would actually be really useful."

<div align="right">–P4</div>

Regarding the relationship between predictive algorithms and support systems, P3 envisioned them as complementary. She pointed out that either algorithms or support systems could detect anomalous behavior first, and then the other would support or confirm the detection:

"They'll (support system) notice that something is wrong first because they know you better than an AI model. So maybe getting an alert will confirm it."

<div align="right">–P3</div>

The point raised by P3 highlights a new direction for algorithmic prediction. While predictive algorithms in mental health have traditionally focused on predicting ground truth, which does not take into account information from support systems, our study suggests that future AI research should consider incorporating the support system perspective as a factor in defining and detecting relapse. In addition, future human-AI interaction research should explore how AI models interact not only with the patient, but also with the support system. For example, are there ways for a support system to provide input into relapse detection? How can we foster a healthy collaboration between an AI model, a support system, and a patient? We discuss this further in Section 6.1.

**5.2.2 Opportunity for Reflection.**—The prototype includes a "Review Your Facebook Information" page that allows users to review their posts that contribute to the prediction. This feature is intended to give users a clearer insight into the basis of the predictions. By reviewing their own posts, participants demonstrated how they could relate their posts to the predictions.

Many participants identified aspects that they would check in their own writing. For example, P9 said he would check for grammatical correctness and logic because disorganized thinking and speech are symptoms of schizophrenia. He introduced the term "word salad" to describe symptomatic writing and added that he would evaluate the mood of his posts, noting, "Everything looks positive and happy, nothing overly negative (P9)." P4 believed that the extremely high volume of posts could indicate manic episodes. Through their personal review, participants actively sought connections between their social media activity and the AI model's decisions.

Beyond interpreting predictions, the review process facilitates self-refection. P8 described how reviewing these social media posts not only helps to understand the AI's conclusions, but also provides an opportunity to reminisce:

"You get a look at your posts, and you can be like, 'yeah, I can see that and I remember that.' So you can kind of reflect a little bit. It's nice to do that. […] You know, I was kind of off my rocker on Facebook. So that's good."

<div align="right">–P8</div>

Adding to the discussion of self-refection through social media, P3 shared a remarkable experience. She once received a notification from Facebook that her posts had been fagged by other users, urging her to be aware of her online activities. This notification caused her to re-evaluate her posting behavior and eventually recognize a manic episode she was going through. She drew parallels between being fagged by other users and being notified by the prototype: both provide an opportunity for introspection. P3 felt that such introspection could be particularly beneficial for people experiencing manic episodes. However, she emphasized that the prototype should be more transparent than Facebook's user-fagging system. When she was fagged on Facebook, the message did not specify who fagged her or the exact reasons. She expressed a desire for more explicit explanations for fagged content.

In summary, the prototype's "Review Your Facebook Information" page provided a unique window into the intricate relationship between social media activity and mental health indicators as perceived by an AI model. Participants found it valuable not only for understanding AI-based predictions, but also for personal introspection and self-awareness. Their experience underscores the importance of transparency and clarity in any tool that aims to provide mental health insights, especially around adverse events like relapse.

## 6 DISCUSSION

### 6.1 Implications for Human-AI Interaction

In sections 3.2.1 and 3.2.2, we highlighted the challenge of detecting symptom escalation in psychosis, an epistemological challenge in defining and identifying reality. Due to the complexity of the disorder, people with schizophrenia often rely on their support systems for symptom and relapse detection, a communal aspect often overlooked in AI research on relapse detection [57]. As discussed in section 3.2.3, participants expressed interest in using AI to facilitate discussions within their support networks, indicating a shift in human-AI interaction. The individuals with schizophrenia use feedback from these networks to monitor symptoms, suggesting a potential role for AI not just as a solitary intervention tool, but as part of a collaborative approach with these support systems. This highlights the need for human-AI interaction research to consider users' existing work practices and social dynamics in order to introduce AI solutions more effectively.

As we introduced in our prototype, one potential application of AI in this context is to initiate dialogues between patients and their support systems. This is critical because patients often find it challenging to initiate such conversations. As noted in Section 3.2.3, there is a discernible tension between patients and their support networks. Our study participants demonstrated considerable trust in their support systems. However, they also expressed reservations about relying too heavily on these systems. They expressed a preference for sharing AI model predictions when they felt it would benefit their symptom management. As a result, we advocate that future mental health AI tools give patients the autonomy to share AI model predictions with their support networks as they see ft. In addition, future AI technologies for patients with schizophrenia should play a role in helping them initiate conversations with their support systems. Although AI model predictions can be a catalyst for collaboration between patients and their support systems, the final decision should be made by these human actors, not by AI. This proposed minimal intervention by

AI technology in mental health suggests an evolving perspective in human-AI interaction research. It suggests a shift toward AI tools that act as initiators of collaboration rather than mere informants.

We would like to note the remaining challenges that our prototype must overcome. First, our design features may not be effective when a patient user is experiencing an active episode. Our primary intent was for self-care during stable periods; however, future technologies should also support patient users during active symptoms. For instance, a patient undergoing an active episode may have heightened concerns about data sharing and relapse prediction, which may reduce user engagement. Second, our participants expressed a desire to receive notifications when predictions indicate a worrisome status. Given the continuous nature of social media data and prediction tasks, determining the optimal frequency for AI-driven predictions remains a question. We envision that future research should explore these aspects through a more rigorous deployment study. We believe the findings and implications of this study will inform such future efforts.

## 6.2 Designing Technologies To Empower Individuals with Schizophrenia Spectrum Disorders

HCI research has a rich history of empowering individuals with chronic conditions [46], particularly those who face cognitive and communication challenges, such as individuals with autism [60, 63] and dementia [41, 69]. Such efforts allow researchers to employ innovative methods that honor the autonomy and agency of these individuals [34]. As a result, we have seen the creation of numerous technologies [95] and an expanded understanding of the challenges and work practices associated with these conditions [94]. This paper adds to this body of work by focusing on individuals with schizophrenia, a group relatively underrepresented in HCI.

Our study underscores the fact that people with schizophrenia have deep knowledge about their symptom management and treatment. Participants clearly outlined their self-care management strategies and detailed the barriers they faced during treatment and recovery. They also recognized the diversity of symptom presentations and coping strategies in their community. This suggests that patients with schizophrenia do not simply passively experience their illness, but actively interpret their illness experiences and tailor their self-care strategies accordingly [72, 74].

Yet, disappointingly, current AI models aimed at treating schizophrenia often fail to recognize this vast diversity and the unique nuances of individual patient experiences. This oversight presents a number of unresolved challenges: For example, how can an AI system differentiate and respond to a patient who experiences mild to moderate psychotic symptoms on a daily basis from a patient who rarely experiences symptoms? This leads to another key question: How can the design of technologies effectively incorporate and respect the distinctive and varied experiences of patients?

Moreover, the proactive engagement of individuals with schizophrenia in managing their symptoms, as highlighted by our participants, presents a vital perspective for technology design. It suggests that technology should not only aim to assist in symptom management

but also empower users by enhancing their autonomy and supporting their agency. Technologies that facilitate access to information, enable the customization of self-care strategies, and encourage active participation in treatment planning can significantly enrich the support ecosystem for individuals with schizophrenia.

Finally, our work provides insights for helping people with schizophrenia at different stages and in different contexts. For effective treatment and recovery, individuals with these disorders must have insight or a clear self-awareness of their condition. All participants demonstrated this self-awareness, which motivated them to be more proactive and collaborative in their recovery journey. Future efforts should consider strategies to support those who lack this self-awareness. The role of support systems also merits further investigation. Given the debilitating nature of the disease, many rely heavily on such systems. However, not everyone has access to or can afford them. Our findings are based on the existence of these support mechanisms. To truly advance our knowledge and design technologies that are appropriate for people with schizophrenia, we must also engage with those without such support structures.

In light of these considerations, our research opens the door to a broader exploration of how technological innovations can be sensitively and effectively tailored to meet the complex needs of people with schizophrenia. Future work should explore collaborative design processes that involve people with schizophrenia from the outset, ensuring that technological solutions are grounded in the real-world contexts and challenges they face. In addition, exploring the potential for technologies to support not only individuals but also their support networks could further enhance the effectiveness and impact of technology-enabled mental health interventions.

### 6.3   Utilizing Social Media Data for Mental Health AI Technologies

In our work, we focused on social media data as a source of input for mental health AI technologies. This is because social media data is considered a powerful means of understanding mental health [38], and the HCI community has spent the last decade developing AI models for mental health using social media data [30, 106]. We recognize the privacy and security concerns and potential harms of using sensitive personal data for mental health [29]. Therefore, we have carefully considered concerns from the patient perspective throughout our study.

Our participants agreed that their social media activity may reflect their mental health or symptoms based on their own experiences, as reported in section 3.2.5. However, they also expressed concern that AI models may not take into account the complex and personal contexts of individual patients, potentially reducing the value of predictions. This highlights both the potential and the challenges of using non-health related social media data in health contexts. Previous literature suggests that written texts and online social behaviors may indicate certain aspects of mental health symptoms. For example, an extremely high volume of posts may indicate manic episodes [117]. However, it remains unclear how future technologies will account for the complexity and uniqueness of personal contexts within the dataset. Current AI research in mental health has predominantly focused on broad classification and prediction, rather than prioritizing individual-level analysis [43]. Future

research should explore how individual contexts can influence the performance and utility of AI models.

There is a more pressing question to consider: should we use social media data for AI technologies in mental health? We believe that social media data presents both potential benefits and harms, similar to many other technologies. Given previous examples of exploitation of social media data by malicious parties [67], we must be extremely cautious when using such data in sensitive and high-stakes domains such as mental health. We chose Birnbaum et al.'s AI model because of its careful measures for patient safety and security [19]. We argue that future technologies that rely on social media data should exercise a high degree of caution and prioritize safety and security. We hope that the ethical concerns we have highlighted from a patient perspective can guide future researchers in developing safer technologies.

### 6.4 Limitations and Future Directions

Our work makes significant contributions to the fields of human-AI interaction and digital mental health, particularly by soliciting patient feedback on AI-driven predictions of schizophrenia relapse. However, we acknowledge several limitations of our research. First, the patient participants in our study may not represent a holistic cross-section of our target population. However, our primary goal is not to generate generalizable knowledge, but rather to integrate patient perspectives into the design of AI technology and to highlight design implications for subsequent research. It is possible that participants who participated in Phase 1 and 3 of our research may have tended to favor the prototype because their feedback was used to develop it. However, we believe that this iterative process allowed us to receive more insightful feedback as the participants are already familiar with our initial prototype designs. For a broader and more generalized understanding, follow-up studies focusing on larger and more diverse samples would be essential. During our interviews, we used a state-of-the-art AI model for context. While this provided a tangible foundation and grounded our findings in the current landscape of AI research in mental health, it may have limited the breadth of feedback from our participants. Encouragingly, future research that takes a more open and exploratory stance may uncover innovative design insights that complement and deepen our findings. We acknowledge that although the results have been thoroughly reviewed by researchers, the auto-transcription system may only be able to transfer factual data and may lose deeper meanings in the interview data.

## 7 CONCLUSION

In light of our research, it is clear that current AI models for relapse prediction in schizophrenia may overlook important social cues that patients use in their support networks. Our study highlights the indispensable role that family, friends and caregivers play in detecting relapse signals. This discovery underscores the potential for refining AI models to become collaborative tools that bridge the gap between patients and their support systems, ensuring more holistic mental health care. In addition, our exploratory venture into patient perspectives uncovered critical concerns about the accuracy, relevance, and moral implications of AI in schizophrenia relapse detection. By echoing the concerns and needs

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of patients, we call for future research to shape a more patient-centered paradigm in HCI research, focusing on the development of AI models tailored to the needs and concerns of patients.

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## CCS CONCEPTS

- Human-centered computing → Empirical studies in HCI; Empirical studies in interaction design.

Based on the language patterns in your Facebook posts,
as well as the volume and timing of your posts,
**the analysis performed by the AI model indicates
that you are at a high risk of relapse leading to hospitalization.**

**About the AI model:**
The AI model looks at different things in your Facebook activity, like the words you use and how often you post. It has a 66% chance of correctly predicting if someone is at high risk of having a relapse that could lead to hospitalization. That means if the algorithm says someone is at high risk, it's right about two-thirds of the time.

**Figure 1:**
An example of the mental health AI technology that was shown to participants during interviews.
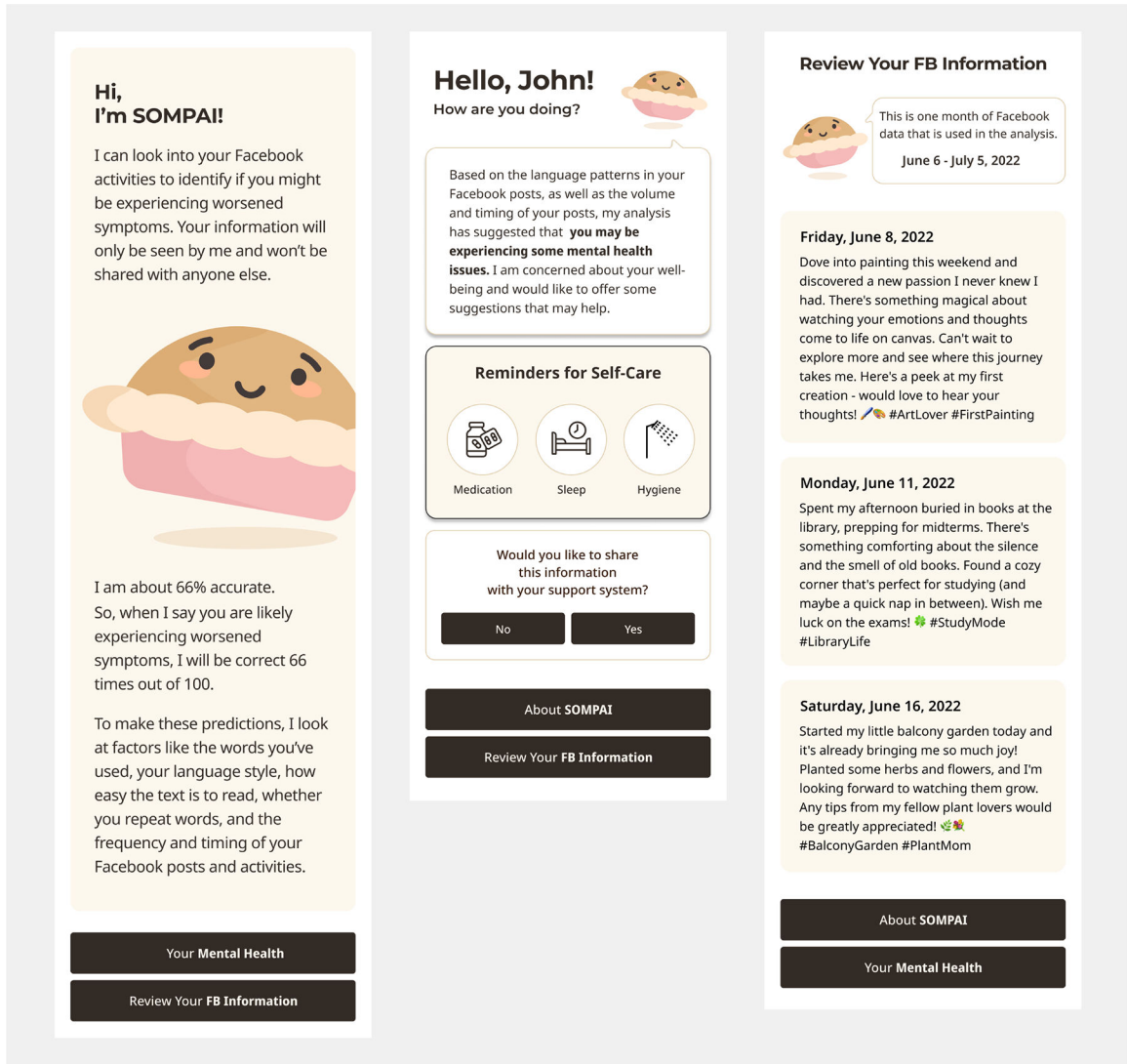
**Figure 2:**
These are three pages from the prototype. The leftmost page is the 'About SOMPAI' page, which explains what this tool is and provides additional information about the AI model behind it. The middle page, titled 'Your Mental Health,' allows users to view their prediction results. Notably, we have replaced the term 'relapse' with more caring and suggestive language, based on feedback from the Phase 1 interview study. The rightmost page is the 'Review Your FB Information' page, where users can review the Facebook posts utilized by the AI model for making predictions. The Facebook posts depicted in this figure are mock-ups, not actual posts from the participants.
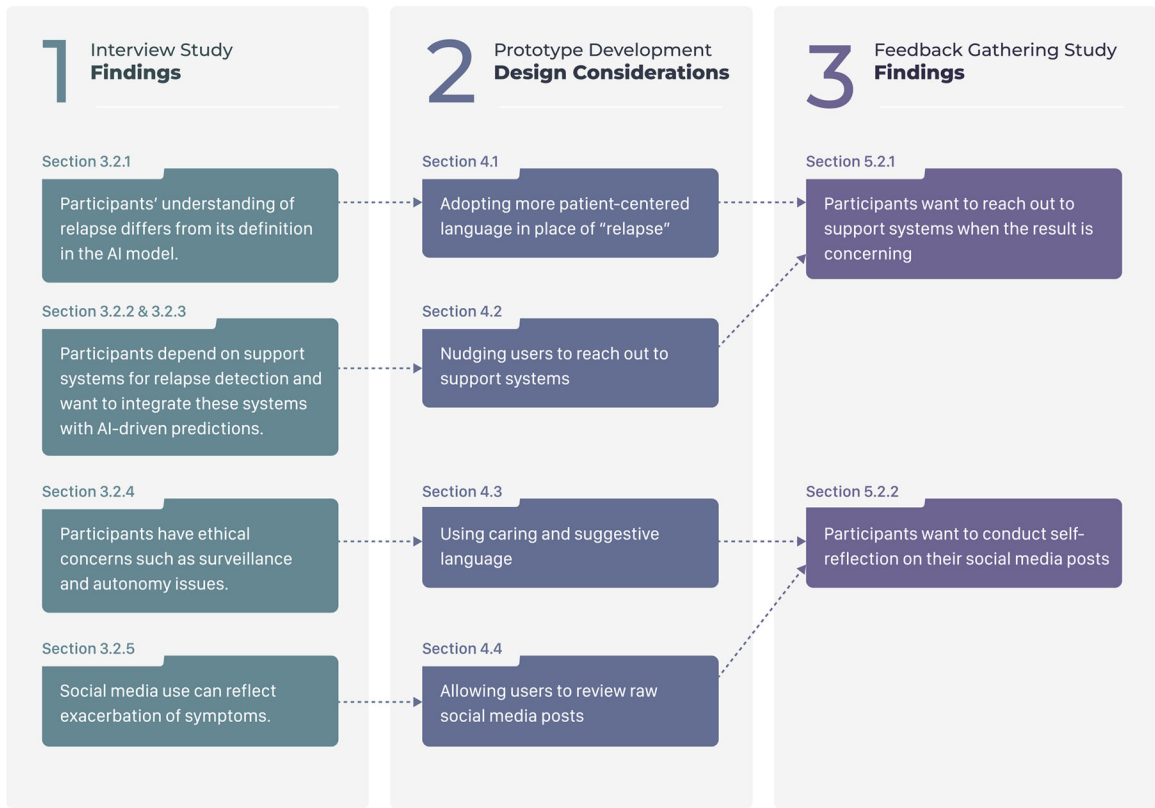
**Figure 3:**
The three-phase study process and the summary of findings.

**Table 1:**

Demographic information of the participants. All participants self-reported that they were diagnosed with schizophrenia.

| ID | Age | Sex | Race | Education | Occupation |
|---|---|---|---|---|---|
| P01 | 35 | Female | White | Advanced degree | Wage-employed |
| P02 | 26 | Female | Hispanic or Latino | Bachelor's degree | Student |
| P03 | 26 | Female | Asian | Bachelor's degree | Wage-employed |
| P04 | 35 | Female | Hispanic or Latino | Advanced degree | Student |
| P05 | 24 | Male | Middle eastern | Bachelor's degree | Wage-employed |
| P06 | 24 | Female | Asian, White | Some college, no degree | Wage-employed |
| P07 | 25 | Female | White | Advanced degree | Student |
| P08 | 25 | Male | White | Bachelor's degree | Wage-employed |
| P09 | 44 | Male | Hispanic or Latino | Highschool graduate | Unable to work |
| P10 | 23 | Transgender | White | Highschool graduate | Self-employed |
| P11 | 34 | Male | White | Advanced degree | Wage-employed |
| P12 | 23 | Female | White | Bachelor's degree | Student |
| P13 | 30 | Male | Asian | Some college, no degree | Unable to work |
| P14 | 20 | Male | Hispanic or Latino | Some college, no degree | Student |
| P15 | 19 | Male | White | Highschool graduate | Wage-employed |
| P16 | 35 | Male | White | Some college, no degree | Unable to work |
| P17 | 29 | Female | Asian | Bachelor's degree | Out of work |
| P18 | 20 | Female | White | Some college, no degree | Unable to work |
| P19 | 52 | Female | White | Some college, no degree | Unable to work |
| P20 | 22 | Female | White | Highschool graduate | Unable to work |
| P21 | 35 | Female | White | Some college, no degree | Wage-employed |
| P22 | 30 | Transgender | White | Advanced degree | Wage-employed |
| P23 | 35 | Female | Asian | Bachelor's degree | Wage-employed |
| P24 | 29 | Male | White | Bachelor's degree | Unable to work |
| P25 | 25 | Female | White | Bachelor's degree | Wage-employed |
| P26 | 18 | Transgender | White | Highschool graduate | Unable to work |
| P27 | 22 | Female | White | Some college, no degree | A student |
| P28 | 44 | Non-binary | White | Associate degree | Unable to work |

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**Table 2:**

Demographic information regarding the participants in Phase 2. All of them participated in Phase 1 and their IDs are from Phase 1.

| ID | Age | Sex | Race | Education | Occupation |
|---|---|---|---|---|---|
| P3 | 26 | Female | Asian | Bachelor's degree | Wage-employed |
| P4 | 35 | Female | Hispanic or Latino | Advanced degree | Student |
| P8 | 25 | Male | White | Bachelor's degree | Wage-employed |
| P9 | 44 | Male | Hispanic or Latino | Highschool graduate | Unable to work |
| P12 | 23 | Female | White | Bachelor's degree | Student |
| P14 | 20 | Male | Hispanic or Latino | Some college, no degree | Student |
| P27 | 22 | Female | White | Some college, no degree | Student |