Understanding mental health clinicians' perceptions and concerns regarding using passive patient-generated health data for clinical decision making: a qualitative, semi-structured interview study

Jodie Nghiem, Daniel A Adler, Deborah Estrin, Cecilia Livesey, Tanzeem Choudhury

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Abstract

Background: Digital health tracking tools intend to change mental healthcare by giving mental health clinicians passively measured patient-generated health data (PGHD) (e.g., data collected from connected devices, mobile applications, and wearables with little-to-no patient effort), providing contextual information on patient behavior and physiology from outside of the clinic with minimal data collection burden. While prior work has sought to understand how passive PGHD may be integrated within clinical workflows, researchers have not sufficiently explored how passive PGHD may reshape clinical decision making.

Objective: We conducted a qualitative study to understand mental health clinicians' perceptions and concerns regarding using technology-enabled, passively collected PGHD for clinical decision making. Our interviews sought to understand participants' current experiences with and visions for using passive PGHD.

Methods: Mental health clinicians (eg, psychiatrists, psychologists, clinical social workers) providing outpatient services were recruited to participate in semi-structured interviews. Interview recordings were de-identified, transcribed, and qualitatively coded to identify overarching themes.

Results: 12 mental health clinicians (11 psychiatrists and 1 clinical psychologist) were interviewed. Our results showed that participating clinicians had varied experience with, and interest in, using passive PGHD, specifically highlighting the lack of evidence supporting passive PGHD use, as well as gaps in knowledge on how to best integrate passive PGHD alongside more-traditional forms of clinical mental health data. In addition, participating clinicians were only interested in viewing passive PGHD at moments when they could reflect and act on passive data; drawing an analogy to a prescription or lab test, PGHD could be prescribed or ordered at opportune moments to hyperfocus on the relationships between behavior, physiology, and disease for a discrete period of time. Finally, participants called for safeguards to protect patient privacy within passive PGHD data sharing programs, ensuring passive PGHD is only collected and used to support patients' treatment goals.

Conclusions: While passive PGHD has the potential to enable more contextualized measurement, this study highlights the need for building and disseminating an evidence base describing how and when passive measures should be used for clinical decision making. Clear evidence would more effectively support the uptake and effective usage of these novel tools for both patients and their clinicians.

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Understanding mental health clinicians' perceptions and concerns regarding using passive patient-generated health data for clinical decision making: a qualitative, semi-structured interview study

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Abstract

Background: Digital health tracking tools are changing mental healthcare by giving patients the ability to collect passively measured patient-generated health data (PGHD), i.e. data collected from connected devices, mobile applications, and wearables with little-to-no patient effort. While there are existing clinical guidelines for how mental health clinicians should use more traditional, active forms of PGHD, including patient-reported outcome surveys and health histories, for clinical decision making, there is less clarity on how passive PGHD can be used for clinical decision making.

Objective: We conducted a qualitative study to understand mental health clinicians' perceptions and concerns regarding using technology-enabled, passively collected PGHD for clinical decision making. Our interviews sought to understand participants' current experiences with and visions for using passive PGHD.

Methods: Mental health clinicians (eg, psychiatrists, psychologists, clinical social workers) providing outpatient services were recruited to participate in semi-structured interviews. Interview recordings were de-identified, transcribed, and qualitatively coded to identify overarching themes.

Results: 12 mental health clinicians (11 psychiatrists and 1 clinical psychologist) were interviewed. From our interviews, we identified four overarching themes. (1) Passive PGHD is patient-driven: we found that current passive PGHD use was patient- not clinician-driven: participating clinicians only considered passive PGHD for clinical decision making when patients brought passive data to clinical encounters. (2) Active versus passive data as subjective versus objective data: participants viewed the contrast between active and passive PGHD as a contrast between interpretive data on patients' mental health and objective information on behavior. Participants believed that prioritizing passive over self-reported, active PGHD would reduce opportunities for patients to reflect upon their mental health, reducing treatment engagement and raising questions about how passive data can best complement active data for clinical decision making. (3) Passive PGHD must be delivered at appropriate times for action: participants were concerned with the "real-time" nature of passive PGHD: participants believed that it would be infeasible to use passive PGHD for "real-time" patient monitoring outside of clinical encounters, and more feasible to use passive PGHD during clinical encounters when

clinicians can make treatment decisions. (4) Protecting patient privacy: participating clinicians wanted to protect patient privacy within passive PGHD data sharing programs, and discussed opportunities to refine data sharing consent to improve transparency surrounding passive PGHD collection and use.

Conclusions: While passive PGHD has the potential to enable more contextualized measurement, this study highlights the need for building and disseminating an evidence base describing how and when passive measures should be used for clinical decision making. This evidence base should clarify how to use passive data alongside more traditional forms of active PGHD, when clinicians should view passive PGHD to make treatment decisions, and how to protect patient privacy within passive data sharing programs. Clear evidence would more effectively support the uptake and effective usage of these novel tools for both patients and their clinicians.

Introduction

Digital health tracking technologies continue to gain popularity. The adoption of these tools is steadily increasing, fueled by recent innovations in smartphone and wearable technologies that allow for the collection and storage of health-related data. Patients are using the data collected by these consumer technologies to self-monitor health and well-being [1]. This adoption is disrupting how health-related data has been traditionally collected and used: patients are driving adoption without recommendations from clinical providers on what data to collect, and how collected data should be interpreted and used for health-related decision making.

The increasing adoption of digital health tracking has led to growing interest in using patient-generated health data (PGHD), defined as "health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern", for clinical decision making [2]. PGHD can be categorized by the amount of user participation required for use as health data. *Active* PGHD requires user participation during health data collection, and has traditionally included health surveys such as patient-reported outcome surveys (PROs) collected via analog (eg, pen and paper surveys) and digital (eg, mobile applications) mediums, as well as health histories gathered by patients. More novel forms of active PGHD also include behavioral data collected during specific, health-related active tasks in partially controlled conditions (eg, keystroke data collected during specific typing tasks) [3].

Recently, clinicians have also considered using *passively* collected PGHD within care. Passive PGHD is data automatically collected by digital platforms (eg, smartphones, websites) from everyday life with little-to-no user participation, or data that exists on these platforms from everyday interactions and can be repurposed for health monitoring and treatment without additional user effort. Examples of passive PGHD include activity data automatically collected by smartphones or wearable devices, or data from social media interactions that are repurposed for healthcare use (see Table 1) [4–8]. Both active and passive PGHD can be transformed into digital biomarkers to inform the clinical management of medical conditions, including but not limited to diagnosis, monitoring, and prognosis [9], and clinicians are beginning to use passive PGHD in their clinical practice to treat a wide variety of chronic conditions, such as asthma, cancer, and diabetes [4].

Table 1. Definitions and examples of passive/active patient-generated health data (PGHD).

Characteristic	Passive	Active
Definition		
	Data collected or repurposed for	Health data requiring user participation

	health monitoring and treatment without user participation [5]	for collection [5]
Medium		
	Digital mediums, including smartphones, wearables, or online platforms	Analog (eg, pen and paper) or digital mediums
Setting		
	Collected from everyday life	Collected during specific tasks to measure, or document health-related information
Examples		
	Step counts and inferred activity collected from a smartphone or wearable device [10]	Self-reported health outcomes (eg, PHQ-9, GAD-7)
	Sleep duration approximated from heart rate and acceleration [11]	Health histories gathered by patients
	Mobility information calculated from mobile phone location-based services [12]	Data collected from users during active tasks in partially controlled conditions, for example, keystroke data collected from performing specific typing tasks [3]
	Data from social media interactions repurposed for health monitoring and treatment [6–8]	Journaling as an intervention to improve mental health [13]

In recent years, researchers have speculated on how mental and behavioral healthcare may specifically benefit from collecting and using passive PGHD. About one in five U.S. adults experience mental illness each year, and those experiencing symptoms have difficulties accessing treatment due to a national shortage of mental healthcare providers [14]. Passive PGHD may provide clinicians with contextual data on their patients from outside the clinical encounter to improve decision making between often short, infrequent visits [15,16]. Motivated by this promise and the pressure to vet the many new solutions coming into the market, researchers have investigated the validity of using passive PGHD to measure mental health. For example, smartphones can collect data on behavior and social routines associated with symptoms of affective and mood disorders [17,18]. Data from social media (eg, Facebook, Twitter, and Instagram) adds semantically relevant information to provide a more in depth understanding of patients' psychosocial behaviors [19,20].

Yet, even with refined measures, it is unclear how mental health clinicians' can use passive PGHD for clinical decision making. There are limited clinical guidelines surrounding the use of passive PGHD in mental healthcare. Clinical guidelines exist for the use of specific types of active PGHD traditionally used to measure mental health symptoms, specifically PROs. For example, governmental and professional bodies have outlined the appropriate use of the PHQ-9 and GAD-7

for depression and anxiety screening, respectively [21–23]. Similar guidelines do not exist for the use of passive PGHD, though companies developing passive PGHD data collection technologies, such as the Apple Watch and Oura Ring, have created instruction manuals [24,25] to guide consumer use. Without clinical guidelines, the safe and effective use of passive PGHD for clinical decision making is unclear. In this study, we wished to aid clinical guideline development through speaking with mental health clinicians about their perceptions and concerns with using passive PGHD in clinical care.

Related Work

Prior work has focused on how PGHD may augment the clinical encounter. Wu et al. explored mental health clinicians' perspectives on PGHD and how PGHD fits into current clinical workflows [26]. Ng et al. focused specifically on how passive PGHD may be integrated into an intensive treatment program for veterans with PTSD [27]. This work has primarily sought to understand how PGHD fits into the clinical workflow (an operational process), without considering the broader view of how PGHD may reshape clinical decision making (a cognitive process) [28,29]. While PGHD integration can facilitate adoption [26], it does not guarantee that clinicians will ultimately find this data useful for clinical decision making. In addition, researchers have surfaced ethical tensions surrounding passive PGHD use in clinical care. For example, inherent in the use of "passive data" are reduced transparency in data collection and the automatic repurposing of non-clinical data for clinical use [5]. We aimed to explore with participants how these concerns shape their perceptions of using passive PGHD for clinical decision making.

More recently, Schmidt and D'Alfonso considered with mental health clinicians, mostly psychologists delivering therapy, how "digital phenotyping", a paradigm where mental state is inferred from a patients' digital footprint (including both passive PGHD and digitally collected self-reports), can be used to inform client treatment [30]. In this work, we considered with mental health clinicians, mostly psychiatrists delivering therapy plus other forms of treatment (eg, medication management), the broader potential of passive PGHD in clinical decision making, not only for inferring mental state as implied by the "digital phenotyping" paradigm.

Contribution

We contribute a qualitative study to better understand mental health clinicians' perceptions and concerns regarding using technology-enabled, passively collected PGHD for clinical decision making. Specifically, we conducted 12 semi-structured interviews with mental health clinicians, including 11 psychiatrists and 1 clinical psychologist, and performed a qualitative coding to derive four themes from these interviews. (1) Current Passive PGHD use is patient-driven: participating clinicians' current experiences with passive PGHD were patient- not clinician-driven, limited to moments when patients chose to collect passive PGHD and bring this data to clinical encounters. (2) Active versus passive data as subjective versus objective data: participating clinicians viewed contrasts between active and passive PGHD as a contrast between subjective, interpretive data on patients' mental health, specifically referring to self-reports and health histories traditionally used to measure mental health symptoms, and objective information on behavior, but not necessarily mental health. Participants believed that prioritizing passive over active self-reports would reduce opportunities for patients to reflect on their mental health and change patient engagement in treatment, raising questions about how passive data can complement active data for clinical decision making. (3) Passive PGHD must be delivered at appropriate times for action: our participants were concerned with the "real-time" nature of passive PGHD: within current workflows, participants believed that it would be infeasible to use passive PGHD for real-time patient monitoring outside of clinical encounters, and more feasible to use passive PGHD at moments surrounding clinical

encounters when they can make treatment decisions. (4) Protecting patient privacy: participating clinicians wanted to protect patient privacy within passive PGHD data sharing programs, and discussed opportunities to refine data sharing consent to improve transparency surrounding passive PGHD collection and use.

Methods

Study Overview

We conducted semi-structured interviews with mental health clinicians. These interviews collected qualitative data on clinicians' current understanding and use of PGHD, as well as how clinicians could use PGHD for clinical decision making in the future. Methodologically we were motivated by the speculative design methods referenced by Malpass [31] to open up a conversation with participants on how their current practices may contribute to a future in which passive PGHD is used for clinical decision making. Similar to the notion of speculative design Malpass describes, our objective was not to design any specific technology, but to understand how participants would shape a future where passive PGHD is used for clinical decision making. We were also motivated by the idea of speculative data work introduced by Hockenhull and Cohn [32] to uncover how data, specifically passive PGHD, may be produced, validated, and used by participants in the future. In this section, we detail our methodology, including the study procedures and methods for analysis.

Interview Design

We created an interview guide composed of three sections along the speculative design tradition [31,33]. (1) The interview opened with an introductory section to learn about the participant's clinical practice. (2) We then explored participants' current understanding of PGHD by asking the participant about the forms of PGHD the participant uses and how the participant uses them in clinical decision making. This section included further questioning for participants who were less familiar with PGHD, to establish a baseline along the full spectrum of familiarity with PGHD. (3) Finally, we explored participants' future interests in PGHD by asking them about the forms of PGHD participants would choose to use in clinical care, and how these choices could impact decision making. While participants are approached as clinicians, the semi-structured, open-ended nature of the interview guide was designed to provide participants the opportunity to elaborate upon how any experiences outside the clinical space might influence their attitudes towards PGHD. Please see Appendix 1 for the full interview guide.

Participant Recruitment

We enrolled as participants mental health clinicians, including but not limited to psychiatrists, clinical psychologists, or licensed clinical social workers, delivering outpatient services in the New York City Metro Area in the United States. Our study focused on mental health clinicians delivering outpatient services, as passive PGHD offers particular promise for understanding patients' activities in-between outpatient visits [15,16]. Participants were recruited using both convenience and purposive sampling and were assured that their participation would not impact their relationship with their employer or our research institution [34].

We sought to conduct in-depth, one-on-one interviews, allowing for question adaptation and probes to reveal insights that could not be obtained from surveys. This required us to be respectful of participants' time, not further burdening participants for engaging in this research. Mental health clinicians face many emotional burdens day-to-day, and their bandwidth was reduced during our recruitment period in early 2022, with the ongoing COVID-19 pandemic exacerbating mental health concerns [35]. Given the nature of our work and the pressures our study population faced at the time

of these interviews, we spoke with 12 mental health clinicians. The self-reported demographic information of our participants is summarized in Table 2.

Table 2. Self-reported demographic information of the study participants (N = 12).

Characteristic		Participants
Age (years)*, mean (SD)		50 (17)
Female*, n (%)		5 (42)
Specialty (Degree), n (%)		
	Psychiatry (MD)	11 (92)
	Psychology (PhD)	1 (8)
Years Practicing, n (%)		
	Less than or equal to 10 years	5 (42)
	11-20 years	2 (17)
	21-30 years	2 (17)
	Greater than 30 years	3 (25)
Practice Setting, n (%)		
	Private Practice	6 (50)
	Academic Medical Center	5 (42)
	Employee Assistance Programs	1 (8)

* 1 participant preferred not to disclose their age or gender.

Data Collection and Analysis

Interviews were held via 35-minute Zoom meetings and were conducted by the two co-first-authors. Study sessions were audio-recorded, transcribed using a professional service, and anonymized. The two co-first-authors analyzed the anonymized transcripts using a thematic analysis approach [36–38]. Guided by literature and the research objectives, the transcripts were independently open coded. The coded transcripts were then reviewed to reach a joint interpretation, and agreement towards a final codebook. Final codes were qualitatively clustered into the four themes based upon meaning detailed in the findings section. Specific codes and high-level themes can be found in Appendix 2. Examples of codes included *design and functionality of PGHD solutions*, *validity of passive measures, patient-reported outcomes as PGHD,* and *PGHD and the therapeutic frame*.

Ethical Considerations

Study procedures were approved by the Institutional Review Board for Human Participant Research at Cornell University. Participants were asked to provide informed consent after receiving a complete description of the study. Eligible participants had the option to not provide consent, and could withdraw from the study at any point. Data collected during the interviews (transcripts and notes

taken during the interviews) were de-identified.

Researcher Positionality

One of the two co-first-authors is a medical student at an academic medical center located in New York City, and the second co-first-author is a graduate student in computer and information science. These authors recruited participants, conducted semi-structured interviews, and analyzed the transcripts. All other authors contributed to drafting and revising the manuscript and did not see the data.

Results

Our results are summarized within four themes illuminating participating mental health clinicians' perceptions and concerns using passive PGHD, as well as participants' speculation on how passive PGHD could be used for clinical decision making. These themes and findings are summarized in Table 3. Participants are quoted throughout our results using a participant-specific identification number (eg, P12) to retain anonymity.

Table 3. Summary of themes and findings.

Theme	Findings
Current Passive PGHD Use is Patient-Driven	
	Participants' current experiences with passive PGHD were limited to times when patients collected passive data and brought this data into clinical encounters.
	Participants chose to not use passive PGHD because they believed that passive PGHD only measured a limited set of behaviors related to mental health, and questioned the accuracy of these measures compared to measurements taken during clinical behavioral studies (eg, sleep studies).
Active versus Passive Data as Subjective versus Objective Data	
	Participants perceived that prioritizing passively collected PGHD in place of active, self-reported, data during clinical visits would change patients' engagement in their treatment by reducing opportunities for patients to reflect on and interpret their mental health.
	Participants were interested in reviewing discrepancies between passive and active PGHD with patients.
	Some participants prioritized collecting active PGHD for specific treatments (eg, mental health history in psychodynamic therapy), pending the patient's condition.
Passive PGHD Must be Delivered at Appropriate Times for Action	
	Participants were worried about the burden of and liability to review real-time passive PGHD outside of clinical encounters.
	Participants imagined this liability could be mitigated by "ordering" passive PGHD like a "lab test". Thus, participants would only be liable to review passive measures when there was a clear clinical justification for use.
	Similarly, real-time passive PGHD could be "dosed" like a prescription, restricted

	to times when it made sense to hyperfocus on the relationships between behavior and mental health.
Protecting Patient Privacy	
	Participants wanted consent for passive PGHD collection to be a guided, hands-on process.
	Incorporating goal setting within the consent process was seen as a potential method to clearly align patients' goals with PGHD data collection.
	Participants hesitant to engage patients in data sharing were concerned that PGHD may disclose information to clinicians that patients would have preferred to keep private, potentially violating the therapeutic frame.

Current Passive PGHD Use is Patient-Driven

We began to explore participating clinicians' current experience with passive PGHD by asking participants if they have used passive PGHD for clinical decision making. Participants reported some familiarity with passive PGHD, including "step counts or other things that could be picked up either via their phone or otherwise beyond mental health scales" (P2), or "a sleep app to look at the number of hours slept and the quality of the sleep." (P1) Despite this familiarity, participants, overall, did not appear to currently use passive PGHD in their clinical practice. Instead participants stated that passive PGHD use was patient-driven: in other words, they only used passive PGHD in clinical decision making when patients themselves brought their passive data into the clinical visit. For example, one of our participants mentioned how patients would bring passively collected sleep data to their appointments:

> *"I have a couple of patients who wear WHOOPs [a fitness wearable equipped with sensors to measure physiologic data [39]]. I don't have that much familiarity with what those are, but they will sometimes send me their data. And that tends to come up the most when people are trying to quantify issues with sleep […] And we talk about, how much has your sleep quality been? [...] And they'll like sending me that data and having me kind of follow along with them. I don't recommend doing it, but I accept it when patients want to send it to me."* [P8]

Thus, this participant did not actively recommend that her patients collect this data, but did not refuse to review this data with her patients if they chose to collect it and bring it into the clinical encounter. Other participants shared similar experiences of patients bringing them their passively collected data. For example, P2 mentioned they have "patients who've done sleep studies who have apps that show their sleep" and that they (the participant) "love that."

We asked participants why they did not currently use passive PGHD for clinical decision making, and instead only used passive PGHD when patients wanted to review this data with their clinicians. Participants stated that this was because current passive measures only contained information about a limited set of health behaviors. For example, one participant mentioned that they believed that "steps data gets tricky because I think oftentimes people are physically active in other ways." (P6) Another participant questioned if passive PGHD accurately measured behavior, compared to other "gold standard" ways of measuring behavior for clinical use. For example, this participant stated they "don't know enough to say that those sleep monitors are tracking your sleep compared to a sleep study with an EEG and everything else." (P5)

In summary, participating clinicians were familiar with passive PGHD. But, participating clinicians' current experiences with using passive PGHD for clinical decision making were patient-, not clinician-driven, limited to times when patients chose to collect passive data and review it with their clinician during clinical encounters. Participants did not currently use passive PGHD for clinical decision making because they found existing passive measures only contained information about a limited set of health behaviors (eg, can measure step counts, but not all other aspects of physical activity). In addition, participants questioned if passive PGHD accurately measured behavior compared to clinical studies (eg, sleep studies).

Active versus Passive Data as Subjective versus Objective Data

The prior section highlights that participating clinicians did not choose to use passive PGHD in clinical decision making. Clinicians in this study were more familiar with certain forms of active PGHD, specifically patient-reported outcomes and health history information traditionally gathered by patients to assess mental health symptoms. Given familiarity with these forms of active PGHD, we probed participants further to understand their thoughts and preferences regarding how passive and active PGHD could be jointly used for clinical decision making.

We first compared and contrasted these two types of information with participants to understand participants' perceptions of what each data type offered. Participants drew the contrast between active self-reports and passive data as a contrast between information describing a patient's *subjective* interpretation of their mental health versus more *objective* information on behavior, but not necessarily mental health. For example, one participant directly noted this contrast, stating that, "a patient reflecting on their mental state is not the same as [...] hours of sleep, number of steps, their heart rate, things like that." (P2) In addition, this participant was concerned about how prioritizing passively collected PGHD over active data changed the extent of patient participation in measuring symptoms. In particular, the participant noted how passive PGHD may reshape patients' engagement in symptom measurement and data generation, because when collecting active, self-reported data, "you're asking them [patients] to reflect on their internal experience", while passive data is "just picking updates that's certainly about them [the patient], but it feels like they're less a part of the choice process of, or the generation of that data." (P2)

Participants were also interested in how the two types of data (active and passive) may validate or invalidate each other. While one might expect that such discrepancies would call into question the validity of a patient self-report or passive measure, clinicians in our study were more interested in how these discrepancies could be leveraged within treatment. One participant, an addiction psychiatrist, recalled a time when they used passive PGHD to help change a patient's perception of how their drug use affected their behavior:

> *"I just had someone check their sleep before and after stopping marijuana. Their hypothesis was that they would sleep much poorer without the weed and it turned out they slept much better, as I anticipated. I told them, 'Let's run this experiment.' I think the benefit comes from them [the patient] drawing their conclusions from their data."* [P11]

Thus, engaging with discrepancies across data types became an active part of the treatment process. That being said, not all clinicians in our study agreed that focusing on these differences would benefit clinical decision making. Some clinicians we interviewed thought that focusing on passively collected PGHD may make it more difficult to reconcile patients' subjective experiences with their mental health. For example, one clinician stated that if passive and active data conflicted, they would be less interested in the "conflicting information unless I'm making a biological change." (P12)

We pressed this clinician to elaborate further, on why they may be less interested in the conflicting information. In response, this participant described how the main form of treatment they practiced, psychodynamic therapy, prioritized patients' interpretation of their lived experience:

> *"I mean, the thing is that a person's subjective experience is a kind of reality, right? Sometimes objective information is irrelevant because you're like, 'Okay, well I don't care what that says. What I felt was this.' So subjective information sometimes outweighs objective information. [...] What actually happened doesn't matter. It's what you remember or what you feel that matters."* [P12]

Another clinician we interviewed agreed with this sentiment, stating that it doesn't "really matter what the objective data is" as a patient may self-report "feeling absolutely awful" even though "their objective data, their wearables, look much improved". Thus, if "they [the patient] doesn't feel well, how much does it [the objective data] really matter?" (P4) Yet, this participant did state that de-prioritizing what they called objective data would only make sense in specific situations, for example, if "their metrics [passive data] look bad, but they feel great and they're doing very well and they're not manic or vice versa" (P4), implying that it is important to contextualize data with the patient's current condition (i.e. mania).

In summary, participants viewed the shift from active self-reported towards passive data as a shift from subjective, interpretive data on mental health towards more objective information on behavior. Participants were less concerned about comparing and contrasting the validity of active versus passively collected PGHD, but more interested in how shifting from active to passive data decreases the opportunity for patient reflection, a critical part of mental health care. Clinicians then elaborated on how the complementary, potentially conflicting information between active and passive data could inform treatment by helping patients realize progress and potentially re-engage. Lastly, some participants stated the degree to which they would prioritize active data, highlighting the patient's subjective interpretation of their mental health, would depend upon the patient's clinical state (i.e. "not manic"), as well as the type of intervention being delivered (eg, psychodynamic therapy). We contextualize these discrepancies further in the discussion.

Passive PGHD Must be Delivered at Appropriate Times for Action

The first section highlighted how most participants had limited experience with using passive PGHD for clinical decision making. Despite this limited experience, the prior section highlights that participants still believed passive PGHD could complement more traditional forms of active PGHD to improve clinical decision making. As such, we were interested in exploring how passive PGHD can be delivered within participants' workflows, such that they can act upon passive PGHD for clinical decision making.

As we began to investigate with participants how to best deliver passive PGHD, one participant imagined a system where passive PGHD was integrated, in real-time, into the patients' chart. This data would be available to clinicians outside of specific, clinical encounters. The "real-time" potential of passively collected PGHD worried participants, specifically if the data indicated that a patient is in need of immediate care:

> *"Nobody wants to get, 'My patient's suicidal Saturday at 2:00 PM' So it's got to be done in a very thoughtful way. But if you said your patient's score that you're seeing in 30 minutes just changed from a 10 to a 20, that's helpful. That gives me actionable data at the time I need it to help improve the visit and take better care of them. That I would call useful. But don't just send me random things at random times."* [P2]

Participants further stated that it would be next-to-impossible to expect clinicians to review continuous behavioral data. Participants already experienced data overload during their work, and adding passive data may further contribute to this overload. As one participant warned:

> *"If you're going to overload people with things and then they become required, you're going to be further burning the healthcare workers who are already resigning in droves and burning out very quickly."* [P4]

Participants were further concerned about the inherent liability of not acting upon real-time data outside of the clinical encounter. One participant used an analogy comparing passive data to labs, in that "It's as if you order labs, you have to follow up on those labs. You can't just wait a month or three months to see those labs. Someone's got to track those labs." (P4) Since labs are typically ordered within clinical encounters, "ordering" passive PGHD like a lab test would restrict the use of passive data to moments when clinicians have bandwidth to use passive PGHD for decision making.

It is possible, though, that there could be a clinical justification to collect real-time passive PGHD, potentially to monitor high-risk patients outside of clinical encounters. One participant imagined that real-time passive PGHD could be collected for limited periods of time, essentially "dosing" the use. By dosing passive PGHD like a prescription, "you're getting people for a limited period of time to really hyperfocus on the connections between their mood and their activities and their triggers and all that" (P4). Thus, the potential for real-time monitoring through passive PGHD could be reduced to limited time periods when there is a clinical justification for continuous monitoring.

Participants also speculated that without clearly defining a "dose" for passive PGHD (eg, how frequently to review PGHD, what PGHD to review), the abundance and continuity of passive PGHD may create obsessive tendencies in patients. Many of our participants' patients already experience anxiety, which may increase if patients are able to visualize granular, real-time fluctuations in their behavior and health. Participants worried if one were "to be [collecting passive data] on a very long term basis might just make people obsessive." (P4) As one participant noted, this risk for obsession is especially relevant in mental health, given the interpretive nature of mental health data compared to data collected within other fields of medicine:

> *"It's not the same as blood pressure, where someone's like, 'I measured my blood pressure and these were my readings.' It's going to be a little bit more complicated to tell the story, because there are no vital signs in psychiatry. It's usually a lot more subtle and open for interpretation."* [P9]

In summary, participants were reluctant to adopt passive PGHD for decision making without established clinical guidelines that articulate when and how clinicians and their patients should review and interpret this data. Despite these barriers, participants were not entirely dismissive of using passive PGHD. Some participants imagined how established clinical practices, including ordering labs, or prescribing treatments, could be repurposed to most effectively use PGHD for clinical decision making.

Protecting Patient Privacy

The prior section highlights that participating clinicians, overall, were open to discussing how to appropriately integrate PGHD into the clinical visit for decision making. As we probed participants further, many noted the sensitivity of collecting and storing passive PGHD, as passive measures offer a magnifying glass into daily routines and habits of their patients. One participant stated that "It feels

weird, intuitively feels weird" to collect passive PGHD, and this participant began speculating on who may have access to data in proprietary systems, ("the military? [...] the government? [...] corporations?") begging the question, "would patients feel comfortable" (P12) sharing their data?

Given this tension, we attempted to navigate with participants different controls to protect patient privacy if passive PGHD were used for clinical decision making. For example, many participants raised how to best consent patients into PGHD data sharing programs. One participant stated that consent to share PGHD would need to be a guided, hands-on process, not "another, 'I agree', click button" and that patients "have to actually talk through it with someone." (P2)

We probed this participant to further understand how a patient and their clinician might discuss collecting PGHD. This participant stated that patients would be encouraged to share PGHD if it directly aligned with their treatment goals.

> *"I think the best way is to make it explicit that we decided together this is the goal of treatment and that's why we're tracking it. [...] Can you envision a world in which like in the patient portal, they select their three goals and one of them is exercise? They're actually signing up for it."* [P2]

Through this explicit alignment, participants hypothesized that patients would see a direct benefit to their health in sharing PGHD. As one participant noted, *"if you can show useful outcomes"* and "prove to the patient that this is really going to have an impact", patients "don't mind sharing their data." (P1)

One participant noted that the process of negotiating sharing PGHD with a patient may actually be a useful part of treatment. This participant discussed how it was often difficult for participants to convey certain types of information during the clinical visit. Sharing PGHD may actually help patients open-up about some of these experiences. As this participant stated:

> *"Trauma needs a witness. You've got to get the stuff out there in the world if you're going to be able to do something with it. [...] And now people are more willing to talk about it, to share data, to look at it. When you can get to that point of being open and honest about sort of what's going on inside you or what data you're presenting, it makes it much easier to change."* [P11]

Some participants were more hesitant to engage patients in sharing their PGHD. In particular, these participants stated that patients should remain in complete control over disclosing personal information. These participants were concerned that sharing PGHD may lead patients to unintentionally disclose information to their clinician that they would prefer to keep private. One clinician noted this in regards to the therapeutic relationship:

> *"My goal when I'm wearing my psychoanalytic hat is to see the world through my patient's eyes. Any other data that I get constitutes an interference with that."* [P3]

Thus, participants saw data sharing as a delicate balance. On one hand, sharing PGHD could be a tool to further engage patients on their treatment, creating conversations between patient and clinicians that may be more difficult to motivate without prompted by the information contained within PGHD. On the other hand, participants noted that they would need to be careful on how they engage patients on their PGHD, having the patient remain in control of what information is or is not discussed. This discourse opens up fruitful discussion on how to best center patients' interests within

passive PGHD programs.

Discussion

We conducted a qualitative study with mental health clinicians to better understand their perceptions and concerns regarding using passively collected PGHD for clinical decision making. Our results highlight a range of opportunities and challenges that clinicians foresee towards using PGHD in clinical care. Broadly, our participants believed that passive PGHD could be used to improve engagement in some aspects of care, giving patients and their clinicians the ability to set goals and reflect on highly specific, contextual data within patients' everyday lives. This data would create opportunities to compare and contrast patients' subjective notions of their mental health with behavioral data, to further interrogate where this data is aligned and misaligned, charting a path towards more data-driven, measurement-based clinical decision making. Yet, despite these promises, participants were simultaneously worried about how passively collected PGHD may change clinical workflows, in particular, disrupting norms surrounding how and when patient mental health information is gathered and used for clinical decision making. In this discussion, we contextualize our results within the literature, and attempt to reconcile these opportunities and challenges for using passively collected PGHD within clinical decision making to best serve both the patient and their clinician. Implications suggested in this discussion are summarized in Table 4.

Table 4. Summary of themes with implications discussed.

Theme	Implications
Current Passive PGHD Use is Patient-Driven	
	Researchers can continue to build out an evidence base showing specific use cases where PGHD improved care, and frameworks for evidence generation against these use cases.
	Prior to introducing passive PGHD, organizations should understand clinicians' familiarity with using PGHD, broadly, and build clinical education programs describing how PGHD can be used for clinical decision making.
Active versus Passive Data as Subjective versus Objective Data	
	Passive PGHD may offer an "objective" view into patient behavior and physiology, but clinicians perceive the information gained from passive PGHD as complementary to, but not the same as, mental health symptoms.
	In this context, passive PGHD could be used to give an "outside opinion" on symptoms, providing clinicians and their patients contextual data on the patient from outside of the clinic.
	Use of passive PGHD for clinical decision making may be treatment- or patient-specific.
Passive PGHD Must be Delivered at Appropriate Times for Action	
	Passive PGHD gathering and use was found to disrupt clinical norms, organizational care pathways, and processes.
	Passive PGHD may be able to give a near-continuous lens into the patient state, but the "real-time" nature of PGHD may overburden clinicians, who may already be

	experiencing burnout.
	Guidelines for passive PGHD use could borrow from existing practices in medicine, such as prescriptions and lab tests, to restrict use to moments when both patients and clinicians are interested in and have the bandwidth to use this data.
Protecting Patient Privacy	
	Integrating patient goal-setting into passive PGHD consent may increase patient engagement in treatment and ensure PGHD usage is in line with patients' current goals within care.
	Designing new therapy practices that use passive PGHD would establish norms surrounding usage in an evolved therapeutic frame.

Our participants had mixed experiences with and opinions of using passive PGHD for clinical decision making. Specifically, participating clinicians did not describe well-defined use cases for passive PGHD within current care pathways, instead describing how they currently reviewed passive data only when patients chose to bring this data into a clinical encounter. As Wu echoes, while passive PGHD can capture a wealth of information on patient behavior, it is less clear how this information adds value to improving patient care [26]. Studies often focus on technical efforts of collecting, deriving signals, and visualizing passive PGHD [12,40,41], but less attention has been given to translational research showing the value of using PGHD in improving mental healthcare [42], and trials that have attempted to measure this value thus far show mixed results [43,44]. Thus, more evidence on how passive PGHD should be used for clinical decision making may be required to further engage clinicians.

PGHD researchers can draw lessons from other interdisciplinary collaborations building an evidence base showing how data-driven technologies can improve in clinical care [45]. For example, machine learning has been used for clinical decision support, documentation summarization, and to aid in medical image-based diagnosis [46–49]. In each of these solutions, machine learning has supported progress towards clinical goals (eg, accurate diagnosis and prognosis) and improved clinician efficiency (eg, reduced image analysis time), illustrating the power of creating new capabilities to address pain points while integrating into current workflows. Analogously, mental health clinicians may only become interested in using passive PGHD through building out an evidence base of specific clinical challenges passive PGHD-based mental health tools have solved. Researchers can engage practitioners to uncover these clinical challenges, create instructions for how passive PGHD may solve these challenges, along with frameworks for evaluating efficacy within each specific use-case to better support evidence generation. This work can coincide with ongoing efforts to better validate and standardize mental health digital measurements, often called *digital biomarkers* within the digital phenotyping paradigm, to detect condition-specific symptoms across patients, making more feasible use of passive PGHD [50,51].

A promise of passive PGHD often cited in literature is its ability to offer "objective" information on mental health in contrast to more traditional measures of mental health, in particular patient self-reports [16,52]. While our results do not contest the objectivity of using digitally tracked data to measure behavior, it does question the objectivity of this data with respect to measuring a patient's mental health. Researchers in human computer interaction have echoed this point, that digital measures may reduce mental health to biobehavioral data points, missing more interpretive aspects of mental health that cannot be easily quantified using passive tracking [20,33]. These critiques may

also apply to specific forms of active PGHD, for example, behavioral data collected during health-related active tasks, though participants did not discuss these forms of active data during the interviews. Yet, our findings also show that prioritizing interpretive data alone can be problematic, depending upon the context. For example, as P4 highlighted, self-reported data collected from a patient experiencing mania should not be interpreted at face-value. These tensions highlight the importance of contextualizing the patient's condition when considering the use of both active and passive PGHD.

Our participants were interested in using passive PGHD to help patients further engage in their care, providing real-world behavioral data to understand treatment progression. As P11 and others mentioned, passive PGHD could create opportunities for patients and their clinicians to engage in measurement-based care, giving patients the ability to reflect on the efficacy of their treatments through actual behavioral changes. Prior work reinforces providers' interests in using passive tracking technologies to provide "outside opinions" on symptoms, giving patients opportunities to validate their progression through treatment using passively tracked data [27]. This perspective is considered in the broader literature on passive tracking and computational psychiatry, which suggests passive PGHD could be a tool to reveal additional contextual information on behaviors outside of the clinic, further explaining underlying disease mechanisms or changes in disease severity [15,53]. Yet, this perspective should not completely nullify the potential to use passive PGHD for remote symptom measurement, which motivates machine learning research investigating if passive data can near-continuously predict self-reported mental health symptoms [54–56]. Considering the gap in receiving adequate psychiatric services when one experiences symptoms, passive PGHD symptom measurement may augment, not reduce, mental health measurement, by remotely flagging those in need of a clinical follow-up, where more traditional, interpretive, measures of mental health could then be administered [57,58]. Disentangling the different gaps in care passive PGHD can fill will be essential towards implementing these tools in a clinically useful way.

Participants in our study also expressed a variety of concerns surrounding how PGHD might disrupt clinical norms, organizational care pathways, and processes. Specifically, participants described how the "real-time" nature of passively collected PGHD may overburden already burnt out clinicians (P4), citing the need for actionable data only at opportune moments when clinicians have the bandwidth to care for a patient (P2). Existing data-gathering technologies used by clinicians, such as electronic health records, have created friction in clinical workflows by increasing administrative data entry tasks, and induced "information overload" through saving a large volume of information, making it more difficult for clinicians to prioritize data needed for patient care [59]. Organizations intending to use passive tracking technologies for clinical decision support are thus challenged to balance the promise of these tools for near-continuous, remote monitoring, while fitting into clinical workflows that intentionally limit providers' interactions with patients' data to moments surrounding the clinical visit in order to reduce fatigue [60,61].

Participants thus speculated on how passive PGHD could be used for clinical decision making without exacerbating clinician fatigue. For example, P4 proposed "dosing" passive PGHD use like a prescription, limited to a period of time where it makes sense to hyperfocus on specific connections between behavior and health. Prescription models are often used to regulate the distribution of existing passive biometric data collection technologies, including continuous glucose monitors (CGMs) [62], and researchers have proposed "personalized activity prescriptions" for behavioral tracking, where clinicians and their patients can set specific health goals, which are tracked using passive activity monitors [63]. Continuing this analogy, these prescriptions, like many prescription medications, would have a beginning and end of usage, as well as specific guidance for appropriate use. This guidance may mediate participants' concerns on collecting passive PGHD over a long term

basis and enabling patients' obsessive tendencies towards self-tracking [27]. Another possibility, raised by a participant, would be to treat passive PGHD collection like a lab test, where clinicians request the data during a clinical encounter for a specific purpose, providing boundaries on when clinicians use PGHD. This "PGHD lab" would not make use of passive PGHD's potential to provide near-continuous measurement [60]. Still, thinking through how passive PGHD may fit within current clinical norms and practices (eg, prescriptions, labs) could create opportunities to augment future clinical workflows to realize the full potential of these near-continuous data sources.

Finally, participants highlighted patient privacy concerns regarding the collection and sharing of PGHD [63–65]. Patients living with mental health conditions may be particularly concerned about perceived loss of privacy due to the societal stigma surrounding mental health disorders [66]. Simultaneously, establishing norms around data sharing is important in psychiatry; as our participants stated, specific types of treatments (eg, psychodynamic therapy) ask therapists to see the world through their patients' eyes, often defined as the *therapeutic frame* [33,51,67]. As Nissenbaum notes in their theory of privacy as *contextual integrity*, norms surrounding data sharing are tied to context [68], i.e. in our case, the therapeutic frame. Thus, passive PGHD, which can provide a detailed window into patients' lives outside of the clinical encounter, may disrupt existing norms conceived by the therapeutic frame.

The concerns surrounding privacy highlights again the importance of patient engagement with their data for these data-driven interventions to be acceptable. To address privacy and data sharing concerns, P2 suggested forgoing simple consent procedures (eg, an "I agree" button) to instead work with patients to find opportunities to collect PGHD in alignment with patients' treatment goals. For example, a patient may select exercise as a goal to motivate consent to the collection of step count or other activity data. In concordance with privacy scholars, such active, potentially recurring consent policies, gives patients opportunities to make personalized choices in their treatment plan, as well reflect upon data sharing practices [69]. By taking a proactive approach to patient privacy, providers can also create opportunities for collaborative goal setting, which may increase treatment engagement [70]. In regard to violating the therapeutic frame, new research efforts to measure the clinical actionability of traditionally collected collateral information (eg, conversations with other providers, family members), could be extended to digitally collected collateral information, including passive PGHD [51,71]. By the judicious application of passive PGHD, clinicians can enhance the therapeutic relationship with their patients, reshaping the traditional concept of the therapeutic frame for a new digital age.

Implications

Our findings have a variety of implications for researchers and practitioners surrounding the adoption of technology-enabled, passively collected PGHD in clinical decision making. First, our findings showed mixed mental health clinician experience with passive PGHD. Thus, medical centers, should they endorse practices that use PGHD, may wish to invest in research and training programs to build and disseminate an evidence base showing the efficacy of using PGHD in mental healthcare. In addition, medical centers can invest in technological and organizational infrastructure to promote the effective uptake of passive PGHD data sharing programs. Additionally, our interviews highlight a primary benefit of passive PGHD is to provide clinicians contextual data from outside of the clinic. Yet, the potential of passive PGHD to provide a near-continuous lens into the patient state may further contribute to physician burnout and violate patient privacy if proper safeguards are not enacted. Our findings suggest several methods to address these concerns, including prescribing or ordering PGHD like a medication or lab test, and creating conversations to re-consent patients into data sharing programs. These ongoing conversations should address how the collection of PGHD aligns with patients' specific treatment goals, and how clinicians plan to use PGHD in combination

with other types of information patients share during clinical encounters.

Limitations

This study was a small sample, qualitative, semi-structured interview study to elicit formative information regarding using passive PGHD for clinical decision making. Though these methods allowed us to dive deep with participants into a variety of tensions for using these tools, our results should not be considered generalizable to mental health clinicians broadly. We did not interview individuals in the broader mental healthcare and technology workforce (eg, social workers, nurses, home health aids, primary care physicians, digital navigators), whose opinions will be extremely valuable when considering a future implementation of such tools. In addition, our small sample size, composed mainly of psychiatrists, limits our ability to make specific conclusions towards different types of mental health clinicians (eg, more experienced, less experienced, schools of thought, patient populations treated, etc). We also conducted interviews in early 2022, when mental health clinicians were dealing with the aftermath of the COVID-19 pandemic, which strained the mental health workforce. Thus, we were only able to reach and interview a limited number of clinicians, and we were cognizant of the amount of time we spent with individual clinicians to not strain our participants further.

Future Work

Future work should seek to draw more generalizable conclusions for mental health clinicians. This could involve a larger interview study to qualify the experiences of a more diverse sample along with a survey study to further quantify our findings and the status of mental health treatment. Future work can extend these results towards specific clinical practices and decision making showing if and how passive PGHD is efficacious for both patients and their clinicians, determining how this data should be collected, delivered, and protected. Our results call for closing the research-to-practice gap for both PGHD and measurement-based psychiatric care, broadly, as well as clarifying the information contained within passive PGHD and how this information complements more-traditional forms of mental health data collected during clinical encounters. In addition, future work can create guidelines and clarify norms for best practices surrounding using passive PGHD for clinical decision making. As our results show, this should include guidance for when passive PGHD may provide useful as well as consent procedures for enrollment and continued involvement in passive PGHD data sharing programs. Regulatory bodies and professional associations can produce clear, evidence-driven guidelines, which are imperative towards maximizing the benefit of these novel data sources for both patients and their clinicians and ensuring innovation serves real clinical needs and not just industry ambitions.

Conclusion

We report a qualitative study to understand mental health clinicians' perceptions and concerns regarding the use of technology-enabled, passively collected PGHD for clinical decision making. Our findings highlight the need for building and disseminating an evidence base with guidelines for using technology-enabled, passively collected PGHD for clinical decision making. This evidence base should clarify how to best use passive data alongside more traditional forms of active PGHD used for clinical decision making, when clinicians should view passive PGHD to make treatment decisions, and how to best protect patient privacy within passive data sharing programs. Academic medical centers and industry players can collaborate on clinical trials to generate clear evidence supporting the appropriate use of these novel tools, for both patients and their clinicians, which would more effectively support their uptake and effective usage within mental healthcare.

Acknowledgements

Data Availability

Data collected during this study are not publicly available. The approved study protocol by the Cornell Institutional Review Board did not cover public data sharing, and participants were not asked to consent to sharing data publicly.

Conflicts of Interest

C.L. is co-employed by UnitedHealth Group, outside the submitted work. D.A. and T.C. hold pending patent applications related to the cited literature. T.C. is a co-founder and equity holder of HealthRhythms, Inc. and has received grants from Click Therapeutics related to digital therapeutics. C.L. is on the advisory board for Compass Pathways.

Abbreviations

EMA: Ecological momentary assessment
PGHD: Patient-generated health data
PRO: Patient-reported outcome

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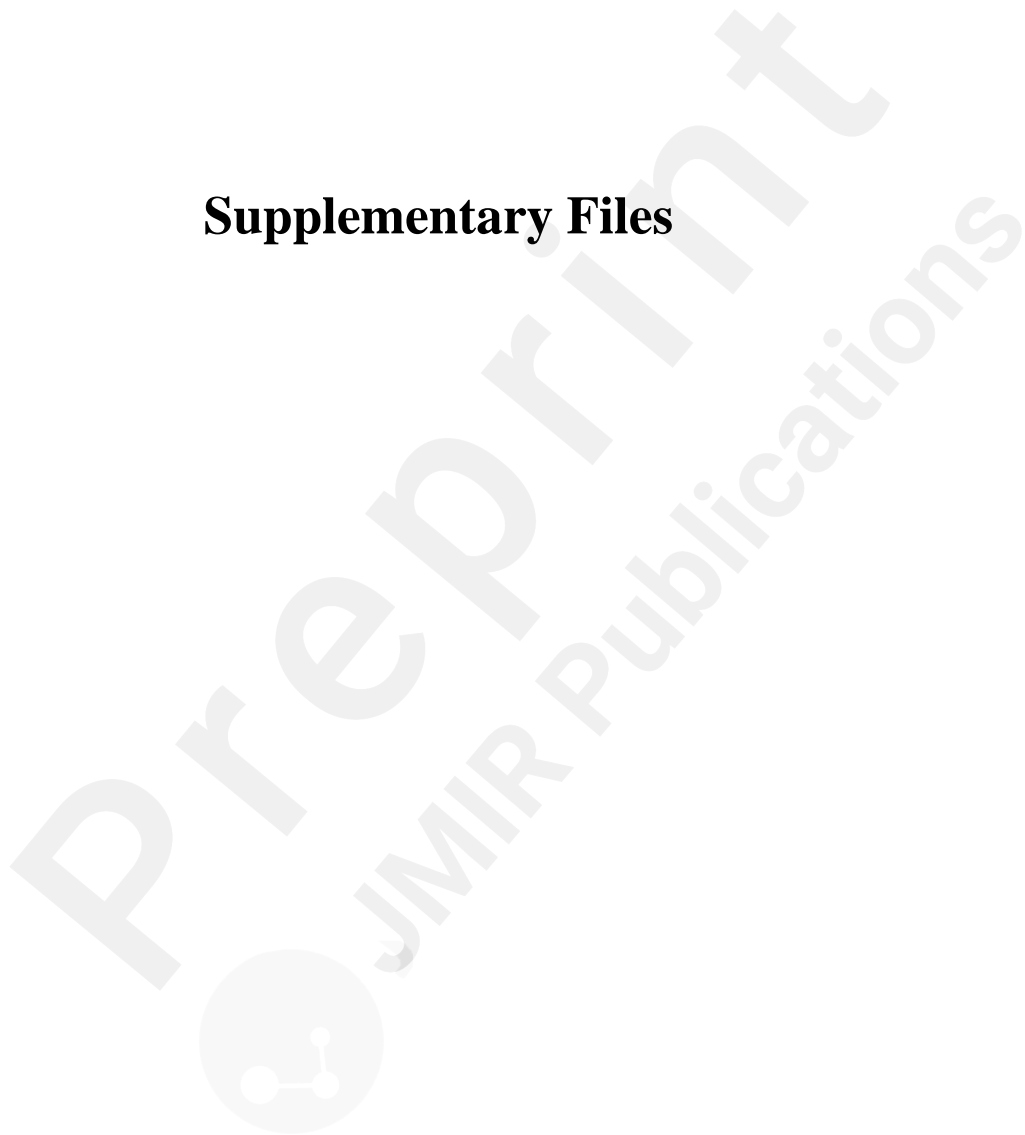
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Supplementary Files

Multimedia Appendixes

Interview guide.
URL: http://asset.jmir.pub/assets/1d41a783e407d51fdb26b7d0cca64f1d.docx

Interview codebook.
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