

Providing Context to the “Unknown”: Patient and Provider Reflections on Connecting Personal Tracking, Patient-Reported Insights, and EHR Data within a Post-COVID Clinic

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COVID Long Haul (CLH) is an emerging chronic illness for which the healthcare system continues to seek a common understanding of symptoms, diagnosis, and treatment. CLH experiences can differ drastically, necessitating personalized care plans. Because patients interact with different clinicians during their CLH journey, it becomes important to ensure interoperability and understand clinical relevance of different data that can support clinicians in making appropriate recommendations. We conducted qualitative research where we interviewed 13 patients, conducted a focus group with 8 clinicians, and analyzed care plan follow-up records. We report patient and clinician expectations from and interactions with clinic data. We uncover logistical challenges, personal contexts, and health barriers impacting patient compliance. As researchers embedded in the clinical system, we identify the potential of using multiple patient data streams to support personalized treatment and clinical decisions. We discuss technology design opportunities and provide actionable recommendations for improving clinical workflows and cross-provider collaboration.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; • **Applied computing** → **Health informatics**.

Additional Key Words and Phrases: Post-COVID; COVID long haul; Long COVID; PASC; health informatics; patient-reported data; clinical data; clinical workflows; electronic health record; cross-provider collaboration; collaborative decision making

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1 INTRODUCTION

COVID long haul (CLH) or post-COVID conditions encompass a wide range of new, reoccurring, or ongoing health problems after infection with COVID-19 [4]. CLH can be diagnosed, per the

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Centers for Disease Control and Prevention (CDC)¹, when a person experiences such symptoms for four or more weeks after the onset of their infection [4]. This emerging chronic illness is far from being well-understood by healthcare providers who continue to seek ways to diagnose, treat, and identify the cause of CLH symptoms [35]. It is estimated that 1/3 of all COVID infections – that is over 200 million people across the globe and 31.7 million people in the U.S. [48] – will result in some form of CLH. To put that into perspective, one of the most common chronic illnesses in the U.S., diabetes², has an estimated prevalence rate of 28.7 million³.

Although recent health-focused research across different domains has examined the presentation of CLH symptoms [31, 53, 86, 110], guides for treatment [97, 124], impacts of social media [70, 100], and modeling [129], the data clinicians⁴ need to support ongoing patient care and collaboration within care teams are yet to be understood and integrated into clinical workflows. Moreover, electronic health records (EHR), though considered the “gold standard” for gaining medical understanding [130], might not be enough for contextualizing individual experiences of CLH and developing personalized treatment plans, given the high variability of CLH symptomology [3]. As discussed in other health contexts [101, 132], there is value in analyzing multiple data streams for building a more complete understanding of patient experiences.

Furthermore, the range in the clinical presentation of CLH means that various care providers (e.g., primary care doctors, specialists such as cardiologists and neurologists) are often collecting important data and entering it in different spaces within the EHR [15]. However, that does not mean that data is easily accessible or readily visible to all providers involved in the clinical care workflow. Developing collaborative treatment plans requires a shared understanding and active engagement amongst providers to effectively treat a patient. Additionally, because patients themselves have a wealth of knowledge about their lived experience with CLH, their perspectives can be valuable for providers to better situate personalized patient care plans. Thus, our work takes into consideration different patient data streams, including EHR, patient-reported, and health tracking data, with the goal of understanding patient perspectives that can be incorporated into clinical care workflows. We triangulate this data to better understand patient CLH experiences, including patient desirability to share subjective health data with clinical providers, and tie it back with clinician perspectives on what data they find relevant for use. We have unique access to both the patient and clinician aspects of CLH care since we are part of a clinically-embedded research team, collaborating with the Parkview Post-COVID Clinic (Parkview PCC) in the Midwest United States.

We investigate the following research questions:

- What are patient experiences with CLH and how do they want to share these experiences with clinicians?
- What is the clinical relevance of patient-reported data and what can be learned from connecting it to clinical data?
- How can design support and enhance clinical care workflows, including provider engagement with rich patient data, to enhance collaborative provider-based clinical decision making?

To address these questions, we conducted a qualitative study, as a part of the larger research endeavor, where 15 patients from the PCC were tracked for 12 weeks. Each week we captured both daily sleep and activity tracking data (using a Fitbit) and survey responses that measured

¹The Centers for Disease Control and Prevention is a federal agency in the United States that conducts and supports health promotion, prevention, and preparedness activities in order to improve public health. CDC website: <https://www.cdc.gov/index.htm>

²<https://www.cdc.gov/chronicdisease/about/index.htm>

³<https://www.cdc.gov/diabetes/data/statistics-report/diagnosed-diabetes>

⁴We use the term clinician throughout this paper to refer to the wide variety of healthcare professionals caring for CLH patients such as doctors, physicians, nurses, physical therapists, and mental health professionals.

symptom progression and adherence to a clinical care plan. Toward the end of the 12-week period, we completed exit interviews with 13 of the 15 patients. We also extracted information related to the patients’ care plan follow-throughs from the EHR via manual chart review. Finally, we conducted a focus group with 8 clinicians who are a part of the PCC⁵. We created a case study using a patient’s Fitbit, survey, EHR, and interview data and used it as a probe during the clinician focus group to give clinicians a sense of the diverse data collected during the research study, highlighting the types and potential of data that could be collected through the larger PCC.

This paper makes three contributions. First, we provide a detailed account of patient experiences with the Post-COVID Clinic, including their expectations around data, interactions with clinicians, and follow-through on care plan recommendations. Patients described wanting to share more contextual details about their health, personal environments, and other factors (e.g., mental and physical health barriers) that impacted their adherence to care plan recommendations. Second, by introducing a patient case study to clinicians, we uncover clinician data needs and expectations, and identify data forms and representations they found most useful and clinically relevant. Clinicians wanted to see an aggregation of data from different sources (e.g., Fitbit, survey check-ins, EHR) that showed progression of each patient’s overall health and gave an overview of patient care plan compliance. Lastly, we engage with HCI and CSCW literature and draw on our experiences of being embedded in clinical settings to provide actionable recommendations for improving clinical care workflows. We discuss opportunities for future work on supporting interoperability and incorporating patient perspectives into provider-based clinical decision-making. Our work emphasizes the importance of the clinical embeddedness of the research team for providing recommendations that can be integrated into clinical workflows, rendering direct, on-the-ground impact, as the clinical understanding of CLH evolves and clinics continue to see patients. In the near term, we encourage CSCW researchers to leverage existing EHR systems and design components (e.g., dashboard visualizations, support ChatBots), that extend current system functionalities, for improving clinical collaboration workflows instead of brainstorming completely new, disconnected technologies that do the same. We also acknowledge that CSCW as a community needs to actively engage EHR companies (e.g., EPIC, Cerner) so that redesigning EHRs by directly integrating recommendations and expanding their functionalities becomes a realistic possibility in the long-term.

2 RELATED WORK

2.1 Patient Data & Clinical Decision Making

Objective data within the EHR is considered “gold-standard” data. Gold-standard in the health context is most often defined as diagnostic tests and benchmarks, irrefutable evidences of “truth” [130]. Clinical decisions are often grounded in objective data. In many situations clinicians have protocols for when certain treatment modalities are indicated. For example, guideline-directed medical therapy (GDMT) is a treatment for people with heart failure with reduced ejection fraction, wherein a provider will prescribe certain combinations of medications based on a variety of diagnostics results [33]. However, objective data does not provide contexts into the lived experience of an individual [114] but only provides a snapshot of the patient at that given time [24]. This might work in acute or emergent situations but might fall short for chronic and more complex health issues, such as CLH, increasing the patient’s disease burden [73].

Clinical decision making has deep roots within HCI. Early work examined the interplay of health information and temporal coordination [106], importance of informal discussions in connection

⁵This paper is limited to analyzing only the patient interview, clinician focus group, and patient care plan follow-through data. A detailed analysis of the patient survey check-ins, Fitbit, and other EHR data is under review at a different venue.

with health data for consensual group decisions in complex care [56], and design recommendations for transcribing health data into medical records and its impact on decision making in trauma settings [112]. More pertinent to our study, previous CSCW scholarship has explored the complexity related to decision making within multidisciplinary medical teams [69]. Marcu et al. explored how temporality factors into collaborative health services ranging from time critical, acute to more long-term and chronic care [82]. They highlighted the tension between wanting to have standardization in information technology and workflows best suited to long-term/chronic care. Chronic and long-term illnesses are complex and often require data from multiple sources [122], thus needing collaborative decision making from teams of medical professionals [118]. Also incorporating patient input into healthcare decision making is valued by patients [77] and was codified within the U.S. national goals by the establishment of the Patient Centered Outcomes Research Institute as a part of the Affordable Care Act [133]. Collaborative decision making has been correlated with increased understanding, satisfaction, and trust [77], while poor levels of collaboration in clinical decision making is associated with worse patient-reported health outcomes [60].

2.1.1 Integrating Patient Data into Clinical Ecosystems. To address this issue of needed context, many clinicians also include patient-reported and other subjective data points when assessing a patient. Roger found that up to half of the time symptoms go undetected, especially as disease states can change between visits to the clinic [96]. Research has found that integrating patient-reported outcomes into the clinical decision making process positively impacts the patient-provider relationship [75], reduces emergency department use [71], and is correlated with better health outcomes [42]. Patient reported outcome measures (PROMs) are typically collected via surveys [103] and focus on patient perspectives on their health symptoms and impact of disease on their quality of everyday life [12]. With increased popularity of EHR patient portals, PROMs can now be collected at anytime and no longer require a direct clinical encounter [78].

For chronic illnesses, including CLH, continued patient follow-up with healthcare providers is critical [131]. The solicitation and inclusion of patient inputs can facilitate deeper levels of trust and cooperation between patients and providers [12]. However, there are several reasons for patients not following-up with medical recommendations with one of the largest related to social determinants of health – *conditions in the environments where people are born, live, work, play, worship and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks* [7]. Healthcare access [52], costs [107, 123], and social contexts [51] are some of the most common reasons for lack of follow-through on recommended healthcare. Interventions that address these issues have been found to improve health and reduce healthcare disparities [134].

Patient-generated data is also an important topic for the CSCW community [104]. Consistently, studies have highlighted the importance of integrating patient-reported data into the clinical decision making process [22, 25]. Before integration begins, data must first be collected. Chung et al. highlight the importance of preparing individuals to collect data relevant to both their health goals and for clinical collaboration, highlighting that boundary negotiating artifacts could be a vehicle to do this [25]. Although at scale integration of boundary artifacts into the EHR ecosystem is still an evolving question, McLoughlin et al. suggested that integrating boundary objects is most effective with top-down approaches, requiring additional stakeholders beyond the provider and patient [62]. Through the integration process, it is critical to understand that stakeholders not only have different perspectives and needs, but also different data-framings shaping their orientation to patient data [22]. Several studies have provided design considerations for tools and platforms to help with both collaborative and individual clinical decisions [25, 104], and even a more basic function of interpreting the data [22, 25]. For example, Raj et al. identified core implications that included supporting problem identification for sense-making and mutual

intelligibility of individual sense-making [104]. However, there might be tensions between clinician goals of using patient-generated data for clinical decisions and patient expectations from the use of their data [22, 27, 99]. Tensions around such collaboration were further expanded upon by Figueriredo et al. with their exploration of patient-generated health data in the context of fertility challenges. They contextualized these differences in stakeholders approaches and use of patient-generated data, yet all parties shared the goal of “exploring the unknown” [27]. This aspect of making sense of new or unfamiliar phenomena using patient-generated data is a core motivation of Post-COVID studies, including our own. However, our research focuses only on collaborative, provider-based clinical care decisions, and examines the use of patient-generated data to support clinical care processes. We do so by first understanding patient and clinician expectations separately, and then discussing what patient-generated data and in what forms are most valuable for clinicians.

2.2 HCI & Electronic Health Records

The introduction of EHRs has revolutionized healthcare, allowing for clinical decision support and process automation to enhance clinical workflows with the expectation of improving patient health [109] and healthcare quality and safety [16]. The EHR is one of the most robust collaborative technologies in the world. Within the U.S., 78% of office-based physicians and 96% of non-federal acute care hospitals have adopted a certified EHR [2]. The EHR allows clinicians to integrate subjective and objective data, and many systems include patient portals wherein clinicians and patients can enter data. Recent additions have allowed for consumer health technologies like activity trackers and implanted devices to add data directly to the EHR [32].

The HCI community has extensively researched the EHR and data extracted from it. Traditional usability research has looked at EHR usability [89], designing dashboards within [64] and outside of the EHR [30, 136], assessing workflows [81, 121], and assessing dynamics between various stakeholders [21]. Other research has investigated impacts of connecting digital traces with clinical outcomes documented within the EHR [40, 101] and speculated how HCI research could be integrated into future work [55, 102]. HCI research has also examined healthcare processes centered around EHRs, including the EHR’s role in enhancing collaborative work within clinics [14, 128], fostering more complete data sharing [91, 95], and supporting decision making [138]. For example, Zhang et al. discussed complexities of the socio-technical environment in which clinical decisions are made and that real-time data acquisition from the EHR is essential for this process [138]. However, HCI literature needs more discussions focused on patient perspectives on integrating passive data collection, if providers find this data valuable, and effective and efficient ways of passive data integration into the EHR ecosystem.

From an HCI perspective, a missing piece from most design recommendations within this space is the articulation of constraints related to integrating design recommendations into the current technological landscape. In the U.S., Epic and Cerner are the dominant EHR platforms—encompassing 72.5% of all hospital beds [20]. Designers and HCI researchers often do not have access to Epic or Cerner, and thus, any recommendations they propose without engaging with large EHR companies may never make their way into the actual design of EHRs. For designs to be immediately actionable, they must be possible within the current technical infrastructures [1]. Thus, innovations in the design of these systems continue to be challenging due to the ongoing divergence in healthcare delivery and technology development [6]. Our research aims to provide recommendations which are implementable in the near-term and by individual clinics, do not require postulating what larger EHRs could/should do, and “extend” current EHR functionalities, rather than propose redesign of existing elements.

2.3 Critical Reflection & Health Related HCI Research

Technology has revolutionized healthcare from many facets. The EHR has allowed for unprecedented data preservation [115] and interoperability [135]. Because of this data provenance, predictive models [45, 46, 80, 137] and integration of artificial intelligence [66, 79, 85, 88, 108] within the HCI and health research space has rapidly grown. Although this literature integrates health data as part of the development process, it does not question the quality or “correctness” of the data itself.

Outside of the computing community, researchers have questioned the quality of EHR data, including associated biases [36] and issues with EHR data mining [59]. Pater et al. attributed biases in data about clinical eating disorders extracted from social media platforms to implicit biases present in common terminology and language itself [101]. Even with clinical collaborators, there was a gap in the HCI researchers’ understanding of eating disorder characterization in online spaces due to lack of knowledge of biases in clinical data. Moreover, understanding complexities and fragmentation of the healthcare sector is critical. Pine et al. talk about healthcare services as a “black box” to outsiders, given the complex, non-transparent, and fragmented nature of the healthcare sector. They highlight the need for people *to know how organizations work on their own and with each other, and to be able to apply such knowledge of organizations to plan, negotiate, and make decisions as they navigate through the healthcare journey* [54].

Thus, making critical reflections part of our discourse is essential as we continue to further integrate complex computation into the healthcare domain. As more decision making tools become embedded into standards of care (e.g., EPIC predictive Sepsis Model [28]), clinical decision making will become more dependent on the data available within EHR systems, calling into question how PROMS and other patient-reported data are taken into consideration.

3 CLINICAL CONTEXT

This research is part of an ongoing research collaboration within the Parkview Post-COVID Clinic in the Midwest United States. In addition to shared research activities, the research team maintains the clinic’s data registry. Parkview is a not-for-profit health system comprised of hospitals, specialty hospitals, a research center, and a large provider group. The Parkview PCC is a specialty clinic: only patients within the system that are referred by a healthcare provider are eligible for an appointment. The clinic model is one of integrative care. During the visit, patients are seen by a provider (i.e., neurology or rehabilitation specialist providers), physical therapist, pharmacist, and a neuropsychologist. Prior to the patient’s first visit, they are asked to report on three aspects of their CLH journey which includes their top five symptoms in ranked order, their best/worst day with regards to symptoms, and a timeline of their symptoms starting with their COVID diagnosis. New patients also take the Brief Symptom Inventory (BSI), which is a mental health screener measuring aspects of psychological distress, such as, anxiety and depression. The clinic follows a reflective practice model of discussing patients as a collaborative, that is, the PCC clinical team meets to discuss the patient panel. They discuss each case and come to a consensus on plan-of-care recommendations for each patient.

Being embedded within the same health system has allowed the research and PCC clinical teams to develop strong connections, and they meet weekly to discuss ongoing research initiatives as well as registry-related needs. Additionally, research team members have conducted extensive ethnography within the clinic, deepening their understanding of clinical workflows.

4 METHODS

This research study is part of a larger initiative focused on researching the presentation and impact of CLH on patients’ everyday health and wellness [98, 100]. The study was reviewed and approved by the Parkview Institutional Review Board and includes several concurrent components. Patient participants were enrolled in the study for approximately 12 weeks. Patient data streams included daily Fitbit data (activity and sleep tracking), weekly surveys, EHR data, and end-of-study exit interviews (see Figure 1). Patient participants spent approximately two hours in the study (5 min per survey x 12 surveys plus a 60 minute interview). Daily Fitbit data, weekly surveys, and EHR data were collected from each patient participant, analyzed, and then presented back to them for reflection during their exit interviews, in addition to other questions. After completion of the patient portion of the study, a case study was created using patient data (Fitbit activity and sleep tracking, weekly surveys, EHR, interviews) and presented to clinic staff during the PCC clinician focus group. This approach was used as case studies are commonly used in medical practice to present medical findings and research outcomes to clinicians and is an effective means of getting to the heart of one of the research questions [93] - what data are clinically valuable?

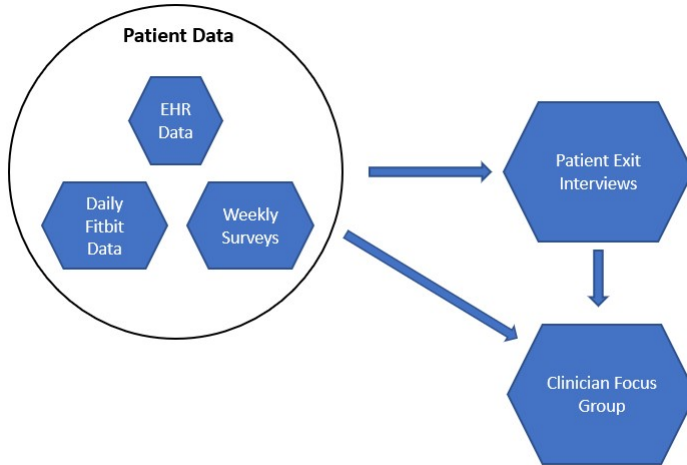


Fig. 1. An overview of the data collection. Patient data, that included daily Fitbit (sleep, activity) tracking data, weekly surveys, and EHR data, was collected over a study period of 12 weeks. Exit interviews were conducted with the patients, wherein aspects of their data were shared back to them for reflection, concluding the patient portion of the data collection. These 4 data streams gathered from patients were used to create a case study which was introduced in the PCC clinician focus group to gather clinician perspective on data collected as a part of the PCC.

4.1 Participants & Recruitment

There were two participant stakeholder groups for this research: patients of the Parkview PCC and Parkview PCC clinicians. Table 1 highlights the demographics for the patient group. For the PCC clinician focus group, 8 people participated (1 male/7 female), ranging from healthcare providers, to clinical staff, to a healthcare student. Reporting out more about focus group participant demographics would be overtly identifying to the individuals and, thus, such details are not provided.

4.1.1 Patients. In order to eliminate study enrollment selection bias, a research nurse reviewed and screened, in a sequential manner, the PPC records for patients who had completed an initial PCC

Table 1. Demographics details of patient participants.

Patient ID	Gender	Age Range	Race	COVID Hospitalization
P150	Male	71-80	White/Caucasian	Yes
P151	Female	40-50	White/Caucasian	No
P152	Male	51-60	White/Caucasian	No
P153	Male	51-60	White/Caucasian	No
P154	Female	71-80	White/Caucasian	No
P155	Female	41-50	White/Caucasian	No
P156	Male	41-50	Black/African American	No
P157	Female	51-60	White/Caucasian	No
P158	Male	31-40	White/Caucasian	No
P159	Female	41-50	White/Caucasian	Yes
P160	Female	31-40	White/Caucasian	No
P161	Female	31-40	White/Caucasian	No
P162	Female	51-60	White/Caucasian	Yes
P163	Male	31-40	Black/African American	No
P164	Female	41-50	Patient Declined	No

visit. Eligible patients (i) were 18 years of age or older, (ii) had completed their initial visit within 30 days prior to study enrollment, (iii) were able to speak and write English fluently, (iv) had an email address and access to a smartphone, computer, or tablet, and (v) were able to understand all aspects of the study and give informed consent for participation in the study. The 30 day eligibility window was chosen so that the PCC visit and plan-of-care recommendations would be fresh in patient participants' memories and progress on recommendations could be tracked, as close as possible, in real-time. Prior to enrollment, screened patients were provided an electronic copy of the study's informed consent form and the research nurse spoke with each potential patient participant via telephone to explain the details of the study. Of particular note, it was explained to the patients that this was not a clinical treatment study but research that was being conducted to better understand their CLH journey, and characterize effective and efficient means of communication and information sharing with clinicians. Between January and February of 2022, 23 PCC patients were sequentially screened, out of which 15 patients consented to participate and 14 completed the 12 week study (P158 was removed due to lack of participation). One patient (P161) did not respond to requests to complete the exit interview, leaving us with complete data for 13 patient participants. Patient participants were compensated through keeping their Fitbits after the end of the study in addition to receiving a \$20 e-giftcard after their exit interview was completed.

4.1.2 PCC Staff. PCC clinicians, administrative support staff, and those serving on the PCC Advisory Council were eligible to participate in the focus group. A list of these individuals was obtained from PCC leadership. To eliminate any potential for coercion or undue influence that could occur if PCC leadership asked individuals to take part in the study, a research nurse contacted the potential focus group participants to assess their interest in participating in the study. Eight individuals agreed to take part, signed the informed consent form, and participated in the focus group. Focus group participants were compensated with lunch and a \$50 e-giftcard after the focus group was completed.

4.2 Data

4.2.1 Patient: Weekly Survey Data. Every Monday for 12 weeks, patient participants were emailed a link to a study survey. The first survey referenced the 5 symptoms, in rank order, that the patient had identified in their EHR as their top symptoms at their first PCC visit. The patient was asked if the symptoms continued to be their top 5 and if the ranked order of severity remained the same. If there were changes, the patient was asked to identify the new symptoms and/or adjust the ranking. They were also asked if the symptoms were resolved, better, worse, or unchanged. The survey then brought forward the PCC healthcare teams’ treatment and testing orders and recommendations, querying the patient about their follow-through on the plan of care. For each item on the treatment plan, patients were asked whether or not they felt it applied to them, if they had started, were making progress, had completed it or if they did not intend to complete it. Finally, the survey asked the patient to rate their overall general health as better, worse, or about the same. Follow-up surveys were identical to the first survey except that the time frame for answering the questions referenced the past 7 days as opposed to their first PCC visit, per the first survey. If a survey had not been completed by mid-week, a study team member sent the patient an email reminder. Follow-up phone calls were subsequently made in the event that a completed survey was still not received. Detailed analysis of the weekly survey data is out of the scope of this paper and a part of a different publication [98].

4.2.2 Patient: Fitbit Data. Patients were mailed a Fitbit Luxe device and were asked to wear it for the duration of the study other than when bathing or charging the device. Included with the Fitbit were instructions on how to access the Fitbit website and set up the device. Follow up emails and/or phone calls were completed as needed if a patient required assistance with Fitbit set up. Individual research accounts were set up for each device so that the study team would have access to the logged data. Patients were free to use all functions of the Fitbit as long as they did not change their log-in information. On completion of the study, patients were sent detailed instructions on how to transfer the Fitbit account from the study email to their personal email as keeping the Fitbit was part of their compensation. Detailed analysis of the Fitbit data is out of the scope of this paper and under review at a different venue.

4.2.3 Patient: Exit Interviews. A total of 13 patients completed the exit interviews. Patient interviews took place during May 2022. All interviews took place via audio-video conferencing and consisted of the patient, a research scientist, and a clinical research nurse. Interviews were recorded for analysis and their duration ranged from 24-69 minutes.

The interviews were semi-structured in nature. The interview guide can be found in supplementary material. Patients were asked about data collection frequency, methods of data capture, and their engagement with the Fitbit. They were also asked about other aspects of their CLH journey that they tracked or that we had not talked about (e.g., personal contexts that impacted care plan adherence). We also shared aspects of their data (e.g., total amount of steps, average daily steps, sleep information, symptom severity, and follow-up with care plans) back with them (e.g., “you averaged about 6K steps daily during the 3 month period of the study”, “your deep sleep weekly average was below recommended level during week X”) during the interview and asked for their reflections on the same, including additional details that could help contextualize why their data looked the way it did.

4.2.4 Patient: EHR Data. Patients’ medical information was obtained via the Parkview PCC data registry and the EHR. The PCC data registry includes key data on every patient seen at the PCC since its inception in March 2021. The data is abstracted manually from patient EHR charts and includes demographic information, medical history, and COVID specific history (e.g., PCC visit data,

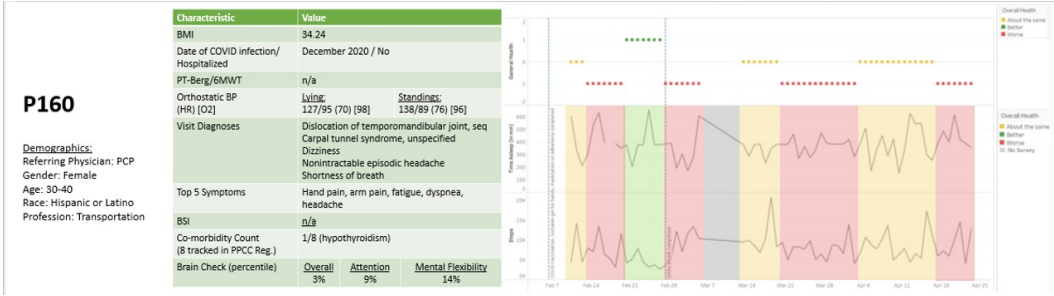


Fig. 2. Focus Group Prompt: Patient 160 EHR and Fitbit Data

hospitalizations, testing results, procedures, prescribed medications). Also abstracted for this study, directly from the EHR, was each patient’s healthcare utilization after their initial PCC appointment, i.e., information on patient healthcare encounters including follow-through on the PCC care plan recommendations. For the scope of this paper, we present only a portion of the EHR data, including patient follow-through records in Table 2), to illuminate certain aspects of the patient journey.

4.2.5 Clinician Focus Group. The PCC clinician focus group took place in September 2022. It was conducted in the same facility, but outside of the PCC clinic space, to reduce the impact on clinic staff. The focus group lasted 45 minutes. Two researchers (one of whom participated virtually) and a clinical research nurse conducted the focus group. The focus group started off with an introduction to the research study. A case study of one patient was presented to the participants. As noted, this approach was used because case studies are commonly used in medical practice to present medical findings and research outcomes to clinicians [93], and is a familiar format to engage clinicians in discussion around their patients. Since a single patient case study is typically used in medical practice, we chose to present the case study of the patient with the most complete data to demonstrate to the clinicians the wide range of data they could have access to and understand what data (and in what formats) they found most valuable for supporting their clinical care workflows. Figures 2 and 3 highlight the probes that were shared in the case study, providing overview of the patient’s data, including interview excerpts from that specific patient. Finally, the moderators asked questions about the data that was collected, the clinical validity of it, and how it could be used within the current clinical workflow (e.g. decision making including referrals, treatments, lifestyle recommendations).

4.3 Data Analysis

4.3.1 Patient Interviews. We analyzed the interviews using reflexive thematic analysis [18]. Two researchers performed an iterative process wherein they individually read and open-coded each interview line-by-line and discussed their analysis after coding each interview, to develop a shared understanding and come to a consensus on their coding. Based on emerging patterns in the data and using a combination of open and axial coding [26], both researchers worked together to group conceptually similar codes into higher-level themes that were used to structure the findings. For example, codes such as “Dealing with other medical & family priorities”, “Insurance & cost-related issues”, and “Physical & mental health barriers impacting compliance” were clustered and used to formulate higher-levels themes, such as “Compliance-related challenges in following care plans & clinic recommendations”. Although codebooks are not part of reflexive thematic analysis, we did document codes and initial themes to facilitate coordination across the researcher team, create a patient case study to use as a probe in the clinician focus group, and structure our results, along with themes emerging from the clinician focus group.

													Overall, General Health	
Date	Week	Symp_1	Symp_2	Symp_3	Symp_4	Symp_5	Last Week Symp_1 progress	Last Week Symp_2 progress	Last Week Symp_3 progress	Last Week Symp_4 progress	Last Week Symp_5 progress			
	Baseline	Hand pain	Arm pain	Fatigue	SOB	Headache								
31-Jan/Week 1	Headache	Fatigue	Hand pain	Arm pain	SOB	No change	No change	No change	No change	Getting better		About the same		
7-Feb/Week 2	Headache	Fatigue	Hand pain	Arm pain	SOB	Getting better	Getting better	No change	No change	No change		About the same		
14-Feb/Week 3	Fatigue	Arm pain	Hand pain	SOB	Headache	Getting better	Getting better	No change	Getting better	Getting better		Worse		
21-Feb/Week 4	Fatigue	Hand pain	Arm pain	SOB	Headache	Getting better	No change	No change	No change	No change		Better		
28-Feb/Week 5	Fatigue	Hand pain	Headache	SOB	Arm pain	Getting better	Getting better	Getting better	No change	Getting better		Worse		
7-Mar/Week 6														
14-Mar/Week 7	Fatigue	Hand pain	SOB	Arm pain	Headache	Getting better	Getting better	No change	Getting better	Getting better		About the same		
21-Mar/Week 8	Fatigue	Hand pain	SOB	Arm pain	Headache	Getting better	Getting better	Getting better	Getting better	Getting better		Worse		
28-Mar/Week 9	Fatigue	Muscle ar	Brain fog	Hand and	Headache	Getting better	Getting better	Getting better	No change	Getting better		Worse		
4-Apr/Week 10	Fatigue	Muscle ar	Brain fog	Hand and	Headache	Getting better	Getting better	Getting better	No change	Getting better		About the same		
11-Apr/Week 11	Fatigue	Muscle ar	Brain fog	Hand and	Headache	Getting better	No change	Getting better	No change	Getting better		About the same		
18-Apr/Week 12	Fatigue	Muscle ar	Brain fog	Hand and	Headache	Getting better	Getting better	Getting better	Getting better	Getting better		Worse		

Recommendations																		
PT for carpal tunnel	Sleep Specialist	72 hr heart holter monitor	Echocard iogram	MRI of brain	Carotid ultrasound	Try voltaren gel for hands	Ortho BP/HR HW	Trial anti-inflammatory diet	Lighthened load at work	COVID Vaccination	Medication adherence	Lifestyle: Diet/ Nutrition/ Hydration	Lifestyle: Exercise	Lifestyle: Sleep Hygiene	lifestyle: Weight mgmt	Lifestyle: stress mgmt	Post-COVID support group	
Haven't st	Haven't st	Haven't st	Haven't st	Haven't st	Haven't st	Haven't st	Making progr	Making progr	Haven't st	Not planning	Completed	Making progr	Making pr	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Making pr	Haven't st	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st
Haven't st	Haven't st	Haven't st	Doesn't a	Not plann	Haven't st	Haven't st	Completed	Making progr	Making progr	Not planning	Completed	Completed	Making prc	Haven't st	Making prc	Making pr	Making pr	Haven't st

Fig. 3. Focus Group Prompt: Patient 160 Survey Results - Symptoms and Action Plan Adherence

4.3.2 Clinician Focus Group. We used consensus coding [23] to analyze the focus group wherein the two researchers and a clinical research nurse individually read and open-coded the focus group transcript line-by-line and then compared their analysis to come to a consensus. Codes such as “Data that provides reassurance” and “Data that shows overall health progression” emerged through the analysis and were tied back to themes which were identified in the patient interviews, such as “Expectations from data & the clinic”, further expanding the scope to clinician-side expectations from data and the PCC. Although the initial themes were formulated from the patient interviews, a few themes (e.g., requirements for mental health-related data) emerged primarily from the clinician focus group analysis.

4.3.3 Healthcare Utilization & Patient Follow-Through Records. One author (a clinical research nurse) conducted manual chart reviews to assess how patients were interacting with the healthcare system, including following up on the care plan recommendations provided to them in the PCC. Manual chart reviews require access to the EHR and looking through various data for individual patients [127]. The research nurse analyzed each individual patient’s EHR for encounters during the study and for one month post study (four months total). Using this data, we created Table 2 for describing patient follow-through on care plan recommendations. We further refer to this table and healthcare utilization data in our findings, backing our qualitative results and understanding of clinical workflows with EHR data.

4.4 Limitations & Other Ethical Considerations

Patient participants for this study skew heavily towards White/Caucasian, middle-aged females. At the time of this writing, the PCC patient panel is 90.2% White/Caucasian, 72.4% are female with an average age of 51.5 years. Thus, the participants in this study skewed more towards female than the PCC patient panel, are slightly younger (average age 49.1), and in-line with the racial makeup of the larger PCC patient panel. Many factors go into why the demographics of this population are not in-line with national averages, mostly due to the physical location of the Parkview health

Table 2. Follow-up with PCC Plan of Care/Clinical Recommendations within 4 months.
* Patient indicated on a weekly survey that they completed this recommendation but there is no documentation in the EHR

Study ID	COVID vaccine	Labs	Follow-up Appointments				Testing			
			Specialist	PCP	PCC	Rehab	Neuro.	Cardio.	Pulmo.	Gastro.
P150	Yes	Yes	Yes (2) No (1)	Yes	-	-	-	-	-	-
P151	Yes	No*	No (1)	-	No	No	Yes (1) No (1)	-	-	-
P152	Yes	No	-	No	-	No	No (1)	Yes (1)	No (1)	-
P153	Yes	-	Yes (1)	Yes	-	-	-	Yes (1)	Yes (1)	-
P154	No	Yes	Yes (1)	Yes	-	No*	-	Yes (1)	-	-
P155	No	Yes	-	-	-	-	-	-	-	-
P156	Yes	No	No (2)	-	-	-	-	-	-	-
P157	No	Yes	-	-	-	Yes	Yes (1)	-	-	Yes (2)
P158	Yes	-	Yes (2) No (1)	-	-	Yes	-	-	Yes (1)	-
P159	Yes	Yes	Yes (1)	Yes	-	Yes	-	-	-	-
P160	Yes	-	Yes (1)	-	-	No	No (1)	No (3)	-	-
P161	No	-	No (2)	-	No	No	-	-	-	-
P162	No	Yes	Yes (1)	-	-	Yes	Yes (1)	Yes (1)	-	-
P163	No	Yes	No (1)	-	-	-	-	Yes(1)	Yes (1) No (1)	-
P164	Yes	Yes	-	-	-	-	-	-	-	-
Non-Comp. Rate	40%	27.3%	47.1%	20%	100%	55.6%	50%	37.5%	40%	0%

system. Moreover, recent data for U.S. adults suggests that women are more likely to experience CLH symptoms than men [47].

During the interviews, we asked patients to reflect on the impact of CLH on their daily lives and care plan compliance. Knowing this could result in emotional discomfort for the patient, the informed consent form addressed this potential concern and patients were notified during and prior to the interview that they could decline to answer any question without explanation. A clinical research nurse was also present for each interview and when patients would express distressing emotions or medical issues, she would engage them about these aspects.

Due to the limited number of clinicians associated with the PCC, we scheduled and conducted 1 focus group. Focus group participants represented the majority of the clinical specialties practicing within the PCC. We do not report out further demographics or identify quotes in this paper specific to the participating clinicians as it would be overtly identifying for those individuals.

We maintained the privacy of all participants by quoting only relevant excerpts from their sessions and removing any personally identifiable information. As noted, the initial themes were constructed using the patient interviews. Key pointers from the clinician focus groups were then introduced, reshaping and refining the structure of the findings using de-identified data to maintain privacy of the participant. Data from the EHR was constrained only to PPC visit, patient care plan adherence records, and post-COVID related healthcare. These were embedded in the findings to highlight certain aspects of the patient journey (e.g., mental health-related hospital visits related to

post-COVID) and current workflow of the clinic. No other protected health data was reviewed or shared. Analysis of sleep and activity tracking data from the Fitbit, weekly survey data, and EHR data (excluding mental health-related visits, healthcare utilization, and patient care plan compliance data in table 2) is not a part of this paper and part of a different publication [98]. There is also the possibility of missing data in the system (e.g., patients not reporting impacts on mental health in their top 5 symptoms, incomplete or non-timely surveys) and its impact on overall understanding of patient lived experiences with CLH and participation in the PCC. Several patients seemed to have some trouble with adhering to certain aspects of the study (e.g., wearing the Fitbit) owing to personal preferences or technical barriers which are reported in our findings (see Section 5.3). Although judging the impact of such barriers/preferences on the data collected and findings is out of the scope of our analysis, they can make it challenging to develop an overall understanding of patient lived experiences with CLH and impact patient participation in the PCC. Yet, we chose to present a case study of a patient with the most complete data during our clinician focus group. This is because the goal of the focus group was to showcase to clinicians the wide variety of data that can be collected as a part of the PCC and gauge what data, out of all the different types, and in what granularity (e.g., weekly, daily) / formats (e.g., notes, health progression visualizations), they felt could be most valuable for facilitating their clinical care workflows and decisions. But even though clinicians might find value in specific kinds of patient data, ensuring data completeness and correctness due to technical/logistic barriers or personal preferences can be a challenge.

Lastly, we re-emphasize the value of being embedded in the clinical context, as also discussed in past CSCW work on decision making tools embedded in the child-welfare system [113]. Although intersectional research means that we have collaborators from various fields contributing to the research, this does not substitute the implicit knowledge gained through true immersion or embeddedness. The idea of knowledge mobilization is gaining traction within healthcare research, especially within quality improvement [83], and is rooted in the idea that better insights are gained when knowledge is collected and created “on the ground” [10]. As degrees of separation are introduced, workflows and data can become perfunctory and difficult to recall with accuracy. Our analysis is a deep reflection of our understanding of clinical workflows, highlighting the need to make actionable recommendations that can be directly integrated into existing clinical workflows and bring on-the-ground impact.

4.4.1 Author’s Positionality Statement. While none of the researchers have direct personal experience with CLH issues, they do have close friends and relatives who have experienced CLH symptoms including fatigue, weakness, and brain fog with severity ranging from mild to severe. The research team is interdisciplinary. Two of the authors have worked with the PCC since its inception developing the patient data registry, with one of them being a nurse who has longevity within the health system. Two authors come from HCI, health, and computer science backgrounds, and one of them was able to shadow within the clinic to better understand the clinical environment. Thus, this team has unique qualifications to assess the different types of data collected.

5 FINDINGS

We present the findings thematically, integrating both patient and clinician comments together. Additionally, healthcare utilization data from the EHR is presented to further illuminate certain aspects of the patient journey. Table 2 summarizes EHR data on patient follow-through on their care plans.

5.1 Patient & Clinician Expectations of Clinical Engagement

Patients were asked about their PCC experience and the data collected during the research, including if they wanted this data shared back to the clinic. Clinicians also described various expectations from the PCC and the data collected. These findings are important as we detail patients' expectations from clinical engagement, including what data and insights they wish to share with their clinicians. As we think about incorporating patient expectations into clinical care workflows (including supporting clinical decision making), it is also important to understand how valuable the data is for clinicians, who will ultimately be using this data and incorporating it into their care workflows. Therefore, we further detail clinician expectations from patient data collected as a part of the PCC/study, specifically detailing what data and in what formats they find it most valuable to support clinical care workflows.

5.1.1 Thoughts on Frequency and Modality of Data Collection & Clinic Check-ins. Patients were split on how frequently they would want to receive check-in surveys from the clinic. Six patients would have preferred monthly check-ins because *"some weeks were the same"* (P160). P154 felt that since their symptoms did not *"change a whole lot from one week to the next"*, they would have preferred monthly check-ins but *"did not mind answering the [survey] questions"* weekly. Similarly, although P164 preferred monthly check-ins, they acknowledged that symptoms may change *"pretty quickly"* after some weeks of stagnation. Eight participants liked weekly check-ins - as they were set up in the study - as they acknowledged the progressive nature of post-COVID symptoms and felt checking-in with the clinic did not take them much time (*"it only takes me a couple minutes to check in"* (P153)). Moreover, two participants felt weekly check-ins gave them *"something to look forward to"* (P150) and acted as a source of *"encouragement"* (P150) to *"keep them going"* (P150, P162):

When you were checking on me every week, it gave me something to look forward to... To see how I am doing... I used it as an encouragement type deal... I think it worked well. I think the encouragement was the push I needed because I think I was slacking. I wasn't feeling good, but I needed something to push to get moving and I think this [weekly check-ins] did help me. (P150)

On the other hand, although P157 noted that weekly check-ins gave them *"a good feeling of how that week went"*, the survey check-in questions were not deep enough and were the same every week, not giving P157 *"a chance to expand on what was going on with each of the symptoms."* With the current depth of the survey questions, P157 shared that they would probably want to shift to monthly check-ins, even though remembering everything only once a month would be difficult for them given they had *"so many things going on."* Similarly, two participants (P152, P163) emphasized this benefit of checking-in weekly as changes in symptoms or other happenings of the week would be easier to remember:

I would want to do it [check-in] weekly because it [changes in symptoms or happenings of the week] would be fresh.. If it [check-in] was monthly... well, with my memory being so screwed up... my short term memory, I would have remembered like, wow, it was here while back. So the weekly would work a lot better for me. (P152)

Clinicians shared similar opinions on survey check-in frequencies and felt it was more important to get an overall view of the patients' health than the day-to-day fluctuations. One clinician described every 3-4 months to be a reasonable frequency for sending patients check-in surveys. They felt this would give patients enough time to complete care plan recommendations and testing, start medical treatments, and allow time for the treatments to take effect. Another clinician stated they did not see *"a lot of quick changes"* in CLH patients and questioned the usefulness of weekly

surveys if symptoms and progress on care plan recommendations stayed “*still the same*”. However, two clinicians contended that long gaps between check-ins might cause patients to forget and not report relevant experiences in much detail. Thus, to make less frequent survey check-ins work (e.g., monthly or quarterly), the clinicians discussed encouraging patients to also reach out to the PCC with additional information “*if something changed*” outside of the PCC-side check-ins.

Patients also expressed preference for modes via which they would want to receive check-in surveys. All but one participant preferred either email or MyChart (over phone calls) for receiving/being notified of the check-in survey. One reason was because patients could reply to emails or MyChart messages in their own time (“*a lot of times I can’t be reached by phone, and by the time I get home... I’m pretty wiped for the day. So just a quick email to that I can catch up on either late at night or at 2:00 o’clock in the morning... works best for me.*” (P160)). One patient did not care what platform they received the check-in notification on as long as they could view it on their iPad. Clinicians did not express any specific opinions on platforms; however, the PCC clinic actively uses the EHR patient portal (MyChart) for patient engagement.

5.1.2 Thoughts on Survey Check-ins, Activity Trackers & Alternate Ways of Health Tracking. Most patients did not find the data collection - survey check-ins and wearing a Fitbit - stressful or burdensome. In terms of the Fitbit, all patients wore the device during the study and did not describe issues except for some technical difficulties with charging and device set up. Although most patients did not suggest alternate ways for tracking activity and sleep data, P150 said he did not particularly enjoy wearing the Fitbit and after the study, would instead use his phone pedometer or mentally track his activity:

I got it figured out now by time I know how much how much I walk. I can walk...about 1/4 miles in one hour, so I will track it that way. I know where I’m at... I’ve had number of weeks to realize this... I will keep track of it [my walking distance] mentally... and I carry my phone with me anyways... (P150)

Thinking towards design implications for data collection, we asked clinicians if they had patients connecting daily tracking data from wearable devices (e.g., Apple Watch, Fitbit) to their EHR. All clinicians agreed that this was not something that they actively looked for or knew about.

In terms of the survey, patients described liking the flexibility for capturing new or “*more important*” (P151) symptoms that developed and reordering their top 5 symptoms as they changed (P152). Additionally, P162 appreciated questions checking on care plan progress as “*they’re reminders to make sure I’m doing what I’m supposed to be doing.*” P155, on the other hand, was skeptical about insights researchers might be able to derive from the survey, since questions were the same every week and their symptoms might not change much.

Patients shared thoughts on improving the survey questions and suggested alternate ways of tracking symptoms and care plan adherence information. This included changing the scale and granularity of tracking. For example, two patients (P157, P160) wanted to change the “better”, “worse”, “same as before” scale for measuring symptom intensity to a number-based severity rating:

Maybe like a degree of... my symptoms are on like a scale of 1 to 10, maybe feel like a three or four this week and then now is that it’s getting worse next week... Maybe it’s now a 7 or an 8, something like that... As opposed to just the three options of the same, better, worse. (P160)

Similarly, P163 described wanting the surveys to capture additional granularity, such as, how symptoms changed during different times of the day (“*when you wake up in the morning, midday, when you go to sleep*”). P153 described taking notes of care plan recommendations he had to complete and his doctor appointments.

Patients were unsure about what types of things to report as “symptoms” in the weekly survey. P164 felt that some symptoms (e.g., fatigue) might never completely “resolve”, but could have temporary solutions (e.g., taking a nap), and hence it might not make sense to report it as a symptom in the long term. However, certain aspects like mental health concerns were rarely reported (reported by only P154). Yet, during the 12 week study period, 2 participants (P157, P159) were hospitalized in a behavioral health unit for mental health issues they attributed to post-COVID and which they discussed in their exit interviews. P157 shared:

I’ve had depression for 25 years, but its never gotten to this point...it’s bad...[a family member] called on me because I was going to attempt suicide. I’m glad I didn’t end up doing it, even though I thought about it. (P157)

Patients also suggested adding questions to the weekly survey asking about medical results and other health & well-being parameters which may not directly come up or be connected to CLH. For example, P162 wanted an additional question on “any new diagnosis since last week” as those might come up in appointments outside the PCC or may not be directly related to CLH or the PCC care plan but could impact and help contextualize some of their symptoms. Other patients suggested capturing their emotional state. For example, P151 felt that the exit interview helped them open up and reflect on their “emotional state” during the study, but it would have been good to have the weekly survey also capture “how people are actually feeling about what’s going on” when it (symptoms, enactment of care plan recommendations) was actually happening.

For PCC clinicians, it was most important to obtain an overall view of each patient’s health. They expressed wanting data and visualizations that show progression of overall health and CLH symptoms of each patient. Aspects of this data exist within the EHR as evidenced by the findings from the manual chart review (see Table 2). 47.1% of patients had not followed up on a recommended referral to a specialist (e.g., cardiology, pulmonology) and 55.6% had not followed up on rehabilitation therapy recommendations. While this data is available, it is not readily accessible when reviewing the EHR for an individual or group of patients.

5.1.3 Data to Support Patients in Dealing with Uncertainty & Provide Reassurance. Patients shared multiple instances of uncertainty during discovery, diagnosis, and management of CLH which impacted how they made sense of and managed their symptoms.

Seven patients described challenges in identifying CLH symptoms and obtaining a diagnosis. It was difficult to discern when symptoms were related to COVID or CLH versus those related to the normal aging process or other life events (e.g., fatigue due to over-working, perimenopause symptoms). This often led to their CLH going undiagnosed until the symptoms began to severely affect everyday life and well-being. For example, P157’s fatigue worsened over time until it started affecting her sleep, and she noticed that “everything started to just kind of change and spiral.”

Other medical complexities and comorbidities (e.g., bronchitis, pneumonia, insomnia, depression, allergies) as well as COVID re-infections heightened this uncertainty. For example, P164 had migraines prior to their COVID infection. Post-COVID they experienced a wide variety of neurological symptoms, including headaches, dizziness, and vertigo and it was difficult to differentiate whether these were symptoms of migraine or CLH or a combination of both. Similarly, P159 described “already having a disability before I [P159] got COVID”, with CLH further affecting their personal life.

Several patients felt this uncertainty compounded by a lack of understanding from others, including clinicians. P154 described how their doctor refused to see or help them manage life-threatening CLH symptoms:

My primary care doctor did not want to see me at all. I was in emergency four different times... I was taken to the emergency first time by ambulance and they said “no, tomorrow you need to see your doctor.” [I] would call the doctor’s office and he said absolutely not... “Go back to ER.” So we went back and forth quite a bit and at the end of the third visit, he ordered a CAT scan of my lungs and said “I am done. I will not do anything else”... Sent me that message by MyChart. (P154)

Such negative experiences and uncertainty induced by CLH and the medical system further impacted patient mental and emotional well-being. P159 described being back in psychotherapy and an admission to the inpatient psychiatric hospital to deal with *“the whole in and out of post COVID stuff”*. When reviewing the EHR data, we found that mental health issues were more prevalent than mental health concerns just the one participant (P154) reported in their top 5 symptoms. Four participants had clinical mental health encounters within the health system and these included hospitalizations for P157 & P159. Two additional patients discussed mental health issues during the exit interviews (P152, P160) without any documentation within the EHR beyond a brief mention within a clinical note.

In light of such uncertainties, patients noted challenges in making sense of and dealing with CLH, describing the process as *“frustrating”* (P164) and their bodies as *“weird and unrecognizable”* (P157). They expressed wanting more information from clinicians about potential complications with comorbidities (P151), side-effects of medicines (P156), and support around mental health effects (P159). Additionally, patients did not appreciate when their concerns were brushed away (e.g., P159’s provider and nurses attributed their breathless to dropping oxygen levels related to a panic attack).

Patients described speaking with other people to learn and share about experiences in dealing with CLH. For example, P151 shared their experiences on Instagram and Twitter as well as made posts to ask others *“how they are dealing with things”*. Similarly, P162 reflected on the benefits of joining a post-COVID support group:

I wish I would have joined that support group right away and I...encourage more people to do that also because to understand they’re not alone and... When you’re running into all these negative naysayers out there that are trying to tell you it’s on your head, it’s not real because they don’t understand that what you’re going through with long COVID is real... But that support group is there to let you know “yes, it is real.” We are going through the same thing with you.(P162)

Along with informational support from clinicians, recognition of the *“reality”* of one’s experiences and reassurance from others emerged as key in supporting patients as they made sense of and dealt with the uncertainties of CLH.

Clinicians, too, described that *“a lot of what I [they] do at the PCC is [provide] reassurance”* and felt objective data (e.g., vitals, test results) helped them provide this reassurance. This became essential due to the long-term (or potentially chronic) nature of CLH. Clinicians discussed the potential of using data collected in the PCC, particularly Fitbit data (*“objective way of quantifying things”*) and subjective data from survey check-ins, to explain to patients their health progression or why their test results looked a certain way. This could help *“address anxiety”* associated with their health and provide reassurance.

5.2 Patient Interactions (& Non-Interactions) with Self-Tracking Data

In this section, we report on patient practices of interacting with their self-tracked data. Understanding various orientations to the data (e.g., are they just tracking and not interacting or are they using self-tracked data to draw insights about their health and recovery) is essential to

motivate ongoing tracking. Additionally, understanding what clinicians found relevant from the self-tracked data is important for potential integration of this data into clinical workflows.

Patients described various interactions as well as non-interactions with their health tracking data. Self-awareness was a major reason patients interacted with their data, especially sleep and activity data collected by their Fitbits. Most patients described “*looking at*” their Fitbit data, in number or graph formats, as a form of interaction. A common approach was checking current sleep and activity (including calories burned) readings on their wrists (P150, P153, P154) or going through the Fitbit application on their phones to check sleep and oxygen levels (P152, P162, P163). P163 further shared instances when their Fitbit showed low oxygen readings (SpO2 at 93%), scaring them but also making them more vigilant to such changes. Patients also described seeing health tracking data in graphical formats as it showed progression over time. For example, P162 described “*pulling up the Fitbit and seeing the graphs that they have for ‘how did I sleep last night’*” on a daily basis. It helped them monitor their sleep apnea, compare their sleep from different nights, and use their BiPap machine accordingly. Thus, P162’s interactions with their sleep data motivated action that helped them manage CLH symptoms and related comorbidities.

Other patients described assessing their overall health and activity levels and acting upon changes that would benefit their health. P150 shared how interactions with their Fitbit activity data became a source of “*encouragement*” to meet their daily walking goal:

I do is... check out my steps [on the Fitbit]. It makes sure I’m doing the right amount and I try to get 3 miles in a day. That was my kind of my goal... I did like it [the Fitbit] though for the fact that I could track myself and make sure... when I’m sitting on my rear end and when I’m moving. (P150)

P157 described tracking their excessive bowel movements and setting up endoscopy and colonoscopy appointments to uncover the reason behind frequent nausea and diarrhea. Other changes motivated by self-assessment of the body and interactions with health data included quitting coffee (P153), seeing a physical therapist to learn “*how to balance heart rate and oxygen levels so that I will continue using the Fitbit to help me monitor that so that I can keep moving forward and not end up regressing*” (P162), and regulating “*night time pills*” (P152). Thus, data interactions motivated by self-awareness often fueled further action for managing and dealing with CLH symptoms.

Patients also described assessing their bodies and engaging with personal health data to answer questions asked by others (including clinicians) and make comparisons. P154’s daughter, who is a nurse, frequently asked questions about P154’s health and hence P154 *tried to get all the answers before she [P154’s daughter] asked them*. Similarly, P163 noted comparing COVID and CLH experiences with their brother and niece. P156 reported to their chiropractor that they averaged a high number of steps daily. The chiropractor was intrigued by P156 tracking their activity using a Fitbit and noted the benefits of walking on the patient’s back pain and overall health.

Further, patients described how being a part of this study, paying close attention to their symptoms and health data became important “*steps*” to help them establish a “*new normal*” post COVID. P162, who was initially hospitalized, engaged with their sleep tracking data to monitor sleep apnea and described moving into a stage of acceptance with their “*new normal*”:

I’m not gonna go back to normal. It’s probably never going to happen... especially now with the scar tissue in the lungs and the problems that is causing. So it’s like, OK, let’s find a new normal and all of these steps are finding that new normal and it’s kind of helping with that.

Similarly, P155 described “*just going with the flow*” and accepting their new normal.

Lastly, a few patients described non-interactions and inability to engage with health data due to memory issues (P152), technical challenges with charging/syncing and accuracy of the Fitbit data (P150, P155, P159), and simply wanting to “*give yourself a break*” (P157) from tracking and stressing about their health.

Although clinicians did not explicitly express how they would want patients to interact with their Fitbit or other health tracking data, they felt it would be helpful to see if patients were being as compliant as they said they were:

patients [are] not always forthcoming about... what activity levels really are on a regular basis... often over emphasize how much and how active they are... would be helpful to see in real time... are they really doing 10K steps or 2K? Are they getting exercise above normal daily activities?

Clinicians had similar questions about patient sleep data and correlation with their activity levels (e.g., if a patient had a busy or active day, how well did they sleep?). The Fitbit could be a tool to help clinicians validate what the patients were telling them. Clinicians also discussed how aggregated data from different streams (e.g., Fitbit, survey check-ins, EHR, interviews) and visualizations created using the same could provide a better overview of the patient’s course and compliance with their plan of care.

5.3 Challenges in Care Plan Adherence & Data Needs around Non-Compliance

Adherence to care plans can only be digitally tracked so far in the current EHR. Patient reports can provide critical data that can shed light into their health status. In this section, we provide patient accounts for adherence to care plans (and lack thereof) and challenges of collecting contextual input from patients in real-time in a manner that is actionable within a clinical workflow.

5.3.1 Logistics & Technology-Use Challenges. Insurance, healthcare costs, and issues related to scheduling appointments were discussed as significant barriers to care plan compliance. Three patients (P151, P152, P160) described their health insurance companies as being “*uncooperative*” in providing information about coverage (P160), paying for treatments and tests prescribed in their PCC care plans (e.g., P152’s insurance did not cover a heart echocardiogram and speech therapy as prescribed in their care plan), and setting up medicine prescription pickups (P151, P152). P154 noted issues with their primary care provider refusing to see or treat them for COVID and CLH, sending them to the emergency room instead. P164, on the other hand, described benefits of their insurance, which made receiving incentives easier if they wore a health tracking device (P164 wore a Fitbit for years): “[*wearing a Fitbit*] is an easy way for us to get our health incentives every quarter to help our insurance payment”. However, for patients whose insurance might not provide similar benefits, continuing to wear a Fitbit, if they had to pay for it, was not a preference (P157, P162).

Patients also described various technical issues related to the Fitbit that impacted their compliance to study protocols. This included Fitbit charging issues (P159, P160, P163), data sync issues between Fitbit device and its mobile application (P150, P151, P153, P155, P157), and phone battery drainage because of the Fitbit application (P156, P157). Two patients (P153, P163) questioned the accuracy of data (sleep, activity, oxygen-level) collected by the device. P153 described himself as an “*electronic illiterate*” and found it to be “*a nightmare when it comes to technology stuff*”. Two patients (P150, P157) reported not wanting to wear the Fitbit because they were not used to wearing anything around their wrists.

5.3.2 Changing Personal Contexts & Requirements. Patients described changing personal contexts, ecosystem barriers, and other life priorities that impacted compliance and care plan adherence.

Six patients described prioritizing immediate needs, including medical needs of close family members and children over their CLH treatment. P160 prioritized her husband's acute health conditions and paying his medical bills:

"My husband was in and out of the hospital for like 2 months... then those bills started rolling in... I see this list [of care plan recommendations] that was recommended for me... which weren't getting covered [by my insurance]... those are definitely going on the back burner until his [treatments] are paid for." (P160)

Two patients described feeling stressed (P152) and overwhelmed with responsibilities (P151) after losing close family members. P151 became the caretaker of their grandmother, who suffers from dementia, after their grandmother's husband passed away. P151 noted that their medical *"stuff got put on the back burner, taking care of myself while I was dealing with all of my family issues."* Three patients described prioritizing caretaking responsibilities of their children. While P162 and P164 had young, school-aged children to care for, P157 shared stressors affecting her adult children:

Besides my son [who is blind], I have a 22 year old daughter and she is a handful. And then I have a 27 year old daughter who is now just getting ready to file for divorce from her husband, who she married less than two years ago. So yeah, besides everything else like I need more things, right? (P157)

Patients shared care plan recommendations that were not possible to follow due to their job requirements and inability to take sick leave or reduce workload. For example, P160 worked in an industry requiring long hours and strenuous activity. They were advised by their doctor and the PCC clinicians to *"lighten the load"* and that they *"need to work less"*. However, this was not an option for P160 which led to them not being able to comply with medical and lifestyle care plan recommendations. Similarly, other patients also described having physically exhausting jobs and busy work schedules (P151, P152, P155) and not taking sick leaves, *"plowing right through it [work]"* (P153) even when ill.

Patients described not compromising on activities they found fun as a personal choice that impacted compliance, even if it involved pushing their physical limits and potentially worsening their CLH symptoms. For example, P153 described non-compliance to sleep and activity care plan recommendations by excessive *"partying"* while on vacation, reporting that they got very little sleep during this period. Additionally, dirt biking *"hard as hell"*, exercising well beyond recommended limits for someone dealing with CLH issues. Other patients also noted not following care plan recommendations (e.g., getting the COVID vaccine, wearing compression socks) due to discomfort or simply as a result of their *"personal preference"*.

Clinicians agreed on wanting more contextual information about patients' lives (e.g., went on vacation and walked 25K steps a day) and environment as that would help them better understand and interpret each patient's health tracking and care plan adherence data. They also wanted to know sources of information (outside of the PCC) on which patients might base personal decisions regarding adherence or non-adherence to specific recommendations so as to ensure, to the best of their ability, that patient knowledge was backed by credible information. Clinicians discussed potential ways of providing patients accurate information outside of the clinic, such as posting on the Parkview social media page, to help address challenges in patient knowledge and sense-making.

5.3.3 Articulating Health Barriers. Patients described various physical, mental, and emotional health barriers which affected their participation in the PCC and adherence to care plan recommendations. Mental health was an issue that impacted several patients in many different ways. P157 reported in their interview that they had been hospitalized for suicidal ideation during the study time period. They shared that they did not like taking medication *"unless it is really required"* and had struggled

with feeling “*down and stressed*.” Their depression had gotten to a point where they were unable to take care of their basic needs and became suicidal, which led to their hospitalization. There were no indicators of this in the patient’s weekly surveys – the depths of their issues were uncovered only through the exit interview. When analyzing the post-PCC encounter data in the EHR, weekly surveys, and exit interviews, a total of eight participants (P151, P152, P154, P155, P157, P159, P160, P163) were found to be dealing with mental health issues. Because of the holistic nature of the data collection we were able to uncover these. If we were only looking at EHR encounters, we would have identified just 4 of these participants. Only 2 would have been found if just looking at the weekly surveys and only 5 noted if using just exit interview data.

Three patients described struggles with “*memory issues*” (P152) and “*forgetfulness*” (P162) which impacted their engagement with the PCC and care plan adherence. P151 described how their bipolar disorder, brain fog, and depression formed a vicious cycle which impacted their sleep, medications, “*social interactions*”, and engagement with the clinic:

I feel like an idiot when I’m talking to people. So... I would withdraw... a lot from social interaction with people and even talking on phones with people... I do suffer from bipolar disorder, so that doesn’t help either because you know not getting the sleep I need and then with the brain fog... you feel so stupid and sends you... into a depressed state even more than before... I do see my psychiatrist. I can’t remember whichever one it is that doesn’t give medication... so I do see them and talk to them and they understand and they know everything... with COVID and how it’s affected me. So we have to be careful with my medication because I don’t want it to make it worse. But yeah, it did impact that. (P151)

Clinicians, too, described wanting mental health information in addition to patients’ physical health tracking and care plan adherence data. This included PHQ-9 scores (depression module of the Patient Health Questionnaire), GAD-7 scores (Generalized Anxiety Disorder assessment), and brainfog tests. Although clinicians agreed that ongoing, repeated screening was ideal, they discussed keeping the frequency of these assessments low and reducing the number of markers (e.g., PHQ-4 which includes 2 depression and 2 anxiety markers) to not overwhelm patients.

Physical health barriers also impacted compliance and care plan adherence. For example, P159 described “*having troubles*” with wearing and charging the Fitbit because they had “*really bad [hand] tremors*” and were not able to get the Fitbit charging device to “*stay on*.” P152’s tendency to “*sleep walk*” affected their sleep and oxygen level at night. P163 noted the impact of headaches, back pain, and body pain on their progress towards medical and lifestyle recommendations.

A few patients reported being adherent to a care plan recommendations but found the recommendation to not work for them. P160 described the cream they were prescribed for hand and arm pain as a “*hit or miss*”. P150, whose symptoms resolved except for fatigue, felt that “*exercise and take[ing] my vitamins*, which were a part of their care plan recommendations, did not help to lessen their fatigue. Two patients described the ineffectiveness of over-the-counter pain medications for helping with CLH symptoms.

Lastly, though getting the COVID vaccine (and boosters) was included as a general recommendation in each patient’s care plan, one patient (P154) described not being able to take the vaccine because of known allergies. P154 noted that this was also acknowledged by their doctor who recommended that P154 not get the vaccine at that time.

6 DISCUSSION

We draw on our embeddedness and experience of being a part of the clinical workflow for over two years to provide actionable recommendations that have potential to render on-the-ground impact. We urge CSCW as a field to go beyond technology design recommendations and create

more opportunities for providing critical reflections that take into consideration on-the-ground constraints not visible to people outside of the clinical system. As our work is deeply anchored within the clinical context, it allows us to fast-track this process and give our clinical partners recommendations which they can immediately integrate and operationalize. Thus, our discussion goes beyond considerations for redesigning dashboards [9, 29, 63] or changing clinical collaboration technologies [49, 87], and emphasizes the need to leverage the existing EHR system to enhance collaboration between clinicians and improve clinical care workflows.

6.1 Differences Between Patient Preferences and Clinical Relevance/Capacity

Our results highlight specific tensions between what patients reported as preferences and what providers found clinically relevant or had capacity for within their clinical workflows. In section 5.1, regarding tracking data, majority patients reported that if the research probes (surveys) were to become part of the clinical workflow, they would want to report their symptom progression and weekly progress towards their plans-of-care. Even those who felt monthly frequency would be more ideal, did not find the surveys too burdensome. Thus, patients wanted clinicians to have more nuance about the dynamic nature of their post-COVID experiences. In contrast, clinicians felt survey check-ins every quarter were appropriate as that would give patients the time to make meaningful progress towards their plan-of-care and for treatments to take effect. Both patients and clinicians saw value in adding a feedback mechanism into the standard-of-care within the clinic. This misalignment between patient and provider preferences is in line with previous HCI scholarship, with Jacobs et al. identifying the open question of determining the ideal frequency of patients sharing health information with their providers [65]. Additionally, this level of detail without any type of meaningful interpretive layer could lead to considerable “noise” within patient EHRs and further obfuscate “patient stories” for which this data could provide meaningful context [126].

There were also differences in expectations of patients and clinicians with respect to Fitbit data. Patients used Fitbit data to gain valuable insights and establish new practices (e.g., meeting daily walking goals). Although a few patients were skeptical of using the Fitbit (e.g., P157 wanted a break from tracking and stressing about their health) and reported technical issues (section 5.3.1), the Fitbit was a catalyst to not only start a new habit, but provide real-time feedback that could be connected to patients’ improving health, thus increasing their self-awareness and helping establish their “new normal”. This is encouraging since past research, like Pevnick et al.’s large-scale study demonstrated that patients had little intrinsic desire to share personal fitness tracker data with their providers [68]. Having a chronic illness like CLH could be the intrinsic motivation needed to share this type of data with providers, in contrast to research that focused on more general populations [68]. More naturalistic studies would be needed to confirm this assumption. Moreover, the clinicians in our study felt that this level of sleep and activity data would be clinically relevant for providing objective data related to compliance, when certain activity and sleep goals given to the patients in the clinic. These results are in contrast to recent research that examined if sharing sleep application data with providers enhanced patient sleep outcomes, but there was no demonstrated engagement with the sleep data by providers [111]. Although our study only engaged clinicians on what their preferences were and did not closely observe how they use the collected patient data in actual clinical care activities, the fact that clinicians were connecting these data inputs into current clinical needs demonstrates potential promise of usefulness of personal tracking data within the clinic. Integrating patient personal tracking data in formats clinicians expressed a preference for (e.g., visualizations that show a progression) and examining clinician practices of engaging with it to support clinical care processes and decisions, is a potential avenue for future research.

6.2 Patient Data and Clinical Workflow Recommendations

6.2.1 Incorporating Patient Data into Clinical Care. In section 5.1.1, patients and clinicians described their preferred frequencies for survey check-ins. While patients were motivated to report day-to-day symptom fluctuations, clinicians were more interested in an overall view of the patient’s health, in the form of objective data (e.g., health tracking) or visualizations that show progression. This finding is inline with the past work that found that clinical decisions are often grounded in objective, measurable data [33]. However, we found that contextual information about patients lives was also important to understand their overall health and care plan progress, and patients expressed wanting to share more of these subjective details (e.g., in the form of notes) with clinicians [12]. Although subjective data is important to contextualize individual CLH experiences and needs, it may not be clinically actionable on its own or in its current form (e.g., contextual details get buried in clinical notes which clinicians may not have time to review consistently or regularly).

Current research employs techniques like natural language processing on unstructured clinical notes to identify patients with specific illnesses like Long COVID [139] in the absence of formal diagnoses (e.g. ICD-10 codes). While these advances are important, they are in their infancy and neglect certain components of assessing overall health, like social determinants of health, that are critical in the design of actionable care plans for patients [119]. Thus, to contextualize patient needs and clinical issues, along with subjective data, there is also a need for more objective data within the EHR for clinicians to develop patient care plans, which can be fulfilled by Fitbit (e.g., sleep and activity tracking) and survey check-in data as noted in Section 6.1. Other data, such as mental health-related records and vital sign information (e.g., more accurate oxygen saturation levels) could also be collected as a part of a clinic workflow. The increased accuracy of wearable technologies and inputs from digital spaces like social media have shown promise in contributing to the holistic understanding of a person’s clinical issues [44]. EHRs like EPIC have created ways to connect an Apple Watch or Fitbit activity tracker within their ecosystem⁶. Recent CSCW research has explored qualitative aspects of patients sharing data with providers and potential design recommendations based [25, 27, 104]. More research is needed to understand the process of full clinical adoption of patients sharing this data, and how it is systematically used by clinicians for in-situ clinical decisions. This change to typical data use and workflow also creates the need for ethical considerations associated with integrating subjective health information within an environment where the patient no longer controls what is done with their personal data. Researchers can continue to explore ways to enhance EHR (and all its contents) usefulness in clinical care settings as there are mixed effects with respect to the levels of clinical collaboration that can be had within the EHR [67].

Although direct patient involvement in clinical care workflows and patient-provider decision making is not the focus of our current research, designing to support decision making that involves patients along with the multiple clinicians caring for them, could also help improve patient care plan adherence, as it would (i) take into consideration patient barriers to compliance (e.g., logistic issues, changing personal environments), and (ii) ensure coordination between and consistency in expectations from the different clinicians consulted for various CLH symptoms. After uncovering patient and clinician data expectations, we identify direct involvement of patients as an important next step to enhancing clinician side workflows/decision-making and encourage healthcare researchers and designers to leverage and engage with the existing EHR system (one of the largest collaborative healthcare technologies [94]) to support better clinical and collaborative care, rather than designing new technologies/systems for doing the same.

⁶<https://www.gethealthie.com/blog/how-to-sync-fitness-wearables-with-ehrs>

6.2.2 Refining Clinical Care Workflows & Challenges with Clinical Decision Support Automation.

Clinicians were unanimous in their desire for data support beyond the EHR (e.g., Fitbit as a validation tool to see if patients were actually following their lifestyle recommendations). However there are limitations on visualizing groups of patients within the EHR. EHR design and use factors can lead to inefficiencies and limited understanding of patient trends [76], but other issues like lack of standardized note templates [61] also limit what can be extracted and assessed. Moreover, with clinical decision making becoming progressively automated, integration of clinical decision support tools into the EHR is becoming more common (e.g., Epic sepsis predictive model). Research on these electronic alert systems has found mixed results with some showing a decrease in mortality and thus, positive outcomes [28, 92] and those that showed no positive outcomes [34, 39, 90]. Other health contexts with embedded predictive models are renal failure [117], diabetes [13], and heart failure [105] and one thing common to these conditions: they all have objective lab values and diagnostic criteria that allow for software to have exact inputs. This approach is problematic for conditions such as CLH that currently have no specific diagnostic tests or encompass symptoms that are often conflated with other illnesses [116, 125]. The conflation of indicators could have devastating impacts on the effectiveness of models if they are not appropriately accounted for during development.

Even when there is complete data within the EHR, it can tell an incomplete story. For example, all new patients in the PCC are asked to take a mental health screening called the Brief Symptom Inventory (BSI) which measures multiple aspects of psychological distress including anxiety and depression. Although there is value in doing mental health screening during the initial PCC visit (e.g., reduces the surprises for clinicians due to missing mental health experiences in patient records, including self-reported data such as top 5 symptoms), from the patient interviews we found that this initial snapshot was not sufficient to capture the actual mental health needs throughout a patient's CLH journey. One example is P157 who shared about a recent suicidal ideation during the exit interview, which we also identified as a health barrier to participating in the study and progressing on their plan-of-care (section 5.3.3). Having a mechanism to collect such ongoing issues and changing contexts could be critical to address the dynamic nature of her CLH experience. However, incorporating contextual information in clinical workflows without disrupting clinical relevance of data and conducting frequent mental health screenings without overburdening patients remain open research questions. Within HCI research, we often rely on snapshots of individual phenomenon and implicitly generalize these to ongoing states. Very few studies follow individuals over long periods of time due to constraints of research "in the wild" [19]. For emerging chronic health issues like CLH, future research from the informatics and health paradigms needs to be more iterative and contextually rich (i.e., see full cases of patients) [50]. One example within the CLH domain is the recent CDC funding of a nation-wide CLH Surveillance Study wherein patients will be surveyed about their symptoms regularly over an 18 month time period [5].

Finally, there are limitations to current workflows within clinical settings that are constrained by what providers can actually bill patients for within the clinical setting. While there are breakthroughs made regularly with regard to clinical treatment and technologies, packaging and delivery of the treatment is often inefficient and unfriendly to the general public [58]. Policy reforms are needed at the micro- and macro-levels to encourage and support adoption of technologies that support increased patient support and care.

6.3 Technology & Healthcare System Design Recommendations

In this section, we discuss the role of technology in facilitating and integrating data and clinical workflow-level recommendations (Section 6.2) into the PCC. Although we mention various technologies for creating holistic patient data profiles and balancing patient-clinician data

expectations, our recommendations are grounded in the realities of the EHR system and propose modifications that can be implemented in the near-term, without having to wait for EHRs to evolve or postulating what larger EHR companies could/should do in the long-term. Similar approaches have been used by municipality hospitals in Central Norway that chose to supplement existing, smaller-scaled EHR systems with “components” to support national integration instead of replace with an altogether new technology infrastructure [38]. And, although EHR companies (e.g., EPIC, Cerner that dominate the U.S. EHR market share [20]) allow for customizations, systems configurations are dictated by the affordances of existing, rigid EHR platform designs [37]. Moreover, additional considerations must be made for resources, as any bespoke customizations created within each system’s instance of the EHR will have to be maintained by the system itself since EHR platforms do not provide free support for customizations when their software updates. It also is estimated that customized EHR solutions are often 1.5 - 2.0 times higher than baseline costs [8]. That said, we still highlight an opportunity for the CSCW community to more actively engage with EHR companies so that redesigning EHRs and expanding their functionalities becomes a realistic possibility in the long-term.

6.3.1 Creating Data-Driven Holistic Patient Profiles & Visualizations. Patient-reported compliance (Table 2) and healthcare utilization data embedded in the findings show patient follow-through on clinic recommendations, including their interactions with the larger healthcare system. Although this data is helpful for estimating patient compliance to their care plan, a clinical nurse had to manually go through the EHR and extract each individual patient’s records. Outside of research purposes, providers and other clinical staff may not have time to complete such a chart review, and hence miss out on essential information for contextualizing patient experiences [11]. Thus, automation of this process could be valuable. For example, EHR system designers could consider embedding Chatbots in clinical dashboards which could automate the process on instruction, pulling up patient records and generating visualizations that could help clinicians build a better, more holistic understanding of patients & their interactions with the healthcare system (within and outside of the PCC). However, further engagement with larger EHR companies is required to provide actionable system re-design recommendations. Moreover, digital phenotyping, i.e., using data from sensors and health tracking devices, could also help create a holistic digital picture of patient health, showing clinicians patient progress in terms of symptoms and vital signs (e.g., heart rate, oxygen saturation) and adherence to lifestyle recommendations (e.g., improving activity levels, getting better sleep) [84]. One recommendation that leverages current technology would be for PCCs to embrace standard clinical note templates and include prompts for clinicians to collect patient reported data within the EHR (a feature that is currently available) to create consistent, holistic profiles. Although clinicians expressed a strong preference for data that shows the patient’s overall health progression (Section 5.1), further research is still needed on how to best design dashboard layouts and embedded visualizations which depict a complete picture of a patient’s journey with CLH (including personal contexts impacting compliance) while remaining clinically valuable for providers.

6.3.2 Understanding Clinician Capacities & Considerations around Interoperability in Health Systems. In section 5.1.2, patients described wanting to provide more detailed, granular, and contextual information about their CLH symptoms and health progress to providers. Although this information can be important to understand the full effect of CLH on patient lives, patients may not have a realistic understanding of clinician availability, capabilities, and limitations of using that data. Moreover, as discussed in section 6.3.1, while creating a holistic picture of the patient’s health could help clinicians in developing more tailored patient care plans, further studies are needed to understand clinician capabilities and limitations of engaging with different types of patient

data [32], and make those abilities clearer to patients, setting more realistic expectations from clinicians. Clinics could leverage existing infrastructure to piece key data together instead of placing the burden on providers to collect it or take valuable time away from patient-care. Some of this data already lives within the EHR. What doesn't, could be collected via standardized tools like a digital survey that could be automated to be sent out via the client EHR interface (e.g. MyChart for EPIC). As long as data is discrete, flowcharts can be developed to bring data together in a common operational view and alert clinicians to missing data or data that needs to be updated/validated. If clinical support tools are not integrated, this will be underutilized due to additional steps in the workflow [74]. Thus, working within the technical affordances of the EHR ecosystem is essential.

Past research has found that dashboard visualizations have direct impacts on both quality of care and clinician satisfaction [72]. Quality visualizations decrease the time spent on data gathering, data processing [72], and compliance with evidence-based guidelines [33]. One way to build better dashboards is through human-centered design, which few dashboards report using in their development (e.g. [43, 57, 120]). This approach allows designers to put the various stakeholders at the center of the design to ensure that final products are tailored to the audiences' needs [17]. Dashboard designs can be leveraged to make different clinician abilities and roles (e.g., specialists treating a specific CLH symptom) clear while also ensuring interoperability and collaboration between different clinicians. Moreover, for dashboards to be fully utilized, they need to be embedded within the EHR ecosystem. Currently, large EHR providers like EPIC and Cerner have limited built-in dashboards and functionality to look at nuanced data in the aggregate. Health systems have the ability to customize these, but this requires additional resources for development and maintenance. Beyond data visualizations are issues around data standards and policies that limit integration of health data into the EHR. An example of this is the inability to integrate continuous glucose monitoring data into the EHR which limits the use of patient-generated data in clinical care or decision making [41]. As new technologies come to market, surveillance and research is needed to identify on-the-ground challenges and processes that could be simplified to improve interoperability and facilitate collaboration.

We also acknowledge ethical considerations around interoperability between healthcare systems and the need for major clinical workflow changes mentioned in Section 6.2.2 before such support can be provided in EHR systems. Yet, we encourage CSCW researchers to engage with open questions around making the EHR a better communication and collaboration tool, with the overarching goal of improving quality of care. More work is needed in the design and testing of EHR dashboards, for which engagement with large EHR companies would be essential, or at the very least, integrate actual EHR data.

7 CONCLUSION

We presented results of a qualitative study that examines data and technology needs for supporting clinical workflows within a post-COVID clinic. Patient and clinician participants described preferences for data collection frequency, communication platforms, and formats & representations of data they wished to share and receive from each other. However, expectations can differ for patients and clinicians, with patients wanting to provide subjective, day-to-day details for contextualizing their CLH experiences while clinicians prioritized overall health progress, seeking aggregated and objective data. We also noted patient challenges in compliance which could be useful information for clinicians for developing personalized CLH care plans. Designers could explore visualizations and dashboards that depict holistic patient profiles and enhance interoperability in existing clinical workflows. However, research is required to examine clinical relevance of different subjective and objective data streams and their potential for facilitating clinical decision making. As a clinically-embedded research team, we provide critical reflections

that could be integrated into existing EHR systems and clinical care workflows. We encourage the CSCW community to go beyond technology design recommendations and leverage data from existing EHR systems and outside the EHR (e.g., activity/sleep tracking, survey check-ins) to enhance collaboration in clinical care settings.

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