



Patients Waiting for Cues: Information Asymmetries and Challenges in Sharing Patient-Generated Data in the Clinic

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Patient-generated data (PGD) show great promise for informing the delivery of personalized and patient-centered care. However, patients' data tracking does not automatically lead to data sharing and discussion with clinicians, which can make it difficult to utilize and derive optimal benefit from PGD. In this paper, we investigate whether and how patients share their PGD with clinicians and the types of challenges that arise within this context. We describe patients' immediate experiences of PGD sharing with clinicians, based on our short onsite interviews with 57 patients who had just met with a clinician at a university health center. Our analyses identified overarching patterns in patients' PGD sharing practices and the associated challenges that arise from the information asymmetry between patients and clinicians and from patients' reliance on their memory to share their PGD. We discuss the implications of our findings for designing PGD-integrated health IT systems in ways to support patients' tracking of relevant PGD, clinicians' effective engagement with patients around PGD, and the efficient sharing and review of PGD within clinical settings.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing.**

Additional Key Words and Phrases: Patient-generated data, data tracking and sharing, doctor-patient communication, patient empowerment, qualitative study

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1 INTRODUCTION

With the widespread use of mobile health apps and wearable devices, an increasing number of people are tracking their personal health data [77]. Ranging from manually recorded data (e.g., food intake, mood) to automatically captured data (e.g., heart rate, step count), we consciously or unconsciously generate many types of health-related data within the course of our daily lives. Hospitals, health systems, and other stakeholders in the healthcare industry (e.g., electronic health

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records vendors, health insurance companies, technology companies) are also paying keen attention to the rise of patient-generated data, looking for potential innovations geared towards more patient-centered and data-driven healthcare. Building on the research framework of personal informatics and patient-generated health data [30, 82], we define the term patient-generated data (PGD) as *health-related data created, recorded, or gathered by patients (or by family members or other caregivers) to help address their health concerns whether they are tracked through pen and paper, some form of technology, or “in their heads”* [30]. While PGD shows great potential for more patient-centered and data-driven healthcare, the mere act of collecting and generating PGD does not necessarily lead to clinically meaningful outcomes unless the data are shared and used by clinicians. Sharing of PGD among stakeholders, such as patients and clinicians, and meaningful discussion around PGD can help reap the potential benefits of PGD when the data can be useful. Recognizing the importance and challenges of PGD sharing in the clinical context, we are motivated to ask the following research questions: (1) What types of PGD are actually shared within a primary care setting? (2) What kinds of factors and cues prompt or prevent patients from sharing their data with clinicians?

Prior studies have explored a range of topics around PGD, including how people track various types of data, associated challenges, and the potential benefits of tracking and sharing PGD with clinicians [4, 17, 22, 25, 29]. Studies have also investigated clinicians' experiences with PGD and identified a range of concerns and challenges, as well as clinicians' skepticism about PGD use in clinical settings [2, 19, 63, 81, 82]. However, these studies have largely been conducted within pre-arranged research settings, with specific tracking devices or monitoring programs given to participants (e.g., Fitbit activity trackers, CareSmarts diabetes self-management program summary report) [57, 62, 63, 75]. Most prior studies have employed retrospective approaches to gather data from participants, relying on their ability to recall their PGD sharing experience [4, 20, 82]. Also, many of these studies focused on patients with particular health condition(s), such as multiple chronic conditions, irritable bowel syndrome, overweight, and Parkinson's disease [4, 20, 57]; thus, their findings regarding PGD tracking and sharing practices were constrained to specific health conditions. Furthermore, the patients who had previously tracked and shared their PGD with clinicians were specifically chosen or recruited to participate in these studies [20, 82]. Hence, while the literature reveals a range of insights about PGD tracking and use in clinical settings, we have little knowledge about patients' PGD sharing practices during real-world clinic visits.

In an attempt to fill these research gaps, we conducted *short onsite* interviews with 57 patients who had just met with their clinicians, aiming to understand their data sharing practices within the context of the specific clinic visits. Due to the nature of the study context where participants were leaving the clinician's office, these interviews were relatively short (on average 7 minutes). However, we explicitly chose to use onsite field interviews to capture patients' vivid recollections of their PGD sharing experiences within a relatively naturalistic setting. In this way, we were able to rely on participants' immediate, rather than retrospective recall, enabling us to avoid the problems that can arise due to memory limitations and recall bias, and thus to collect more accurate and clearly articulated data [44]. Also, when recruiting participants, we did not limit our participant pool to patients who have specific health issue(s), except for excluding mental health patients due to the university health center's request, or to patients who have prior PGD sharing experience. Through the analyses of our onsite interviews with 57 patients at a university health center, we investigate patients' practices and challenges in sharing PGD with clinicians during their clinical visits.

Our interview data revealed that participants were well aware of the benefits of sharing PGD with their clinicians, and most participants (53 of 57; 93%) reported sharing at least one type of PGD in the clinic. However, there was only a small overlap between the PGD that the patients tracked in

their everyday life and the PGD that they actually shared with their clinicians. In response to brief probing from the interviewers, patients elaborated on a range of factors that they considered when deciding whether or not to share their PGD with their clinicians. Also, among the patients who shared their PGD with clinicians, most relied on their memory rather than referring to specific PGD tools or records.

The contributions of this paper to the CSCW community include: (1) an empirical understanding of the first-hand experiences of patients as they share (or do not share) their PGD with clinicians in their everyday life clinical visits; (2) an identification of the nuanced challenges in PGD sharing that arise within the interactions between patients and clinicians and within patients' individual perceptions during the visits; and (3) a set of suggestions for the design of health information technologies that can help address the specific challenges we have uncovered surrounding PGD sharing within clinical visit contexts.

2 BACKGROUND

2.1 Growth in Patient-Generated Data and Associated Developments in Health IT Environments

In a 2020 survey of 4,522 U.S. adults, 42% responded that they used some form of technology, such as websites, smartphone/tablet apps, personal medical devices, or fitness trackers, to monitor their health and fitness, reflecting a significant increase over 2013 when this figure was just 17% [8, 32]. Specifically, with a growing number of mobile health apps and the increasing popularity of fitness trackers and smartwatches, more people are tracking various types of PGD, such as step count, heart rate, exercise, weight, food intake, symptom, mood, and sleep cycle, within their everyday life. Accordingly, the volume of PGD continues to grow [24, 47, 71, 72].

In this context of tremendous growth in personal health data, organizations in the healthcare industry have been paying keen attention to developing more capable health IT systems that leverage and integrate PGD into their electronic health record (EHR), healthcare data management systems, and analytics tools [24, 26, 42]. These entities in the healthcare industry include hospitals, health systems, EHR vendors, insurance companies, and technology companies. For example, Cerner, one of the major EHR vendors, works with other health technology companies to integrate data from many different patient PGD tracking sources into their EHR systems, which are in use in many U.S. hospitals and health systems [34, 76]. Also, technology companies, such as Google, Apple, and Amazon, have been keen on developing products and services in healthcare sectors in collaboration with hospitals, health systems, fitness tracker manufacturers, and EHR vendors [5, 26, 49]. Apple partnered with many U.S. hospitals and health systems to provide a rich set of patient health data to its users (e.g., users of the Apple Health app) by integrating patients' medical health records from EHRs and their PGD into their Apple Health app [26]. Also, Amazon launched its fitness tracker Halo, which can enable its users to have their resultant PGD directly integrated into EHRs [3]. Along with these changes and technology development in the healthcare industry, there are increasingly more patients who have interests in tracking and sharing PGD. Sara Riggare, Dana Lewis, and Hugo Campos, all with chronic conditions, are among those who engaged in accessing and self-tracking their health data and decided to share their concerns and insights with their clinicians as a way to have better care [9, 13, 40, 70]. They wrote and advocated for patients playing an active role in their care, and Lewis helped develop DIY devices "Do-It-Yourself Pancreas System" for patients managing type 1 diabetes [40]. As many different entities within the healthcare industry move forward to engage with PGD and develop health IT systems incorporating PGD, it is useful to examine the current uses of PGD and associated challenges in clinical settings and how

understanding these practices and challenges can help inform the design of emerging health IT systems.

2.2 Clinicians' Concerns and Challenges around PGD Use in the Clinic

Many studies have illuminated the challenges that clinicians experience in dealing with PGD in clinical contexts. First, clinicians' concerns relate to having insufficient time to review and interpret PGD during consultations and the challenges that arise in trying to understand unfamiliar and inconsistent forms of data [81, 82]. Clinicians are presented with PGD that may be inaccurate or incomplete and that have varying degrees of relevance to patients' current health issues [41, 53]. In addition, clinicians often have concerns about potentially violating patient privacy when they handle the health data of patients, including children and adolescents, under strict health and privacy laws [22, 68, 82]. Furthermore, effectively using PGD in clinical practices may require a collaborative process of "meaning making" between clinicians and patients, where clinicians need to spend additional time with each individual patient in their already busy schedule [66, 73]. Examining clinicians' use of patients' Fitbit data, Mentis and colleagues found that the use of PGD is a collaborative process in which clinicians and patients work towards a mutual understanding of the data [57]. Chung and colleagues have discussed this process as involving various boundary-negotiating artifacts [50], such as PGD records, clinicians' notes, and care plans, which are used during PGD-related communication and collaboration processes between patients and clinicians [20]. Clinicians' challenges regarding PGD use range from issues related to the accuracy, completeness, and relevance of the PGD itself and its varied forms of display, to the time and effort required to interpret and utilize PGD for collaborative care within their existing clinical workflows and incentive structure [2, 24, 45, 69].

2.3 Patients' Challenges in PGD Sharing

Prior studies have also discussed a range of potential benefits of tracking and sharing PGD, which include helping to improve patients' self-management and health literacy, empowering patients to take increased control over their health, and helping clinicians and patients to make more informed healthcare decisions [16, 24, 54, 74]. Patients often track their PGD to communicate with their clinicians more effectively [82] and expect that their PGD sharing will support clinicians' diagnosis- and treatment-related decision-making [20].

However, some studies have uncovered the challenges that patients face in capturing and utilizing PGD within clinical settings [19, 43, 46]. For example, manual tracking of PGD can be perceived to be burdensome [21, 51], especially for older adults and those who are experiencing complicated health problems [4, 33]. Maintaining consistent records is difficult [46], and inconsistent PGD tracking is likely to make the data less useful for clinical purposes [81]. Another set of challenges relates to privacy and security concerns. While some studies report that privacy is often less important to patients than the potential benefits they may gain by sharing their PGD with clinicians [21, 38], other studies have highlighted patients' privacy concerns around PGD sharing, emphasizing the importance of trust and rapport between patients and clinicians to the effective sharing of PGD [20, 24, 36]. Additionally, two recent WebMD surveys of 1,211 clinicians and 1,762 patients in the U.S. revealed that clinicians believed that patients were only moderately motivated to provide their PGD to their clinicians [38], but more than half of the responding clinicians (65%) and patients (66%) felt that their counterparts were more engaged when PGD was used or shared during the office visits. Patients and clinicians alike perceive the benefits of PGD sharing, but it is not always the case that patients share their PGD in clinical contexts. Studies have shown that patients were more likely to share their PGD when they thought it would be used to develop their treatment plan or to find the most suitable health and wellness programs for them [21, 38]. These findings

indicate that patients are more likely to share their PGD in certain conditions that will benefit them and that do not have the potential for harm. However, it is still unclear whether and why patients share or do not share PGD in clinical settings. Although studies have identified several barriers to patients' sharing of PGD with clinicians, such as a perceived lack of time during clinical encounters, complexity around their health issues, and concerns about negative responses from clinicians [19, 69, 82], further research is needed to gain a better and deeper understanding of the challenges around PGD sharing.

2.4 Patient PGD Sharing in Clinical Contexts

While prior studies have explored the barriers to, and enablers of, PGD use in healthcare, many have focused more on patients' motivations and challenges regarding PGD tracking and clinicians' difficulties in using PGD, rather than the PGD sharing practices between patients and clinicians [4, 20, 68, 73, 74]. A few recent studies have examined patients' PGD sharing with clinicians; however, these studies were conducted with particular subsets of patients, such as patients who had previous experience sharing their PGD with clinicians, patients who had a high BMI or who were overweight, or patients who were diagnosed with Idiopathic Parkinson's disease [20, 57, 82].

Zhu et al. interviewed 12 patients aged 18 to 65 who have experience collecting PGD and sharing it with their clinicians [82]. Based on their findings, the authors identified two dimensions and four different categories of PGD sharing channels, whether synchronous or asynchronous, and whether co-located or distributed. They pointed out that the major challenge for PGD sharing was patients' concern that clinicians would not welcome their PGD sharing. Also, the authors focused on the tensions between clinicians and patients around the accuracy and relevance of PGD, and on the lack of time, describing such concerns of clinicians around PGD in detail. However, while this paper identifies a range of challenges on PGD sharing within clinics, it does not reveal much about the patient view regarding challenges in PGD sharing. In another study, Chung et al. examined the collaboration between patients and clinicians on PGD tracking and use, recruiting survey participants through pre-screening of the medical records of a large academic medical system looking for patients with a BMI over 26 or who were suspected to have irritable bowel syndrome [20]. Among the subset of survey participants who had experience tracking and sharing their tracked data with clinicians, 18 interview participants were selected by the research team. As the authors mentioned, their study sample tended to favor patients who could be more open to or interested in using self-tracking data. Chung et al. identified what patients expected from their PGD sharing and how they collaborated with clinicians to make sense of PGD and to meet their expectations. However, this paper did not address whether and why patients have challenges in sharing their PGD with clinicians. Using retrospective approaches, the interviewees in both Zhu et al. [82] and Chung et al. [20] relied on their recall to talk about their past interaction with clinicians. The authors of these studies recruited patients who had experience with PGD sharing and/or those who were more likely to be open to sharing self-tracking data, which led to samples with specific attitudes and behaviors around PGD sharing [7, 8]. Mantis et al. [57] also recruited participants with a specific illness (Idiopathic Parkinson's disease) and conducted their study in a pre-arranged format where patients were given Fitbit fitness trackers and then met with clinicians after they had used the Fitbits for a period of 4 weeks.

Unlike earlier studies, our investigation was not limited to patients who have a specific health condition or to those who have previous experiences sharing their PGD with their clinicians. By naturally recruiting from all patients as they come out of their clinicians' offices, without imposing predefined health or PGD tracking/sharing criteria, we aimed to minimize sampling bias [8]. Our study also differs from earlier studies in that we conducted interviews on the spot at the clinic, with patients remaining in the same building in which they saw their clinicians, allowing us to

gather ecologically valid data with minimal loss or distortion of data due to memory limitations and recall bias [39, 44, 56]. By employing naturalistic, onsite visit interviews, our study gathers unique empirical data about whether and how patients actually share their PGD with clinicians, why they do or do not do so, and what types of challenges can arise during this process.

3 METHODS

To understand patients' immediate experiences sharing their PGD with their clinicians, we recruited patients who had just met with a clinician at a university health center (UHC) in the eastern U.S. and conducted short one-on-one semi-structured interviews with 57 patients over a six week period (between February to March 2018). We asked participants about their PGD tracking practices, whether they had shared their PGD during the particular visit, and their experiences and rationale for sharing (or not sharing) their data with the clinician. The participants were mostly young and relatively tech-savvy patients, and a majority (46 of 57; 81%) rated their health as good, very good, or excellent. Following the UHC's guidance, we recruited participants on the second floor of the health center, where there were a range of clinics, including Primary Care, Women's Health, Behavioral Health, Immunization/Allergy, and Alternative Medicine. Per UHC's request, the research team did not recruit participants exiting the Behavioral Health (mental health) office. UHC's policy and rules also included external onsite researchers fulfilling the UHC's security and privacy training and immunization requirements. All the researchers involved in the data collection completed the training and fulfilled the immunization requirements, including taking blood tests, getting a range of shots, and making appointments with clinicians. In addition, we were allowed to conduct research within the specific time schedule which was reported to the UHC, always wearing name badges in the building. In this specific onsite research context, we made efforts to maintain a balance between depth (individual interview time) and breadth (number of interview participants) of the data collection, which involved instant recruiting of patient participants in the clinic hallway. Thus, we designed a 10-minute onsite survey and an immediate, optional 10-minute follow-up interview to gather the data we needed in an effective and efficient format to the extent possible. This study was approved by the Institutional Review Board at the university of the research site, as well as by the UHC where the data collection took place.

3.1 Data Collection and Participants

For this onsite study, three researchers set up desks at an area designated by the UHC for the research study and conducted research sessions in that area. We approached patients as they exited clinicians' offices and asked them whether they had just met with a doctor. By asking this question, we intended to exclude those who had just visited the UHC for other reasons, such as simply receiving a vaccination or alternative therapies, such as massage. If the patient responded that they had just met with a doctor, we invited them to participate in a survey about their health literacy and their experiences with tracking and sharing their PGD during the clinic visit (the survey study was reported separately in [54]). At the end of the survey, we asked participants if we could inquire more about their personal health information tracking and sharing in an immediate, brief (up to about 10 minutes) follow-up interview. As often used in onsite research interviews with patients [10, 12, 78], this brief follow-up interview was designed in consideration of the potential challenges of patients taking additional time for the study participation when they potentially did not feel well, which might be the reason for their clinic visits, the busy context of participants taking time to visit a clinic between classes, and the set amount of time we had for conducting research onsite at the clinic. However, since it was an immediate follow-up of the onsite survey, we were able to skip the introduction of the study, the explanation of the terms and concepts, and the process of putting the participants into the context of PGD tracking and sharing, and instead go straight to

ask specific follow-up questions in an efficient, semi-structured format. If they expressed interest in the interview at the end of the survey, we continued the study session with a one-on-one interview with them in the same sitting. In this paper, we focus on what we learned from our interviews.

Among the 57 patients we interviewed, 47 (82%) were female, and their ages ranged from 18 to 37 ($M = 21.98$; $SD = 4.21$). In addition, 31 (54%) had visited the UHC that day for “Inquiry/exam for a Specific Injury, Illness, or Condition”; 14 (25%) for “Follow-up Visit”; 10 (18%) for “Regular Check Up”; and 2 (4%) for “Other” reasons. In terms of perceived general health, 10 participants (18%) perceived that their general health was Excellent, 11 (19%) Very Good, 25 (44%) Good, 10 (18%) Fair, and 1 (2%) Poor. To make effective use of participants’ time, the follow-up interviews were designed to be semi-structured and succinct; each interview lasted about 5 to 15 minutes, averaging approximately 7 minutes long. During the interview, we asked participants about their current PGD tracking practices; their experience sharing their PGD with their clinicians during their appointment on that day (if applicable); and the reasons behind their decision to share or not share their PGD with the clinician they had just consulted. With participants’ consent, interviews were audio-recorded and then transcribed for further analysis. Survey participants received a campus dining gift card (USD 5 value), and interview participants received an additional campus dining gift card (USD 5 value) for their participation.

3.2 Data Analysis

We used both deductive and inductive approaches to collaboratively analyze the interview data [11]. First, initial codes were developed based on our research goals of examining participants’ PGD tracking and sharing practices, and then additional codes and sub-codes were developed through an iterative and collaborative open coding process performed by all research team members. The codebook and coding results were shared among the team members through a secure cloud platform. In offline code review meetings, our research team went over the codes and discussed issues until we reached agreement regarding any areas of ambiguity or conflicts that arose among team members. Additionally, for each participant, we extracted an individual’s data sharing and tracking practices to identify patterned behaviors, which we report in the supplementary material. We included patients’ tracking “in their heads” (as well as tracking in other forms and technologies) as one form of their PGD tracking practices, drawing on the prior findings on the prevalence of this form of PGD tracking and the challenges and opportunities associated with this form of tracking that requires patients’ recall of the data [30].

Through the iterative coding process consisting of a blend of deductive and inductive approaches, we have identified a range of themes regarding patients’ PGD sharing with clinicians. The research team focused their analysis on developing a clear understanding of patients’ experiences and identifying the nuanced challenges patients encountered with regard to sharing their PGD with clinicians.

This paper contributes ecologically valid, empirical findings and analyses of patients’ PGD sharing challenges drawn from our short onsite interviews with patients who had just met with a UHC clinician. Instead of interviewing patients about their general experience on PGD-sharing, we aimed to gather patients’ immediate and concrete experience tied to a specific clinic visit. Through interviewing patients right after their meetings with clinicians, we were able to collect more accurate and situated responses regarding whether patients had just shared their PGD with their clinician and the specific reasons that triggered their PGD-sharing decisions. In the remainder of this paper, we present our empirical findings, discuss the challenges we identified around patients’ PGD sharing decisions, and draw from our findings to discuss important implications for designing health information technologies that will help to facilitate the effective leveraging of PGD for more patient-centered, collaborative care.

4 RESULTS

While the onsite survey focused on the quantitative relationships between patients' health literacy, data tracking, and data sharing practices [54], our analysis of the interview data aimed to uncover the qualitative insights of patients' data sharing practice. We identified themes regarding participants' attitudes towards sharing their PGD with clinicians, the types of PGD they tracked vs. those they shared, the ways in which they shared their PGD, as well as the triggers and unseen challenges around sharing PGD during their clinical visits.

4.1 PGD Sharing Attitudes: Benefits vs. Privacy Concerns

Participants showed a high degree of willingness to share their PGD to inform clinicians about their health. They clearly perceived that there were benefits to PGD sharing. For example, P1 believed that PGD "*would give them (clinicians) a more holistic picture of what kind of, what patterns of certain things are going on, and it would help finding if there were any abnormalities.*" Rather than being concerned about their privacy, P54 was willing to share PGD to help inform clinicians: "*I'm not concerned with privacy issues or anything, more just giving as much information as I can to the doctor so he can tell me best what is going on*" [P54]. Furthermore, P7 believed that sharing PGD with clinicians has a "*mutual benefit*" for both clinicians and patients. He did not "*see a point in keeping information from a doctor*," which might prevent doctors "*from doing their job*." He also argued that if patients held things back, then they were going to prevent themselves "*from getting the best diagnosis and help*".

However, a few participants (P16, P48, P53) expressed concerns about sharing PGD with entities in the healthcare industry other than their clinicians. Although they still were willing to share their PGD with clinicians, they were concerned that entities such as technology companies might gather their PGD and use it for commercial or marketing purposes—purposes other than their care.

4.2 The Gaps Between Data Tracked vs. Data Shared

When asked about their data tracking practices, all of the participants reported that they had kept track of at least one type of PGD, including daily activities (e.g., exercise (27), sleep (25), food (21)) and physiological measures (e.g., weight (24), heart rate (6)) (Figure 1). Five participants also tracked their menstrual cycle (see supplementary material for the details).

Most participants kept track of their PGD in their heads (30, 53%) or using mobile apps (27, 47%). Six participants (11%) used smartwatches and/or fitness trackers (e.g., Fitbit, Apple Watch) and two participants (4%) used a paper-based journal. Among the 57 participants, 53 (93%) said that they had shared their PGD with the clinician during their visit on the day of the interview. However, in many cases, there were differences between the types of PGD that participants had tracked and the types of PGD that they shared with their clinicians during their visit, as detailed below.

4.2.1 Data Tracked, but Not Shared. Participants reported tracking various types of PGD related to their *daily activities*, such as exercise, step counts, food, sleep, and water intake, to monitor and understand their health. However, during the clinic visit, only a few of the participants shared these data with clinicians. For example, 27 participants reported tracking their exercise, but only 5 (19%) participants shared their exercise data with their clinician. Similarly, 25 participants reported tracking their sleep, but just 7 (28%) shared their sleep data with their clinician. We note that participants could share PGD with clinicians without having to actively track them, and thus, those who shared a given data type were not necessarily a subset of those who tracked that given data type.

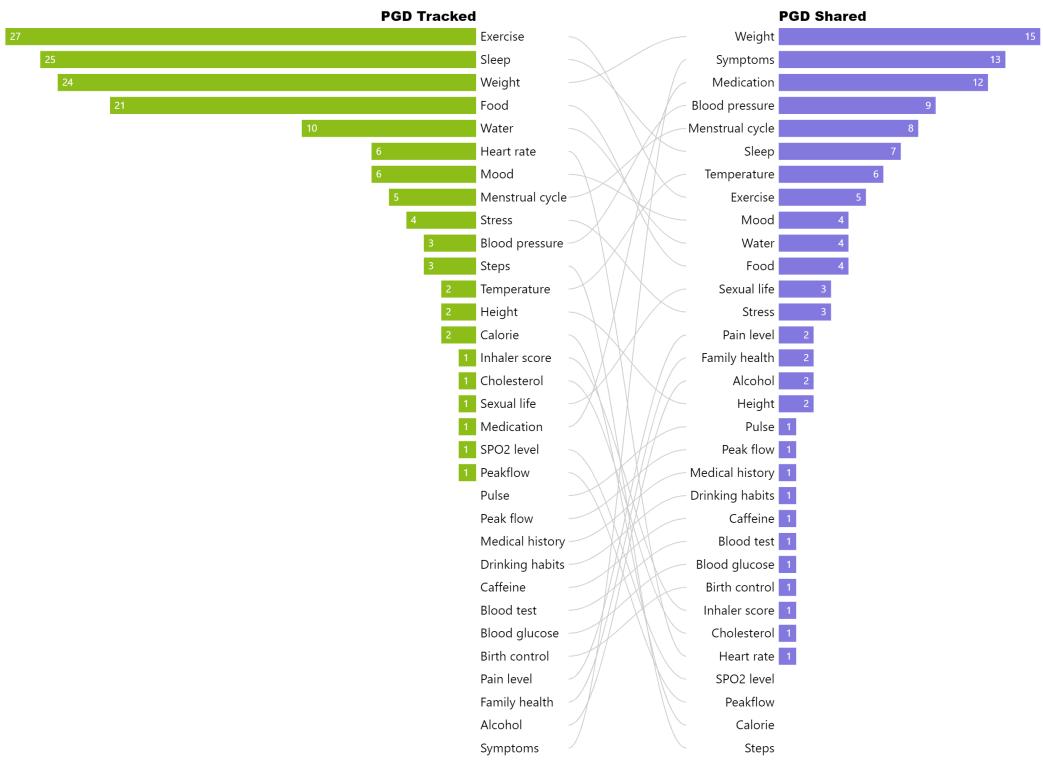


Fig. 1. The types of PGD that participants tracked vs. the types of PGD that they shared with clinicians during their visits (unit count: the number of participants who tracked or shared each type of PGD). Some of the commonly tracked PGD items such as exercise, sleep, and food were not commonly shared. On the contrary, symptoms and medications were commonly shared PGD although they were not commonly tracked. We note that participants could share PGD with clinicians without having to actively track them, and thus, those who shared a given data type were not necessarily a subset of those who tracked that given data type.

4.2.2 Data Not Tracked, but Shared. Participants often shared PGD that they had not tracked, but were able to recall from their memory. Among the 53 participants who reported sharing their data, 36 (68%) had shared one or more types of data that they had not been tracking. This excludes the cases of sharing clinic-measured physiological data (e.g., weight, height, blood pressure) with their clinicians. The types of PGD that these 36 participants shared with their clinicians include exercise, medication intake, menstrual cycle, personal life activities, alcohol consumption, mood, food intake, water intake, caffeine intake, and symptoms. Although they had not purposefully tracked these data, they were able to recall the data in a retrospective manner and then shared the data verbally with their clinicians. For example, among the 12 participants who had shared their medication intake data with their clinicians, none of them had actually tracked their medication intake (note: the one participant who tracked medication did not share the data with the clinician).

4.2.3 Data Tracked and Shared. We found a small overlap between the types of PGD that participants tracked and the types they shared with their clinicians (see Columns 2 and 5 in Table 1 in the supplementary material for all instances). One type of data that was commonly both tracked and shared was weight, which was reported by 11 (19%) participants. Other instances that fit within

this category of data both tracked and shared include menstrual cycle (P5, P10, P46), food intake (P14, P20, P29), and mood (P43, P48).

Our interview data indicated that patients' interaction and engagement with their clinicians can play an important role in helping them decide whether to both track and share their PGD with their clinicians. For example, P29 realized the need for tracking particular data during her meeting with her clinician, and she decided to keep track of symptoms relating to hormonal and gastrointestinal issues, as she wanted to provide this data to clinicians in her future visits: *"I made the decision to do it (tracking) 'cause I noticed it was issue I didn't like. So, I knew after my first visit I wanted to be more informed about myself, so that in future visits I can just tell them, and they can give me a better input about what's going on with me"* [P29]. P29 became motivated to track and share her PGD with clinicians when she realized the need for and the relevance of specific types of PGD for her health issues during her first visit and interaction with her clinician.

4.3 Ways of PGD Sharing

We found that in most cases, patients reported sharing their PGD with clinicians verbally, relying on their memory (46, 81%); a few participants shared their PGD by referring to their data logs on their tracking devices (e.g., mobile health apps) (3, 5%) or shared their PGD through online forms or messages on the university health center's patient portal (5, 9%). In other cases, participants considered the automatic sharing of clinic measures (e.g., weight, blood pressure) with clinicians as a type of PGD sharing (13, 23%).

4.3.1 Verbal Sharing through Recall (46 of 57, 81%). A notable pattern of PGD sharing entailed verbally sharing PGD while relying on one's memory, often in the process of answering clinicians' specific questions. For instance, when P26 was asked a range of questions by her clinician, she answered these questions relying solely on her memory. This participant shared that her usual practice was to verbally provide a rough average of her PGD (e.g., hours of sleep), unless clinicians asked for an exact number.

P51 also relied only on her memory when she shared her PGD (sleep) in the clinic, but she forgot to share other potentially relevant types of PGD with her clinician. She indicated that she *"could have shared a little bit more about what was going on"* by sharing her exercise data, but *"it kind of slipped"* her mind, and she only talked about her sleep when meeting with her clinician.

We observed that some participants who reported only verbally sharing their PGD with clinicians actually did have a record of the PGD that they had been tracking but did not use it. P10 explained that keeping track of her PGD had increased her awareness of her health data and related experiences, which enabled her to recall her PGD from her memory and verbally share this data with her clinician: *"I memorize things based off the app (app for period tracking) as well. Like, as you document things, you remember them. 'Cause I know... I can tell her (clinician) like when my period came. Like, I can tell her the things I experienced"* [P10].

However, as P10 continued, she talked about situations where she would need to rely on her mobile health app to check her PGD, specifically when she wanted to share the PGD that she had tracked some time ago (e.g., previous month).

4.3.2 Using Records and Devices (3 of 57, 5%). As indicated by P10's comment, there were cases where participants reported using their devices and tracking records to share their PGD with clinicians during their visits. This data sharing practice was often not a simple relay of PGD to clinicians. While referring to the PGD (period and symptoms) recorded in her mobile calendar app, P29 first tried to remember what happened when her data were recorded before sharing them with her clinician: *"I didn't show him the screen, I just read it, because I wanted to recall what happened during something"* [P29]. Rather than directly presenting her calendar app with her PGD records on

it, P29 took the time to quickly reflect on her PGD and related contexts and read the record herself to her clinician.

Unlike P29, P48 and P53 showed their mobile app screens directly to clinicians. These two participants had tracked their period using menstrual tracking apps, and they thought it would be easy for their clinicians to recognize period cycles and other related information by looking at the data on the screen.

"I showed my app. Yeah, my menstrual tracker is an app, and then other things that I remembered. ... I just showed it to her. I was able to pull it up because it aggregates data and system weightings. ... Because it's easy to recognize what I'm talking about. It's color-coded so I can see there's poor sleep here, you should be able to see it. Even though it's an app designed for a specific purpose, it also keeps other kinds of data" [P48].

These patients directly presented their mobile app's aggregated records to their clinicians, making it possible for them to share their PGD in a visualized and more organized format.

4.3.3 Through Health Center Portals (5 of 57, 9%). Beyond the setting of an in-person encounter with clinicians, a few patients (P25, P31, P36, and P46), shared their PGD with clinicians in another way. They talked about their experiences filling out online forms on the health center portal when making their appointments. They considered this to be a type of PGD sharing practice and saw opportunities in this specific practice for enhancing ways to share their PGD with their clinicians: *"When you make an appointment at the health center (portal website), I guess they give you an area to describe any additional comments. I guess that's helpful, but she (clinician) didn't bring it up in my ... Like when I met her in person, I brought it up. So I don't (know) if she read it ahead of time and was just waiting to see what I would say. Maybe if she isn't reading it ahead, maybe (she could) read it ahead to get a picture of what I'm coming in for" [P46].*

As mentioned above, P46 had left additional comments about her health at the health center portal when making an appointment and found the comment area helpful. She expected her clinician to look at her data and to have gained some ideas about her health issue prior to her visit to the clinic. P57 also had an experience using the health center portal to communicate with her clinician. She shared her health issues with her clinician through direct messages sent via the health center portal, and her clinician was very responsive to her messages.

As such, UHC patients provided some of their health data prior to their visit by manually adding comments in online forms or sending messages on the health center portal. In relation to this health data sharing option, P31 discussed the potential benefits of incorporating patients' PGD into the health center portal, where patients' specific health data might be tracked through their apps and then shared with clinicians through the system: *"I guess there is that portal that you're supposed to use when you make an appointment and they ask you certain questions. So I guess if there was an app where they had students track their health things throughout the week or something, or just record certain things that they notice for the past couple of days before their appointment, that kind of thing (would be helpful)... instead of just in and out" [P31].*

P46 and P31 both expressed an expectation for systematic PGD sharing through the health center portal, which can be done in advance, in addition to their in-person PGD sharing during their appointments.

4.4 PGD Sharing Triggers (or Lack Thereof)

As reported earlier, participants were generally willing to share their PGD and relied on their memory or, less frequently, their records when sharing their PGD with clinicians. However, we also identified a prevailing theme regarding patients not sharing their PGD with clinicians for a variety of reasons, as detailed below.

4.4.1 No PGD Sharing if Clinicians Do Not Ask. Except for a few participants who had proactively shared their PGD with their clinicians, it was a much more dominant pattern that patients did not share their PGD unless they were asked to do so by their clinicians. Among the 53 participants who shared their PGD with clinicians, 41 (76%) shared their PGD as they answered clinicians' questions. Only 7 of 53 (13%) participants initiated PGD sharing themselves. For example, P53 shared about her inhaler use, weight, and menstrual cycle in answer to her clinician's questions, but she did not share any of the other types of PGD that she had tracked through her Fitbit. She had never been asked by clinicians to share the types of PGD that she tracked on her Fitbit, and thus, did not share these types of health data (e.g., sleep, steps, heart rate patterns) with her clinician, even though she actually felt that these data were "*sort of important as an indicator of*" her health.

P6 also thought that it might have helped him to share his PGD if his clinician had asked questions about his PGD related to his daily activities: "*I thought maybe if they had asked for my water intake or sleep data, that might have been more useful because that would have painted a picture of kind of how much sleep I've been doing to combat the fact that I'm sick or how much fluid I've been drinking*" [P6].

In addition, P6 reported that he did not share his PGD during the visit, except for his height and weight data. He thought that the specific PGD he had tracked (e.g., sleep data) were not important for his current health issue, as his clinician did not ask about them. When his clinician did not ask about his PGD, P6 interpreted it as a cue that those types of PGD were not important enough to share.

4.4.2 Patients' Own Judgments on the Relevance of PGD. Some participants (P26, P47, P49, P52) made their own judgments as to the relevance of their PGD to their clinic visit. They did not share their PGD with clinicians when they thought that the data they had tracked were not relevant to their current health issues. For example, P52 did not share her sleep data, which she had tracked in a mobile health app, with her clinician because she did not believe that it had ever been relevant to her health issues. Similarly, P26 did not share her steps and exercise data with the clinician during her visit, because she did not think that they were relevant to her flu symptoms. However, both P52 and P26 implied that they would have shared their PGD if their clinician had asked about it.

As such, patients often made decisions on their own about the relevance of their PGD to their current health issues and whether to share their PGD. At the same time, however, their decisions with regard to PGD sharing were likely to be influenced by whether clinicians had directly asked them about the specific types of PGD they had tracked.

4.4.3 Patient-Clinician Relationship. While all participants were generally willing to share their PGD with clinicians, a few participants preferred to have an existing relationship and some rapport developed with their clinicians before sharing their PGD or giving clinicians access to their PGD. These participants were interested in ensuring more comfortable and effective PGD sharing by developing their relationship with clinicians through multiple encounters with them over time. P48, for example, perceived that clinicians tended to be more open to her health data sharing when she had met with them more than once. Similarly, P52 preferred "*to have gone to them (clinicians) for a while before giving them access*" to her PGD on her mobile health apps.

4.4.4 Gaps between Clinicians' Questions and Patients' PGD Tracking. Often, patient PGD sharing did not take place due to the gap between clinicians' questions and the specific types of PGD that participants had tracked. Participants were not able to answer clinicians' questions about their health data at all when they had not tracked or could not recall the particular type(s) of PGD that their clinicians asked about. For example, P28 was asked questions on her appetite and water intake by her clinician, but she was not able to share such data with her clinician because she had neither

thought of tracking any of those specific types of PGD (appetite, water intake) nor was able to remember anything about those PGD items. P48 also mentioned a gap between clinicians' questions and the health data that she kept track of. Although she was tracking many types of PGD, such as food intake, weight, mood, menstrual cycles, caffeine intake, and appetite, she was not able to answer her clinician's questions about other types of health data that she did not necessarily pay attention to.

"I'm not keeping track of when I have a dry mouth, or things ... like do my palms sweat when I wake up in the morning? Little things. ... so when she (clinician) goes 'Well, have you had any sweaty palms?' or 'Have you had morning headaches?' I'm like, 'Well I don't know, I haven't been looking out for them.' So I think if I had been cued in to what I should be looking for, then I would have had more comprehensive information" [P48].

So although P48 was relatively active in PGD tracking, her PGD sharing was limited due to the discrepancy between what her clinician was interested in and what data she had actually tracked without knowing in advance the types of PGD that her clinician would perceive to be relevant.

5 DISCUSSION

Our onsite interviews with 57 patients and analyses of the resulting data revealed important discrepancies between the types of data patients track and the types of data they share with their clinicians. As reported, only a small proportion of our participants shared the specific types of PGD that they had tracked with clinicians despite their belief in the value of sharing their PGD with clinicians. Although sharing specific types of PGD might not be necessary or helpful in all cases, our analyses revealed a range of challenges interwoven within the collaborative PGD tracking and sharing process, which can prevent the potential leveraging of PGD for enhancing patient care. Implications are drawn from our analyses to help inform the design of emerging healthcare technologies that incorporate PGD to provide more data-driven, patient-centered care.

5.1 Information Asymmetries and Information Gaps

Without exception, all of the participants in our study were willing to share their PGD with their clinicians. They believed that the more data they shared, the more helpful it would be for their clinicians in diagnosing their health issues and making optimal care decisions. However, although they regularly tracked their PGD, a majority of participants did not share much of the data that they had tracked with clinicians during their visit. Patients perceived that clinicians were the experts and had more information about their health issues, and thus, many of them believed that it was unnecessary to proactively share their PGD with clinicians. They held back on sharing their PGD unless their clinicians specifically asked about the data. Without receiving information from clinicians about the relevance of their PGD for their clinical care, patients tended to perceive that their PGD was irrelevant to their health issues and unnecessary to share. The resulting lack of PGD sharing from patients likely kept clinicians from accessing and using potentially helpful patient data. These findings echoed with our survey results, which showed that the uncertainty regarding the relevance and usefulness of one's PGD had prevented patients from sharing their data [54].

5.1.1 Information Gaps for Patients. This finding implies that there are likely two types of information asymmetries between patients and clinicians [14, 15, 27]. First, our participants believed that their clinician had more knowledge and information about their health than they did and that their clinician would know what additional information was needed to examine their health issues. Thus, participants assumed that it was not necessary to share their PGD unless clinicians directly asked for it. They mainly relied on clinicians' prompts or requests when deciding whether or not to share their PGD. Many participants described feeling unable to determine whether their PGD

sharing would be beneficial for their care. This finding indicates that patients' PGD sharing (or non-sharing) can be influenced by an information gap—although our participants were generally willing to share their PGD with clinicians, they often did not do so because they did not know whether the specific types of PGD they had tracked would be relevant to their current health issue.

5.1.2 Information Gaps for Clinicians. Another aspect of information asymmetry pertains to patients tracking and storing their PGD only in their personal information spaces. Patients have more information about their PGD than their clinicians. Although PGD have great potential to contribute to more patient-centered care [22, 41, 63], it is of little value in clinical contexts if it is not shared with and processed by clinicians. While clinicians are experts in knowing whether tracking and sharing certain types of PGD can be helpful for their patients' care, patients are experts in knowing what types of PGD they keep track of and how and why they do so [31]. Without specific communication between patients and clinicians, it is hard for clinicians to know what types of PGD their patients currently track and why—data which could help inform their clinical decisions and enable them to better engage with their patients. With an awareness of the specific types of PGD their patients track, clinicians could check in with their patients, confirming the value of tracking certain types of PGD that are most relevant to each patient's health concerns and/or encouraging patients to track other types of PGD or to track their data differently (e.g., more frequently). This engaged interaction around PGD could, in turn, affect patients' PGD tracking and sharing practices and enhance the potential value of PGD for clinician decision-making and data-driven patient care [16, 20, 82].

Drawing on these two types of information asymmetries, our findings illuminate significant information gaps between patients who are willing to share their PGD with clinicians (but wait for their clinicians to ask) and clinicians who see a potential benefit from being able to leverage patient PGD (but wait for their patients to offer). There is a need for mediation that can bridge these gaps so that PGD can be effectively leveraged to benefit patient care.

5.1.3 Potential of Connected Health IT Systems to Bridge Patient and Clinician Information Gaps. Prior studies have encouraged clinicians' active engagement with patients' PGD tracking practices, especially at the early stage of care, as a way to help improve the quality and relevance of PGD [16, 82]. This type of early engagement can also be an effective intervention to address the PGD-related information gaps between patients and clinicians. Effective communication and engagement between patients and clinicians about PGD tracking and sharing will not only help clinicians learn more about their patients' PGD and PGD tracking practices, but also help patients learn about the most relevant types of PGD for them. Thus, this PGD-related early engagement between clinicians and patients could function as a way to bridge the information gaps for both clinicians and patients. In this context, we see a great potential for a PGD-integrated health IT system, whether it is an EHR patient portal (e.g., Epic MyChart¹, Cerner HealtheLife², Meditech Expanse³), a personal health record app (e.g., Apple Health⁴), or a combination of both, to function as a means for enhanced engagement regarding PGD between patients and clinicians. However, although PGD-integrated health IT systems would allow patients to inform their clinicians of the types of PGD that they track, thereby narrowing PGD-related information gaps for clinicians, it is unclear how these systems would facilitate the engagement and communication between patients and clinicians regarding PGD. Prior studies have consistently pointed out a variety of challenges that arise in PGD sharing and use in the clinical settings within existing workflows, such as the burden imposed by the

¹<https://www.mychart.com/>

²<https://www.cerner.com/solutions/patient-engagement>

³<https://ehr.meditech.com/>

⁴<https://www.apple.com/ios/health/>

need to process potentially unfamiliar or complicated data, and the problem of limited resources [2, 24, 45, 69]. One of the significant challenges we face is to identify concrete ways to enable patients and clinicians to effectively engage with each other regarding PGD tracking and sharing within their health IT systems or communication channels (e.g., PGD-integrated EHR patient portals).

Considering this opportunity and concern, we suggest that emerging health IT systems be designed in ways to establish effective information flow between patients and clinicians regarding PGD at the early stage of care. More specifically, designers and administrators of emerging health IT systems, such as PGD-integrated EHRs [34, 49, 61] and personal health record apps [37, 59], are encouraged to consider creating features that guide more focused patient-clinician collaboration around PGD, facilitating the communication of relevant PGD and minimizing unnecessary data sharing and efforts. For example, new patients can use a PGD-integrated EHR patient portal to first share the types of PGD that they track so that clinicians can be easily informed of the existing PGD landscape of the patients. Then when a patient and clinician meet for the first time, the clinician can check in to learn about the PGD as part of their clinical communication in order to assess and understand patient problems and guide what types of PGD would be most appropriate to be tracked and shared in the future [23, 64, 65]. Upon being informed of the most appropriate PGD to track, patients can then focus on tracking more relevant types of PGD during the care process and selectively share only the types of PGD that will be more useful to their clinicians and for their specific care contexts. These relevant PGD can be effectively shared with clinicians through PGD-integrated EHRs, which can potentially take data also from personal health record apps or other tools through standards-based, interoperable technologies, such as SMART on FHIR⁵ [55, 60]. This focused PGD tracking and sharing will help minimize clinicians' time to review PGD as well as lowering the burden and uncertainty around PGD tracking for patients [58, 69]. When more relevant and manageable amounts of PGD are provided to clinicians through this facilitated engagement, it will help further narrow the information gap for clinicians regarding patients' health data and help clinicians to collect relevant information in a more time-efficient manner.

The designers of PGD-integrated health IT systems will also need to consider ways to allow patients to add more types of PGD that they track (e.g., using manual note-taking, mobile health apps, tracking devices, or medical devices such as glucometers) beyond the limited types of tracking tools or records (e.g., Fitbit, Amazon Halo, Apple Health). This open, inclusive approach to gathering patients' PGD would help provide clinicians with a more comprehensive picture of their patients' PGD and PGD tracking landscape.

The active engagement between patients and clinicians early in the process, supported by carefully designed health IT systems that facilitate more focused PGD tracking and sharing practices, would help narrow the information gaps between patients and clinicians; alleviate their burdens in PGD tracking, sharing, and reviewing; and support the effective use of PGD for more data-driven and collaborative care.

5.2 Reliance on Memory

Our findings revealed another challenge related to patients' PGD sharing with their clinicians: the common practice of tracking and sharing PGD by relying only on one's memory. Tracking PGD solely in one's head can lead to missing or inaccurate data, as patients are apt to forget some proportion of their data and may thus be unable to share correct data with their clinicians. If our study participants, who were young and relatively tech-savvy patients, experienced this challenge, it is likely that this can be a more significant factor affecting the PGD sharing of patients in other

⁵<https://smarthealthit.org/>

demographic groups, such as older adults. Missing data also restrict patients' ability to accurately reflect on their PGD. When seen through the lens of personal informatics systems [52], patients who only track their PGD in their heads are less likely to reflect on their PGD compared to patients who use specific tools to track PGD.

5.2.1 Leveraging Clinician Engagement to Facilitate Concrete PGD Tracking. In our interviews, patients who tracked their PGD only in their head or who paid little attention to their specific PGD reported that they often did not remember the details when they were asked about PGD during their clinic visits. On the contrary, patients who kept records of their PGD, for example, on their phones, were able to overcome the limitations of their memory by pulling out their phones and referring to their records to answer clinicians' questions. This finding corroborates our companion onsite survey results that quantitatively showed a positive relationship between the number of data types that patients tracked and their self-assessed ability to actively engage with clinicians [54]. Therefore, findings from both the interview and survey underscore the importance of patients recording PGD in a concrete form, rather than merely in their heads. But how can we help patients record their PGD in a concrete form? Prior work suggested that patients are more likely to keep track of their PGD when clinicians get involved with their PGD tracking [46]. Also, patients tend to be more motivated to track PGD [82] and more likely to provide relevant data [20] when clinicians specifically ask for it. Likewise, our interview data (e.g., P29) indicate that interaction with clinicians can help patients make decisions to track PGD in a concrete form for future PGD sharing with clinicians. Thus, it would be important for clinicians to engage with patients regarding PGD tracking during the visits and through health IT systems early in the care process. When patients capture the suggested health data in concrete forms and have it available in the connected health IT systems, it would help address the issue of patients' reliance on memory and their limited ability to recall PGD. Also, such PGD recorded in concrete forms and made available within the connected EHRs will not only help patients and clinicians use their meeting time efficiently, but also enable clinicians to examine patient data in a more flexible manner—in advance, remotely, or during the first few minutes of a clinical encounter—in their time-sensitive work environment [69, 81].

5.2.2 Supporting Features in Connected Health IT systems. Our interviews showed that clinicians often asked patients about specific types of PGD that the patients had not necessarily been tracking. In this case, patients needed to recall the data from their memory. We see the opportunity of leveraging such clinician-patient conversations to guide patients to track specific PGD for future appointments. For example, important and relevant types of PGD that are mentioned by clinicians during the visit could be recorded and highlighted in the connected EHR systems with convenient data entry techniques, such as using voice to create clinical notes [1, 67]; and the new information about the suggested PGD could be made available to patients through their connected EHR systems, tracking devices, or mobile health apps to encourage and facilitate patients' tracking of the suggested types of PGD.

In addition, PGD-integrated health IT systems can support patients' recall and clinicians' review of PGD more effectively through visualizations. Feller et al. [28] demonstrated that an interactive tool featuring hierarchical clustering and a heatmap visualization was more time-efficient than traditional logbook formats for enabling clinicians to identify associative patterns between blood glucose levels and per-meal macronutrient composition. Collaborative review of PGD by clinicians and patients can be more effective when PGD is available in the form of reports with trend data rather than just raw data [69]. Various entities in the healthcare industry are also working to develop visualizations to present PGD in a more effective and engaging format [5, 26]. We suggest that PGD-integrated health IT systems consider using visualizations whenever relevant to support both patients and clinicians, helping patients to recall and understand their PGD and helping clinicians

to efficiently review the PGD. Also, the PGD-integrated health IT systems could be designed to notify patients of their progress and patterns regarding PGD, both on a regular basis and just prior to their appointments, enabling them to efficiently recall and reflect on their PGD during their visit and empowering them to collaboratively discuss their health issues with clinicians [18, 20].

5.3 Patients' Control over PGD Sharing

We noted patients' preference for having some level of control over how their PGD would be shared or used in the broadly connected health IT systems, as reported in Sections 4.1. and 4.4.3. Specifically, some participants had concerns about sharing their PGD with entities other than clinicians (e.g., healthcare/technology companies) (P16, P48, P53), being unsure about how those entities might use their health data for purposes other than their own care. This is in line with the discussions on concerns around mobile health app users' personal data and what the mobile health apps might do without their awareness or permission, considering the personal and sensitive nature of health information [25, 79].

Also, in terms of relationship development and PGD sharing with clinicians, P48 perceived that her clinicians were more open to her health data sharing when she had seen them more than once, and P52 expressed her preference to have gone to clinicians for a while before giving them access to her PGD on her mobile health apps.

Although a majority of participants found no issues in sharing PGD in clinical settings, the above mentioned concerns and preferences around PGD sharing might hinder some patients' PGD sharing through PGD-integrated health IT systems and early engagement between patients and clinicians. If emerging health IT systems are to effectively support PGD sharing and PGD-related interaction between patients and clinicians early in the care process, the designers of these systems should consider ways to address these concerns and support patient preferences when designing the user workflow and related options.

5.3.1 Features Supporting Patients' PGD Sharing Management. The accounts of P48 and P52 about the importance of developing rapport and relationships with their clinicians before sharing PGD with them suggest that some patients would appreciate having control over when they share or release their PGD to their clinicians. In this light, it can be useful for designers and providers of emerging health IT systems to consider addressing patient concerns about their ability to control the sharing of their personal health data within the PGD-integrated health IT systems [37, 48, 80]. Specifically, designers of PGD-integrated health IT systems could consider this need when developing patients' opt-in processes for sharing and releasing their PGD to health IT systems and to clinicians. For example, patients might be given the options to make their PGD available to all eligible clinicians or to specify whether and when to share their PGD with each individual clinician. The systems could also ask patients these types of PGD sharing management questions when they first enter the specific types of PGD that they track into the health IT systems, before they begin discussing PGD with clinicians. This type of patient empowerment for PGD sharing management could help reconcile the potential conflict between the need for early and active patient-clinician engagement regarding PGD and the need to address patient concerns and preferences around control over their PGD.

Further research on patient adoption of PGD-integrated health IT systems and patients' preferences regarding control over sharing their PGD in the connected health IT systems would help to ensure the effective adoption of and transition to emerging health IT systems, including PGD-integrated EHR patient portals and interoperable personal health record systems [34, 37, 80].

5.4 Reflection on the Onsite Interview Method

Typical interview studies rely on participants' "*ability to recall and explain a process that they are removed from that moment*," often neglecting important details, generating recall bias, or leaving researchers with a superficial understanding of participants' activities and thoughts [35]. While researching patients' experience at clinics, researchers often conduct onsite observation and interviews to draw insights from the real-world context [6, 10, 12, 83]. However, observation studies could bring up privacy concerns for both patients and clinicians [6]. We conducted an onsite interview study at the UHC, with patients who had just met with a clinician, collecting patients' immediate experiences while mitigating privacy concerns. Unlike prior studies that have often interviewed patients retrospectively after some time had passed since their clinic visit [20, 82], our onsite interview helped contextualize the situation where patients interacted with clinicians [10], prompting patients to elaborate their PGD-sharing practice when their memory is fresh. As such, this approach strengthened the ecological validity of our findings, allowing us to closely examine what data patients shared with clinicians, what triggered their sharing decisions, and what challenges they encountered regarding their PGD sharing.

However, we note that such onsite interview studies could impose several challenges, including (1) extra effort required to prepare the study (e.g., coordinating with the clinic/health center, completing the training, vaccination, & immunization requirements), which would not be the case for off-site or online interviews; (2) uncertainty in recruitment (i.e., we were able to recruit 1 to 10 participants per day ($M = 3.56$)); and (3) difficulty in doing a long, in-depth interview due to the limitations with the interview setup and patients' limited availability. Despite these challenges, the onsite interview study protocol could be considered when researchers choose to prioritize the ecological validity of a study.

5.5 Limitations

As with other empirical research, the findings of this study should be understood and interpreted within the specific contexts within which it was conducted. The interview participants were patients of a university health center, whose ages ranged from 18 to 37 ($M = 21.98$; $SD = 4.21$) and who were more likely tech-savvy than other populations. Also, a majority of the participants (81%) rated their current health status as at least good, on a scale ranging from Poor to Excellent (Poor, Fair, Good, Very Good, Excellent). Thus, our findings cannot be generalized to other clinical settings or to other groups of people in different social and clinical contexts. However, the types of challenges that our young and relatively tech-savvy participants faced, such as information gaps and reliance on recall for their PGD sharing, would likely be amplified among older, less tech-savvy populations or patients with more complicated health issues. In this paper, we draw on our brief, onsite interviews with patients to provide vivid empirical accounts of their experiences and challenges around PGD sharing. Particularly, our findings contribute to a deeper understanding of the nuanced challenges around PGD sharing-related decision-making. The findings of this study also revealed specific implications to consider when designing PGD-integrated health IT systems, and emphasized the need for future studies pertaining to empowering patients to control and manage their own PGD and how it is used within emerging, interoperable health IT systems.

6 CONCLUSION

This paper describes an onsite study that we conducted to investigate the PGD sharing practices of 57 patients who had just seen a clinician within a university health center in the U.S. Our findings provide ecologically valid empirical data about patients' PGD sharing practices within the clinic setting, drawing on short one-on-one semi-structured interviews. The participants in this study,

who were relatively young and tech-savvy, experienced a range of challenges in sharing their PGD with their clinicians, which prevented them from utilizing PGD to the fullest extent possible for their care. One of the central challenges we identified was the information asymmetry between patients and clinicians. While patients may be tracking specific types of data, they may not share this data unless asked to do so by their clinicians. Meanwhile, clinicians may not think to ask their patients about this potentially useful resource. Based on our findings and additional analyses, we suggest ways to enhance patients' PGD sharing practices within the context of emerging health IT system environments where PGD plays an important role in driving more patient-centered and data-driven healthcare. Particularly, we have identified the issues of information gaps for patients and for clinicians, patients' reliance on recall for their PGD sharing, and their concerns and preferences around giving health IT systems access to their PGD. Drawing on our findings, we discuss the opportunities to design PGD-integrated health IT systems in ways to help close the information gaps between patients and clinicians and facilitate the effective use of PGD in clinical contexts. As healthcare technologies incorporating PGD promise patient-centered, data-driven care, more work is needed to better understand and address the potentially varying challenges around patients' PGD sharing with clinicians in the connected health IT environments.

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