Sharing Patient-Generated Data in Clinical Practices: An Interview Study

Haining Zhu, BS[1], Joanna Colgan, BA[1], Madhu Reddy, PhD[2],
Eun Kyoung Choe, PhD[1]
[1]Pennsylvania State University, University Park, PA;
[2]Northwestern University, Evanston, IL

Abstract

Patients are tracking and generating an increasingly large volume of personal health data outside the clinic due to an explosion of wearable sensing and mobile health (mHealth) apps. The potential usefulness of these data is enormous as they can provide good measures of everyday behavior and lifestyle. However, how we can fully leverage patient-generated data (PGD) and integrate them in clinical practice is less clear. In this interview study, we aim to understand how patients and clinicians currently share patient-generated data in clinical care practice. From the study, we identified technical, social, and organizational challenges in sharing and fully leveraging patient-generated data in clinical practices. Our findings can provide researchers potential avenues for enablers and barriers in sharing patient-generated data in clinical settings.

1. Introduction

Novel technologies have started to provide patients the ability to track their own health data[1]. Apple's HealthKit and Google's Google Fit are just two recently available platforms designed for capturing, storing, and retrieving personal health and fitness data. Startup companies, such as Fitbit[2, 3] and Jawbone[4], are also offering self-tracking devices. Self-tracking (or self-monitoring) has an extensive history in research and is noted to generally serve either therapeutic or assessment purposes, with assessments relying heavily upon data accuracy[5]. We build upon this preexisting framework for self-tracking and aim to understand how best to leverage Patient-Generated Data. In this paper, we define 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. These data include physical activity, sleep, food, and blood glucose levels. They can be collected using manual journaling, consumer health tracking devices, smartphone apps, or medical devices (e.g., blood glucose meter). In addition, PGD includes any independent lab results or tests ordered by the patients themselves (e.g. ubiome[6], 23andMe[7], and LabCorp[8]).

Enabling people to track their own personal health data provides the potential to leverage the data in medical contexts, but to do so requires an effective means of data sharing among patients and clinicians. Moreover, patients who suffer from a chronic disease often find that self-tracking is burdensome and the sharing of data adds to that burden[9]. Even motivated patients can be hindered by awareness of the disease, the scattered nature of self-tracking tools, and data collection burden, making PGD hard to collect, and thus share[10]. With the goal of designing technology that allows for effective and meaningful sharing of PGD among patients and clinicians, we conducted semi-structured interviews with both patient and clinician participants to understand how they currently share PGD and to identify what barriers they face. Based on our findings, we suggest design considerations for creating technologies to support PGD data sharing among patients and clinicians.

2. Background

In this section, we provide a background of the Quantified Self movement, patient-generated data, and patient-generated data sharing.

2.1. The Quantified Self Movement

Advancements in mobile and wearable sensing technologies have spawned a movement called the "Quantified Self."[11] Those who practice Quantified Self (Q-Selfers) track data (e.g., food consumption, mood, physical activity) by manual journaling or self-tracking technology for various reasons such as health behavior change and curiosity[10]. Coupled with participatory health initiatives, big health data, and trends in patient engagement, data provided by Q-Selfers will hopefully be freely exchanged across healthcare sectors and result in personalized preventive medical practices[12]. The shift to personalized preventive medicine might combat contemporary health challenges, including sleep disorders, mental health issues, and chronic disease management[12]. Recognizing these potential benefits, we note a growing number of patients who practice Quantified Self as an approach to preventive health or chronic health management[10, 13]. Barriers and enablers in the Quantified Self movement vary by individual and situation. Q-Selfers might find the inability to customize and add specific tracking parameters to a ready-made tool to be a

barrier; furthermore, ready-made systems that are intended for diagnostic purposes benefit from precision and accuracy to enable reliable diagnoses, while interactive systems require methods of collaboration and communication to enable the relay of contextually relevant data[13]. Despite the increasing number of online services and available platforms (e.g. Electronic Health Records (EHRs), Personal Health Record (PHRs), electronic patient portals), adoption rates of Quantified Self in medical practices are low and the efficacy of these platforms' abilities to empower Q-Selfers or improve health outcomes remain untested[14]. Thus, we want to understand the barriers patients and clinicians face with the Quantified Self approach and devise ways to leverage the extensive data patients are generating.

2.2. Patient-Generated Data (PGD)

PGD have the potential to lead to novel medical insights[15, 16] and can promote positive changes in contemporary medical practices. For example, data generated by patients using continuous glucose monitoring systems[17] and self-reported surveys[18] have provided insights into complications in hypoglycemia patients, which might have been missed in verbal communication during clinical visits. PGD such as patient status and history have also been successfully utilized in clinical policy decision making, but this decision making would likely improve with the addition of new data categories, such as patient drug combinations, vitals, and blood results[19]. Despite these potential benefits, however, there are inherent limitations to PGD, including the reliability and accuracy of data, forgetfulness of patients, innate attitudes towards technology[20], and patients' self-bias. To utilize PGD in medical practices and research, these barriers need to be overcome. One way researchers have addressed these limitations is by suggesting ways to lower the patients' manual tracking burdens and increase their adherence to tracking[21]. To further lower the tracking burden, automated sensing is commonly embedded in self-tracking technologies (e.g., Lullaby[22], MyBehavior[23]). In addition, systems that allow users to edit or add to data inferred by devices are more reliable and credible[24]. Thus, innovative technologies and cultural changes related to the Quantified Self movement have allowed for patients to collect more accurate and reliable health data. These changes related to patient self-management and empowerment through tracking are therefore necessitating the creation of successful methods of leveraging PGD in medical applications.

2.3. Patient-Generated Data Sharing

Sharing can occur in many ways, including between a clinician and a patient and amongst patients, with each having unique challenges. Our work focuses on the contexts of sharing PGD between a clinician and a patient. From the patients' perspective, self-tracking and data sharing can impose extra burden on top of other efforts for managing chronic conditions[25]. Clinicians also have a less than positive view of sharing PGD; they have concerns about large amounts of PGD interfering with their abilities to provide timely and efficient healthcare to their patients[26]. Sharing PGD can also impose privacy burdens on hospitals. Modern medical practices protect patient records with strict laws such as HIPAA[26]. Although PGD is not traditional medical data, it has certain characteristics of it, and thus, there is a growing concern over whether it is subject to HIPAA when the data gets shared with clinicians via mobile devices. However, clear legal standards do not exist[27]. PGD allows patients to actively engage in clinician-patient collaboration[28]; such data can be shared during clinical visits (i.e., synchronous communication) or outside of clinical visits (i.e., asynchronous communication[29]). Asynchronous communication tools, such as patient portals[30] create secure opportunities for dialogue, but this interaction often loses the benefit of non-verbal communication (e.g. using body language and tone); these tools are most beneficial if they compensate for nonverbal deficiencies and if used by motivated, technologically savvy patients[30]. However, real-time tracking tools (i.e. mobile phone), which can be used for synchronous communication (i.e. in person, telemedicine, phone call), allow for more consistent data recording in patients[31]. These tools might thus mitigate issues of patient compliance, but they often lack support for data sharing. Our work specifically aims to understand what impedes PGD sharing during clinical practices, including technical, social, and organizational challenges.

3. Method

We conducted semi-structured interviews with 21 participants (12 patient participants and 9 clinician participants). We wanted to identify the enablers and barriers inherent to sharing PGD for patient-clinician communication, and to gain insights into design requirements for future technology interventions. The purposes of this study are to help patients become active observers and participants in their care and to inform clinicians of PGD data to enable them to provide better care.

Participants: Participants were recruited by word-of-mouth referrals and advertisements in handouts placed in public locations, hospitals, and online (e.g., university mailing lists). In this qualitative study, we sought diverse perspectives from broad participants. To be eligible as a patient participant, individuals had to (1) have experience collecting PGD (e.g., sleep, diet, exercise) for themselves or for their loved ones (e.g., a parent tracking health data for his or her child); and (2) have experience sharing the collected data with clinicians. Patient participants were not limited to current patients. Patient participants did not require a clear diagnosis to be eligible. We excluded individuals who were minors or non-English speakers. Clinician participants were individuals who (1) regularly consulted with patients (e.g. therapist, physician); and (2) had experience seeing patients who wanted to share their PGD during the visit. Table 1 and Table 2 show our participants' demographic information.

Table 1. Participant Demographics: Clinicians

ID	Background	Age	Gender	Years of practice	Tracking Initiation* (CI/PI)
C1	Physical therapist	31-50	M	17	CI/PI
C2	Internist	31-50	F	11	CI/PI
C3	Internist	31-50	F	6	CI/PI
C4	Internist	31-50	F	8	CI
C5	Primary care	31-50	M	24	CI/PI
C6	Psychologist	31-50	M	10	CI
C7	Pediatric nephrologist	31-50	M	10	CI/PI
C8	Internist	18-30	F	1	CI/PI
C9	Pediatric nephrologist	31-50	F	3	CI

*CI denotes tracking was initiated by clinicians (clinician-initiated), whereas PI denotes tracking was initiated by patients (patient-initiated).

Study Procedure: We conducted semi-structured interviews. Interviews were conducted either via phone ($n = 10$), Skype ($n = 7$), or in-person ($n = 4$). We also collected screenshots of how PGD was shared, including tracking tools, diary sheets or notes, and visualizations. We designed the interview to guide participants to discuss their firsthand experiences with self-tracking. Interview questions for patient participants included the following: (1) What motivated you to track and share data? (2) How and with whom did you share PGD? (3) What were barriers and enablers to sharing PGD? (4) How did the activity of tracking and the knowledge it provided affect your general life? Interview questions for clinician participants included the following: (1) How do patients typically share PGD? (2) What are some barriers that prevent sharing PGD during clinical visits? (3) How could PGD be utilized to support the clinician and care team? From these interviews, we gained a deep understanding of the key barriers, which inhibit clinical utilization of PGD and ways in which we might mitigate the identified barriers. The research was approved by the Institutional Review Board.

Data Collection & Analysis: All interviews were audio-recorded and transcribed to facilitate analysis. Each interview ranged from 30 to 90 minutes. To ensure the confidentiality of participants, we assigned a unique participant identifier to refer the roles of the participant: C# to denote a clinician participant, and P# to denote a patient participant. Two researchers analyzed each transcript of the individual interviews and used qualitative open coding to note prominent themes that were discovered across the data pool. Once the team agreed on the high-level themes identified, one researcher then iteratively coded the data and updated the coding scheme. The high level

Table 2. Participant Demographics: Patients.

ID	Medical / Health Condition	What they track	Current patient (Y/N)	Age	Gender	Tracking Initiation* (CI/PI)
P1	Pre-hypertension	Biking, cholesterol, blood pressure, blood sugar	Y	51-65	M	PI
P2	Pregnancy	Pregnancy symptoms, activity and calorie tracker	Y	18-30	F	PI
P3	Family history of cancer	Blood tests, telomere testing, neurofeedback, fecal biome test	Y	>65	M	PI
P4	Coronary artery disease	Weight, exercise, training, steps, lab results, key life events	Y	>65	M	PI
P5	Chronic sleep problem	Exercise, sleep, period, weight, heart rate	Y	31-50	F	PI
P6	High-level of blood glucose	Blood pressure, blood glucose, annual labs	N	51-65	F	PI
P7	Restless leg syndrome	Weight, physical activities, blood pressure, heart rate, food journaling	Y	51-65	M	PI
P8	Mycosis fungoides & lung cancer	Medications and medication reactions	Y	51-65	M	PI
P9	Artificial heart valve replacement	Cardiovascular fitness, steps, cholesterol, triglycerides, sleep, weight	Y	51-65	M	CI
P10	Type I diabetes	Blood sugar, weight, carb counting	N	18-30	M	PI
P11	Autoimmune conditions	Symptoms, activity, humidity, medication, stress level, sleep, period	Y	31-50	F	PI
P12	Chest muscle problem	Ride, time, speed, distance, and heart rate	N	18-30	M	PI

*CI denotes tracking was initiated by clinicians (clinician-initiated), whereas PI denotes tracking was initiated by patients (patient-initiated).

categories we include are as follows: motivations for patients to collect and share health data; motivations for clinicians to adopt PGD; methods and means to share PGD; tensions between clinicians and patients; barriers and drawbacks to PGD sharing; and enablers and workarounds to share PGD.

4. Results

In this section, we present the results from the interview study to report existing gaps in PGD sharing. In particular, we describe the nature of patients' tracking, address the difficulty in sharing data between patients and clinicians, and report the barriers which inhibit the utilization of PGD—from both patients' and clinicians' perspectives.

4.1. Clinician-Initiated versus Patient-Initiated Tracking

In the clinical context, tracking was initiated either by a patient or clinician. In our patient dataset, most of the patients initiated the tracking without any prompting from clinicians (Table 2, last column). On the other hand, all clinicians we recruited had experience initiating the tracking by providing patients with a diary and asking them to track certain items (Table 1). Moreover, most of the clinician participants had experienced patients bringing their data to visits and sharing it voluntarily. We observed that clinicians' receptiveness to PGD varied depending on who initiated the tracking. When clinicians initiated the tracking, it was often the case that they required PGD for a specific medical reasoning, thereby the value of the data was high. In these instances, patients became a "diagnostic agent" for clinicians, and thus played an active role in personal diagnoses[32]. Patient-initiated tracking, however, was not always welcome by clinicians, which we further describe in the following.

Clinician-Initiated Tracking: Clinicians asked patients to self-track for various reasons. C3 was particularly interested in pushing patients for engagement purposes. C3 said, *"…knowing the actual data is less important than just hearing their perspective and knowing where they've come from and engaging them on that… if they're tracking… addressing it is a way to sort of reinforce their engagement."* Clinicians' authority helped with motivating patients to track, as C5 perceived: *"it's very rare that they* [patients] *record anything unless you ask them to."* Most of the clinician participants noted it was common to ask patients to provide data such as reactions, side effects, and symptoms when they receive new medications. The practice of asking for data and making decisions based on it was essentially what it meant to be a clinician. Clinician participant C5 suggested that clinicians initiated tracking for the purpose of accurately assessing a patient's issue: *"Maybe for sleep disorders and sleep insomnia, when people complain to that, you try to get them to do a two-week sleep log so you'll really know how they're sleeping."* Tracking was most often initiated by clinicians in cases with chronic diseases (e.g., diabetes, hypertension) or persistent symptoms: *"Once you diagnose a patient with diabetes, you'll send them to the diabetic educators, we'll teach them how to use a glucometer and then go over with them kind of how to keep track of their blood sugar values…"* [C8]. Participant P9 also explained that clinicians initiated a tracking regimen after certain medical procedures or during rehabilitation: *"After I had heart surgery, I was in a cardiac rehab program for several months and that was a daily or a three times/week tracking."* Finally, C8 explained that PGD is useful for discussing lifestyle changes and barriers preventing patients from achieving their health goals.

Patient-Initiated Tracking: The most common purpose for a patient to initiate self-tracking was to develop self-awareness and self-management skills, with 8 participants offering similarly themed explanations. Patient P11 stated, *"…if I'm going to go out and drink… I will expect to have a bad night of sleep. So if I need to be ready to give like a presentation, I'll just plan for that and not go out. I feel like I know better how things affect me and how long they're going to affect me. It has helped me optimize myself."* In cases with patient-initiated tracking, another common tracking motivation was individual curiosity—for example, curiosity about how one's lifestyle affects weight, or whether a treatment works. P8 remarked, *"Gathering that information or looking at that information has given me hope…This drug that I have is effective at first but doesn't seem to be as effective right now… we may discontinue it and start something else."* Patients with medical problems, such as diabetics, often tracked data related to those medical problems. Three patients tracked data so that they could better collaborate with clinicians or answer their questions more effectively. Two other patients stated that they shared data with clinicians to initiate conversations and keep them informed. P9 specifically noted, *"I think tracking helps me feel like I am participating in my health and my medical care directly and that I'm being proactive about it. It enables me to have informed conversations with my medical providers that are based on data."* Furthermore, some patients wanted to show the data to collaboratively alter their medications, or to come off medications. P4 noted *"…it's very easy to say, 'Your cholesterol is too high, take more medicine because we know you'll go down 10% if you double the dose.' But by tracking I did, I'm able to say, 'Hey, if I get my weight down 12 pounds, I will reduce my cholesterol 20 points and do the same thing that way.'"* Five patients mentioned this desire to collect data to help change treatment plans. As such, many patients appeared very eager and motivated to be equal partners in the promotion of their health, and the

fact that these patients track multiple factors suggests that some are trying to promote whole health, rather than treat specific symptoms. Lastly, a clinician participant mentioned that patients' tracking can potentially be due to the patients' mental health disorder or obsessive behavior.

4.2. How is PGD Shared

Patients track a wide array of health information. In our study, patients tracked factors such as exercise, treatment changes or medically relevant factors, food, alcohol, caffeine consumption, travel and lifestyle, symptoms and ailments, weight, period data, sleep and sleep patterns, test results, general health history, and chronic or persistent health problems (e.g., diabetes, high blood pressure). We examined how data is shared among patients and clinicians by employing the space-time matrix[29]. According to the space-time matrix, PGD sharing can be categorized based on where it occurs (distributed vs. co-located) and when it occurs (synchronous vs. asynchronous)[33] (Table 3).

Table 3. How Patient-generated Data is Shared: Space-time Matrix.

|	Co-located	Distributed
Synchronous	During the visit (i.e., in-person)	Phone Telemedicine
Asynchronous	-	Email Fax

Synchronous Co-located Sharing: Verbal communication during visits was the most common data sharing method in clinical practices. Most participants had shared data verbally during visits, as C5 reported: *"[Patient typically shares data during the visit] because that's the only time we have contact."* Some patients collected their personal data but chose not to share it in any other form but verbally so that they could maximize face to face time with their clinicians: *"You get a ton of data, but if you give him all these numbers and stuff to go through, then you're going to bleed out the time for the visit..."* [P4]. There were two cases in which a patient specifically mentioned why they did not use *technology* to share data with a clinician. Those two instances were specifically the inconvenience of traveling with a laptop and the uncertainty of proper etiquette. P12 noted, *"I was worried that he* [clinician] *might feel annoyed if I pulled out my mobile phone... Normally clinicians don't want patients to pull it out."* Using a tool (e.g., spreadsheets, images, timelines, videos, data visualizations) was the second most common way of sharing data during visits; the most common tool used by patients was paper. C3 confirmed this by stating, *"They may just have a piece of paper with everything they ate for the last 48 hours. Or they might have an ache diary.... It may just be written on a piece of paper."* Information visualizations were thought to be good tools for quickly sharing data to uncover significant insights, especially for those who had the skillset to create visualizations. For example, P11 was a designer who could draw a timeline using Adobe Illustrator, which she printed out and shared with clinicians. P11 expressed, *"I think the clinicians have appreciated the timeline format... a visual timeline like a graph, a timeline on a graph would be helpful for sharing* (Figure 1).*"* Patients commonly used data collection tools, such as medical devices and wearable trackers, as data sharing tools, because there were few available tools explicitly designed for data sharing. C8 noted, *"Some patients who feel like it's going to take too much time and efforts for them within their lifestyle will just bring in the glucometer because it's easier for them to just bring it in."* Patients also presented clinicians data on their mobile phones or desktop applications. Some patients even brought a computer to a clinical visit to demonstrate trends in data. Although any device with the ability to store and present data could potentially be utilized for PGD sharing, clinicians found it especially difficult to manage the data presented by data collection tools. As stated by C8, *"...trying to kind of figure out how to maneuver and like data summary of the data from each different app, can be a little challenging and time consuming in an acute visit."*
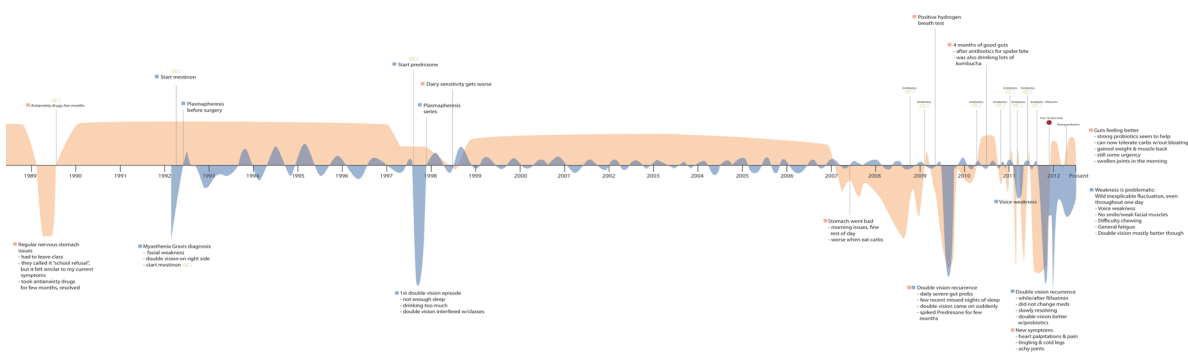
Figure 1. P11 used Adobe Illustrator to create a medical timeline, and brought the printed version when visiting to a new doctor. The peach color represents gastrointestinal symptoms, and the blue represents Myasthenia Gravis.

Synchronous Distributed Sharing: Phone calls offered a quick and convenient way to share data, especially when other electronic means such as emails could not be utilized or when patients wanted immediate responses but were unable to make an appointment. Furthermore, phone calls provided a benefit over email communications, as they provided important cues such as tone of voice as well as opportunities for clinicians to ask for clarification. The majority of clinician participants asked patients to give a phone call in certain situations: *"I get most of my data from the patient during their actual visit…. there will be times when I will ask them like if I make a change in their medication regimen to keep track of their sugars for the following week and call the clinic with those numbers so I can make further adjustments over the phone if necessary"* [C8]. Telemedicine offered unique opportunities and drawbacks, and clinician participants had conflicting opinions towards it. Two clinician participants agreed that telemedicine could help them see more patients, and that more patients would benefit from their treatments if clinicians could provide electronic or telephone based communication. Two other clinician participants however questioned the accuracy and reliability of the data shared via telemedicine tools (e.g., phone): *"If they're giving you information over the phone, can you trust that their sugar levels are recordable?... it's an electronic device that doesn't transmit it electronically."* Other participants had neutral reactions toward telemedicine but potentially showed a slight preference for email communications. Currently, synchronous distributed sharing is typically uncompensated effort, however, and this significant drawback might have resulted in clinicians being more reluctant to look at PGD and more resistant to using technology outside of clinical visits. C2 explained, *"… it's better that it* [PGD] *comes to me in an office visit…. I do a lot through like on patient portal and do a lot of management that way but we have no way of compensating that time…. it's a lot of uncompensated effort on my part… that's something that I do it because I wanted to be I want them to get better."* Although the work was uncompensated, some clinicians still asked patients to send data via email or phone, took time to look at the data, and offered medical opinions because they believed that it is beneficial to patients.

Asynchronous Distributed Sharing: Asynchronous distributed communication was beneficial in situations where patients and clinicians had conflicts of schedules. Faxes, emails, or patient portals could enable the sharing of data immediately, while allowing for a clinician to respond when he or she has the time to do so. C8 noted, *"…via the patient portal, they can actually send a message directly to me if they have any questions or concerns between visits."* Patient P4, who has a software engineering background and is a retired medical doctor, was the most extreme and unique case. He designed and built his own software, which assisted in the sharing of data in an asynchronous distributed manner (Figure 2-c, 2-d): *"I just put him* [clinician] *to my websites... if he just puts in my URL that he can access it from the note, and it's actually easier for him."*

(a)   **(b)**   **(c)**   **(d)**
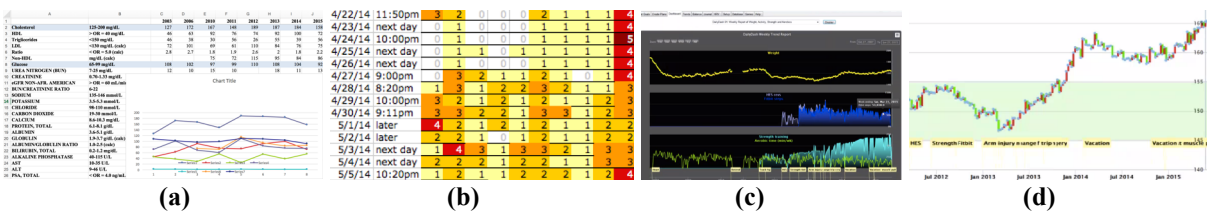
Figure 2: Example of screenshots that patients shared. (From left to right: P1, P11, P4, P4). P1 and P11 used excel spreadsheets to track their health data, here shown as (a) and (b). P4 created software that generates graphs to show the correlations of certain fitness data, such as Fitbit steps, Aerobic time, and weight.

4.3. Tensions around PGD

Tensions existed between clinicians and patients, which discouraged the sharing of data. Not all clinicians were receptive to patient-generated data. We report major tensions existing in the current medical practice.

Tensions Between Clinicians and Patients: The first tension we observed was the misalignment of the clinician's agenda and the patient's expectations; this includes such things as patients recording clinically irrelevant data, or not recording relevant data, and differences of opinion between clinician and patient regarding healthcare needs. C2 noted, *"Because sometimes their ideas of why they're there are different from my ideas of why they need to be there. Then, we have a discussion."* We also observed that patients' desires to maximize their time with clinicians often created tension between them and clinicians. In many of those cases, clinicians were unable to provide time outside of their visits. One clinician participant expressed, *"you don't have time outside of that* [in-person visit]. *In*

medicine, it has to be as the patient is visiting. Because otherwise, you're taking time either from somebody else or from yourself" [C5]. Many clinician participants and a few patient participants were concerned that clinicians could be overwhelmed by raw PGD. Many participants specifically expressed concerns about clinicians receiving too much data at once and not knowing how to process it. *"If people come in with so much information that you can't make sense of it, it doesn't help clarify things..."* [C3]. The third tension, experienced by most clinicians, was the issue of the reliability and accuracy of PGD. *"It's not usually accurate because they don't have all the data to support it so they're kind of giving you this memory of what they think"* [C4]. Concerns regarding data reliability and accuracy were not limited to patients' data reporting errors. Clinicians also pointed out that uncalibrated machines, improper testing protocols, transcription errors, device errors, or some other unknown factors could result in unreliable or inaccurate data. Thus, clinicians were mistrustful of PGD shared by their patients unless accuracy can be verified. C8 noted, *"...people just don't actually check their blood sugars routinely enough, and if they do they kind of do it sporadically and don't write down the exact date and time, etc. (...) that can be a little bit more challenging."* Although data collected by a patient could be entirely accurate, and thus reliable, it was not meaningful to a clinician if it did not contain all of the data that the clinician might need.

Attitude towards using technology: Clinicians responded differently and sometimes ambivalently to the use of technology for tracking and sharing PGD. About half of the clinician participants expressed preference for paper based data tracking over technology-assisted tracking. C3 noted, *"...The electronic stuff is a lot easier to collect, but I think it's a lot harder to analyze because it's less common to be able to see everything all on one screen...."* However, half of the clinician respondents also reacted favorably to the use of technology for tracking, or negatively to paper based tracking. These groups were not mutually exclusive; there were individuals who both preferred paper methods and reacted favorably to technology-assisted methods. A few clinician participants reacted neutrally towards technology. C3 suggested her reaction was pragmatic, and said, *"So whatever method is easiest for them to get you good accurate data.... My patients would lose the piece of paper, if they did something on their phone they would do better with that."* Our data suggests that the clinician's reaction to technology versus paper-based method is a multifaceted issue; clinicians' responses to the use of technology likely corresponded to their initial attitudes towards technology in general. Clinicians tended to believe that both paper and technology-assisted method have their own merits and pitfalls as well as niches, which could explain the apparent ambivalence or even neutral responses noted by participants.

Table 4: Barriers and Enablers to Leveraging Patient Generated Data.

Barriers	Supporter	Enablers	Supporter
Inability to transfer PGD to electronic medical records	P4,P7,P9,P11,C1,C2, C3,C4,C7,C8,C9	Integrate PGD into clinicians' workflows	P4, C7
HIPAA intruding into medical care	C1,C5,C6,C7	An amicable sharing platform and automatic upload of PGD	P1,P7,P11,P12, C1,C4,C7,C8,C9
Data security and privacy concerns	P3,C1,C2,C3,C5,C6	Portable and shareable patient-stored medical records	P3,P4,P7,P9,C1
Difficulty with accessing and using PGD within EMR	P12,C1,C2,C5,C6,	Using data visualization and summarization for efficient sharing	P2,P7,P9,C2,C4, C6,C7
Limited amount of clinicians' time during visits	C1,C3,C4,C5,C8	Sending data to clinicians prior to visits	P11,C2,C5,C7,C9

4.4. Barriers and Enablers to Leveraging Patient Generated Data

Most clinicians consistently noted the difficulty or inability of transferring PGD to EMR as a barrier for data sharing. C4 said, *"...it [PGD] doesn't go into the electronic health record. So unless your clinic is setup where a nurse practitioner or someone else can go through all of that data, set that up, make sure they have it and they give that information to the clinician, it's not really helpful to anybody else."* A related concern was HIPAA and data security and privacy issues as C5 explained: *"We have to send them, 'We cannot respond to this [PGD], this is a violation of HIPAA. Just go away or go to a secured server'"* [C5]. However, it was not clear whether EMR was the right place to store all the patient-generated data collected outside the hospital because (1) there is currently not a good user interface within EMR to upload and view PGD; and (2) the data can be quickly buried in the EMR system. In fact, P4 stated, *"...since I have the data, if I get referred to a specialist, I'm not counting on his transfer... I wrote up a little summary with my graphs and charts... [the specialist] said, 'I just read what you had, it was easier.'"* We also learned that storing PGD in the EMR system was not just a data integration issue, but a bigger issue of integrating PGD into clinicians' workflows, making the data easy to access, use, and transfer. A patient participant noted this challenge: *"Patients are self-trapped, when they come in with data that's difficult for the*

doctor to digest and the doctor doesn't like that. (...) The key thing is, that's the work for the patient but it has to create this thing that's so easy for doctor, so that make their life easier too or they'll find a way to ignore it" [P4].

A majority of clinician participants mentioned time constraints as an important barrier impeding data sharing, which was apparent to patients as well. P9 noted, *"I have to prioritize what I think is important to share. I'm sensitive that I don't get a lot of time with them that they have a lot of information to process"* [P9]. Participants shared ideas for efficient PGD sharing, for example, sending data to clinicians before visits, as noted by C2: *"So if a patient can handle technology and can send the information in preparation for a visit…That would be great."* Likewise, data visualization was noted to have aided efficient data sharing. *"I think the visualization is great… So we know there are high levels of innumeracy in patients so figuring out ways to present the data, not just for the patients, but me so I can get a quick overview…"* [C4]. We believe that providing insights using visualizations in the context of PGD sharing opens up many possibilities for future research, especially designing a PGD sharing platform that can ensure quick and efficient sharing while providing insights.

5. Discussion

In the previous section, we highlighted a variety of issues related to the sharing of PGD between patients and clinicians. We now turn to four discussion points surrounding PGD sharing. These issues are (1) aligning clinician/patient perceptions about PGD by including clinicians in the early stages of patients' tracking; (2) integrating PGD into clinical systems; (3) aligning organizational policies; and (4) empowering patients as partners in healthcare.

First, it is important to align the clinicians' and patients' perceptions about PGD as closely as possible. Both clinicians and patients are interested in seeing health trends and patterns or documenting treatment efficacy, but the two groups might have very different perceptions about the type and value of the data. One of the primary motivations for patients to collect PGD was to gain an as in-depth picture as possible of their health, which they can then share with their clinicians. Based on our interviews, however, we learned that when patients initiated tracking, clinicians often ignored the data collected and did not find the data useful, especially when it was either incomplete or irrelevant to the current issue. For clinicians to leverage the data, clinicians must know that data is accurate, reliable, and aligned with their agenda. We therefore see opportunities in making the PGD more useful and relevant by involving clinicians early on to provide guidance to patients on how and what data to collect and to help patients understand why such data is important. With such guidance from clinicians (e.g., what to track, how often to track, what format to use), patients might be able to collect more clinically relevant data, thereby making clinicians more likely to leverage that data in their clinical practice. Likewise, if patients could provide contextual information regarding their testing and data collection, clinicians might be more accepting of PGD.

Second, although PGD could have immense value for patient care, clinicians cannot effectively use this data until it is integrated into the clinical systems. The integration will require the development of a technical infrastructure to transfer the information from the patient to the clinician. Although patient portals have started to be used for sharing patient information with clinicians,[34] it is not being used for PGD data sharing, especially the synchronous co-located manner, which was the most prevalent way of sharing PGD. Data visualizations, analytics, and summarization techniques will play an important role in making PGD valuable for clinicians and patients, helping them quickly gain critical insights and reflect on the data[35].

Third, clinicians need to be incentivized to incorporate PGD into their everyday workflows. While the technical challenges of integrating PGD into clinical systems are important, it will be just as important to re-align organizational policies to incentivize clinicians to utilize PGD. It is unclear at this point whether sharing PGD will lead to more patient encounter time (if sharing is done inefficiently) or even less patient encounter time (if sharing is done efficiently) than what is currently allocated for patient encounters for clinicians. The effectiveness of sharing would depend on how a PGD sharing platform is designed and how well the data is presented to the clinicians.

Lastly, clinicians need to understand and adapt to the cultural shift in healthcare, in which more patients are attempting to make healthcare a collaborative endeavor. The patient participants we talked to wished to alter their treatment plans and create conversations with their clinicians; they wanted to be equal partners in healthcare and careful observers of their bodies, as opposed to traditional passive patients. Furthermore, some of these patients promoted their whole health through employing tracking for preventive purposes, rather than to treat an illness, thus changing the current paradigm of receiving healthcare. Patients are also motivated by clinicians; they will engage in their healthcare more if clinicians welcome their involvement. One way of inviting patients into the care team is through encouraging patients to start tracking their data in a way that can help clinicians.

6. Limitations and Future Directions

Our study's limitations include the small participant sample size and purposive sampling towards receptive patients and clinicians due to our inclusion criterion of requiring prior PGD collecting and sharing experience. The study results are therefore unlikely generalizable to the entire population. However, our goal was to discover current practices and barriers in patient-clinician data sharing, and we argue that our inclusion criteria are necessary to gain meaningful data, as we were looking for initial insights into existing phenomena. Our findings could be used to create an in-depth study of PGD sharing behaviors, by creating a prototype intervention and testing it with a representative sample. We also selected participants from multiple localities and medical subdivisions, and with various health conditions to recruit a diverse population, because we were interested in the coverage of various issues. We also note that the patient participants were not necessarily the clinician participants' patients; this is why most of our patient participants indicated that they had initiated their tracking (patient-initiated, or PI), but all of our clinician participants indicated that they initiated the tracking (clinician-initiated, or CI) or both CI and PI. Therefore, our patient participants might have been particularly motivated in collecting and sharing PGD whereas our clinician participants might have actively encouraged patients to track. In the future, we are planning to study patient and clinician pairs, so that the selection bias may be reduced. The findings of this study will help us design a future platform for PGD sharing to enhance patient-clinician communication.

7. Conclusion

In this study, we described the current practices of PGD sharing among patients and clinicians. We particularly examined the differences between tracking initiated by clinicians versus patients. We then employed the space-time matrix to analyze various PGD sharing practices. After describing tensions between clinicians and patients, we identified barriers and enablers to PGD sharing. Many of the barriers were related to the lack of infrastructural support for data integration, but this was not merely a technological issue; a bigger challenge was how PGD sharing could be incorporated into clinicians' workflow. Most of these barriers can compound to further inhibit clinician-patient communications. Understanding a clear picture of how PGD is currently shared and its associated challenges are important for the design of systems that can leverage PGD and integrate the data into clinical practices. This initial study provides new opportunities to study PGD sharing between patients and clinicians with better focus on the significant issues we identified. We are particularly interested in how information visualization can be designed to aid efficient data sharing. With the ever-increasing growth of personal health mobile applications and wearable sensors, patient generated data will only increase. We are only starting to understand the challenges that we need to address to integrate this data into the healthcare process.

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