doi: 10.1093/jamia/ocz045

Advance Access Publication Date: 22 April 2019

Research and Applications



Research and Applications

Early experiences with patient generated health data: health system and patient perspectives

Julia Adler-Milstein¹ and Paige Nong²

¹Department of Medicine, School of Medicine, University of California San Francisco, San Francisco, California, USA and ²Department of Learning Health Sciences, University of Michigan Medical School, Ann Arbor, Michigan, USA

Corresponding Author: Julia Adler-Milstein, PhD, UCSF, School of Medicine 3333 California St., San Francisco, California 94118, USA (julia.adler-milstein@ucsf.edu)

Received 20 October 2018; Revised 13 February 2019; Editorial Decision 18 March 2019; Accepted 19 March 2019

ABSTRACT

Objective: Although patient generated health data (PGHD) has stimulated excitement about its potential to increase patient engagement and to offer clinicians new insights into patient health status, we know little about these efforts at scale and whether they align with patient preferences. This study sought to characterize provider-led PGHD approaches, assess whether they aligned with patient preferences, and identify challenges to scale and impact.

Materials and Methods: We interviewed leaders from a geographically diverse set of health systems (n=6), leaders from large electronic health record vendors (n=3), and leaders from vendors providing PGHD solutions to health systems (n=3). Next, we interviewed patients with 1 or more chronic conditions (n=10), half of whom had PGHD experience. We conducted content analysis to characterize health system PGHD approaches, assess alignment with patient preferences, and identify challenges.

Results: In this study, 3 primary approaches were identified, and each was designed to support collection of a different type of PGHD: 1) health history, 2) validated questionnaires and surveys, and 3) biometric and health activity. Whereas patient preferences aligned with health system approaches, patients raised concerns about data security and the value of reporting. Health systems cited challenges related to lack of reimbursement, data quality, and clinical usefulness of PGHD.

Discussion: Despite a federal policy focus on PGHD, it is not yet being pursued at scale. Whereas many barriers contribute to this narrow pursuit, uncertainty around the value of PGHD, from both patients and providers, is a primary inhibitor.

Conclusion: Our results reveal a fairly narrow set of approaches to PGHD currently pursued by health systems at scale.

Key words: patient generated health data, health systems, patient engagement, meaningful use, EHRs

INTRODUCTION

As part of recent efforts to create a more patient-centered health care system, patient generated health data (PGHD) has received significant attention because of its potential to foster better patient–provider communication, improve care coordination, and strengthen patient engagement. Although smartphones and other mobile devices have rapidly expanded opportunities for patients to capture and monitor

their own health data, PGHD efforts to date are predominantly small-scale pilots focused on specific conditions or technologies. ^{3,6–11} Health care delivery organizations have been slow to build PGHD capabilities at scale. ³ This is likely because working with PGHD at scale requires addressing not only technical challenges, ¹² but also determining how to incorporate the data into multiple workflows and clinical decisions in a safe, efficient, and effective way.

To strengthen incentives for provider organizations to address these challenges and realize the value from PGHD, policymakers included a measure for the incorporation of PGHD into electronic health records (EHRs) in the Stage 3 Meaningful Use (MU) final rules. 13 The corresponding EHR certification criterion required that EHRs allow for the transmission and incorporation of PGHD.¹⁴ Recent changes to the meaningful use program (now called Promoting Interoperability Program) removed the proposed PGHD measure because it was not sufficiently aligned with program goals, 15 which called into question the extent to which health systems will pursue PGHD. Against this dynamic policy backdrop, there is a critical need to evaluate early experiences with PGHD in order to build an evidence base to guide future policy and practice efforts. It is particularly valuable for early assessments to determine what types of PGHD providers are accepting at scale, models of care built around PGHD, and how these approaches align with patient preferences.

In this study, we identified current PGHD approaches pursued by leading health systems and supported by vendors, and we subsequently incorporated patient perspectives to capture the degree of alignment between patient preferences and health system approaches. We also captured PGHD-related challenges, cited by health systems, vendors, and patients, along with suggested solutions. Capturing these results in the early phase of scalable PGHD uptake reveals whether we are heading in the right direction and whether there are early barriers and signs of misalignment—particularly between provider capabilities and patient preferences—that could limit the value from PGHD. It also serves to guide provider organizations as they decide whether and how to pursue PGHD.

METHODS

Sample

We sought to recruit health systems, vendors, and patients to participate in this study. We identified health systems with PGHD experience through the American Hospital Association's IT Supplement survey (those reporting in 2016 that they support PGHD) and the American Medical Informatics Association's Implementation list-serv. We recruited selectively for geographic diversity (2 Northeast, 2 Midwest, 1 Southeast, 1 West) until we achieved the target number of 6 health systems. Next, we sought to recruit 6 vendors: 3 large EHR vendors (based on market share) and 3 "pure play" vendors that focused on PGHD solutions for health systems identified during health system interviews (Supplementary Table 1).

Then we recruited 10 patients through the University of Michigan's Health Research platform. In order to participate in the study, patients were required to meet the following 4 criteria: 1) be a current or former Michigan Medicine (the University of Michigan Health System) patient, 2) have at least 1 chronic condition, 3) speak English, and 4) be over 18 years old. The first 10 patients who met these criteria (as determined by the Health Research platform screening tool) and scheduled an interview with our research team were included. Half of these patients had experience submitting PGHD to their provider and half did not, which allowed us to capture both hypothetical and empirical perspectives.

Interview guides and data collection

We developed 3 interview guides, 1 for each interviewee type. The health system and vendor guides were similar and covered current PGHD efforts and capabilities, clinician uptake and response, successes/challenges, and future plans for PGHD (Supplementary

Exhibits 1–3). The patient interview guide covered PGHD experiences, priorities, motivations, and preferences. In order to assess alignment between current provider approaches and patient preferences, we also asked patients about their opinions of specific PGHD approaches identified through health system and vendor interviews.

To facilitate this analytic design, we first developed the health system and vendor interview guides and conducted interviews (by phone) between August 16 and December 13, 2017. After analyzing transcripts from these interviews (as described later), we developed the patient interview guide and conducted patient interviews (by phone) between April 9 and May 1, 2018. All interviews were recorded and transcribed. Our study was approved by the University of Michigan IRB (HUM00132510).

Analysis

We performed content analysis of interview transcripts, first for health system and vendor transcripts and then separately for patient transcripts, following the same approach as follows: we created a codebook prior to beginning the interviews and then supplemented it with additional codes based on new concepts that emerged in the interviews. Each interview transcript was coded with the final version of the codebook. Coded interview content was entered into an analytic matrix organized around primary topics from the interview protocol, and analytic table entries were synthesized.

Content analysis of health system and vendor interviews

We used content analysis to characterize the types of PGHD collected by health systems and supported by vendors. Then, for each type of PGHD, we identified the associated data capture devices, approaches to data transmission and integration into the EHR (if any), and workflows reported by respondents. All data types and data collection devices were captured and reported; that is, if a health system predominantly used a portal to allow patients to report data but also allowed internet-enabled device reporting, we captured both. Next, we sought to identify the challenges and contextual factors that prevented effective use of PGHD by comparing analytic matrix content and selecting illustrative quotes from coded interview transcripts. We also used this approach to identify the solutions that respondents perceived as useful to addressing the challenges they faced.

Content analysis of patient interviews

Content analysis of patient transcripts assessed alignment between health system PGHD approaches (identified in content analysis described previously) and patient PGHD preferences, patient motivation for reporting PGHD, and challenges faced by patients. Because patients were asked to react to the specific PGHD models identified in the health system and vendor interviews, we were able to directly assess alignment (ie, whether the 3 models met patient needs and preferences) as well as analyze associated challenges and solutions across each category of respondent (ie, for health systems/vendors and for patients).

We present results of the content analyses by integrating health system/vendor findings and patient findings as follows. First we describe the identified PGHD models and patient responses to them. Next we describe patient motivations for reporting PGHD. Finally, we present the challenges and associated solutions in the emergent domains of value, policy, and operational.

Table 1. Models of PGHD use

PGHD Models					
Model	Data type	Data collection devices	Data transmission	Data integration	Workflow
Health History	Health history data traditionally collected on paper from the patient (eg, family history, allergies and current medications)	- In-clinic tablets - Patient personal devices (eg, laptop, smartphone)	— EHR patient portal	- Stored in the portal - Note in the EHR - Discrete data in the EHR	 Review and approval of data by care team prior to data integration/ action
Questionnaires and Surveys	Validated questionnaires and surveys related to a wide variety of conditions (eg, depression screenings, PROs)	- In-clinic tablets - Patient personal devices (eg, laptop, smartphone)	- EHR patient portal - Apps that upload to the EHR portal - Stand-alone apps or portals	- No integration/separate dashboard - Stored in the portal- Note in the EHR - Discrete data in the EHR	- Messages to notify the care team that data is submitted - Alerts for care team if threshold values are exceeded
Biometric and Patient Activity	Biometric data— typically blood pressure, weight and blood glucose but also may include exercise and nutrition	- Patient purchased devices (not Bluetooth connected) - Patient purchased devices (Bluetooth connected) - Health system devices provided for patients	- Direct entry into EHR portal - Devices upload to the app, then to the EHR portal - Devices upload to the EHR portal directly	- No integration/separate dashboard - Stored in the portal - Note in the EHR - Discrete data in the EHR	- Messages to notify the care team that data is submitted - Alerts for care team if threshold values are exceeded

Abbreviation: PROs, patient reported outcomes.

RESULTS

Types of PGHD supported by health systems and vendors

We identified 3 main types of PGHD collected by health system respondents and facilitated by vendor solutions (Table 1). The first type was health history data. This type of PGHD largely replaced health history data that was collected on paper intake forms for data like current medications, family medical history, and allergies. The second type included validated questionnaires and surveys. As with the first type, these largely replaced data that used to be collected on paper, but, in some cases, respondents indicated greater use of questionnaires and surveys because they could be administered electronically. The third type of PGHD was biometric data (such as weight, blood pressure, and blood glucose) and patient activity data (such as exercise and nutrition). Health systems often limited this category of PGHD collection to patients with certain conditions, such as COPD and diabetes.

Models of PGHD collection and use by health systems and vendors

The data capture devices, data transmission methods, and integration into the EHR and clinician workflows were largely similar across PGHD types (Table 1). However, we observed variation both within and across respondents, suggesting that the models that wrap around each type of PGHD are not yet mature. For example, within a given PGHD type across respondents, the specific devices and applications used to collect the data varied significantly. Even within a single health system for a single type of PGHD, several respondents reported the use of multiple approaches to data integration. There was also variation in whether the PGHD was integrated into the patient's medical record, or stored and accessed in an EHR-tethered or untethered repository. Similarly, we observed variation in how, when, and by whom PGHD was reviewed and evaluated (Table 1).

Patient perspectives on PGHD models

Patients felt that the 3 data types and available transmission methods identified in our PGHD models met their preferences and needs. The 1 exception was the collection of biometric and activity data by third parties on behalf of health systems, which patients found generally unacceptable due to privacy concerns; they preferred to share their information directly with their provider or health system. This held true even if their provider was able to view the data that they submitted to the third party. Patients did not expect immediate responses to PGHD but identified some suboptimal aspects of how providers integrated it into patient interactions (described later).

Patient motivation for PGHD engagement

Patients with and without direct PGHD reporting experience identified common motivations for PGHD engagement. First, patients had specific health goals or wanted to increase their knowledge of their own health through tracking and reporting their data. Second, patients wanted to streamline their office visits and saw PGHD as a potentially effective way to avoid wasting valuable time with their provider by describing their health history or biometric data. Third, patients wanted to provide any information that may be helpful to their provider for effective diagnosis, management, and overall care. Patients cited specific PGHD experiences that they believed led to improved outcomes like symptom tracking leading to an accurate

diagnosis after several misdiagnoses or using nutrition data to support the behavior change needed to lower cholesterol.

Challenges and solutions

Health systems and vendors identified similar challenges that fell into 3 categories: value, policy, and operational (Table 2).

Value: Challenges. The first value challenge was how to identify actionable insights from PGHD. As an example, respondents pointed to the lack of evidence about the clinical importance of daily or weekly fluctuations in step data and heart rate data from wearable devices. It was therefore not clear when to act on such data by, for example, titrating medications. A second value challenge was information overload and the concern that providers would be presented with an overwhelming amount of information if many patients were able to submit PGHD. A third but less concerning challenge was the validity of data and how providers could feel confident that reported data were accurate.

A fourth value challenge, cited by patients, was the burden involved in tracking and reporting data. Some patients with experience submitting data or updating their medical records through their patient portal reported that it was not clear to them whether the data was utilized in their care. This led them to question the value of the time and effort spent submitting PGHD (for challenges and quotes, see Table 3).

Value: Solutions. In response to these challenges, health systems and vendors identified the need for an evidence base for the clinical significance of commonly reported types of PGHD and, in particular, thresholds for intervening. In the interim, to minimize the volume of clinically irrelevant data, health systems focused PGHD collection on patients with certain conditions and those considered likely to benefit from routine PGHD reporting.

To address patient value concerns, health systems and patients identified patient-provider communication as crucial, pointing to the specific importance of providers demonstrating or explaining to patients how PGHD was used in clinical decisions. Demonstrating alignment with patient responses, 1 health system respondent reported that patients will submit their data "if they feel it's valuable to their care, so it's very important that the provider explains how it was used or references it. Otherwise the patient will think we're wasting their time and they won't complete it."

Policy: Challenges. Health systems and vendors also identified PGHD policy concerns related to reimbursement and liability. They cited lack of a business case for PGHD because it is not reimbursed and can take substantial time to integrate into workflow and review. Liability concerns stemmed from the fact that important patient data might be missed—particularly if patients can report PGHD 24 hours per day and there are not established norms for when and how to respond.

Patients expressed an additional policy-related concern about data security. Patients were apprehensive about the security of their data, particularly when submitting it to a third party. For some patients, this concern was sufficiently salient to prevent them from submitting PGHD.

Policy: Solutions. Policy solutions discussed by health system and vendor respondents included CPT codes to facilitate reimbursement for reviewing PGHD. There was not a suggested solution for liability concerns; however, health systems felt comfortable receiving PGHD by relying on automated alerts for out-of-range values to ensure that critical patient data was not missed.

Table 2. Challenges to PGHD use and suggested solutions

Category	Challenge	Description	Solution	Description
Value	Finding a signal in the data	Concerns about how to analyze PGHD to identify clinically actionable results	Building evidence base	Identifying the clinical value, thresholds and most appropriate responses based on frequently reported data points
	Information over- load	Concerns about the volume of PGHD overwhelming the organization and individual providers	Targeting PGHD collection	Accepting PGHD only from patients with conditions particularly responsive to PGHD
	Data validity	Concerns about whether PGHD is accurate	No solution identified	-
	Burden of report- ing data	Concerns about the value of the time and effort required to submit PGHD	Provider communicates value	Providers communicate to patients how PGHD is used in clinical care
Policy	Compensation	Lack of reimbursement for PGHD use	PGHD reimbursement models	Codes for reimbursement of PGHD review
	Liability uncer- tainty and risk	Concerns about lack of legal precedent for PGHD "standard of care" and lia- bility risk from timeliness of response to PGHD	Sensitive thresholds and alerts	Setting alerts in the EHR for values that fall outside of a provider- specified range, such that a pro- vider is notified when a concerning value is entered
	Data security	Concerns that personal health informa- tion is vulnerable to security breaches or inappropriate access	No solution identified	
Operational	Initial patient engagement	Technological barriers for patients to learn how to capture and report PGHD	Technical support	Providing tools, guidance and IT support for patients engaging with new tools for PGHD
	Ongoing patient engagement	Concerns about maintaining patient willingness to continuously report PGHD	Provider communicates value	Providers communicate to patients how PGHD is used in clinical care
	Data provenance	Concerns about how to visually differentiate PGHD from clinically-generated data	User interface design that differentiates data types	Visual differentiation in the EHR to clarify which data has been sub- mitted by the patient and which has been entered by clinical staff

Operational: Challenges. Engaging patients in adhering to PGHD submission was a common concern among health systems and vendors. The level of manual effort required and technical barriers to PGHD entry were seen as contributing factors, especially to initial engagement. Most PGHD required that patients manually enter data into a portal or tablet, or sync devices with apps that required technical savvy. Insufficient provider communication about the value and application of PGHD was an additional contributor to the engagement challenge. A second operational challenge was how best to represent PGHD in the EHR, in particular, how to differentiate PGHD from provider-generated data and integrate it into provider workflow.

Operational: Solutions. To engage patients, respondents again emphasized the role of providers in communicating the value of PGHD and how it is used (as described previously). There was also hope that there would be more seamless ways to track and share PGHD that did not require the patients to possess technical expertise or that technical support could be made available to patients. The capability to visually differentiate between PGHD and clinician-entered data in the EHR was seen as a user-interface design solution to the problem of unclear data provenance. However, several respondents noted that presenting PGHD on a stand-alone dash-board to a dedicated nurse or third party might be a better approach because it avoids the broader challenge of integrating data into frontline provider workflow.

DISCUSSION

PGHD has received significant attention because of its potential to foster better patient engagement, offer providers a clearer picture of patient health status, and improve patient care. 1-5 Whereas the technical capabilities to support PGHD exist, health care delivery organizations have been slow to build PGHD capabilities at scale. To our knowledge, our work is the first to describe PGHD efforts that go beyond pilot programs to scalable approaches and we identify 3 emerging models being pursued at scale, each based around a different type of data: health history, validated questionnaires/surveys, and biometric/activity. Perhaps more importantly, we identify the early challenges as described by health systems vendors, and patients, to pursuing PGHD in ways that create value. Addressing these challenges requires specific policy actions related to reimbursement, a stronger evidence base connecting PGHD to clinical outcomes, vendor engagement to deliver a technically seamless experience, and provider communication with patients about the value of PGHD.

We found a stark contrast between the 3 models of PGHD pursued by health systems and the PGHD hype and vision of the "quantified self" patient who measures and shares with their provider every aspect of their health status and health behaviors. Indeed, 2 of the 3 PGHD models consisted of replacing or supplementing data collection that occurs today on paper which many may not consider PGHD. For the third type, biometric/activity

Table 3. Challenges and illustrative quotes

Category	Challenge	Description	Illustrative quotes
Value	Finding a signal in the data	Concerns about how to analyze PGHD to identify clinically ac- tionable results	"For most providers, they wouldn't know what to do with daily blood pressure data on a patient because they've never seen it before. What do you do differently when you were used to seeing a blood pressure once every 3 months and now this patient is sending me daily blood pressures? How much tweaking should I be doing? So, some of our providers do have a sense of not knowing what to do Because it's data most doctors haven't seen before, there's a question of what to do with it that would meaningfully help the patient's health The data availability has outpaced the science, so the science needs to catch up to show us where the 'there' is." (Health System)
	Information over- load	Concerns about the volume of PGHD overwhelming the organization and individual providers	"The struggle is going to be the care management staff you need to take that on people are still trying to figure out who's going to do the regular monitoring to help physicians stay on top of it." (Health System)
	Data validity	Concerns about whether PGHD is accurate	"Providers do want to distinguish between new data that came in and hasn't been validated yet versus the validated clinical med list they keep on their own. They will often review and accept PGHD in their review workflow to say 'yes these patient-added allergies make sense, and I want that integrated with their allergy list'." (Vendor)
	Burden of report- ing data	Concerns about the value of the time and effort required to submit PGHD	"I think the value is streamlining their office. I don't think the value is to me as a patient." (Patient) "If you track your blood pressure for a month, every single day, and then go to your doctor 2 months later they're not going to look at it for every single day. They're not going to look at my little notebook that says my blood pressure. They're just going to say 'your blood pressure today is this. It's good'." (Patient)
Policy	Compensation	Lack of reimbursement for PGHD use	"There's not really a sustainable means to get reimbursed for this data we still have a lot of work to do to provide financial means to support this. The cost angle of how are we going to pay for this and who is going to pay for this is definitely a huge barrier." (Vendor)
	Liability uncer- tainty and risk	Concerns about lack of legal precedent for PGHD "standard of care" and liabil- ity risk from timeliness of response to PGHD	"There's concern about liability, like if someone puts in a bad blood pressure repeatedly and no one is there to act on it, that's a liability that we don't want. So we only accept patient data if a clinician is willing to supervise and provide feedback to the patient." (Health System)
	Data privacy	Concerns that personal health information is vulnerable to security breaches or inappropriate access	"I'm a strong believer that everything you put online, no matter how secure it is, can be seen by a lot of people. So there's always that concern about privacy." (Patient)
Operational	Initial patient engagement	Technological barriers for patients to learn how to capture and report PGHD	"The challenge we have with technology in general is we don't have patient technical support. We have portal support specialists but they're not necessarily technical and their mandate isn't necessarily to help someone get their blood pressure numbers right. We would need people who know how to troubleshoot. With that structure we could reassure the clinics that it's a matter of just getting the data and not becoming technical support." (Health System)
	Ongoing patient engagement	Concerns about maintaining patient willingness to continuously report PGHD	"It's not clear what the value to the patient isWhat is the return on investment? From the patient level you're asking them to do extra work without any value. If that value can be a \$200 check, then sure they'll spend the extra time entering that data." (Health System)
	Data provenance	Concerns about how to visually differentiate PGHD from clinically-generated data	"Clinical data models have not historically had a notion of the patient as a direct contributor to the medical record, which has required significant thought and IP investment around how best to store and maintain provenance across concepts." (Vendor)

data, there was limited appetite for frequently collecting this data from all patients (even if patients themselves wanted to report it) primarily because of the limited evidence base to understand how it is clinically actionable. We observed substantial variation in PGHD models, particularly in terms of how PGHD was captured, where it was stored, and the integration into workflow, suggesting that even

the 3 common models are early in their development. The observed variation has important implications for issues such as PGHD preservation and access. If PGHD is not integrated into the patient's medical record, it may not be maintained for future use or made available to any future provider treating the patient. We also did not hear about models that considered how government agencies or

other entities that may benefit from PGHD access to support epidemiologic or public health efforts might be able to access PGHD while ensuring appropriate privacy protections.

To move toward maturation of PGHD models and expanded use of PGHD, a diverse set of challenges needs to be tackled by various stakeholders. Chief among them are value and reimbursement. There is little evidence that ties day-to-day fluctuations in biometric data, even well-established measures like blood glucose, with the types of clinical actions that should be taken in response in order to improve clinical outcomes. In addition, for new types of data, such as step count outside of postoperative recovery, there is even less evidence on how daily data should be interpreted and made clinically actionable. ¹⁶

Once the clinical evidence base is more robust and suggests that frequent review of PGHD is clinically beneficial, it is likely that reimbursement models will need to change to pay for the time required to review and act on PGHD. Today, there are select cases where providers are reimbursed for reviewing PGHD, such as CPT code 95251 which allows reimbursement for analyzing continuous glucose monitoring data. These codes could be expanded in response to the evidence. In addition, growth in value-based payment models may result in greater use of PGHD if such use can be tied to avoidable readmissions, adherence to evidence-based guidelines, and other outcomes. However, in our interviews, value-based payment was not cited as a driver of PGHD. More broadly, development of quality measures generated from PGHD across a range of conditions may spur uptake and facilitate integration into reimbursement models.

In order for PGHD to be successfully implemented at scale, technical advances will also be important. Whereas there has been a substantial policy effort to ensure that all providers use 2015-certified EHRs with application programming interfaces (APIs), these APIs are read-only, which does not guarantee that EHR vendors or health systems will configure EHRs with the ability to "write" data such as PGHD. If APIs move toward read–write capabilities, it will be additionally important to ensure that patients have apps and devices that are easy to use. ¹⁸ The current manual and technical requirements for patients to submit PGHD are sufficiently complex that they prevent many patients from engaging, which indicates a need for more simplified and automated reporting. Lastly, advances in data visualization and analytics that move away from information overload of frontline providers to distilled actionable insights will help ensure that PGHD translates into improved outcomes.

Limitations

This study has several limitations. First, because we examined PGHD early in its development, the sample size is small and, for health systems, includes early adopters that were predominantly large organizations (though the sample varied on other important dimensions including rural/urban and safety net status). Relatedly, our patient sample was limited to patients from a single health system who wanted to engage in research. Therefore, while our results speak to early experiences with PGHD, it is not clear the extent to which results will hold true for later adopters. Second, the definition of what constitutes PGHD is not widely agreed upon. Whereas all respondents agreed that telehealth/remote monitoring was distinct from PGHD and therefore out-of-scope for this study, we did encounter some definitional ambiguity, such as a health system that sends a home health agency to the homes of frail elderly and enters data about their home life and health behaviors. We therefore chose to focus on the 3 models that were common across health system respondents. Finally, we were unable to go into depth on all topics

related to PGHD including, for example, unique data security considerations for PGHD.

CONCLUSION

PGHD is still nascent and a variety of largely non-technical challenges are preventing broader uptake. The 3 PGHD models identified here provide a starting point for health systems considering pursuing PGHD capabilities, and the challenges and solutions we identify serve to guide their approaches. Ultimately, it is unlikely that PGHD will rapidly expand until there is compelling evidence that reveals how to make PGHD clinically actionable in ways that improve patient outcomes.

FUNDING

This work was supported by The Commonwealth Fund grant number 20171044.

AUTHOR CONTRIBUTIONS

JAM and PN contributed to the conceptualization, data collection, analytic plan, and drafting/revision of the manuscript. PN performed data analysis. Both authors approved the final version of the manuscript and are accountable for all aspects of the work.

SUPPLEMENTARY MATERIAL

Supplementary material is available online at *Journal of the American Medical Informatics Association*.

CONFLICT OF INTEREST STATEMENT

None declared.

REFERENCES

- Office of the National Coordinator (ONC). Conceptualizing a Data Infrastructure for the Capture, Use and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024: Draft White Paper for a PGHD Policy Framework. Washington, DC: Accenture Federal Services, 2016.
- Dullabh P, Sondheimer N, Katsh E, et al. Final Report: Demonstrating the Effectiveness of Patient Feedback in Improving the Accuracy of Medical Records, NORC. 2014. https://www.healthit.gov/sites/default/files/ 20120831_odrfinalreport508.pdf. Accessed April 3, 2019.
- Reading MJ, Merrill JA. Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review. J Am Med Inform Assoc 2018; 25 (6): 759–71.
- Lai A, Hsueh P-Y, Choi Y, et al. Present and future trends in consumer health informatics and patient-generated health data. Yearb Med Inform 2017; 26 (01): 152–9.
- Murthy HS, Wood WA. The value of patient reported outcomes and other patient-generated health data in clinical hematology. *Curr Hematol Malig Rep* 2015; 10 (3): 213–24.
- Nelson EC. Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health. Lebanon, NH: Dartmouth Institute for Health Policy and Clinical Practice: 2012.
- Feller DJ, Burgermaster M, Levine ME, et al. A visual analytics approach for pattern-recognition in patient-generated data. J Am Med Inform Assoc 2018; 25 (10): 1366–74.

- Wong JC, Neinstein AB, Look H, et al. Pilot study of a novel application for data visualization in type 1 diabetes. J Diabetes Sci Technol 2017; 11 (4): 800–7.
- Lv N, Xiao L, Simmons ML, et al. Personalized hypertension management using patient-generated health data integrated with electronic health records (EMPOWER-H): six-month pre-post study. J Med Internet Res 2017; 19 (9): e311.
- Cohen DJ, Keller SR, Hayes GR, et al. Integrating patient-generated health data into clinical care settings or clinical decision-making: lessons learned from Project HealthDesign. JMIR Human Factors 2016; 3 (2): e26.
- Cheng KG, Hayes GR, Hirano SH, et al. Challenges of integrating patientcentered data into clinical workflow for care of high-risk infants. Pers Ubiquit Comput 2015; 19 (1): 45–57.
- Wong JC, Neinstein AB, Spindler M, et al. A minority of patients with type 1 diabetes routinely downloads and retrospectively reviews device data. Diabetes Technol Ther 2015; 17 (8): 555–62.
- 13. Centers for Medicare and Medicaid Services (CMS). Medicare and Medicaid programs; Electronic Health Record Incentive Program-Stage 3

- and modifications to Meaningful Use in 2015 through 2017. (80 FR 62761). Federal Register; 2015: 62851–2.
- 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications, 80 Fed. Reg. (Mar. 30, 2015) (45 CFR 179.315). Federal Register; 2015.
- CMS. Medicare program; proposed Medicare and Medicaid Electronic Health Record (EHR) incentive programs (Promoting Interoperability Programs) requirements for eligible hospitals, critical access hospitals, and eligible professionals. (83 FR 20164). Federal Register; 2018: 20534.
- Gollamudi SS, Topol EJ, Wineinger NE. A framework for smartphoneenabled, patient-generated health data analysis. *PeerJ* 2016; 4: e2284.
- American Association of Clinical Endocrinologists. New and Updated Codes for Continuous Glucose Monitoring (CGM) in 2018. Jacksonville, FL: American Association of Clinical Endocrinologists; 2018. https:// www.aace.com/files/socioeconomics/new_revised_codes_2018.pdf. Accessed April 3, 2019.
- Jung M. Consumer health informatics: promoting patient self-care management of illnesses and health. Health Care Manag (Frederick) 2016; 35

 (4): 312–20.