

Leveraging Patient Generated Health Data to Improve Outcomes and Decrease Cost



THE IMPORTANCE OF PATIENT GENERATED HEALTH DATA

Patient-generated health data (PGHD) is defined as any information that a *patient* captures and records. As patients engage with innovative mobile apps, smart watches, and other personal devices, valuable information about their own health status is created. PGHD reflects lifestyle choices, health history, biometric data, symptoms, and medication and treatment information.¹ Unlike traditional medical settings, where physicians collect and manage data within their offices, PGHD is collected throughout the course of a “normal day” to provide insight about how patients are responding to regular treatments and functioning in their lives. These measurements may better reflect a patient’s true health status.



Currently, the healthcare industry relies heavily on episodic care to collect patient information. The increased use of PGHD allows providers to expand their knowledge about the patient outside of clinical encounters, creating a more holistic view that informs better medical decision making. Research

suggests that patients who contribute PGHD are more actively engaged in their care and may have increased understanding about their health status.

WHAT IS DRIVING THE GROWTH OF PGHD?

The explosive availability and popularity of consumer health devices, as well as the increased willingness and ability of consumers to capture and share personal information, drives the growth of PGHD in both clinical and research settings. Consumers want to contribute to research for the “general good.”² Apple was able to recruit 7,000 participants for a Parkinson’s Disease study in just a few hours, whereas a comparable study was only able to recruit 1,700 subjects in over a year’s time.³

Increased private and public investment in analytics and “Big Data” is also driving PGHD. Due to its real-time nature, and rich information enabled by new technologies, big data science potentially offers advanced intelligence, with the aura of truth, objectivity, and accuracy.⁴ According to Nokia Health, almost two-thirds of healthcare providers are investing in remote patient monitoring solutions and analytics to support patients post-discharge, including programs at the Mayo and Cleveland Clinics.⁵ Collection of massive amounts of data further enables the growth of big data science. The National Institutes of Health (NIH) started the [All of Us Research Program](#), which seeks to build a national research cohort of one million or more U.S. participants. PGHD is likely to improve the success of research aimed at gathering large amounts of data. By collecting the information of millions of volunteers across the country, *All of Us* could have the statistical power to detect associations between biological, environmental, and behavioral influences of a wide range of diseases and a variety of health outcomes.⁶



HOW IS PGHD COLLECTED?

Patients generate their healthcare data in different ways and it is collected by a variety of methods. Consumer-level devices, which include wearables like Fitbit and Apple Watch, are becoming more popular and affordable to consumers. Mobile applications allow patients to manually enter their information and track lifestyle measurements such as physical activity, diet, and medication adherence. Registered medical devices track data such as heart rate, blood glucose, and other biometric data, often through remote monitoring. Remote monitoring involves the collection and transmission of medical data from medical devices that patients use in their homes or daily lives, which are transmitted to providers.

TYPES OF PATIENT GENERATED HEALTH DATA

Consumer Level Devices

Tend to fall in the wearables category and collect data such as steps, heart rate, and sleep patterns

Smart clothing	Biometric sleep sensor	Interactive footwear

Mobile Applications

Collect data such as caloric intake, physical activity, hydration, tobacco and alcohol use, medication adherence, mood, sleep, medication adherence, and ability to perform activities of daily living

MyQuit Coach	Hydro Coach & Drink Water Drink Reminder Apps	Sleep Cycle!

Registered Medical Devices

Offer remote monitoring and collect data such as heart rate, blood glucose, blood pressure, temperature, and weight

Stethoscope	ECG Monitor	Interactive weight scale

LEVERAGING PGHD IN PATIENT CARE

Utilizing PGHD allows providers to identify trends and outliers and creates opportunities for more efficient data analysis and monitoring, which in turn creates the potential for earlier diagnosis. Tracking PGHD during care helps clinicians identify and treat high-risk patients sooner. Leveraging PGHD proves to be valuable in many facets of care, including chronic and acute. With PGHD, patients experience improved outcomes and providers can take advantage of lower costs through reduced admissions and readmissions, increased patient engagement, and more opportunities for reimbursement through value-based care.

Leveraging PGHD in Chronic Care & Acute Care

Decreased

- ↓ ER visits
- ↓ Readmissions
- ↓ Penalties



PGHD is especially beneficial for chronic care management. A recent meta-analysis of randomized controlled trials sought to identify the impact of remote patient monitoring on clinical outcomes and found early promise in improving outcomes for patients with select conditions, including obstructive pulmonary disease, Parkinson’s disease, hypertension, and low back pain.⁷ By tracking the routine and biometric measurements of patients with chronic disease, providers are able to intervene earlier, helping to minimize progression of the disease and prevent complications that result in expensive emergency room visits.

Although industry remains in the early adoption stage, forward-thinking organizations are recognizing the value in PGHD and have begun pilot testing and researching its use for specific chronic diseases. For example, Ohio State University is studying “SensiVest,” a wearable vest that uses radar technology to proactively monitor fluid inside the lungs of heart failure patients.⁸ This data improves the management of heart failure and related conditions before they worsen, while reducing costs directly associated with readmission, as well as the Affordable Care Act penalties which hospitals face for high readmission rates within 30 days of discharge.⁹

PGHD benefits acute care by helping patients and doctors manage short-term treatment. PGHD provides reminders, early intervention, and post-discharge information, education that allows patients to improve understanding of their condition and recovery needs, and the ability to track medication adherence and pain management, through a variety of innovative methods. Patients can generate information about their handling of transitions of care to help apprise providers of any red flags or concerns. In this manner, PGHD is a tool to evaluate the effectiveness of treatments and customizations of care plans between visits.

Patient Engagement Improves with Use of PGHD

With PGHD, patients have ownership over their own data, can share insights, contribute to their care, and control when and how data is shared with their care team. In a 2016 survey from WebMD and Medscape Education, over 60% of patients reported feeling more engaged when PGHD is a part of their clinical encounters. In this survey, most patients stated they are more likely to measure, collect, and provide PGHD to their provider if they believe it will be used in their care or to develop their treatment plan.¹⁰ In a recent interview, one physician noted, “Sometimes patients are honest and sometimes they are not. Using PGHD helps



to make the patient more accountable. This way, when I see them for their next visit, I can see how well they've been adhering to their plans."¹¹

PGHD allows patients to take responsibility for their data. Reporting this information to doctors opens an avenue for increased communication and shared decision-making. When a patient is more engaged in the design of their treatment plan, they are more likely to have the skills, ability, and willingness to manage their health and act on providers' recommendations. Now that the industry is shifting to a value-based payment system, increased patient participation has the potential to lead to improved health outcomes, and in turn, better financial outcomes.

PGHD & Remote Monitoring Provides Independence to Seniors

The nation has an aging population which is living longer. Estimates demonstrate that the U.S. will be home to 71 million people aged 65 or older by the year 2030.¹² PGHD can be used in home care and assisted living to mitigate the risk of falls, encourage independent living, improve adherence to complex medication plans, and offer greater confidence to caregivers. PGHD also alerts providers when a patient deviates from their normal routine, needs caregivers or family members to check in, or requires rapid response to a medical emergency. Remote patient monitoring provides an opportunity for aging patients to maintain their independence, avoid the high costs of assisted living and nursing homes, improve quality of life, and hopefully prevent instances of serious illness or death.

PGHD Supports Value-Based Care Reimbursement

The shift to value-based care has created more opportunities for clinicians to benefit financially for their use of PGHD in patient care through Advanced Payment Models (APMs). The Centers for Medicare & Medicaid Services (CMS) recently decided to reimburse providers for remote patient monitoring services billed under CPT code 99091. The Medicare program will pay for the collection and interpretation of physiologic data that is digitally stored and/or transmitted by the patient and/or caregiver to the qualified health professional requiring a minimum of 30 minutes of time.¹³

"As the industry moves to Alternative Payment Models, Accountable Care Organizations, etc., everybody is pretty clear in that you won't succeed [financially] unless you have an engaged patient at the table with you, keeping you informed. That's the only way you get ahead of the curve on the preventative side."

-Mark Savage, Center for Digital Health Innovation, University of California San Francisco
18



The Hospital Value-Based Purchasing (HVBP) Program has incorporated the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, a patient satisfaction survey tool which includes measures related to communication with doctors and nurses, into its inpatient prospective payment system.¹⁴ Meaningful communication between a patient and his or her care team leads to more engaged patients and ultimately stronger patient satisfaction scores. Patients that are satisfied with their experience are more likely to revisit the same provider, creating a revenue around treatment.

CHALLENGES IN THE USE OF PGHD

There are many benefits to incorporating PGHD into physician practices, however challenges exist. Patients may be limited in their ability to share PGHD because of the severity of their condition, limited access to technology,

level of health literacy, and time constraints. More studies examining the effectiveness and use of PGHD are needed and challenges related to data accuracy, data visualization, and interoperability, privacy and security should be explored.

Data Accuracy

Providers may question the accuracy and reliability of some devices used to collect PGHD, such as consumer-grade wearables. A study done in collaboration with Accenture and The Office of the National Coordinator (ONC) reported that some popular wearables are consistently inaccurate at measuring energy expenditure, such as calories burned, when compared to gold-standard measurements.¹⁵ Some suggest that biomedical signals should only be measured by medical-grade wearables. Others believe that having data, measured by validated devices or not, is still a valuable opportunity to inform providers about their patients' measurements and activities in-between visits. As devices and measurements continue to improve, a consensus may be reached over time.



Data Visualization and Interoperability

When collecting PGHD, considerations must be made about the way a patient's information is entered in their record and appears in the physician's workflow. Simply collecting PGHD is not enough to improve outcomes and lower costs. Physicians are already overwhelmed with patient data, therefore concerns that PGHD would only burden workflow are legitimate. For data to reach its true potential, actionable information must be presented to busy physicians in a comprehensive snapshot through a standard interface that allows both patients and providers to easily share data.

“By simplifying the secure exchange of personal health data, we are supporting the adoption of PGHD by health providers and health systems to improve care delivery and clinical outcomes.”

*-Patricia Mechael,
PCHAlliance¹⁷*

Tools should be available to clinicians that identify trends in patients' data, separate meaningful data points, and help aggregate, summarize, and visualize PGHD in meaningful ways.¹⁶ To effectively use PGHD, interoperability must continue to improve the data flow from devices into patient records. The Personal Connected Health Alliance (PCHAlliance), a not-for-profit organization that helps to make health and wellness an effortless part of daily life, published *The Continua Design Guidelines (CDGs)* “to enable the secure, private, reliable, and accurate sharing of patient-generated health data with healthcare providers, built-on HL7 FHIR (Fast Healthcare Interoperability Resources) specifications.”¹⁷

Privacy and Security of PGHD

Patients, providers, payers, and device makers need to consider the safe and secure transport of patient information from clinical-grade and consumer-level medical devices. Not all devices are covered under HIPAA regulations and patients will have to entrust the privacy of their information with physicians. Providers need to educate themselves on the ways devices or apps might use or share patient data outside of care and be able to help patients understand their rights and options during the consent process. According to Mark Savage, the Director of Health Policy at the Center for Digital Health Innovation at UC San Francisco, “It is important that we do not undermine the trust relationship that patients have with their doctors. The way to do that is to do a better job on educating the patients of what the privacy and security expectations are around devices that are transmitting PGHD.”¹⁸

Limited Rigorous Research

“Traditionally, the tech space has offered rapid innovation and disruptive technologies but lacked the scientific rigor and clinical research,” says Dr. Eric Peterson, Distinguished Professor of Medicine in the Division of Cardiology and the Associate Director of the Duke Clinical Research Institute.¹⁹ Research is in the early stages and more rigorous research is needed to establish the effectiveness of PGHD and the technologies that measure and collect this data. Patrick Dunn, Fellow of the American Heart Association Center for Health Technology and Innovations, points out that, “Technology is constantly improving, so if you are conducting research over one year, for example, and the technology improves within that time frame, you are no longer researching the most up to date technology, which then reduces the legitimacy of your results.” Dr. Dunn recommends standards specifically for PGHD research.²⁰

The American Heart Association Center for Health Technology and Innovation developed a health technology research model that breaks the traditional study model into 3 cycles, resulting in a series of ‘mini studies’. As technology advances with each cycle, the variables are reset, unlike a traditional randomized control trial where the variable is forced to remain static throughout the duration of the study. The last phase of evaluation uses cycles-of-learning, which allow the technology to evolve throughout the study. The endpoint is always being tracked and the ‘mini studies’ combine into one complete study.

CONCLUSION

Physicians have a small amount of time to spend with their patients, although the healthcare industry relies heavily on episodic care to garner patient information. Collecting PGHD allows providers to monitor patients’ biometric measurements and lifestyle behaviors between visits and to gain a more holistic view of the patient’s health. The availability of PGHD has accelerated with the explosion of consumer health devices and an increased willingness of patients to share their information. However, concerns about the accuracy and security of devices that collect PGHD remain. Standards and processes need to be developed so providers avoid additional administrative burdens in their daily workflow.

Despite these challenges, PGHD has the potential to improve quality of care and to lower costs. The benefits of investing in PGHD immensely outweigh the challenges, particularly with the explosion of consumer devices, a growing aging population, and a shift to value-based care.

- **Patient outcomes improve** when providers determine diagnoses sooner, proactively monitor changes in routine, identify conditions before they worsen, and engage patients in their care.
- **Patient engagement improves** when patients participate in shared decision making and have more opportunities to communicate with their providers. When a patient is more engaged in the design of their treatment plan, they are more likely to manage their health and act on providers’ recommendations.
- **Providers benefit financially** from using PGHD to reduce unnecessary admissions and emergency visits, prevent readmissions, and to avoid penalties for high readmission rates. Additionally, the healthcare industry’s shift to value-based care has created opportunities for reimbursement when providers review PGHD and improve patient satisfaction scores.

The future will continue to see rapid advancements in the technologies that measure, analyze, and display PGHD. For almost two decades, eHealth Initiative (eHI) has spearheaded the collective efforts of stakeholders to

Leveraging PGHD to Improve Outcomes and Lower Cost



improve healthcare through technology, data, and innovation and is committed to convening thought leaders to discover and promote industry best practices in leveraging PGHD in a patient's care.

Organizations dedicated to addressing challenges related to healthcare interoperability can advocate for the development of standards which will enable effective exchange of PGHD between devices and patient records. As research models are being adapted to account for rapidly improving health technology, the industry should continue to monitor the latest scientific literature, which may soon include more rigorous research examining the effectiveness of PGHD. Considering these potential advancements in technology, policy, and research, the value of leveraging PGHD in a patient's care may be even greater in the future.

END NOTES

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