

Including Patient-Generated Health Data in Electronic Health Records

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Healthcare providers and health information technology (HIT) suppliers across the country have been busy preparing for what could be one of the most significant proposals for stage 3 of the “meaningful use” EHR Incentive Program—a proposal that has wide implications for healthcare providers as well as for health information management (HIM) professionals.

The proposal under discussion is for the incorporation of patient-generated health data (PGHD) into electronic health records (EHRs). Meaningful use is not the sole driver for PGHD; this focus also includes the impact on patient care and the potential to drive better patient outcomes. This Practice Brief will assist in defining PGHD and outlining some important considerations for the inclusion of PGHD in EHR systems.

What is Patient-Generated Health Data?

According to [HealthIT.gov](https://www.healthit.gov), PGHD is comprised of “health-related data created, recorded, or gathered by or from patients (or family members and other caregivers) to help address a health concern.”¹

PGHD may include such information as:

- Health history recorded through a portal by the patient
- Biometric data obtained from home health monitoring equipment
- Lifestyle information, such as the information captured from exercise or fitness devices or recorded on mobile apps

Health data generated in clinical settings or through encounters with providers is distinguishable from PGHD in two ways:

1. With PGHD, patients have the primary responsibility for recording the data.
2. The patient decides when and with whom to share PGHD.

Consumer Interest in PGHD Growing

Patients and consumers are beginning to see the value of participating in their own healthcare. According to a white paper published by the Institute for Patient- and Family-Centered Care:

Patients and families have experience, expertise, insights, and perspectives that can be invaluable to bringing about transformational change in healthcare and enhancing quality and safety. With that being said a variety of clearly defined roles for patients and families to participate as partners in quality improvement and in the redesign of healthcare needs to be in place in all types of healthcare organizations.²

Achieving healthcare’s “Triple Aim” of improving the quality of care, improving the health of populations, and reducing healthcare costs depends on patients taking an active role in their own healthcare.

Patients are reporting that they value health data, and the amount of PGHD being collected is growing rapidly. According to a recent Pew Research report, seven in 10 US adults say they track at least one health indicator:

- 60 percent of US adults track data on weight, diet, or exercise routine
- 33 percent of US adults track data on health indicators or symptoms such as blood pressure, blood sugar, headaches, and sleep patterns
- 12 percent of US adults track data on a health indicator on behalf of someone for whom they care³

The growth of consumer interest in healthcare can be seen in the increased availability and adoption of home monitoring devices, fitness trackers, and mobile applications for various types of activity or lifestyle monitoring. It can only be anticipated that the proliferation of these types of products will increase, and as this occurs, the provision of this type of information by patients to their clinicians may increase as well.

Preparing Organizations for PGHD

Historical information is the type of information that clinicians are familiar with obtaining from patients. It typically includes items such as the patient's past medical history, allergies, medications, family history, and social history.

Most clinicians have experience collecting information from patients who use home medical devices, such as glucose meters or blood pressure monitors. But biometric data such as the data gathered from consumer-owned fitness trackers also have the potential to be incorporated into the health record. This data, as well as other types of PGHD, could be made available for care decisions if the technology is in place to capture and store it.

The advisability of incorporating PGHD may seem like a relatively straightforward decision, but the implications for managing this data are rather complex. If clinical decision making is to be made on the basis of data that is supplied by patients and documented in the EHR, clinicians must also be certain that the data are accurate and trustworthy. Though the patient may have the power to control the entry of PGHD into the EHR, the clinician could ultimately be responsible for ensuring that it is reliable and actionable.

With the anticipated growth in use and availability of mobile apps and data collection devices, strategic planning for incorporating this type of PGHD should start now.

Regardless of the challenges, incorporating PGHD is an important step in the advancement of consumer-driven healthcare. Well-designed and properly executed systems that both incorporate and present PGHD in a usable fashion have the potential to improve decision making and enable patients to become active participants in their own healthcare.

Forms of PGHD

There is an expanding array of electronic tools that patients and their families can utilize to assist them in managing their health. Clinicians are increasingly promoting the use of remote monitoring devices for managing patients with chronic diseases such as congestive heart failure, chronic lung disease, and diabetes. Information gathered from these remote devices can be captured in the EHR and used for patient care and monitoring.

Some other examples of PGHD include data from a patient's standalone personal health record (PHR), data gathered from fitness devices, data obtained from a home blood glucose monitor, blood pressure readings done outside the clinician's office, or information obtained from the patient about their functional status at home or work.

Managing Ongoing Patient Communications

There are significant concerns about including PGHD in the health record and the liability that clinicians bear for reviewing it. When PGHD is received, providers will need to address how to handle the receipt of the information, workflow challenges, and liability issues to ensure the information is handled effectively. The organization should address the use of PGHD for treatment purposes in their legal health record and designated record set policies.

Sound record keeping principles suggest that any documents or information filed, maintained, or scanned into a patient's health record—including PGHD—are part of the legal health record (see the "Fundamentals of the Legal Health Record and Designated Record Set" Practice Brief, available online in AHIMA's HIM Body of Knowledge).⁴ These records are then subject to all applicable state and federal regulations concerning privacy, security, use, maintenance, and disclosure. Legal implications and liability issues must be considered when making retention decisions about PGHD.

Many healthcare organizations currently do not include PGHD as part of their designated record set because it is not used to make healthcare decisions. It may therefore be kept with the health record, but with a mark of distinction that it is not part of

the legal record, such as a different folder or tab in the EHR.

Preparing to Incorporate PGHD into the EHR

With the momentum increasing for greater patient engagement, efforts to improve population health have driven a shift towards value-based care. With the implementation of new tools to meet EHR incentive program requirements and the rapid expansion in both the quantity of applications available and capabilities of mobile health applications, the challenge of how to manage PGHD will be a growing concern for HIM professionals. The following are some considerations for HIM professionals as they embark on the PGHD journey.

Collecting Data from Personal Health Devices/Mobile Apps

HIM professionals should work with their EHR vendor and technology partners to ensure that information from personal health records, mobile applications, and other interactive websites are able to be incorporated into the EHR. It is essential to consider how the information will be designated or stored within the record—especially if it has not been actively used for clinical decision making.

Engaging Clinicians in Culture Change

Clinicians need to be engaged in the concept of incorporating PGHD into patient care delivery. Some payment and care delivery approaches now tie reimbursement to the attainment of positive health outcomes for patients. It is important to foster a culture that recognizes that PGHD is beneficial and to gain buy-in from healthcare providers for any additional work that may be required to obtain and validate the information.

Addressing Safety and Risk Through Policy

Policies and procedures should be developed and implemented that outline the conditions for when and how PGHD will be incorporated into the record. For example, policies should outline the inclusion of PGHD in the health record when it is used by clinicians and whether it will be flagged in the record as PGHD. The role of HIM in developing policies and procedures that allow the incorporation of PGHD into health records, and the provision of education around those policies and procedures, will expand as the demand grows for the inclusion of PGHD in health records.

PGHD Functions as a Collaboration Tool

With PGHD in the picture, EHRs can be leveraged as a powerful collaborative healthcare tool. With the ever rising numbers of smartphones, tablets, fitness trackers, and devices for remote monitoring of chronic conditions, the incorporation of PGHD into the EHR can provide new ways for providers to interact with their patients and increase consumer engagement in their healthcare.

It should be noted that there is a significant amount of work going on currently at the Office of the National Coordinator for Health IT (ONC) and other organizations relative to PGHD. ONC has developed a fact sheet that provides information and guidance on PGHD.⁵ In addition, Health Level Seven (HL7) has introduced an implementation guide that outlines a standard method for capturing PGHD, recording PGHD, and making PGHD interoperable within the current framework of structured documents.⁶ There has even been some recent discussion on developing standards for incorporating PGHD into the EHR.⁷ An “Issue Brief” from ONC on PGHD and information technology also expounded on the opportunities for increased consumer engagement:

The increasing number of smart phones, mobile applications and remote monitoring devices, coupled with providers’ deployment of electronic health records (EHRs), patient portals, and secure messaging, offers innovative ways to connect patients and providers and to strengthen people’s engagement in their health and care. Over 30% of Americans online are eager to use their smart phones or tablets for health management or services and over 60% say they would like to communicate with their providers electronically.⁸

All of this innovative technology—and the desire to use it—creates new opportunities for care providers and patients to collaborate in managing patient-generated data to enhance care and improve outcomes.

Records Management for PGHD

Providers may use PGHD to assist the patient in managing some of their own health needs. PGHD has the potential to reduce the need for office visits, emergency room visits, or inpatient treatment. HIM professionals can assist providers by developing guidelines and procedures to evaluate whether to incorporate PGHD into the patient records and help promote the benefits of PGHD for patient care.

Technology, education, health literacy, financial limitations, patient age, and a number of other elements need to be factored into the general acceptance and willingness of patients and clinicians to collect and use PGHD.

PGHD's Role in the EHR and Information Governance

Any information that is filed, maintained, or incorporated into the patient's health record, including PGHD, becomes a part of the legal health record. These records are therefore subject to all applicable state and federal regulations concerning privacy, security, use, maintenance, and disclosure. Legal implications as well as risk and liability issues must be considered when making decisions related to the inclusion of PGHD in the EHR.

A framework of organizational policies and solid information governance practices can help to successfully engage providers while continuing to ensure the privacy, security, availability, and appropriate use of PGHD.

With PGHD, as with all forms of information in healthcare, there is a need to ensure the data are accurate, timely, reliable, valid, and complete. An information governance program helps support the core goal of collecting PGHD, which is the safe and effective delivery of patient care. As with other healthcare information needs, the industry needs safe and reliable ways to manage PGHD. An information governance program can assist in making certain that all information—PGHD included—supports the strategic goals of the organization.

Recommendations for Working with PGHD

It is broadly accepted that reforming the US healthcare system requires engaging patients and their caregivers. While effective PGHD management will require new technology and policies and procedures that support its inclusion in the care delivery model, using PGHD is an important strategy for building a partnership that will connect patients and caregivers with their healthcare team.

Recommendations for working with PGHD include:

1. Create a strategic information governance framework that best meets clinician and patient needs for reliable collection, dissemination, and use of PGHD. Planning for PGHD should be part of an overall information governance initiative.
2. Develop policies and procedures that assist in determining when PGHD coming from an unverified source should be incorporated into the EHR. Considerations should include the intended use and reliability of the PGHD technology that is being used to collect PGHD and incorporate it into the existing EHR system.
3. Work with information technology leadership and EHR vendors to design a system that meets consumer and clinician needs. Consider technology solutions that allow for segregating PGHD in the EHR in such a manner that it is clearly designated as having been patient-generated. This would help illuminate for the providers the unverified nature of the data, yet still allow flexibility for the use of the data to promote consumer engagement and allow for better clinician decision making.

The culture of the US healthcare system is rapidly changing as consumer demands for PGHD increase. HIM professionals must be ready and willing to assist in ensuring that those demands can be successfully met.

Notes

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Prepared By

Lucia Aschettino, HITPRO-CP
Kevin Baldwin, MPH, CPHIMS
Beth Friedman, BSHA, RHIT
Reginald Grady, RHIA
Leah Grebner, MS, RHIA, CCS, FAHIMA
Margaret E. Hennings, MBA, RHIA
Lesley Kadlec, MA, RHIA
Annessa Kirby
Melanie Meyer, MHA, RHIT, CCS
Rosann M. O'Dell, DHSc, MS, RHIA, CDIP
Sandra Pearson, MHA, RHIA
Jill Roberson, MBA, RHIA, CHPS, CCS
Vera Rulon, MS, RHIT, FAHIMA
Bryanna Schoeffel, RHIA
Alisha Smith, RHIA
Anne Tegen, MHA, RHIA, HRM
Lydia Washington, MS, RHIA, CPHIMS

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Cecilia Backman, MBA, RHIA, CPHQ, FHIMSS
Linda Bailey-Woods, RHIA
Susan Clark, RHIT, CHTS-IM, CHTS-PW
Marlisa Coloso, RHIA, CCS
Julie Dooling, RHIA, CHDA
Katherine Downing, MA, RHIA, CHPS, PMP
Margaret Hennings, MBA, RHIA
Michelle Lakins-Waller, MBA, RHIA, RN, BSN
Cathy Munn, MPH, RHIA, CPHQ
Kelli Provost, RHIT
Angela Rose, MHA, RHIA, CHPS, FAHIMA
Heidi Shaffer, RHIA
Alicia Smith, RHIA
Lou Ann Wiedemann, MS, RHIA, CDIP, CHDA, CPEHR, FAHIMA

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