Patient-Generated Health Data and its Impact on Health Information Management
Patient engagement is a growing focus in healthcare. Stimulated by its inclusion within Meaningful Use criteria, hospitals and physician practices are strengthening patient relationships through patient engagement and portal utilization. As defined by the Center for Advancing Health, engagement includes “the actions individuals must take to obtain the greatest benefit from the healthcare services available to them.” The Institute for Healthcare Improvement (IHI) suggests the need for strong patient engagement as a route to achieving the Triple Aim framework: improve patient experience of care (including quality and satisfaction), improve population health, and reduce the per capita cost of health care.

Consumerism cannot be overlooked as technology and access to information increases and as transparency in a digital world gives patients a significant role in defining the future. With the development of mobile monitoring apps and wearable fitness tracking gear that count calories, monitor heart rate, and measure body movements, patients are playing a more active role in their own health care. These apps and devices generate a large amount of data that patients can share with their providers. As patients collect patient-generated health data (PGHD), it is being implemented into their electronic health record (EHR) and has the potential to improve population health and patient engagement.

PGHD is poised to become the tipping point for consumerism in healthcare. Recognizing the growing surge of PGHD, the assessment of its impact on health information management (HIM) is integral in supporting its integration into EHRs.

Defining PGHD
The Office of the National Coordinator (ONC) defines patient-generated health data as “health-related data — including health history, symptom, biometric data, treatment history, lifestyle choices, and other information — created, recorded, gathered or inferred by or from patients or their designees (e.g., care partners or those who assist them) to help address a health concern.”

PGHD supplements existing clinical data and provides information about a patient's condition between medical visits. Information is collected on an ongoing basis rather than only at one point in time.

The Value in PGHD
PGHD may provide a comprehensive look into a patient's overall health; therefore, there is value in integrating PGHD into electronic health record systems. PGHD provides relevant information for preventative and chronic care management which can result in cost savings and improvements in quality and care coordination. The patient-provider relationship can be strengthened through shared decision-making regarding their care which gives patients a voice, and helps them become actively involved in their health care. They track their results and provide providers with the PGHD to review and evaluate combined with clinical data during the care process.

PGHD helps medical care teams avoid medical mistakes and errors by providing supplemental information such as family history, allergies and symptoms, and avoid miscommunication and misinformation due to information gaps and poor coordination. Providers gain efficiencies as a result of leveraging patients as a resource in the care process while patients gain an added convenience.

Consumer Use of Health Tracking Technology
Although PGHD is not a new concept, the term is relatively recent and with advancements in mobile and wearable technology to record and share information, the use of PGHD is certainly gaining momentum. As more apps and devices are introduced into the market, consumers have more opportunities to track their health and wellness.

According to the Pew Research Center:

- 60% of U.S. adults track their weight, diet, or exercise routine.
- 33% of U.S. adults track health indicators or symptoms, like blood pressure, blood sugar, headaches, or sleep patterns.
- 12% of U.S. adults track a health indicator on behalf of someone they care for.
Support of PGHD from Health IT
Given the increasing availability of health monitoring technology, it is clear that consumer interest in healthcare is profound. As the types of health monitoring products increase, the delivery of information by patients to their clinicians may increase. Additionally, with the increase of patient portals, patients have access to submit health information electronically. Online questionnaires, secure email messaging of health information to patients, and reminder and follow-up notifications are a few features available through patient portals in support of PGHD.
Health IT plays an integral role in enabling the use of PGHD. The support from health IT connects patients and providers through innovative ways and strengthens patient engagement in their health care.

**Impact on Population Health and Patient Engagement**

Data tracked outside of clinical settings and shared with a provider offer a more comprehensive look into overall patient health, thereby improving outcomes.

According to the Pew Research Center, tracking health indicators produces results:

- 46% of trackers say that this activity has changed their overall approach to maintaining their health or the health of someone for whom they provide care.
- 40% of trackers say it has led them to ask a doctor new questions or to get a second opinion from another doctor.
- 34% of trackers say it has affected a decision about how to treat an illness or condition.

The benefits of a more engaged patient result in improved care, especially in chronic illnesses. The Pew Research Center reports that people living with chronic conditions and caregivers are more likely than other adults to track health indicators, more likely to track in a formal way, and more likely to report that it has had an impact on their health.

Key Concerns in Using PGHD
The influx of portable technology continues to enrich the growing surge in the capture of PGHD. However, HIM is impacted with challenges that must be considered, notably in information integrity, privacy and security, and technology.

Information Integrity Issues
Information integrity concerns are exacerbated when multiple sources to monitor PGHD are used at one time. Inaccuracies could result in erroneous information and provide a faulty assessment of a patient's condition which ultimately affects their treatment plan. Providers may also feel that the influx of information burdens them with reviewing large amounts of PGHD in a short period of time or PGHD may not be received in a timely fashion at all. In these cases providers experience increased liability and unrealistic patient expectations concerning their health care. The lack of information integrity poses a risk to quality of care; however, the presence of information integrity prompts better analytics results, allowing for improved health outcomes.

Policies and procedures must be in place to help ensure information integrity and determine if PGHD should be used as part of a patient's care plan prior to incorporating it into the EHR. Any data upon which providers make medical decisions should be in the health record; however, many of the EHRs do not have the infrastructure to handle real-time incidents based on PGHD.

Privacy and Security Issues
Devices and applications that collect PGHD have the ability to interface into other applications and interact with covered entities. PGHD then becomes protected health information (PHI).

Whenever PHI is being captured, transmitted and stored, security is a high priority. Every stakeholder should be assured that PGHD is private and secure and PGHD should be treated the same as any other PHI. The patient's identity should be authenticated. Providers are concerned that PGHD may not be appropriately linked to the correct patient. PGHD should be linked to its original source to easily track as it moves from system to system. Security should be maintained when the data is at rest and while in motion. Additionally, when secondary sharing occurs, patient authorization will need to be addressed if a patient chooses not to share PGHD with other providers.

Ultimately, everyone has a role in protecting and securing PHI. “The identity of and authorization for providers and staff receiving or accessing the information needs to be established. Transmission must be secure; encryption may be desired.”

Technical Issues
The capture, transmission, receiving and digestion of PGHD can be challenging. Technology and process improvements are critical to reduce the complexity and improve the usefulness of PGHD. The transfer of PGHD across systems can be difficult and costly. Potentially large volumes of PGHD may exceed workloads and have a negative effect on productivity and decrease pay-for-volume reimbursements. Recording and preserving PGHD-data provenance is still in the early stages of development. Advanced technology is needed to improve workloads and reduce liability concerns as PGHD migrates through systems and processes.

Data Provenance
Data provenance refers to an organization's ability to track and verify the origin of clinical data, identify the creator, determine who has ownership of use, and track changes made to the data during its lifecycle. It enables segmentation of information based on source, enhances provider trust in information being exchanged between providers and enhances provider trust in information received from a patient.

Data provenance in PGHD is important because providers have the ability to track what data is submitted regarding their health. This data is incorporated into a patient's EHR as PHI and must be governed accordingly.

Data Provenance Challenges and Opportunities
Provenance at the data element level is generally lacking. EHRs often export at document level only. Personal health records (PHRs) may import at the document, section, and data element levels, but exports at document level only. Yet, health information exchanges (HIEs) can export at data element level, but sufficient information is not available.
In 2013, ONC funded an environmental study on data provenance, i.e., methods of recording and conveying the source of data. Their study found:

- Most systems do not capture origin with sufficient granularity to meet providers’ needs related to PGHD;
- At the time of the study, no dominant provenance model existed within the HIT community;
- No uniform way of handling data provenance when data is originally created and/or shared and integrated, including reconciliation;
- No harmonized standard at the time of the study; and
- Upcoming work included HL7 (a set of standards, formats and definitions for exchanging and developing EHRs) data provenance and privacy support in C-CDA initiative (Consolidated-CDA is the new standard for EHRs).¹

Must Have Policies and Procedures in HIM

Data collected outside the clinical setting is just as useful as data collected inside clinical visits as both types contribute to health outcomes. Currently, there are no established policies and procedures for the optimal use of PGHD, data collected outside clinical settings. A framework of standards would assist in engaging providers and patients. Additionally, it would help reduce technology issues while ensuring the integrity and privacy and security of PGHD.

Policies and procedures for the secure and effective capture and use of PGHD will help to support delivery and payment reform. Information to consider when developing policies and procedures:
• What information will be received?
• Through what channel will information be received?
• Who will review the PGHD and when?
• What response will be given to the patient and when?
• If/when/how the information might be entered into the patient’s medical record
• How to distinguish provider documentation from PGHD
• How will privacy and security be ensured?
• How are providers notified when their patients’ PGHD “arrives” for review?
• Are patients able to determine the data priority level to alert their providers (e.g., low, medium, high)?

Reviewing ONC’s Patient-Generated Health Data and Health IT Practice Brief will assist with developing and implementing policies and procedures. Establishing a strategic information governance framework will lead to greater success in the PGHD integration process.

Education Ahead
Patient populations and consumers should be educated on privacy and security of PGHD and the use of PGHD to help improve their health outcomes. Providers should understand the impact and relevancy of PGHD in practice, clinic, hospital and other ancillary settings. Those preparing for a career in HIM will find it useful to be competent in the utilization, management and maintenance of PGHD.

HIM professionals can play active roles in the integration and management of PGHD by:

• Contacting EHR vendors to begin conversations about PGHD
• Establishing policies and procedures
• Educating providers about the importance of PGHD
• Educating patients about the impact of PGHD

PGHD is no different than any other PHI. HIM professionals serve as data stewards and must ensure that the integrity, privacy and security of PGHD are maintained.

Incorporating PGHD into EHRs
PGHD should be incorporated in EHR records not as an encounter, but as an ongoing “global” diagnostic monitor. It provides a comprehensive outlook into a patient’s overall condition, including preventative and chronic care management. Data received in PGHD is only as good as the documentation. The need for HIM to continuously monitor data for quality and timeliness is vital.

Incorporating and leveraging PGHD requires strong leadership and strategy. Focus on the goal and value of PGHD and the benefits to patients and clinical care. Consider the criteria for success and who will be responsible for the success of its implementation. Determine what types of PGHD would be most valuable and start building on successes. Processes must be adjusted to take advantage of health IT, so it is important to understand where the use of PGHD will fit into the care process.

Training and education on the value of PGHD as well as how it impacts health outcomes are required when incorporating it in EHRs. The management, flow of data and maintenance of PGHD is also vital to the success of the integration. Leaders must recognize technical and procedural concerns surrounding the upload of PGHD into EHRs and other systems—including information integrity, privacy and security. Patients must be educated on the benefits, use and ways to provide health information for providers to aid with their health assessments.
Conclusion

Working collaboratively with IT, EHR vendors, providers and patients by establishing a strategic framework for managing and utilizing PGHD will help advance overall engagement. The continuous engagement of patients to provide feedback and participate in preventative and chronic disease management will improve the quality of care through IT enablement and applied analytics. Emphasis should be placed on prevention and not just treating patients once they are sick. Everyone is becoming more involved in health initiatives, including corporate businesses that provide their employees with wellness programs and encourage them to live an active and healthy lifestyle.

New technological advancements in apps and fitness tracking gear is setting the stage for patient empowerment and engagement and helping improve population health. Patient engagement is increasing and patient-provider communication barriers are being broken. As with any patient engagement tool, communication is critical to its success.

For more information about PGHD, read AHIMA’s practice brief titled Including Patient Generated Health Data in Electronic Health Records. The Office of the National Coordinator (ONC) published a PGHD white paper that outlines uses, challenges and opportunities.

References


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