Enabling Consumer and Patient Engagement with Health Information - Retired

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Healthcare providers are continually developing new models to assist in efficiently delivering high quality care while reducing overall costs. A critical success factor in this transformation of healthcare is the expectation that healthcare delivery models will increasingly become consumer- and patient-centered. A focus on both consumer engagement and patient engagement will play a central role in improving care outcomes and reducing healthcare costs.

Though open to debate, the two terms can be defined as:

- Consumer engagement—engaging healthcare consumers while maintaining their own health as well as while they are caring for others
- Patient engagement—focusing on patients when they are dealing with illness or health challenges

The purpose of this Practice Brief is to understand the relationship between health information management and consumer/patient engagement, and examine how HIM professionals can advance and support engagement. Its focus is on policies and practices that enable the individual's access to and use of health information.

Defining "Engagement"

While currently no standard definition for either "consumer engagement" or "patient engagement" exists, and in many cases the two terms are used interchangeably, a general understanding of these terms is that they both mean enabling people to work with healthcare professionals in full participation of maintaining their own healthcare and making informed healthcare decisions.

This understanding implies that the "enabling" of people must start with healthcare professionals. However, the Center for Advancing Health has offered a definition of patient engagement as "actions individuals must take to obtain the greatest benefit from healthcare services available to them."[1] This definition seems to put the onus for engagement on the individual. These two different perspectives are not mutually exclusive, but demonstrate the current need for a standard definition.

According to recent research, active consumer/patient engagement is associated with decreased utilization of health services and lower healthcare costs and has thus become a central focus of healthcare policy and economics. Patient engagement can be a powerful tool in achieving the healthcare "triple aim" of improving outcomes, providing better patient care, and lowering cost. However, many barriers prohibit full engagement, including:

- Limited access to healthcare
- Low health literacy
- Health disparities
- Financial disincentives in the healthcare system
- Limited EHR portal access

The requirement to make greater use of health information technology in stage 2 of the Centers for Medicare and Medicaid Services' (CMS) "meaningful use" EHR Incentive Program is beginning to address these barriers. However, it is evident that improved consumer-friendly access to high quality health information requires more than technology.

No Engagement Without Health Information

While no one would argue that patient engagement is virtually impossible without the provision of high quality health information, traditional HIM policies and practices may create barriers for patients seeking relevant information. Due to this possibility, these policies and practices should be continuously examined and updated to ensure that they do not present impediments to patient engagement.

Individuals require access to health information in order to:

- Better understand their own current care and treatment, as well as that of family members in their care
- Coordinate care and reduce duplication of services among multiple care providers
- Maintain a personal longitudinal health record that tracks their health conditions and care provided over time

Health information must be timely, accessible, accurate, and understandable in order for it to be beneficial and useful to consumers. However, whether it is provided on paper printouts or through technologies such as web portals, portable media, or mobile devices, consumer/patient engagement must be supported through:

- Up-to-date organizational policies and practices that address patient access and availability and reflect the requirements for consumer engagement
- Continuous education of patients, providers, and other healthcare professionals in their respective roles relative to health information to support engagement
- Advocating for consumer/patient engagement through public policy and standards implementation

Recommended Best Practices for Consumer/Patient Engagement

- Establish or participate in an organizational committee, council, or information governance board, whose charge is to address facilitation of patient engagement. This group should review all existing and proposed policies and procedures related to health information access with an eye toward gaps and barriers to patient engagement.
- When health information is accessed electronically by patients through portals, ensure that requests for clarifications, corrections, or amendments can be supported by automated workflow that confirms receipt of the request and routes the requests to the appropriate place and person.
- Reach out to community groups as a speaker on patient engagement.
- Work with clinicians to include a comprehensive set of clinical information, including doctors’ notes and other forms of documentation, within the patient portal that goes beyond limited information such as appointment dates and lab results.
- Take on a leadership role with the patient portal, managing portal processes.
- Establish a central and convenient (to patients) location for receiving and processing requests for all types of health information regardless of media, department, or source. This means establishing a “one-stop shop” for archived paper records, compact discs, diagnostic imaging media, pathology slides, etc.
- Create policies and design workflows for accepting and managing patient-generated health information.
- Eliminate fees to patients for providing them with electronic copies of their health information.
- Stay up-to-date with public policy proposals and standards development that addresses and supports consumer engagement.

Organizational Engagement Policies and Practices

As organizational policies are developed or reviewed, the following are considerations in which traditional and existing health information management practices should be carefully reviewed and updated to ensure that they support patient engagement.

Removing Financial Barriers

In particular, practices such as charging fees for patients accessing or reviewing online health information should be carefully scrutinized. Not only does the practice of charging fees for patient access to health information conflict with the requirements for hospitals and providers seeking to meet stage 2 meaningful use requirements, but it is also in fundamental conflict with new care models such as accountable care and patient-centered medical homes that benefit from patients having easy access to their health information. In addition, charging patients for records in the per-page-plus-flat-rate format does not comply with the HIPAA Omnibus Final Rule, which requires that the charges be based on the cost of "labor and supplies" only. Technological tools such as online patient portals and the Blue Button initiative, discussed below, can reduce if not eliminate the labor and supply costs that are otherwise needed for retrieving and copying paper-based health information in response to patient requests.

CMS has confirmed that it is inappropriate for healthcare organizations to charge the patient a fee to access a certified EHR technology solution regardless of whether the solution is in the form of a provider-specific portal, an online personal health record, community portal, or some other online solution.[2]

It is important for healthcare providers to weigh the financial benefit of charging for records and information access, which is usually a relatively small revenue stream, against the larger goals and perhaps greater financial benefit of meaningful use incentive payments, enhanced patient care quality, and lower costs that can potentially be realized through new care and payment models that place a large value on patient engagement.

Increased Demands for Transparency

While many healthcare organizations have begun to routinely provide access to laboratory test results, medication lists, and visit summaries through patient portals, relatively few provide unfettered access to the notes and other documents in the medical record written by physicians and other providers. However, research performed in a study on the OpenNotes initiative provides evidence that greater transparency through giving patients full access to physician notes results in patients feeling more in control of their care. Patients also had a better understanding of their health and medical conditions, and greater compliance in following prescribed treatment, according to the study. At the same time, physicians in the OpenNotes study did not experience the anticipated additional workload or demands from patients due to confusion or worry about the information contained in the notes. Rather, physicians perceived that sharing notes with patients frequently resulted in strengthened communication and enhanced patient trust.

Other studies, such as a 2013 study from the global outsourcing firm Accenture, indicated that transparency is so important that 40 percent of patients stated that they would be willing to switch physicians in order to gain online access to electronic health records.[3]

Building the Integrity of Health Information

Patients and the caregivers with whom they share their information play a critical role in ensuring the integrity of their health information. The advent of EHRs and patient portals has allowed health information to become more readily available. Consequently, one of the outcomes of providing greater patient and caregiver access to the health information has been an increase in the number of requests for corrections or amendments.

Constraining access to health information through long-standing practices such as limiting the times patients can review records can also potentially impact integrity. For example, many hospitals have traditionally not allowed patients to review or access their records or health information during hospitalization, citing the need for the record to be complete, including all signatures, before the patient is allowed to see or access it. This may be a missed opportunity to improve physician-patient communication and/or catch errors in documentation earlier. Access during the hospitalization may result in an improvement in the accuracy, integrity, and trust in the health information.

Handling of Patient-Generated Health Information

As patients assume more responsibility for their own care, it is anticipated that remote monitoring and mobile health applications initiated either by patients or at the direction of the patient's physician will become more prevalent. This information could include health questionnaires, data points such as blood pressures or glucose levels, self management diaries, patient/family health histories, and healthcare directives among other types of health data and information. Patients and their caregivers have an expectation that this information will be reviewed and utilized in healthcare decision making. Policies, practices, and procedures developed in collaboration with clinicians and other stakeholders need to address communication with patients about the information they provide as well as training of staff on how to manage this information.

Educating the Community About Health Information

Many HIM professionals believe they have a professional responsibility to educate the public and their communities about health information, and in doing so address a very real health literacy need among consumers. Some may be well-suited to provide education about the content of health records in general terms and explain how that content is used, as well as provide information about patient rights to access, review, copy, and amend or correct information contained in health records. They may also be well-positioned to address how health information can be used to improve and maintain health, including how it can be used to facilitate communication with physicians and other care providers. They can share their knowledge of how to access health records to assist patients in navigating the healthcare system.

However, the community also extends to providers and healthcare workers, and there may be a need to educate healthcare providers who see patient engagement only within the limited context of patient compliance or non-compliance. These individuals may not fully understand their legal and ethical obligations related to educating patients on information access and use of health information. This is especially true of providers in physician practices and other healthcare settings who may not have access to professional HIM support. HIM professionals can provide education about health information management in these areas in order to facilitate consumer engagement. This may include issues such as patient rights under the HIPAA Privacy and Security Rules; requirements for EHR meaningful use, and operational recommendations that facilitate patient engagement.

Finally, there is a need to ensure that HIM professionals maintain their own education and stay up-to-date with the quickly changing requirements to support consumer engagement. This may include a wide variety of issues, such as:

- The relationship with, and impact of, re-disclosures of health information
- Health information exchange
- Charging patients for their own health information
- Training of contracted release of information providers
- Segregation of high-risk data
- How to manage patient-generated health information from mobile devices and other technology

Consumer Engagement and Advocacy

HIM professionals can also play an important advocacy role in making health information actionable and usable for patients and consumers. By providing review and public comment on proposed interoperability standards as well as public policy proposals such as meaningful use, HIM professionals can help remove barriers to patient and consumer access to health information. Leaders also have an opportunity to influence state legislation that impacts access to health records. Locally, HIM professionals can adopt or encourage the adoption of standards such as the Blue Button initiative to directly influence consumer/patient engagement.

Get Involved with Blue Button

The Blue Button initiative is a standard platform that allows patients to download and easily distribute their protected health information. Although Blue Button is in its early stages, many in HIM hope that it will be endorsed by most provider organizations, insurance companies, and EHR vendors. The Blue Button initiative makes health information actionable and usable by providing an easy way for consumers to securely download their health information from a provider or payer's website in a human-readable or machine-readable format. Health information can then be saved, printed, and shared with other providers or third party applications. For more information visit www.healthit.gov/bluebutton.

Notes

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