Consumer-Facing Health Information Practices (2016 update) - Retired

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Increased adoption and use of health information technology by healthcare providers has made greater consumer access to health information possible, as well as increased general engagement in health maintenance and care. The opportunities for improving quality and efficiency afforded by this new capability require a comprehensive review of existing health information management (HIM) policies and practices to ensure that consumers are supported in this effort. Additionally, any organizational barriers to access and use of health information by consumers must be reduced or eliminated.

Drivers such as health information exchange, and accountable care organization efforts-in which the consumer's role is central to reducing cost and improving the quality of care-require providers to take a fresh look at traditional disclosure and release of information policies and practices in hospitals, physician offices, and other care settings.

Increased patient access often results in the identification of errors, which creates an opportunity for HIM professionals to address them and results in an increased accuracy and integrity of health information.

Consumer-facing health information practices-addressed in detail in this practice brief-are broadly defined as policies, processes, or procedures controlled or supported by a healthcare organization that facilitate the access to and use of health information by individuals, family members, and other proxies. The term "healthcare organization" (HCO) includes providers that deliver healthcare in any setting, inclusive of ambulatory, acute, and post-acute care where personal health information is collected and used in the diagnosis and treatment of patients.

In many HCOs, HIM professionals may play a key role in easing the burdens of the bureaucratic process and the cost associated with obtaining access to health information for individuals. In addition, they may assume a leadership role in education and advocacy for consumer access to health information-both inside and outside their organizations.

Consumer-facing health information practices generally can be categorized into four areas:

- Access management
- Information transfer and exchange
- Information integrity
- Consumer education and advocacy

Access Management Practices

As an extension of electronic health record systems, portals can facilitate online communication between providers and their patients. They include functionality such as appointment scheduling, review of lab results, immunization checks, requests for prescription refills, review of bills, and e-mail exchange with providers.

Many portals also allow both providers and patients to record and monitor health indicators such as blood sugar and blood pressure. All of these functions exist to support patients looking to take a more active role in their healthcare.

Because portals permit access to and exchange of protected health information online, they must be actively managed by professionals with detailed knowledge and training in health information privacy and security. Both of these areas typically fall within HIM expertise. Policies and processes must be put in place to address issues of trust and accessibility, not only for the individual to whom the information pertains, but for those who may serve as a proxy as well-such as parents, spouses, and adults caring for elderly relatives.

These policies and processes may include registration and authentication to receive access to the portal as well as obtaining, validating, and revoking authorization of third parties when appropriate. Special authorizations for health services and

conditions that require extended protections, such as those associated with behavioral health, reproductive health, and substance abuse and treatment, must also be considered in managing portals. Once policy decisions have been made, the processes to support them should be transparent to users and facilitated through system functionality whenever possible.

As the use of EHRs grows, and access to patient portals and other personal health information tools also continues to expand, robust access management processes will be a key factor in consumer adoption of personal health records (PHRs) and patient engagement. Access management includes protecting patient confidentiality and ensuring that appropriate privacy and security policies are in place.

Information Transfer and Exchange Practices

As electronic health information sharing becomes more prevalent, so too will the need to transfer health information to consumer-managed PHR systems, as well as the need to incorporate consumer-generated health data into portals or EHRs.

Initiatives such as the US Department of Veterans Affairs' "Blue Button" project, which allows individuals to access and download information from provider Web sites to PHRs, are expected to be widely adopted by healthcare providers in the future. These initiatives will allow individuals greater control over their health information and provide them with a more efficient method for sharing that information with other providers. This capability is not yet widely available, however, and delays associated with manual processing of requests for information that is not available through the portal presents a barrier for information exchanges that require a shorter timeframe to provide the best coordination of care.

HCOs with an interest in promoting patient engagement will need to ensure that policies, processes, and technology are in place to expedite information sharing and transfer.

In addition, the capability of capturing patient-generated data within provider records requires a careful evaluation of current barriers and viable methods to support the required functionalities. Mobile technologies such as smart phones and tablets can facilitate efficient collection of health data by individuals who may or may not be directly connected to medical devices.

For a variety of reasons, however, such information has not been routinely included in provider records and sometimes has been seen as a medico-legal risk should it be missed or not considered by the provider in care planning. Again, it is necessary to have clear policies regarding how this information will or will not be used and what its status is within the context of the official patient health record. Many consumers expect that providers will use this information, and there may be a need to manage these expectations through education and communication.

Cost as a Barrier

Major policy considerations should include those designed to reduce barriers to access. A potential major barrier is the cost to consumers for accessing information.

In many locales, the practice of charging patients for copies of paper medical records still presents a significant barrier to individuals seeking information that would help them to actively participate in their own healthcare. The move to self-service portals currently being promoted as part of provider adoption of EHRs significantly decreases-or eliminates-the labor and other costs associated with producing copies of paper records. It is highly recommended that HCOs totally remove or reduce this cost barrier for patients whenever possible, but especially when online availability is provided to individuals seeking access to their health records.

Failure to remove the cost barrier may not only have a negative impact on patient engagement in their own healthcare but may also negatively impact the HCO's ability to demonstrate compliance with Federal, state, or local regulations which promote providing increased patient access to health information.

Information Integrity Practices

As an individual's ability to access health information increases through the use of portals, electronic records, health information exchanges (HIEs), and PHRs, so too will the likelihood of discovering errors in the information.

HIPAA regulations require covered entities to have policies in place to manage patient requests for amendments and corrections. Providing consumers with wider access to their health information-and thus allowing them the personal ability to identify errors-presents an opportunity for improving accuracy and integrity not only at the level of individual records, but for all instances where information systems, documentation practices, coding, or other processes may have an unintended negative effect on health data.

While the types and circumstances of errors identified by consumers will need to be reviewed carefully on an individual basis, policies and procedures to address them will also need to be developed and implemented. Health information practices designed to support requests for amendments or corrections should be developed in conjunction with online tools that support at least the following:

- Ease of reporting potential errors, omissions, and request amendments
- Timely communication, follow up, and response
- Availability of educational resources such as FAQs, glossaries of medical terms, and disease-specific patient education materials

In order to provide a high service level and incorporate best practices in handling requests for corrections and amendments to health information, HCOs will need to:

- Assure adequate staffing to handle the expected significant increase in requests after providing electronic access
- Consider workflow automation to efficiently route requests to staff evaluating and making decisions regarding requests
- Report and track requests by type of error and incidence and timeliness of response
- Consider whether the HCO has an obligation to communicate changes and amendments to those who may have already received uncorrected information

Consumer Education and Advocacy Practices

As online access to health information increases, healthcare organizations have a responsibility to help consumers understand the content, meaning, and use of such information, as well as the provider's policies regarding access to the information. Educational materials may be provided either online or in print and written in consumer-oriented terms and language. Such information may include:

- Requirements for authorizations
- Who may request information and how caregivers may obtain information
- Privacy policy explanation
- Special disclosure information, such as mental health, HIV/AIDS, and substance abuse records
- Policies specifically regarding mail, fax, e-mail, verbal, or other methods of communicating health information
- Description of the content of the health record
- Explanation of fees

When HCOs elect to charge for providing hard copies or digital copies of health records, information about fees should be made available to the public, along with information about state laws governing the rates being charged. The purpose of the fees should be specified, including those associated with services such as record retrieval and photocopying, and costs such as postage and handling.

The fee structure should also identify specific rates for different reasons or recipients for which information is being disclosed. For example, fees will most likely be different for a digital copy than they would be for paper, or when providing the information to a third party as opposed to the patient.

When it is necessary to provide authorization for release of information to a third party, HCOs must also make provisions for explaining the necessary forms and assisting with their completion. Such assistance can be provided with online or print materials, as well as through telephone or in-person support. It may be desirable to include a brief description of HIPAA and any applicable state laws. Providing a reference where the consumer can obtain more information is another option.
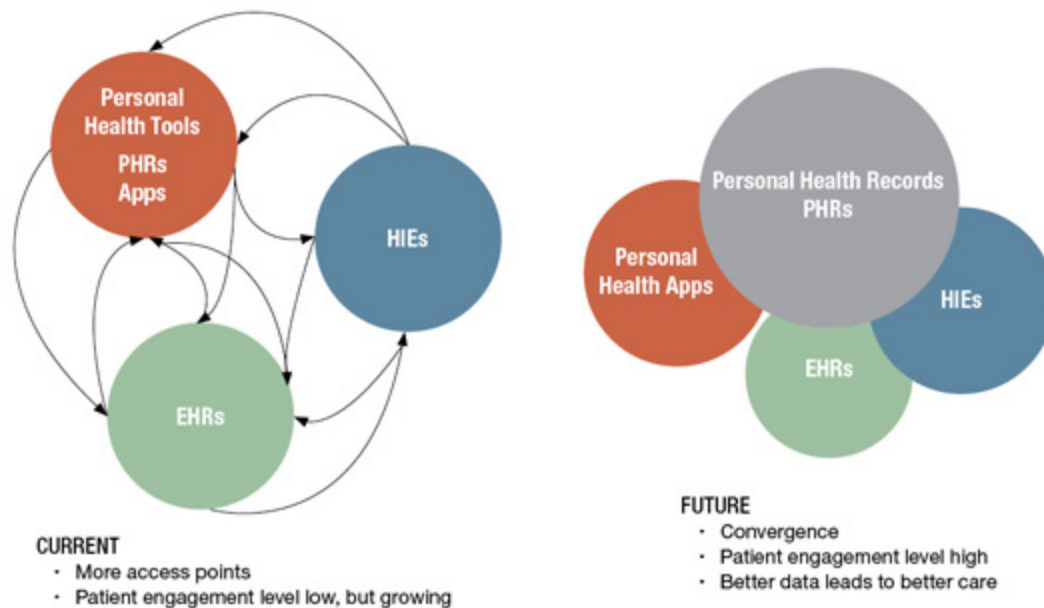
As HIE evolves, current inefficiencies associated with transferring records among providers and transitions of care are expected to decrease. However, this will not occur until some of the issues that create these inefficiencies are resolved. These issues stem from:

- Misinterpretation of current privacy laws, especially HIPAA and conflicting state laws
- Lack of understanding about consents and authorizations
- Confusion about exactly what information is needed by the requester
- Excessive charges or confusion about charges for record copies
- Misunderstanding about ownership of information

These issues frequently cause significant hassle and worry for consumers, requiring them to pay for duplicate diagnostic tests and services-whether through health insurance or out-of-pocket. In the era of healthcare reform, providers can no longer afford these inefficiencies and must work to develop clear policies that address information exchange processes.

Evolution of Access and Engagement

With the Continued expansion of EHR use and development of patient portals and other personal health information tools, access management processes are a key factor in the successful and effective evolution of current consumer engagement methods.

CURRENT
· More access points
· Patient engagement level low, but growing

FUTURE
· Convergence
· Patient engagement level high
· Better data leads to better care

HIM Professionals Must Advocate for Consumers

Possessing an in-depth understanding of health record content and its management and use, as well as the regulatory environment, ideally positions many HIM professionals to both educate consumers and advocate on their behalf as patients gain greater access to health information and begin to fully participate in their own care.

HIM professionals have historically been strong privacy advocates and passionate leaders in providing community-based education that encourages consumers to develop and maintain personal health records. They advance their advocacy by:

- Removing barriers and inefficiencies associated with providing consumer access to health information within their HCO
- Encouraging and educating consumers to maintain an up-to-date depository of critical information related to medications, allergies, current conditions, and immunizations that they can bring to visits with healthcare providers
- Developing plans for inclusion of consumer-generated health information in provider records
- Serving as a resource for the development of PHRs and other consumer health tools

Supporting Consumer Engagement

Consumer engagement is a business imperative for healthcare provider organizations who expect to thrive and survive in the new era of healthcare reform and transformation. This engagement cannot take place without developing a supportive foundation of access to health information for consumers that will provide them with a new level of control in their healthcare. Robust consumer-facing health information practices that address access management, information transfer and exchange, health information integrity, and consumer education and advocacy will continue to be necessary for success.

Traditional policies and processes designed for the release of information processes associated with paper-based health records may not adapt well to an electronic environment, and therefore need to be evaluated carefully to ensure the adoption of technology does not also create new barriers. Policies and processes should ensure that the evolving needs of healthcare consumers are being consistently met as the healthcare delivery system changes.

Disaster Preparedness: Implications for Consumer-Facing Health Practices

Consumer managed health information or ready access to electronic health information maintained by healthcare providers can be a lifeline during natural or manmade disasters. HCOs must consider patient access to health information as an integral part of their disaster planning efforts and should take steps to ensure that unnecessary barriers are removed and that appropriate access is expedited in emergencies. In addition, HCOs should take steps to educate consumers on the importance of maintaining health information as a part of personal emergency planning.

For more on this topic, read the feature article "Consumer Preparedness in the Face of Disaster."

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