AHIMA Public Policy Statement: Consumer Engagement

AHIMA's Position:

AHIMA supports the use of public policy to empower individuals to make better decisions about their own health using trusted data from traditional and emerging data sources. Health information professionals have the operational expertise to help inform public policy decisions that seek to empower individuals to make decisions about their health using trusted information. To empower individuals to become better informed and more involved in decisions that affect their health and healthcare, AHIMA believes that public policy must:

1. **Guarantee an individual's right to access their health information,** regardless of where it is captured, stored, or exchanged. This includes having secure access to their health information in the form and format they choose.

2. **Support the development of secure, consumer-centric digital tools to enable individuals to further engage with their health information**. This includes the development and implementation of open application programming interfaces (APIs) and modern technical standards to support new applications, platforms, and services that allow individuals and/or their caregivers to participate in their care more easily. Improved usability of existing technology, including patient portals, mobile apps, and other digital tools is also necessary to further enhance consumer engagement.

3. **Prioritize privacy and security.** Engaging consumers requires attention to providing them with details regarding how their information will be used and how they may exercise their rights to maintain their privacy. Policy must also address patient identification to protect the confidentiality, privacy, and security of a consumer's health information.

4. **Promote positive patient-provider relationships to enhance trust and engagement.** Policy must encourage providers to be transparent and communicate clearly with individuals and their caregivers to enable shared decision making and promote engagement in their health and healthcare. This includes fostering a collaborative care approach that is socially, ethnically, and culturally sensitive and designed with the input of the individual and/or their caregiver and the clinicians involved in their care.

5. **Address limited health literacy.** New approaches to enhancing consumer engagement must recognize the role of health literacy in improving consumers' ability to engage in their health and healthcare. Improving health literacy requires health information to be accurate, accessible, in plain-language, and actionable. It also includes promoting changes in the healthcare system that improve health information, communication and informed decision-making, and dissemination and use of evidence-based health literacy practices and interventions.

Background:

Consumer engagement involves actions taken by individuals to become better informed and more proactively involved in decision-making about their health and healthcare.[1] Studies suggest that individuals who engage in the management of their own health can achieve enhanced self-management of their conditions, higher participation in preventative and healthy practices, and improved outcomes.[2] Increasingly, digital health apps and patient portals are seen as powerful tools to engage individuals further in their health and healthcare. However, despite the fact that 90 percent of US health systems and providers offer online portal access to health information, only 30 percent of patients use a single portal feature.[3, 4] As consumers increasingly take advantage of digital tools outside of the clinical setting, certain challenges must be addressed.

Key Points:

Enhancing consumer engagement could result in a number of benefits, including:

- Increased empowerment of an individual (and their caregiver) in managing and understanding their health and healthcare;

- Enhanced communication and shared decision-making between the patient and clinician;

- Improved adherence to treatment plans, resulting in improved patient outcomes;

- Reduction in duplicative testing and diagnostic procedures;

- Improved accuracy and quality of a patient's health information, which may reduce risks to patient safety; and

- Lower overall healthcare costs for patients. [5, 6]

To realize the benefits associated with consumer engagement, a number of challenges must be addressed including:

- Limited awareness by patients and their caregivers concerning their health data, including how to access the information itself and how to correct errors;

- Limited adoption of digital health tools by individuals that can assist in the management of their health;

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[1] Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6996004/.
[2] Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4103232/.
[3] Available at: https://www.gao.gov/assets/gao-17-305.pdf.
[4] Available at: https://www.healthit.gov/sites/default/files/page/2019-05/Trends-in-Individuals-Access-Viewing-and-Use-of-Online-Medical-Records-and-Other-Technology-for-Health-Needs-2017-2018.pdf
[5] Available at: https://www.healthaffairs.org/do/10.1377/hpb20130214.898775/full/.
[6] Available at: https://healthpayerintelligence.com/news/patient-engagement-cuts-healthcare-spending-among-payers.

- Lack of access to digital health technologies due to limited broadband internet access;

- Lack of consumer trust in the privacy and security of health information that is maintained electronically;

- Limited health literacy to empower individuals to become engaged in their health and healthcare; and

- Inequities in the ability to leverage consumer-centric digital health tools on the basis of age, gender, race, ethnicity, language, geography, and income.

Current Situation:

Over the past decade, Congress and related federal agencies have increasingly sought to improve the ability of consumers to engage in their health and healthcare.

With the passage of the Affordable Care Act (ACA) in 2010, greater emphasis was placed on quality measurements and reporting that are "patient-centered"—examining patients' experiences of care satisfaction, engagement, perception, perspective, and/or patient-centeredness. Indeed, as healthcare has increasingly shifted from traditional fee-for-service models to value-based care models, greater emphasis has been placed on patient-centered care and strategies to improve consumer engagement. Other initiatives to enhance consumer engagement include the Promoting Interoperability Programs (formerly known as the Medicare and Medicaid EHR Incentive Programs), as part of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009. The HITECH Act seeks to provide patients and/or their caregiver with timely access to view, download, and transmit their health information.

The 21st Century Cures Act, signed into law in 2016, is viewed as a vehicle for building the digital infrastructure to support consumer engagement. A key aspect of the Cures Act Final Rule is the advancement of policies and technical standards that support third-party access to provider information systems through APIs at the direction of individuals. Similarly, the CMS Patient Access and Interoperability Final Rule supports patient access to plan information systems via an API for certain plans under Medicare. Both rules seek to enhance consumer engagement by improving the ability of consumers to access and share their health information, as well as provide them with the tools needed to further coordinate their healthcare.

Building a consumer-centric health system requires active engagement. Healthcare is a system wherein consumers and their caregivers must be empowered to make informed decisions based on provider and care team knowledge, as well as a consumer's own skills, abilities, principles, beliefs, and goals. Health information professionals play an important role in making health information available, actionable, easily accessible, and secure for healthcare consumers to make informed decisions.

As policymakers consider how to empower individuals to make decisions about their health and healthcare using trusted data from existing and emerging sources, AHIMA stands ready to share its expertise and experience as part of these conversations.