AHIMA Policy Statement: Individual Access to Health Information

AHIMA's Position:

AHIMA supports the right of individuals to access their accurate and complete health information in a timely manner. Health information (HI) professionals are the frontline professionals when individuals seek access to their health information, and they have the expertise and knowledge to inform and enhance public policy that seeks to improve individuals' access to their health information. To enhance individuals' access to their information, AHIMA believes that public policy that seeks to increase and automate individual access to health information must:

1. **Guarantee an individual's right to access his or her health information.** Policy must ensure that an individual has the right to access their health information regardless of where it is captured, stored, or exchanged.

2. **Address complex record request workflows and processes.** Policy must take into account existing workflows and processes and allow providers to streamline and make their workflows and processes more transparent for patients.

3. **Leverage application programming interfaces (APIs) and modern technical standards.** Policy must encourage adoption and implementation of APIs and standards, such as fast healthcare interoperability resources (FHIR) to foster the development of new applications ("apps") and services that facilitate an individual's seamless electronic access to and control of their health information. This includes the adoption of appropriate privacy and information security policies that ensure the privacy, confidentiality, and security of health information.

4. **Encourage a common interpretation of the designated record set.** Policy must encourage a consistent, standardized interpretation of the designated record set (DRS) across federal agencies to reduce discrepancies between institutions, providers, and other stakeholders in the access, exchange, and use of electronic health information (EHI). Such interpretation must expand over time to include additional data elements, as standards to support such elements become electronically available and capable of being deployed.

5. **Embrace the role of health information professionals.** New standards and approaches must recognize the expertise HI professionals have in facilitating and supporting individuals' access to their health information while adhering to state and federal requirements.

Background:

The ability of individuals and their caregivers to access, exchange, and use their health information is essential to managing their care. Today, nearly all hospitals provide patients with the ability to electronically view and download their health information.[1] However, despite these

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[1] Available at: https://www.healthit.gov/sites/default/files/page/2019-04/AHApatientengagement.pdf.

technological advances and the right of individuals to access their health information under the Health Insurance Portability and Accountability Act (HIPAA), individuals continue to struggle with accessing their health information in a manner that is seamless, timely, and electronic.

Enhancing individuals' access to their health information could yield significant benefits, including improved patient outcomes and enhanced patient safety. However, certain challenges must be addressed including cumbersome, opaque record request processes for individuals. As policymakers aim to address this important issue, AHIMA members have the expertise to offer insight.

Key Points:

Improving individuals' access to their health information could result in a number of benefits, including:

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

- Enhanced communication and shared decision-making between the individual (or caregiver) and the clinician about the individual's care plan;

- Improved patient outcomes and care quality, including better adherence to treatment;

- Reduction in duplicative testing and diagnostic procedures, while facilitating greater coordination of care between multiple providers; and

- Improved data quality and patient safety because the individual can electronically access and review the documentation and request amendments to their record.

To realize the benefits of individuals' access to their health information, certain challenges must be addressed including:

- **Cumbersome and decentralized processes for individuals requesting records.** Today, the record request process may involve logging into a patient portal or going online, downloading an authorization form, printing it, and then mailing or faxing it in. On other occasions it may involve travelling to the provider's location and filling out a form in person.

- **Lack of staff training and policies to facilitate individuals' access to their health information.** New approaches to improving individuals' access to their health information will require appropriate training and policies for patient-facing staff to reduce discrepancies in how requests are processed and fulfilled.

- **Lack of transparency during the record request process.** New approaches will require greater transparency regarding what information may be released, how it can be requested, the status of an individual's request, how long the process takes, whether additional information may be required to process the request, and the potential costs associated with the record request.

- **Manual workflows for HI professionals in fulfilling access requests.** New approaches must take into account practices intended to protect the confidentiality of an individual's health information in accordance with state or federal laws, while streamlining existing workflows to expedite an individual's request for his or her health information.

- **Lack of common interpretation of the designated record set.** Healthcare organizations have interpreted differently and applied inconsistently information that may be included in the DRS. This variation has not only led to discrepancies and confusion in the information provided to individuals during the medical records release process but could lead to confusion and inconsistent application of the definition of EHI under the ONC Cures Act Final Rule.[2]

- **Conditions that may limit individuals' access to their records** including geographic location, socio-demographic characteristics, internet access and use, and health conditions.

Current Situation:

Enhancing individuals' access to their health information has remained a focal point of policymakers since HIPAA first guaranteed this right when it was enacted in 1996. In 2009, this right was extended to include protected health information in electronic format under the Health Information Technology for Economic and Clinical Health (HITECH) Act. More recently, the 21st Century Cures Act of 2016 sought to improve nationwide interoperability, unleash innovation, and promote patient access to their electronic health information.

In December 2018, the HHS Office for Civil Rights (OCR) issued a request for information (RFI) seeking input from the public on how HIPAA could be modified to promote coordinated, value-based care. In particular, OCR sought feedback on whether modifications to the individual right of access would enhance care coordination and/or case management by enabling more timely transfer of protected health information between covered entities, or between covered entities and other healthcare providers.

In March 2020, the Office of the National Coordinator for Health IT (ONC) finalized its rule, which in part establishes secure, standards-based APIs to support individuals' access to their electronic health information. At the same time, the Centers for Medicare and Medicaid Services (CMS) in a separate final rule requires health plans in Medicare Advantage, Medicaid, the Children's Health Insurance Program (CHIP), and through the federal Exchanges to share claims data and other health information electronically via API with patients.

Compliance and implementation of the ONC and CMS rules are still under way. As healthcare transitions to these new standards, applications, platforms, and systems that seek to promote individuals' access and control of their electronic health information, AHIMA will advocate for individuals' seamless, electronic, and timely access to their accurate and complete health information.

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[2] Lye CT, Forman HP, Gao R, et al. Assessment of US Hospital Compliance With Regulations for Patients' Requests for Medical Records. *JAMA Netw Open.* 2018;1(6):e183014. doi:10.1001/jamanetworkopen.2018.3014