



Statement on Data Stewardship

Approved November 2008

AHIMA's Position

AHIMA calls for a nationwide effort among the healthcare and information technology industries, relevant government agencies, federal legislators, employers, and consumers to establish or identify and authorize a national health data stewardship entity (NHDSE). A NHDSE would ensure that rules for standards are established for uniform and consistent data* and that health information technology (HIT) would enable the exchange of health information.

This NHDSE would coordinate the bodies that support the life cycle and collection of data exchanged over electronic and other health information exchange (HIE) systems and the data stored in a variety of repositories or registries. Currently there is no universal authoritative source, law, or regulation that addresses and defines stakeholder rights and responsibilitiesⁱ and further ensures consistency and integrity in data collection (including common data definitions), distribution, and storage that allows for appropriate use of such data. There is a clear need in the healthcare industry to move toward a standard approach to developing the policies for a uniform and consistent method for health data integrity and exchange that transitions the concept of data ownership to that of access, use, and control of data.

Facts That Support the AHIMA Position

In our statement on *Quality Healthcare Data and Information*ⁱⁱ AHIMA raised the issue that healthcare data and its transformation should be a central concern for consumers, healthcare providers, the healthcare industry, and the government. We called for the development and implementation of standards for data content, data mapping, and documentation across the continuum within the healthcare industry. We believe the call for a stewardship entity in the 2007 request for information by the Agency for Healthcare Research and Quality (AHRQ) highlighted this need and suggested that there be a body or entity that can serve as a steward to establish principles and guidelines that ensure the uniform and consistent collection and exchange of data for quality measurement and other purposes.

Healthcare data collected during the course of patient care has the ability to support a variety of initiatives such as quality and performance measurement, patient safety initiatives, research, population health reporting, and administrative uses. HIT is transforming HIE at an increasing pace, thus enabling the collecting and sharing of clinical data for broader uses. As a result of this increasingly data-rich environment, information should be collected once and repurposed many times. As organizations adopt HIT and begin leveraging HIE, there are issues and concerns that must be addressed through data stewardship by developing uniform rules and guidelines:

- *Principles and Guidelines* – The principles for standardizing content of clinical documents and data definitions will greatly facilitate downstream data collection and aggregation, increase data quality, and give

* Sources of data are generally categorized as primary, secondary, or tertiary depending on their originality and proximity to the source of origin. Primary use of data is associated with the provision of patient care. Secondary use of data is associated with uses other than for direct patient care, but influences the environment in which patient care is provided. Tertiary use of data is that data that has been reformatted, compiled, or condensed beyond secondary use and may even lose some data integrity as it is processed further.

tremendous guidance to care delivery organizations, entities that build products based on data requirements, and electronic health record (EHR) system vendors.

- *Data Access, Use and Control* – In an increasing electronic environment, defining the guidelines to support this concept is critical for setting clear rules of engagement. Considering the rights of key stakeholders that must gain access and use healthcare data for various purposes is a key factor to ensure the privacy and security of a person’s healthcare data remains intact.

To succeed in its transition to an interoperable healthcare system, the U.S. must strive for the development of a consistent and uniform approach towards data standards and definitions and data that is leveraged for various uses. Achieving uniformity in structure, business policies and practices, and processing and delivery of data will reduce costs, streamline workflows, improve data compatibility, harmonize reporting requirement and reduce the reporting burden for healthcare organizations. These challenges have been highlighted by numerous organizations such as AHRQ, the American Medical Informatics Association (AMIA), and the National Committee on Vital and Health Statistics (NCVHS).

Recommendations

In order to move toward a nationwide goal of uniformity and consistency of data, AHIMA recommends the following:

- **Objective:** Identify and authorize a partnership of stakeholders that will establish national coordination in a transparent process with other entities to set uniform rules and the requirements for principles of data stewardship to achieve uniformity and consistency of data.
Action: Establish mechanisms for collaboration among representative groups to ensure support and utilize the strengths from all organizations.
- **Objective:** Increase transparency in the operation and management of data access, use, and control. Individuals should have the opportunity to be informed of all potential uses of their health data.
Action: Develop a framework for policy development to enable patients and consumers to meet their informational needs of transparency.
- **Objective:** Establish coordinated objectives at the federal, state, and local levels to improve data collection and use efficiencies and reduce the burden of cost.ⁱⁱⁱ
Action: In concert with all partners, identify and coordinate priorities, policies, and practices that are needed to develop and implement harmonized data reporting initiatives. As the need for data collection and reporting continue to increase, the administrative burden increases as well. These initiatives could benefit from improved coordination among the bodies through standards in reporting requirements.
- **Objective:** Enable an effective method for the standardized release of data to approved agencies and organizations as permitted by law.
Action: Develop and implement a data release framework for policy development to promote and advance the trusted release of data for other uses.

The American Health Information Management Association (AHIMA) is the premier association of health information management (HIM) professionals. AHIMA’s 52,000 members are dedicated to the effective management of personal health information needed to deliver quality health care to the public. Founded in 1928 to improve the quality of medical records, AHIMA is committed to advancing the HIM profession in an increasingly electronic and global environment through leadership in advocacy, education, certification, and lifelong learning.

www.ahima.org

ⁱ Burrington-Brown, Jill; Hjort, Beth; Washington, Lydia. "Health Data Access, Use, and Control." *Journal of AHIMA* 78, no.5 (May 2007): 63-66.

ⁱⁱ AHIMA Statement on Quality Healthcare Data and Information, 2007, <http://www.ahima.org/dc/positions/>

ⁱⁱⁱ Mon, Donald. "Development of a National Health Data Stewardship Entity: Response to Request for Information." 2007. Available at http://www.ahima.org/dc/documents/MicrosoftWord-AHIMANHDSERFIresponse-final_2007-08-03_.pdf.

Other References

American Medical Informatics Association and American Health Information Management Association Terminology and Classification Policy Task Force. "Healthcare Terminologies and Classifications: An Action Agenda for the United States," 2006.

National Committee on Vital and Health Statistics (NCVHS) Report to the Secretary of Health and Human Services. "Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data," December 2007.

AHIMA Statement on Confidentiality, Privacy and Security of Health Records, 2007. Available at <http://www.ahima.org/dc/positions/>