



September 28, 2007

Office of the National Coordinator for Health Information Technology
Attention: Personalized Healthcare Use Case
Mary Switzer Building
330 C Street, S.W. Suite 4080
Washington, DC 20201

Dear Personalized Healthcare Use Case Team:

The American Health Information Management Association (AHIMA) welcomes the opportunity to comment on the Office of the National Coordinator's Personalized Healthcare Prototype Use Case.

AHIMA is a not-for-profit professional association representing more than 51,000 health information management (HIM) professionals who work throughout the healthcare industry. AHIMA's HIM professionals are educated, trained, and certified to serve the healthcare industry and the public by collecting, managing, analyzing, reporting, and utilizing data which is vital for patient care, while making it accessible to healthcare providers and appropriate researchers when it is needed most.

AHIMA and its members participate in a variety of projects with other industry groups and Federal agencies related to the use of healthcare data for a variety of purposes including direct care, quality measurement, reimbursement, public health, patient safety, biosurveillance, and research.

Our comments focus on those areas of particular interest to our members. We believe the use case is a good foundation; however, we have outlined some recommendations as ONC continues to expand the document in preparation for the detailed use case.

Section 3.0 Use Case Stakeholders

- The stakeholders defined in the use case are appropriate; however, the HIM professionals responsible for managing, collecting, aggregating, and reporting on the genetic data should be added to the list of stakeholders. Serving as essential data stewards of a healthcare organization, they provide a critical link in the chain of health information management. HIM professionals have in-depth knowledge of the challenges associated with disparate data collection and reporting requirements and information workflow.





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- Part of the foundation of the data flow rests with system vendors who are responsible for the development and implementation of systems or applications that capture, aggregate, and submit the data for genetic information. It is not clear where the vendors fit into or are integrated into the overall collection and feedback flow. In order to align with these concepts, AHIMA recommends that the use case reflect system vendors.

Table 1: Recommended Additions to Section 3.0 Use Case Stakeholders

Stakeholder	Working Definition
Data Management Professionals	Those coordinating the electronic and manual data collection, validation, integration and reporting of healthcare data to support genetic data collection, including professionals in the field of health information management, information technology, informatics, etc.
System Vendors	Organizations which are responsible for the implementation of the software development lifecycle (SDLC) for such applications that will support the capture and management of genetic information.

Section 4.0 Issues and Obstacles

Confidentiality, Privacy, Security, and Data Access – The document does not address the unique legal issues regarding genomic data. There are state laws that are specific to the handling of genomic data, and this is just not security of the data. AHIMA recommends the document reflect the issues and obstacles that individuals will face while trying to exchange data among different states.

Confidentiality, Privacy, Security, and Data Access – There is no indication within the document if genetic/genomic information is treated similarly as HIV/AIDS, mental health, or drug related information. AHIMA recommends the document reflect whether genetic information must undergo similar protections or more restrictive measures to protect the data and comply with state regulations.

Genetic/Genomic Data Interoperability – Currently there is an explosion in laboratory testing in the industry, and to indicate technology standards are developing in an "ad hoc" manner does not recognize the fact that development of technology - and testing - is essentially the number one push of those supporting and conducting the research. The cost of sequencing an individual's genome is being pushed by industry to be reduced to approximately \$1,000.

This reduction in cost for the consumer will have a direct impact on the increase in technological advances. AHIMA recommends the case study needs to at least recognize that keeping pace with technological advances will be a significant obstacle, which may have to be addressed some way other than to require standardization.

Section 6.0 Candidate Workflows

6.1 Clinical Assessment – The first paragraph discusses the need to gather past medical history and other information in support of developing a care plan. AHIMA recommends the concept of capturing the information in a standard way also be identified, in addition to the concept of an interoperable form that has been articulated in the paragraph.



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6.1 Clinical Assessment – It is not clear to the reader whether the data management professionals are included in the category of “clinicians”. Data management professionals will be and are critical to the assembly, aggregation, validation and evaluation of the data that has been collected from the patient and his/her family to construct a complete clinical assessment. It is anticipated that these professionals will be charged with conducting the activities as described through the collection of data from hospital EHRs, ambulatory EHRs, family member EHRs and other sources. AHIMA recommends that there be consideration given to the data management professionals who will be charged with conducting the data collection activities to support the development of a care plan as described in Section 6.1.

If AHIMA can provide any further information, or if there are any questions regarding this letter and its recommendations, please contact Allison Viola, MBA, RHIA, AHIMA’s director of federal relations at (202) 659-9440 or allison.viola@ahima.org, or me at (202) 659-9440 or dan.rode@ahima.org.

Sincerely,



Dan Rode, MBA, FHFMA
Vice President, Policy and Government Relations

cc: Allison Viola, MBA, RHIA