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October 16, 2009

Department of Health and Human Services
Office of the National Coordinator for Health Information Technology
Requirements Document Team
Mary Switzer Building
330 C Street, S.W. Suite 1100
Washington, DC 20201

Attention: Office of Interoperability and Standards (OIS) Public Comment on the Consumer Preferences Draft Requirements Document

The American Health Information Management Association (AHIMA) welcomes the opportunity to comment on the U.S. Department of Health and Human Services (HHS) Office of the National Coordinator for Health Information Technology's (ONC) request for comments on the Consumer Preferences Draft Requirements Document dated October 5, 2009.

AHIMA has actively participated in industry initiatives to accelerate the adoption of standards-based electronic health records (EHRs) and personal health records (PHRs). In addition to leading or participating in many standards development efforts, we host www.myPHR.com, a consumer-oriented website for personal health information. We also have hundreds of members who serve as consumer education coordinators around the country. These individuals provide consumer education in town halls, patient education sessions, and the like as part of our public information campaign.

AHIMA has also been deeply involved in the establishment of health information exchange (HIE), health information organizations (HIOs) and a nationwide health information network (NHIN). Among the many health information management principles, we have advocated strongly for privacy, confidentiality and security, of which consumer preferences plays a large part.

AHIMA is a not-for-profit professional association representing more than 54,000 health information management (HIM) professionals who work throughout the healthcare industry. AHIMA's HIM professionals are educated, 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. The AHIMA Foundation has received numerous grants and contracts to validate the mapping between terminologies and classification systems, study sustainability, governance, and privacy issues related to HIE, and recommend future industry action to streamlining data collection issues surrounding secondary data use.

General Reaction and Recommendations

Correctly Framed Around Access, Use, and Control

AHIMA strongly supports consumer rights for determining who can access and use their health information. We commend ONC for framing consumer preferences, and the process for creating and managing such preferences, in the context of *access, use and control*, rather than "who owns the data"—a phrase that should be discontinued in the industry.

Highlight Technical Limitations (Current State of Technology)

The October 5, 2009 Consumer Preferences Draft Requirements Document does an excellent job in delineating the project's scope, as well as the issues and policy implications (section 4.0) that must still be resolved. In addition, the document explains very clearly the health information exchange process to create, update, communicate, and reconcile consumer preferences (sections 6.0 and 7.0), along with data set considerations (section 9.0). We recommend that another section be added that outlines the technical limitations the industry now faces and must be overcome before consumer preferences can be truly implemented with the granularity mentioned in the document.

If written in the way section 4.0 discusses "Issues and Policy Implications," this added section would recognize the following:

- That the technical capability of some health information technologies to support consumer preferences does not now exist, may not exist for some time, and must be developed over time
- That the consumer preferences initiative could be another driver to develop or enhance those technical capabilities to the point where HIT could support consumer preferences in a granular fashion
- That the technical limitations must be overcome, and such limitations will be addressed in future requirements documents and initiatives

This added section might address the technical limitations outlined below, among others.

- First the need for EHR and PHR system standards. The standards available today focus largely on the exchange of health information between entities and their respective systems. They focus less so on EHR and PHR system functionality which must implement the consumer preferences—masking portions of the record; the audit trail, metadata, or journaling capabilities to document that a consumer preference has been executed; and extracting subsets of data from an electronic clinical document *without losing context*, are but a few examples. This stands to reason since most of the standards are interoperability, rather than EHR system, standards. Moreover, the HL7, ISO, and CEN EHR and PHR system and architecture standards that do exist need to strengthen their functionality requirements to implement consumer preferences. From a policy perspective then, there may need to be some public policy or programs that help drive the

enhancement of current EHR and PHR system standards in this area, in addition to interoperability standards.

- Then the need for EHR and PHR systems to provide functionality based on those standards. Not all EHR and PHR systems on the market today have the capability to abide by consumer preferences in a granular fashion. From a programmatic standpoint, a number of informatics research studies may be needed in this area to help inform policy—e.g., the level of contextual loss and its affect on clinical decisions when subsets of data are extracted from a clinical document.
- Only then can consumer preferences be executed by EHR and PHR systems. Though some of the necessary standards are in place, few PHR and EHR systems on the market today are exchanging health information between each other in accordance with consumer preferences largely because both systems lack the functionality to execute the required process. It is important to couple this technical limitation with the policy implications outlined in section 4.0 because even if policy implications were resolved (e.g., the PHR as a trusted source of information), the health information exchange required in this document would still not occur if neither EHR nor PHR systems were able to abide by consumer preferences in a granular fashion.
- The technology to manage multiple consent directives located in multiple places is not yet in place at many of the end nodes of the HIE process—EHR and PHR systems as previously mentioned, but at the systems of health information organizations (HIOs) who wish to provide consent directory services to HIO participants, as well. Policy and programmatic initiatives need to be put in place to drive the development of such technology.

This section should also add a word caution: All future requirements, standards, and resulting programs must take into account the administrative complexity involved. For example, as some of the published articles in the Journal of the AHIMA have pointed out, sequestering data by type of data is not only a consumer preference, it has implications for the facility's ability to maintain a health record for legal, business, and disclosure purposes. Reasonableness must be a watchword.

Distinctions between Consent for the Disclosure of Health Information and Authorization for the Release of Information Must Be Clarified

In our studies of HIE and HIOs, we have found that there is still confusion in the industry regarding the differences between consent for the disclosure of health information (for TPO) and authorization for the release of information. Confusion between these two sets of *permissions* manifests itself in some facility-level and statewide consent/authorization forms, where these forms intend to capture the consumer's preferences, but in fact may not meet the requirements for either or both the consent or authorization.

AHIMA strongly recommends that such a distinction is specifically stated in:

- Event 6.3 Discussion Regarding Consumer Preference Choices because consumers need to be educated on the differences between the two so that they can more accurately decide and express their preferences (Event 6.5), which, in turn, are accurately captured

when the preferences are created (Event 6.7). Event 6.3 can still be out of scope for this document. However, it is important to state this distinction in Event 6.3 so that all stakeholders can see the linkage between consumer education/discussion and the electronic creation of consumer preferences.

- Event 6.7 Create Preference because the requirements for both consent and authorization must be accounted for when standards are developed
- Event 6.9 Audit and Reporting of the Preference and/or Associated Information because healthcare entities must be able to accurately implement consents and authorizations within consumer preferences, which, in turn, enables them to accurately audit and report the information to the consumer

We would also like to point out that the requirements focus primarily on the consumer and health information technology. The requirements should also emphasize that much provider education is needed. Many of these issues above can be deflected if the provider is capable of offering clear guidance and explanations about process and policy.

Lastly, as HHS and its agencies and offices work to educate the public, the public should be informed of the transition to the electronic environment that is underway and the work being done by providers, government and the industry, so that the public understands that the nation is moving smoothly towards "the preferred future."

Address Policy Implications As Quickly as Possible to Facilitate Standards Development

AHIMA understands that this is a requirements document to further standards development. Nevertheless, we urge that the policy implications outlined in section 4.0 be addressed as quickly as possible to provide much needed direction for standards development efforts. In addition to the issues in section 4.0, the ability for policy direction to foster standards development is also indicated for section 9.0 Data Set Considerations.

It will be difficult to operationalize section 9.2 Data Classification without further clarity in policy. For example, mental health medications are extremely important from a patient safety perspective. It would impact patient safety to allow a consumer to suppress this information from treating providers. Policy in this area must consider areas related to access, in addition to consumer preferences. For example, emphasis must be placed on better access restrictions to ensure that only those with a need to know were accessing the record. In short, policy clarification in this area would expedite standards development in this area.

Specific Recommendations

Page 25, Code 6.14 Event: Stop Flow of Information

Code 6.14.1 states that, if the consumer decides to Opt Out of sharing/exchanging their EHR, the primary receiving organization "must not allow for or stop the flow of this information to exchanges and/or to other healthcare providers." We suggest reversing the verb phrase to read,

"must stop, or not allow for, the flow of information…" as it might be read as "must NOT STOP the flow of information" as it is currently written. More importantly, we recommend that the role of the primary receiving organization should be clarified, or further enhanced. The requirement stops at the primary organization's need to cease the flow of information to exchanges and/or healthcare providers. In fact, there may be instances where information has inadvertently flowed even after the consumer preference has been created. The requirement should also account for the actions that the primary organization needs to take in these instances.

Page 29, Code 6.25.2 Action: Reconciliation of Consumer Preferences Between Entities

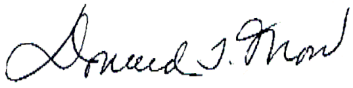
We urge that this action should stay within scope. It is germane to protecting the privacy of health information. Though it may be addressed in a future requirements document, we recommend that this action be in scope sooner rather than later, as there is much work to do in this area.

Page 36-37, Section 9.2 Data Classification

We suggest that certain Sexual and Reproductive information be added as 1.a.ix.

Thank you for the opportunity to provide our input. If AHIMA can provide any further information or if there are any questions regarding this letter and its recommendations, please contact me at (708) 250-4374 or Donald.Mon@ahima.org. You may also contact AHIMA's vice president, policy and government relations, Dan Rode, at (202) 659-9440 or Dan.Rode@ahima.org. If we can be of further assistance to you as you continue to explore consumer preferences, we would welcome the opportunity to provide our support.

Sincerely,



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cc: Dan Rode, MBA, CHPS, FHFMA
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