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June 30, 2010

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RE: Comments on the HIT Standards Committee Recommendations Regarding Vocabularies

Gentlemen:

The purpose of this letter is to convey the comments of the American Health Information Management Association (AHIMA) on the vocabulary recommendations made to Dr. Blumenthal in your letter of April 28, 2010. The June 8, 2010 *Federal Register* (75FR32472) requested that comments on these recommendations be delivered in the HIT Standards Committee meeting today. In addition to verbal comments in the June 30, 2010 meeting, AHIMA, with this letter, is providing additional written information in support to our brief verbal comments.

## **AHIMA**

AHIMA is a nonprofit professional association made up of over 57,000 of health information management professionals. For many decades AHIMA and many of its members have been involved in the accurate use of terminologies and classifications to further the utility and integrity of health information. To this end AHIMA volunteers and staff are actively engaged in a number of national and international standards bodies' initiatives looking at the improved use of vocabulary in pursuit of data interoperability and integrity, including active participation in:

- World Health Organization (WHO) – ICD-10 and ICD-11,

- International Health Terminology Standards Development Organization (IHTSDO) – SNOMED,
- International Organization for Standardization (ISO),
- Health Level 7 (HL7),
- International Federation of Health Records Organizations (IFHRO), and
- International Medical Informatics Association (IMIA).

In the United States AHIMA volunteers and staff are actively involved with:

- Cooperating Parties for ICD,
- ICD-9-CM Coordination and Maintenance Committee,
- ICD Coding Clinic Editorial Advisory Body (AHA),
- CPT Editorial Advisory Body (AMA), and the
- Health Care Procedure Coding System (HCPCS) Coding Clinic Editorial Advisory Body (AHA).

AHIMA volunteers and staff have also been closely involved in a variety of mapping projects with the National Library of Medicine (NLM), the Centers for Medicare and Medicaid Services (CMS), and the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC).

In recent years, AHIMA has been proud to work with organizations such as the National Quality Forum (NQF), the Clinical Data Interchange Standards Consortium (CDISC), and the Agency for Healthcare Research and Quality (AHRQ) to pursue not only data interoperability and integrity, but also support the “collect once, use many” concept to ensure that vocabulary and data requirements associated with electronic health records (EHRs) are used in such a way to appropriately leverage clinical data from the health record and achieve simplification and consistency in the secondary uses of data from the EHR and other electronic health data sources.

In 2006, AHIMA volunteers and staff joined with the American Medical Informatics Association (AMIA) to form an expert task force on terminology and classification policy chaired by Keith E. Campbell, MD, PhD, Chief Technology Officer, Informatics, Inc., and Assistant Clinical Professor, Department of Medical Informatics and Clinical Epidemiology, Oregon Health and Science University. The task force took a year to complete an in-depth study of this issue and produced a report *Healthcare Terminologies and Classifications: An Action Agenda for the United States*, which can be found at [www.ahima.org/infocenter/whitepapers](http://www.ahima.org/infocenter/whitepapers). Additional information on this same topic can be found at <http://www.ahima.org/resources/infocenter/clinicalterms.aspx>.

With this background and experience, AHIMA extends its recognition and appreciation to the HIT Standards Committee for finally highlighting the need for and governance of terminologies and classifications in the US. The AMIA/AHIMA report suggested an in-depth study, and the committee and its task force have now initiated this process. AHIMA and AMIA stand ready to

support any work that will further this country's attention to and governance of healthcare vocabularies.

## **Comments and Recommendations on the HIT Standards Committee Recommendations on Vocabulary**

In general, AHIMA agrees with the recommendations that have been made; however, **these recommendations should not be accepted as they currently stand** because if the US is to gain oversight of its healthcare vocabularies and align itself with other countries, these recommendations will fall short of achieving these goals due to their unilaterally focusing only on Meaningful Use.

### **Federal Agency & Oversight**

AHIMA agrees that a single federal program office or agency should be responsible for ensuring the appropriate creation, maintenance, dissemination and accessibility of all controlled vocabularies, vocabulary value sets and subsets designated for use through the HIT Policy Committee or similar industry authority. AHIMA understands the need to address those relating to Meaningful Use, **it would be very short-sighted not to include other needed controlled vocabularies, et al.**

In addition to a designated federal program office or agency, AHIMA, **advocates that a FACA advisory panel of healthcare data stakeholders be established to work with the selected office or agency in its new oversight role.**

### **Rational**

For true semantic interoperability and data integrity as well as patient safety, oversight is required across all of the many terminologies and classifications that are needed as well as the related value sets and subsets that will potentially be used in this country. In this regard, establishment of a centralized oversight authority should accomplish the following goals.

- Ensure consistency in processes, system coordination, responsiveness to end user (vendors and those who use their systems), and the availability of robust and valid terminology linkages (e.g. maps).
- Produce uniform regulations, rules, and guidelines for standardized terminology and up-to-date classification systems across the country.
- Ensure that the organizations authorized to develop, deploy, and maintain such regulations and guidelines assume ongoing responsibility to publish and disseminate the standards or guidelines in a manner that is generally understood, provide clarity as required, and generate timely responses to all requests for clarification.

At the same time as the oversight addresses the development and maintenance of terminologies and classifications et al., in line with HIPAA, there must be some industry enforcement to maintain uniformity and consistency of use; since the lack of such consistency has been a problem in administrative transactions that we do not want to see occur in clinical data exchange.

Patently, Meaningful Use has been the primary focus of both HIT Committees, and we understand that the vocabulary standards associated with the MU function might require some priority in the attention of an oversight agency. **AHIMA believes that the ONC and the HIT Committees' charges from Congress are far more reaching than just the Meaningful Use requirements. Rather, these charges relate to the use of a fully functional EHR as well as interoperable health information exchange (HIE) and the ability to use health information for a variety of secondary uses such as population health, patient safety, and healthcare quality.** In our international work, we have witnessed the value of such governance and coordination displayed. The U.S. cannot continue to have a laissez-faire approach to managing vocabularies and hope to achieve semantic interoperability and improved population health outcomes.

In addition to the designated federal office or agency – central authority – a **public/private advisory committee made up of health data experts employed under FACA rules is crucial.** Such a committee must work directly with the agency or office, and include experts from both the public and private sectors made up of stakeholder and end users. Vocabularies, especially terminologies and classifications, are not easy to understand nor are they the same as functional/transaction standards. This lack of understanding is one of the reasons it has taken the healthcare industry so long to comprehend the role vocabularies must play in administrative and clinical data exchange. Vocabularies are interactive; so linkages, such as mapping must exist between and among various terminologies and classifications. While it is appropriate for ONC and the HIT Committees to oversee which vocabularies, value sets and subsets must be harmonized with one or more transactions, it must be this central authority and its advisory committee that ensure the necessary interaction of vocabularies.

In addition to the central authority's oversight on vocabularies, **the governance process must also provide oversight for the development of the reference value sets, tool requirements, and reference standard semantic repository, as well as mapping key vocabulary on an ongoing basis.**

### **Processes, Activities, and Funding**

The HIT Standards Committee recommends the processes and activities should include:

- Identifying what vocabularies and code sets are needed,
- Determining who will be responsible for producing and maintaining each set,
- Determining how often updates will be made available, and
- Establishing standard formats for production and dissemination of vocabularies.

Further, the HIT Standards Committee suggests that the entity “should ensure funding as needed to establish, support and maintain these activities, and to make Meaningful Use vocabularies, value sets and subsets available to users of EHR technology for US-wide use at no cost.”

It is not typically a vocabulary governance body’s role to unilaterally determine which terminology, classification or value set(s) should be used for a functional transaction. This is a role of the transaction standards harmonization process in consultation with the vocabulary governance body. On the other hand, the vocabulary governance entity must select the candidate vocabularies so that it can ensure consistency in process, systems coordination, release timing, and the availability of robust, valid maps on a scheduled basis to support EHRs and EHR systems and oversee the appropriate development of implementation guides. This process should provide for uniform rules, and guideline for an up-to-date classification system and value sets used nationwide. It also means the vocabulary governance entity should also identify and prioritize vocabularies, value sets and subsets. To do all of this the governance body and its parent federal agency/office must have sufficient authority to coordinate efforts among the various agencies and stakeholders to ensure congruency and collaboration, not competition.

Many of our US vocabulary standards are international standards. They are the backbone of vocabulary use in research and population health. We believe the governance entity should be the official body to designate official US representation as needed with the international bodies related to terminologies and classifications acknowledging the current role of the CDC-NCHS. Also, the US must be open to dealing with timetables and changes in the various international classification and terminology standards organization and take an active part in supporting and participating in these international activities.

Specifically, since the US is a charter member of the IHTSDO we believe the central authority would best serve in such a role. The oversight entity would define the governance structure for the US role and would oversee the SNOMED<sup>®</sup> national release center in the US where questions regarding the process for requesting new terms or establishing regional extension would be resolved. This fits with previous US actions with regard to SNOMED.

AHIMA and AMIA noted in the 2007 recommendations that an oversight entity would require funding for a variety of supporting roles including the creation of the governance model. Since then with the development of value sets and subset there is also a need for the development and maintenance of a centralized reference standard semantic repository to house value sets and subsets.

The oversight entity’s supporting functions should also include ongoing monitoring, research, and evaluation results to address:

- Quality of encoded data,
- Quality of encoding systems,

- Value of encoding data,
- Patient safety issues pertaining to encoded data,
- Reproducibility of encoded data,
- Quality reproducibility value, and patient safety pertaining to mapping and to different versions of encoded data in the same system,
- Development and recommendations of standards for coded data (that is for computer – assisted coding),
- Biosurveillance, and
- Use of health informatics data to improve public health practices as well as medical readiness.

When AMIA and AHIMA made our initial recommendations funding was of concern, however, legislation such as HITECH and programs such as Meaningful Use were not in place. Today, there are similar governing bodies that function as we have suggested in other countries. We recommended studying these bodies to determine how they have handled funding. Obviously, there are expectations of federal funding for the standards related to Meaningful Use and perhaps others. Likewise, the federal government must contribute to the work in vocabularies and value sets, since they will serve to facilitate quality measurement review, research, and population activities spurred on by government requirements. However, other fees might have to be established as well and the U.S. is not the first country to take this approach.

### **Candidate Offices/Agencies, FACA Advisors, and Funding**

We agree with the HIT Standards Committee that a single federal office or agency needs to be selected. Given the unique nature of terminologies, classifications, and mapping, we believe that the National Institute of Health's (NIH's) National Library of Medicine (NLM) is the best candidate. The NLM has experience in the arena of terminologies, classifications, and mapping among such standards. The NLM is also the US liaison to IHTSDO and works closely with the NCHS. In recent history, the NLM has supported the work of the National Committee on Vital and Health Statistics (NCVHS) as well as the HIT Committees, workgroups, and task forces. In addition, it is our understanding that the National Cancer Institute (NCI), also under the NIH, has received funding for development of a semantic repository that might serve for the repository discussed.

The NLM would require specific funding and staff to take on all the necessary roles being suggested. Certainly, additional staffing is in order to accommodate the immediate needs of Meaningful Use, which will include those with expertise in terminologies and classifications, value sets and subsets.

### **Establishing an Authoritative Vocabulary Infrastructure**

**Although AHIMA agrees with the need to establish an authoritative infrastructure for development, maintenance and dissemination of standard value sets and subsets, we do not**

**believe that these should focus on only those related to Meaningful Use.** Such an infrastructure should be established for all health care vocabulary terminologies and classifications as well as the value sets and subsets.

AHIMA agrees with the need for a central semantic repository. There are a variety of government-funded initiatives producing repositories and ontology mapping tools and **the Secretary should call for these Health and Human Services Department (HHS) agencies to work together toward a single harmonized repository that has the ability to reference other sources – a federated model – rather than the status quo.** The US needs a reference standards semantic repository that can harmonize common elements and value sets and support the long-term requirements for meaningful use of EHRs. As noted, the NIH/NCI is beginning to establish a repository that might fit this purpose. We understand the need to prioritize Meaningful Use requirements, but the **semantic repository infrastructures should be created in a manner that supports broader use.**

AHIMA agrees that the infrastructure for development and maintenance of terminologies and standard value sets and subsets should be a transparent and open process. We believe that the oversight body or central authority must commit to the adoption of sound principles for operation of a terminology and classification standards development organizations.

Primary among the principles should be an infrastructure for development and maintenance that includes within the developers a transparent process with policies and procedures that can support open standards and ensure that those who build content are engaged in any consolidation or integration of their products. This commitment would also include:

- Simplified coding guidelines and reimbursement policies/regulations so that mapping rules can be more readily developed and maintained.
- Use case maps from reference terminology to administrative code sets (for instance, SNOMED CT® to ICD-9-CM and ICD-10-CM and PCS, SNOMED-CT to CPT, and LOINC to CPT) that are validated with an easy, no-cost distribution mechanism.
- Educational resources to train healthcare professionals on the use and interpretation of coded data and its relationship with clinical terminologies, classification systems, and mapping technologies. Since much of this relationship is still misunderstood and somewhat difficult to fully grasp, educational resources that clearly and succinctly describe the mapping process and the importance of reference terminologies and classification systems are truly needed.

Obviously, the establishment of an oversight body is not easy and must deal with more detail than even laid out above. We commend the HIT Standards Committee on taking this initial step in pointing out this need and volunteer our Association experts to work with ONC and other HHS offices and agencies to lend our expertise to the tasks at hand. We also want to remind you of the resources mentioned above for use by an industry or government group.

Again we thank you for this opportunity to comment on these recommendations and for your consideration. If I or any of our AHIMA staff can respond to any questions or need for

clarification, please let me know. I can be reached at the above number or at [dan.rode@ahima.org](mailto:dan.rode@ahima.org). In my absence, please contact Sue Bowman, RHIA, AHIMA's director of coding and compliance at (312) 233-1115 or [sue.bowman@ahima.org](mailto:sue.bowman@ahima.org) or Crystal Kallem, RHIA, CPHQ, AHIMA's director of practice leadership at (312) 233-1537 or [crystal.kallem@ahima.org](mailto:crystal.kallem@ahima.org).

Sincerely,

A handwritten signature in blue ink that reads "Dan Rode". The signature is written in a cursive style with a large initial "D" and a long, sweeping underline.

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

Cc: Betsy Humphreys, NLM Deputy Director  
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