

Comments for HHS Vocabulary Taskforce

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Introduction

The Indian Health Service (IHS) appreciates the invitation from the Office of the National Coordinator and the Department of Health and Human Services (HHS) Vocabulary Taskforce to participate and comment on the question of vocabulary and value set management.

First, we will provide background information on the IHS Information Technology (IT) infrastructure as it relates to the work of the HHS Vocabulary Taskforce. Second, our remarks focus on the meaningful use criterion. We believe that collaboration among federal agencies is essential to aid in the ease of standards development and adoption to provide safe, quality care to our beneficiaries. And last, we would like to share our Agency profile.

IHS Information Technology Infrastructure

The Resource and Patient Management System (RPMS) is the IHS enterprise health information system. The RPMS consists of more than 60 software applications and is used at approximately 400 IHS, tribal, and urban locations. Approximately 95 percent of the IHS service population receives care at facilities using RPMS.

The RPMS evolved alongside the Veteran's Health Administration's (VHA) VistA solution, and there are many similarities between the two health information systems. Many RPMS applications originated in VistA and have been adapted for use in IHS. However, many other RPMS applications were developed specifically for the Indian health care environment. The Patient Care Component (PCC) is the core data repository for encounter data in IHS.

Local RPMS data are used to evaluate clinical quality as well as population and public health status. Aggregate data is used to report on clinical performance measures to Congress. The IHS also maintains a centralized database of patient encounter and administrative data for statistical purposes, and for public health and epidemiological analysis. The IHS telecommunications infrastructure connects IHS, tribal and urban facilities and links to the HHS telecommunications

network. The IHS participates in HHS enterprise-wide initiatives to improve IT infrastructure and works with the VHA and other federal partners to develop software and share technology resources. These collaborations are reflected in the IHS IT architecture and 5-year IT strategic plan.

Current IHS Terminology Management

Formal terminology management within the IHS is evolving. A number of well-known standard code sets, such as International Statistical Classification of Diseases and Related Health Problems (ICD)-9, Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV, Current Procedural Terminology (CPT), and Healthcare Common Procedure Coding System (HCPCS), have been used for many years and are integrated into RPMS. Other Agency-specific code sets have been developed for specific needs and reside in the IHS Standard Code Book. Depending on the domain, these typically fall under the ownership of the IHS Division of Program Statistics or the Health Information Management program; their inclusion and updating within the IHS health information system are managed by the RPMS Database Administrator. Adoption and/or creation of terminologies have tended to be somewhat *ad hoc* in response to specific business needs; available terminology standards have been researched and incorporated where possible.

However, the imperatives of interoperability and Meaningful Use clearly require that the standardization and management of terminology sets be formalized and matured, both within IHS and between the federal and private partners. IHS has begun the engagement of terminology asset management best practices. The adoption and rollout, for example, of Logical Observation Identifiers Names and Codes (LOINC), Unified Code for Units of Measure (UCUM), Systematized Nomenclature of Medicine--Clinical Terms (SNOMED-CT), RxNorm, and especially ICD-10, are multi-year projects that clearly must be repeated but have no defined resources within the IHS. IHS must rely on its larger federal partners to clearly define and maintain the terminologies and value sets that will be part of future interoperability standards. We can contribute our expertise but respectfully request that a centralized management entity be created as outlined in our responses to the panel questions below.

Responses to Panel Questions

1. Who should determine subsets and/or value sets that are needed?

A United States central authority needs to be established. The National Library of Medicine would be a logical location for such an effort. The entity should be as independent as possible and insulated from both political and vendor influences. Working with such bodies as Health Level (HL) 7, X12, Health Information Technology Standards Panel (HITSP) (or

its successor), the National Health Information Network (NHIN) and the National Institutes of Health, content should be developed by a central authority. A process for requests, change management and versioning requirements also needs to be developed.

2. *Who should review and approve subsets and/or value sets?*

The decision on what additional value sets are needed must include input from multiple clinical end users as well as terminology experts. For instance, subsets and value sets need to be expanded to nontraditional determinants of health.

Domain experts for clinical value sets must be the final arbiter of content. A venue such as the HL7 Clinical Information Interoperability Council should be considered (http://btc.hl7.org/index.php?title=Main_Page) for such an activity.

3. *How should subsets and/or value sets be described, i.e., what is the minimum set of metadata needed?*

Minimum data sets should reflect the needs of clinical, research, public and population health needs. If we use this domain, there are many gaps in this definition of a minimum data set. Value set metadata should be based upon ISO11179. Review of this data set indicates that extensions to this metadata will be necessary to meet all of our needs.

4. *In what format(s) and via what mechanisms should subsets and/or value sets be distributed?*

I recommend collaborating on the development and use of the Common Terminology Services 2 (CTS2) specification being developed by HL7 and the Object Management Group (OMG). The method and format of distribution need to be defined. Downloads must be centralized and able to be accessed 24/7 through a Web service.

5. *How and how frequently should subsets and/or value sets be updated, and how should updates be coordinated?*

Updates will be impacted by the sponsoring organizations' schedules and the domain in which the value set is based. At a minimum, the updates should be published twice a year. For those value sets that cover pharmacy or other domains that are subject to frequent change, the updates will be more frequent. Larger terminologies such as SNOMED-CT and LOINC should be annually, unless there is additional need for more frequent updates.

Frequent updates impact our HIT system as well as our clinical delivery system. The impact of frequency at the application and delivery point of care should not be underestimated. Minimizing updates is essential to decreasing secondary disruption.

6. *What support services would promote and facilitate their use?*

A fairly extensive infrastructure would be needed to make the value sets accurate and accessible. I recommend examining and adopting best practices from organizations such as Canada Infoway, the UK National Health Service or the Australian National eHealth Transition Authority (NEHTA).

At a minimum:

- a. Detailed implementation guidance and support ranging from the basics of what is a vocabulary to the use of terminologies within electronic health records and detailed implementation and conformance guidance.
- b. Create a library of common data elements with their vocabulary bindings.
- c. Develop additional open source tools that can support rapid deployment, semantic interoperability and cross walks

7. *What best practices/lessons learned have you learned, or what problems have you learned to avoid, regarding vocabulary subset and value set creation, maintenance, dissemination, and support services?*

- a. There is significant difficulty and cost encountered in integrating and maintaining new vocabulary data sets. The impacts of frequent updates and/or changes are onerous within a distributed environment. The IHS has tried to limit this disruption through limitations of upgrades and changes.
- b. Our system includes updates that are relevant to our work process and delivery model. Multiple data standards that are of dubious benefit either at the point of care or in the population health arena are not adopted within our system. The national HIT work must recognize the limits that confront fiscally constrained clinical care systems. In these systems, vocabulary standards dissemination and support are a 'second thought'. However, an environmental survey that could help establish best practices would be helpful and should include the review and documentation of both private and public sectors (e.g. the Veterans Administration and major vendors with the US and other countries; including feedback from terminology vendors such as Apelon, and Health Language).

8. *Do you have other advice or comments on convenience subsets and/or value sets and their relationship to meaningful use?*

While the HITSP data dictionary and other documentation, as well as United States Health Information Knowledge Base (USHIK) HITSP Web portal, are good first steps, the provisioning of value sets for meaningful use must be more robust and automated. The value sets must be easy to use and understand, easy to integrate, and accompanied by cross walks from old data sets to new sets as much as possible.

Example: In preparing the IHS to meet Meaningful Use criteria for such commonly used value sets such as preferred language, the process was more of a hunt than a seamless

identification of a resource. The IHS team was faced with conflicting standards within federal agencies (e.g. Health Resources and Services Administration (HRSA) requiring the use of the Uniform Hospital Discharge Summary data point), referral to the International Organization for Standardization (ISO), Bureau of the Census, the Centers for Disease Control and Prevention (CDC) Public Health Information Network (PHIN) Vocabulary Access and Distribution System (VADS) system, as well as employment of the United States Health Information Knowledgebase (USHIK) HITSP portal. Which is the designated value set?

The integration of new data sets into an electronic health record is at best a burden for communities and health care systems with limited resources. Promulgation and acceptance of data sets must include a return on investment scenario for the electronic health record vendor as well as the end user. If standards are developed that cannot easily be integrated or cross-walked in a passive way, then their adoption will be delayed or possibly not attempted. If Meaningful Use standards continue to be accelerated with no assessment of the difficulty to the developer and end user, they will not be integrated.

We also urge the development and/or inclusion of vocabulary sets that address behavioral health as well as non-traditional determinants of health including variables such as homelessness, poverty, and other barriers to access, adverse childhood events, and so forth.

9. *What must the federal government do or not do with regard to the above, and/or what role should the federal government play?*

The federal government must provide a central authority by which the value sets are created and housed. This entity is key to the management of the terminology and the interoperability specifications needed to support the continued evolution of interoperable electronic health record systems.

We are a federal agency that reflects what the private sector and others are encountering in the process of identifying the value sets and integrating the standards. There must be a clearly articulated process, and supporting infrastructure in place to meet design, implementation and conformance.

In summary, the IHS encourages the following be the immediate focus of the vocabulary taskforce:

- Enlist federal agencies in the development and subsequent support of terminology services – specifically the Common Terminology Services (CTS2) effort being undertaken by HL7.
- Establish an independent central coordinating body for the creation and maintenance of content; expand the role of this body to ensure that a Return on Investment has been conducted PRIOR to the promulgation of new standards that may have minimal benefit in clinical care delivery systems.

- Clinical content needs to be managed by experts and include data addressing behavioral health as well as non-traditional determinants of health including variables as homelessness, poverty, and other barriers to access, adverse childhood events, and so forth.

Indian Health Service Profile

- *Our Mission...* to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level.
- *Our Goal...* to assure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people.
- *Our Foundation...* to uphold the Federal Government's obligation to promote healthy American Indian and Alaska Native people, communities, and cultures and to honor and protect the inherent sovereign rights of Tribes.

The (IHS) is organizationally an operating division of the Department of Health and Human Services. Established in 1955, the agency provides care to members of 564 federally recognized American Indian and Alaska Native Tribes and their descendants. The IHS provides a comprehensive health service delivery system for approximately 1.9 million of the nation's estimated 3.3 million American Indians and Alaska Natives. The IHS strives for maximum tribal involvement in meeting the needs of its beneficiaries, most living on or near reservations and in rural communities in 35 states. As such, the IHS has a service population comparable to that of a small state, but challenged further by a wide geographic distribution and rural isolation.

Current Patient Population Profile

The 2005-2007 Current Population Survey revealed that the American Indian and Alaska Native (AI/AN) population has larger families, less health insurance (the number of AI/ANs without health insurance is more than double that for U.S. all races), and a poverty level nearly twice that of the rest of the population.

- Approximately 57% of American Indians and Alaska Natives living in the United States rely on the IHS to provide access to health care services in 45 hospitals and over 600 other facilities operated by the IHS, Tribes, and Alaska Native corporations, or purchased from private providers.
- American Indian and Alaska Native people have long experienced lower health status when compared with other Americans. Lower life expectancy and a disproportionate disease burden exist due to multiple factors, including disparities in education, access to health care

and socioeconomic status, among others. These are broad quality of life issues rooted in economic adversity and poor social conditions.

- American Indians and Alaska Natives die at higher rates than other Americans from tuberculosis (500% higher), alcoholism (519% higher), diabetes (195% higher), unintentional injuries (149% higher), homicide (92% higher) and suicide (72% higher). (*Rates adjusted for misreporting of Indian race on state death certificates; 2003-2005 rates.*)
- Given the higher health status enjoyed by most Americans, the lingering health disparities of American Indians and Alaska Natives are troubling. In trying to account for the disparities, health care experts, policymakers, and Tribal Leaders are looking at many factors that impact upon the health of Indian people, including the adequacy of funding for the Indian health care delivery system.

MORTALITY DISPARITIES RATES

American Indians and Alaska Natives (AI/AN) in the IHS Service Area
 1996-1998 to 2003-2005 and U.S. All Races 1997 and 2004
 (Age-adjusted mortality rates per 100,000 population)

	AI/AN Rate 2003-2005	U.S. All Races Rate – 2004	Ratio: AI/AN to U.S. All Races	Ratio: AI/AN to U.S. All Races
ALL CAUSES	1015.6	800.8	1.3	1.2
Alcohol induced	43.3	7.0	6.2	11.3
Breast Cancer	20.0	24.4	0.8	0.7
Cerebrovascular	49.7	50.0	1.0	1.0
Cervical Cancer	4.0	2.4	1.7	1.6
Diabetes	72.2	24.5	2.9	3.3
Heart Disease	219.7	217.0	1.0	1.0
HIV Infection	3.3	4.5	0.7	0.6
Homicide (assault)	11.3	5.9	1.9	1.8
Infant Deaths 1	8.4	6.8	1.2	1.2
Malignant Neoplasm	179.9	185.8	1.0	0.9
Maternal Deaths	17.8	13.1	1.4	1.0
Motor Vehicle Crashes	47.9	15.2	3.2	2.7
Pneumonia/Influenza	33.0	19.8	1.7	0.9
Suicide	18.8	10.9	1.7	1.6
Tuberculosis	1.2	0.2	6.0	5.0
Unintentional Injuries	94.0	37.7	2.5	2.7

1/ Infant deaths per 1,000 live births. NOTE: Rates are adjusted to compensate for misreporting of American Indian and Alaska Native race on state death certificates. American Indian and Alaska Native death rate columns present data for the 3-year period specified. U.S. All Races columns present data for a one-year period. ICD-10 codes were introduced in 1999; therefore, comparability ratios were applied to deaths for years 1996-1998. Rates are based on American Indian and Alaska Native alone; 2000 census with bridged-race categories.