The Future of Public Health
Vocabularies and Public Health Data Standards

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Data Content Standards Include:

- Data elements, e.g., gender, presenting complaint
- Descriptions of entities, e.g., birth certificate
- Messages, e.g., lab test order
- Allowable values for data elements, which can be entire **vocabularies**
- Mappings between different value sets, e.g., between SNOMED and ICD-9-CM
- Information models that define the context in which standards are used
- Survey questions and any coded responses
- Guideline, protocol, and algorithm formats
Electronic Health Data Standards and Standard Vocabularies

- Key element of the information infrastructure

- Needed for:
  - Safe and effective health care
  - Efficient clinical and health services research
  - Timely public health and bioterrorism surveillance

- Public health requirements must be fed into the standards development process

- Public health must participate in testing and promoting the use of standards
Barriers to Standardized Health Data

- Lack of interest among system buyers
- Competing candidates and no “perfect” candidate, especially in vocabulary area
- Presumed increased costs of data creation
- No hard data on value of vocabulary standardization
  - E.g., for which data elements is there a real payoff?

- Establish a mechanism for designating U.S. Standards - HIPAA, NCVHS, CHI
- Pick best available as starting point - NCVHS, CHI
- Broaden participation in standards development
- *Support development, maintenance, and low/no cost distribution
- Promote use and improvement
- Coordinate development of selected standards to achieve non-overlapping, interlocking set
Support Development, Maintenance, and Low/No Cost Distribution – *NLM-led Actions*

- **1999** – LOINC (lab tests/instrument observations) - contract support
- **2002** – RxNorm (clinical drugs) - direct development
- **2003** – SNOMED CT contract & license for U.S-wide use (as distributed by NLM in UMLS)
- **2004** – HL7 (messaging) contract support to
  - Align HL7 messages with CHI vocabularies
  - Create implementation guide(s) for the use of HL7 to transmit electronic health record (EHR) data
Accelerate Adoption and Use

- Promote use of standards in NIH-funded clinical research networks
  - NIH Roadmap priority: *Re-engineering the clinical research enterprise*

- Encourage manufacturers to include LOINC in device output/test kit packaging
  - Need help to identify manufacturers important to public health community

- Collaborate with other HHS agencies to support demonstration/testing
Types of Health Data

- Administrative health data
  E.g., health insurance claims, billing, ordering

- Clinical data
  E.g., lab test results, problems, diagnoses, history and physical

- Public health data
  E.g., disease surveillance, immunization rates, environmental monitoring

Note: Health Services Research spans all three types of data.
Administrative Health Data

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

Purpose is to:

- Improve the efficiency and effectiveness of the health care system, by standardizing the electronic transmission of certain administrative and financial transactions
- Protect the security and privacy of health information
Administrative Health Data (2)

- Regulations cover (effective dates):
  - Transactions and Code Sets (10/16/2003)
  - Privacy (4/14/2003)
  - Security (4/21/2005)
  - Claims Attachments (final rule expected 2004)
- Unique Identifiers
  - Employers (7/30/2004)
  - Health Care Provider (final rule expected 2004)
  - Health Plan (final rule expected 2004)
  - Individuals (on hold indefinitely)
Clinical Data

- Enhanced ability to provide access to knowledge where clinical decisions are being made
- Generation of research data as a by-product of health care
- Efficient exchange of data between health care and public health
Clinical Data (2)

- **National Committee on Vital and Health Statistics (NCVHS)**
  - Recommended messaging and vocabulary standards for Patient Medical Record Information

- **Consolidated Health Initiative (CHI)**
  - Adopt existing clinical vocabulary & messaging standards to enable interoperability *in the federal health care enterprise*

- **Public/private collaborations recommending standards**
  - Markle Foundation’s Connecting for Health
  - EHealth Initiative
Public Health Data

- National Electronic Disease Surveillance System (NEDSS)
  - Facilitates electronic transfer of appropriate information from clinical information systems to PH departments

- Public Health Information Network (PHIN)
  - Enables consistent exchange of response, health, and disease tracking data between PH partners

- Consolidated Health Informatics (CHI)
  - Evaluated existing vocabularies for several domains important to PH including population health, immunization, etc.

- National Library of Medicine (NLM)
  - Partnering with other federal agencies to identify vocabularies relevant to environmental health
Clinical Versus Public Health Concepts

Clinical
- Anthrax
- Asthma
- Influenza
- Fever
- Diabetes

Public Health
- Anthrax
- Asthma control
- Adult influenza vaccination schedule
- Fever >104
- Diabetes prevention
Unified Medical Language System®
(UMLS®) Metathesaurus® -
a Vocabulary Database

- Preserves the meanings, hierarchical connections, and other relationships between terms present in its source vocabularies.

- Adds certain basic definitional information about each of its concepts.

- Establishes new relationships between concepts and terms from different source vocabularies.

- Distributes many vocabularies in a common, explicit format.
UMLS Source “Vocabularies”

- Widely varying purposes, structures, properties, but all are in essence “sets of valid values” for data elements:
  - HIPAA code sets, e.g., ICD-9-CM, CPT
  - NCVHS and CHI recommended clinical standards, e.g., SNOMED CT, LOINC, RxNorm
  - Thesauri for biomedical literature, e.g., MeSH
  - Other lists of controlled terms, e.g., HL7 value sets
2004AA UMLS Metathesaurus (May 2004)

- ~1,022,000 concepts
- ~2,383,000 unique “strings” (Eye, Eyes, eye = 3)
- ~3,030,000 source vocabulary terms
- 111 source vocabularies
- 15 different languages

- Includes active SNOMED CT (English)
  - Spanish will appear in 2004AB; inactive in 2004AC
Expedite Enhancement, Coordination, Alignment, & Dissemination of Standards

- UMLS® Metathesaurus® – common distribution format/mechanism for CHI standards and HIPAA code sets

- 2004AA - UMLS distribution format changes to support
  - Complete “Source Transparency”
  - Easier extraction of subsets for particular purposes
  - Complete “change sets” from previous versions
  - Sophisticated, purpose-specific inter-vocabulary mapping
Electronic Health Record (EHR)

- EHRs currently in use are for closed systems
  - Intermountain Health Care, Utah
  - Regenstrief Medical Record System, Indianapolis, IN

- Need to develop standards so records can be shared across systems
  - HL7 just successfully balloted standard for EHR – first step in the process

- NLM contract with HL7 to create implementation guide(s) for the use of HL7 to transmit EHR data

- Widespread use of EHRs will facilitate collection of PH data in a timely manner and enhance tools for disease control and prevention
National Health Information Infrastructure (NHII)

- Initiative to improve the effectiveness, efficiency and overall quality of health and health care in the United States

- Comprehensive knowledge-based network of interoperable systems that would improve decision-making by making health information available when and where it is needed

- NOT a centralized database of medical records or a government regulation
Development of a PH Vocabulary

- CDC Web Redesign Controlled Health Thesaurus
  - Good example of the process needed for developing a PH Vocabulary
  - Developed to meet the needs of the CDC for their Web site redesign
  - Will need input from PH community in order to become a PH vocabulary
CDC Process

- Analyzed CDC Website for PH concepts
  - 19,000 unique concepts identified
  - 11,000 not matched to existing terminology

- Best matches:
  - MeSH - provided the highest number of matches
  - CRISP
  - Alcohol & Other Drugs Thesaurus

- SNOMED RT had 4,400 concept matches, many overlap with MeSH

- Demonstrated clear need for PH specific terminology
CDC Process (2)

- Imported a good portion of MeSH to form initial framework of vocabulary tool

- Structure adopted from MeSH only shows clinical perspective – need to adjust to show PH perspective. E.g.:
  - For obesity – define a relationship between:
    - Obesity and BMI or CDC 5-a-day program
  - For diabetes (or other diseases) – define a relationship between:
    - Diabetes and prevention programs or specific measurements

- Evaluating top 3 levels of the hierarchical structure to see if it provides a complete framework

- Creating placeholders for what needs to be added
Looking at concepts extracted from CDC programs and services

Evaluating search logs of CDC Web site – what are people looking for?

Matching site map for new CDC Web site against the Thesaurus, adding concepts as identified.
- CDC migrating information by topic – fill in concepts as new topic pages developed

Ongoing process
Future Steps for CDC

- Continue enhancing and refining Thesaurus
- Determine the amount of overlap with SNOMED CT

Fall 2004
- Begin talking with vocabulary developers about enhancing their vocabulary with concepts from CDC Thesaurus (MeSH, SNOMED CT, etc.)
- Talk with NLM about including what remains in NLM’s UMLS Metathesaurus
Future for Public Health

- Public health requirements must be fed into the development process.
- Public health must participate in testing and promoting the use of all elements of the developing systems.
- Involvement in the Public Health Data Standards Consortium (PHDSC) is a good place to start.
Additional Information

- CDC Web Redesign Controlled Health Thesaurus
  - Mamie Bell
    CDC/Information Resources Management Office
    email: zvt9@cdc.gov

- PHIN Standards (www.cdc.gov/phin)

- Consolidated Health Informatics (CHI)
  - www.whitehouse.gov/omb/egov
    Choose “Government to Business”

- National Committee on Vital and Health Statistics (NCVHS)
  - ncvhs.hhs.gov
Contact Information

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