

More and Better Data for Research: *U.S. Health Data Content Standards*

Vivian A Auld
Senior Specialist for Health Data Standards
National Library of Medicine

AcademyHealth
Annual Research Meeting
June 26, 2004



Presidential Executive Order

April 27, 2004

With goal of ubiquitous electronic health records and a national health information infrastructure in 10 years:

New **National Health Information Technology Coordinator** in HHS with responsibility for strategic plan to:

“(i) Advance the development, adoption, and implementation of *health care information technology standards* nationally through collaboration among public and private interests, and *consistent with current efforts to set health information technology standards for use by the Federal Government*;

(ii)”

www.whitehouse.gov/news/releases/2004/04/20040427-4.html

ONCHIT



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Federal Health IT Initiatives

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What's New

- **Secretary Leavitt Announces Vision for Health IT Including [American Health Information Community](#) and [Requests for Proposals](#)**
[News Release](#)
- **HHS Releases Report on Nationwide Health Information Exchange**
[full story](#)
Summary Report [[PDF](#) - 764KB]
- **HHS Secretary and Leading U.S. Companies Say Health Information Technology Should Be Urgent Priority**
[full story](#)
Final Report [[PDF](#) - 498K]
- **Dr. Brailer Addresses HIMSS Conference in Dallas, TX, February 17, 2005**
[full story](#)
- **President Visits Cleveland Clinic to Discuss Health IT**
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- **E-Prescribing Standards Proposed by CMS**
[full story](#)

Resources

- [Stay informed! Join our new Listserv for automatic updates](#)

Last revised: June 21, 2005

www.hhs.gov/healthit

HIT Strategic Framework Goals

JULY 2004

www.os.dhhs.gov/healthit/strategicfrmwk.html

- Inform Clinicians
 - Incentivize and reduce risk of EHR adoption
- Interconnect Clinicians
 - Foster regional collaborations, develop NHIN, coordinate Federal systems
- Personalize Care
 - Encourage PHRs, enhance informed consumer choice, promote use of telehealth systems
- Improve Population Health
 - Unify surveillance systems, streamline quality and health status monitoring, accelerate research and dissemination of evidence

Report on Nationwide Health Information Exchange

- HHS issued “Request for Information” (RFI) in November 2004
 - Sought recommendations on the best way to achieve widespread interoperability of health information through a nationwide health information network (NHIN)
- Received over 500 responses totaling nearly 5,000 pages of information
- Report summarizing the responses to the RFI published in June 2005
 - www.hhs.gov/healthit/rfisummaryreport.pdf
- Results used to prepare “Request for Proposal” (RFP)

HHS Requests for Proposals

June 2005

- Nationwide Health Information Network (NHIN) prototype architectures, operational models – up to 6 awards (ONC)
- State-based assessments/plans re: security & privacy laws/business practices – up to 40 awards (ONC & AHRQ)
- EHR compliance & certification process (ONC)
- Standards harmonization process (ONC)

HHS Secretary Leavitt's 500-Day Plan to Transform Health Care Systems

- Expressing a clear vision of health information technology that conveys the benefits to patients, providers and payers
- Convening national collaboration re: developing setting, and certifying HIT standards and outcomes for interoperability, privacy and data exchange
- Realizing the near-term benefits of health information technology in: adverse drug-incident reporting, e-prescribing, lab and claims-sharing data, clinic registrations, insurance forms
- Creating an integrated network of population data, genetic information, and medical records to accelerate discovery
- Improving the clinical research network
- Providing early warning of threats through improved domestic and international surveillance

Congress Drafting Health IT Bills



McHugh - Gonzalez (H.R. 747)	Murphy - Kennedy (H.R. 2234)	Kennedy (S. 16)	Jeffords (S. 544)	Dodd (S. 1223)	Stabenow - Snowe (S. 1227)	Frist - Clinton (S. 1262)
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Health IT Legislation Crosswalk

Official Title	National Health Information Incentive Act of 2005	21st Century Health Information Act of 2005	Affordable Health Care Act	Patient Safety and Quality Improvement Act of 2005	Information Technology for Health Care Quality Act	The Health Information Technology Act of 2005	Health Technology to Enhance Quality Act of 2005
HIMSS Endorsed	TBD	Yes	TBD	Yes	TBD	Yes	Yes
Co-sponsors	40	19	18	9	1	2	2
Status	Referred to Energy & Commerce and Ways & Means	Referred to Energy & Commerce and Ways & Means	Referred to Finance Committee	Referred to Health, Education, Labor and Pensions (HELP)	Referred to Health, Education, Labor and Pensions (HELP)	Referred to Finance Committee	Not Referred Yet
Codifies ONCHIT	Yes	No	Yes	No	Yes	No	Yes
Promotes Standards Adoption	Yes	Yes	Yes	Yes	Yes	Yes	Yes - Mandatory Federal program; voluntary for private sector
Proposes Advisory Body	No	No	No	No	No	No	Yes

www.himss.org/Content/files/LegislationCrosswalk-109thcongress.pdf

NLM's Role in Health Data Interoperability Standards

Electronic Health Data Standards (including Standard Vocabularies)

- Key element of the health information technology infrastructure for:
 - Effective decision support
 - Safe, evidence-based, and coordinated health care
 - Cost-effective care, assisted by robust market-place and increased/informed choice
 - More efficient clinical, public health, and health services research
 - Timely public health and bioterrorism surveillance

Types of Health Data

- Administrative health data
e.g., health insurance claims
- Clinical data
e.g., lab test results, problems, diagnoses, history and physical
- Public health data
e.g., disease prevalence, immunization rates, environmental monitoring

All potentially relevant to health services research

Data Content Standards include:

- Data elements, e.g., gender, presenting complaint
- Descriptions of entities, e.g., birth certificate
- Messages, e.g., medication order
- Allowable values for data elements, which can be entire *vocabularies*
- Mappings between different vocabularies
- Survey questions and any coded responses
- Guideline, protocol, and algorithm formats
- Information models that define the context for standards

Standard Clinical Data

- Enhanced ability to provide access to knowledge where clinical decisions are being made (e.g. guidelines, decision logic, etc.)
- Generation of research data as a by-product of health care
- Efficient exchange of data between health care and public health

NLM Long Range Plan

- Work with other agencies and organizations to support establishment, maintenance, testing and use of health data standards.
 - Active partners: *Office of the Secretary - HHS, AHRQ, CDC, CMS, FDA, other NIH components, VA, DoD, NCVHS, standards development organizations, vocabulary producers, professional associations*
- Use the UMLS Knowledge Sources and programs to facilitate maintenance and distribution of vocabulary standards.

Federal Standards Selection Mechanisms

- **HIPAA** (1996)- *Health Insurance Portability and Accountability Act of 1996 requires administrative standards*
- **NCVHS** - *National Committee on Vital and Health Statistics, a long-standing (50+ years) advisory committee to HHS expanded by HIPAA, recommends standards*
- **CHI** (2001) – *Consolidated Health Informatics project, a cross-agency eGov initiative designates U.S. gov't-wide clinical data standards; now part of the Federal Health Architecture*
- **Medicare Modernization Act** (2003) - *requires e-Prescribing standards; establishes Commission on Systemic Interoperability*

Recommended Steps to Achieving U.S. Health Data Standards (1990-2003)

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

Standards Have Been Selected

- U.S. *National* Administrative Standards
 - HIPAA transactions and code sets
www.cms.hhs.gov/hipaa/hipaa2/default.asp
- U.S. *Government-wide* Target Clinical Standards
 - CHI message and vocabulary standards
www.whitehouse.gov/omb/egov/c-3-6-chi.html
- U.S. *National* Public Health Reporting Standards
 - PHIN (Public Health Information Network)
www.cdc.gov/phinf/index.html

NLM-led Support for Development and Maintenance

- **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*)

NLM No-Cost Distribution



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Unified Medical Language System

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2005AB Metathesaurus now available to [download](#) from the UMLSKS. Includes the **RRF Browser** (beta) for viewing your subsets. ●●● New to the UMLS? [Register now](#).

▶ [About the UMLS Resources](#)

Metathesaurus; Semantic Network; SPECIALIST Lexicon and lexical programs; MetamorphoSys

▶ [Accessing UMLS Knowledge Sources](#)

Metathesaurus license; Semantic Network; SPECIALIST Lexicon; DVD

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Metathesaurus Source Vocabularies

- [SNOMED CT](#)
- [LOINC](#)
- [RxNorm](#)
- [MeSH](#)
- [List of Sources](#)
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More Resources

- [Metathesaurus License](#)
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umlsinfo.nlm.nih.gov

About

NLM's Unified Medical Language System (UMLS) project develops and distributes multi-purpose, electronic "Knowledge Sources" and associated lexical programs for system developers. Researchers will find the UMLS products useful in investigating knowledge representation and retrieval questions.

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

2005AB UMLS Metathesaurus (June 2005)

- 1,196,265 concepts
- 4,752,383 unique “strings”
(Eye, Eyes, eye = 3)
- 5,578,532 source vocabulary terms
- 114 source vocabularies
- 17 different languages

Other UMLS Resources

- Semantic Network
- SPECIALIST lexicon
- Natural language processing programs
 - In combination with the Metathesaurus, powerful tools for interpretation/indexing of electronic full text

Letter from HHS Secretary to NCVHS

Sept. 2004

- “As you requested ..., NLM to serve as the central coordinating body within HHS for PMRI [Patient Medical Record Information] terminologies. ... several ... mapping recommendations currently are being implemented by the NLM.”

Coordination means:

- Uniform distribution of designated standard vocabularies through the UMLS Metathesaurus
- Reducing peripheral overlap and establishing explicit relationships between standard clinical vocabularies (e.g., SNOMED, LOINC, RxNorm)
- Aligning standard clinical vocabularies with standard record and message formats
- Mapping between standard clinical vocabularies and administrative code sets and/or other important vocabularies

NLM- HL7 Contract Arrangement

Sept. 2004

- Align HL7 message standard with standard vocabularies (*NLM-initiated*)
 - Specify which subsets of standard vocabularies are valid for particular message segments
 - Replace HL7-maintained lists of coded values with subsets of standard vocabularies, where feasible
- Create implementation guide(s) for transmitting an entire Electronic Health Record between systems (*on behalf of HHS*)

Mapping Projects planned/underway

- CHI standards – HIPAA code sets
 - SNOMED CT - ICD-9-CM, ICD-10-CM
 - SNOMED CT – CPT
 - LOINC – CPT
- SNOMED CT - “other” vocabularies
 - Medical Dictionary for Regulatory Affairs (MedDRA)
 - International Classification of Primary Care (ICPC)
 - Medcin
- Will require:
 - Robust testing/validation
 - Alignment of update schedules
- Draft mappings available in the UMLS Metathesaurus for testing by end of 2005

Key NLM Assumptions about Mappings

- Participants must include:
 - Producers of vocabularies on both ends; prospective users and recipients of the output, e.g., health care providers, payers, as testers and validators
- Mapping may/will prompt changes/corrections to content and adjustment to update schedules
- Mappings must be updated every time either end is updated
- Mappings will be distributed in the UMLS (not exclusively); use will be governed by terms applicable to both ends
- Mapping is still an R & D problem - it will take iteration to build highly functional maps

Accelerate Adoption and Use

- Promote testing use of standards by Federal partners, grantees, and contractors
 - *CDC's Public Health Information Network (PHIN)*
(www.cdc.gov/phin)
 - *NIH emphasis on use in clinical research networks*
- Encourage manufacturers to include standard identifiers (e.g., LOINC) in device output/test kit packaging
- Collaborate with other HHS agencies to support demonstration/testing

Broaden participation: Public Health

PHDSC WRC HOME PAGE - Microsoft Internet Explorer

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www.phdatastandards.info



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ABOUT THE CONSORTIUM

WEB-BASED RESOURCE CENTER

Public Health Data Standards Consortium

Do you think something should be done to improve and integrate population health data and information? Do you have trouble knowing what is happening to the health in your community? Are there too many health data systems that don't talk to each other? Are you worried that a bio-terror attack or emerging health threat might escape detection?

As members of the Consortium we are public health professionals and health services researchers expanding educational resources, informing stakeholders, and organizing to assure that health data standards and health data meet our needs and ultimately the health needs of the public.

We are a determined "hands-on" group who work with information technology, recognized public health leaders, researchers, and standards organizations. We actively participate in decisions that impact our ability to use data to improve the lives of mothers, children, students, workers, the aged, and all Americans. Click on "[About the Consortium](#)" to learn more about our organization and activities, including our [Strategic Plan](#), [Our Members](#), [Ongoing Initiatives](#), [How to Join](#) and [Subscribing to our ListServ](#).

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http://www.phdatastandards.info/wrc_default.htm

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Broaden participation: Clinical Research



NIH Roadmap

ACCELERATING MEDICAL DISCOVERY TO IMPROVE HEALTH



nihroadmap.nih.gov

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Re-engineering the Clinical Research Enterprise

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What's New

- ▶ **Press Release:** [NIH "Roadmap" Grants Will Establish Nine Screening Centers in Seven States](#)
- ▶ **Symposium:** [NIH Director's Pioneer Award Symposium](#)
- ▶ **Workshop:** [Metabolomics Standards Workshop](#)
- ▶ **Notice:** [Meeting Announcement: Enhancing the Discipline of Clinical and Translational Research](#)
- ▶ **Cancellation:** [Planning Grants for Regional Translational Research Centers](#)
- ▶ **Notice:** [Limited Competition Request for Applications: Nanomedicine Development Centers](#)



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Strategy for Adoption and Implementation of Standards



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Commission on Systemic Interoperability

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Welcome to the Commission on Systemic Interoperability Homepage

The Commission on Systemic Interoperability was authorized by the Medicare Modernization Act, and held its first meeting on January 10, 2005. The Commission is developing a strategy to make healthcare information instantly accessible at all times, by consumers and their healthcare providers.

The report that the Commission will deliver will provide:

- A comprehensive strategy for creating such an information network
- Costs and benefits—both financial and medical—of the network
- Details about barriers to—and opportunities in—creating the network

The final report will be released on October 24, 2005.

- [Official Vision Statement](#)

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www.nlm.nih.gov/csi/csi_home.html

Commission on Systemic Interoperability

Members - appointed late 2004

- **Scott Wallace**, JD, Chair, National Alliance Health IT
- **Simon Cohn**, M.D, Kaiser
- **Don Detmer**, M.D., Pres & CEO, AMIA
- **Vicki Gregg**, CEO, BlueCross BlueShield TN
- **Gary Mecklenberg**, Pres. & CEO, Northwestern Memorial Healthcare
- **C. Martin Harris**, MD, CIO, Cleveland Clinic
- **Herbert Pardes**, M.D., Pres. & CEO, NY-Presbyterian Hosp
- **Thomas S. Priselac**, Pres. & CEO, Cedars-Sinai
- **Ivan Seidenberg**, Chm. & CEO, Verizon of NY
- **Frederick Slunecka**, CEO, Avera McKennan Hosp
- **Bill Stead**, M.D. Assoc. Vice Chancellor for Health Affairs, Vanderbilt



HIPAA Privacy Rule

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Overview

privacyruleandresearch.nih.gov

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule is the first comprehensive Federal protection for the privacy of personal health information. Research organizations and researchers may or may not be covered by the HIPAA Privacy Rule. This website provides information on the Privacy Rule for the research community.

HIPAA Resources

- The Privacy Rule - Final Modification ([PDF/TXT](#))
- Office for Civil Rights HIPAA Information ([Medical Privacy Home Page](#))
- Office for Civil Rights HIPAA Guidance ([PDF/RTF](#))
- Office for Civil Rights Summary of the HIPAA Privacy Rule ([PDF/RTF](#))
- Center for Medicare & Medicaid Services HIPAA Information ([Covered Entity Decision Tool](#))

Highlights

- **NEW** [HRSA Issues a Privacy Rule Resource Guide for HIV Services Providers](#)
- [Clinical Research and the HIPAA Privacy Rule](#)
- [The Privacy Rule and Public Health](#)
- [Research Repositories, Databases](#)
- [NIH/AHRQ May 2004 conference on the HIPAA Privacy Rule and Research](#)

Take Home Messages

- Health data standards have “arrived”; electronic health records are arriving
- Both will affect health care, public health functions, and the data available for HSR
- It's not too early (*or too late*) to get involved:
 - to contribute to standards development, testing, and refinement
 - to study the impact of standards on health care, public health, and clinical research
- If you work with electronic data, the UMLS resources might be helpful