

More and Better Data for Research:

U.S. Health Data Content Standards

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National Library of Medicine

AcademyHealth

Annual Research Meeting

June 3, 2007



DEPARTMENT OF HEALTH
AND HUMAN SERVICES

Presidential Executive Order

April 27, 2004

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


Established 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)”

HHS Health IT

U.S. Department of Health & Human Services www.hhs.gov

Health Information Technology



- HIT Home**
- American Health Information Community**
- AHIC Workgroups**
- Office of the National Coordinator (ONC)**
- Product Certification**
- Standards**
- Nationwide Health Information Network**
- Use Cases**
- Privacy & Security**
- Initiatives**
- Contracts**
- News Room**
- Frequent Questions**
- Acronyms**

Health Information Technology Home

Health Information Technology

Health information technology (Health IT) allows comprehensive management of medical information and its secure exchange between health care consumers and providers. Broad use of health IT will:

- Improve health care quality;
- Prevent medical errors;
- Reduce health care costs;
- Increase administrative efficiencies;
- Decrease paperwork; and
- Expand access to affordable care.

Interoperable health IT will improve individual patient care, but it will also bring many public health benefits including:


- Early detection of infectious disease outbreaks around the country;
- Improved tracking of chronic disease management; and
- Evaluation of health care based on value enabled by the collection of de-identified price and quality information that can be compared.

Making Health Information Technology Personal

Health information technologies can be tools that help individuals maintain their health through better management of their health information. Health IT will help consumers gather all of their health information in one place so they can thoroughly understand it and share it securely with their health care providers so they get the care that best fits their individual needs.

Accomplishments Report

HHS issues a report: [The HHS Health Information Technology Initiative Major Accomplishments](#) [pdf].



Mission Statement

"We will make wider use of electronic records and other health information technology to help control costs and reduce dangerous medical errors."
-- President Bush, January 31, 2006

[More on the President's Vision for Health IT](#)

"...to link all health records through an interoperable system that protects privacy as it connects patients, providers and payers, resulting in fewer medical mistakes, less hassle, lower costs and better health."
-- HHS Secretary Mike Leavitt

The [Strategic Framework](#) lays out the vision and goals of HHS' HIT Initiative

Coming Up

www.hhs.gov/healthit



Strategy for Achieving U.S. Health Data Standards

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

Use Cases

U.S. Department of Health & Human Services www.hhs.gov

Health Information Technology



- [HIT Home](#)
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- [Nationwide Health Information Network](#)
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AHIC Use Cases

In Development

- [Stakeholder Overview Presentation \(5/15/2007\) \(PPT\)](#) (894KB)
- [Consumer Empowerment: Consumer Access to Clinical Information DRAFT Detailed Use Case](#)
- [Medication Management DRAFT Detailed Use Case](#)
- [Quality DRAFT Detailed Use Case](#)

2007 Use Cases

- [Emergency Response - Electronic Health Record Use Case \(PDF\)](#) (377KB)

2006 Use Cases

- [Harmonized Consumer Empowerment \(Registration & Medication History\) Use Case \(PDF\)](#) (258KB)
- [Harmonized EHR Lab Use Case \(PDF\)](#) (271KB)
- [Harmonized Biosurveillance Utilization Use Case \(PDF\)](#) (208KB)

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Coming Up

www.hhs.gov/healthit/usecases

Healthcare Information Technology Standards Panel (HITSP)



ANSI
Standards Activities

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Healthcare Information Technology Standards Panel



- Organizational Structure
 - Technical Committees
- Membership
- News Items
- HITSP Member Announcements
- Meeting Calendar
- Document Library
- Membership in ANSI
- Staff Contacts
- Frequently Asked Questions

[HITSP Interoperability Specifications HERE](#)

[HITSP Requirements, Design and Standards Selection HERE](#)

[HITSP Comment Tracking System HERE](#)

The mission of the Healthcare Information Technology Standards Panel is to serve as a cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications, as they will interact in a local, regional and national health information network for the United States.

Comprised of a wide range of stakeholders, the Panel will assist in the development of the U.S. Nationwide Health Information Network (NHIN) by addressing issues such as privacy and security within a shared healthcare information system.

The Panel is sponsored by the American National Standards Institute (ANSI) in cooperation with strategic partners such as the Healthcare

ANSI BSP
Biofuels Standards Panel
more info

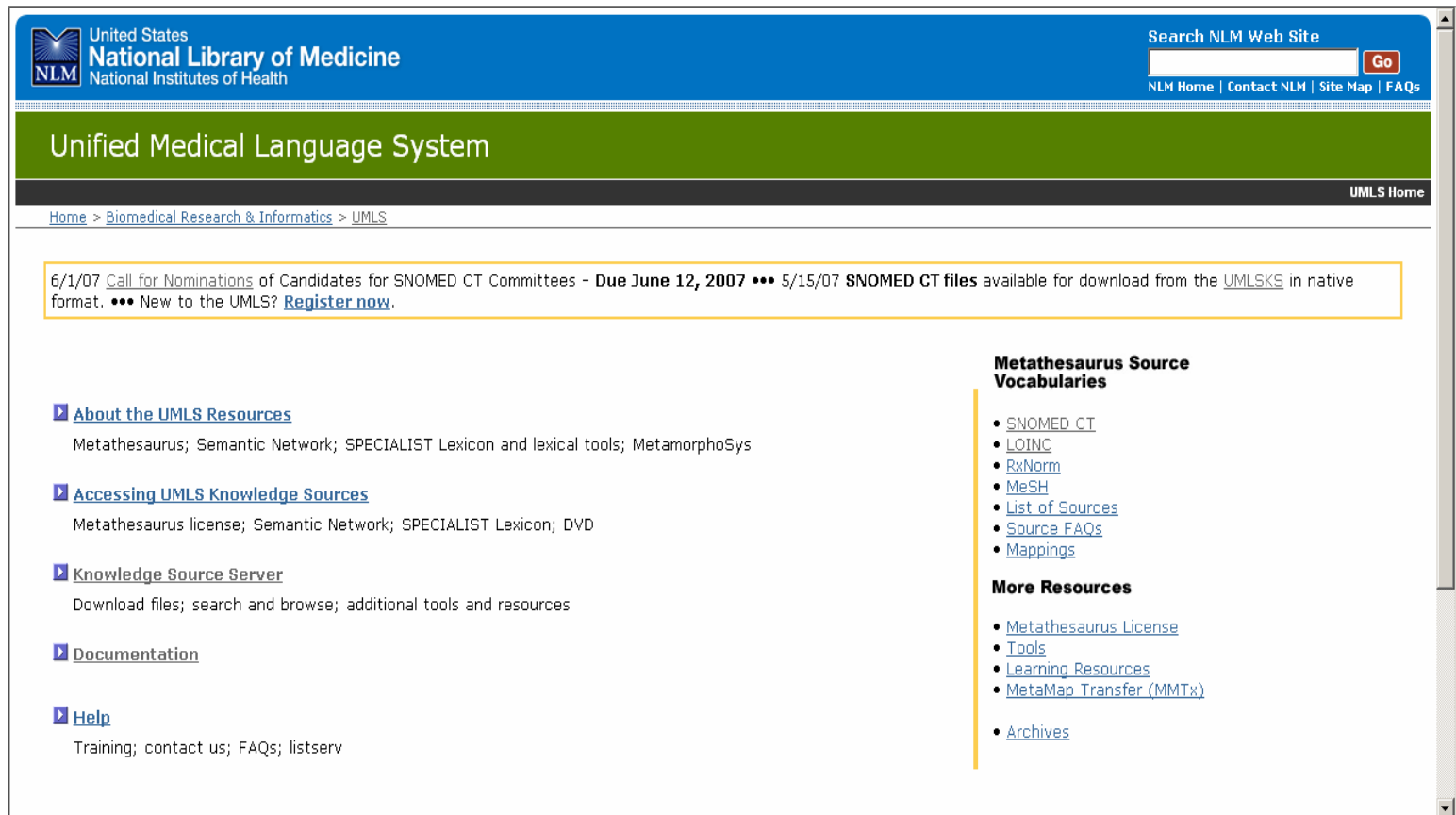
www.ansi.org/hitsp/

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*)

Unified Medical Language System

UMLS



The screenshot shows the UMLS website homepage. At the top left is the NLM logo and text: "United States National Library of Medicine National Institutes of Health". At the top right is a search bar with the text "Search NLM Web Site" and a "Go" button, with links for "NLM Home", "Contact NLM", "Site Map", and "FAQs". Below this is a green banner with the text "Unified Medical Language System" and a "UMLS Home" link on the right. A breadcrumb trail reads "Home > Biomedical Research & Informatics > UMLS". A yellow-bordered box contains a notice: "6/1/07 Call for Nominations of Candidates for SNOMED CT Committees - Due June 12, 2007 ••• 5/15/07 SNOMED CT files available for download from the UMLSKS in native format. ••• New to the UMLS? Register now." The main content area is divided into two columns. The left column has four sections, each with a blue arrow icon: "About the UMLS Resources" (Metathesaurus; Semantic Network; SPECIALIST Lexicon and lexical tools; MetamorphoSys), "Accessing UMLS Knowledge Sources" (Metathesaurus license; Semantic Network; SPECIALIST Lexicon; DVD), "Knowledge Source Server" (Download files; search and browse; additional tools and resources), and "Documentation". The right column has two sections: "Metathesaurus Source Vocabularies" with a bulleted list of links: SNOMED CT, LOINC, RxNorm, MeSH, List of Sources, Source FAQs, and Mappings; and "More Resources" with a bulleted list: Metathesaurus License, Tools, Learning Resources, MetaMap Transfer (MMTx), and Archives.

umlsinfo.nlm.nih.gov

2007AA UMLS Metathesaurus (Jan 2007)

- ~1,373,000 concepts
- ~4,967,000 “terms” (Eye, Eyes, eye = 1)
- ~5,546,000 unique “strings” (Eye, Eyes, eye = 3)
- ~6,773,000 “atoms” or source vocabulary strings (Eye [from MeSH], Eye [from SNOMED CT] = 2)
- 139 source **vocabularies** (121 “families”)
- 17 different languages
 - *Multi-purpose – MUST be customized for any specific purpose*



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:

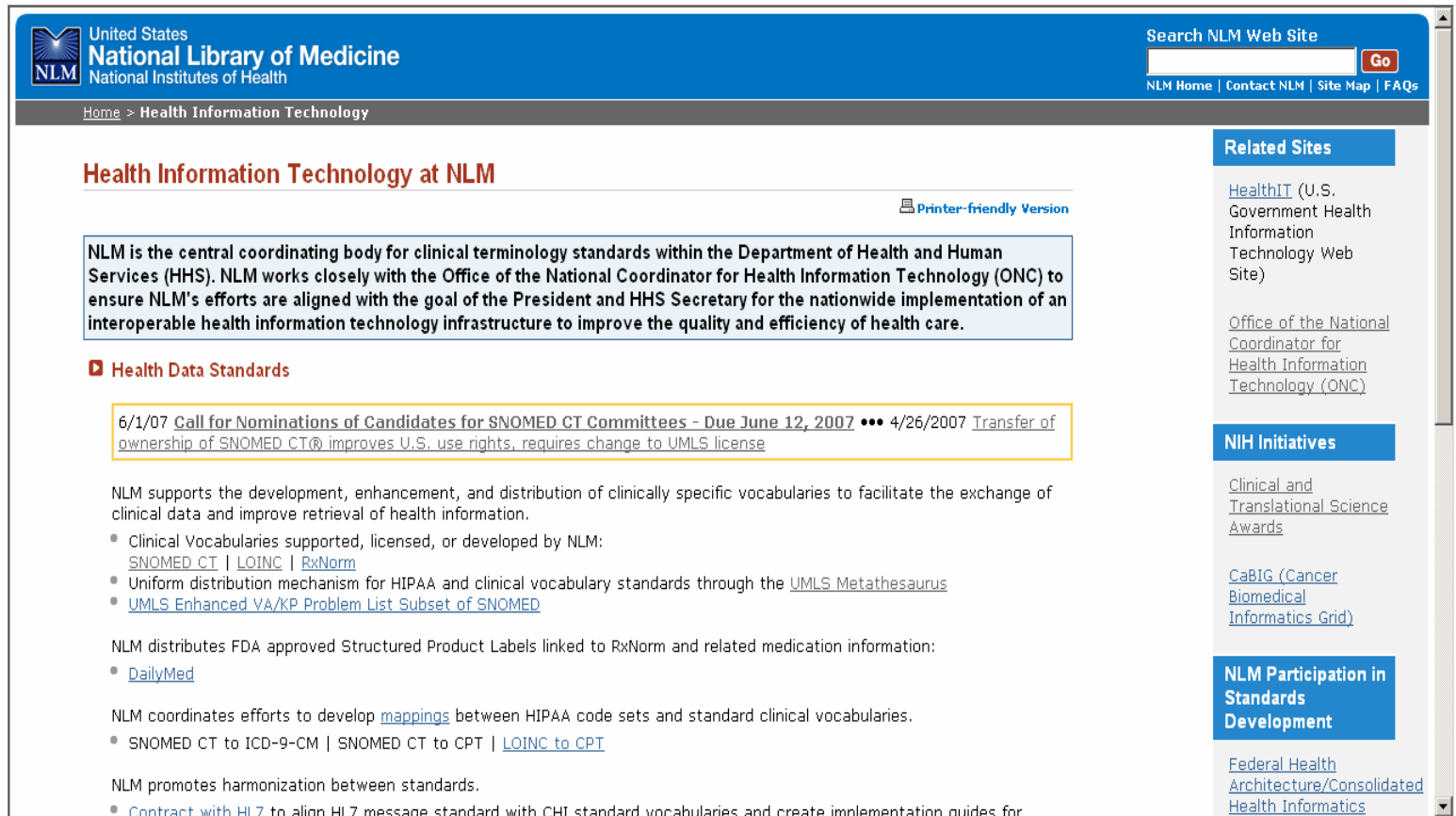
- Uniform distribution of designated standard vocabularies through the UMLS Metathesaurus
- Reducing peripheral overlap and establishing explicit relationships between standard clinical vocabularies (e.g., SNOMED, LOINC, RxNorm)
- Aligning standard clinical vocabularies with standard record and message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

NLM Long Range Plan for 2006-2016

3.2 Promote Development of “Next Generation” Electronic Health Records

- Continue and enhance current standards efforts:
 - Develop, support, license, disseminate vocabulary standards via UMLS
 - Develop subsets, mappings, and other tools in collaboration with actual clinical systems
 - Contribute to health information technology policy development
- Expand research and development to define and develop more advanced electronic health records

Health IT at NLM



The screenshot shows the NLM website's Health Information Technology section. At the top left is the NLM logo and the text "United States National Library of Medicine National Institutes of Health". At the top right is a search bar with the text "Search NLM Web Site" and a "Go" button. Below the search bar are links for "NLM Home", "Contact NLM", "Site Map", and "FAQs". A breadcrumb trail reads "Home > Health Information Technology". The main heading is "Health Information Technology at NLM" with a "Printer-friendly Version" link. A text box states: "NLM is the central coordinating body for clinical terminology standards within the Department of Health and Human Services (HHS). NLM works closely with the Office of the National Coordinator for Health Information Technology (ONC) to ensure NLM's efforts are aligned with the goal of the President and HHS Secretary for the nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care." Below this is a section for "Health Data Standards" with a highlighted link: "6/1/07 Call for Nominations of Candidates for SNOMED CT Committees - Due June 12, 2007 ••• 4/26/2007 Transfer of ownership of SNOMED CT® improves U.S. use rights, requires change to UMLS license". The page lists NLM's support for clinical data exchange, supported vocabularies (SNOMED CT, LOINC, RxNorm), distribution mechanisms for HIPAA and clinical standards (UMLS Metathesaurus, UMLS Enhanced VA/KP Problem List Subset of SNOMED), FDA approved Structured Product Labels (DailyMed), and efforts to develop mappings between HIPAA code sets and standard clinical vocabularies (SNOMED CT to ICD-9-CM, SNOMED CT to CPT, LOINC to CPT). It also mentions promoting harmonization between standards (Contract with HL7).

United States
National Library of Medicine
National Institutes of Health

Search NLM Web Site
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Home > Health Information Technology

Health Information Technology at NLM

[Printer-friendly Version](#)

NLM is the central coordinating body for clinical terminology standards within the Department of Health and Human Services (HHS). NLM works closely with the Office of the National Coordinator for Health Information Technology (ONC) to ensure NLM's efforts are aligned with the goal of the President and HHS Secretary for the nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care.

Health Data Standards

[6/1/07 Call for Nominations of Candidates for SNOMED CT Committees - Due June 12, 2007 ••• 4/26/2007 Transfer of ownership of SNOMED CT® improves U.S. use rights, requires change to UMLS license](#)

NLM supports the development, enhancement, and distribution of clinically specific vocabularies to facilitate the exchange of clinical data and improve retrieval of health information.

- Clinical Vocabularies supported, licensed, or developed by NLM:
[SNOMED CT](#) | [LOINC](#) | [RxNorm](#)
- Uniform distribution mechanism for HIPAA and clinical vocabulary standards through the [UMLS Metathesaurus](#)
- [UMLS Enhanced VA/KP Problem List Subset of SNOMED](#)

NLM distributes FDA approved Structured Product Labels linked to RxNorm and related medication information:

- [DailyMed](#)

NLM coordinates efforts to develop [mappings](#) between HIPAA code sets and standard clinical vocabularies.

- SNOMED CT to ICD-9-CM | SNOMED CT to CPT | [LOINC to CPT](#)

NLM promotes harmonization between standards.

- [Contract with HL7](#) to align HL7 message standard with CHI standard vocabularies and create implementation guides for

Related Sites

- [HealthIT \(U.S. Government Health Information Technology Web Site\)](#)
- [Office of the National Coordinator for Health Information Technology \(ONC\)](#)

NIH Initiatives

- [Clinical and Translational Science Awards](#)
- [CaBIG \(Cancer Biomedical Informatics Grid\)](#)

NLM Participation in Standards Development

- [Federal Health Architecture/Consolidated Health Informatics](#)

www.nlm.nih.gov/healthit.html



Change in Ownership of SNOMED CT

2003- NLM/CAP* License and Contract

- U.S-wide license for the use of SNOMED CT:
 - Perpetual rights to the last version received under the contract
 - Ongoing updates to the English and Spanish versions for 5 years (follow-on contracts likely)
 - Free distribution to U.S. users via NLM's Unified Medical Language System (UMLS)
 - International use requires separate license from CAP
 - Terms of agreement determined with extensive input/advice from HHS agencies, VA, DOD

***College of American Pathologists**



IHTSDO principles

- Openness, fairness, transparency, and accountability to Members
- Responsible, ethical conduct to ensure long-term viability, value, utility, clinical & technical fitness of terminology products
- Collaboration with others to facilitate interoperability
- Encouragement of intellectual contributions under terms that permit others to use and distribute their own work

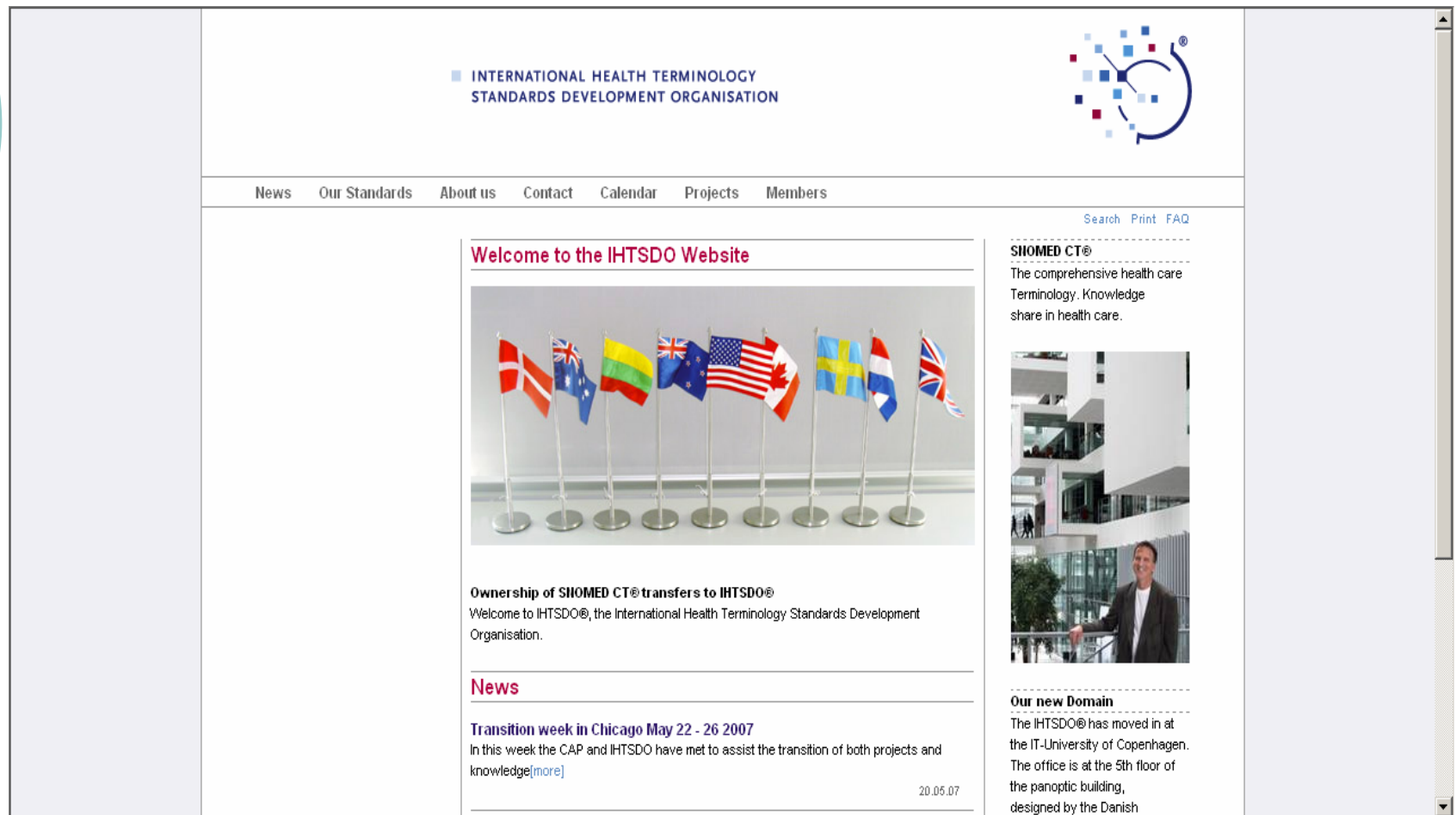


April 26, 2007:

Change in ownership announced

- International Health Terminology Standards Development Organisation (IHTSDO)
 - Charter members from 9 countries:
 - Australia, Canada, Denmark, Lithuania, Netherlands, New Zealand, Sweden, UK, USA
 - Each member country represented by one entity
 - NLM – the initial entity for USA

International Health Terminology Standards Development Organisation (IHTSDO)




The screenshot shows the IHTSDO website homepage. At the top, the organization's name is displayed in blue text next to a logo consisting of a blue circle with a white arrow and several small blue and red squares. Below the name is a navigation menu with links for News, Our Standards, About us, Contact, Calendar, Projects, and Members. A search bar with 'Search Print FAQ' options is located on the right. The main content area features a 'Welcome to the IHTSDO Website' section with a row of eight international flags on poles. Below this is a news item titled 'Ownership of SHOMED CT® transfers to IHTSDO®' with a brief description and a 'more' link. Another news item is titled 'Transition week in Chicago May 22 - 26 2007' with a similar description and 'more' link. On the right side, there is a 'SHOMED CT®' section with a description and a photo of a man in a suit. Below that is an 'Our new Domain' section with a description and a photo of a modern building.

INTERNATIONAL HEALTH TERMINOLOGY
STANDARDS DEVELOPMENT ORGANISATION

News Our Standards About us Contact Calendar Projects Members

Search Print FAQ

Welcome to the IHTSDO Website




Ownership of SHOMED CT® transfers to IHTSDO®
Welcome to IHTSDO®, the International Health Terminology Standards Development Organisation.

News

Transition week in Chicago May 22 - 26 2007
In this week the CAP and IHTSDO have met to assist the transition of both projects and knowledge[[more](#)]

20.06.07

SHOMED CT®
The comprehensive health care Terminology. Knowledge share in health care.



Our new Domain
The IHTSDO® has moved in at the IT-University of Copenhagen. The office is at the 5th floor of the panoptic building, designed by the Danish

www.ihtsdo.org/

Chronology

- IHTSDO formed in Denmark - March 9, 2007
- IHTSDO IP purchase from CAP for \$7.8 million and 3-yr support contract with CAP – final on April 24, 2007
- Public announcement – April 26, 2007
- NLM ends contract with CAP – April 30, 2007
- IHTSDO – SNOMED Editorial Board/WG transition meeting – May 23-25, 2007 (Chicago)
- NLM sets up new contract with IHTSDO - by June 30, 2007

IHTSDO - Country Participation

- Member countries
 - Annual fees based on World Bank GNI values, pegged to current US fee (\$5.5 million in '07)
 - Charter members (other than US) also contributed to initial IP payment
 - After start-up, new members pay joining fee, as well as annual fee
- “Sponsored countries”
 - For countries below a GNI threshold, a one-time payment (8 X annual fee) provides permanent rights; can be paid by anyone, e.g., foundation

IHTSDO Member* Rights

- Use and reformat the International release
- Create national extensions in accordance with IHTSDO standards
- Create derivatives, e.g., subsets, mappings, etc.
- Distribute the international release to “Affiliates” (=licensees) under standard license terms
 - **Must distribute in native format**, in addition to any other formats
- Continue to use and distribute the last version received if membership ceases

***In US, NLM**

“Affiliate” License Terms

- One license for everyone – e.g., vendors, hospitals, researchers
- Right to use, create extensions and derivatives, incorporate international release in products
 - No use fees in Member or Sponsored countries; some in non-member countries
 - IHTSDO may “annex” certain extensions
- Required to check if additional requirements apply (e.g., use of national releases) for use in member countries



IHTSDO Governance

- General Assembly - 1 vote per member country
 - Initial US member: Betsy Humphreys (Alt. Vivian Auld)
- Management Board (up to 12 members)
 - Now: 9 members: 1 per member country
 - NLMers cannot serve due to Contract;
 - Initial US member: Andrew Wiesenthal, MD, Kaiser (Alt. Simon Cohn, MD, Kaiser & Chair, National Committee on Vital and Health Statistics)



IHTSDO Governance

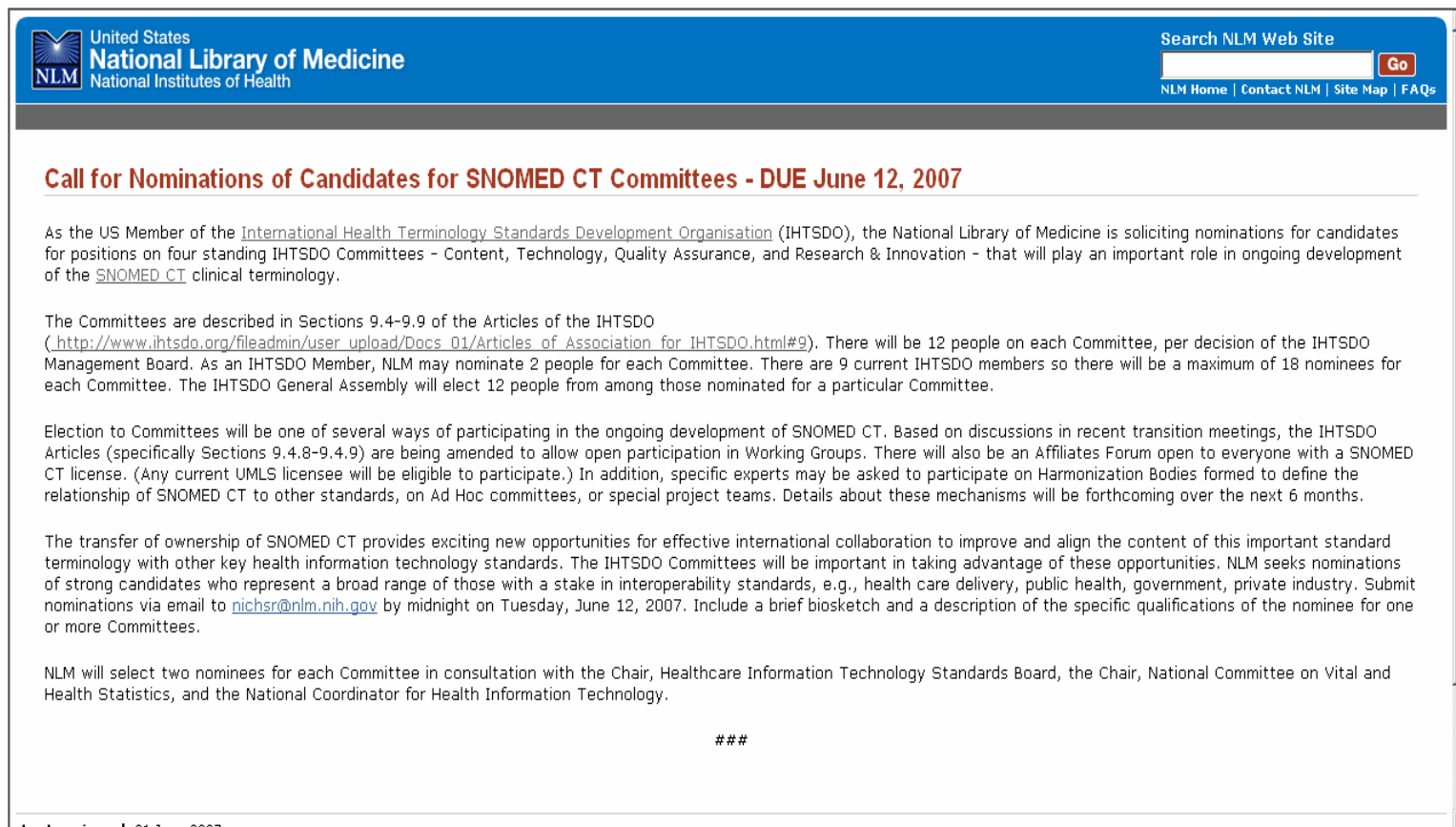
- Executive Officers
 - CEO, Chief Terminologist, Chief Technologist, Chief QA Officer
 - Initial *interim* appointments:
 - Ulrich Andersen (Den), CEO
 - Kent Spackman (USA), Chief Terminologist
 - International recruitment for permanent officers



IHTSDO Governance

- Committees: Content, Information Technology, Quality Assurance, R & D
- Harmonization Boards
 - Jointly established with other standards bodies, e.g., WHO, LOINC, etc.

Call for Nominations – Due 6/12/2007



The screenshot shows the top navigation bar of the National Library of Medicine website. On the left is the NLM logo with the text "United States National Library of Medicine National Institutes of Health". On the right is a search box labeled "Search NLM Web Site" with a "Go" button and links for "NLM Home", "Contact NLM", "Site Map", and "FAQs".

Call for Nominations of Candidates for SNOMED CT Committees - DUE June 12, 2007

As the US Member of the [International Health Terminology Standards Development Organisation](#) (IHTSDO), the National Library of Medicine is soliciting nominations for candidates for positions on four standing IHTSDO Committees - Content, Technology, Quality Assurance, and Research & Innovation - that will play an important role in ongoing development of the [SNOMED CT](#) clinical terminology.

The Committees are described in Sections 9.4-9.9 of the Articles of the IHTSDO (http://www.ihtsdo.org/fileadmin/user_upload/Docs_01/Articles_of_Association_for_IHTSDO.html#9). There will be 12 people on each Committee, per decision of the IHTSDO Management Board. As an IHTSDO Member, NLM may nominate 2 people for each Committee. There are 9 current IHTSDO members so there will be a maximum of 18 nominees for each Committee. The IHTSDO General Assembly will elect 12 people from among those nominated for a particular Committee.

Election to Committees will be one of several ways of participating in the ongoing development of SNOMED CT. Based on discussions in recent transition meetings, the IHTSDO Articles (specifically Sections 9.4.8-9.4.9) are being amended to allow open participation in Working Groups. There will also be an Affiliates Forum open to everyone with a SNOMED CT license. (Any current UMLS licensee will be eligible to participate.) In addition, specific experts may be asked to participate on Harmonization Bodies formed to define the relationship of SNOMED CT to other standards, on Ad Hoc committees, or special project teams. Details about these mechanisms will be forthcoming over the next 6 months.

The transfer of ownership of SNOMED CT provides exciting new opportunities for effective international collaboration to improve and align the content of this important standard terminology with other key health information technology standards. The IHTSDO Committees will be important in taking advantage of these opportunities. NLM seeks nominations of strong candidates who represent a broad range of those with a stake in interoperability standards, e.g., health care delivery, public health, government, private industry. Submit nominations via email to nichsr@nlm.nih.gov by midnight on Tuesday, June 12, 2007. Include a brief biosketch and a description of the specific qualifications of the nominee for one or more Committees.

NLM will select two nominees for each Committee in consultation with the Chair, Healthcare Information Technology Standards Board, the Chair, National Committee on Vital and Health Statistics, and the National Coordinator for Health Information Technology.

###

Last reviewed: 01 June 2007

http://www.nlm.nih.gov/news/snomed_candidates.html

What Will Be Different for U.S.?

- Annual fee NLM is paying may decrease over time
- UMLS users must review and accept new license terms (easy online process) – BY MAY 15, 2007
- SNOMED CT and its documentation will be available in native format from NLM (on MAY 15, 2007)
 - in addition to UMLS format
- Better international distribution rights for US users
- Good prospects for:
 - More transparent governance, priority setting
 - More efficient updating
 - International collaboration on subsets, tools, etc.
 - More commercial products

www.nlm.nih.gov/snomed



Next on the list for NLM & SNOMED CT

- New U.S. process for input to SNOMED CT development
 - Begin by coordination with existing NCVHS, HITSP, AHIC activities
 - Align LOINC and RxNorm development with SNOMED CT
 - Tightly integrated with feedback from real clinical implementations



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
- Get involved!
 - Contribute to standards development, testing, and refinement
 - Need studies evaluating the impact of standards on health care, public health, and clinical research
- Take advantage of the resources available from HHS, NLM, etc.