

Transition of SNOMED CT to the New International Organization

Betsy L. Humphreys, Deputy Director

Vivian Auld, Senior Specialist for Health Data Standards

National Library of Medicine

National Institutes of Health

U.S. Department of Health and Human Services

May 2, 2007

NLM/CAP_(College of American Pathologists) License

- 2003 NLM established a 5 year license with CAP for the use of SNOMED CT:
 - Continue to use and distribute the last version received under the license (perpetual usage rights)
 - Receive ongoing updates to the English and Spanish versions
 - Right to distribute through NLM's Unified Medical Language System (UMLS)
 - Freely available in the U.S, not internationally
 - Terms of agreement determined with extensive input/advice from HHS agencies, DoD, VA
-

US Objectives for Transition in Ownership

- Don't get less
- Don't pay more

US Focus –

- Rights/responsibilities of Members in International Organization
 - License terms
 - NO involvement in negotiations with CAP
-

Players in the Negotiations

- College of American Pathologists
 - 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
-



Ownership of SNOMED CT® transfers to IHTSDO®



Welcome to the IHTSDO® Website

Welcome to IHTSDO®, the International Health Terminology Standards Development Organisation.

SNOMED 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 Architect Henning Larsen.

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
-

Key Steps

- ❑ 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 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
 - Non-Member countries
 - Annual fee for each user (e.g., hospital) of a product containing SNOMED CT; set to make country membership desirable; cheaper in poorer countries
-

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

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; Other Feds need ethics review to determine
 - Initial US member: Andrew Wiesenthal, MD, Kaiser (Alt. Simon Cohn, MD, Kaiser & NCVHS)
 - Chair: Martin Severs (UK)
 - **Deputy chair: Karen Gibson (Australia)**
-

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
 - Committees: Content, Information Technology, Quality Assurance, R & D
 - Chairs will be Board members
 - Initial membership to be set in late May– Feds OK
-

IHTSDO Governance

- Harmonization Boards
 - Jointly established with other standards bodies, e.g., WHO, LOINC, etc.

“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
 - Required to check if additional requirements apply (e.g., use of national releases) for use in member countries
-

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 Information and pointers to:

- IHTSDO Articles of association
- Affiliate licence terms (in full or short summary)
- Procedures for updating existing UMLS License or obtaining a new one

Available at:

<http://www.nlm.nih.gov/snomed>
