Working Together to Advance Safe and Effective Interoperability

I Foro de Historia Clinica Electronica en el Sistema Nacional De Salud Programa

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IHTSDO: The Vision

- To enhance the health of human-kind by facilitating better health information management

- To contribute to improved delivery of care by clinical and social care professions

- To facilitate the accurate sharing of clinical and related health information, and the semantic interoperability of health records

Achieving the Vision will require

- A globally co-ordinated effort

- Agreement on a core terminology for recording and sharing of health information

- Pooling of resources to share the costs and benefits relating to the development and maintenance of the terminology products

- Consistent promotion of the uptake and correct use of the terminology

- Active harmonization activity with other SDOs

What is the IHTSDO?

- The IHTSDO is a Danish Association

- The Association is a registered not-for-profit entity in Denmark [23rd March 2007]

- Articles of Association detail the who, what, where and how of the Association

- The Association owns the intellectual property

- Intellectual property in SNOMED CT and antecedent works (SNOMED 3.5, RT etc.) transferred to the IHTSDO [26th April 2007]

Key things to understand (1)

- The Association owns SNOMED CT®, <u>not the Members</u>.

- Members govern the Association through the Articles of Association.

- All authority resides with/is derived from the General Assembly (GA).

- Most management decision-making delegated to the Management Board (and executive officers).

- Some decisions stay with GA (fees, business plans, strategy etc).

- Management Board is accountable to GA for all its decisions.

Intent:

- Members do not have a property right in SNOMED CT® that they could exert or exploit to the disadvantage of others.

- IHTSDO decision-making arrangements are effective, responsive, agile and accountable.
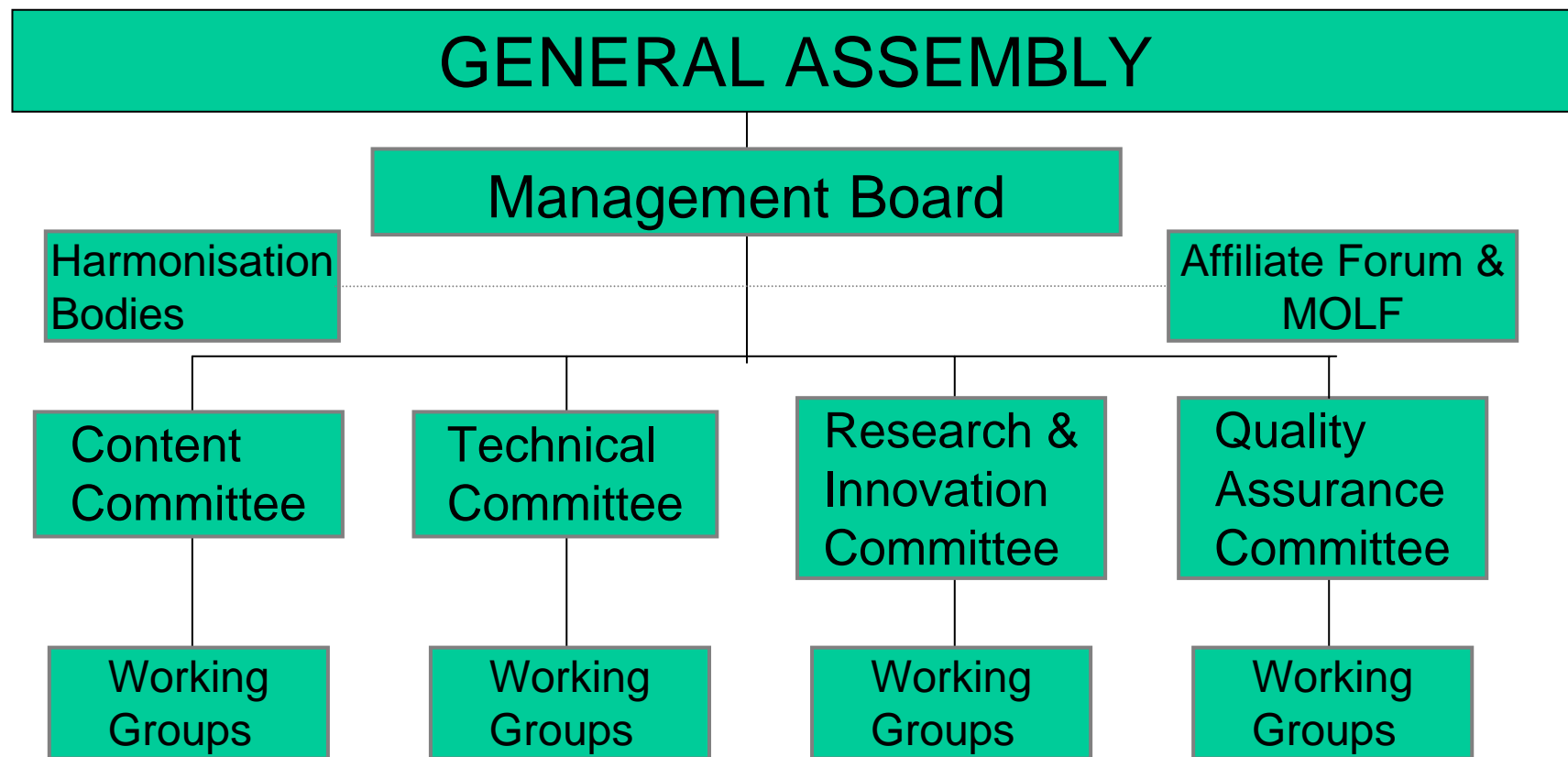
Key things to understand (2)

- Members are countries; through their designated agents

- Members pay Fees that are calculated based on a trusted third party metric namely the World Bank GNI Atlas

- Single form of end-user license (Affiliate License); started May 2007

- Affiliate License: Permits world-wide use of SNOMED CT

- Affiliates pay:

  - **NO fees** to IHTSDO for use in any Member nation. [Note: Cost-recovery is permitted by Members]

  - **Charges** as set by the IHTSDO for use in non-member nations

Note: The Articles have provisions to help the poorest countries without distorting the fundamental principle of a fair share funding model & support research

IHTSDO Structure

GENERAL ASSEMBLY

Management Board

Harmonisation Bodies

Affiliate Forum & MOLF

Content Committee

Technical Committee

Research & Innovation Committee

Quality Assurance Committee

Working Groups

Working Groups

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Working Groups

What is SNOMED CT?

- Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT): So-called "core" components:
  - Concept codes
  - Descriptions (terms)
  - Relationships
- A comprehensive clinical terminology covering diseases, clinical findings, and procedures
- Represents the meaning of concepts using formal definitions
- Helps to structure and computerize health records allowing for a consistent way of indexing, storing, retrieving and aggregating clinical data

Status Updates (1)

- IHTSDO provides new organizing structure
  - Broader participation and use, including by researchers
  - New ways to access and influence SNOMED CT
  - User-driven priorities for progress
  - Active discussions with potential new members & users – others always welcome!
- July 2008 Release
  - \> 315,000 active concepts, ~ 806,000 descriptions, > 1M defining relationships in international release
  - Continuous improvement focus

Status Updates (2)

- Multilingual and multi-cultural/dialect support
  - Guidelines for concept-based translation
  - Input from broader range of countries/cultures
    - Also opportunity for extensions and reference sets
  - Number of translations increasing
- Tooling and other supports
- Growing implementation base
  - New ways to access and use SNOMED CT
- Increasing range of harmonization activities

Terminology But Not Just Terminology

Just some of the challenges ...

- What is the patient's problem list?

- Is a new drug safe to prescribe?

- What are the latest test results?

- Is recommended preventive care due?

- How long are patients waiting?

- Are there emerging patterns in infectious disease outbreaks?

IHTSDO is a place where internationally where three communities can work towards international consensus;
Organisations: Policy, Care Provider, Care Commissioners, etc
Clinicians: Different Clinical Professions and Specialties, public health experts etc
Technical experts: Researchers, Vendors, Technical Leads, etc

Harmonization is a Founding Principle

- "The Association will seek to establish and maintain optimum mechanisms and organisational structures aimed at developing and achieving a high degree of interoperability and harmonisation between SNOMED CT and standards produced by International Standards Development Organisations other than the Association"

  - IHTSDO Articles of Association

Opportunities

- Drive from the user community to facilitate EHR development and adoption
  - Clearer use cases starting to emerge (vendors, national programs, users of systems)
- Address and harmonize areas of potential duplication
- Identify potential synergies and gaps
- Better leverage globally scarce expert resources
  - Many participate in multiple standards activities
- Increase efficiency of standards processes (and of harmonization!)

Challenges

- Relatively short history of effective harmonization activities for any SDOs
  - Priorities differ for different users and stakeholders
- Different governance, IP arrangements, ways of working, standards adoption processes, sustainability models
  - In some cases, historical barriers to joint work
- Significant up-front work on harmonization pulling on limited bandwidth even aside from technical harmonization activities
  - Opportunities to streamline with more experience

Where We Are Today (1)

- Focus on ensuring openness and transparency
    - Open access to Working Group materials and participation through the Collaborative Space
    - Special Interest Groups open to all
    - Mechanisms to facilitate global participation (e.g. local teleconference service, no registration fee to participate in IHTSDO conferences, increased access to SNOMED CT)
- Long-established joint activities with some SDOs that are continuing
- SNOMED CT increasingly embedded in industry and other standards
    - Growing implementation base

Where We Are Today (2)

- Establishing harmonization agreements with several SDOs and related organizations
  - Variety of models to respond to unique circumstances of different SDOs and user communities
  - Increasingly starting with template that speeds progress
  - More to come over time
- Liaison arrangements with other SDOs and related organizations
  - ISO Liaison A status
  - Establishing Memoranda of Understanding with several SDOs
  - More to come over time

A Wide Range of Relevant Organisations

- HL7
- OpenEHR
- WONCA
- ICH MedDRA
- ICN
- IEEE
- LOINC
- ADA
- Continua
- CDISC
- OHT
- ISO TC 215/ CEN TC 251
- IUPAC
- WHO Family of International Classifications

Working Together: The Road Ahead