INTERNATIONAL HEALTH TERMINOLOGY STANDARDS DEVELOPMENT ORGANISATION

# IHTSDO
## (aka “SNOMED SDO”)
# Recent Developments

Kent Spackman

# About me

- Current:
  - “Continuity” Chief Terminologist for IHTSDO
  - Clinical Professor of Pathology & Medical Informatics, Oregon Health & Science University, Portland, Oregon, USA
- Background primarily in academic medical informatics, and clinical pathology
  - MD – Canada. Primary care training.
  - PhD in CS, machine learning, U of Illinois
  - Specialty training and (former) practice in hematopathology, blood banking, transfusion medicine & coagulation
- 1997-2006 Scientific Director of SNOMED, for the College of American Pathologists

# About IHTSDO

- International Health Terminology Standards Development Organization

- Formed in Denmark, 23rd March 2007
  - 7 months old
- Area of standardization:
  - Terminology for interoperability of electronic health information

# The purpose of the IHTSDO

- To acquire, own and administer the rights to SNOMED CT and other relevant assets (collectively, the "**Terminology Products**");
- To develop, maintain, promote and enable the uptake and correct use of its Terminology Products around the world;
- To undertake activities required to achieve these purposes

# Status of 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
  - http://www.ihtsdo.org/about-us/governance/
- 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]

# Status of the IHTSDO

- Members are countries
  - Eligible Members are all voting members of the United Nations
- The Members control the organization and the Articles of Association; [subject to Danish Law]
- Nine Charter [initial] Members:

  Australia, Canada, Denmark, Lithuania, Netherlands, New Zealand, Sweden, United Kingdom, United States of America

# Status of the IHTSDO

- Physical office in the IT University in Copenhagen
  - Web site www.ihtsdo.org
- Three year support contract with the College of American Pathologists [First IHTSDO Release July 2007]
- New roles within the IHTSDO [at outset interim]; recruiting permanent posts
- At outset:
  - Chief Executive Officer [Ulrich Andersen]
  - Chief Terminologist [Kent Spackman]
  - Chief Quality Officer [Ed Cheetham]
  - Small number of administrative staff

# What's different now?

- Articles of association
- **2.3 Principles**
  - 2.3.1 The Association will seek to govern itself and conduct all of its activities in accordance with principles of openness, fairness, transparency and accountability to its Members.

# What's different now?

- Open collaborative working
- For access to IHTSDO committee documents, work groups, project groups and discussion forums:
  - Send email to support@ihtsdo.org

# What's different now?

- The Association's work is funded by annual Membership fees paid by the Member nations
  - "Fair share" is determined by World Bank GNI Atlas
- Use in Member territories does not carry an IHTSDO fee
- Use in non-Member territories comes under a single world-wide license (called an "affiliate license") [more on licensing later]
- SNOMED CT is much more available (no fees for evaluation or for qualifying research projects)

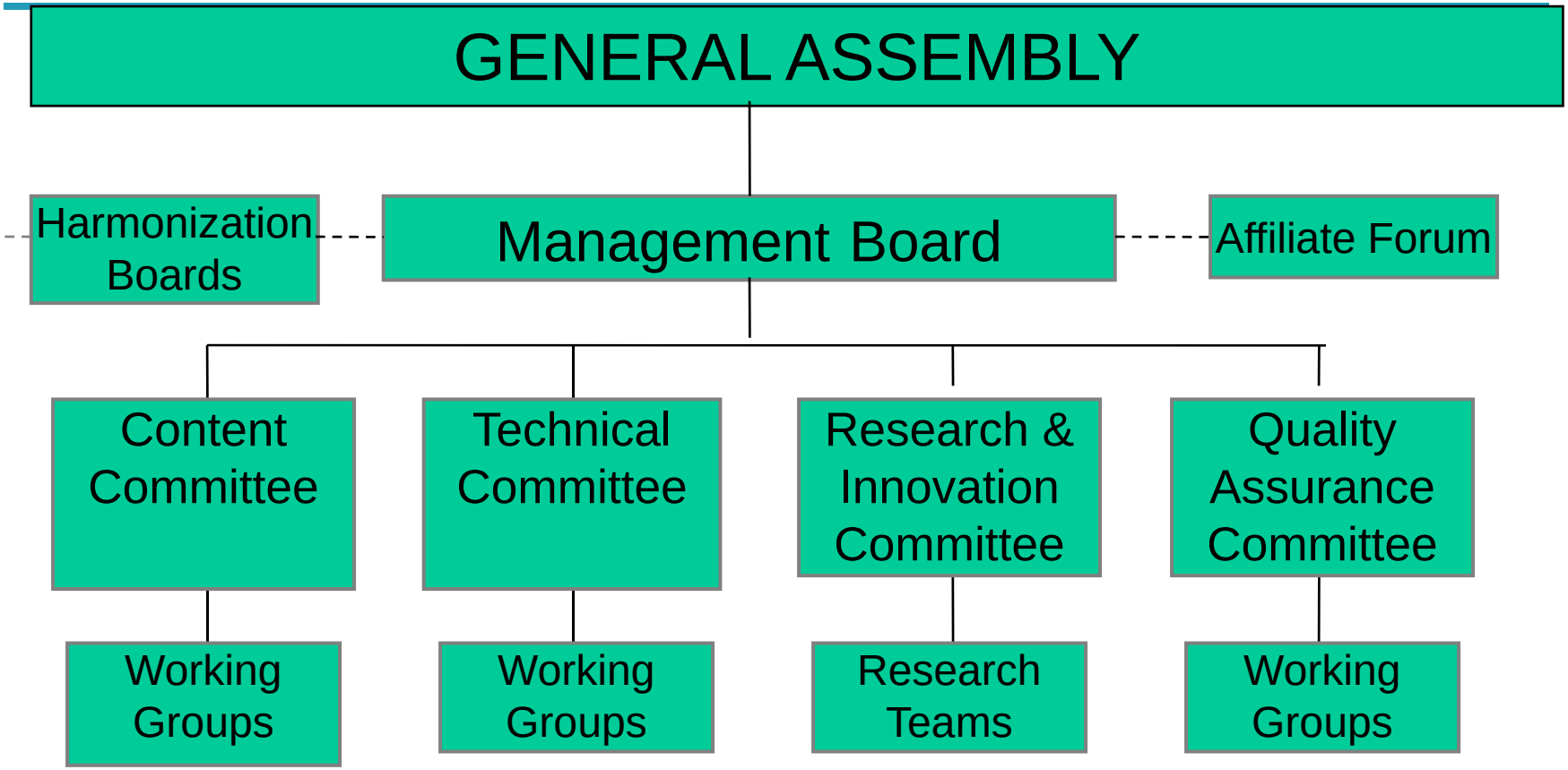
# What's different now?

- Genuine and increased intensity of efforts to cooperate and harmonize with other standards bodies
- Active discussions are ongoing with:
  - HL7, LOINC, IUPAC, WHO, WONCA
- Other contacts have been made or are planned between IHTSDO and:
  - CEN, ISO, IHE, openEHR, RadLex, & others

# What's different now?

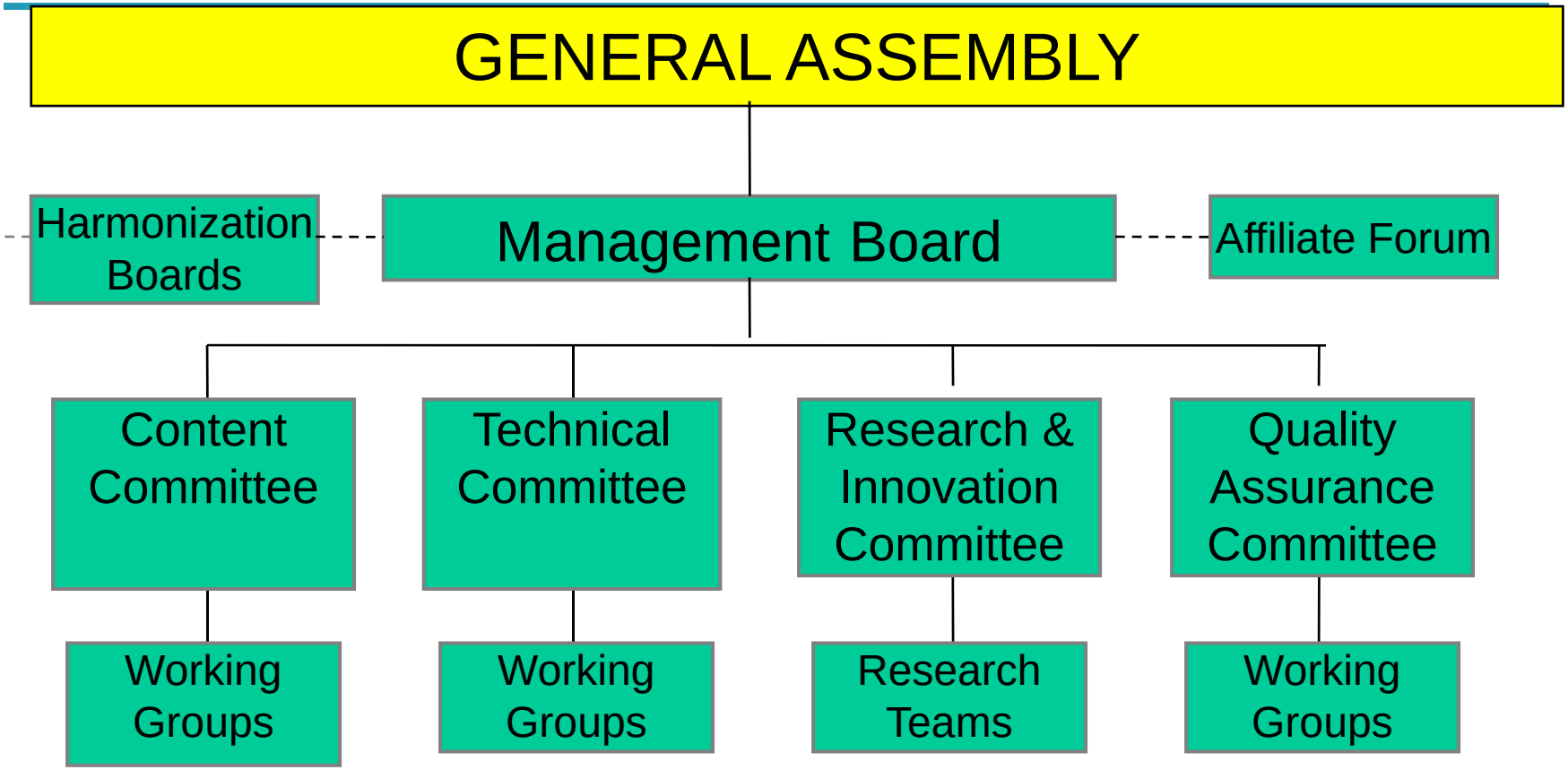
- Role of the College of American Pathologists
  - Support Organization, by contract (3 years)
  - Perform maintenance and release
  - NO governance responsibility
  - Name change to reflect changed role and status
    - SNOMED Terminology Solutions (CAP STS)

# IHTSDO Organizational Structure




IHTSDO Status 30th Oct 2007

# IHTSDO Organizational Structure

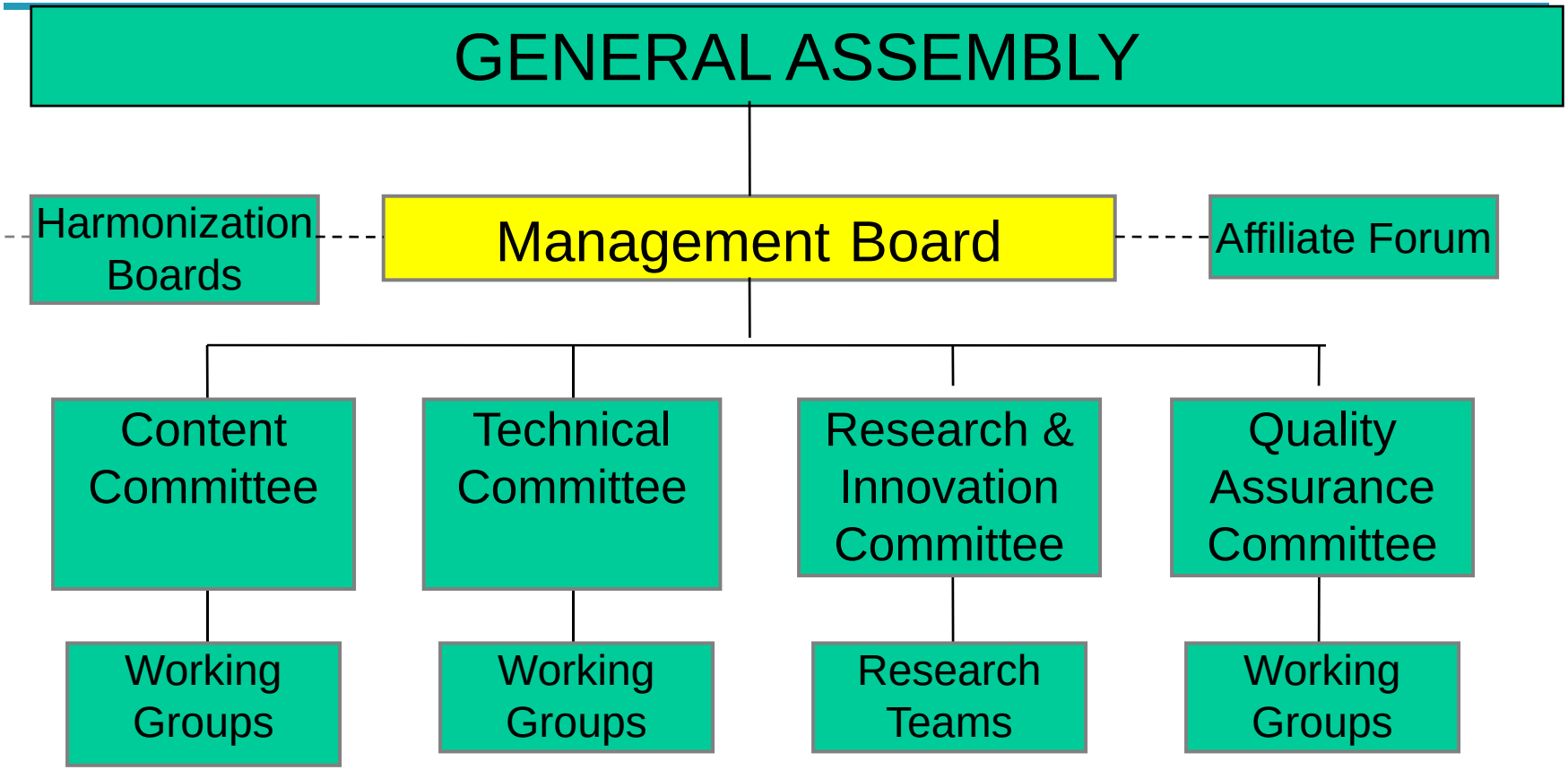



IHTSDO Status 30th Oct 2007

# General Assembly

- Each Member appoints a representative to the General Assembly
- The General Assembly governs the Association (the SDO).
- Meets twice per year April and October
  - Approves Budget, Work Plan, Management Board and Committee members;
  - Reviews Annual Report and annual audited accounts
- Met four times this year [fourth meeting in Copenhagen a few days ago]
- Meetings of the General Assembly are open to the public

# IHTSDO Organizational Structure

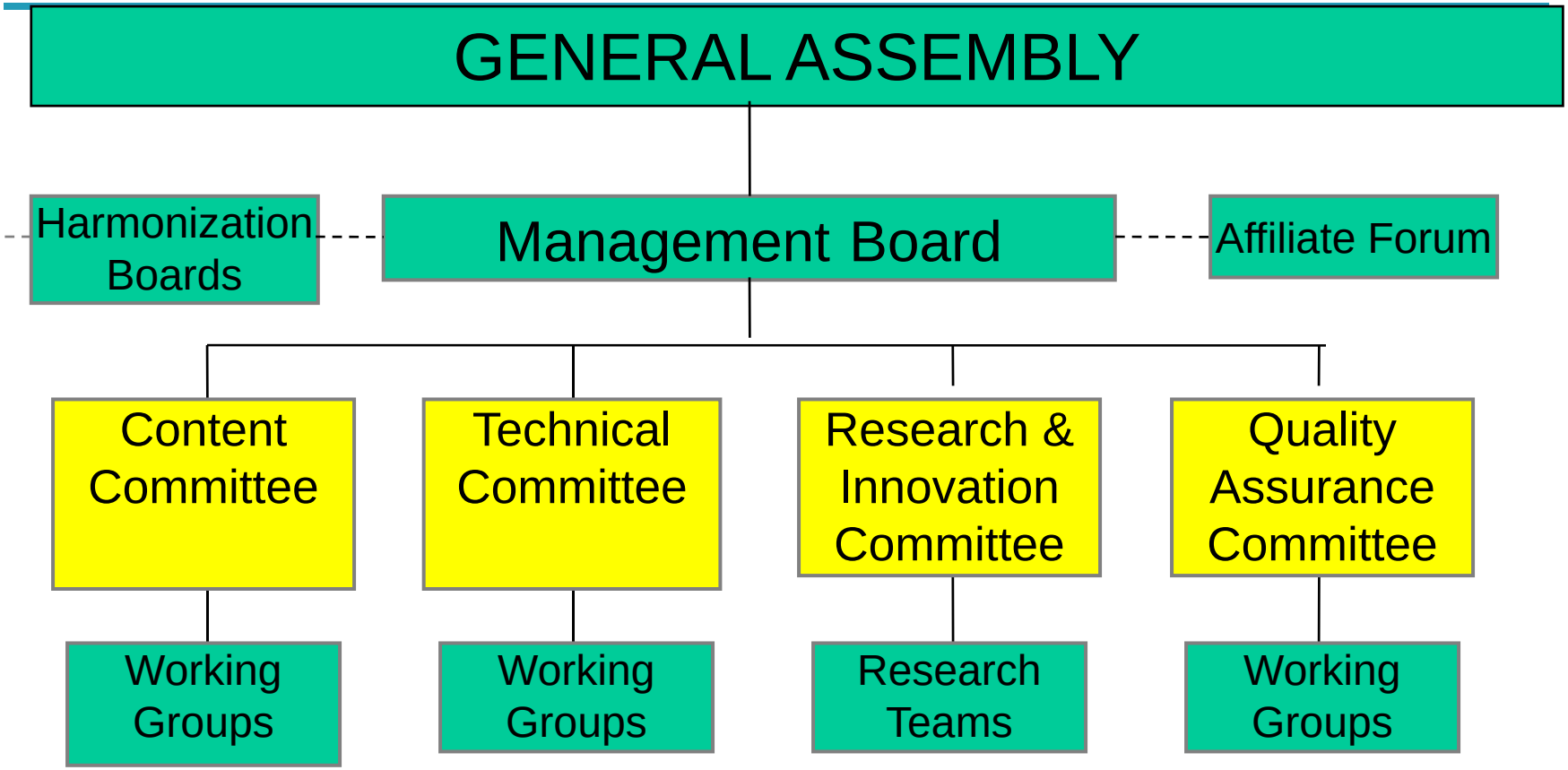



IHTSDO Status 30th Oct 2007

# Management Board

- Members of the Management Board are elected by the General Assembly (GA)
- Number of Directors is from 3 to 12 (GA determines)
  - Currently nine (one from each Charter Member)

# IHTSDO Organizational Structure

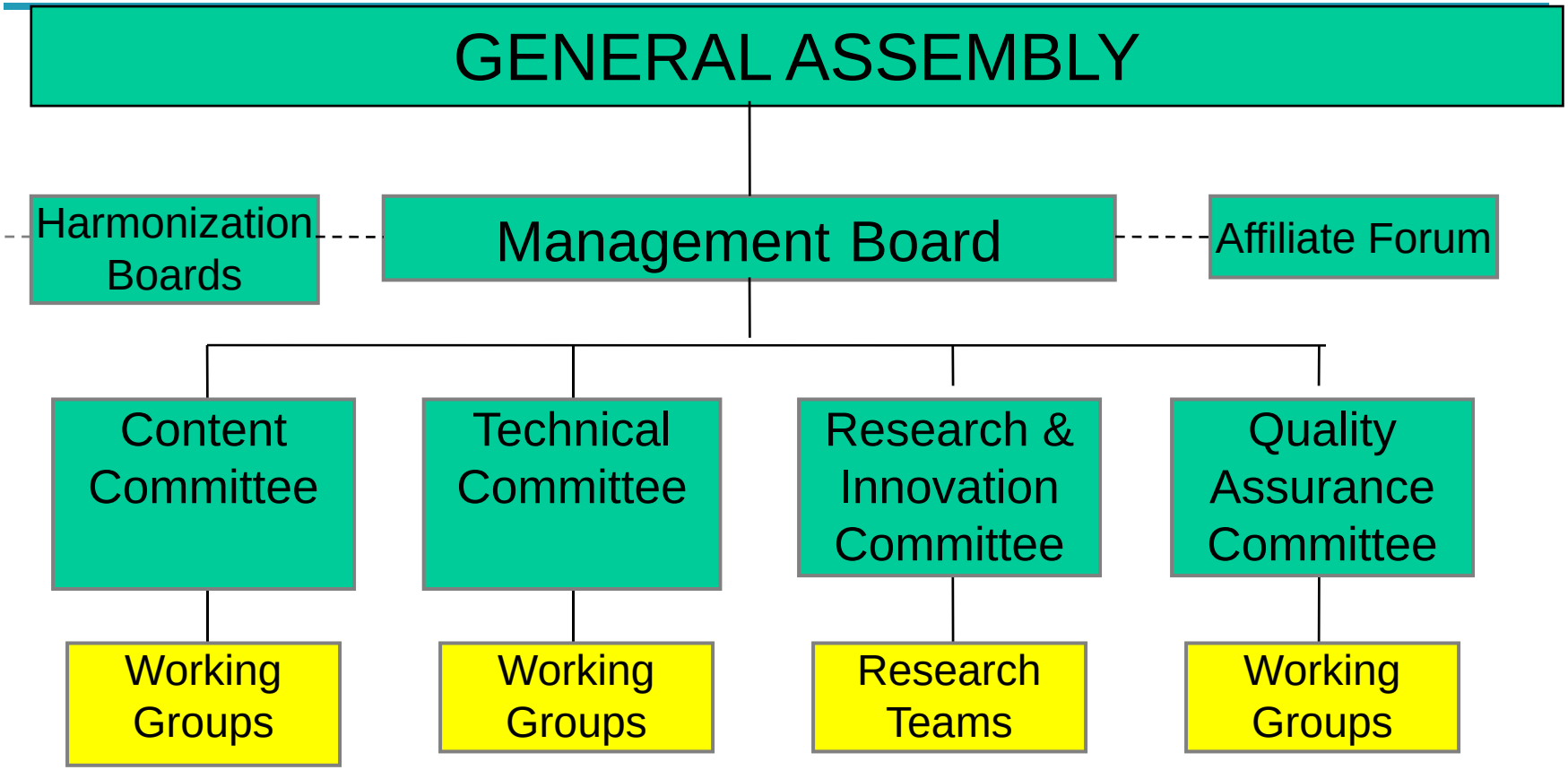



IHTSDO Status 30th Oct 2007

# Committees

- Four Standing Committees
  - Content
  - Technical
  - Research & Innovation
  - Quality assurance
- Committee members are elected by the General Assembly
- Worthy of note that Members have nominated and individuals have been elected from outside Member jurisdictions
  - E.g.: Stefan Schulz – Content Committee
- Committee meetings are also open to the public (but only elected committee members have a blanket right to participate)

# IHTSDO Organizational Structure

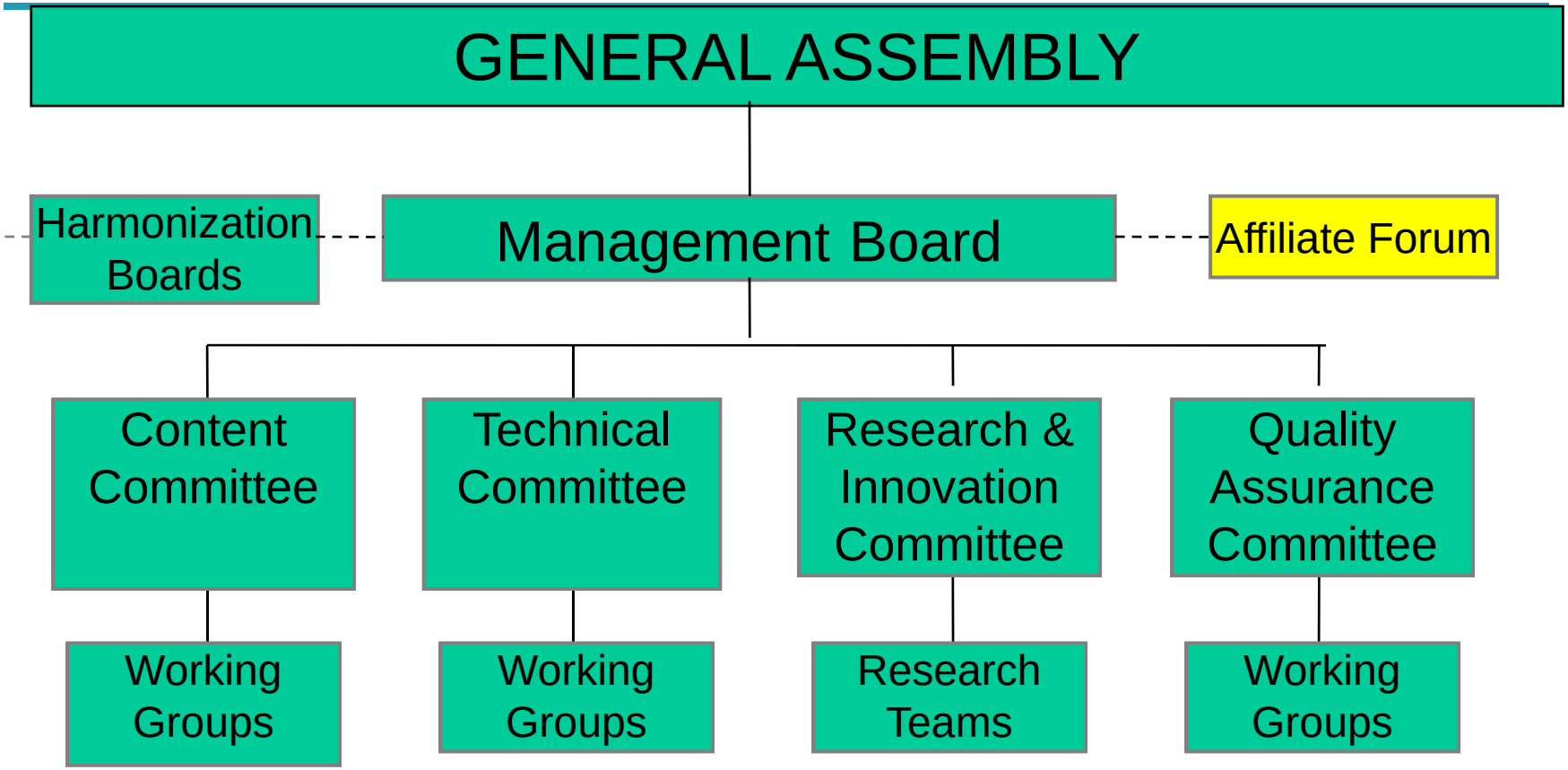



IHTSDO Status 30th Oct 2007

# Working Groups

- Transition from old to new complete
- Two types of Working Group [both are entirely open]
  - **Project Group**: [Task focused]
  - **Special Interest Group** (SIG): [Domain focused e.g. profession (nursing), specialism (mapping)]
- First Global Profession SIG for Pathology and Laboratory Medicine- September [Special thanks to World Association of Societies of Pathology and Laboratory Medicine]
- New Working Groups already set up:
  - SIGs: Nursing, Primary Care, Mapping, Translation, etc.
  - PGs: Collaborative work space; Allergen class modeling; etc.
  - Total so far = 19 [SIG:9 & PG:10]

# IHTSDO Organizational Structure




IHTSDO Status 30th Oct 2007

# Affiliates

- What is an “affiliate”?
  - Anyone other than a member nation who has a license (the “Affiliate License”) for use of IHTSDO Terminology Products
- What is the affiliate license?
  - The single world-wide license for use of SNOMED CT
    - http://www.ihtsdo.org/about-us/governance/licensing/

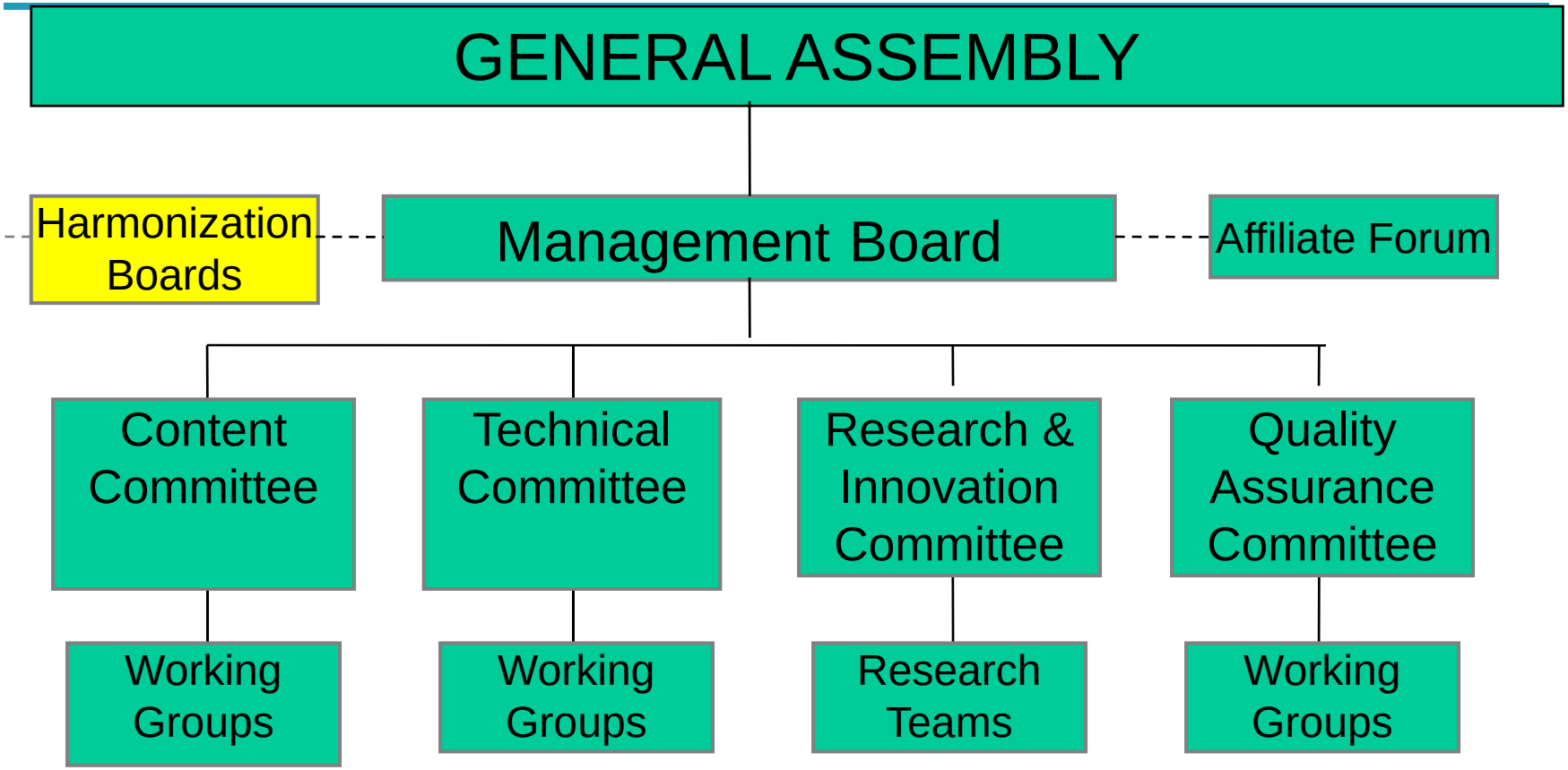
# Licensing of SNOMED CT

- Single form of end-user license (Affiliate License)
- SNOMED CT will be made much more available for research purposes
- Permits world-wide use of SNOMED CT
- Affiliates pay:
  - **NO fees** to IHTSDO for use in any Member nation. All obligations are met by the Member through their IHTSDO membership agreement. Cost-recovery is permitted
  - **Charges** as set by the IHTSDO for use in non-member nations

# Licensing of SNOMED CT

- The Articles have provisions to help the poorest countries without distorting the fundamental principle of a fair share funding model
- Charges are based on broad categories of affiliate use e.g. per hospital AND are banded according to World Bank GNI Atlas [i.e cheaper in poorer countries]
  - Charges and fees are published on the IHTSDO web site
- Aim; Simplicity and cost minimization of licensing effort [for the IHTSDO AND Affiliates]

# IHTSDO Organizational Structure




IHTSDO Status 30th Oct 2007

# Harmonization Boards – Recent Efforts

- HL7
  - Positive discussions, Aug. in Brisbane, Sept. in Atlanta
  - Discussions propose joint endorsement of Terminfo work product as a standard
- WHO
  - Positive discussions, August 2007 Brisbane
  - Milestones and high level work proceeding
  - Goal to have a joint harmonization board begin in February 2008
- LOINC
  - Positive discussions Sept Atlanta & after
  - Detailed preparatory work proceeding; no milestones yet agreed
- IUPAC
  - Detailed preparatory work – October 2007
- WONCA

# WHO FIC & IHTSDO Harmonization Board

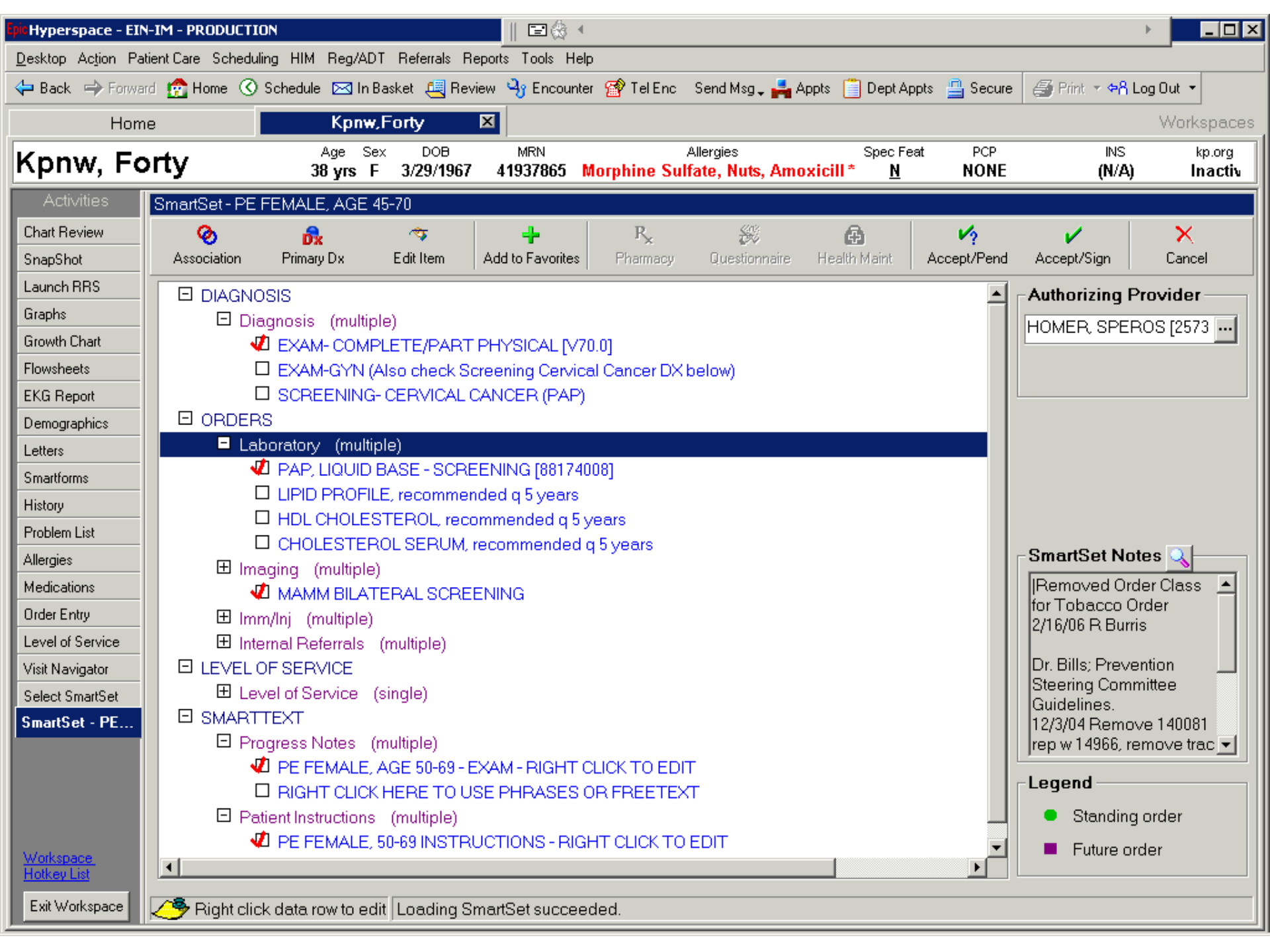
- Discussions and a formal workshop between IHTSDO & World Health Organization Family of International Classifications (WHO FIC) representatives
- Initial Agreement on:
  - Product: A set of high quality, maintained mappings between SNOMED CT and WHO FIC Classifications to meet the stated use cases
  - Scope: WHO owned international classifications
  - Priority: ICD 10 second edition
  - Use cases for priority
  - Integrated and shared process for progress [organizational and technical]
- Goal: To have the initial 'WHO FIC & IHTSDO Harmonization Board' on February 4th 2008

# What is SNOMED CT for?

- Semantic interoperability of health data

# Are there SNOMED implementations?

- There is no such thing as a SNOMED Implementation, but
- There are implementations of electronic health record systems that utilize SNOMED CT


Epic Hyperspace - EIN-IM - PRODUCTION
Desktop Action Patient Care Scheduling HIM Reg/ADT Referrals Reports Tools Help
Back Forward Home Schedule In Basket Review Encounter Tel Enc Send Msg Appts Dept Appts Secure Print Log Out
Home
Kpnw,Forty
Workspaces
Kpnw, Forty
Age 38 yrs
Sex F
DOB 3/29/1967
MRN 41937865
Allergies Morphine Sulfate, Nuts, Amoxicill *
Spec Feat N
PCP NONE
INS (N/A)
kp.org Inactiv
Activities
Chart Review
SnapShot
Launch RRS
Graphs
Growth Chart
Flowsheets
EKG Report
Demographics
Letters
Smartforms
History
Problem List
Allergies
Medications
Order Entry
Level of Service
Visit Navigator
Select SmartSet
SmartSet - PE...
Workspace Hotkey List
Exit Workspace
SmartSet - PE FEMALE, AGE 45-70
Association
Primary Dx
Edit Item
Add to Favorites
Pharmacy
Questionnaire
Health Maint
Accept/Pend
Accept/Sign
Cancel
DIAGNOSIS
Diagnosis (multiple)
EXAM- COMPLETE/PART PHYSICAL [V70.0]
EXAM-GYN (Also check Screening Cervical Cancer DX below)
SCREENING- CERVICAL CANCER (PAP)
ORDERS
Laboratory (multiple)
PAP, LIQUID BASE - SCREENING [88174008]
LIPID PROFILE, recommended q 5 years
HDL CHOLESTEROL, recommended q 5 years
CHOLESTEROL SERUM, recommended q 5 years
Imaging (multiple)
MAMM BILATERAL SCREENING
Imm/Inj (multiple)
Internal Referrals (multiple)
LEVEL OF SERVICE
Level of Service (single)
SMARTTEXT
Progress Notes (multiple)
PE FEMALE, AGE 50-69 - EXAM - RIGHT CLICK TO EDIT
RIGHT CLICK HERE TO USE PHRASES OR FREETEXT
Patient Instructions (multiple)
PE FEMALE, 50-69 INSTRUCTIONS - RIGHT CLICK TO EDIT
Authorizing Provider
HOMER, SPEROS [2573
SmartSet Notes
|Removed Order Class for Tobacco Order 2/16/06 R Burris
Dr. Bills; Prevention Steering Committee Guidelines.
12/3/04 Remove 140081 rep w 14966, remove trac
Legend
Standing order
Future order
Right click data row to edit
Loading SmartSet succeeded.

# Decision support

- Central to the Value of Semantic Interoperability
  - Numerous studies document the ability of computerized decision support to decrease costs and improve quality
  - But use is limited
  - One major barrier is lack of standardization
  - Clinical terminology standards help fill this need
    - but we aren't there yet

# Terminology enables decision support:

## influenza vaccination

- decision support program criterion:
  - chronic cardiorespiratory disorders
- patient record:
  - mild persistent asthma

# Terminology enables decision support:

## hemoglobin $A_1C$ interpretation

- decision support program asks for:
  - hereditary anemia due to disturbance of hemoglobin synthesis

- patient record says:
  - $A\gamma\ \beta^{+}$ HPFH and $\beta^{0}$ thalassemia in cis

# Terminology enables decision support:

## antibiotic therapy

- decision support program asks for:
  - bacterial effusions

- patient record says:
  - tuberculous ascites

# State of the art?

- Currently implemented systems are a long way from standardized delivery of semantic interoperability of clinical data

# What's the problem?

- No single barrier
  - Inertia of existing systems
  - Cost of change & lack of clear return for investments in change
  - Barriers due to questions about standards:
    - Choice of different standards for same purpose
    - Inadequate coordination between those with different purposes (e.g. terminology vs. information model)
    - Quality, reliability, and implementability

# Categories of Standards to Support Interoperability

- Data exchange / messaging
- Terminology standards
- Document standards
- Information Model / EHR standards
  - Architecture standards
  - Application standards

# Terminology – information model interactions

- Some of the key standards:
  - HL7
    - RIM & CDA: Terminfo project
  - ISO/EN 13606
  - *open*EHR
  - Archetypes
  - IHE XDS

# Terminology – information model interactions

- Basic tasks of “terminfo” project
  - Identify gaps and overlaps
  - Design a strategy to
    - Fill the gaps
    - Manage the overlaps
  - Demonstrate implementability

# Act.code & Observation.value (1)

- HL7 theory
  - code → nature of observation
  - value → value of the observation
- Practical implementation
  - Simple for numeric observations
    - Hemoglobin level (code) = 14g/dL (value)
  - Reasonable for observations with coded results
    - Visual acuity (code) = Can count fingers (value)
  - Tricky for observations where the distinction between the nature and value is arbitrary
    - "Blood group AB" could be …
      1. ABO Blood grouping (code) Blood group AB (value)
      2. Blood group A antigen (code) Present (value)
         *and* Blood group B antigen (code) Present (value)
      3. Blood group AB (code)

# Act.code & Observation.value (2)

- The code-value split is even more arbitrary for general clinical observations
- For example
  - Finding of abdominal tenderness …
    1. Examination (code) abdomen tender (value)
    2. Abdominal examination (code) abdomen tender (value)
    3. Abdominal palpation (code) abdomen tender (value)
    4. Abdominal tenderness (code) present (value)
    5. Abdomen tender (code)

# Code and value - guidance

- HL7 code and value distinction should be used for
  - Numeric and non-numeric results of measurement procedures
- A single coded attribute should express the full semantics
  - If there is no non-arbitrary reproducible distinction
  - Recommended Implementation
    - Act.Code = ASSERTION
    - Observation.Value = Coded SNOMED expression
- Rationale
  - SNOMED CT clinical findings are
    - not  just the value of a particular type of observation
    - equivalent to an observable or observation type with a value

# Interoperability - summary

- Interoperability depends on standards
- There are important interactions of terminology and information model standards
  - Sorting them out is a prerequisite to implementation
    - And therefore a prerequisite to standardization

- IHTSDO welcomes harmonization initiatives

# IHTSDO Summary

- New International Standards Development Organization
  - Members are Nations
  - Nine current members
  - More are likely to join (and are very welcome!)
- Scope is Health Terminology
  - Clear interactions with other standards
  - Focus is supporting health records interoperability
- Major recent changes
  - International governance, openness and availability
- Questions?