ICD Revision Process: Building the infrastructure of ICD -11

Dr. T. Bedirhan Üstün
Classifications, Terminologies, Standards

Aggregated Statistics 1665
WHO Family of Classifications

REFERENCE Classifications

- International Classification of Diseases
- International Classification of Functioning, Disability & Health
- International Classification of Health Interventions (under development)

DERIVED Classifications

- International Classification of Diseases for Oncology, Third Edition (ICD-O-3)
- The ICD-10 Classification of Mental and Behavioural Disorders
- Application of the International Classification of Diseases to Dentistry and Stomatology, Third Edition (ICD-DA)
- Application of the International Classification of Diseases to Neurology (ICD-10-NA)
- ICF, Children & Youth Version (ICF-CY)

RELATED Classifications

- International Classification of Primary Care (ICPC)
- International Classification of External Causes of Injury (ICEI)
- The Anatomical, Therapeutic, Chemical (ATC) classification system with Defined Daily Doses (DDD)
- ISO 9999 Technical aids for persons with disabilities – Classification and Terminology
Placing WHO Classifications in HIS & IT

Population Health
- Births
- Deaths
- Diseases
- Disability
- Risk factors

Clinical
- Decision Support
- Integration of care
- Outcome

Administration
- Scheduling
- Resources
- Billing

Reporting
- Cost
- Needs
- Outcome

ICD ≈ Common Language? Pseudoconsensus?

- Communication: ↑↓
  - Mutual data exchange ↔ Confusion
- Research & Science: ↑↓
  - Common framework ↔ Straitjacket
- Clinical utility: ↑↓
  - Reliable assessment ↔ Reductionism
- Public Health: ↑↓
  - Guides decision making ↔ Conformism
- Human Rights: ↑↓
  - Protection ↔ Discrimination & Stigma
Problems with ICD

1. No standard of knowledge representation
2. No linkages with health terminology and ontologies
3. Driven by billing and mortality use cases
4. Does not interoperate with eHR
5. Used in 117 out of 193 countries for official statistics
6. Limited web presence – utility for masses

Construction of ICD-10: Revision Process

- 8 Annual Revision Conferences (1982 - 89)
- 17 – 58 Countries participated
  - 1-5 person delegations
  - mainly Health Statisticians
- Manual curation
  - List exchange
  - Index was done later
- "Decibel"? Method of discussion
- Output: Paper Copy
- Work in English only
- Limited testing in the field
Construction of ICD-11: Revision Process

- Internet-based permanent platform
  - All year round
  - Open to all people in a structured way
  - Content experts focus

- Digital curation
  - Wiki enabled collaboration
  - Ontology based

- Enhanced discussion & peer review
  - TAGs serve as the editorial group

Electronic copy → print version

- Work in multiple languages

- Planned field tests
  - Based on Use Cases

Tentative Timeline

- 2010: Alpha version (ICD 11 alpha draft)
  - +1 YR: Commentaries and consultations

- 2011: Beta version & Field Trials Version
  - +2 YR: Field trials

- 2013: Final version for public viewing
  - 2014: WHA Approval

- 2015+: implementation
ICD-11 Revision Goals

1. Evolve a multi-purpose and coherent classification
   - Mortality, morbidity, primary care, clinical care, research, public health...
   - Consistency & interoperability across different uses

2. Serve as an international and multilingual reference standard for scientific comparability and communication purposes

3. Ensure that ICD-11 will seamlessly function in an electronic health records environment.
   - Link ICD logically to underpinning terminologies and ontologies (e.g. SNOMED, GO, ...)
   - ICD Categories “defined” by “logical operational rules” on their associations and details

ICD-11 Revision Organization Structure

WHO

Update & Revision Committee

Revision Steering Group

- Mental Health
- External Causes
- Rare Diseases
- Neoplasms
- Internal Medicine

New TAGs

- Neurology
- Musculoskeletal
- Ophthalmology
- Maternal - Gender
- Dermatology
- Dentistry
**Definition of Disease**

a set of dysfunction(s) in any of the body systems including:

- with a known pattern of signs, symptoms & findings
  - symptomatology - manifestations
- probably with an underlying explanatory mechanism
  - etiology
- a distinct pattern of development over time
  - course and outcome
- a known pattern of response to interventions
  - treatment response
- with linkage to underlying genetic factors
  - genotypes, phenotypes and endophenotypes
- with linkage to interacting environmental factors

---

"One day I read a book and whole my life changed."
Orhan Pamuk, Nobel Literature Laureate, 2006.
What is Ontology?

- Ontology (philosophy)
  - the Organization of Reality
- Ontology (computer science)
  - the explicit – operational description of the conceptualization of a domain:
    - Concepts: entity and quality (properties and attributes)
- An ontology defines:
  - a common vocabulary → a shared understanding/exchange:
    - among people
    - among software agents
    - between people and software
    - to reuse data - information
    - to introduce standards to allow interoperability

ICD-11 Alpha Draft Vision

An Electronic Product

- A Database
  - DIGITAL KNOWLEDGE BASE
  - INTEROPERATING ONTOLOGY SET
- Architecture:
  ~ 15,000 + n Categories
  16 ± n Parameters
THE CONTENT MODEL

Any Category in ICD is represented by:

**Title of Entity:** Name of disease, disorder, or syndrome...

1. **Textual definition**
2. **Synonyms - Inclusion – Exclusion - Index terms**

### Descriptive characteristics

1. **Type**
   - Disease, disorder, syndrome, injury, sign/symptom, external cause, reason for encounter;
2. **Body System(s)** *(pathophysiology)*
3. **Body Part(s)** *(anatomical site)*
4. **Manifestation Attributes**
   - a. Signs & Symptoms
   - b. Diagnostic Findings
5. **Etiology**
   - a. Causal Mechanisms /Agents
   - b. Genomic characteristics
6. **Temporal Properties**
7. **Severity and/or Extent**
8. **Functional Impact**
9. **Treatment**

### Maintenance attributes

A. Unique identifier
B. **Subset, adaptation, and special view flag**
   1. Primary Care
   2. Clinical Care
   3. Research
   4. Special indices (e.g., Public Health Indices or Resource Groupings)
C. **Hierarchical relationships**
   - Parents and children in ICD structure
D. **Mapping relationships**
   - Linkages to other systems like SNOMED etc.
E. **Other rules**
"Semantic Cloud" & "Multiple Tabulations"

Mortality version

<table>
<thead>
<tr>
<th>C15</th>
<th>Malignant neoplasm of oesophagus</th>
</tr>
</thead>
<tbody>
<tr>
<td>C16</td>
<td>Malignant neoplasm of stomach</td>
</tr>
<tr>
<td>C17</td>
<td>Malignant neoplasm of small intestine</td>
</tr>
<tr>
<td>C18</td>
<td>Malignant neoplasm of colon</td>
</tr>
</tbody>
</table>

Primary Care version

Digital ICD-11

ICD entities

ICD Category Definitions
Structured according to the CONTENT MODEL

Knowledge base

ontology

ICD concepts

ICD Presentations
- Mortality List
- Morbidity List
- Primary Care

Publication
Rewriting ICD Using SNOMED
example of Depressive Disorder F32.0

A. Low mood
   - Loss of interest (417523004)
   - Low energy (248274002)

B. 1. Appetite (decrease, increase) (64379006, 72405004)
   2. Body weight (decrease, increase) (89362005, 8943002)
   3. Sleep (decrease, increase) (59050008, 77692006)
   4. Psychomotor (decrease, increase) (398991009, 47295007)
   5. Libido loss (8357008)
   6. Low self esteem (286647002, 162220005)
   7. Guilt, self blame (7571003)
   8. Thoughts of death …
   9. Suicide Ideation (102911000, 6471006)

Classifications, Terminologies, Standards
… Building Blocks of Health Information …

Proposed TAG Editorial Function
Workflow Management

Managing Editor
Postmaster

Peer Review
Min 3 reviews – 2 approvals

Filter

TAG Review

Other TAGs

OK

RSG
ICD11 Use-Cases

1. Mortality
2. Morbidity
3. Case Mix Groupings
4. Primary Care
5. Quality and Safety
6. Scientific definition of Clinical Phenotypes

What do user wish to do with ICD-11?

- Record data
- Capture data from records
- Annotate data
- Link data
- Mine data
- Aggregate data
- Model possible diseases
- Create subsets, serializations,
- Use for decision support
- …
Public Health Use Case
Data Aggregation across populations – settings

- **Search using Concepts** above Words
- **Extraction of Concepts** from Health Records
- **Statistical Index on Community** Collections
- **Concept Navigation** across Collections

---

**The Picasso Test:**
*Can you make computers understand ICD?*

Computers are stupid:
- They cannot **ask questions**
- They may –if they can-- only **give you answers**.

*Pablo Picasso*
Use Case 1: Mortality Statistics

**Analogue Information System**

- **Certification of death** by:
  - Medical Doctor
  - Coroner
  - Lay etc.

- **Codification**
  - **Selection of COD** by:
    - Manual Data Entry
    - Medical Coders
    - Medical Doctors
    - Scanning
    - Computer assistance

**Digital Information System**

- **Certification of death** in eHR by:
  - Medical Doctor
  - Coroner
  - Lay etc.

- **Codification**
  - **Selection of COD** in eHR assisted by:
    - Computers

- **Computerization**
  - Additional Benefits:
    - Standardisation
    - Accuracy
    - Population Aggregation
    - Efficiency

Becomes redundant
Exploration of Cough

- Fever
- WET COUGH
  - sputum
  - Hemoptisia
    - Blood in Sputum
      - X-ray: Tbc?
      - Culture
      - Diagnosis: Tuberculosis
      - Treatment: DOTs

A Harriet disease network

Node size:
- 41
- 34
- 30
- 25
- 21
- 15
- 10
- 5
- 1
Synthesis of all “Health Information levels”
Integrating biomedical data
ICD-11 Start-Up Linearization

*editing ICD-10 tree structure*

- Add extensions of all Clinical Modifications
- Other Independent Proposals from ICD-10 +
  - Add a new entity
  - Delete an entity
  - Split a class(es)
  - Merge classes
  - Prune and Graft a branch / subtree
  - Move a set of classes to different location(s)
  - Create a new abstraction
  - Link two formerly unidentified categories
  - Identify new superclasses
- Record/capture reasons for these changes
- Identify rules for application

Population of Content Model

- Add all existing related information
- Open up for extended outside entry
- Evaluate if use case requirements are met in pilot applications
- Start
  - Peer Review Process
  - TAG Editorial functions
- Prepare & Test
  - larger scale web2.0 collaboration & social networking
**What does WHO want?**

- **Meaningful exchange** of health information
  - Enable **aggregation of health information** from different sources

- **One stop-shop** for different users / developers
  - In multiple languages

- **Crystallization spiral for knowledge representation**
  - formalization → **conceptualization** → formalization
    - Linkages between different domains of health information
    - **Translational research** tool + semantic zooming

**ICD-11**

- **A reference ontology-set**
  - provision of **semantics** to enable users to interpret descriptions in a consistent manner

- **Provision of possible services** (implementations of the semantics) for:
  - classification
  - terminology
  - linkages (aka mappings)
  - Annotations
    - For use cases such as:
      - Mortality coding
      - Morbidity coding
      - Billing
      - Safety
      - Quality monitoring
      - Scientific Definition of a phenotype
WHO Commitment

• Collaborative development
  – Content expertise
  – Social computing

• Open Public Good
  – Free access / Free of charge for public use

• Evidence based classification
  – Links with Public Evidence Sources (PubMED, …)

• Ontology supported linkages
  – Linkages with GO, SNOMED CT...

• Continuous Quality Improvement
  – Evaluation
  – Update and maintenance

Issues at Classification – Terminology linkages:
Symptoms & signs

– There is no point to separate “symptom” and “sign”
– It will be useful to record the source of information when that is explicit
  • subject
  • observer
  • Carer
**Diagnosis & Disorder / Disease**

- “Diagnosis” is used as a provider based pattern name
  - Useful as a summary construct
    - By providers
    - By patients
  - It may or may not be the same as disease
    - May include reason for encounter or other entities
    - May be mis-diagnosis
  - It is frequently used for DRGs administratively

**Terminology Classifications Linkages and Dynamics**

- There is no single best way to link classifications and terminologies
- The best we can do is:
  - recognize the rules how constellations occur
  - express them in a logic-based model
- This logic does not merely apply to the ontological model of the terminology
- But also to the classifications.