ICD-11 in eleven points
An update
James Harrison
ICD-11 in ten points
An update
James Harrison
Acknowledgement

Draws on presentations by Bedirhan Ustun, Chris Chute, Can Celik and Tania Tudorache and WHO Web-site.
1. What, why & when?

- The World Health Assembly has given the WHO office the task of producing the eleventh revision of the ICD. Announced in 2007.
- Twenty years have passed since the tenth revision was published. Much has changed:
  - Subject matter: e.g. due to better understanding of the genetic basis of some diseases
  - Context: e.g. the rise of electronic health records & terminologies (n.b. SNOMED)
- ICD-11 is due to be presented to the WHA for endorsement in May 2015.
  - Implementation? Some time after that…
  - But some ICD-11 developments are likely to ‘leak’ into ICD-10
Construction of ICD-10:
Revision Process in the 20th Century

- 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 in the 21st Century

• 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
2. Players

- WHA and the WHO member states
- WHO office: Terminology & Classifications
- Revision Steering Group
- WHO-FIC Collaborating Centres
- Topic Advisory Groups
- Working parties, honorary consultants, etc.
- (Interested public…)

Research Centre for Injury Studies • Flinders University • Adelaide
3. The big idea

• Bring the classification up to date
• Fix problems
• Document the ICD better
  – Internally (definitions, etc.)
  – Externally (connect items to external sources)
• Prepare the ICD to operate with electronic health records
• Provide versions for several purposes
  – Mortality and hospital admissions (of course)
  – Primary care, research, lower resource settings …
• Maintain comparability with ICD-10
4. Primer in ICD 11-speak

- Terminology
- Ontology
- Semantic wiki
- Linearization
- Content model
- Use-case …
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
5. The products

• First priority
  – Version for coding causes of death and
  – Version for coding hospital in-patient cases

• Also…
  – Primary health care, lower resource settings, research…

• All derived from an underlying database
  – which will facilitate updating
6. Process

• Complex and has become more so.
• Elements include:
  – WHO-FIC, esp. at annual meetings (South Africa now)
  – Revision Steering Group (mostly teleconferences)
  – RSG Executive (recent creation; role emerging)
  – TAGs. Their processes are diverse.
  – Large meetings: several planning meetings and two “iCamps”
Alpha drafting process

Topic Advisory Groups

Classification Experts

TAG Managing Editors

Reviewers

Topic Advisory Groups

Revision Steering Group

WHO officers
7. Content model

• What should be specified for categories in ICD-11?
• What must be specified if it is to function properly as a database?
Each category in ICD-11 has a set of attributes, which are the Content Model

**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) (physiology)**

3. **Body Part(s) (anatomical site)**

4. **Manifestation Attributes**
   a. Signs & Symptoms
   b. Diagnostic Findings

5. **Causal Properties (etiology)**
   a. Causal Mechanisms /Agents (+ special set for External Causes)
   b. Risk Factors
   c. Genomic characteristics

6. **Temporal Properties**
7. **Severity and/or Extent**
8. **Functional Properties**
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**
8. Development platform
ICD-10 Plus
- Key Tasks
  - Clinical Modification Owners enter their CM version Codes
  - TAG and Workgroups enter proposals
- Access
  - ANY USER can REVIEW proposals or comments.
  - REGISTERED USER can POST proposals and discuss.

ICD-11 draft
- Key Tasks
  - TAG Experts for ICD-11
  - WHO editors
    - Taxonomic rules
    - Definitions
    - Diagnostic criteria
- Access
  - ALL USERS can see drafts and comment.

ICD Terminology
- Key Tasks
  - Ontology Model
  - Linkages between ICD and:
    - SNOMED
    - Other ontology & terminologies
    - Clinical interface algorithms
- Access
  - ALL USERS can see drafts and comment
iCAT Overview

- iCAT – the Initial/ICD Collaborative Authoring Tool
- Web-based application – accessed from a browser
- Browsing and editing the ICD Content Model
- Collaborate – discuss issues, peer review, etc.
- Developed by Tania Tudorache et al. in Mark Musen’s group at Stanford
iCAT Overview

Protégé Server

Find term

NCBO Bioportal

Import concept references

168 ontologies
723,806 concepts
iCAT Functions

Manage Hierarchy

Enter and Edit Content

Collaboration: Add notes and discussions on concepts and content
Details for A15.0 'Tuberculosis of lung, confirmed by sputum microscopy with or without culture'

ICD Code: A15.0

ICD Title: Tuberculosis of lung, confirmed by sputum microscopy with or without culture

External Definitions:

Definition:

Editorial Status Definition: Select a value
ICD11 Components

Foundation layer: ICD entities with
- Definitions, synonyms
- Clinical descriptions
- Diagnostic criteria
- Causal mechanism
- Functional impact

Find Term
SNOMED-CT
certain other sources
(e.g. ICF, ICECI)
9. TAGs

- Topic Advisory Groups
  - Content-areas (‘Vertical’)
    • E.g. Mental health, Internal medicine, Cancer, Injury & External Causes, Rare diseases, etc.
  - Cross-cutting (‘Horizontal’)
    • Informatics, Mortality, Morbidity, Quality & Safety, Paediatrics
  - Supplemented by work groups, etc.
  - Supported by Managing Editors
  - Mainly self-funded/volunteer
TAG Injury & External Causes

• Managing editor: David van der Zwaag
• Core members & Honorary consultants
• Focus groups and advisors e.g.
  – External Causes: structure
    • Kirsten McKenzie, Lois Fingerhut
  – Spinal injury
    • Dr Bonne Lee and ISCoS
  – ‘Out of injury chapter’ issues
    • Prof Colin Cryer
  – Work-related injury
    • Tim Driscoll
  – And others
• Links with other TAGs
  – E.g. Quality & Safety
10. How to stay informed and contribute

- TAGs
- WHO-FIC Australian Collaborating Centre
- WHO web-site
  - http://www.who.int/classifications/icd/revision/
The International Classification of Diseases 11th Revision is due by 2015

ICD is the international standard to measure health & health services
- Mortality statistics
- Morbidity statistics
- Health care costs
- Progress towards the Millennium Development Goals
- Research

The alpha draft can be viewed online at: ICD-11 alpha browser

- Alpha draft is updated daily as the work progresses
- It is intended to show the new features to stakeholders early
- Commenting will be available in July 2011

ICD-11 Highlights

Register to become involved
WHO wants to know if you are interested in being involved in the ICD Revision.

Timelines
Learn about the ICD-11 Timelines

Caveats
Read more on what to expect in the ICD-11 Alpha Draft

New ICD-11 Features

Content Model

Definitions

Field Tests

Internet Based Platform

Electronic Health Record Ready

Multiple Languages

ICD Revision

Revision News

Steering Group

Topic Advisory Groups

WHO-FIC Network Meeting 2011

2011 Network Meeting in Cape Town, South Africa

SNOMED-CT to ICD-10 Maps Preview Release

The World Health Organization and The International Health Terminology Standards Development Organization (HTSDO) are pleased to announce that a preview release of SNOMED CT to
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- Timelines
- Cautions
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ICD Revision Timelines

May 2011
Open ICD-11 Alpha Browser to the public for viewing

July 2011
Open ICD-11 Alpha Browser to the public for commenting

May 2012
Open ICD-11 Beta to the public

ICD-11 Beta Information
WHO will engage with interested stakeholders to participate in the ICD revision process.

Individuals will be able to:

- Make comments
- Make proposals to change ICD categories
- Participate in field trials
- Assist in translating

May 2015
Present the ICD-11 to the World Health Assembly
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ICD-11 Highlights

New ICD-11 Features

ICD Revision

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Cutaneous strongyloidiasis

Parent(s)
- Strongyloidiasis
- Parasitic infestations affecting the skin

Definition
An infestation of the skin with larvae of the nematode roundworm, Strongyloides stercoralis. Larvae may reach the skin either by direct penetration of the skin or by autoinfection from larvae of intestinal worms. Clinical signs are similar to cutaneous larva migrans but the larvae move across the skin faster than in that condition and there is often associated urticaria.

Synonyms
- Strongyloidoid ground itch
- Larva currens

Body Site
- Skin structure (body structure)
  - Entire skin (body structure)

Causal Mechanisms
- Strongyloides stercoralis

http://apps.who.int/classifications/icd11/browse/
Questions?
ICD-11 Revision Goals

• Evolve an ontologically coherent classification
• Linked logically to underpinning terminologies (e.g. SNOMED)
• Rubrics “defined” by aggregation logics of associations and details
• Human language definitions will be explicit
• Incorporate genomic disease definitions
• Maintain longitudinal consistency through linear derivatives
• To what extent will ICD-11 implement initial vision of deep integration with a ‘cloud’ of terms? (largely SNOMED)

• Remains to be seen
  – SNOMED is being used as primary source for definitions of entities in the content model
  – Beyond that…?