ICD-11 in eleven points

James Harrison

Acknowledgement

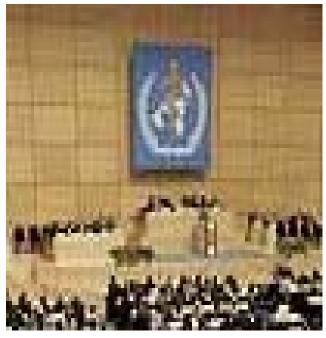
Draws on presentations by Bedirhan Ustun, Chris Chute, Can Celik and Tania Tudorache

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.
- Nearly 20 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)
- Preliminary alpha May 2010
- ICD-11 is due to be presented to the WHA for endorsement in May 2014.
 - 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:

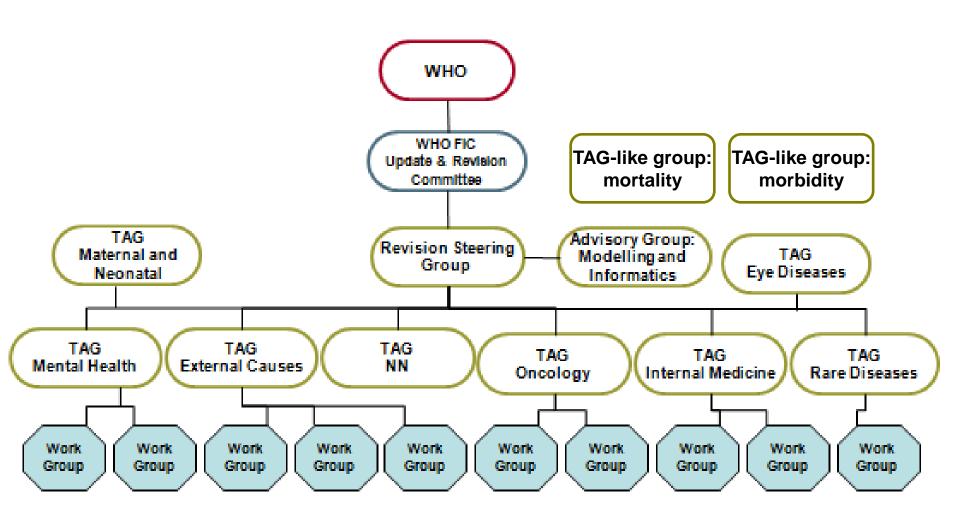
Revision Process in the 21st Century



- 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
- Special TAG-like groups
- Working parties, honorary consultants, etc
- (Interested public...)



3. The big idea

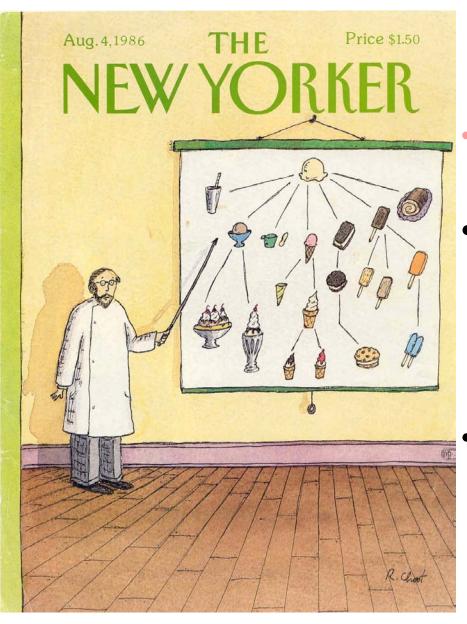
- Bring the classification up to date
- Fix problems
- Document the ICD better
 - Internally (definitions, etc.)
 - Externally (connect items to external sources)
- Prepare the ICD to operate with electronic health records
- Provide versions for additional purposes
 - Mortality and hospital admissions (of course)
 - Primary care, research, lower resource settings ...

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

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

Use cases

- Several versions of ICD-11, each specific to a major type of use
 - Certainly: Mortality and Morbidity
 - Others foreshadowed:
 - Primary health care
 - Research
 - Lower resource settings
 - etc.
- Each will be specified in terms of the same 'foundation layer'
 - Relationship between use-case versions is less clear

5. The products

- First priority
 - Version for coding causes of death
 - Version for coding hospital in-patient cases (and supporting case-mix funding)
- Also...
 - Primary health care, lower resource settings, research...
- All based on an underlying database

6. Process

Complex and has become more so.

Drafting process

Topic Advisory Groups

Classification Experts

TAG Managing Editors

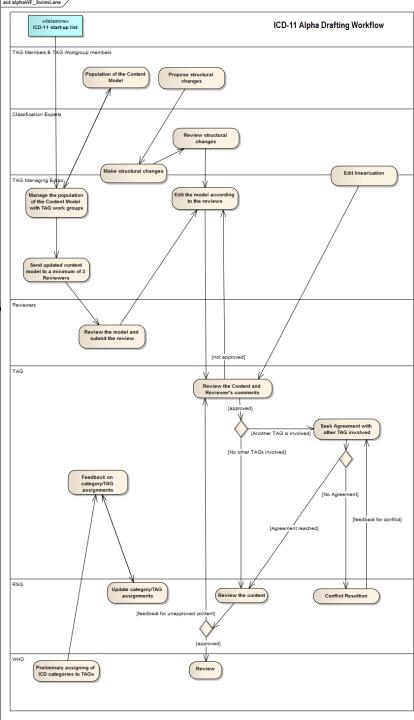
Reviewers

Topic Advisory Groups

(and TAG-like 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
 - 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

Extension for External Causes

Descriptive characteristics

- 1. Intent
- 2. Mechanism
- 3. Object/substance
- 4. Place
- 5. Activity

8. Development platform

ICD Terminology ICD-11 draft ICD-10 Plus Hi-Ki Protégé/OWL ICD-10 + Application Joint-authoring Tool **LEXGRID** WEB Application WIKI like application Clinical Modification Owners TAG Experts for ICD-11 Ontology Model enter their CM version Codes · Linkages between ICD and: WHO editors Key Tasks TAG and Workgroups enter - SNOMED Taxonomic rules proposals - Other ontology & terminologies Definitions Diagnostic criteria Clinical interface algorithms ·ANY USER can REVIEW · ALL USERS can see proposals or comments. ·ALL USERS can see Access drafts and comment. drafts and comment REGISTERED USER can POST proposals and discuss. ICD-10 + ICD-11 ICD Ontology - Proposals Technical - Comments - Entities - Comments Layer - Discussions Attributes - Discussions - Evidence Linkages - Evidence

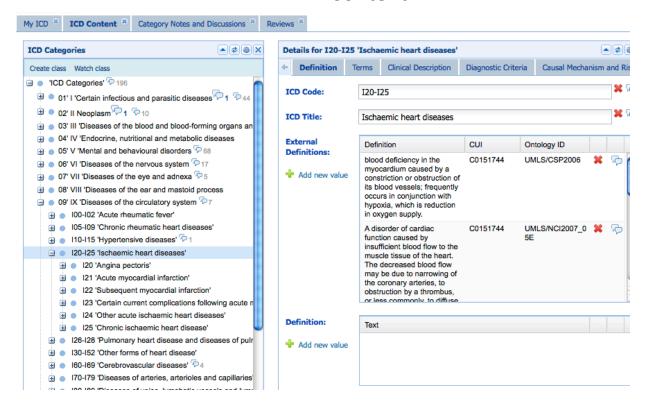
iCat Overview

- iCAT the Initial/ICD Collaborative Authoring Tool
- Web-based application access it 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
- In consultation with Injury/Ext Causes TAG, modified to accommodate proposals for external causes chapter

iCAT Functions

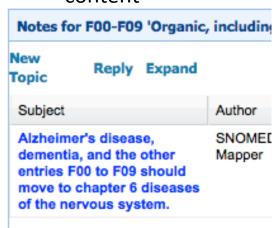
Manage Hierarchy

Enter and Edit Content





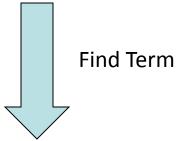
Collaboration: Add notes and discussions on concepts and content

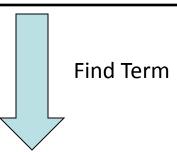


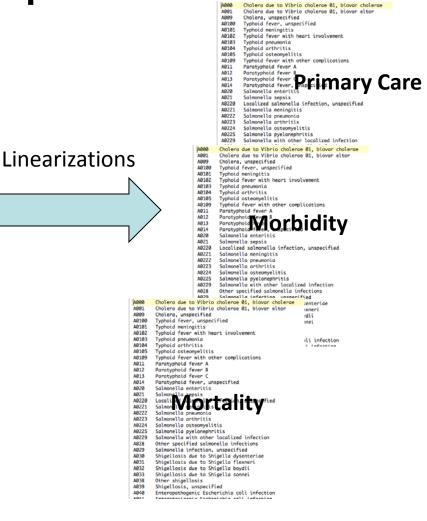
ICD11 Components

Foundation: ICD categories with

- Definitions, synonyms
- Clinical descriptions
- Diagnostic criteria
- Causal mechanism
- Functional impact







SNOMED-CT, International Classification of Functioning, Disability and Health (ICF), ICECI ...

9. TAGs

- Topic Advisory Groups
 - Mental health, Internal medicine, Injury & External Causes, Malignancies, Rare diseases, etc.
 - Supplemented by work groups, etc.
 - Supported by Managing Editors
 - All self-funded/volunteer
- Special variants
 - TAG-like groups: mortality and morbidity
 - TAG-information modelling and informatics

TAG Injury & External Causes

- Managing editor: Adam Harrison (no relation!)
- Core members & Honorary consultants
- Focus groups
 - External Causes: structure
 - Kirsten McKenzie, Lois Fingerhut
 - Spinal injury
 - Dr Bonne Lee and the ISCoS
 - Relationship with AIS
 - Maria Segue-Gomez
 - Out of injury chapter' issues
 - Prof Colin Cryer
 - Work-related injury
 - Tim Driscoll
 - And others but there are topics in need of leaders

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Adam is waiting to hear from you... adam.harrison@flinders.edu.au

10. iCAMPs

Nine-day workshop in September 2009

TAG technical editors and leaders

Classification experts

IT experts

WHO Terminology and Classifications group

https://sites.google.com/site/icd11revision/home

Find by searching with Google: ICD-11 iCamp

iCAMP 2: September 27-30, 2010



WHO ICD Revision: iCAMP Day 6

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Sixth day of the World Health Organization's International Classification of Diseases (ICD) Revision iCamp Meeting. This meeting will discuss the Collaborative Authoring Tool ... voutube.com



WHO ICD Revision: iCAMP Day 3

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WHO ICD Revision: ICAMP Day 4

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11. When & how to get involved

- Reflect: what should change in ICD-11?
 - Will you have another chance…?
- Connect with the revision process
 - Now (ASAP)
 - a TAG e.g. Injury/External Causes via adam.harrison@flinders.edu.au
 - External causes structure: Kirsten McKenzie, Lois Fingerhut.
 - the mortality or morbidity 'TAG-like group' (recently formed)
 - Members of the ICD Revision Steering Group
 - Later
 - Respond to drafts during public consultation phase (2011-ish)
 - Repent at leisure (why didn't I put forward my brilliant idea...?)

Questions?