A new way to build the ICD

What can we learn
and share within the
UN Family of Classifications

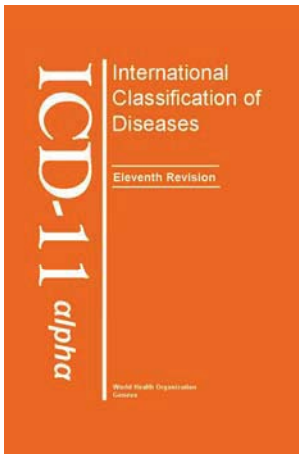
Dr. T. Bedirhan Üstün
Coordinator, Classifications, Terminologies, Standards.
World Health Organization

ICD -11

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



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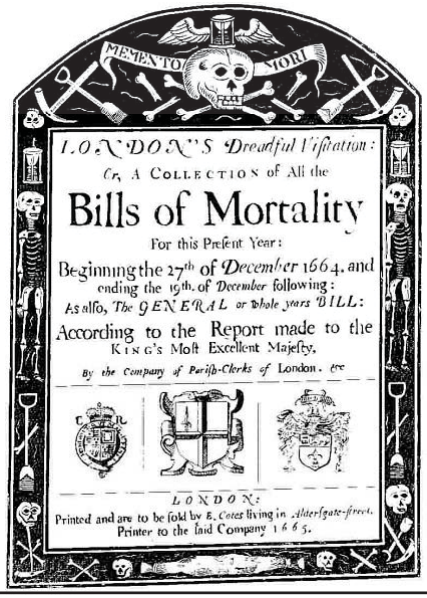
1666 → 2011



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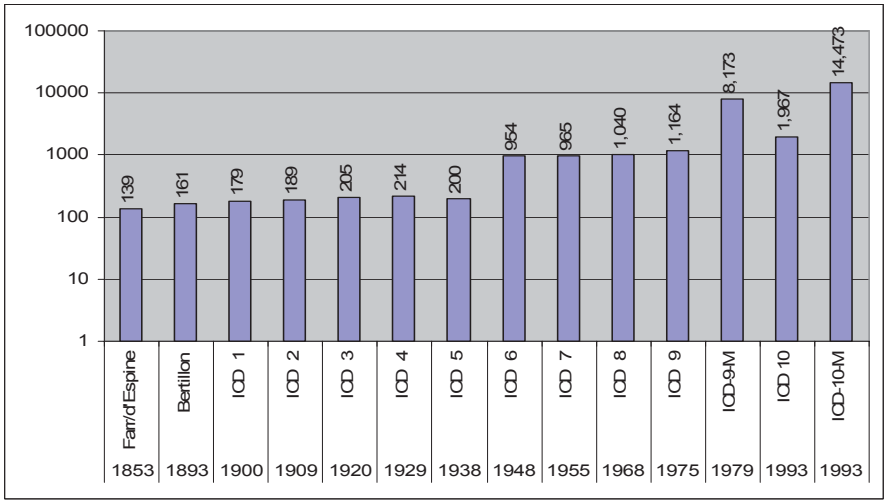
ICD Revisions



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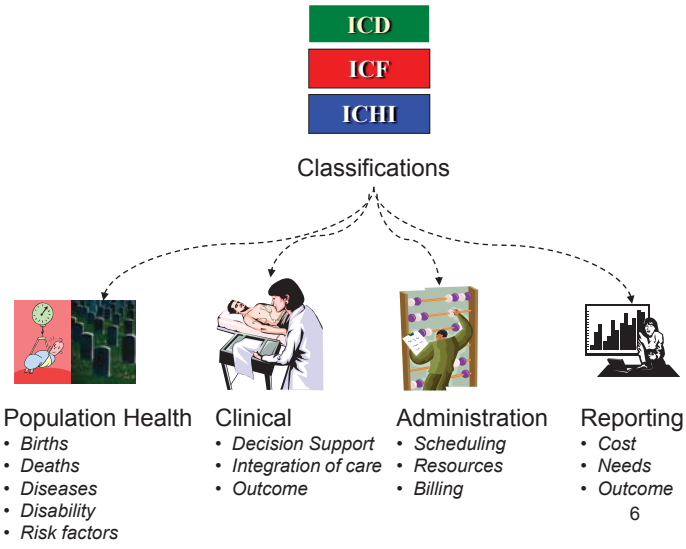
Placing WHO Classifications in HIS & IT



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Problems with ICD-10

1. Driven by **mortality** and **billing** use cases
2. Used in **117 out of 193** countries for official statistics
3. **Limited web presence**
4. **Does not interoperate** with **electronic health records**
5. "Frozen historical accidents"
6. Is just "**a laundry list** " – **no definitions**

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Start-ℓ-ing Point

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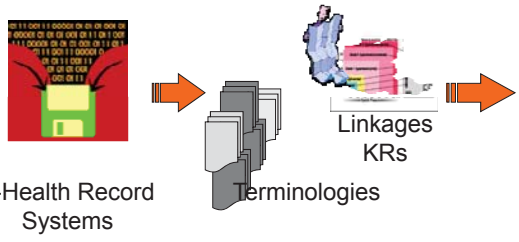
Placing WHO Classifications in HIS & IT



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

Clinical
- *Decision Support*
- *Integration of care*
- *Outcome*

Administration
- *Scheduling*
- *Resources*
- *Billing*

Reporting
- *Cost*
- *Needs*
- *Outcome*

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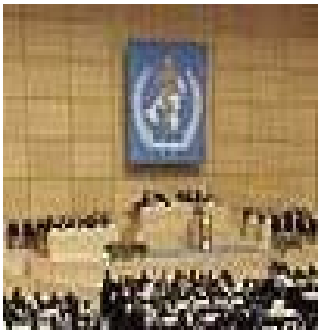
Construction of ICD-**10**:

Revision Process in the 20th Century



- 8 Annual **Revision Conferences** (19**82 - 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

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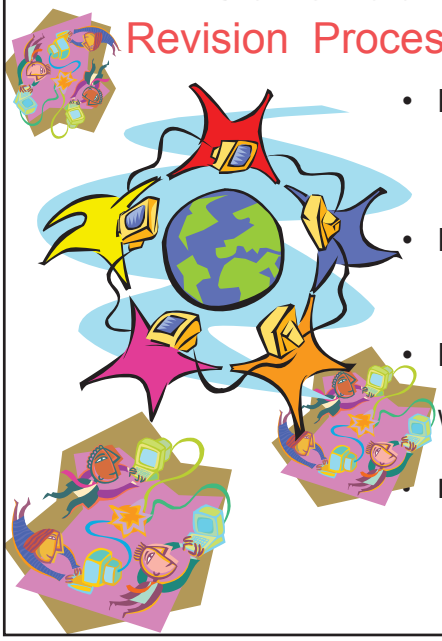
Construction of ICD-**11**:

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-like** collaboration
  - Enhanced **discussion & peer review**
- **Electronic copy** → print version
- Work in **multiple languages**
- **Planned field tests**
  - Based on Use Cases

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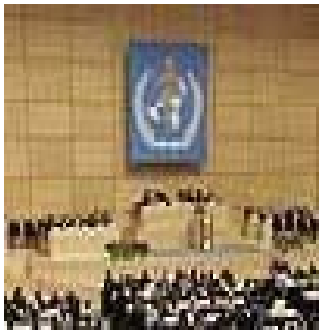
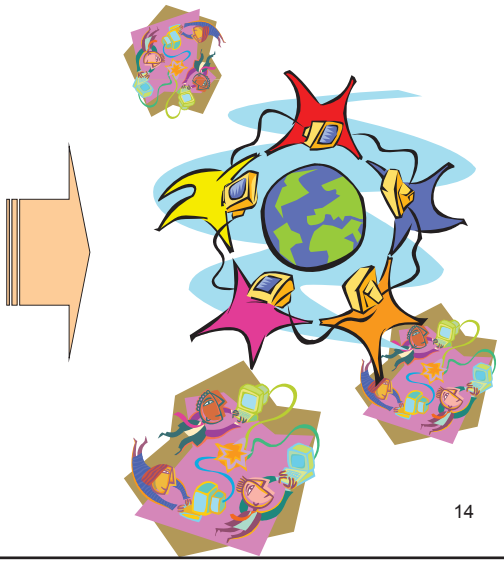
How do we go from Here to 21st Century?





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Key Differences in ICD-10 → ICD-11

1. **Production style**
   - *Annual Revision Conferences* → ***Collaborative Authoring***

2. **Deliverables**
   - Paper Books → **Digital** + Paper Books
   - Manual Production → digital production of **multiple linearizations**

3. **Category Information**
   - Codes & Titles → **Textual Definitions** for all ICD entities
   - Additional information in specialty adaptations only → **Structured descriptions in line with a formal model**

4. **Linkages to terminologies and ontologies**
   → e.g. **SNOMED-CT**, Gene Ontology

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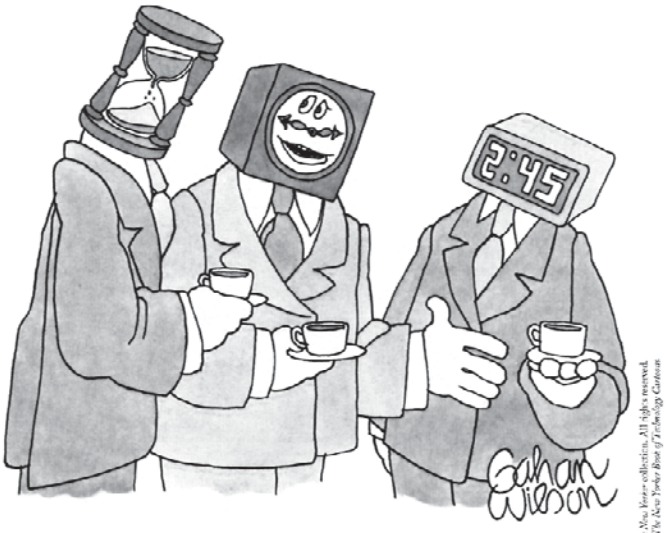
Interoperability



"Basically, we're all trying to say the same thing."

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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 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*

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ICD-11 Timeline

- **2011** : **Alpha version** (ICD 11 alpha draft)
  - **+1 YR : Commentaries and consultations**
- **2012 : Beta version** & Field Trials Version
  - **+2 YR : Field trials**
- 2014 : **Final version** for public viewing
- **–2015 : WHA Approval**
- **2015+ implementation**

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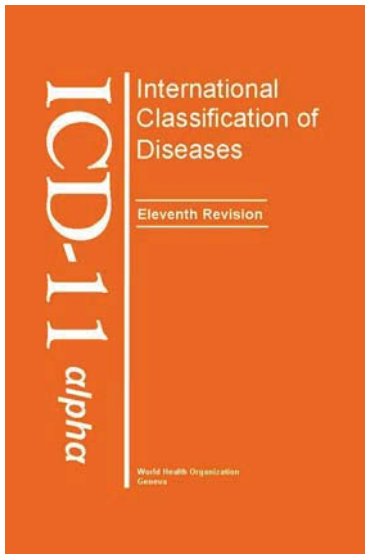
ICD11 αlpha



http://www.who.int/classifications/icd/revision

- **Alpha – Browser & Print**
  10 look & feel **+ descriptions – code structure !**

- ***ICD-11 alpha draft is INCOMPLETE***
- *updated on a **daily** basis*
- ***NOT TO BE USED** for CODING at this stage*
- ***not yet been approved** by the TAGs, RSG or WHO*

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Good News

- **"Alpha" has proven feasible**
  - Continuity: respectful to **ICD traditions** – break with non-essential features
  - Content Model proves useful & relevant
- **Computerization is feasible**
- **Unprecedented linkage possibilities to:**
  - **SNOMED CT**
  - **ICF**
  - other **WHOFIC and UN Family of Classifications**
  - other ontology, terminology and standard sources (**QSM, TM, ICPS…**)
- **Better Multilingual Production opportunities**

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NOT so-good News

- **Below expected targets yet**
  - < 80% definitions
  - < 20% content model
- **Not all TAGs are at similar development stage**
- **Engagement of international Stakeholders**

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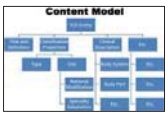
NEW ICD-11 Features

Internet Based Platform

Input from all Stakeholders



Content Model

Definitions

Field Trials for Use Cases

Electronic Health Record Ready

Multi Lingual Representations

العربية	Arabic
官话	Chinese
English	English
Français	French
Русский язык	Russian
Español	Spanish
Deutsch	German
Português	Portuguese

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NEW Participation of Interested Stakeholders

- Using a "**Collaborative Authoring Tool**"
  - WHO aims to engage all experts and stakeholders to
    - **Make comments**
    - **Make proposals**
    - **Take part in Field Trials**

      – Engage in **translations – multilingual representatsion**

      – use it in **special projects**

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Input from all interested stakeholders

- **Structured input** according to a formal **Content Model**
- **Direct participation by users: content experts**
- Subjected to a **scientific peer review** process guided by **T**opic **A**dvisory **G**roups

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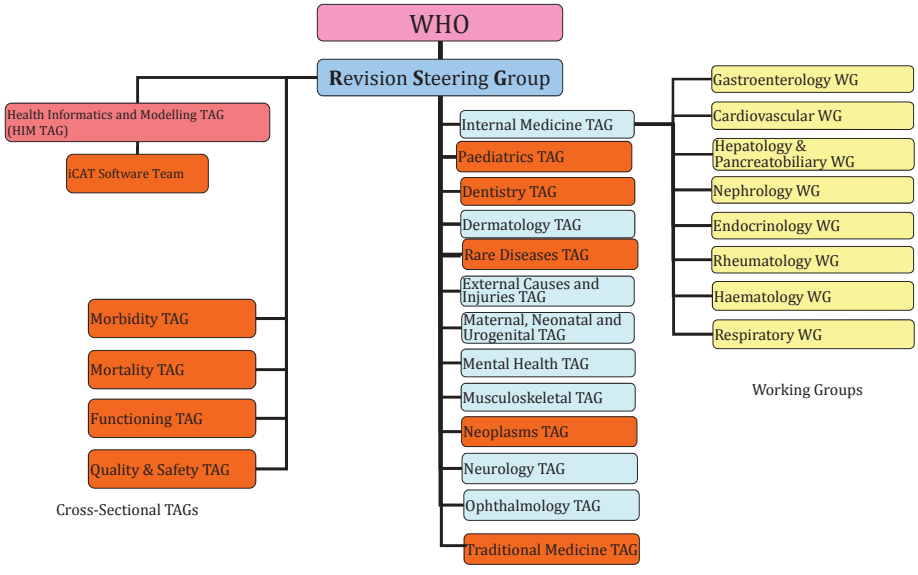
ICD Revision Organizational Structure



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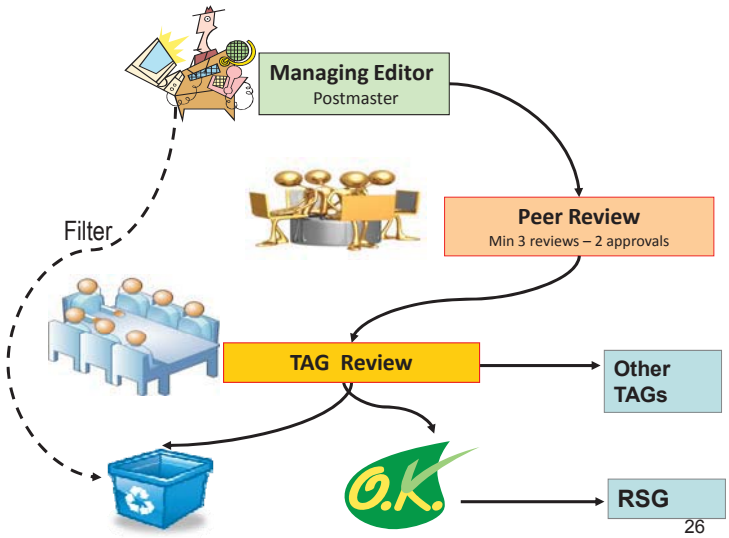
Life-cycle of a Proposal



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Definitions

- All ICD entities will have **definitions**:
  key descriptions of the **meaning** of the category in human readable terms – to **guide users**
  - *Limited definition in Print Version – 100 words*
  - *Detailed definitions ONLINE*

- Definitions will be *compatible* with:
  - the **Content Model**
  - **Diagnostic Criteria**
  - across the **whole classification** and the versions

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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

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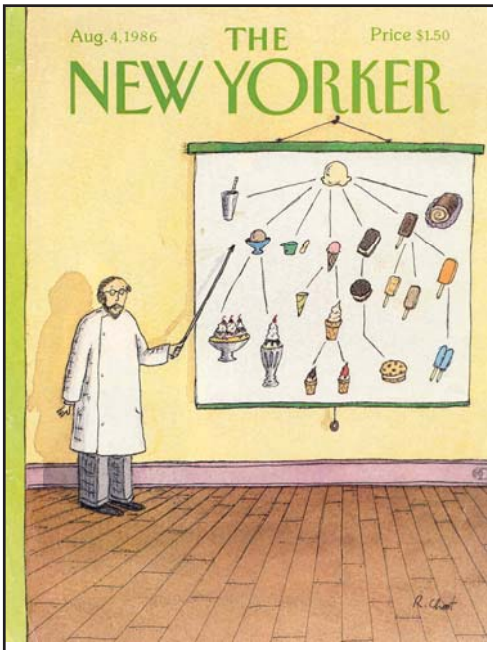

What is Ontology?

- 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

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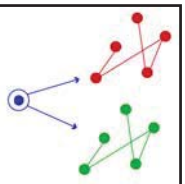
Content Model



- A **structured framework**
  - captures the **knowledge** that underpins the **definition** of an ICD entity
  - Represents ICD entities in **a standard way**
  - Allows **computerization**
- Each ICD entity is defined by **"parameters"** representing different dimensions
- A parameter is expressed using standard terminologies **"value set"**

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THE CONTENT MODEL

Any Category in ICD is represented by:

1. ICD Concept Title
- 1.1. Fully Specified Name

2. Classification Properties
- 2.1. Parents
- 2.2 Type
- 2.3. Use and Linearization(s)

3. Textual Definition(s)

4. Terms
- 4.1. Base Index Terms
- 4.2. Inclusion Terms
- 4.3. Exclusions

5. Body Structure Description
- 5.1. Body System(s)
- 5.2. Body Part(s) [Anatomical Site(s)]
- 5.3. Morphological Properties

6. Manifestation Properties
- 6.1. Signs & Symptoms
- 6.2. Investigation findings

7. Causal Properties
- 7.1. Etiology Type
- 7.2. Causal Properties - Agents
- 7.3. Causal Properties - Causal Mechanisms
- 7.4. Genomic Linkages
- 7.5. Risk Factors

8. Temporal Properties
- 8.1. Age of Occurrence & Occurrence Frequency
- 8.2. Development Course/Stage

9. Severity of Subtypes Properties

10. Functioning Properties
- 10.1. Impact on Activities and Participation
- 10.2. Contextual factors
- 10.3. Body functions

11. Specific Condition Properties
- 11.1 Biological Sex
- 11.2. Life-Cycle Properties

12. Treatment Properties

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13. Diagnostic Criteria

Internet Based Platform

- **Open all year round**:
  - with ***continuous*** *updates*
- **Open** to **all interested people**
  - Health Care Providers, Information Managers ….
  - Structured **review** by experts (TAGs)
- In a **structured** web platform: **iCAT suite**

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iCAT

- Open and collaborative process
  - Users are empowered
  - Web based
  - Like **WIKI – Trip Advisor**
    - But **structured**
    - **Editorial Oversight**

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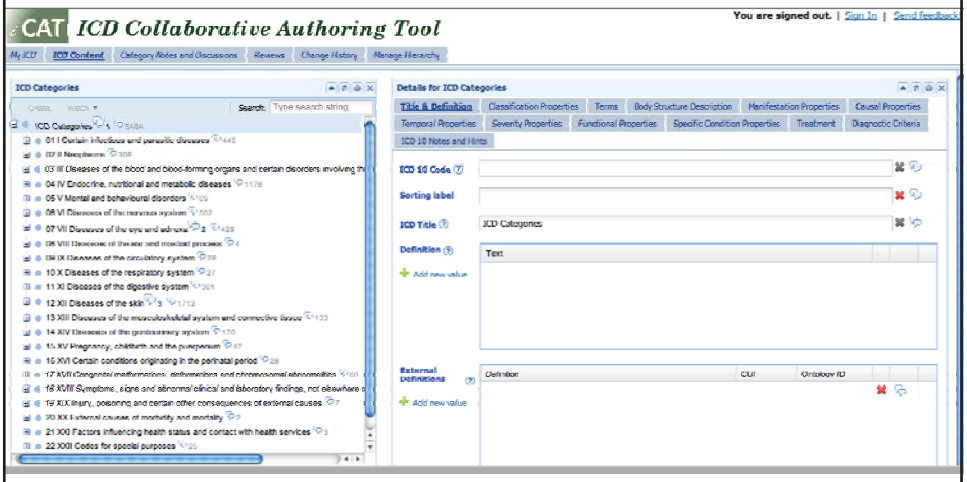
iCAT



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ICD11 Components

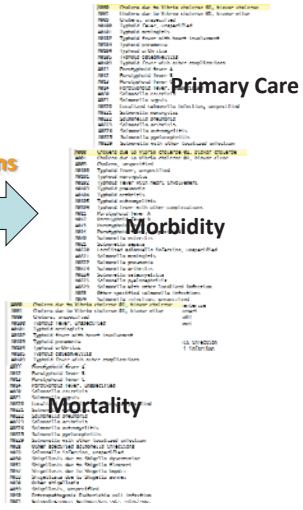
Foundation: ICD categories with

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

Find Term

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

Linearizations



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SNOMED : Old and Current

Former SNOMED Enterprise

College → Network

American → Global

Pathologists → Overall Health Care

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ICD-11

- Simultaneous development in **Multiple Languages**
  - التصنيف الدولي للأمراض
  - 國際疾病與相關健康問題統計分類
  - **International Classification of Diseases**
  - **Classification internationale des maladies**
  - **Международная классификация болезней**
  - **Clasificación internacional de enfermedades**

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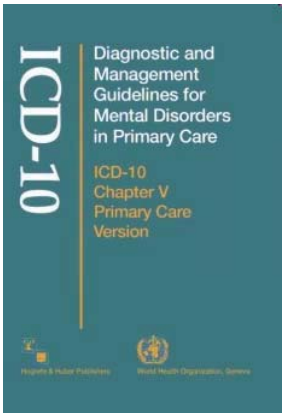
ICD-11

- **Multiple Settings:**
  - Primary Care
  - Clinical Services
  - Research
- **Specialty Adaptations:**
  - Children and Youth
  - Oncology
  - Mental Health
  - Neurology
  - Musculoskeletal
  - Dermatology
  - Dentistry



e.g. ICD-10 Diagnostic Guidelines for Mental Health in Primary Care

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NEW ICD-11 Features

Internet Based Platform

Input from all Stakeholders

Content Model

Definitions

Translations

Field Trials for Use Cases

Electronic Health Record Ready

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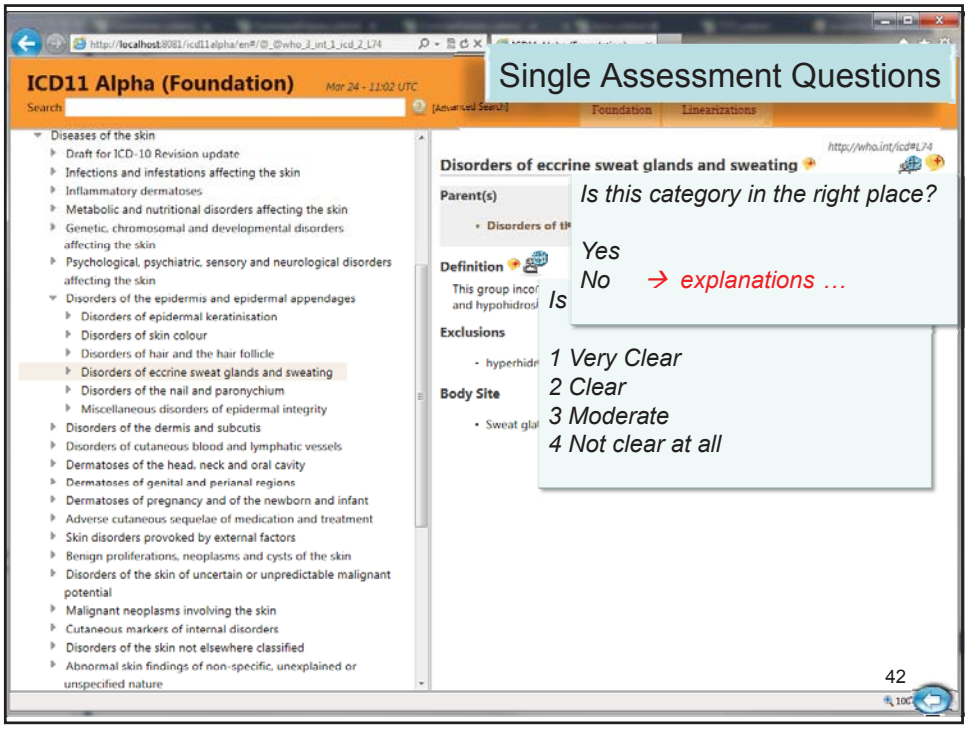

SAQs
Single Assessment Question
[1]

*VIEWER sees "**a category**" in the Browser:*

- Is this "category" in the right place?
  - Yes
  - NO
    - Where would you put it?
    - Why – state your reason?
    - Can you point to a web evidence?

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BETA PHASE FIELD TESTS:
How TWO different users code the same case ?

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YouTube WHOICD11

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Frequent Criticisms

- too **ambitious**
  - recreation of a **Textbook of Medicine**
  - competing with **SNOMED-CT**
  - replicates the work done elsewhere: **DSM, ICPC, …**
- too **academic** – far from what ICD is needed for
- will overhaul **national statistics**

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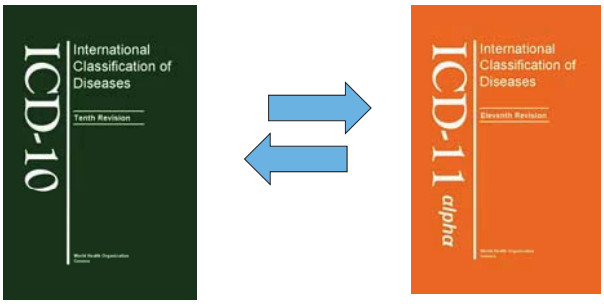
ICD11 alpha - DIFF

- Shows the change from ICD-10
  - Backwards compatible



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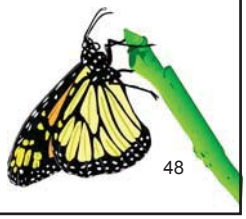
ICD11 alpha

A caterpillar,
This deep in fall-
Still not a butterfly

Basho



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ICD-11

- **International Public Good**
  - Openly Accessible
  - **Free** for WHO Member States
- Available in **multiple formats:**
  - Printed Book editions
  - Internet-edition
  - Various computerized tools

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Roadmap

- Collaborative Authoring Tools
- Review Mechanisms
- Field testing
- Multilingual Production
- USE CASES
- Linking Classifications