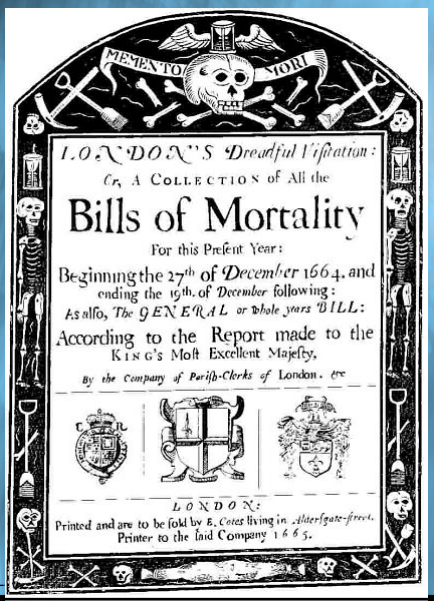
ICD Revision Process:
Building the infrastructure of ICD -11

... building blocks of health information ...

Dr. T. Bedirhan Üstün
Classifications, Terminologies, Standards

Aggregated Statistics 1665

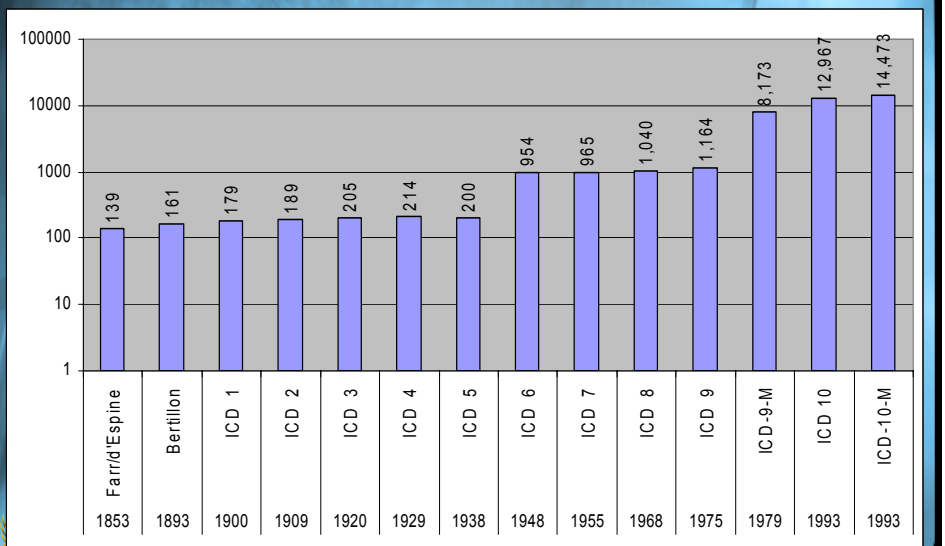

MEMENTO MORI

LONDON'S Dreadful Visitation:
Or, A COLLECTION of All the
Bills of Mortality
For this Present Year:
Beginning the 27th of December 1664. and ending the 19th. of December following:
As also, The GENERAL or Whole years BILL:
According to the Report made to the KING's Most Excellent Majesty.
By the Company of Parish-Clerks of London, &c

LONDON:
Printed and are to be sold by E. Cotes living in Aldersgate-street. Printer to the said Company 1665.

A generall Bill for this present year, ending the 19 of December 1665. according to the Report made to the KINGS most Excellent Majesty.

ICD Revisions



WHO Family of Classifications

REFERENCE
Classifications

I nternational
C lassification of
D iseases

I nternational
C lassification of
F unctioning,
Disability & Health

I nternational
C lassification of
H ealth
I nterventions
(under development)

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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)

WHO Family of Classifications

RELATED Classifications

*International Classification of **Primary Care** (ICPC)*

*International Classification of External Causes of **Injury** (ICECI)*

The Anatomical, Therapeutic, Chemical (ATC) classification system with Defined Daily Doses (DDD)

*ISO 9999 **Technical aids** for persons with disabilities – Classification and Terminology*

REFERENCE Classifications

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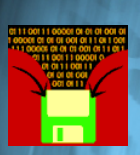
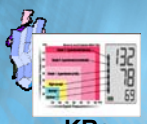
CLASSIFICATIONS, Terminologies, Standards
... BUILDING BLOCKS OF HEALTH INFORMATION ...

Placing WHO Classifications in HIS & IT



e-Health Record Systems

Terminologies



KRs
Mappings

ICD
ICF
ICHI

Classifications

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

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

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

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

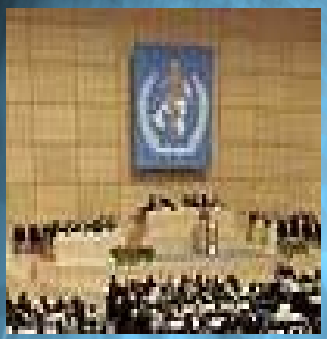
ICD ≈ Common Language ?
Pseudoconsensus ?

- **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

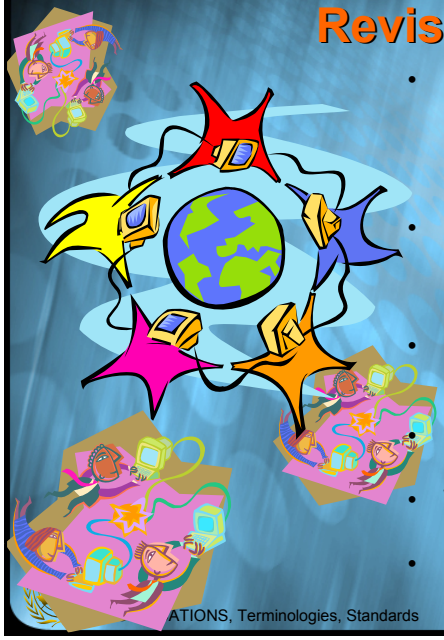
1. No standard of knowledge representation
2. No linkages with health terminology and ontologies
3. Driven by billing and mortality use cases
4. Does not interoperate with eHR
5. Used in 117 out of 193 countries for official statistics
6. Limited web presence – utility for masses

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**

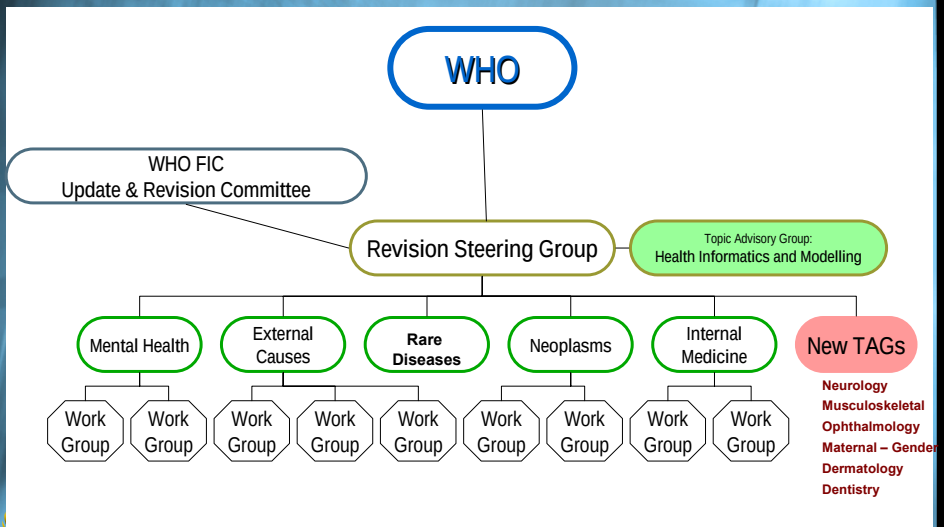
ICD-11 Revision Goals

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



Definition of Disease

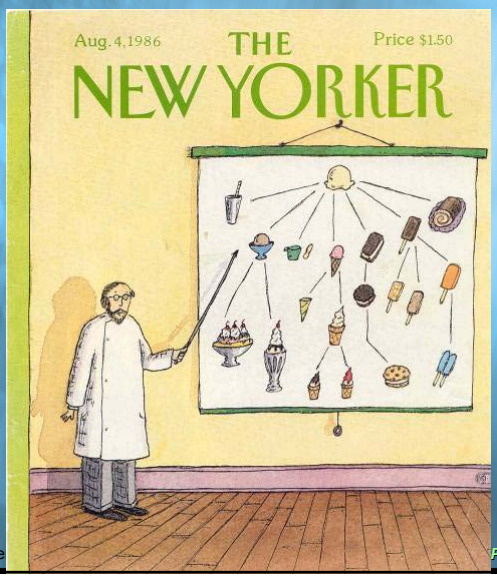
a set of dysfunction(s) in any of the body systems including:

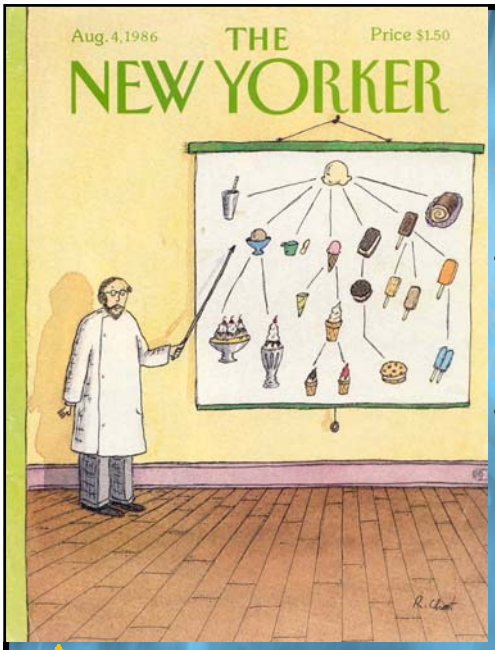
- with a known pattern of signs, symptoms & findings
  - » *symptomatology - manifestations*
- probably with an underlying explanatory mechanism
  - » *etiology*
- a distinct pattern of development over time
  - » *course and outcome*
- a known pattern of response to interventions
  - » *treatment response*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

ICF Ontology: Knowledge Representation

"One day I read a book and whole my life changed "
Orhan Pamuk, Nobel Literature Laurate, 2006

Common sense/intuition → Disciplined definitions





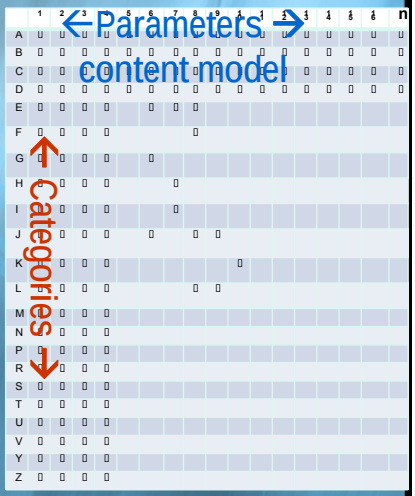
What is Ontology?

- 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 KNOWLEDGEBASE
  - 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

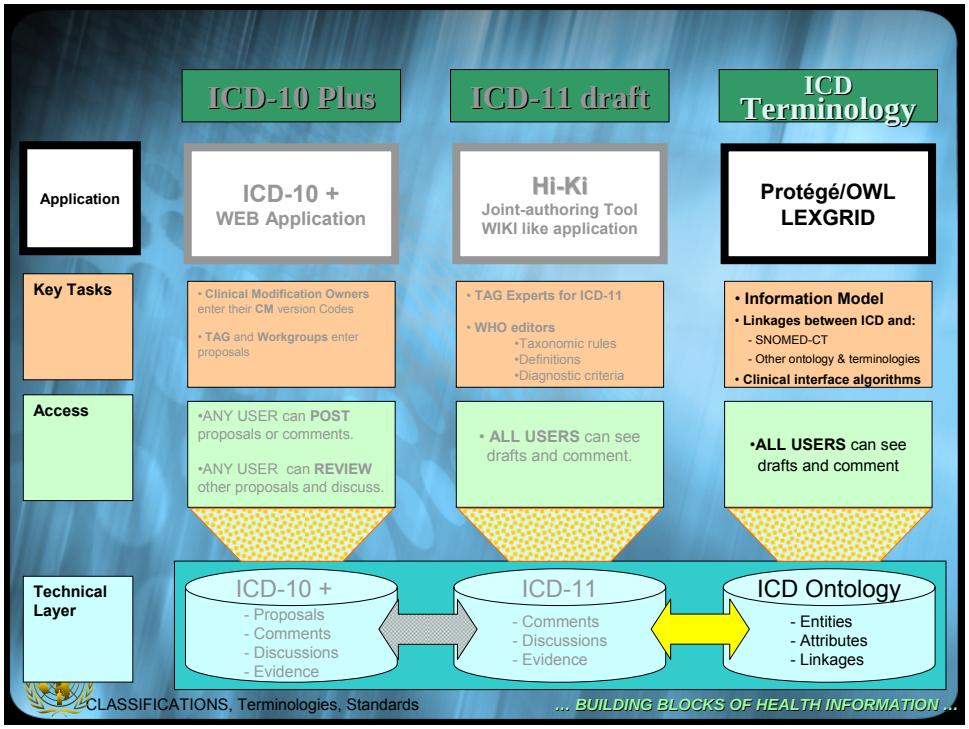
A. **Unique identifier**

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

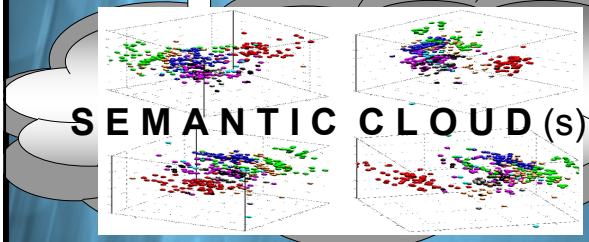
...

C15 Malignant neoplasm of oesophagus
C16 Malignant neoplasm of stomach
C17 Malignant neoplasm of small intestine
C18 Malignant neoplasm of colon

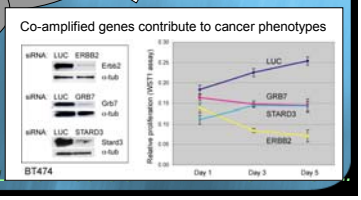
...

Primary Care version

F32x
Depression



S E M A N T I C C L O U D (s)



Digital ICD-11

ICD entities

ICD
Category Definitions
Structured according to the CONTENT MODEL

knowledge base

ICD
concepts

ontology

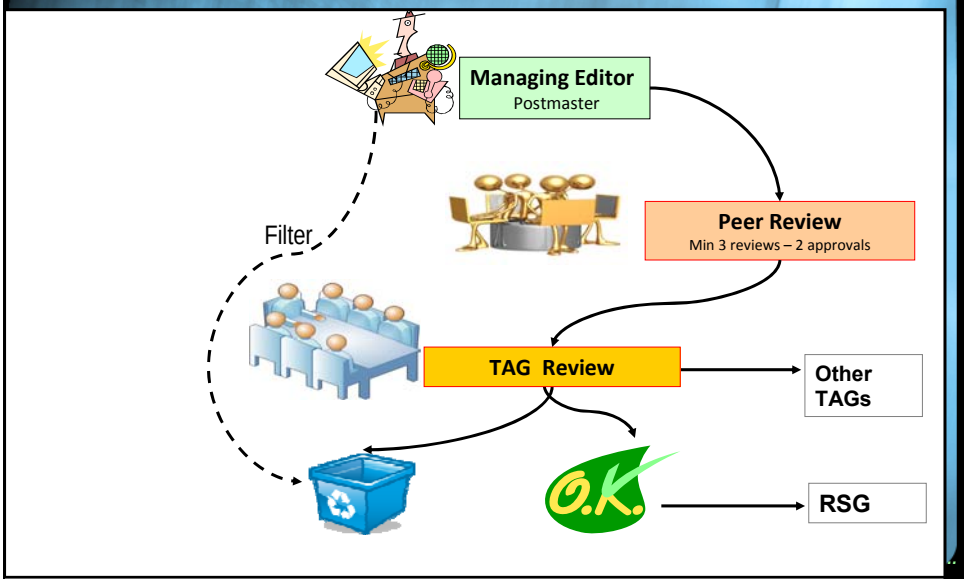
ICD
Presentations
- Mortality List
- Morbidity List
- Primary Care

Publication

Rewriting ICD Using SNOMED
example of Depressive Disorder F32.0

A.	**Low mood**		{41006004}
	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}

Proposed TAG Editorial Function
Workflow Management



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 → → **Codification** *Selection of COD* → **Computerization**

by:
- Medical Doctor
- Coroner
- Lay etc.

by:
- Medical Coders
- Medical Doctors
- Computer assistance

by:
- Manual Data Entry
- Scanning

Use Case 1: Mortality Statistics
Digital Information System

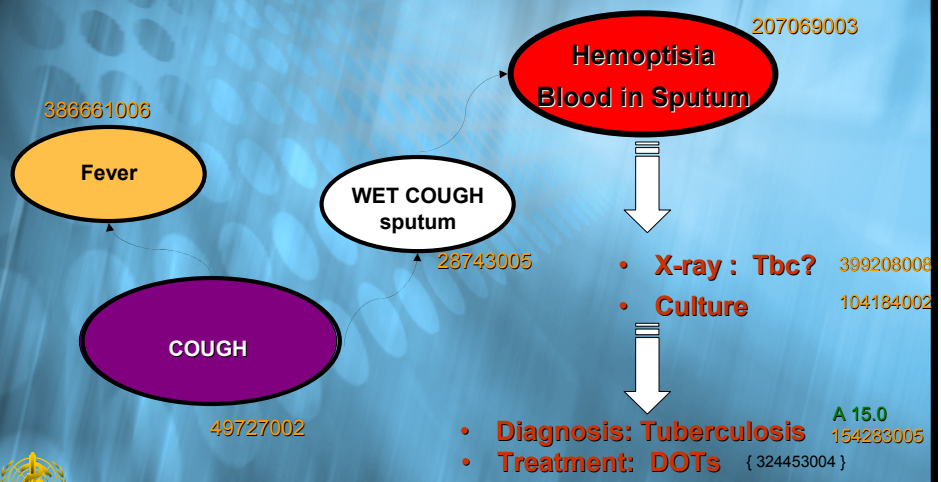
Certification of death in eHR → → **Codification** *Selection of COD* **in eHR** → **Computerization** *Becomes redundant*

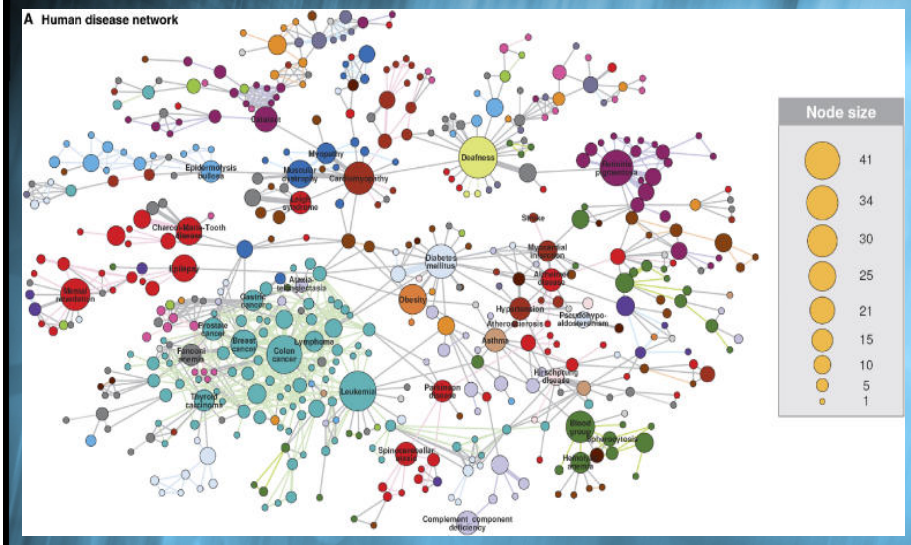
by:
- Medical Doctor
- Coroner
- Lay etc.

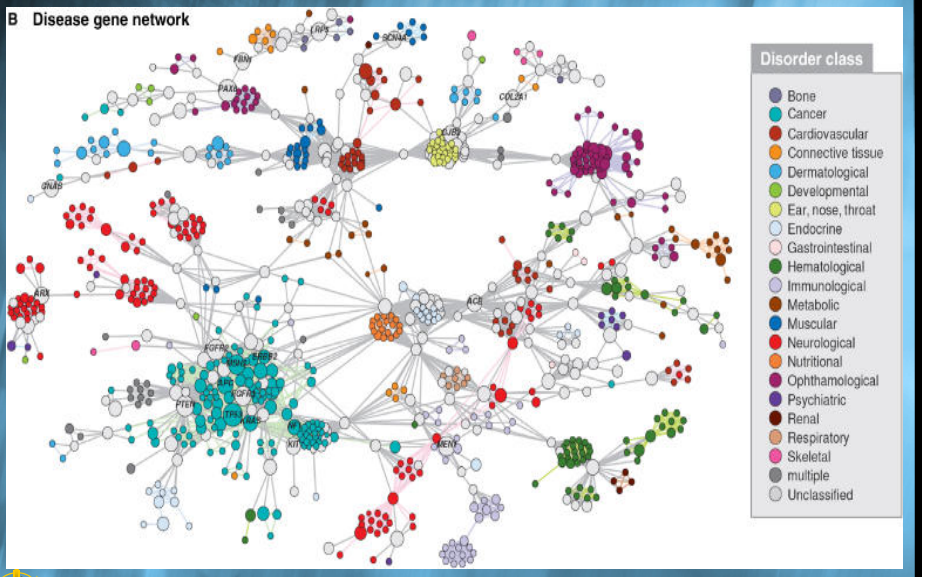
Assisted by:
- Computers

+ Additional Benefits
- Standardisation
- Accuracy
- Population Aggregation
- Efficiency

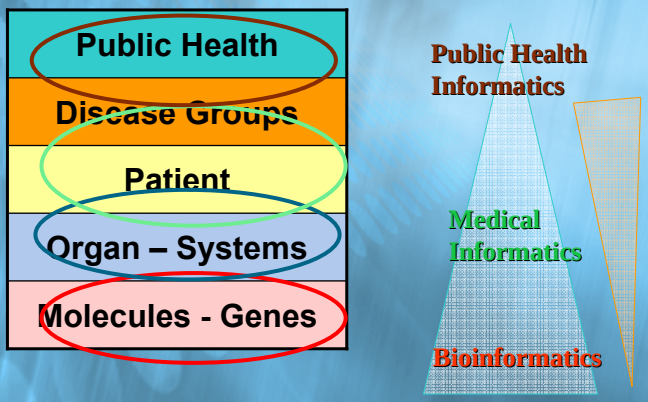
Exploration of Cough







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.