

ICD Revision Process: Building the infrastructure of ICD -11

... building blocks of health information ...

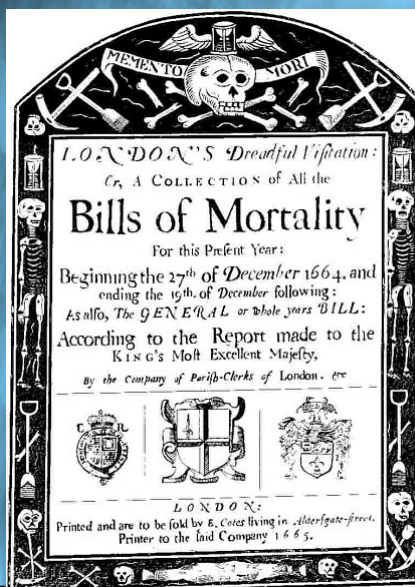
Dr. T. Bedirhan Üstün
Classifications, Terminologies, Standards



CLASSIFICATIONS, Terminologies, Standards

... BUILDING BLOCKS OF HEALTH INFORMATION ...

Aggregated Statistics 1665

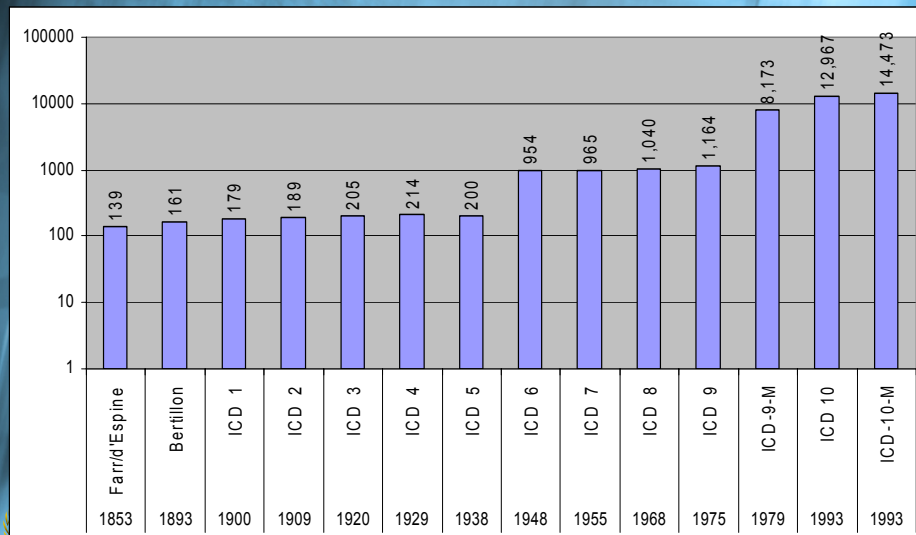


A general Bill for this present year, ending the 19 of December 1665, according to the Report made to the KING's Most Excellent Majesty.

By the Company of Parish Clerks of London, &c.

Parish	Male	Female	Total
St. Andrew	14	12	26
St. Dunstons	15	13	28
St. Giles	16	14	30
St. James	17	15	32
St. John	18	16	34
St. Martin	19	17	36
St. Michael	20	18	38
St. Nicholas	21	19	40
St. Paul	22	20	42
St. Peter	23	21	44
St. Thomas	24	22	46
St. Vincent	25	23	48
St. George	26	24	50
St. Andrew	27	25	52
St. Dunstons	28	26	54
St. Giles	29	27	56
St. James	30	28	58
St. John	31	29	60
St. Martin	32	30	62
St. Michael	33	31	64
St. Nicholas	34	32	66
St. Paul	35	33	68
St. Peter	36	34	70
St. Thomas	37	35	72
St. Vincent	38	36	74
St. George	39	37	76
St. Andrew	40	38	78
St. Dunstons	41	39	80
St. Giles	42	40	82
St. James	43	41	84
St. John	44	42	86
St. Martin	45	43	88
St. Michael	46	44	90
St. Nicholas	47	45	92
St. Paul	48	46	94
St. Peter	49	47	96
St. Thomas	50	48	98
St. Vincent	51	49	100
St. George	52	50	102
St. Andrew	53	51	104
St. Dunstons	54	52	106
St. Giles	55	53	108
St. James	56	54	110
St. John	57	55	112
St. Martin	58	56	114
St. Michael	59	57	116
St. Nicholas	60	58	118
St. Paul	61	59	120
St. Peter	62	60	122
St. Thomas	63	61	124
St. Vincent	64	62	126
St. George	65	63	128
St. Andrew	66	64	130
St. Dunstons	67	65	132
St. Giles	68	66	134
St. James	69	67	136
St. John	70	68	138
St. Martin	71	69	140
St. Michael	72	70	142
St. Nicholas	73	71	144
St. Paul	74	72	146
St. Peter	75	73	148
St. Thomas	76	74	150
St. Vincent	77	75	152
St. George	78	76	154
St. Andrew	79	77	156
St. Dunstons	80	78	158
St. Giles	81	79	160
St. James	82	80	162
St. John	83	81	164
St. Martin	84	82	166
St. Michael	85	83	168
St. Nicholas	86	84	170
St. Paul	87	85	172
St. Peter	88	86	174
St. Thomas	89	87	176
St. Vincent	90	88	178
St. George	91	89	180
St. Andrew	92	90	182
St. Dunstons	93	91	184
St. Giles	94	92	186
St. James	95	93	188
St. John	96	94	190
St. Martin	97	95	192
St. Michael	98	96	194
St. Nicholas	99	97	196
St. Paul	100	98	198
St. Peter	101	99	200
St. Thomas	102	100	202
St. Vincent	103	101	204
St. George	104	102	206
St. Andrew	105	103	208
St. Dunstons	106	104	210
St. Giles	107	105	212
St. James	108	106	214
St. John	109	107	216
St. Martin	110	108	218
St. Michael	111	109	220
St. Nicholas	112	110	222
St. Paul	113	111	224
St. Peter	114	112	226
St. Thomas	115	113	228
St. Vincent	116	114	230
St. George	117	115	232
St. Andrew	118	116	234
St. Dunstons	119	117	236
St. Giles	120	118	238
St. James	121	119	240
St. John	122	120	242
St. Martin	123	121	244
St. Michael	124	122	246
St. Nicholas	125	123	248
St. Paul	126	124	250
St. Peter	127	125	252
St. Thomas	128	126	254
St. Vincent	129	127	256
St. George	130	128	258
St. Andrew	131	129	260
St. Dunstons	132	130	262
St. Giles	133	131	264
St. James	134	132	266
St. John	135	133	268
St. Martin	136	134	270
St. Michael	137	135	272
St. Nicholas	138	136	274
St. Paul	139	137	276
St. Peter	140	138	278
St. Thomas	141	139	280
St. Vincent	142	140	282
St. George	143	141	284
St. Andrew	144	142	286
St. Dunstons	145	143	288
St. Giles	146	144	290
St. James	147	145	292
St. John	148	146	294
St. Martin	149	147	296
St. Michael	150	148	298
St. Nicholas	151	149	300
St. Paul	152	150	302
St. Peter	153	151	304
St. Thomas	154	152	306
St. Vincent	155	153	308
St. George	156	154	310
St. Andrew	157	155	312
St. Dunstons	158	156	314
St. Giles	159	157	316
St. James	160	158	318
St. John	161	159	320
St. Martin	162	160	322
St. Michael	163	161	324
St. Nicholas	164	162	326
St. Paul	165	163	328
St. Peter	166	164	330
St. Thomas	167	165	332
St. Vincent	168	166	334
St. George	169	167	336
St. Andrew	170	168	338
St. Dunstons	171	169	340
St. Giles	172	170	342
St. James	173	171	344
St. John	174	172	346
St. Martin	175	173	348
St. Michael	176	174	350
St. Nicholas	177	175	352
St. Paul	178	176	354
St. Peter	179	177	356
St. Thomas	180	178	358
St. Vincent	181	179	360
St. George	182	180	362
St. Andrew	183	181	364
St. Dunstons	184	182	366
St. Giles	185	183	368
St. James	186	184	370
St. John	187	185	372
St. Martin	188	186	374
St. Michael	189	187	376
St. Nicholas	190	188	378
St. Paul	191	189	380
St. Peter	192	190	382
St. Thomas	193	191	384
St. Vincent	194	192	386
St. George	195	193	388
St. Andrew	196	194	390
St. Dunstons	197	195	392
St. Giles	198	196	394
St. James	199	197	396
St. John	200	198	398
St. Martin	201	199	400
St. Michael	202	200	402
St. Nicholas	203	201	404
St. Paul	204	202	406
St. Peter	205	203	408
St. Thomas	206	204	410
St. Vincent	207	205	412
St. George	208	206	414
St. Andrew	209	207	416
St. Dunstons	210	208	418
St. Giles	211	209	420
St. James	212	210	422
St. John	213	211	424
St. Martin	214	212	426
St. Michael	215	213	428
St. Nicholas	216	214	430
St. Paul	217	215	432
St. Peter	218	216	434
St. Thomas	219	217	436
St. Vincent	220	218	438
St. George	221	219	440
St. Andrew	222	220	442
St. Dunstons	223	221	444
St. Giles	224	222	446
St. James	225	223	448
St. John	226	224	450
St. Martin	227	225	452
St. Michael	228	226	454
St. Nicholas	229	227	456
St. Paul	230	228	458
St. Peter	231	229	460
St. Thomas	232	230	462
St. Vincent	233	231	464
St. George	234	232	466
St. Andrew	235	233	468
St. Dunstons	236	234	470
St. Giles	237	235	472
St. James	238	236	474
St. John	239	237	476
St. Martin	240	238	478
St. Michael	241	239	480
St. Nicholas	242	240	482
St. Paul	243	241	484
St. Peter	244	242	486
St. Thomas	245	243	488
St. Vincent	246	244	490
St. George	247	245	492
St. Andrew	248	246	494
St. Dunstons	249	247	496
St. Giles	250	248	498
St. James	251	249	500
St. John	252	250	502
St. Martin	253	251	504
St. Michael	254	252	506
St. Nicholas	255	253	508
St. Paul	256	254	510
St. Peter	257	255	512
St. Thomas	258	256	514
St. Vincent	259	257	516
St. George	260	258	518
St. Andrew	261	259	520
St. Dunstons	262	260	522
St. Giles	263	261	524
St. James	264	262	526
St. John	265	263	528
St. Martin	266	264	530
St. Michael	267	265	532
St. Nicholas	268	266	534
St. Paul	269	267	536
St. Peter	270	268	538
St. Thomas	271	269	540
St. Vincent	272	270	542
St. George	273	271	544
St. Andrew	274	272	546
St. Dunstons	275	273	548
St. Giles	276	274	550
St. James	277	275	552
St. John	278	276	554
St. Martin	279	277	556
St. Michael	280	278	558
St. Nicholas	281	279	560
St. Paul	282	280	562
St. Peter	283	281	564
St. Thomas	284	282	566
St. Vincent	285	283	568
St. George	286	284	570
St. Andrew	287	285	572
St. Dunstons	288	286	574
St. Giles	289	287	576
St. James	290	288	578
St. John	291	289	580
St. Martin	292	290	582
St. Michael	293	291	584
St. Nicholas	294	292	586
St. Paul	295	293	588
St. Peter	296	294	590
St. Thomas	297	295	592
St. Vincent	298	296	594
St. George	299	297	596
St. Andrew	300	298	598
St. Dunstons	301	299	600
St. Giles	302	300	602
St. James	303	301	604
St. John	304	302	606
St. Martin	305	303	608
St. Michael	306	304	610
St. Nicholas	307	305	612
St. Paul	308	306	614
St. Peter	309	307	616
St. Thomas	310	308	618
St. Vincent	311	309	620
St. George	312	310	622
St. Andrew	313	311	624
St. Dunstons	314	312	626
St. Giles	315	313	628
St. James	316	314	630
St. John	317	315	632
St. Martin	318	316	634
St. Michael	319	317	636
St. Nicholas	320	318	638
St. Paul	321	319	640
St. Peter	322	320	642
St. Thomas	323	321	644
St. Vincent	324	322	646
St. George	325	323	648
St. Andrew	326	324	650
St. Dunstons	327	325	652
St. Giles	328	326	654
St. James	329	327	656
St. John	330	328	658
St. Martin	331	329	660
St. Michael	332	330	662
St. Nicholas	333	331	664
St. Paul	334	332	666
St. Peter	335	333	668
St. Thomas	336	334	670
St. Vincent	337	335	672
St. George	338	336	674
St. Andrew	339	337	676
St. Dunstons	340	338	678
St. Giles	341	339	680
St. James	342	340	682
St. John	343	341	684
St. Martin	344	342	686
St. Michael	345	343	688
St			

ICD Revisions



WHO Family of Classifications

REFERENCE Classifications

International
Classification of
Diseases

International
Classification of
Functioning,
Disability & Health

International
Classification of
Health
Interventions
(under development)



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(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)



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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*

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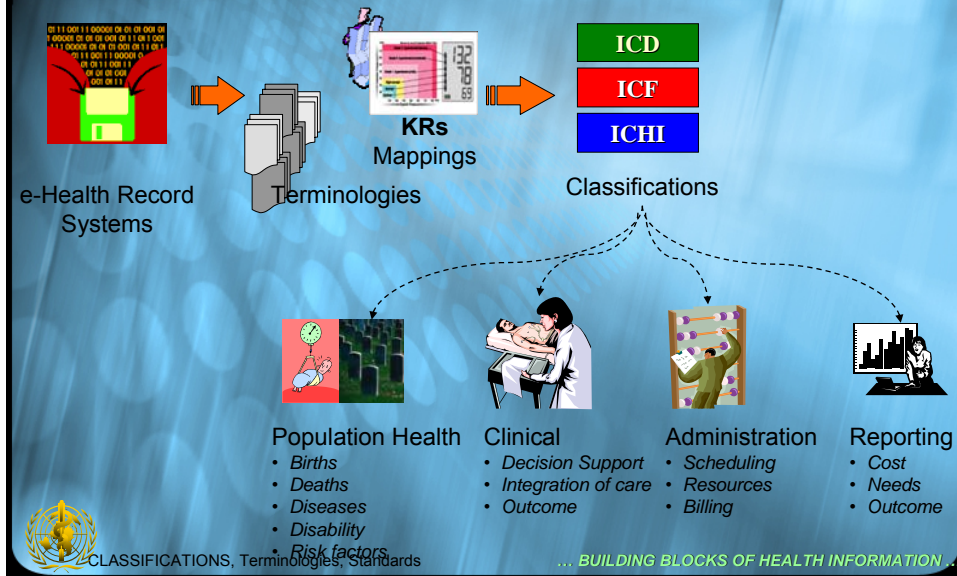
ICF, **Children & Youth Version**
(ICF -CY)



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Placing WHO Classifications in HIS & IT



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



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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



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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

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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**



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ICD-11 Revision Goals

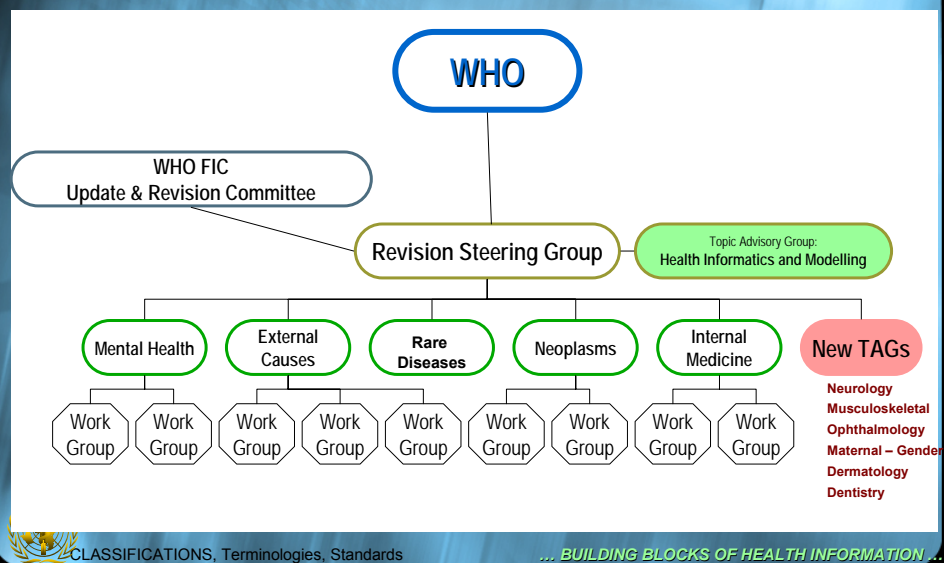
1. Evolve a **multi-purpose** and **coherent** classification
 - **Mortality, morbidity, primary care, clinical care, research, public health...**
 - **Consistency & interoperability** across **different uses**
2. Serve as an **international** and **multilingual** reference standard for **scientific comparability** and **communication** purposes
3. Ensure that ICD-11 will 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



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ICD-11 Revision Organization Structure



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Definition of Disease

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

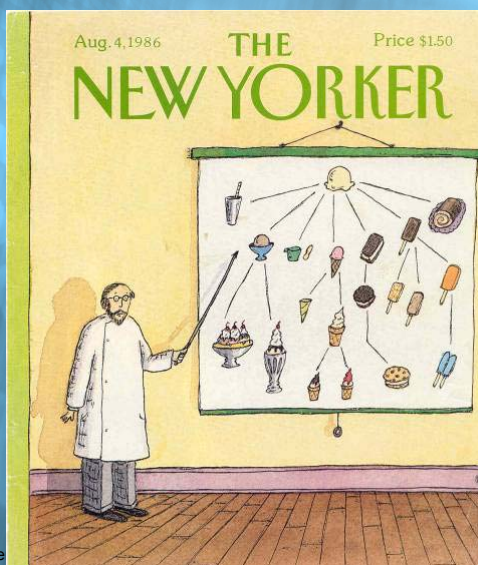
- with a known pattern of signs, symptoms & findings
» *symptomatology - manifestations*
- probably with an underlying explanatory mechanism
» *etiology*
- a distinct pattern of development over time
» *course and outcome*
- a known pattern of response to interventions
» *treatment response*
- with linkage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



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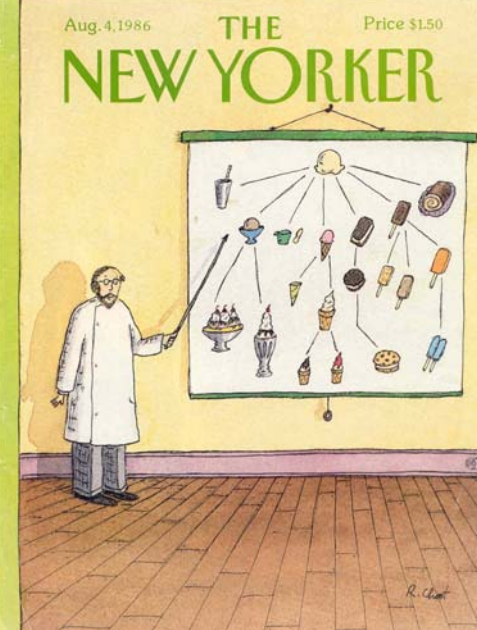
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"One day I read a book and whole my life changed"
ICF Ontology: Knowledge Representation
Orhan Pamuk, Nobel Literature Laureate, 2006
Common sense/intuition → Disciplined definitions




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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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ICD-11 Alpha Draft Vision

An Electronic Product

- **A Database**
 - DIGITAL KNOWLEDGEBASE
 - INTEROPERATING ONTOLOGY SET
- **Architecture :**
 - ~15,000 + n **Categories**
 - 16 ± n Parameters

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	n
A	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
B	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
C	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
D	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
E	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
F	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
G	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
H	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
J	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
K	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
L	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
M	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
N	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
P	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
R	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
S	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
T	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
V	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Y	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Z	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0



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THE CONTENT MODEL

Any Category in ICD is represented by:

TITLE of ENTITY: Name of disease, disorder, or syndrome...

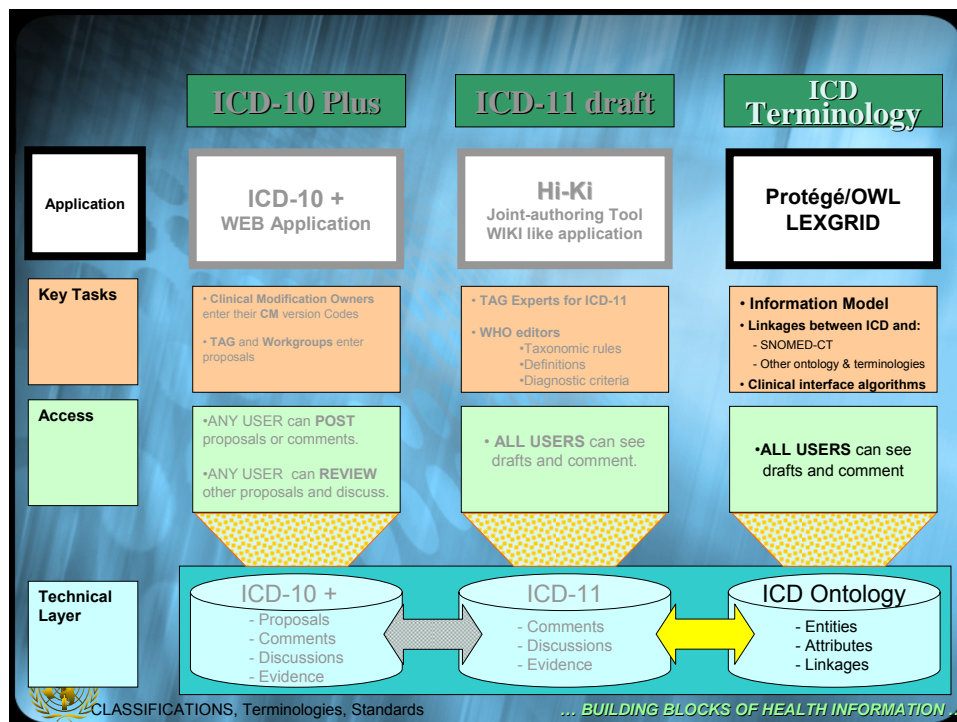
1. **Textual definition**
2. **Synonyms - Inclusion – Exclusion - Index terms**

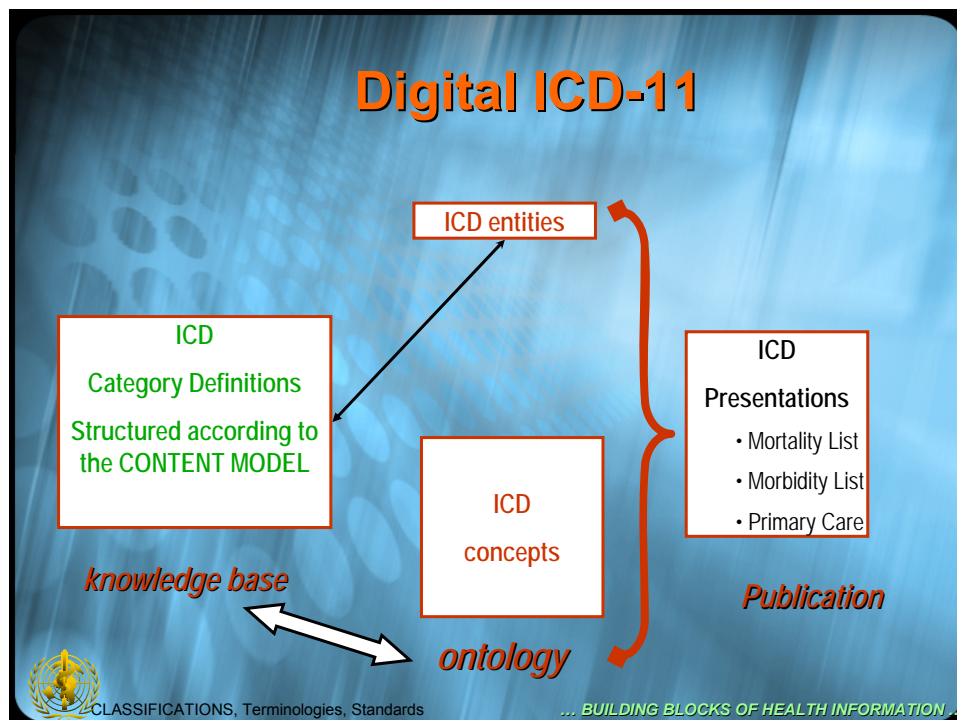
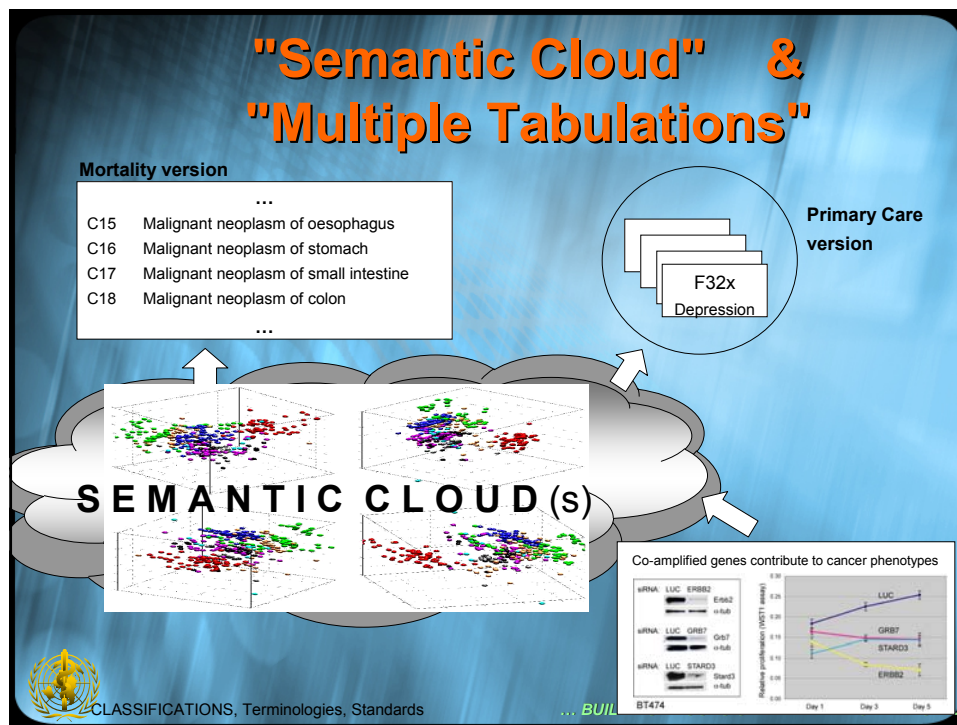
Descriptive characteristics

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**





Rewriting ICD Using SNOMED example of Depressive Disorder F32.0

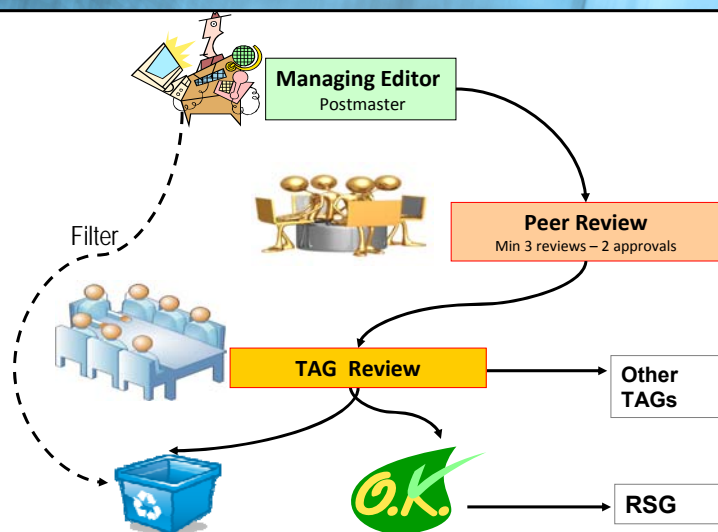
- A. Low mood {41006004}
- Loss of interest {417523004 }
- Low energy {248274002}
- B. 1. Appetite (decrease, increase) {64379006, 72405004}
2. Body weight (decrease, increase) {89362005, 8943002}
3. Sleep (decrease, increase) {59050008, 77692006}
4. Psychomotor (decrease, increase) {398991009, 47295007}
5. Libido loss {8357008}
6. Low self esteem {286647002, 162220005}
7. Guilt, self blame {7571003}
8. Thoughts of death ...
9. Suicide Ideation {102911000, 6471006}



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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



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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
- ...



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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



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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



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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



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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**

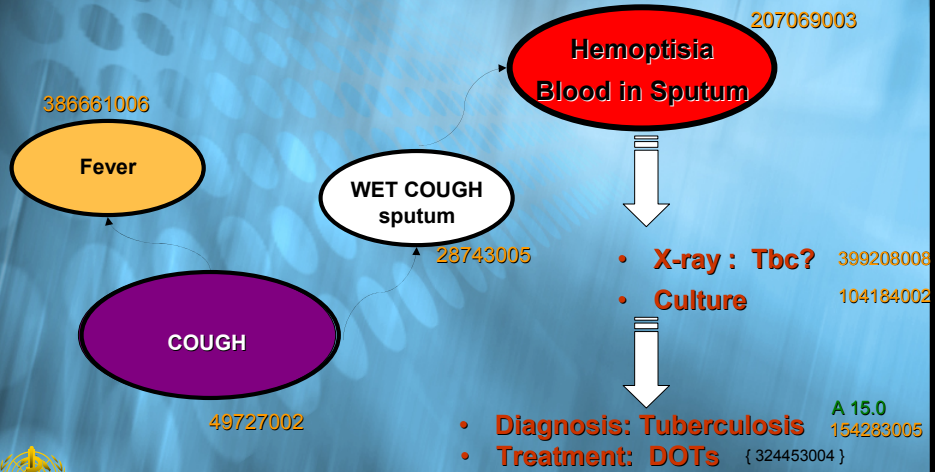
- Standardisation
- Accuracy
- Population Aggregation
- Efficiency



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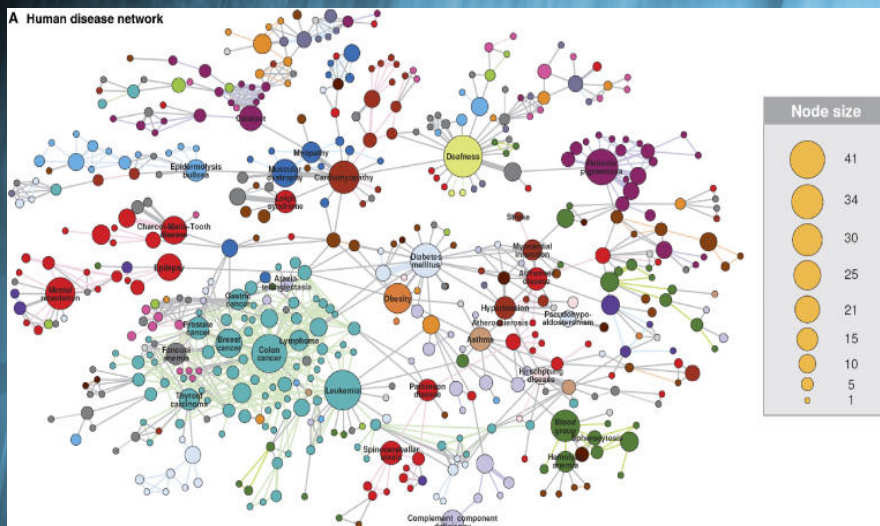
Exploration of Cough



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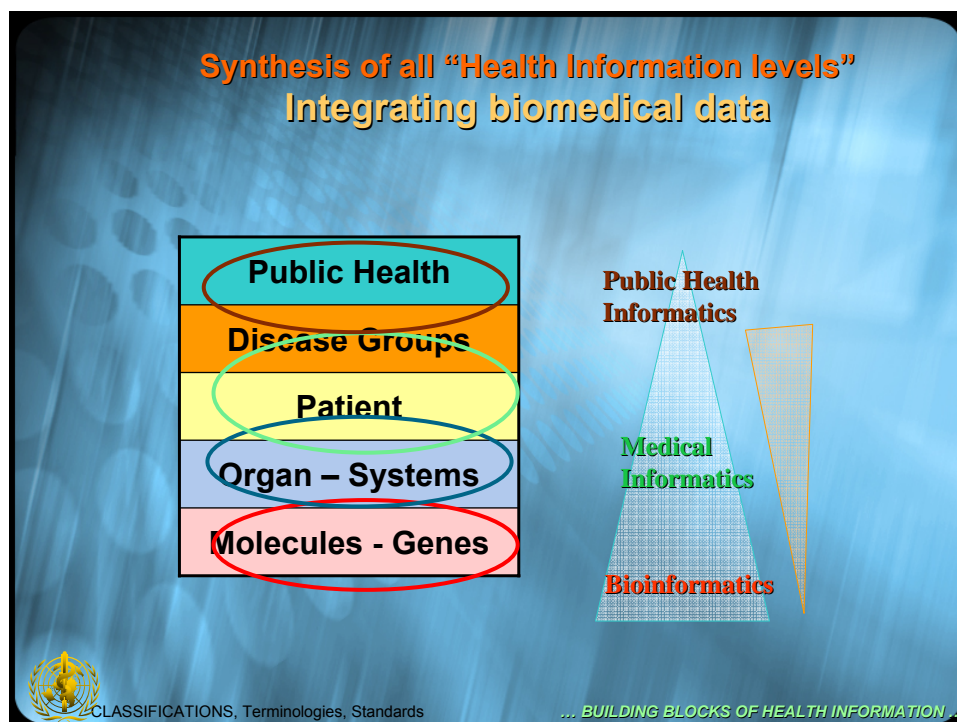
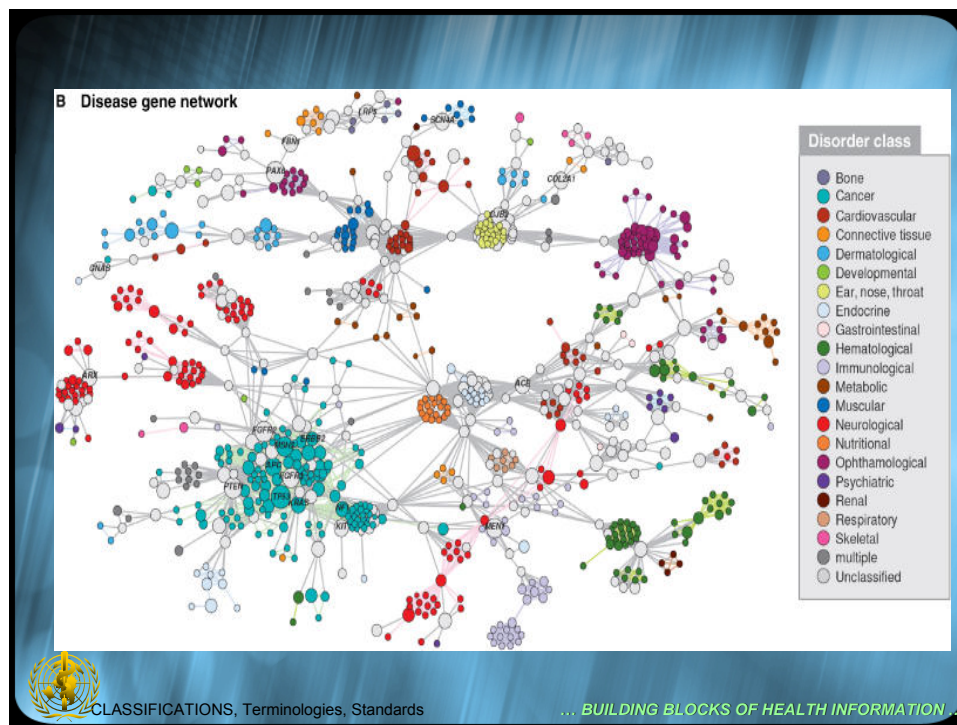
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A Human disease network



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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



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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



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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**



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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



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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



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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
-



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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



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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.



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