ICD 11 Revision Update

NCBO Forum
April 29, 2008

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ICD-11 Revision Steering Group Chair
World Health Organization
Professor and Chair, Biomedical Informatics
Mayo Clinic
Familiar Points Along Continuum
Modern Health Vocabularies

• Nomenclature – Highly Detailed Descriptions (SNOMED)
• Classification – Organized Aggregation of Descriptions into a Rubric (ICDs)
• Groupings – High Level Categories of Rubrics (DRGs)
Aggregation Logics by domain
rule-based aggregations
The Genomic Era

• The genomic transformation of medicine far exceeds the introduction of antibiotics and aseptic surgery
• The binding of genomic biology and clinical medicine will accelerate
• The implications for shared semantics across the basic science and clinical communities are unprecedented
The Continuum Of Health Classification
Biology meets Clinical Medicine

Chasm of Semantic Despair
ICD11 Use Cases

• Scientific consensus of clinical phenotype

• Public Health Surveillance
  • Mortality
  • Public Health Morbidity

• Clinical data aggregation
  • Metrics of clinical activity
  • Quality management
    • Patient Safety
  • Financial administration
    • Case mix
    • Resource allocation
## Morbidity?

<table>
<thead>
<tr>
<th>Public Health Surveillance</th>
<th>Clinical administrative data</th>
<th>Other clinical aggregations</th>
</tr>
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<tr>
<td>PH morbidity statistics</td>
<td>Reimbursement</td>
<td>1. Episode duration focused</td>
</tr>
<tr>
<td>1. Population focused</td>
<td>1. Patient focused</td>
<td>2. Grouping patients by Dx</td>
</tr>
<tr>
<td>2. Must have main dx</td>
<td>2. Must have main dx</td>
<td>3. Routinely Obtained from clinical records</td>
</tr>
<tr>
<td>3. Grouping pt by main dx</td>
<td>3. Episode focused</td>
<td>4. Used for staffing, scheduling, planning</td>
</tr>
<tr>
<td>4. obtained by sampled</td>
<td>4. Group Dx by Pt</td>
<td>5. Quality and pt Safety</td>
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<tr>
<td>survey of clinical records</td>
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<tr>
<td>5. May have mandatory</td>
<td>5. Routinely Obtained from</td>
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</tr>
<tr>
<td>reporting for some dx</td>
<td>clinical records</td>
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</tbody>
</table>

- **Public Health Surveillance**
  - Population focused
  - Must have main dx
  - Grouping pt by main dx
  - Obtained by sampled survey of clinical records
  - May have mandatory reporting for some dx

- **Clinical administrative data**
  - Patient focused
  - Must have main dx
  - Episode focused
  - Group Dx by Pt
  - Routinely Obtained from clinical records
  - Used for payment

- **Other clinical aggregations**
  - Episode duration focused
  - Grouping patients by Dx
  - Routinely Obtained from clinical records
  - Used for staffing, scheduling, planning
  - Quality and pt Safety
Traditional Hierarchical System
ICD-10 and family
Addition of structured attributes to concepts

Concept name
- Definition
  - Language translations
- Preferred string
  - Language translations
- Synonyms
  - Language translations
- Index Terms
Addition of semantic arcs - Ontology

Relationships
- Logical Definitions
- Etiology
- Genomic
- Location
  - Laterality
- Histology
- Severity
- Acuity
Serialization of “the cloud”
Algorithmic Derivation

[1] ICD10WHO
[2] ICD10 Certain conditions originating in the perinatal period (CHAPTER XVI)(P00-P06)
[3] ICD10 Birth trauma(P10-P16)
  [4] ICD10 Birth injury to peripheral nervous system(P14)
    [5] ICD10 Birth injuries to other parts of peripheral nervous system(P14.8)
    [6] ICD10 Birth injury to peripheral nervous system unspecified(P14.9)
    [7] ICD10 Erb’s palsy due to birth injury(P14.0)
    [8] ICD10 Klumpke’s palsy due to birth injury(P14.1)
    [9] ICD10 Other brachial plexus birth injuries(P14.3)
    [10] ICD10 Phrenic nerve paralysis due to birth injury(P14.2)
    [12] ICD10 Birth injury to scalp unspecified(P12.9)
    [13] ICD10 Bruising of scalp due to birth injury(P12.3)
    [14] ICD10 Cephalhaematoma due to birth injury(P12.0)
    [15] ICD10 Cephalocele due to birth injury(P12.1)
    [16] ICD10 Epicanthal subaponeurotic haemorrhage due to birth injury(P12.2)
    [17] ICD10 Monitoring injury of scalp of newborn(P12.4)
    [18] ICD10 Other birth injuries to scalp(P12.8)
  [19] ICD10 Birth injury to skeleton(P13)
    [20] ICD10 Birth injuries to other parts of skeleton(P13.8)
    [21] ICD10 Birth injury to femur(P13.2)
    [22] ICD10 Birth injury to other long bones(P13.3)
    [23] ICD10 Birth injury to skeleton unspecified(P13.9)
    [24] ICD10 Fracture of clavicle due to birth injury(P13.4)
    [25] ICD10 Fracture of skull due to birth injury(P13.0)
    [26] ICD10 Other birth injuries to skull(P13.1)
  [27] ICD10 Intracranial laceration and haemorrhage due to birth injury(P10)
    [28] ICD10 Cerebral haemorrhage due to birth injury(P10.1)
    [29] ICD10 Intraventricular haemorrhage due to birth injury(P10.2)
    [30] ICD10 Other intracranial lacerations and haemorrhages due to birth injury(P10.8)
    [31] ICD10 Subarachnoid haemorrhage due to birth injury(P10.3)
Linear views may serve multiple use-cases
Morbidity, Mortality, Quality, ...
Task

- Distributed editing of a complex information resource (aka ICD family members)
- Intuitive and simple user interface
- No cost to users; open source resources
- Low-profile application; thin-client (web based)
- Capacity to set hierarchy of permissions
Second Phase Requirements

1. Robust back-end for content
   • Capable of appropriate exports (e.g. ClaML)
2. Description Logic capability
3. Aggregation Logic (rule) support
4. Leverage industry and community standards
   • Semantic Web, DL, open-source tools
5. Integrate with existing terminologies
   • IHTSDO, Gene Ontology, LOINC,
ICD11 Draft Information Model

- Historically developed last year
- Substantially modified early last week
- Limited trial use by RSG/TAG members
- Restructured following trial input
- Working Premise Developed
- ICD 11 Structured Content will be restricted to Definitional Characteristics of Disease, Disorders, or Health Related Condition
• Name of disease, disorder, or syndrome

• Textual definition
  • synonyms
  • index terms -

• Definitional characteristics
  • Type [pick one]
    • disease, disorder, syndrome, injury, sign, symptom
    • exposure to external causes, health problem, reason for encounter; relationship types

• Pathophysiology
• Anatomical site
• At the most specific level relevant to the condition
• Manifestation Attributes
  • Symptoms
  • Signs
  • Diagnostic results
  • Functional impact

• Etiology
  • causal agents
  • mechanism
  • Genomic characteristics

• Temporal Relations
  • chronicity (including acute)
  • episodicity

• Severity and/or Extent

• Hierarchical relationships (parents and children)
Adjunct Informatics Components
ICD 11 Information Model

• Maintenance attributes
  • Subset, adptation, and special view flag
    E.g. Primary Care, Clinical Care, Research,
    Special indices (e.g. public health Indices or
    resource groupings)
  • Unique identifier
  • mapping relationships
  • sanctioning rules
Implies Suite of ICD 11 Development Tools

• Light-weight distributed editor
• Robust DL capable editor
• Robust persistence (storage) layer
  • Archival Back-end
  • Formats for input/output
    • RDF, XLM, ClaML, OWL, HL7, CSV (Excel), etc.
  • Interlinkage with Terminology content
• Workflow management
  • Workflow status
Tool Collaboration
Open-source distributed authoring

• Mayo Clinic, Division of Biomedical Informatics
• Apelon – terminology consultants
• NCI – National Cancer Institute
  • caBIG – Bioinformatics Grid
  • NCI Thesaurus development task
• Stanford – Biomedical Informatics Research
  • Developers of Protégé and Collaborative Protégé
  • National Center for Biomedical Ontologies
ICD 11 Editing Process in Development

ICD in LexGrid

Export and Load

OWL RDF dump

OWL DL

Collaborative Protégé

Change Sets

HL7/ISO format

Review and select

World Health Organization; Mayo Clinic - ICD-11
Wiki
Basis for *Light-weight editor*

- The largest and most successful “social computing” project in history
- Tools and resources to permit huge communities to asynchronously author and edit complex resources
- Computer engineering of impressive capacity
  - Wikipedia manages >12,000 hits/second
  - Includes transactional edits
W3C Semantic Web

- Explosion of methods, standards, tools
- Transform the practicality of complex concept management
  - XML – simple, interoperable syntax
  - RDF – simple data structure for semantic content
  - OWL – ontology authoring and interchange
Goal: Marrying Wikipedia and the Semantic Web

- Wikipedia has many resources and content, but: many manual processes for text-based search
- Semantic Web has advanced information processing, sophisticated queries, but: few data

Queries, Automation → Tools → Semantic data
Wikipedia → Users → Semantic Web
LexWiki

(Redirected from Main Page)

Leave a comment ...

ICD10+ Collaborative Revision Platform
This is an ICD10+ collaborative content development platform based on Semantic MediaWiki.
See Quick Start Guide - A walk through the wiki and workflow process

ICD10 Classifications


LexWiki SandBox

Users may play here to get familiar with ICD10 content representation and proposal creation. See Help Page.

[-] SandBox ICD10 Other leukaemias of specified cell type(C94)

User Scenarios and Usability

- **User Scenarios** - a page to describe the potential user roles and general user scenarios.
- **ICD Collaborative Platform Integration** - a collaborative effort for integration of the LexWiki with the WHO ICD Revision Platform.
- **LexWiki Feature Request** - a page to add your feature request.

testGraph

Getting started with Wikis
ICD10CM

This 2007 release of the International Classification of Diseases, 10th revision, Clinical Modification (ICD-10-CM) is being published by the United States Government in recognition of its responsibility to promulgate this classification throughout the United States for morbidity coding. The International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10), published by the World Health Organization (WHO), is the foundation of ICD-10-CM. [From ICD-10-CM PREFACE, July 2007 Release]

[-] ICD10CM
  [+1] ICD10CM Accidents(V00-X58)
  [+1] ICD10CM Certain conditions originating in the perinatal period (CHAPTER 16)(P00-P96)
  [+1] ICD10CM Certain infectious and parasitic diseases (CHAPTER 1)(A00-B99)
  [+1] ICD10CM Congenital malformations deformations and chromosomal abnormalities (CHAPTER 17)(Q00-Q99)
  [+1] ICD10CM Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism (CHAPTER 3)(D50-D89)
  [+1] ICD10CM Diseases of the circulatory system (CHAPTER 9)(I00-I99)
  [-] ICD10CM Diseases of the digestive system (CHAPTER 11)(K00-K93)
  [+1] ICD10CM Diseases of appendix(K35-K38)
  [+1] ICD10CM Diseases of esophagus stomach and duodenum(K20-K31)
  [-] ICD10CM Diseases of liver(K70-K77)
    [+1] ICD10CM Alcoholic liver disease(K70)
    [+1] ICD10CM Chronic liver disease not elsewhere classified(K73)
    [+1] ICD10CM Fibrosis and cirrhosis of liver(K74)
    [+1] ICD10CM Hepatic failure not elsewhere classified(K72)
    [+1] ICD10CM Liver disorders in diseases classified elsewhere(K77)
    [+1] ICD10CM Other diseases of liver(K76)
    [+1] ICD10CM Other inflammatory liver diseases(K75)
    [+1] ICD10CM Toxic liver disease(K71)
    [+1] ICD10CM Diseases of oral cavity and salivary glands(K00-K14)
    [+1] ICD10CM Diseases of peritoneum and retroperitoneum(K65-K68)
ICD10WHO


Note: We are working on the latest version of ICD10 and it will be available soon...

[+] ICD10WHO

[+] ICD10 Certain conditions originating in the perinatal period (CHAPTER XVI)(P00-P96)
[+] ICD10 Certain infectious and parasitic diseases (CHAPTER I)(A00-B99)
[+] ICD10 Congenital malformations deformations and chromosomal abnormalities (CHAPTER XVII)(Q00-Q99)
[+] ICD10 Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism (CHAPTER XII)(L00-L99)
[+] ICD10 Diseases of the circulatory system (CHAPTER IX)(I00-I99)
[+] ICD10 Acute rheumatic fever(I00-I02)
[+] ICD10 Cerebrovascular diseases(I60-I69)
[+] ICD10 Chronic rheumatic heart diseases(I05-I09)
[+] ICD10 Diseases of arteries arterioles and capillaries(I70-I79)
[+] ICD10 Diseases of veins lymphatic vessels and lymph nodes not elsewhere classified(I80-I89)
[+] ICD10 Hypertensive diseases(I10-I15)
[+] ICD10 Ischaemic heart diseases(I20-I25)

[+] ICD10 Acute myo cardiac infarction(I21)
[+] ICD10 Acute myocardial infarction unspecified(I21.9)
[+] ICD10 Acute subendocardial myocardial infarction(I21.4)
[+] ICD10 Acute transmural myocardial infarction of anterior wall(I21.0)
[+] ICD10 Acute transmural myocardial infarction of inferior wall(I21.1)
[+] ICD10 Acute transmural myocardial infarction of other sites(I21.2)
**Lexical**

**Concept Code:** I21.0  
**Preferred Name:** Acute_transmural_myocardial_infarction_of_anterior_wall  
**Coding Scheme:** ICD10WHO SECOND EDITION  
**ICD10_textualPresentation:** Acute_transmural_myocardial_infarction_of_anterior_wall  
**URI:** ICD10WHO SECOND EDITION:I21.0

**References**

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**See ICD10xm Hierarchy**

<table>
<thead>
<tr>
<th>ICD10CM</th>
<th>ICD10AM</th>
</tr>
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<tbody>
<tr>
<td>[-] ICD10CM ST elevation (STEMI) myocardial infarction of anterior wall (I21.0)</td>
<td>[-] ICD10AM Acute transmural myocardial infarction of anterior wall (I21.0)</td>
</tr>
<tr>
<td>[-] ICD10CM ST elevation (STEMI) myocardial infarction involving left anterior descending coronary artery (I21.02)</td>
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<td>[-] ICD10CM ST elevation (STEMI) myocardial infarction involving left main coronary artery (I21.01)</td>
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<tr>
<td>[-] ICD10CM ST elevation (STEMI) myocardial infarction involving other coronary artery of anterior wall (I21.09)</td>
<td></td>
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</tbody>
</table>
Concept Code: PatId197
Preferred Name: Lesch-Nyhan syndrome
Coding Scheme: umi.dns.bmi.mayo.edu:orphanet

Definition: Deficiency of hypoxanthine-guanine phosphoribosyltransferase (HPRT) activity is an inborn error of purine metabolism associated with uric acid overproduction and a continuum spectrum of neurological manifestations depending on the degree of the enzymatic deficiency. The prevalence is estimated at 1/380,000 live births in Canada, and 1/235,000 live births in Spain. Uric acid overproduction is present in all HPRT-deficient patients and is associated with lithiasis and gout. Neurological manifestations include severe action dystonia, choreoathetosis, ballismus, cognitive and attention deficit, and self-injurious behaviour. The most severe forms are known as Lesch-Nyhan syndrome (patients are normal at birth and diagnosis can be accomplished when psychomotor delay becomes apparent). Partial HPRT-deficient patients present these symptoms with a different intensity, and in the least severe forms symptoms may be unapparent. Megaloblastic anaemia is also associated with the disease. Inheritance of HPRT deficiency is X-linked recessive, thus males are generally affected and heterozygous female are carriers (usually asymptomatic). Human HPRT is encoded by a single structural gene on the long arm of the X chromosome at Xq26. To date, more than 300 disease-associated mutations in the HPRT1 gene have been identified. The diagnosis is based on clinical and biochemical findings (hyperuricemia and hyperuricosuria associated with psychomotor
User may input the reason for this proposal
Some fields can be disabled from editing.

User may change preferred name, add Definition to this category, ...
User may remove or change an existing property

User may add a new or an existing property
User may remove or change an existing association.

User may define a new association or define a new association value by using an existing association name.

Note: This indeed creates the links between two concepts.
User may track change using this tab

User may attach evidence using this tab

Other Users may add comments to this proposal

Leave a comment …

See Comments/References

Curation Status: NewChange
Reason for change: Test for WHO

Categories: WorkFlow ICD10 Proposal | WorkFlow Curation Status NewChange | SandBox ICD10 Other leukaemias of specified cell type(C94)
A power user (e.g. a TAG member) may change the curation status and make the proposal into a closed discussion layer. A toolbox for voting and commenting is also provided.
My Proposal management

Todo List for Mayo

- Category/ICD10: Acute rheumatic fever (03-02)
  - Guojian Jiang - This category should be reviewed by Guojian
- Category/ICD10: Balanced rearrangements and structural markers not elsewhere classified (Q08)
  - Guojian Jiang, Deepak Sharma - This category should be reviewed by Guojian
- Category/ICD10: Disorders of chondrod and ratlings (Q08/Q09)
  - Guojian Jiang, Kevin Peterson - This concept should be reviewed by Guojian
- TO DO List
  - Kevin Peterson, Deepak Sharma, Guojian Jiang - create a form to assign the tasks (i.e., Todo items)
  - Kevin Peterson, Deepak Sharma, Guojian Jiang - customize Voting extension, ArticleComments extension, ViewChange extension, MyWorkflow extension
  - Kevin Peterson, Deepak Sharma, Guojian Jiang - documentation
  - Kevin Peterson, Deepak Sharma, Guojian Jiang - autocompletion enhancement
  - Kevin Peterson, Deepak Sharma, Guojian Jiang - customize new lexiki instance in Imagen2 for GE Project

My Proposals (last editdate, proposal name, last editor)

- 12:45, 9 April 2008: Change Proposal by Mayo at 20080409124516 - Mayo
- 23:17, 9 April 2008: Change Proposal by Mayo at 20080409231723 - Mayo
- 18:40, 14 April 2008: Change Proposal by Mayo at 20080414184042 - Mayo
- 18:34, 14 April 2008: Change Proposal by Mayo at 20080414183422 - Mayo

My Proposals with Curation Status New/Change

- New/Change

My Proposals with Curation Status New/Concept

My Proposals with Curation Status New/Removal

My Proposals with Curation Status Ready/ToOpenDiscussion

My Proposals with Curation Status Ready/ToClosedDiscussion

My Proposals with Curation Status Rejected

My Proposals with Curation Status Accepted

I list all my proposals

Done
Proposal browsing by different curation status
ICD 11 Editing Process in Development

ICD in LexGrid

Export and Load

OWL RDF dump

Review and select

HL7/ISO format

OWL DL

Collaborative Protégé

Change Sets

ICD10WHO

navigation
- Main Page
- Community portal
- Current events
- Recent changes
- Help

external contents:
- ICD10WHO
- ICD10CM
- ICD10AM
- Query/Code

ICD10 proposals
- Add Proposal
- Add New Concept
- Browse Proposals

ICD10 Proposals

Proposals With Curation Status New
- Draft of ICD10 Acute erythroblastosis (C84.0) by LexWI
- Draft of ICD10 Acute megakaryoblastic leukaemia (C84.2) by Mayo at 2007
- Draft of ICD10 Acute myelofibrosis (C84.5) by Mayo at 2007
- Draft of ICD10 Other leukaemias of specified cell type (C84.6) by LexWI at 2007
- Draft of ICD10 Other leukaemias of specified cell type (C84.6) by Mayo at 2007
- Proposal A test proposal by Mayo

Proposals With Curation Status New Concept

Proposals With Curation Status Submitted

World Health Organization; Mayo Clinic - ICD-11
Instances of Changes
ICD 11 Editing Process in Development

World Health Organization; Mayo Clinic - ICD-11

ICD in LexGrid

Export and Load

OWL RDF dump

OWL DL Collaborative Protégé

Change Sets

Review and select

ICD10WHO

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ChAO: Change and Annotations Ontology

N. Noy, A Framework for Ontology Evolution in Collaborative Environments, ISWC06
ICD 11 Editing Process in Development

ICD in LexGrid

Export and Load

OWL RDF dump

OWL DL Collaborative Protégé

Review and select

Change Sets
Authoring Support in Collaborative Protégé

Instances of Changes

World Health Organization; Mayo Clinic - ICD-11
ICD-11 Revision organization structure

WHO

WHO FIC Update & Revision Committee

Revision Steering Group

Advisory Group: Modelling and Informatics

Topical Advisory Groups:

- Mental Health
- External Causes
- NN
- Oncology
- Internal Medicine
- Rare Diseases

Work Group
Work Group
Work Group
Work Group
Work Group
Work Group
Work Group
Work Group
Work Group
Work Group
Proposed Hierarchy of Wiki Authority by ICD Domain (not implemented)

0  Revision Steering Committee

1  Revision Domain/Topic Working Groups & WHO-FIC Network

2  Accredited Experts
   •  Designated by Working Group Members & WHO-FIC Network

3  Accredited Persons
   •  Designated by Experts

4  Registered Interested Persons (Public)
Discussions with IHTSDO
International Health Terminology (IHT)

• IHT (SNOMED) will require high-level nodes that aggregate more granular data
  • Use-cases include mutually exclusive, exhaustive,…
  • Sounds a lot like ICD

• ICD-11 will require lower level terminology for aggregation logic definitions
  • Detailed terminological underpinning
  • Sounds a lot like SNOMED
Potential Future States

ICD-11

SNOMED

Ghost SNOMED

Ghost ICD
Joint Alternate Future Effort
Advantages to Collaboration

- Both organizations avoid “Ghost” emulations
- Both organizations leverage expertise and content
  - More resources brought to the table
- Both organizations retain independent intellectual property and derivatives (e.g. Linear formats of ICD-11)
- Mappings become moot
  - Aggregation of SNOMED is definitional to ICD
Caveat
ICD and IHTSDO

• No agreements have been finalized
• Intellectual property sharing is expected
• Shared tooling is being discussed
• Harmonization Board has been proposed
WHO has announced the beginning of the process to develop the 11th Revision of the International Classification of Diseases – ICD-11 – expected to be completed in 2015. The NCHS, maintainers of the ICD-9-CM and producers of the ICD-10-CM, welcome this new initiative, and agreed with the leadership of the ICD-11 revision on the implications for ICD-10-CM introduction in the United States.
ICD-11 and ICD-10CM – 1 of 2

• ICD-11 will be built upon a robust ontological framework, with definitional linkages to underlying terminologies such as SNOMED CT.

• ICD-10-CM development will migrate to the technical platform used in the development of ICD-11, benefiting from the state-of-the-art informatics environment.

• The new ICD-11 Revision will be informed by the clinical modifications of WHO Collaborating Center members, including ICD-10-CM.
NCHS will work closely with the ICD-11 Revision Committee to ensure the gradual evolution of ICD-10-CM to ICD-11 content through the regular updating of ICD-10-CM; this will avoid a disruptive transition to ICD-11 some time after 2015.

Transitioning to ICD-10-CM will provide a mechanism for tightening the linkages between classification and their applications in electronic medical records, with broad implications for improving patient quality, safety, public health surveillance, and the adoptions of clinical best practices.