World Health Assembly Update of May 25, 2019

Member states agreed to adopt the eleventh revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-11), to come into effect on 1 January 2022.

More info here

ICD-11 WAS RELEASED ON JUNE 18

This release is an advance preview; it will be presented at the World Health Assembly in May 2019 for adoption by Member States and will come into effect on January 1, 2022.

Check the news release here

Purpose

The purpose of this page is to provide background information on ICD-11, the WHO 11th Revision of the International Classification of Diseases (currently, the eHDSI MVC contains codes from ICD-10, the 10th Revision of the Classification).

ICD-11 has been released on June 18, 2018. It is an advance preview to allow countries to plan how to use the new revision, prepare translations, and train health professionals.

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Information on ICD-11 presented during the 5th F2F meeting of the eHMSEG Semantic Task Force (Norbert SIGMOND):

ICD-11 present...2018-02-27.pdf

Other relevant links and resources:
- ICD-11 on the WHO site
- ICD-11 Browser
- ICD-11 Maintenance Platform
- ICD-11 Coding Tool
- ICD-11 Reference Guide (Draft 2017-10-09)

Update on ICD-11 Presentation by Donna Pickett and Robert Anderson (NCHS). January 12, 2018

**Brief reminder of ICD**

ICD is a tool for reporting and grouping conditions and factors that influence health. It contains categories for diseases, health-related conditions, and external causes of illness or death.

The purpose of ICD is to allow the systematic recording, analysis, interpretation, and comparison of mortality and morbidity data collected in different areas and at different times. With that aim, ICD is used to translate diagnoses of diseases and other health problems into an alphanumeric code, which permits storage, retrieval, and analysis of the data.

ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes.

The Chapter structure reflects major aspects of diseases. Chapters are not intended to delimit areas of medical expertise or domain of specialties. ICD includes categories for diseases, disorders, syndromes, signs, symptoms, findings, injuries, external causes of morbidity and mortality, factors influencing health status, reasons for encounter with the health system, and traditional medicine. These categories are complemented with additional detail such as anatomy, substances, infectious agents, or place of injury. Finally, ICD-11 also contains a set of rules and explanations for its use, required reporting formats, and necessary metadata.
Need for an 11th Revision

- Substantial advancements in Medicine and in Biological Sciences have occurred over the last 30 years - since ICD-10 was adopted
  - ICD-10 is now outdated, both clinically and from a classification point of view
  - Crucial structural changes were needed for some Chapters
  - Changes could not be handled through the normal updating mechanism
  - Changes needed well beyond the major update cycle
- Imperative to operate in an electronic environment
- Need to capture more information, especially for morbidity use cases
- In 2007 it was decided to begin work on ICD-11

General features of the 11th Revision

ICD-11 presents a main structural innovation: it is built on a foundation component from which the tabular list can be derived.

The addition of this foundation component and the electronic design of ICD-11 makes necessary to introduce new terminology not used in previous editions of ICD:

<table>
<thead>
<tr>
<th>ICD-11 Term</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Found stem code</td>
<td>Underlying data base content that holds all necessary information to generate print versions of the tabular list and the alphabetical index as well as additional information needed to generate specialty versions of ICD-11 and country-specific modifications.</td>
</tr>
<tr>
<td>Stem code</td>
<td>Codes that can be used alone. They are found in the tabular list of ICD-11 for Mortality and Morbidity Statistics. They may be entities or groupings of high relevance, or clinical conditions that should always be described as one single category. Their design make sure that in use cases that require only one code per case, a meaningful minimum of information is collected.</td>
</tr>
<tr>
<td>Extension code</td>
<td>Some users and for specific cases, more details are required in reporting that this provided by the stem code. This additional detail can be coded using an extension code. They can never be used without an stem code, on the contrary, they are used together to define in full detail a reported condition.</td>
</tr>
<tr>
<td>Cluster coding</td>
<td>Stem codes can be post-co-ordinated, or jointly used together, with extension codes or with other stem codes to fully describe one condition. In these cases, the post-co-ordinated codes will be grouped together to show which ones belong together to describe the disease; this mechanism is called ‘cluster coding’.</td>
</tr>
<tr>
<td>Primary and secondary parents</td>
<td>ICD-11 presents the same hierarchy definition as previous editions of ICD. Specific diseases and concepts within the classification can be connected to another parent code and this possibility was introduced to enable specific extracts of the Tabular list for medical specialties or for specific use cases.</td>
</tr>
</tbody>
</table>

Example: a code for a malignant neoplasm of the skin is included in the Chapter for malignant neoplasms the primary parent for this code is a code or a block from this Chapter. Nevertheless, a physician specialized in skin diseases might prefer to see only codes from the classification that are relevant for his/her practice. Consequently, a secondary parent was defined in the skin Chapter, which will only show the code in this Chapter if the specific extract of code for his/her use case is selected.

Coding scheme

- The Chapter numbering is in Arabic numbers and not in Roman numerals as before
- Categories have now 4 characters and there are 2 additional levels of subcategories
- Codes have now a letter in the second position to differentiate them from the codes in ICD-10
- The first character of the code refers to the Chapter number; it may be a number or a letter. Now in ICD-11, the range code of a Chapter always has the same character in the first position
- When describing a casual relationship between conditions in a code title the preferred term is ‘due to’
- When describing the concurrence of two conditions in a code title the preferred term is ‘associated with’

Mechanisms to add specific details
The extension mechanism uses the extension codes (groups of codes: anatomy, agent, histopathology, and others) to provide details to a code.

- They cannot be used alone and need to be added to a stem code.
- Not all extension codes can be used with every stem code and sometimes only a subgroup of an extension code can be used along with a specific stem code (this is indicated in the Tabular list, where the valid extension codes are shown for every stem code). Likewise, an extension code might be valid for a group of stem codes and that extension code will be indicated in the Tabular list at the highest level within the hierarchy.

"Code also" instructions

Inform about additional etiological information that needs to be coded in conjunction with certain categories due to the relevance of that additional information for primary tabulation.

- The 'code also' statement mark the categories that should be used only in conjunction with the indicated second code(s).
- In some instances, they may be a reason for treatment in their own right, where etiology is unknown.

Cluster coding

Mechanism of marking codes that are post-coordinated to describe one condition.

- This is a relevant new feature of ICD-11 by which a link is created, when desired, between core diagnostic (stem code concepts) and/or to add clinical concepts captured in extension codes to primary stem codes.
- This is one of the most significant changes in ICD-11 compared to ICD-10.

Other general features of ICD-11

Short description and long definition of categories

In ICD-11 categories have a short description and a long definition labeled ‘additional information’.

- The description is a short characterization of the entity, maximum of 100 words, that states things that are always true about a disease or condition and necessary to understand the scope of the rubric. It appears in the Tabular list.
- The long ‘additional information’ is the full definition, without length restriction, including detailed information that appears in the foundation component only.

Special tabulation lists

They continue to exist in ICD-11, although there are three additional ones: the Startup Mortality List (SMoL), the list for verbal autopsy and infectious diseases by agent.

Additional special tabulations can be derived from the new multiple parenting technique (e.g. all WHO notifiable diseases, listing all conditions that are assigned to the relevant section of the infectious diseases chapter). Special tabulations allow the representation of content for a specific specialty, creating subsets, and allowing the pre-coordination of more detail, if desired.

Definition of main diagnosis

For morbidity, this definition has changed to be the reason for admission after assessment at the end of the stay.

This new definition is less prone to interpretation and for countries that switched from the ‘biggest resources’ definition to the ‘reason for admission at the end of the stay’ using ICD-10, noticed only small changes in their activity statistics (see definitions in ICD-10 here).

Example:

1B10.0 Respiratory tuberculosis, confirmed

Parent

1B10 Tuberculosis of the respiratory system

Description

A disease of the respiratory tract, caused by an infection with the bacteria Mycobacterium tuberculosis, which has been confirmed by laboratory testing. This disease is characterized by chronic cough, sputum production, or haemorrhage. Fever, sweats, dyspnoea, dysphagia can arise if the upper airway is involved by tuberculosis. Respiratory tuberculosis is diagnosed by sputum smear microscopy and mycobacterial culture, or tissue biopsy. This category refers to respiratory tuberculosis that has been bacteriologically or histologically confirmed.

Show all index terms [81]
The Foundation Component and the Tabular Lists

The Foundation Component is a multidimensional collection of all ICD entities. Entities can be diseases, disorders, injuries, external causes, signs and symptoms. Some entities may be very broad, while other are more detailed (e.g. ‘injuries to the head’ and ‘Superficial injury of nose’).

The Foundation Component contains also the necessary information to use the entities to build a tabular list - a mono hierarchy in the style of a traditional statistical classification, information on where and how an entity is represented in a tabular list, whether it becomes a grouping, a category with a stem code, or whether it is mentioned as an inclusion in a particular category.

Different tabular lists can be built from the Foundation Component: a set of the so-called congruent tabular lists can be built on the same hierarchical tree. Later, data collected with any tabular list of such congruent lists can always be aggregated to the smallest common denominator, provided that the same rules for reporting, coding, and selection were applied.

In a tabular list, entities of the foundation become categories. The categories are mutually exclusive and jointly exhaustive, and linked to a mono hierarchical tree, i.e. they have only one parent. The information referring to an entity that has become a category and has multiple parents is still available from the foundation.

The core tabular lists for international use are:

1. Mortality and Morbidity Statistics (MMS)
2. Primary care low resources settings (PCL)
3. Primary care intermediate resources setting (PCM)
4. Verbal Autopsy (VA)
5. Simple Mortality List (SMoL)

Pre- and Post-Coordination, Cluster

Post-coordinating allows describing a health condition to any level of detail by combining:

- two or more stem codes
- stem codes with one or more extension codes

Stem codes hold all pertinent information in a pre-combined fashion or pre-coordinated way, while when additional detail that refers to a single condition is described by combining multiple codes, this is called post-coordination. Cluster coding is the mechanism that shows which codes are post-coordinated.

Example:

- Single code (pre-coordination) ‘Type 1 diabetes mellitus’

  5A10 Type 1 diabetes mellitus

  Parent
  Diabetes mellitus

  Description
  Diabetes mellitus type 1 (type 1 diabetes, T1DM, formerly insulin dependent or juvenile diabetes) is a form of diabetes mellitus that results from destruction of insulin-producing beta cells mostly by autoimmune mechanisms. The subsequent lack of insulin leads to increased blood and urine glucose.

  Exclusions
  - Type 2 diabetes mellitus (5A11)
  - Diabetes mellitus, other specified type (5A13)
  - Diabetes mellitus in pregnancy (J46)

  Show all index terms [13] 181

  Post-coordination

  Add detail to Type 1 diabetes mellitus

  Has manifestation (use additional code, if desired)

  Search

  • Single code (pre-coordination) ‘Adenocarcinoma of ascending code or right flexure of colon’ (in pre-coordination, both site and pathology are combined in a single pre-coordinated diagnostic code)
2B90.00 Adenocarcinoma of ascending colon or right flexure of colon

Description
A malignant tumour with glandular differentiation arising from epithelium of ascending colon and right flexure.

All Index Terms
- Adenocarcinoma of ascending colon or right flexure of colon

Post-coordination

Add detail to Adenocarcinoma of ascending colon or right flexure of colon

Specific anatomy (use additional code, if desired)
- XX3A53 Ascending colon
- XX3A63 Hepatic flexure of colon

Histopathology (use additional code, if desired)

Search

- Cluster coding (post-coordination) Stem code: 'Other specified malignant neoplasms of bronchus or lung' and extension code: 'Bilateral'

2C25.Y Other specified malignant neoplasms of bronchus or lung

Description
This category is an 'other specified' residual category.

Post-coordination

Add detail to Other specified malignant neoplasms of bronchus or lung

Specific anatomy (use additional code, if desired)
- XX3U Bilateral

Histopathology (use additional code, if desired)

Search

- Cluster coding (post-coordination) Stem code: 'Invasive ductal carcinoma of breast' and extension code: 'Upper inner quadrant of breast'
# 2C61.0 Invasive ductal carcinoma of breast

## Parent

- 2C61 Invasive carcinoma of breast

## All Index Terms

- Invasive ductal carcinoma of breast
- Infiltrating ductal carcinoma of breast
- Intraductal noninfiltrating papillary adenocarcinoma with invasion of unspecified site
- Infiltrating duct carcinoma of unspecified site
- Infiltrating duct carcinoma of unspecified site
- Infiltrating duct carcinoma of unspecified site
- Infiltrating duct carcinoma of unspecified site
- Infiltrating duct carcinoma of unspecified site
- Infiltrating duct carcinoma of unspecified site
- Infiltrating duct carcinoma of unspecified site

## Post-coordination

### Add code to Invasive ductal carcinoma of breast

#### Laterality (use additional code, if desired)
- XX66 Bilateral
- XX65 Left
- XX64 Right
- XX69 Unilateral, unspecified
- XX69 Unspecified laterality

#### Specific anatomy (use additional code, if desired)
- X0053 Breast
- X0053 Mastectomy
- X0053 Breast
- X0054 Laxation duct
- X0051 Central portion of breast
- X0058 Upper inner quadrant of breast
- X0058 Upper inner quadrant of breast
- X0054 Upper outer quadrant of breast
- X0058 Lower outer quadrant of breast
- X0058 Axillary tail of breast

#### Histopathology (use additional code, if desired)
- X0055 Infiltrating duct carcinoma, NOS
- X0055 Infiltrating duct carcinoma, NOS
Multiple Parenting

It happens that entities can be correctly classified in two different places in ICD, for example, lung cancer can be classified by site or by etiology; it can be classified as a condition of the respiratory system and also as a cancer under malignant neoplasms.

The Foundation Component will incorporate the "includes" notes for these situations mentioning both possible parents (multiple parents), although, for the tabulation of statistical out from a tabular list, there can only be one parent for primary tabulation. In the foundation view, both parents will be displayed the same way and in a tabular list the primary parent place will show the entity and its parents in black, and possibly the secondary parent place in grey.

Example:

An 'Invasive ductal carcinoma of breast' is a malignant neoplasm as well as a disease of the genitourinary system
The Content Model

All the content of ICD-11 is contained in the Foundation Component.

In the Foundation Component every entity is specified by a definition, machine-readable properties that have values, and one or more parent-child relationships; plus additional links providing information for post-coordination all this multidimensional information is then projected on one line with mutually exclusive categories as a Tabular list.

The foundation contains information on where and how a specific entity is represented in a tabular list. An entity might become a grouping, a category, or just a term, which is included in the Index.

**The Content Model is the structured framework that defines each entity in ICD in a standard way.** It presents the background knowledge that provides the basis for defining each ICD-entity in a systematic way that allows for computerization. As an entity can be seen from different dimensions, the Content Model represents each one of these dimensions as a ‘property’ there are 13 main properties defined in the Content Model to describe an entity.

A disease is defined using a set of relevant aspects from the list below - a disease is then considered a set of dysfunctions in a body system defined by:

<table>
<thead>
<tr>
<th>Property</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Symptomatology or manifestations</td>
<td>Known pattern of signs, symptoms, and related findings</td>
</tr>
<tr>
<td>2 Etiology</td>
<td>An underlying explanatory mechanism</td>
</tr>
<tr>
<td>3 Course and outcome</td>
<td>A distinct pattern of development over time</td>
</tr>
<tr>
<td>4 Treatment response</td>
<td>A known pattern of response to interventions</td>
</tr>
<tr>
<td>5 Linkage to genetic factors</td>
<td>e.g. genotypes, patterns of gene expression, etc.</td>
</tr>
<tr>
<td>6 Linkage to environmental factors</td>
<td></td>
</tr>
</tbody>
</table>

The key components of the definition of a disease are included as different properties within the Content Model.

The 13 main properties of the Content Model are:

1. ICD Entity Title
2. Classification Properties
3. Textual Definitions
4. Terms
5. Body System/Body Part
6. Temporal Properties
7. Severity of Subtypes Properties
8. Manifestation Properties (Signs, Symptoms or Investigation Findings)
9. Causal Properties
10. Functioning Properties
11. Specific Condition Properties
12. Treatment Properties
13. Diagnostic Criteria
Example:
The ICD entity 'Invasive ductal carcinoma of breast' is defined:

<table>
<thead>
<tr>
<th>Properties</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anatomy</td>
<td>breast</td>
</tr>
<tr>
<td>Morphology</td>
<td>invasive ductal carcinoma</td>
</tr>
</tbody>
</table>

The full range of values for a specific property is predefined using standard terminologies and ontologies constituting a Value Set.

Definitions
- Fully Specified Name
- Description
- Additional information

Clinical or Diagnostic Criteria
Functioning Properties

ICD-11 Conventions

Code Structure
Codes in ICD-11 are alphanumeric: ranging from 1A00.00 to ZZ9Z.ZZ

- Codes starting with ‘X’ correspond to Extensions codes (codes used to provide more detail to stem codes and not intended to be used alone)

- A letter in the second character position permits a clear distinction between ICD-11 codes and ICD-10 codes
- Letters ‘O’ and ‘I’ are excluded to avoid confusion with the numbers 0 and 1
- The terminal letter ‘Y’ is reserved for the residual category ‘other specified’

- The terminal letter ‘Z’ is reserved for the residual category ‘unspecified’

- WHO defines technically the coding scheme as shown below:

  EDEE.EE

  where:
  - E corresponds to a ‘base 34 number’ (0-9 and A-Z, excluding O and I)
  - D corresponds to a ‘base 24 number’ (A-Z, excluding O and I); and
  - 1 corresponds to the ‘base 10 integers’ (0-9)
  - the first E starts with ‘1’ and is allocated for the Chapter (e.g. 1 for the first Chapter ‘Certain infectious or parasitic diseases’ Chapter character; for example, 1A00 is a code in Chapter 1, and BA00 pertains to Chapter 11.)
Update of ICD-11

Updating cycle

It has been agreed that ICD-11 update will be performed at different levels with different frequencies so to keep stability for mortality while allowing faster updates for morbidity use:

- 10 years, Mortality and morbidity rules
- 5 years, updates with impact on international reporting (the 4- and character structure of the stem codes)
- 1 year, updates at a more detailed level
- 1 year, additions to the index or extension codes

(Member State Information Session, Geneva, May 14, 2018)