ICD Revision Process: Beta Phase and Finalization

This document summarizes the ICD Revision Process, in particular, in terms of the timelines for the finalization date and submission to WHO Governing Bodies. The WHO Secretariat has decided to postpone the submission of ICD to WHA to 2017 May in various consultations with the WHO Member States and relevant international stakeholders taking into account the developmental stage of ICD 2013 Beta, and allowing for reasonable time to complete the remaining tasks: reviews; additional proposals; field trials; translations; and the transition preparations.

Outline:

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B. Timelines for the submission of ICD to WHO Governing Bodies
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   2. ICD revision process: Maintenance of ICD after finalization

A. Background: Need and Mandate for the ICD Revision

The World Health Organization (WHO) has a constitutional mandate to develop international standard classifications and terminologies for health. ICD has been maintained by WHO starting from its sixth edition with periodic revisions approximately every 10 years. It serves as the international health information standard for collection, classification, processing, and presentation of disease-related data in national and international health statistics. In 1967, all WHO Member States accepted the first international regulations to use ICD for mortality and morbidity statistics.

ICD 10th Edition was produced between 1982 and 1989 by annual revision conferences and it was adopted in 1990 by the World Health Assembly. It was foreseen that 10 yearly (decennial) editions would continue as the method of revision with interim annual updates in between. When the 11th revision was due in 2000, the “ICD Revision” topic was discussed in the WHO Executive Board in 1999 and a moratorium was suggested for the Secretariat to come up with a modern revision strategy in consultation with the Member States. The reason for this suggestion was the level of ICD-10 adoption by Member States: ICD was then used by only 96 Member States out of 191; its adoption and implementation had several problems including Year2K complications in health information systems. Hence a moratorium suggested better informatics support towards implementation.

In the following years, WHO addressed the implementation issues within the WHO Family of International Classifications (WHO FIC) Network and then formulated a revision strategy between 2003 and 2007. The objectives of the ICD Revision Process are listed as below:

The objectives of the ICD Revision Process:

1. To revise the ICD classification in line with scientific advances, to serve multiple purposes including mortality and morbidity statistics as well as clinical use in primary care, specialty care and research;

2. To continue to serve as an international standard in multiple languages and settings to allow for comparable data;

3. To link with computerized health information systems (directly use standard terminologies and other health informatics applications to be “electronic health application ready”).

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1 the WHO Nomenclature Regulations adopted by the World Health Assembly (resolution 20.18, May 1967) [http://www.who.int/classifications/icd/docs/en/NOMREGS.pdf](http://www.who.int/classifications/icd/docs/en/NOMREGS.pdf)
To achieve these objectives, an **International Revision Process Plan** was developed to revise the classification content in line with advances in health sciences and to add the desired functionality using modern health informatics standards. The revision process aimed to gather input from **all stakeholders** in an **open** and documented way. This revision process was initiated by a letter from Director General of WHO to all Member States in April 2007. An Internet platform was developed that allowed participation of all interested parties in the revision process. To learn from the improvements that individual countries have already made in their ICD clinical modifications (*i.e.* **ICD Australian Modification, Canadian Modification, German Modification, US Modification**), their additions were systematically merged and sorted for the ICD revision. The organization of the Revision Process is summarized in Section 1, below.

### 1. ICD Revision Process: General Organization Structure

To coordinate the International Revision Process, a large project platform was developed and all Member States were invited to contribute. Key elements of this process included:

a. **Public Internet Platform** – where all interested parties could see the current ICD-10 and make additional proposals and comments. This platform later included a “Collaborative Authoring Tool” (iCAT), an enhanced WIKI tool, which: (i) is well-structured with formal links to other classifications and standard terminologies and (ii) has an editorial control mechanism. iCAT enables all users to apply the same building blocks and procedures in support of standard classification development. In addition to iCAT, the public Internet platform has multiple components including making proposals, making comments, and participating in: translations; field trials; and the review process.

b. **Topic Advisory Groups (TAGs)**: Several expert groups have been established to guide and review the work in the **subject areas** of the ICD. TAGs were formed for key uses of ICD for “**Mortality**” and “**Morbidity**” as well as particular areas such as “**Quality and Safety**” Indicators” and “**Functioning and Disability**”, which cross-cut the whole classification; hence the name “**horizontal TAGs**”. Specific content areas have their own “**vertical TAGs**” which include: Internal Medicine, Pediatrics, Neoplasms, Injuries, Mental Health, Neurology, Dermatology, Ophthalmology, Genito-Urinary and Reproductive Medicine, Musculoskeletal Disorders, Oral Health, Rare Diseases, Environmental Health, Occupational Health, and others. A special group worked on the “health informatics and modeling” and another one on “software development”. There are 24 TAGs or working groups currently active since 2007 along with established guidelines and standard operating procedures to revise the ICD.

c. **A Revision Steering Group (RSG)** that includes the heads of the Topic Advisory Groups has been overseeing the revision work to assist the WHO Secretariat in coordinating the overall revision process. This group meets by monthly web meetings and has met face-to-face at least once per year between 2007 and 2012. As this group has now more than 34 members,
a **Small Executive Group (RSG-SEG)** has been formed by 6 members that meets on weekly basis since 2010 and has produced 19 Information Notes on key issues to the revision process. An additional 9 Information Notes are on their agenda to sort out the emerging issues. The RSG and RSG-SEG discuss and resolve problems reported by the TAGs and others.

d. The work of the ICD Revision Process is continuously shared with the **WHO FIC Network**, which includes WHO Collaborating Centers for WHOFIC, some international Non-Governmental Organizations and some Academic Research Centers. Initially formed by 7 WHO Collaborating Center Heads in 1972, this network has grown since 1998 to some 40 formal member institutions and entities. The WHO FIC Network advises WHO of the key technical issues in the area of Classifications. As this network, however, does not fully cover all WHO Member States, and as the revision process requires a larger effort than the network capacity, the Revision Process has been defined purposefully outside the WHO FIC Network’s Mandate. The Revision process in the final instance will be submitted to the WHO Governing Bodies for formal approval. It is foreseen that when the Revision Process is completed, the future ICD updates and maintenance tasks will be undertaken by the WHO FIC Network’s Update and Revision Committee (URC) again. Moreover, Mortality and Morbidity Topic Advisory Groups have at least 50% of their membership from the Network. The WHO Collaborating Centers have also actively participated in the revision process by incorporating their national modifications, reviewing the ICD drafts and making suggestions. Currently, they continue to participate in the review process and may also take part in the field trials or coordinate them in their respective countries.

e. As ICD has multiple uses and users, extensive consultations have been made with a larger constituency of stakeholders. These include several medical organizations and specialty groups, health information management organizations (e.g. IFHIMA and AHIMA), the insurance sector, the labor sector (ILO), and the informatics sector including other standards development organizations (such as IHTSDO, HL7 and ISO). WHO has developed formal links with IARC (International Agency for Research on Cancer) and other international and national groups supporting the development, review and testing of the new ICD classification. In particular, further to the discussions in the WHO Executive Board in 2005 and 2006, WHO has established a Collaborative Arrangement with the **International Health Terminology Standards Development Organization (IHTSDO)** to avoid redundancy and align ICD and Standardized Nomenclature of Medicine (SNOMED) by an official agreement reached in 2009. Since then, SNOMED to ICD-10 maps have been produced and more detailed binding of SNOMED to ICD-11 has been developed. When ICD and SNOMED are used jointly, it is envisaged that the coding of electronic health information into ICD will lead to wider applications that are more efficient and cost-effective.

f. In addition, the ICD Internet platform has a large outreach to networks of different groups which serves as a “**social computing**” organization. ICD Web Pages have currently 2.5 million visits per month with 10 million average page views. Approximately 500,000 sessions/month are estimated to be directly related to the ICD revision. The ICD Internet
ICD Revision Process: Beta Phase and Finalization

Since the start of the revision process in 2007, ICD has been significantly re-engineered to continue to serve multiple purposes as the international scientific standard to classify diseases and other related health problems. This work has been carried out in multiple phases:

a) **Alpha phase**: An early “alpha” draft of ICD was developed within a closed group of experts and WHO circles including WHO Collaborating Centers and invited advisors, which amounted to around 1200 international experts. This was a significant planning and development phase where the architectural and modeling alternatives were discussed, implemented, and agreed.

b) **Beta Phase**: Alpha draft evolved to a “relatively stable” yet unfinished ICD Beta draft which included all national modifications, TAG proposals, and other suggested organizations. The Beta Draft was presented to the “public” allowing interested parties to review, comment, and make proposals and test according to the established protocols. This phase is presented with caveats that the ICD Beta Draft is not final, is not yet an approved standard by WHO, and is under continuous development. Measures to avoid potential conflicts-of-interest and to maintain the intellectual property rights of ICD are also put in place.

c) **Finalization and Maintenance Phase**: Once the Beta phase results in a more stable ICD, it will be submitted to WHO Governing Bodies for adoption. It is envisaged that the current revision process is adopted for the continued day-to-day maintenance and updates to the ICD in the forthcoming decade after the completion of the revision process. In this direction, a transition strategy is being developed for both WHO to synchronize and harmonize the current update process of ICD-10 and the future maintenance of ICD-11. (See Section B2 Future Maintenance Strategy)

The main accomplishments of the ICD Revision Process (2007-2013) to date have been:

**ALPHA PHASE:**

a. Building on the ICD-10 content and structure, additional improvements in the ICD national modifications have been incorporated as well as changes that could not be carried out by the classical ICD-10 update process have been included.

b. Scientific advances in the health sciences have been systematically searched and incorporated under the expertise of various Topic Advisory Groups.
c. A robust computerized system for ICD has been developed using contemporary health informatics standards. This system has a “foundation component” which includes all ICD entries and allows selection of code subsets named as “linearizations” which are tabular lists for different purposes: such as mortality; morbidity; primary care; and specialty care. ICD informatics infrastructure also links to standard terminologies in a systematic way.

d. Internet based digital editing capability has made it possible that experts collaboratively author the ICD on a continuous basis in a more effective way. Similarly, this infrastructure enables conducting (i) reviews, (ii) translations, (iii) field trials and (iv) making new proposals using the same Internet platform.

BETA PHASE:

At this point in time, January 2014, an ICD Beta 2014 Version has been produced for review purposes and later for field trials after 6 years of drafting phases. The current ICD 2014 Beta version has a set of relatively stable code sets (i.e. linearizations) for at different uses. The following table summarizes different linearization examples that are part of ICD11 production:

<table>
<thead>
<tr>
<th>Level</th>
<th>Name</th>
<th>Use Case</th>
<th>Size</th>
<th>Pre –Post Coordination</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>SHORT Linearization</td>
<td>• Primary Care – Low Resource</td>
<td>700-1200 categories</td>
<td>Pre-coordinated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Verbal Autopsy</td>
<td>100-200 categories</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Intermediate Linearization</td>
<td>• Primary Care – High Resource</td>
<td>2000 Categories</td>
<td>Pre-coordinated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• (Mortality Tabulations)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Reference Linearization</td>
<td>• Joint Linearization for Mortality and Morbidity Statistics (Volume I tabulation)</td>
<td>15,000 Categories</td>
<td>Pre-coordinated (mortality)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Pre + Post Coordinated (morbidity)</td>
</tr>
<tr>
<td>4</td>
<td>Extension Linearizations</td>
<td>• Specialty Linearizations</td>
<td>&gt; 15,000 Categories</td>
<td>Pre + Post Coordinated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• National Linearizations</td>
<td></td>
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</tr>
</tbody>
</table>

The Foundation Component is the largest set of ALL categories that may then take place in any given ICD Linearization. All ICD items are catalogued in a systematic fashion in the Foundation Component using modern health information technology. This systematic structure uses the ICD Content Model which defines the linkages to standard parameters of information for each category such as: fully specified name, definitions, inclusion and exclusion terms, as well as signs-symptoms, laboratory findings, diagnostic criteria and other information.

Linearizations are lists of selected ICD categories for a purpose; hence they may be of different size and granularity, which are fit for that particular purpose. For example a primary care provider may need to use broad categories of illness such as “upper respiratory tract infection” whereas a specialist may need to use “tonsillitis due to a specific agent”. One of the key purposes of ICD11 architecture is to make these two categories to be linked in a meaningful way- with a proper grouping logic between different linearizations. Formerly in ICD10 such linkage was made in a limited way (by truncation of codes or creating equivalence tables).
In ICD11 hierarchical organization these corresponding concepts in different linearizations are designed to be linked in two possible ways:

(a) through the exact matching of two entities directly in the foundation component – i.e. without any nesting in the hierarchy of classes;

(b) through the “nesting or telescoping principle”: there is a parent – child relation at each level and the granularity of the categories increases as they branch out within the same “parent”. In this way, it is possible to link the children to their relevant parents or grandparents within certain bounds of certainty for common reporting purposes; as in the example shown below:

**LEVEL 1:** Myocardial Infarction  
* (Verbal Autopsy, Primary Care – for low resource settings)

**LEVEL 2:** Myocardial Infarction  
* (Tabulations)

**LEVEL 3:** Acute Myocardial Infarction, ST Elevation  
* (mortality input; morbidity reporting)

**LEVEL 4:** Acute Myocardial Infarction, ST Elevation, Inferior Wall, post-procedural  
* (specialty)

It is essential that in a particular linearization all selected items have to be **mutually exclusive** and **jointly exhaustive** for statistical purposes to avoid double-counting. Selecting ICD categories for a given linearization conforms to this principle and generates residual categories and groupings accordingly. Given the digital nature of ICD it is possible to have one category represented in two or more places in the ICD classification – but with **one single primary code**. This feature is called “multiple parenting”. For example, Malignant Melanoma is both a neoplasm and a skin disease. It can be represented in both Neoplasms chapter and Skin Diseases but with the primary code in neoplasms.
B. ICD Revision Beta Phase 2014-2017:

The former ICD Revision Process timeline foresaw the ICD submission to the WHA in 2015; however, WHO Secretariat has decided to postpone the final ICD submission to WHA to 2017 May in various consultations with the WHO Member States and relevant international stakeholders. Underlying this decision the following factors were taken into account:

a. the developmental stage of ICD 2013 Beta

b. allowing for reasonable time to complete the remaining tasks:
   1. Reviews
   2. Additional Proposals
   3. Field Trials
   4. Translations
   5. Transition Preparations.

A more detailed explanation of remaining tasks and time requirements is given below and shown in the Appendix 1 in more detail. In terms of the deferral decision the following factors were taken into account:

a. The Developmental stage of ICD 2013 Beta – WHO Secretariat has developed the first draft ICD 2013 Beta to be reviewed by Mortality and Morbidity TAGs and scientific peers. A consultation meeting was held in December 9-13 2013 to identify the remaining issues with the Joint Linearization for Mortality and Morbidity Statistics. From this point on, the classification linearization is expected to be relatively stable and will be in a graceful evolution by incorporating the results of the review. Depending on the results of the review, necessary changes will be incorporated into the ICD with appropriate version control mechanisms. The ICD Beta will be then presented in the WHO Internet site incorporating several measures for continuous quality improvement such as: incorporation of new proposals, results of the field trials, checking internal consistency, and others.

b. The remaining tasks:

1. Review process: An international scientific peer review process has been designed where designated experts will review certain sections and aspects of ICD. WHO assigned Topic Advisory Groups will act as “Editorial Boards” to evaluate the results of the review. The review process will consist of the following steps:
   a. INITIAL REVIEW:
      i. Linearization Review for Mortality and Morbidity Statistics
      ii. Content Review for specific chapters

   b. ONGOING and FINAL REVIEW
      i. Review of incoming proposals and additional changes
      ii. Review of Final ICD before it is released for official use
It is expected that each round of review will take **at least 4 months** to complete depending on the size of the review unit and responsiveness of the selected reviewers.

The review must be repeated when changes are made and before the final ICD product is submitted to the World Health Assembly.

The reviews are made by voluntary contribution of reviewers and they are conducted remotely through e-mail and therefore may last longer than initially estimated.

WHO Secretariat will bring the key parties (i.e. Mortality and Morbidity TAGs together to discuss the results of the review and agree on the Joint Linearization for Mortality and Morbidity Statistics).

2. **Public Proposals** – WHO has made an internet platform where registered users can make proposals for adding new categories to the ICD as well as other comments and suggestions for naming, inclusions and other references. These proposals will also be evaluated through the review process above in systematic fashion. It is expected that many additional comments and proposals will be coming in from the interested parties, which are useful to indicate the problematic areas, missing elements and alternative formulations. These additional proposals will be subjected to the peer review process and may take a period of 6 months to complete and integrate into the ICD.

3. **Field Trials** – WHO has designed certain field trials to test the (i) **applicability** (ii) **reliability** (iii) **utility** of the ICD in the hands of the actual users. These standard protocols are to be carried out by a large number of users and provide feedback on the finalization process. A set of standard field trial protocols is currently being pilot tested in a number of collaborating centers. These field trial protocols proved to be applicable and in three different countries. A wider scale implementation across different countries and setting may take 24 to 36 months. By 2015, some Field Trials such as testing the bridge-coding between ICD-10 and 11 for mortality and morbidity coding may be complete. It is requested to give more time to non-English speaking countries for field trials in 2015 and 2016. Noting that the resources available for field trials to WHO is limited for the development of protocols and central data analysis, implementation of field tests in different countries would require additional funding from local participants. Consideration has to be given to make continuous incorporation of field trials results in the overall ICD revision later during the maintenance phase in line with proper quality improvement principles.

4. **Translations**: WHO has created a computerized translation platform, which makes use of the existing ICD translations of ICD to enable timely availability of the revised ICD in **multiple languages**. Priority is given to WHO official languages (Arabic, Chinese, English, French, Russian, and Spanish; in addition to German and Portuguese as WHO Regional Office languages). Countries who wish to participate in ICD translations on their own resources will be encouraged to do so. With the Internet based ICD tools, ICD translations could benefit from the previous
translations of ICD-10 and could be shared between multiple translators. It is estimated that translation of ICD-11 with definitions may take 12 months for a language depending on the dedicated translators. Additional resources may be useful to expedite this process.

5. **Finalization of ICD-11 as a package** (Joint Linearization, Reference Guide and Index): Use of ICD requires “instructions” which are organized as a knowledgebase of rules, explanations, examples, instructions and other guidance. A Reference Guide is provided as both an online tool and a printed volume. ICD use requires an “index” which matches medical phrases to codes. An index has been produced both as a print and digital tool. Additional materials and documentation (e.g. transition tables) will be produced in course to assist training and implementation of ICD and assist countries in transition to ICD. Once field trials results are incorporated and the results of reviews are obtained, it is planned to finalize the production of:

- **Volume 1**: Joint Linearization for Mortality and Morbidity Statistics;
- **Volume 2**: the Reference Guide
- **Volume 3**: the ICD11 Print Index

The preparation of the final package for presentation to the World Health Assembly for approval is expected to take at least 6 months. The final package will be open for public consultation and will include additional material for transition guidance, tables for correspondence between ICD-10 and ICD-11. Currently the ICD Revision Process includes “stability analyses” that constantly track changes to the ICD-10 categories. These will be presented as “cross-tabulations” to allow transition in mortality and morbidity statistics.

In Summary, these multiple streams of work will continue as parallel processes through complex integration challenges. Co-ordination of work and communication of the issues identified will present an immense challenge in terms of carrying out the resulting edits from proposals, field trials and appropriate consultations with expert groups.

The DRAFT project plan includes the detailed steps for the completion of ICD Revision Process.

2. **ICD Revision Process: Future Maintenance Strategy:**

The ICD revision process has provided a useful infrastructure, mechanisms and operating procedures for the development and maintenance of the new ICD. In view of this experience, it is proposed that the revision infrastructure is adopted for the continued day-to-day maintenance and update of the ICD in the forthcoming decade after the completion of the revision process.

The current model of “one foundation – multiple compatible linearizations for different uses” enhances the comparability of ICD related code sets in different settings; allows flexibility to capture more detail when needed in a computerized structure. Similarly its implementation in the iCAT platform with universal identifiers provides: (i) well-structured formal links to other classifications and terminologies; and (ii) controlled editorial system including systematic peer review. After finalization, the ICD Revision mechanisms for “new proposals” and “review” may continue to serve as the basic maintenance and continuous update process. If agreed, this will replace the current “ICD-10 Update mechanism”.

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In this new maintenance scheme, it is envisaged that the update proposals may come throughout the year and will be handled immediately according to a standard operating procedure. A review will be finalized by October of each year and submitted to the WHOFIC Council and a new linearization for the next year will be approved for use in the upcoming year. In this way, ICD will be named as ICD 2017, ICD 2018, ICD 2018 and so on. This mechanism will facilitate the version control with constant updates through graceful evolution ensuring stability and backward compatibility. WHO will continue to support ICD-10 Updates in a similar way for a defined period until most Member States adopt the new style. Countries who may need more frequent update cycles (e.g. twice per year) may also use the same mechanism.