

ICD Revision Process

Prepared by WHO

ICD Revision Process: SUMMARY

This document summarizes the ICD Revision Process:

1. *Background: need and mandate*
2. *General organization structure of the multiple streams of work*
3. *Progress and current status*
4. *The remaining steps*
5. *Further maintenance of ICD after finalization*
6. *Timelines for the finalization date and approval by WHO Governing Bodies*

1. 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 serves as the international health information standard for collection, classification, processing, and presentation of disease-related data in national and international health statistics. ICD has been maintained by WHO starting from its sixth edition (since 1948) with periodic updates approximately every 10 years. 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 through a process of 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 were:

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 maintain the ICD classification as the **international standard** in multiple languages and in multiple settings to enable **comparable data**;
3. To link the ICD classification with **computerized health information systems**, which required ICD directly uses standard terminologies and links with other health informatics applications to be “**electronic health application ready**”.

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. This revision process was initiated by a letter from Director General of WHO to all Member States in April 2007. The revision process aimed to gather input from **all stakeholders** in an **open** and documented way. An Internet platform was developed to enable 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 2, below.

2. 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 is (i) well-structured with formal links to other classifications and standard terminologies and (ii) have an editorial control mechanism. iCAT enables all users to apply the same building blocks and procedures towards standardization. In addition to iCAT, the public Internet platform has multiple components including making proposals, 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 since 2007. 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 their 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 Platform also includes **discussion forums** and **social media links** with groups in Linked-in, Facebook and Twitter, which in the coming years will have more participation in terms of testing and reviewing the classification.

3. Progress and Current Status of ICD Revision:

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:

1. 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.
2. Beta Phase: Alpha draft evolved to a “relatively stable” yet unfinished **ICD Beta draft** which was presented to the “public” allowing interested parties to review, comment, 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.
3. Finalization and Maintenance Phase: Once the Beta phase results in 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 6: Future Maintenance Strategy)

The main accomplishments of the ICD Revision Process 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 subsets 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, **1 September 2013**, an ICD2013 Beta version has been produced for review purposes and field trials after 6 years of drafting phases.

The current ICD 2013 Beta version has relatively stable **classification lists** (i.e. linearizations) for Mortality and Morbidity recording. It will be reviewed by the specific Mortality Reference Group and the Morbidity Reference Group to see how well it fits the purpose and proposed transition from ICD-10.

In addition, the Beta version has planned processes for:

- (i) Systematic international scientific peer review
- (ii) Submission of additional proposals from public groups and scientists
- (iii) Conducting field trials for its applicability and reliability
- (iv) Production support in multiple languages (translations) starting with WHO official languages
- (v) Preparations for transitions from ICD-10 to ICD-11.

All these activities have been achieved with funding and resources summarized in the Table 2.

These five processes in the Beta Phase are summarized in the next section.

4. ICD Revision Process - Remaining Steps:

1. REVIEW PROCESS:

An **international scientific peer review process** has been designed where certain sections and aspects of ICD will be reviewed by designated experts. 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
 - 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

2. ADDITIONAL 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.

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.

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 with 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. Currently, Italy, Korea, and Japan have started this process.

5. TRANSITION PREPARATIONS

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.

5. Future Maintenance Strategy:

The revision process has provided 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 Collaborative Authoring Tool is an enhanced WIKI which is: (i) well-structured with 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 process. If agreed, this will replace the current “ICD-10 Update mechanism”.

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 2015, ICD 2016, ICD 2017** and so on. This mechanism will facilitate the version control with constant updates through graceful evolution ensuring stability and backward compatibility. WHO may 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.

6. Timelines

The current ICD Revision Process timeline foresees that the ICD is submitted to the WHA in 2015 May and could then be implemented. Between now and 2015, there remains 20 months to conduct the remaining tasks summarized above as: 1. Reviews, 2. Additional Proposals, 3. Field Trials, 4. Translations, and 5. Transition Preparations.

Given the technical requirements these steps could be expedited in the **next 20 months**. The experience obtained thus far, however, suggests that this timeframe will be extremely tight for paying due diligence to the work especially in terms of: appropriate consultations with expert groups; communication and dissemination with stakeholders; and sufficient time for field testing in multiple countries and settings, and carrying out the resulting edits.

WHO Secretariat would like to discuss this with all stakeholders and evaluate the possible options:

- a. Keep ICD submission to WHA to 2015 as originally planned and implementation/adoption date may be free by any Member State (current position – no change).
- b. Postpone submission to WHA to a later year to allow longer time for field trials and other transition preparations.

To make better-informed decision on these options, a more detailed explanation of remaining tasks and time requirements is shown in **Table 1**. In terms of basic tasks:

1. Finalization of ICD Content – WHO Secretariat has developed the first draft **ICD 2013 Beta** to be reviewed by Mortality and Morbidity TAGs and scientific peers. 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. The remaining time (20 months) is expected to be sufficient to carry out this task and produce ICD 2014 and ICD 2015 versions accordingly with continuous quality improvement.
2. Review process – will be conducted in two paths (a) horizontal reviews: which involves the Mortality Linearization Review and the Morbidity Linearization Review; (b) vertical reviews: each chapter content will be reviewed by international scientific peers in a systematic way. It is expected that each round of review take **at least 4 months** to complete. The review must be repeated when changes are made and before the final ICD product is submitted to the World Health Assembly. The time for review is therefore tight and the estimates are optimistic. The reviews are made by voluntary contribution of reviewers and they are conducted remotely through e-mail and therefore may last longer than estimated. It will be better to have resources to bring the key parties (i.e. Mortality and Morbidity TAGs together to discuss the results of the review and agree on the final Linearizations).
3. Public Proposals – 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 proposals will be subjected to the peer review process and may take a period of 6 months to complete and integrate into the ICD.
4. Field Trials – A set of standard field trial protocols are 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 the 2015 deadline, some Field Trials such as testing the bridge-coding between ICD-10 and 11 for mortality and morbidity coding may be complete. Non-English speaking countries may,

however, have a time disadvantage to fit in the timeline. It is requested to give more time to non-English speaking countries to allow for more field trial results 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.

5. Translations: 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.
6. Finalization of ICD-11 (Linearization, Reference Guide and Index): Once field trials results are incorporated and the results of reviews are obtained, it is planned that production of combined Mortality and Morbidity Linearization with the Reference Guide and Index would require 6 months to present to the World Health Assembly for approval.
7. Transition preparations: 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. Finalization of the stability analyses work will be concluded when the final instance of ICD 11 is produced to guide the transition from ICD-10 to ICD-11 including appropriate software, documentation and training materials.

In conclusion:

- (a) WHO Secretariat could produce an ICD 2015 ready including Mortality and Morbidity Linearizations, Reference Guide and Index with the appropriate resolution to go to the World Health Assembly. This timeframe, however, is extremely tight for paying due diligence to the work especially in terms of: appropriate consultations with expert groups; and sufficient time for field testing in multiple countries and settings, and carrying out the resulting edits
- (b) If the timeline is advanced to 2016, there will be more time to have ICD 2016 version with more translations and incorporations of some field tests results.
- (c) If the timeline is advanced to 2017, ICD 2017 will be ready with most Field Test results incorporated and maintenance scheme tested.

Table 1. Finalization steps for ICD Revision

STEPS	Tasks	Time	Resources	Comments
1. finalization of ICD 2013 Beta for Review		01-Sep	WHO HQ Staff	will be on going
Special Chapter work	Complete Chapter work	Near Final	Meetings	Derma, Eye, Neurology, Mental Health have still pending input...
Content	Update definitions, content	Ongoing	TAG work	Sexual Health: to be discussed in particular
Pre-Post Coordination	Implement rules	22-Aug		Rules OK - application ongoing
Stability Analysis	10 to 11 crosstabulations)	22-Aug		Mortality OK - Morbidity to be updatedOK
Volume II - Reference Guide	Coding rules	01-Sep		Mortality OK - Morbidity to be written
Index	Print Index, Electronic Index	22-Aug		WHO OK (1) print; (2) electronic
Dissemination	Communications strategy, WEB, Social Media		Communications	Wikipedia, hiring staff, publications
2. Review process		4 + 24 Months	Software ready by 1 Sept.	initial review complete 2014
horizontal	Mortality Review, Morbidity Review	Initial Review (4 months), Ongoing Review		Mortality OK - Morbidity ?
vertical	Each Content Chapter, Review Units	Initial Review (4 months), Ongoing Review		Ongoing discussions particularly in ownership and definitions
3. Public Proposals		24 months		
evaluation of Proposals -review		ongoing		useful - public input
integration		6 months		WHO Staff support
4. Field Trials		24-36 months	Protocols ready	Field Trials complete 201* (4- limited, 5, some, 6 reasonable)
		Currently pilot phase	Resources needed for implementation and analysis	
5. Translations		12 month	Staff - WHOFIC Network, other linkages	Translations complete 201*(4- limited, 5, some 10)
			Resources sought	
6. Finalization of ICD-11 Vol I		6 months	doable with dedicated staff	Work ongoing 2014
7. Transition preparations				Work to start in 2015
Software functions		country dependent	individual groups of Countries	
Print Documents	Preparation; WHO Press		ready	new rules necessary for IP right - subscription model vs other modes
Training Materials			invest in training; tools to be developed	
Publications				
CONCLUSION		201 * ? (5, 6, 7, 8)		
				2015 - ICD 2015 will be ready as Mortality and Morbidity Linearization, Reference Guide and Index -
				2016 - ICD2016 will be ready as above with more translations and some field tests - continuous improvement
				2017 ICD2017 will be ready as above with Field Test result incorporated - maintenance scheme tested

Table 2: Funding and Other Resources

Area	<i>Amount (US \$)</i>
<p>WHO Core Budget support for the WHO/HQ ICD-11 team <i>4 staff members i.e. 4 Full Time Equivalent/year over 9 years (2007-2015)</i></p>	7,200,000
<p>Other WHO HQ departments support estimated at 2 Full Time Equivalents/year over 6 years <i>In the fields of Mental Health, Neurology, Metabolic Disorders, Environmental Health, Occupational Health, Genito-Urinary and Reproductive Health, and Oncology (at IARC) have formal staff members or consultants dedicated to work on this project. These WHO departments have either used their regular budget or obtained funding to support these personnel.</i></p>	2,400,000
<p>WHO Collaborative Project with Japan Hospital Association (2007-2015) to support the ICD implementation and revision (300,000 USD/year) <i>These funds have been used to support the development of the ICD software platform, annual meetings of the Revision Steering Group and several other consultations.</i></p>	2,700,000
<p>WHO Collaborative Project International Classification of Traditional Medicine (2010 – 2013) 3.6 Million US dollars pledged to date. <i>These funds have been exclusively used in TM classification for its inclusion in the ICD format, but they also synergistically supported the classification software development, the review process and the field trials.</i></p>	3,600,000
<p>European Commission support to ICD revision process (2009 -2013) Two FP6 and FP7 grants 150,000 Euros/year <i>(i) to review the definitions in particular areas; and (ii) to formulate the use cases for clinical care and public health informatics.</i></p>	800,000

OTHER RESOURCES	<i>(In kind estimated)</i>
WHO FIC Network	
<ul style="list-style-type: none"> - developing parts of the software platform <i>Stanford University has developed the iCAT software with partial funding and the Italian Collaborating Center has developed the Social Media add-ons</i> 	320,000
<ul style="list-style-type: none"> - Seconding expert staff to WHO. Australian Collaborating Center has provided a coding expert to assist WHO/CTS. 	600,000
<p>World Federation of Chiropractic has been supporting a 1 FTE/year assistance from their membership 2013-2015.</p>	
<p>A large number of volunteers from WHO Collaborating Centers</p>	200,000
<ul style="list-style-type: none"> - Direct Meeting support 	50,000