

## End of Mission Report – ICD-11 JLMMS Task Force

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### Background

The 11<sup>th</sup> revision process of the International Classification of Diseases (ICD) was officially launched in 2007 in Japan, after discussions that had begun several years earlier. The World Health Organization (WHO) invited expert input for the revision from more than 20 subject-specific Topic Advisory Groups (TAGs), while setting in place key strategies through large meetings (i-camps) and governance committees. This large and innovative international public good initiative engaged hundreds of experts from scores of nations, resulting in a large volume of proposals and advice and a suite of tools for managing and organizing them.

From early in the revision process, much attention was given to the information framework and technical underpinnings for ICD-11, designed to enable the classification to operate in digital information environments. A significant feature is the Foundation, a database of many information entities relevant to a classification of diseases. It had been decided in 2013 that a common code set, suitable for both mortality and morbidity statistics, would be drawn from the Foundation. This code set, initially known as the Joint Linearization for Mortality and Morbidity (JLMMS), is now known as the ICD-11 for Mortality and Morbidity Statistics (ICD-11 MMS), and frequently just referred to as “ICD-11”.

By 2014 it was clear that the proposals and advice developed to date needed much refinement and organization if they were to serve the requirements of statistical classification of mortality and morbidity. This realization prompted the WHO to commission an external review of the ICD-11 Revision process.

The review report, submitted to WHO in April 2015, noted the progress of the ICD Revision, and made recommendations on what should be done to enable its successful completion:

*“The main recommendation from this Review is to finalise limited ICD-11 electronic and hard copy products consisting of the JLMMS with instructions and rules, Index, and Reference Guide and to have this available for report to the World Health Assembly and full field trials by 2017. To achieve this, there needs to be disciplined project management and strict reporting lines. We have recommended that urgent action be taken to employ a project manager and an additional classification expert at WHO CTS to help manage and carry out this work. Also, there should be oversight of progress by a JLMMS Steering Group, constituted from members and invitees of the successful JLMMS informal meeting in Geneva in March 2015 plus, at a minimum, representatives from the Nordic and German Collaborating Centres but ideally with other Collaborating Centres involved. The idea of constituting this group when so many already exist is to act as a circuit breaker and build on the positive outcomes of the March 2015 meeting. Progress should be reported regularly within WHO, to existing management groups such as RSG SEG<sup>1</sup> and to the ICD community, especially to the Network of WHO-FIC Collaborating Centres”<sup>2</sup>*

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<sup>1</sup> (RSG-SEG) Revision Steering Group - Small Executive Group

<sup>2</sup> <http://www.who.int/classifications/icd/reportoftheicd11review14april2015.pdf>

Soon after receiving the review report, WHO initiated the second phase of the revision process, adopting the review's recommendations. The WHO response to the recommendations stated (inter alia) that:

*“WHO will establish the JLMMS Task Force with responsibility to finalize the JLMMS work. The first meeting of the Task Force will be organized end August/early September [2015] in Geneva together with the RSG-SEG. The Task Force will report to the RSG-SEG.”<sup>3</sup>*

The Task Force was constituted and started its work in September 2015 and met for the last time in October 2018, several months after public release of the ICD-11 MMS for implementation preparation. This document provides a summary report of the work of the Task Force and its conclusions and recommendations.

## **Mission Objectives**

The Task Force served as the primary source of strategic and technical advice to the WHO as the agency finalized development of the ICD-11 MMS. The focus of the Task Force was to recommend on the subset of the ICD-11 Foundation to be included as code categories and subcategories in the ICD-11 MMS, as well as how to appropriately structure those codes to enable tabulation and aggregation for international reporting. The Task Force also provided guidance and support for the development of the ICD-11 MMS reference guide, including mortality and morbidity coding rules, the use of postcoordination in the ICD-11 MMS, and on the suitability of the product for use as a classification. The Task Force sought advice, as necessary, from other project stakeholders, such as the Revision Steering Group (RSG), the subject-specific TAGs and their successors, the WHO-FIC Network, WHO departments and other identified experts.

## **Composition of the Task Force**

The Task Force was comprised of 17 members, two of whom acted as co-chairs (Dr Stefanie Weber and Professor James Harrison), and 10 other permanent participants and observers.<sup>4</sup> WHO staff working on the ICD-11 Revision also participated in all Task Force meetings and discussions.

The membership was carefully selected by WHO to include mortality and morbidity experts with experience in application and updating of ICD-10 and collection and analysis of ICD-10 coded data. These included individuals with expertise in the development and operation of national modifications of the ICD, patient safety applications, and classifications for primary care. The first phase of revision drew heavily on TAGs and the RSG, and continuity with that process was achieved by including in the Task Force the chair of the RSG and leading members of two TAGs (dermatology; injury and external causes). During the work of the Task Force, the Mortality and Morbidity Reference groups of the WHO Family of International Classifications (WHO-FIC) Network were engaged with the ICD-11 revision, and the co-chairs of both groups accepted invitations to participate in Task Force meetings, ensuring a strong connection between these groups and enabling resolution of specific questions by their groups. Expertise on IT implementation of classifications was also included in the Task Force.

## **Working method**

The Task Force met in ten face-to-face-meetings and held monthly telephone conferences in the interim. Minutes of all face-to-face-meetings were published and can be accessed online.<sup>5</sup>

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<sup>3</sup> <http://www.who.int/classifications/icd/whoresponse.icdrevision.review.pdf>

<sup>4</sup> [http://www.who.int/classifications/icd/revision/JTF\\_LOP.pdf](http://www.who.int/classifications/icd/revision/JTF_LOP.pdf)

The work of the Task Force covered many aspects of ICD-11 development; content questions (e.g. how to code diabetes), structural issues for application (e.g. cluster coding syntax) as well as process and implementation questions. A list of issues was prepared before each face-to-face meeting and members prepared for the discussion based on their national experiences and consulted national or international experts, as necessary. During the meetings all aspects for the topic at hand were brought to the table and after comprehensive discussion a recommendation to WHO on how to move the topic forward was formulated. Once visited and discussed, a topic was only addressed again if relevant new aspects were discovered or if the recommendation given to WHO could not be applied without further discussion. With this method, a great number of topics could be addressed within a relatively short period of time, and overall progression was achieved.

Creation of a statistical classification necessarily requires deciding between alternatives (for example the primary location of each category can only be in one chapter), and so the work of the Task Force involved debate and compromise on many matters of detail.

The Task Force maintained communication with the WHO-FIC Network and other relevant stakeholders throughout the mission. Open sessions at WHO-FIC Network annual meetings enabled the Task Force to report on its progress and to invite thorough discussion and comment. The feedback both guided and encouraged the Task Force in its work.

### Work of the Task Force

During its three years of operation the Task Force addressed many topics and the work evolved over those years. The first year focused on assessment of problems, refinement of the structure of ICD-11 and frequently-criticized topics of high statistical importance. In the second year, by which time the working method of the Task Force was well established, a thorough review of content issues played a major part in the work. In the final year, the emphasis shifted to resolving controversial issues and preparing for the release of ICD-11 and its implementation requirements. Highlights of the work are listed below. They demonstrate the breadth and diversity of topics addressed during the mission.<sup>6</sup>

Content related issues:

- Infectious diseases chapter: the Task Force recommended applying a new framework for this chapter based on advice from infectious disease specialists from the Nordic Centre and WHO. (September 2015)
- The Diabetes categories were reviewed and a revised approach agreed upon (September 2015)
- The role of the Traditional Medicine chapter in ICD-11 MMS use-cases was discussed (September 2015)
- The Task Force advised a review and further development of the Reference guide (September 2015)
- The Task Force undertook a review of all chapters over a few months, discussed results and proposed changes at consecutive meetings (April until July 2016)
- Taxonomic principles: Proposed principles were discussed and accepted. The Task Force recommended that they be applied consistently across all chapters, as far as possible, with any exceptions to be documented. (April 2016)
- Functioning: The Task Force recommended inclusion of a subset of activity and participation categories as stem codes, grouped together. (July 2016)

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<sup>5</sup> <http://www.who.int/classifications/icd/revision/JTFReports/en/>

<sup>6</sup> For further detail please see full minutes of meetings. Date of meeting is referenced in brackets.  
<http://www.who.int/classifications/icd/revision/JTFReports/en/>

- The External Cause chapter was discussed. A revised model with fewer stem codes and more use of post-coordination & clustering was recommended. (February 2017; July 2017; April 2018)
- Member-state comments: Assisted WHO in addressing the points made in the list of comments and a detailed report from Germany. Recommendations were made on implementation. (July 2017; October 2017)
- Factors chapter: Proposals for clarification of and changes to scope and content were recommended. (July 2017)
- Field tests: A summary report was received and commented upon. The Task Force addressed open issues from a review performed by the Morbidity Reference Group (Mbrg) and the Mortality Reference Group (MRG) (October 2017; April 2018)
- Other content issues: Further topics were considered, including sepsis, dementia, and substances. (October 2017)

#### Issues related to the structure of ICD-11:

- Postcoordination and clustering: The Task force reviewed the approach taken to that time and advised changes. It considered and accepted the cluster coding syntax which was included in the draft Reference Guide. The Task Force recommended that its use should be permitted but not mandatory for mortality coding (April 2016; September 2015; July 2017)
- Inconsistency in code-length and granularity throughout the classification was considered. The Task Force advised checking ICD-11 MMS for stem codes longer than 5 characters and making changes to remove long codes. (September 2015)
- Sanctioning Rules (permitted code combinations): It was recommended to fully describe the model and prepare examples of where and how to use the rules. When assessed in January 2016, it was judged to be unlikely that the Sanctioning Rules would be completed by 2018. It was recommended that WHO should be clear about this.
- Extension codes: The Task Force recommended that the codes should be a section rather than a chapter. (April 2016)
- Terminology: The Task Force recommended using the term “exclusion” only where 2 codes may never be used together. In all other situations “exclusion” should be replaced by the “code also” notation, or by coding hints. (April 2016)
- Coding rules for mortality and morbidity were revised by the Task Force based on input from the MRG and changes recommended. (October 2017)

#### Issues related to the application of ICD-11:

- Primary care: JTF received a report from the Primary Care working group. JTF concluded that progress was sufficiently promising to continue the process of developing a primary care version of ICD-11. The issue was followed up in consecutive meetings (September 2015)
- The Reference Guide should include description of the use of the classification. (January 2016)
- Naming: The JTF recommended that the title of the classification be changed from ICD-11 JLMMS to ICD-11 MMS. (April 2016)
- Readiness requirements for 2018 release version were addressed. They include stable Tabular list codes, complete Index, stable basic rules including postcoordination within a comprehensive Reference guide, maps to and from ICD-10 and an implementation package (Advocacy and training materials; quick guide). It was noted that the updating and governance system needed to be specified (July 2017)

#### Issues related to the process of the revision and to future maintenance of ICD-11:

- Status and project plan (‘The narrative document’): Detailed summary by the Task Force, as at October 2015, of “where we are, where we go from here and how”, which guided the work of the Task Force, particularly in its first year of operation. (October 2015)

- Advised that the focus should be placed on finalization of content as the most important thing, with specific attention to text and structure (January 2016)
- Timeline: The Task Force concluded that a WHO timeline for release of ICD-11 in 2017 might not be possible, and recommended that changes be allowed after the proposed deadline if testing and review showed that to be necessary. The Task Force re-stated that it is more important to have a quality product that is fit for purpose than to rush publication to meet a deadline. (April 2016)
- ICD-11 updating cycle: The Task Force provided advice about the ICD-11 updating cycle, with input from the MRG and MbRG, The updating cycle might differ in the first years of ICD-11 if more changes than usual are required. (February 2017)
- ICD-11 MMS maintenance process: Task Force recommended that WHO prepare and properly support a work flow and working methods for maintenance of ICD-11 MMS. (February 2017)
- Governance and transition: The Task Force had detailed discussion and gave planning advice. (October 2017)
- Implementation Package: The Task Force assessed the status and identified gaps (April 2018)
- Release event: The Task Force advised on steps needed prior to the release event in June 2018 (April 2018)

## Lessons Learned

### Project sequence and schedule

When the Task Force began its work in 2015, the revision had achieved much but, as found by the External Review, this did not take full account of the requirements of a statistical classification. An early focus of the Task Force was, therefore, to identify divergences from these requirements and to plan a program of work to ensure that they were met by ICD-11 MMS. Duplication of categories between chapters, categories that were much more specific in some sections than others, incomplete specification of code structure and great variation in the extent to which the ICD-11 content model had been populated were found early on. Code structure and the principles for code use, including postcoordination, were incompletely specified.

This implied a need for much enhancement but, by 2015, the revision project had already continued for longer than originally intended. This meant that, from the outset, there was time pressure on the Task Force and the WHO staff who supported it.

In hindsight, the assessment of the Task Force is that much less enhancement would have been needed if the earlier phase of the revision had given more attention to the main technical requirements of statistical classification. Moreover, the project would have progressed more quickly if certain parameters had been applied at a relatively early stage, even if on a basis that they might have been subject to reconsideration (e.g. depth of hierarchical tree; principles for postcoordination).

This conclusion concerning the early stage of the revision refers to its emphasis, not to its fundamental nature. The Task Force recognizes that the early encouragement of innovation and change was crucial to allowing the revision to take proper account of the changes in knowledge and perspective that had occurred since ICD-10 was written. It also allowed fundamental re-development of the information model and technical systems that underpin the ICD, changes which were essential if the system was to adapt to the digital and networked era.

## Process

The working method of the Task Force proved efficient and was well accepted by the WHO-FIC Network and all stakeholders in the Revision Process. Its composition with a few selected experts who covered all relevant aspects of ICD application has proven to be helpful.

Provision of more resources by WHO to support TAGs and the secretariat in the WHO office would have allowed the revision to have been completed more quickly.

## Transparency

Making all minutes of Task Force face-to-face meetings publicly available was welcomed by all stakeholders in the ICD-11 Revision process. Even though the timely completion of comprehensive minutes was not always easy to accomplish, the transparency of the discussion, the listing of the arguments brought forward, and the clear formulation of the recommendations helped to raise acceptance of the work of the group. Future processes similar to the ICD revision would benefit from ensuring similar transparency from the outset.

## Conclusion

The Task Force was charged with assisting the WHO to complete the revision of the ICD. That was achieved by late 2018: the chapter structure and stem codes are stable, the postcoordination mechanism and syntax are in place, the coding tool is functional, the reference guide is mature and the governance mechanisms for maintenance are in place.

The view of the Task Force is that ICD-11 is ready for the transition from the revision process to implementation. As with ICD-10, the process of implementation is expected to reveal details that require clarification or refinement after discussion or testing. Likewise, there will be a need for ongoing maintenance and updating of ICD-11. Hence, stating that the revision has finished does not mean that absolutely nothing will change. However, ICD-11, like ICD-10, is stable and ready for the processes leading to implementation.

Successful implementation of ICD-11 will require time and resources. It will also require strong ongoing communication between WHO and member states (including through the WHO-FIC Network) as implementation plans are developed. In particular, it is seen as critical that the WHO and member states (including those with Collaborating Centres) work together to understand and overcome barriers to implementation through prioritization and, as appropriate, coordination of work programs, marshalling of resources and focusing of the efforts of the WHO-FIC Network and other groups and networks of Member States. The varied requirements of Member States should also be considered, some having used ICD for many years, others having introduced it recently and still others not yet using it extensively. Support for WHO in supporting and managing this body of work should be considered a high priority.

ICD-11 will be a key component of international public health infrastructure. Now developed, it is essential to ensure that ICD-11 is sustained. This implies ongoing provision of adequate resources for its maintenance. In particular, the WHO office must resource positions which allow central support for the proposals and updating process and for the electronic tools that are crucial to ICD-11.

In light of these conclusions, the Task Force

RECOMMENDS:

- The Secretariat should submit ICD-11 to the Executive Board in January 2019 and the World Health Assembly (WHA) in May 2019, for adoption.
- The Secretariat and WHA should allow enough time for member states to prepare for implementation of ICD-11 for international reporting. Given the complexity of preparation, which will vary between use cases (mortality, morbidity) and countries, preparation will generally require several years, as was the case for ICD-10.
- The Secretariat needs to provide adequate resources for maintenance and implementation of ICD-11.
- Work should continue to be undertaken during the period of preparation for implementation on matters that go beyond the core task of revising the ICD for morbidity and mortality statistics, and which are necessary if the potential utility and value of ICD-11 are to be tapped, as was the case for ICD-10. This includes, in particular:
  - Further work to allow the ICD-11 classification to interoperate with electronic health records, including those that make use of formal terminologies
  - Projects to draw on the great potential of the ICD-11 Application Programming Interface for electronic communication and application
  - Development of specialty versions based on the ICD-11 Foundation, as required.
  - Translations.
  - Measures to facilitate the adoption of ICD-11 by countries that have not previously used ICD to a great extent

## Acknowledgements

The Task Force acknowledges the hard work done by the small WHO team that aided and guided the work of the Task Force. Without the assistance of WHO staff and contractors the work of the Task Force would have been more burdensome and would have taken longer to complete.

The Task Force also acknowledges all the experts and colleagues who have assisted the process. They answered our questions, despite other pressing responsibilities, while patiently waiting for the Task Force recommendations and for the completed ICD-11 MMS.

## Annex

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