Initial WHO response to the report of the external review of the ICD-11 revision

Department of Health Statistics and Information Systems

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Summary

This brief document summarizes the initial response of WHO to the external review of the ICD revision. WHO is grateful to the external review team who have put together a comprehensive broad-based review on this complex topic in a short period of time and provided a practical set of recommendations.

WHO believes that the progress in the ICD revision and the external review's recommendations provide an excellent entry point for initiating a second phase in the revision process. The products of **Phase I** have been described and resulted from major inputs from a wide range of stakeholders through vertical Topic Advisory Groups and other mechanisms. **Phase II** should now focus on progressing a high quality classification that meets the needs of the main stakeholders so that ICD-11 can be adopted by the World Health Assembly in 2018, as suggested in the Review.

Proposed key actions for the second phase include the establishment of the Joint Linearization of Mortality and Morbidity Task Force (JLMMS), a meeting of the JLLMS and the RSG-SEG in August 2015, a discussion of the WHO Governing Bodies on the progress on ICD-10 implementation and ICD-11 revision in 2016, a ICD revision conference in Japan in October 2016, field testing during 2016-2017 and a final version of the 11th revision for World Health Assembly adoption in 2018.

A revised workplan will be formulated before the end of June and submitted for approval to the RSG-SEG. During 2015 the WHO secretariat will be strengthened in terms of project management, communication of progress and plans, documentation and transparency of decision-making and classification expertise, as recommended by the reviewers.

Background

WHO commissioned a review of the ICD revision process October 2014, in order to obtain an independent view of current progress on contents and process of the revision. A small team of individual consultants was put together, including Rosemary Roberts (team leader), Marjorie and Helene Richardsson. Through a structured questionnaire and interviews, inputs were solicited from a wide range of stakeholders as well as from the secretariat. The final report of the consultancy interim assessment of the 11th revision was delivered on April 14 2015.

This note provides brief responses to the recommendations of the report, with particular emphasis on short-term actions.

General observations

The first phase of the ICD revision has focused on the technical development benefiting from the tireless inputs of a large number of collaborators and experts. While there are still many technical issues that need to be addressed, the review tells us that there is great commitment and strong belief in the utility of ICD-11, with critical innovations such as a common foundation component and electronic capabilities. The review report also tells us that much work still needs to be done to ensure relevance to different types of users and maintain compatibility with ICD-10 for statistical purposes.

Currently, as in May 2015, the ICD Revision Process has achieved its objectives partially:
- **Objective 1**: The Joint Linearization for Mortality and Morbidity Statistics is underway and nearing completion for its next review point. Other linearizations are also under development.
- **Objective 2**: There is scope for compatibility/reference to other classifications such as national modifications and specialty adaptations.
- **Objective 3**: The ICD revision established solid linkages with terminologies such as SNOMED-CT; and has developed computerized infrastructure for editing and sharing including web-based tools such as iCAT, ICD Browser, Mapping Tool, Coding Tool (electronic index) and others which are freely available to stakeholders. A computer assisted Multi-Lingual ICD Tool has been created for all languages making use of previous ICD translations, with available linguistic tools to enable digital translations in all languages with a priority on WHO official languages.

To ensure clinical meaningfulness, 20 scientific Topic Advisory Groups (TAGs) and working groups were formed and are maintained to improve scientific content of the classification, resulting in a major increase in volume and quality of the contents compared to ICD-10. Maximizing the relevance of the emerging classification use cases is of critical importance, based on the work by the TAGs and Working Groups on mortality, morbidity, quality and safety, functioning and disability, and Primary Care.

The progress in the ICD revision and the external review's recommendations provide an excellent entry point for Phase II of the revision. The products of Phase I have been described and resulted from major inputs from a wide range of stakeholders, such as the vertical TAGs. Phase II should now focus on working towards a high quality classification that meets the needs of the main stakeholders and can be adopted by the World Health Assembly in three years' time (see below). Phase II should also include an integrated approach in which the 11th revision of ICD is progressed as part of a work programme that also includes the continued enhancement of the implementation of ICD-10.

Based on specific recommendations of the external review, WHO is proposing to operationalize the following actions:

A. Timeline for implementation between March 2015 and May 2018

Recommendation	Proposed actions
1. **Limit goals for** 2017 to JLMMS. Make clear to stakeholders what product will be released in 2017 – JLMMS with instructions and rules, Coding Tool and Index, Reference Guide.	Within the given timelines noted in the report, building to an approval by WHA in 2018 as recommended, WHO will produce of the **Tabular List** (Volume I) , **Reference Guide** (Volume II) and **Index** (Volume III) with the Coding Tool and other electronic infrastructure such as the iCAT, Browser and Translation Tool. The revised project plan will define exactly the contents of each volume.
2. **Develop a JLMMS Steering Group** based on the Informal Workshop on JLMMS (Geneva, March 2015) with the addition of representatives from, at a minimum, Nordic and German WHO-FIC Collaborating Centres. Charge this group with oversight of this timeline.	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 in Geneva together with the RSG-SEG. The Task Force will report to the RSG-SEG.
3. **Employ at least two more staff at CTS (urgent!)** a) **Project Manager**. Responsible to CTS coordinator and to the Director of the Department of Health Statistics and Information Systems and reporting also to the JLMMS Steering Group on progress	As of May 1, WHO established an ICD revision project management team consisting of Ties Boerma (Director HSI), Bedirhan Ustun (Coordinator CTS) and Anneke Schmider (Project Manager).
b) **Classification Expert**	WHO is strengthening its classification expertise by recruiting one or more short term classification experts, with full-equivalent of at least 12 months
c) Clarify roles of CTS staff, especially communication and marketing	The project management team will ensure roles and responsibilities are clarified and sharpened within the team; and will also focus on communications, making greater use of general WHO expertise in this area.
4. **March, April 2015**. a. Make changes to classification from JLMMS March meeting and work on instructions, rules and revision of	The proposed timeline for the release of the different versions for comments is useful. A revised WHO workplan will provide a more

Reference Guide
   b. Disseminate this assessment report
5. **May 2015**. Release frozen version for review across the classification by MTAG and MbTAG to feed into review and endorsement by JLMMS Steering Group. **June, July 2015**. Incorporate changes from this review
6. **August 2015.** Release another frozen version for peer review and limited field trials for morbidity and mortality with end date of **December 2015**.
7. Incorporate changes
8. **October 2015**. Report to WHO-FIC Annual Meeting on status of this report and its recommendations.
9. **May 2016**. Release frozen version for review by JLMMS Steering Group
10. **June, July 2016**. Incorporate changes as a result of this review
11. **August 2016**. Print and prepare electronic products – Tabular List (JLMMS), Index in hard copy and as electronic Coding Tool and Reference Guide
12. **October 2016.** Table ICD-11 at Revision Conference to be held in conjunction with WHO-FIC Network and IFHIMA meetings in Tokyo and with strong participation from members of the RSG SEG and the RSG.
13. **December 2016**.
14. Release ICD-11 to WHA Executive Board for report to WHA
15. In report to WHA, include recommendation for ongoing development and maintenance of ICD-11
16. **January – June 2017** ICD-11 Field Trials.
17. **May 2017.** Report to WHA re ICD-11.
18. **October 2017**. Second Revision Conference in conjunction with WHO-FIC Annual Meeting and with strong participation from members of the RSG SEG and RSG.
	detailed timeline, but here we summarize the main propositions.
	
	End May 2015: as per the recommendations, release the ICD11 2015 Beta Draft for review (Implementing the March Meeting recommendations).
	
	Jun-Jul 2015: Mortality and Morbidity TAGs review the ICD11 2015 Beta Draft
	
	August 2015: Following the JLMMS Task Force & RSG SEG meeting, WHO will release a package that is frozen for peer review and limited testing.
	
	A report will be provided to the October WHO-FIC meeting.
	
	January 2016: WHO proposes a slight change in timelines, bringing forward formal reporting to the Executive Board and WHA. In January, the Executive Board (followed by the World Health Assembly in May) will discuss the status of ICD in 2016. This discussion will do two things:
	  1) Update on the current situation of ICD-10 implementation, in the context of global developments linked to the demand for mortality by age, sex and cause created by the SDGs, increased country and regional action on strengthening of civil registration and vital statistics system, and the lack of quality vital statistics in the majority of countries.
	  2) Provide an update on the ICD-11 revision process, propose May 2018 as the target for discussion and adoption by the WHA, and explain the intermediate steps and member state involvement between 2016 and 2018. This will allow for a longer period of "reviews" between 2016 and 2018.
	
	October 2016: Global ICD revision conference, as recommended, in Japan. Discussions have already been initiated with Japan to organize this meeting separately from the WHO FIC network meetings aiming for alignment of views of multiple stakeholders: balancing scientific content, achieving consistency and utility, and ensuring continued transparency.

19. **December 2017**. Release for WHA Executive Board 20. **May 2018** WHA for adoption of ICD-11	2015-2016: Limited Beta testing for example translations, clinical use, statistics 2016-2017: Comprehensive QA testing **May 2018: Adoption WHA**
B. Communication, marketing, outreach, transparency	
i. Improve communication internally and with external stakeholders to make processes more visible ii. Prepare monthly or bimonthly newsletter or bulletin to stakeholders for update on progress and to provide formal ongoing information regarding process iii. Ensure greater transparency in decision making and use of resources	WHO will take more proactive stand in communicating the process and steps taken in the revision process through multiple media including regular news updates to stakeholders. A communication plan is to be developed and released with the project plan at end June 2015. In addition a briefing for Member States will be made to prepare for the ICD discussions in the World Health Assembly.
C. Planning	
i. Plan future roadmap for other linearizations and completing Foundation Component ii. Plan ICD-11 updating process and communicate with stakeholders (WHOFIC and member states).	An updated Project Plan will be developed and ready for comments by end June 2015.
D. Project Management	
i. Implement and oversee timeline for implementation **ii. Prepare business plan for ICD-11** including licence fees or other revenue development and sale of hard copy. Seek additional resources iii. **Address issues with IHTSDO** (re SNOMED CT in Foundation Component and joint updating between IHTSDO and WHO)	The project plan quarterly reviews will be published over the web and communicated to the stakeholders. A business plan for ICD-11 has been under development including licencing, revenues, and dissemination. Use of SNOMED-CT and ICD-11 has been discussed in the Joint Coordination Group and Joint Advisory Groups and a common understanding will be communicated to public in a short note.

iv. **Address issues with WONCA** (re Primary Care Linearizations to meet their needs and role of ICPC)	WHO has been working with WONCA and correspondence between ICD11 Primary Care linearizations and ICPC has been a common goal which has been achieved to a large extent.
v. **Address issues with WHO-FIC Network** and the role of its members in ICD-11 release and update	WHOFIC Network is an invaluable resource for ICD and its revision. The fact that ICD is about all WHO Member States requires mechanisms which include WHOFIC Network but go beyond it. At least half of the members of the JLMMS, Mortality TAG, Morbidity TAG, Quality and Safety TAG and Functioning and Disability TAG are WHOFIC Members. WHOFIC Network has been included in subject matter TAGs, review process and proposal mechanism.
E. **Governance**	
i. **Clarify the responsibility for decision making in the Revision process, including the JLMMS Steering Group** ii. **Clarify roles of RSG, CTS, WHO-FIC regarding responsibilities** iii. **Build on goodwill and hard work of stakeholders** around the world and the reputation of WHO and ICD	In addition to the Revision Steering Group (RSG) and RSG- Small Executive Group which has the main decision making authority on the Revision Process issues, WHO will establish the JLMMS Task Force to be responsible for the work on the Joint Linearization. A first meeting of the RSG-SEG and JLMMS group will be held in late August/early September to progress the revision.
F. **Education**	
Education during and after Field Trials through WHO-FIC and member states	WHO has planned work and started developing materials for education on ICD11 and field testing together with consultants and WHOFIC Network Education and Implementation Committee.
G. **Trust**	
Work on gaining trust of ICD community internally and externally through communication and involvement as well as providing evidence that this report is being acted upon and recommendations implemented.	The ICD is truly a unique and collaborative international undertaking. It has not, however, been without its challenges, as noted by the review. With the implementation of the solutions in response to this review; and building on the achievements thus far, **Phase II** of the revision should successfully ensure full participation and transparency in the ICD Revision, leading to greater involvement and trust of the relevant stakeholders.