

WHO ICD Maintenance Advisory Structures

Draft Discussion Paper Prepared by the ICD-11 Joint Management Team for consultation with Chair, RSG-SEG, Co-Chairs JLMMS TF and the Co-Chairs WHO FIC Council

Background

WHO commissioned a review of the ICD-11 Revision with a review report and a WHO response released in May 2015. The review report strongly recommended a focus on the essential needs of the ICD-11 through the Joint Linearization for Mortality and Morbidity Statistics (JLMMS); a recommendation which recognizes the continued centrality of mortality and morbidity statistics to countries, and to global health.

The ICD must also have a sustainable maintenance model (processes and products) to ensure the ICD-11 can effectively deliver principle information for statistical purposes in public health, and serve as a specialized classification for clinical and related data needs. As the Phase 2 progressed over 2015, the current advisory structure was discussed in various formal meetings, resulting in a governance document released at the end of 2015, which defined the present revision structure (Appendix). It also generated new thinking about the advisory structures which are needed to support the ICD.

Proposal

To achieve the longer term goals for ICD, especially during the transitory Phase 2 stage (2016-2017), WHO is proposing to restructure the present ICD Revision Advisory arrangements towards longer term goals. The proposal does not include processes for ICF and ICH. These have to be considered separately.

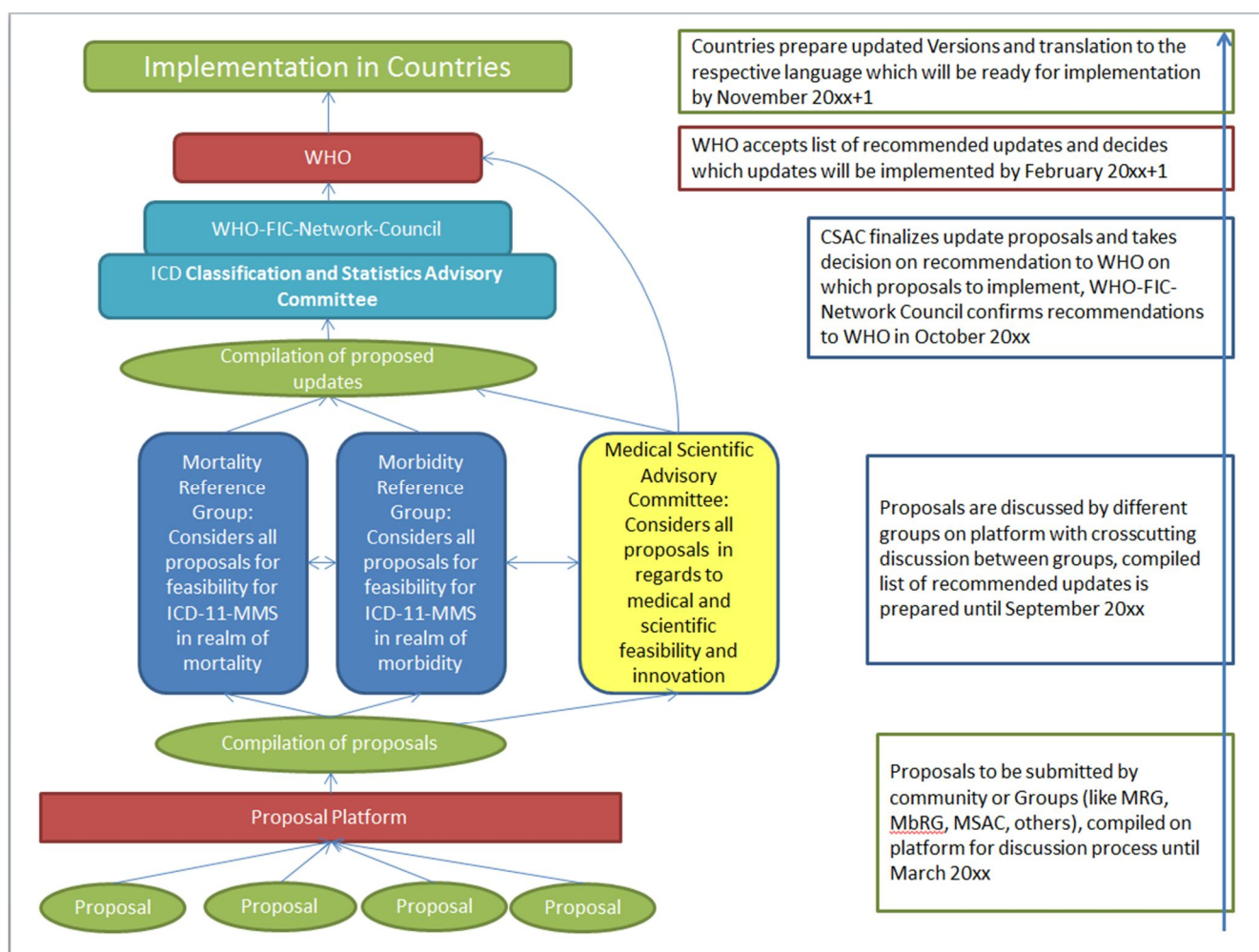
It is proposed to reorganize the current ICD Revision structures towards a long term maintenance framework. This would include revisiting the governance design, and evolving the status quo into a new proposed structure:

- An ICD Classification and Statistics Advisory Committee (CSAC) will be created in 2018, as the principal ICD-11 advisory committee to the WHO, focussing mainly on the ICD-11-MMS. The present URC for ICD, JLMMS TF, and certain RSG-SEG functions will be transitioned into this Committee. The Committee will be informed by two groups to prepare the decisions based on proposals:
 - Mortality Reference Group: to prepare update proposals for ICD-11 and to comment on proposals from other sources in respect of mortality requirements
 - Morbidity Reference Group: to prepare update proposals for ICD-11 and to comment on proposals from other sources in respect of morbidity requirements
 - Functioning and Disability Reference Group: role and function to be discussed

CSAC can seek advice from other groups.

- A Medical Scientific Advisory Committee (MSAC) will be launched at the Revision Conference in 2016 comprised of approximately 10 experts selected by WHO, some of whom will be drawn from the existing vertical TAGs. The main role of the MSAC will be to advise on scientific content for the ICD-11. Advice to be provided to the CSAC.
- The MSAC will review all proposals in parallel and will be consulted on medical and scientific questions arising from the three groups as well. The MSAC is also responsible for providing advice on medical and scientific information in the foundation.
- Additional Special Projects may be established to develop and evaluate links to other classifications and terminologies and to advise on the associated informatics and architecture considerations. ITC may play a role in these projects.

The diagram below shows how the management of annual proposal submission and preparation of decisions is envisaged after World Health Assembly approval of ICD-11.



Proposed Process for Development and Negotiation

- Terms of Reference for MSAC are negotiated from existing functions (Discussion Paper June 2016; Agreement September 2016). It will start its work for the final steps of ICD-11 development and will comment on field trial feedbacks and content proposals received between October 2016 and October 2017 as well. It will work in close consultation with ICD-11-MMS Task Force over this period of time.
- MSAC is launched at the ICD Revision Conference (October 2016). As membership is drawn from existing vertical TAGs and RSG the functions of vertical TAGs and RSG will be taken over by MSAC.
- Terms of Reference for CSAC are defined from existing functions including the URC and JLMMS TF functions (Discussion Paper June 2017; Agreement September 2017).
- CSAC is launched at the WHO FIC Annual Meeting (October 2018).
- The first cycle of update proposals will start in 2018. Updates to ICD-11-MMS received after submission of ICD-11 to WHA and before October 2018 will be handled by ICD-11-MMS-Task Force, MSAC and WHO.
- Considerations of foundation structure and common ontology of ICD-11 and other terminologies and classifications are to be handled by the ITC (Informatics and Terminology Committee of the WHO-FIC Network)
- Morbidity and Mortality Reference Group are Groups of the WHO FIC Network.
- CSAC will draw its membership mostly from the WHO-FIC Network with additional representation from the MSAC. Additional members could be appointed by WHO (e.g. from regions otherwise not represented in the network).
- ITC will have the opportunity to comment on proposals if relevant for common ontology or foundation structure purposes.

MSAC: DRAFT Terms of reference

1. MSAC recommends scientific-based changes or enhancements to the foundation with notification to the CSAC. The CSAC will consider the foundation changes in the context of the linearization(s).
 - a. MSAC will establish and rely upon a Web of Trust among the scientific community, with processes to be designed, to facilitate consideration of proposals for change.
 - b. Any changes which have an effect on the linearization(s) must be approved by both MSAC and CSAC in parallel. Any changes which do not have any effect on the linearization(s) can be approved by the MSAC with notification to the CSAC.
2. MSAC may be consulted by other committees or reference groups (e.g. MRG, mbRG, CSAC) about questions of medical or scientific validity in the context of the foundation component, if and when requested.
3. MSAC will evaluate links to other classifications and terminologies and advise WHO on the associated informatics and architecture considerations.

Appendix

ICD11 Governance and Process for RSG, RSG-SEG and JLMMS¹ Task force

In the current Phase 2 of the ICD-11 Revision, the JLMMS task force has joined the top level revision advisory groups. This document supersedes earlier documents and it provides an overview of the governance arrangement that is in place in this phase. All groups are advisory to WHO, which has the final authority for the ICD.

JLMMS Task Force (JTF)

The Joint Linearization for Mortality and Morbidity Statistics Task Force (JTF) is the steering group for JLMSS. The JTF provides strategic and technical advice to WHO for the finalization of the JLMSS development. The input to JLMMS will draw on scientific advice, where recommended by the JTF or WHO. Design of the JLMMS linearization will not be subject to alteration by the RSG. Scope of the JTF is to provide strategic and technical advice to WHO on:

- The subset of the Foundation Component content to be included in the JLMMS
- The primary parents in the JLMMS that define the hierarchy in the ICD-11 JLMMS
- The recommended versions of coding and browsing tools, in print or electronic formats, and related inclusion of secondary parents
- The level of detail for single-code coding²
- The relevant dimensions³ for use in optional post-coordination
- The morbidity and mortality coding and reporting rules⁴
- The suitability for use as a classification:
 - categories to be mutually exclusive⁵
 - jointly exhaustive⁶
- User guidance where using more than one code per condition⁷
- Seek advice, as necessary, from vertical TAGs, cross-cutting TAGs and other project stakeholders to inform their work

RSG-SEG

The RSG-SEG advises on the high-level connections within and outside ICD-11, and helps resolve possible conflicts arising in the design of the JLMMS. The co-chairs of the JTF and the Primary Care Task Force may also be invited to be members of the RSG-SEG. The RSG-SEG meets on a monthly basis by teleconference, with occasional urgent meetings on an as-needed basis. This also includes ad hoc electronic communication as needed.

The RSG-SEG responsibilities include advice on:

- High-level ICD-11 design and the integration of components, specifically:

¹ JLMMS: Joint Linearization for Mortality and Morbidity Statistics – usage equivalent of ICD-11 with current ICD-10

² this refers to ‘shorelining’ or ‘stem codes’, i.e. the codes that will include pre-coordinated concepts vs. post-coordination, meaning using multiple codes to code one condition

³ Extension code chapter, clinical forms, etc.

⁴ included in the reference guide

⁵ non-redundant; exclusion notes, coding hints

⁶ appropriate residual categories and groupings

⁷ Sanctioning Rules, coding hints

- The Foundation Component
- Relationships between and among linearizations
- The Ontological Component
- links to terminologies outside ICD
- Production of frozen versions of the Foundation Component to ensure the stability of derived linearizations
- Decisions regarding tools for the continuing development and use of ICD-11
- Work with all linearization activities to facilitate alignment or interoperability
- In conjunction with the JTF, review and coordinate TAG activities (including proposal activities with focus on the structure and user guidance) to ensure continued scientific validity, correctness, and ultimately completeness of the Foundation Component content and relationships
- Resolution of problems where they arise in the design

Vertical Topic Advisory Groups (TAGs)

Vertical TAGs have the role of scientific editorial boards, with responsibility to advise WHO on the scientific validity of content and relationships in the Foundation Component, upon request. This is designed for the maintenance of ICD-11. In more detail, the TAGs advise on:

- the accuracy and validity of Foundation Component content
- updates and revisions of the Foundation Component to reflect new knowledge or understanding
- new content and relationships in the Foundation Component to enhance completeness
- identification of possible third party reviewers upon request
- updates proposed by other groups
- changes to completed sections of JLMMS where strong medical or scientific evidence necessitates doing so, or upon request

Cross-Cutting Topic Advisory Groups (TAGs)

Cross-cutting TAGs provide expertise in coding practice and guidelines, as well as classification development and implementation, with responsibility to advise WHO on the utility and quality of the classification, particularly with regard to the structure, upon request. In more detail, the TAGs advise on:

- the accuracy of relationships between Foundation Component entities
- completeness of the coverage of the Foundation Component
- updates and revisions of the structure of the Foundation component to reflect new knowledge, understanding, or perspectives
- new relationships in the Foundation Component to enhance completeness
- identification of possible third party reviewers upon request
- updates proposed by other groups
- changes to completed sections of JLMMS structure where strong medical or scientific evidence necessitates doing so, or upon request
- requirements for use of ICD-11 in various Member States and clinical settings

Revision Steering Group (RSG)

In Phase 2 of the ICD-11 Revision, the RSG will serve as a forum for the bilateral exchange of information and concerns of the TAG chairs representing the membership of TAGs, and dissemination of revision or maintenance-related general information. Membership includes the RSG Chair, all Co-Chairs of the Topic Advisory Groups for ICD-11 Revision, and all Task Force Co-Chairs, as well as the WHO-FIC Council Co-Chairs, the chairs of URC the FDC, as well as other Committee and Reference Group Co-Chairs as indicated. The group will meet by teleconference on a quarterly basis. Meetings will serve to cover:

- reporting of progress in the Foundation and JLMMS
- issues or resolutions relevant to all RSG members
- strategic reporting from the RSG-SEG
- other topics as necessary

Organizational Observations

In order to facilitate inter-group communication and connection with the WHO-FIC Network, next year's schedule of meetings will be synchronized across the above mentioned groups.

- It is agreed that the WHO-FIC Network Annual Meeting in 2016 include at least a one-day track for a JLMMS face-to-face meeting, analogous to the Glion event.
- It is agreed that the quarterly RSG meetings be synchronized with this meeting.
- As all members of the RSG-SEG are invited to attend the JTF, RSG-SEG and JTF meetings will be scheduled to alternate so as to enable consideration of higher-level ICD-11 structural issues that may arise in the JTF.
- RSG-SEG will have teleconferences monthly on the first Thursday of the month
- JLMMS TF will have teleconferences monthly on the third Thursday of the month
- RSG will have teleconferences quarterly, on the fourth Thursday of the month
- Should organize a group, by language, to develop information and training of countries for the introduction of material linearization of ICD-11 is a new concept and should begin your explanation)