ICD-11 Revision Conference

Report

Tokyo, Japan
12-14 October, 2016

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Introduction

In October 2016, WHO and Member States reached a major milestone towards finalization of the 11th Revision of the International Classification of Diseases. The ICD-11 Revision Conference in Tokyo, Japan, was held from 12 – 14 October 2016.

Hundreds of individuals and institutions from around the world attended the ICD-11 Revision Conference in Tokyo, Japan. In addition, a wide range of countries attended the Tokyo Revision Conference including: Albania; Algeria; Argentina; Australia; Brazil; Cambodia; Canada; China; Denmark; Egypt; Ethiopia; Finland; India; Indonesia; Iran; Japan; Kenya; Korea; Kuwait; Malaysia; Mexico; Mozambique; Myanmar; Namibia; Nepal; Netherlands; Philippines; Republic of Korea; Russian Federation; Rwanda; Slovakia; Sri Lanka; Sweden; Tanzania; Thailand; Turkmenistan; Uganda; United Kingdom; and the United States of America.

This report summarizes the proceedings, including the Member State feedback received during the conference. The conference documentation, including agenda, posters and presentations, can be found on the WHO ICD-11 Revision website[1].

1. Main Conference

The opening session of the ICD revision conference was jointly held with the International Federation of Health Information Management Associations (IFHIMA) congress and the annual meeting of the Japan Association of Health Information Management.

The Director-General of the World Health Organization, Dr Margaret Chan, opened the meetings (see Annex A for opening remarks), as well as the Japan Ministry of Health which was hosting the conference. Opening remarks were also made by the president of the IFHIMA, and the president of the Japan Association of Health Information Management. Special gratitude was conveyed to the president of the Japan Hospital Association, which has been instrumental in financing the ICD revision process during the past decade.

1.1 Health information in the new era

The opening session aimed to frame the ICD in the global health, the Sustainable Development Goals (SDGs) 2016-2030 and country realities. The presentation by WHO focused on global data priorities, especially the health targets in the era of the SDGs, showed the increased attention for cause-specific mortality and morbidity in all countries, and the role and value of the ICD in the present and future data context.

A presentation by the UN Statistical Division highlighted the data challenges of the SGDs and the role of national planning for better data. Data strategies, challenges and improvements in the Latin Americas and Caribbean region through a network approach were highlighted by the Pan-American Health Organization, with much emphasis on improving the quality of vital statistics. The Japan presentation highlighted past and present experiences of Japan in implementing the International Classification of Disease, with a focus on ageing.

Presentations were also made on the ICD-11 use case and design process, and the business model and future governance for the ICD. The first phase of the revision process had been concluded in 2015, and a simplified structure with a Joint Mortality and Morbidity Statistics Task Force is moving the agenda forward. WHO is now establishing a Medical and Scientific Advisory Committee,

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[1] http://www.who.int/classifications/network/meeting2016/en/

replacing previous mechanisms. In the future, it is envisioned that the Mortality and Morbidity Statistics Task Force will be transformed into a Classification and Statistics Advisory Committee.

The plenary discussion focused on tools and technology that will help implementation, the need for training and an implementation strategy, the importance of having a short list for mortality.

1.2   ICD-11 advances and use

The simplified coding structure of ICD-11 and the embedded user guidance for coding were demonstrated using individual scientific presentations. The new structure allows countries to code broad, simple conditions with one code. In addition, combinations of codes can be used to describe complex detail of individual conditions. As a result, coding quality will improve, using ICD will require less training and the categories will provide scientifically up-to-date information at the level of detail desired by countries and individual settings.

The plenary discussion with the panel focused on:
• Benefits of ICD-11: implementation will have to show a benefit to countries, especially in terms of efficiency and resources needs. Implementation of electronic systems is still fragmented in many parts of the world, and WHO will continue to produce a hardcopy version of the ICD.
• Complexity: some chapters are quite sophisticated and there were concerns about the time required to complete the detail. The complexity is available for those who need it. The core structure and associated coding is now simpler than with ICD-10.
• Training needs: the need to understand the new terminology of ICD-11 will require complete new training for ICD coders. Training needs for ICD-11 will differ to those for ICD-10, and can be scaled to suit country coding needs. The opportunities to facilitate coding with electronic tools are substantial.
• ICD decision making: decision making bodies such as the task force should include more representation from low resource countries so that implementation concerns can be taken into account.
• Statistical considerations: the use of ICD-11 for data and statistics may be queried where statistical information may be compromised if there is more than one way to code. Statistical training and instructions will be needed. User guidance for coders should be built into the classification, and accessible from one place (not scattered over several places like in ICD-10). This will guide users to code in a uniform way, better than with ICD-10.
• ICD-10 comparability: dual coding is part of the field testing. For mortality and morbidity the necessary bridge coding studies are easier where documentation has been electronic.

1.3   Integrated medicine: Traditional Medicine chapter

The presentation on the ICD-11 TM chapter focused on its statistical use case and uses in countries around the world. It was noted that the inclusion of Traditional Medicine for the first time as a chapter within the ICD. This has enabled a standard list of diagnostic categories to identify and report on conditions. These codes will be able to be used for statistical and administrative purposes.

Presentations were given by China, Japan and the Republic of Korea which have all been instrumental in developing the chapter, both technical and in terms of financing. Further insights were provided from Australia and Europe where traditional medicine – or complementary medicine – plays an important role but is often not integrated. India showed its advances in developing a AYUSH related classification, and expressed its interest in joining the ICD.

1.4   ICD for health financing

This session outlined the uses of ICD for varied financing purposes in countries, including aggregate data uses to understand population health needs, and the granular use of ICD for data and financing within a health system.   The potential application of ICD-11 in casemix systems was discussed, and a presentation from Australia highlighted the significant value of ICD to health system financing.

The discussions focused on the use of national and clinical modifications and the need to consider whether ICD-11 can eliminate the need for clinical modifications.

1.5   ICD-11 informatics and tooling

This session provided an overview of the ICD-11 structure and function as it relates to application within electronic systems. The role and function of the ICD-11 Foundation Component was highlighted. It enables conventional representation of the ICD, and it also provides the basis for specialty classifications, in which the categories can be arranged according to the requirements of the respective field.

ICD-11 tools for implementation and maintenance were presented. The coding tool provides access to the browser containing the classification. The browser has instructions and help functions to facilitate the use of ICD-11. For implementation, the translation tool and the index reflecting the local clinical terminology are paramount to the use of the classification. The mapping allows the user to quickly find correspondences between ICD-10 and ICD-11 and to understand differences. The use of unique identifiers allows tracking individual conditions of interest that may not have their own category in the classification, e.g. some rare diseases that need to be identified for national purposes. The proposal platform and the commenting features permit broad participation in the maintenance of ICD-11. The authoring environment lays the foundation for the new features of the classification that guide users and bridge the gap between simple use and advanced reporting. For mortality coding, the role of automated approaches were outlined as important to ensuring a standardised data set globally.

Finally, the current state of SNOMED-CT development and implementation was presented. Interoperability between SNOMED CT and ICD-11 is desirable in electronic systems. Joint use can lead to important data quality advances, more efficient reporting, and more meaningful exchange of data in health information systems. The linkage between SNOMED and ICD has progressed in form of mappings, and will require further investments.

2. ICD-11 Way Forward

This session considered the way forward and focused on country comments about the ICD-11 as it had been presented throughout the conference.

2.1   Joint Task Force on Mortality and Morbidity Statistics: next steps

Presentations were provided by ICD-11 Joint Task Force members from Australia and the United States. Task Force representatives recommended that countries should prepare their national decision makers about the ICD-11, and that it was important that all levels of government were involved.

From the Australian perspective, it was presented that future data needs would be an important area for consideration. The demand for data keeps growing. Data integration has become important, including patient pathways for diagnosis, treatment and outcome. ICD-11 provides opportunities to consider extended information opportunities, including cluster coding and post-coordination. Australia is also looking at whether there will be potential efficiency gains with ICD-11

if there no longer is a need to maintain a national modification. The USA provided an overview of its thinking regarding ICD-11 for mortality data, highlighting the importance of coder training, conducting bridge coding exercises as there will inevitably be some discontinuities and finding ways in which the new features of ICD-11 can best be leveraged (e.g. cluster coding).

The Task force will continue its role in providing technical advice on ICD-11 for mortality and morbidity statistics, and will meet again in February 2017.

2.2   Country comments

Myanmar, Rwanda, Mozambique and Nepal provided their perspectives on the ICD-11 as part of a panel. Common themes included the current state of systems (many countries do not yet have the systems to support cause of death reporting, nor morbidity), the need for ICD-based statistics, and the current progress in many to implement ICD-10. In implementing ICD-11, no country should be left behind, and that significant implementation planning and support is required, especially to build systems and capacity. Collaboration between all partners is necessary to achieve this goal.

Several member states commented from the floor. The Netherlands noted a positive impression of ICD-11, but also indicated that much work still needs to be done before ICD-11 is fit for purpose. There was support for the transition process as proposed by WHO in which ICD-11 will not be brought to the World Health Assembly for adoption, but rather be implemented in an incremental manner and formally adopted at a later stage. The Netherlands supported the need for an implementation plan, and a broad role for ICD-11 (everything, for everybody) and noted that the use case for morbidity is much stronger than mortality, and that the concept of added value must be made much stronger. A complete fit for purpose ICD-11 is needed, and the Netherlands indicated its willingness to support the WHO in the process.

Tanzania noted that it was the first time the country had been invited. It discussed that it currently uses both ICD-9 and ICD-10 and has a national insurance fund that uses ICD-9. To harmonize the way data is used, it will advocate to use ICD-10 across the country in preparation for ICD-11. Tanzania noted the challenges of reporting mortality, with many not wanting to report deaths. Kenya similarly stated that if the country were to implement ICD-11 today, the system would still miss out on those who die in the community, as it remains a problem to know who is dying and what they are dying from. The country noted that a collaborative effort between ICD and SNOMED is exciting, since in Kenya, the private sector uses SNOMED but did not know how to use both, one is clinical, and the other is higher level so looking forward to the mapping. Namibia commented that it is currently using ICD-9 for morbidity and mortality, and will be moving to ICD-10 at the end of April, DHIS being piloted now, collaboration with Ministry of Health and the National Statistical Office, which is an opportunity to strengthen data and to learn more about ICD-10.

Finland thanked WHO and the network for modernizing the classification, commenting that it was good practice to have the experts involved. The country stated that moving to ICD-11 will be a major challenge, requiring major investments in translation. Therefore, the transition needs to be planned carefully and sufficiently long to plan for this change. Denmark and Sweden also provided comments on the modernization of the classification, and the challenges of moving to a new classification system.

3. Side Sessions

3.1   Future data and the Family of Classifications

This session highlighted the opportunities for the ICD-11 to work with other classifications more seamlessly in modern health information systems. A presentation from WHO noted the new global policy for rehabilitation, framed in the era of the SDGs. Major health strategies for promotion, prevention, and curative, rehabilitative, palliative services are serviced by either ICF or ICD, with ICHI a cross-cutting information standard. Data strengthening must occur by mainstreaming these classifications interoperable at the individual, program and health information system level.

The IHTSDO (SNOMED-CT) presented on the challenges of implementing data. It was discussed that it was important for systems to be working together, with data collected well at the individual level. The benefits will be better data, better standardisation of information, improved exchange, and improved quality of analysis.

Country presentations highlighted the value of classifications working together. The presentation from Japan highlighted the importance of the ICD for data in Japan, with ICF used for the long term care management for the elderly, as well as for employment support for people with a disability. In the UK, across the spectrum of information about the health of the elderly, it was noted that there is a need to understand and consistently classify information from multiple sources of information, and about multiple conditions. Concepts for functioning, morbidity and mortality must be joined up conceptually.

WHO noted that this was a critical juncture in population health, and there was a commitment and pressure to get systems right. In 2015, WHO released a framework for healthy ageing, and in 2016 the G7 Health Ministers noted the importance of ICD and ICF, especially in the context of ageing.
There is a need to focus on how classification can work together. The need is not necessarily to increase the sophistication of classifications, but to adapt classifications to suit varying contexts. Bundling and packaging classifications is an important consideration for future classifications use. The challenge of implementation for ICF may change now that there is a difference in context and emphasis, especially the changes in advice on the models of care, and the opportunities to link classification to others. It is important that the network ensures that the linking of classifications takes place. Capacity is still an issue, requiring concrete steps for low resource member states. There is a need to consider relevant entry points, and also the limitations in terms of capacity in country contexts, especially with the burden of reporting.

3.2   Women's and children's health

The side session on global data developments for women's and children's health comprised three presentations. The presentations demonstrated the critical role of data for the Sustainable Development Goals and for the Global Strategy for Women's and Children's Health. The underlying principle is that data should drive country analysis to address causes of death, morbidities, and disability as underpinned by efforts to improve measurement capacity to improve data quality for improvement and accountability.

The challenges of measurement, including the need for classifications applicable across different settings was considered; with the ICD seen as an important tool. The presentation highlighted the weaknesses in current classification and data systems, and the need to strengthen the collections, using data to inform programmatic action.

The discussion included emphasis on the importance of re-visiting the maternal death definition; the difficulties in reconciling the different sets of global estimates that have been published - even though, they understood that technical and scientific methodologies could underlie these differences; the need to monitor deaths among pregnant or recently pregnant women due to

suicide/homicide/ or other external injuries- even if these remain outside the "standard" definition of maternal mortality - as they have significant public health implications; and the investment case of improved monitoring of women's, children's, and adolescent health outcomes was seen as part of positive efforts to improve country capacity. The use of ICD, and in particular the primary care tabulation of the ICD should be considered for standardized collection of this data.

3.3   Leaving no-one behind

This session highlighted momentum for better civil registration and vital statistics data, including ICD-coded data, and challenges to be addressed into the future. The first presentation identified the value of CRVS data, especially covering births, deaths and causes of death, and the global and regional commitments to this data improvement. The presentation also highlighted the Technical Strategy which had been developed to support better mortality statistics in Africa.

A presentation on ICD implementation challenges overviewed presentations of a range of countries on their improvements and challenges in mortality data collections, and highlighted the role of health information networks in regions to support data and classification improvement.   Challenges and opportunities for better data were discussed, especially the role of electronic systems and streamlined classification approaches providing better entry points for country data improvement.

3.4   Better data for mental health

This side session provided an opportunity to explore in greater depth the proposals and field testing process for mental and behavioural disorders and categories relevant to suicide deaths in the ICD-11. The systematic process of evidence review and field testing used in the development of the mental and behavioural disorders chapter of the ICD-11 was overviewed, including how clinical utility across a variety of settings has been a key principle of the mental and behavioural disorders revision.

The session included presentations that articulated issues in several key areas that account for substantial portions of global disease burden and are central to the public health objectives of WHO and WHO Member States, including the proposed changes for schizophrenia and other primary psychotic disorders in ICD-11; and the revision of disorders due to substance use proposed for ICD-11 that better corresponds to the evolving nature of substance problems confronting Member States. The session also included a presentation about Australian efforts to improve data related to suicide deaths.

Participants emphasized the importance of integrating the work on mental and behavioural disorders into the ongoing work on ICD-11, including the work on functioning.

4. Next Steps

The ICD 2016 version for member state comments was released at the meeting. Member States were invited to provide comments and to field test the ICD-11 for its most relevant use cases.

4.1   Member State comment
WHO invited Member States to coordinate and provide comments in three main areas:
• Features and Structure of the ICD-11;
• Implementation needs;
• Future data needs.

Member State comments can be provided at http://www.who.int/classifications/icd/revision

The website will be open to receive comments until 31 May 2017. Feedback and comments received will be collated into feedback over the course of 2017 on ICD-11, and will be presented in a final report on ICD-11 at its 2018 release.

4.2   Quality assurance
During 2017, ICD-11 finalization will be delivered through a comprehensive quality assurance approach:
• WHO Collaborating Centres and other partners will be conducting quality assurance exercises on the ICD-11-MMS in 2017. Quality assurance will inform further decision making of the Joint Task Force for MMS at two meetings in 2017, and will improve the functionality of the ICD-11-MMS.
• ICD-11 technical finalization will continue in 2017, with the continued functioning of the Joint Task Force for Mortality and Morbidity Statistics, and the formation of the Medical and Scientific Advisory Committee (MSAC).

4.3   Implementation planning
The 2018 version of ICD-11 will be released for member state implementation. The goal is not to have a formal adoption, but to provide member states with a fully functioning robust classification that will allow Member States to plan for a transition in accordance with country priorities and capacities. Formal reporting of mortality data (and in the future morbidity data) based on the ICD-11 is expected to be implementation gradually by Member States post-2018.

4.4   Keep up to date
The latest version of the ICD-11 online for Mortality and Morbidity Statistics can be found at http://apps.who.int/classifications/icd11/browse/l-m/en

The latest information on the ICD-11 Revision including quality assurance can be found at http://www.who.int/classifications/icd/revision/en/

Annex A: Opening remarks by Dr Margaret Chan, Director-General, World Health Organization

Tokyo, Japan, 11 October 2016

'…Excellencies, honourable ministers, distinguished participants, representatives of WHO collaborating centres on health information management and the family of international classifications, ladies and gentlemen,

WHO welcomes you to the Tokyo conference on the 11th revision of the International Statistical Classification of Diseases and Related Health Problems, or ICD-11. I thank Japan for hosting this event and the Japan Hospital Association for its generous financial support over several years.

The conference takes place as WHO releases the 2016 version of ICD-11 for comments from its member states. The work you will do during this conference will prepare ICD-11 for pilot studies and field testing, for further refining the instrument before for its implementation from in 2018.

This has been the most challenging, complex, and far-reaching ICD revision in the 100-year history of this standard statistical instrument. As the external review reported in 2015, revision has been a delicate balancing act between the conservatism needed to maintain statistical compatibility with ICD-10 and the innovation needed to make ICD scientifically up to date and fit for purpose in the digital age.

I thank all participants for giving us your time and your expertise. You are among thousands of clinicians and experts in information technology who have contributed to this comprehensive revision. We are pleased today to welcome participants from our collaborating centres, the International Federation of Health Information Management Associations. I thank the Federation for promoting a well-trained and competent international workforce, fluent in ICD coding, to manage health information.

The opportunities opened by advances in information and communication technologies are huge. The ICD revision aims to make full use of these advances, improving both the ease of use and the specificity and consistency of the coded data. ICD has been scientifically updated to align with new interventions and conditions. It will deliver useful data that reflect current needs of health information.ICD-11 has been built for use in in an electronic environment, especially as more and more countries introduce electronic health records. Coding tools, browsers, different files, print products, and web services take advantage of new technologies in the digital age. ICD-11 also aims to be consistent with other information products, such as the Standardized Nomenclature of Medicine – clinical terms, or SNOMED-CT.

Revision has been further challenged by the fact that ICD is now used by so many, for so many different purposes. For statistical purposes, it groups together medical terms reported by physicians, medical examiners, and coroners on death certificates. In practice, ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes, including reimbursements by governments and insurers.

Ladies and gentlemen,

At the international level, gathering high-quality, specific, and comparable statistical data has never been more important. Cause-specific mortality targets and indicators abound in the 2030 Agenda for Sustainable Development, including for its supremely ambitious health targets. As we learned during the era of the Millennium Development Goals, information systems for civil registration and vital statistics are absolutely critical to track progress and make strategic course corrections. Moreover, in the continuing climate of financial austerity, governments and international development partners need statistical proof that their investments in health bring results.

This is true everywhere, but most especially so in resource-constrained settings where the overarching SDG objective of leaving no one behind faces the biggest challenges. For the first time, we are pleased to welcome experts from many lower-income countries in Africa and Asia, whose presence here is sponsored by WHO and the Japan Ministry of Health.

Speakers during this conference will update you on the many improvements in ICD-11, including expanded content, the use of combined codes, new primary care concepts, and additional coding options. The new foundation component contains all entities for diseases, disorders, injuries, external causes, signs, and symptoms in a network of relationships, enabling a range of improved management options. As another new feature, diagnostic categories used in traditional medicine are covered in a separate chapter. These categories are based on traditional medicine conditions which originated in ancient China and are now commonly used in China, Japan, the Republic of Korea, and elsewhere. Particular attention will be given to testing the chapter in integrated health care settings in target countries where both traditional and Western medicine are practiced.

In summary, this is an historical occasion and an historical opportunity to give the medical, epidemiological, and public health communities a cutting-edge statistical tool. Specific, precise, and comparable data are the foundation of everything we do.

I wish you a most successful conference.

Thank you.'