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June 30, 2017

Dear Sir/Madam,

This is to respond to your request for comments on the 11th Revision of the International Classification of Diseases (ICD-11) (C.L.2.2017).

I am pleased to enclose our comments which were compiled gathering various opinions from experts and administration in Japan. The comment focuses on broad and high-level issues while specific comments are to be provided through the proposal platform and I will be happy to discuss them with you.

I hope that you find our suggestions useful in the finalization of ICD-11.

Yours Sincerely,

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1. Data priorities

(1) Monitoring of multiple chronic conditions

- Having population in Japan and in the world ageing rapidly, public health response to life-style related diseases, dementia and other chronic conditions has become a global policy issue. Advancement in medical care has contributed well to save people's lives and improve their health, and it is now more common to live long with chronic conditions after receiving treatment and overcoming the acute phase. An international classification system should be established to allow monitoring and analysis of these multiple and complex condition among the population.

2. New data options, improved breadth and depth of information

(1) Expectation to electronic use in different environment

- Besides the wide-spread use in national statistics, expectation towards ICD-11 vary in different area such as in surveys, researches, education, health reimbursement, consistent use of medical terms, interoperability among different medical systems etc. We expect the electronic-friendly ICD-11 would address these various needs from different users.

(2) Expectation to the flexible coding function and points for consideration

- Considering monitoring comorbid situations as mentioned above, we welcome code combination (extension codes, clustering etc.) will allow flexible coding and detailed identification of various conditions.
- However, in order to use this complex code system effectively, it is important to establish a solid way of usage, which is still vague from our perspective. More specific explanation and dissemination is necessary to achieve common understanding. For example:
  - Is it allowed to use extensions or stem codes that are not listed in the 'code also/use additional code if desired' instructions? Can you use as much of extension codes as you like? For example, it is clinically important to distinguish heart failure between acute and chronic, and the use of extension code would be essential for this condition, but it is unsure whether and how the codes are to be used.
  - Chronic complications of Diabetes Mellitus: How do we assure the adequate code be selected consistently among different users from the post coordination list?
  - Coding of neoplasms: The guidance given to coders by the Alphabetical Index of ICD-10 has been replaced by a coding tool based on a direct text hit system. Especially in the area of neoplasms, information on the behavior given to each histopathology term was key information to code adequately. The effectiveness of the new tool should be reviewed carefully in this area.

    Further, there are concerns also from medical perspectives, where certain tumors are defaulted to a certain behavior but medically can be either of malignant, in situ, or benign (e.g. Intraductal papillary mucinous neoplasm of pancreas, endocrine tumors such as Insulinoma).

We expect the Field Trial will reveal these problems and be corrected as adequate.

- From a technical view, the random numbers and length of the extension code is difficult to understand. It should be systematized more even it is envisioned to use in electronic environment.

- Although we consider there would be challenges for the actual use, the creation of a new chapter for functioning is an interesting step and we expect further discussion will be made on this issue.
- Having Kampo medicine is used in Japan, we value the creation of a new chapter for traditional medicine. And we expect this will contribute to advance data collection and research in this area, and the technique of code combination (clustering etc.) will help having linkage between western medicine and traditional medicine.

[Request to WHO]

a) Explain and disseminate the usage of ICD-11 in a comprehensible manner while addressing the comments provided above: how to use post-coordination, extension code, clustering and its practical and standard way of using, code description methods and the rule behind it etc.
b) Consider the code numbering of extension codes to be more structured.
c) Assist Member States in making use of the electronic environment provided by WHO in various systems within the country.

3. Chapter updates

We appreciate ICD-11 for having more detailed information based on medical advancement and accumulation of knowledge. However, there are still remaining issues throughout the classification, as shown below for example, and further improvement is required:

(1) General issues

- Shared understanding on high-level decisions for major diseases

  In the last phase of development, it is even more important to gain common understanding on the classification. Currently we receive multiple comments that there are several modification that slip away from the notification system, which may or may not be because of the system but implies that the current support is not enough. Therefore, besides the notification function provided, we would like to request timely provision of easy-to-understand short reports on large decisions such as change in the chapter title, location of major diseases including dementia and cerebrovascular diseases etc. Unfortunately, thus far the feeling of less feedback to each input provided is harming the impression of the process and output of ICD-11.
- Further checking of consistent notation and typos.

  Detailed but important to gain confidence. And important because of the yet direct hit search function nature.

  e.g.: Miller-Fisher syndrome vs Miller Fisher syndrome, CTNL1 should be CTLN1.
- Use of common medical language

  There are several points where clinically unfamiliar terms seem to be selected over common

medical terms. There could be consideration from consistent usage of certain terminologies in the classification, but such cases should be explained more clearly.

- Improvement from the perspective of region and ethnic
  e.g.: EBV hepatitis has not gained a code while CMV hepatitis did. Frequency analysis in shore lining should carefully consider regional balance.
- Addressing genetic diagnosis etc.
  It is expected that understanding of intractable diseases and gene-related diseases would expand along with further accumulation of medical insight. The complex nature of these diseases might become difficult to capture within the traditional classification. This perspective should be taken into account in future organization of the classification system.

(2) Specific issues

- Regarding the location of dementia which is now an international concern, we consider decision should be made based on the latest medical expertise on etiology while also taking into account actual clinical practice among countries. Having the placement of dementia changing several times after the 2016 October version for Member States comment, we will, if necessary, post specific comments to the latest version through the proposal platform.
- Besides this dementia problem, many specific issues were raised from the academia and others. These comments as well are to be posted to the platform from each academic society as their aggregated opinion.

(3) Consideration of Specialty Linearizations

- We welcome the idea of double parenting because naturally certain diseases would have diverse aspect and this could be shown in the classification adequately. However, unfortunately some confusion was seen among the users without clear explanation on its usage and different versions switching it off or on. We understand that the ICD-11 MMS is a classification system focusing on statistics and international reporting. But considering its possible wide use in clinical settings, we should also think of clinical perspectives, while there is still area that is unfavorable in thinking of clinical usage where usually more detailed information is available.
- Making efforts to adapt MMS to such needs on one hand, to address fully and flexibly to the needs from different countries, specialties, or area such as primary care, consideration of national or specialty linearization would become necessary. In this context, we would like to request further explanation in this regard, since there already are requests from specific area but the rules or criteria for creating and maintaining special linearizations are not clear.

[Request to WHO]

a) Review the classification carefully again on the general and specific issues mentioned above.
b) Make sure all changes made to the classification go through the proposal platform and notification system, report on changes made in major areas in a timely manner, and provide

explanation on new concepts such as double parenting, and selection of terminologies.

c) Clarify the scope and guideline for creation of national or specialty linearization addressing different use cases.

4. ICD-11 multilingual needs

We appreciate the multilingual feature of ICD-11 allowing more countries to use ICD in ease. However, frequent update will post burden on countries that will undertake the translation task. This should be taken into account when considering maintenance of the classification.

[Request to WHO]

a) Consider translation burden when thinking of ICD-11 update cycle etc.

b) Consider of expanding technical support for translation such as assistance by automatic translation function etc.

5. Request for assistance in national implementation

(1) Foster common understanding of the classification

As mentioned earlier, common understanding is the key to achieve an internationally comparable and interoperable classification and implement it among different users including the government, medical care stakeholders, patients, and researchers. Currently, even people who contributed much in the development process complain that the classification is difficult to understand, and that explanation from WHO was not enough. Although we understand resource constraint in the Secretariat may have attributed partially to this, in this last phase, we would like to reiterate that we expect delicate explanation from WHO.

(2) Political Leadership

To make the most of ICD-11 as an information basis of public health and medical care system throughout the world, political leadership is necessary. In order to support governments to take the lead, it is useful to prepare briefing materials including new features of ICD-11, data continuity, and major changes from ICD-10 (not only on the technical points but also for international priority areas and areas with high social impact), and also having opportunities to explain directly from WHO would be helpful.

[Request to WHO]

a) Provide a set of document for Member States that can be used for consistent public explanation.

b) Provide specific explanation paper in international health priority areas and areas with high social impact.

c) Coordinate with Member States in publicizing ICD-11 by having opportunities to provide explanation directly from WHO and by any other means that will support country implementation.