Report of meeting of the WHO Joint Task force for ICD-11
Mexico City, 14-15 October, 2017

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Opening
The JTF has been advising for what is required in ICD-11 for Mortality and Morbidity statistics and it
will now focus more on assisting WHO in transitioning from development of ICD-11 to
implementation at both international and national levels.

ICD-11 Progress report – WHO
WHO provided a status update on what has been accomplished since July in editing ICD, preparation
of accompanying materials, and future plans. This included input in relation to implementation that
was sought in regional meetings in India, the Asia Pacific Network, Japan, Eastern Mediterranean Region and 22 countries of the American region. The schedule foresees an editing meeting for mortality coding rules in December 2017, a meeting with the software industry in January or February 2018, a review meeting to show progress and response to Member State feedback and field trials in March 2018, followed by a meeting of the JTF, and the release of ICD-11 end of June 2018.

Discussion:
- Resources need to be planned carefully to ensure completion of ICD-11 for release.
- Additional resources are needed for completion of the anatomy (2 months FTE) and substances (3-4 months FTE) axes of the extension codes.

Member State feedback and Field trial feedback

Additional feedback from Member States
Some Member States have provided feedback after that last meeting of the JTF.
Besides recommendations to improve user guidance and instructions for postcoordination, they mentioned also some content specific points, as:
- To ensure compatibility with ICD-O
- To have categories that could be addressed by verbal autopsy
- Scientific content that needs to be reviewed by subject matter experts
- Changes to code structure
- Addition of some specific genetic information
- Addition of some detail in relation to odontology

Discussion:
- A generic fact sheet on ICD-11 should inform for example, why new codes cannot just be added
- Microbiological agents, substances, genetics change frequently and there needs to be a sustainable process for any of these axes. This is ensured for medicaments - INN that is within WHO or histopathology (maintained in collaboration with IARC). For genetics, there is no such process inside WHO.
- The anatomy is missing detail in relation to teeth

Action items:
- Prioritize what edits could be done easily and what suggestions need scientific discussion
- Add detail for teeth to the anatomy axis of the extension codes
- Consider producing such a fact sheet explaining what can be done and what not

Generic field testing feedback
- There must be clear directions that the coding tool must be used. It is suggested to put some text on the website that the preferred way of coding is to start with the coding tool and then refer to the Browser.
- It should also be made clear that the web services will make available all the features for the coding tool and translations. Software vendors will be able to access these.
- WHO confirmed that the writing of technical guides has started. It needs to highlight that there will be components that will be available for offline use, and describe in detail the required features for 3rd party coding software.
• Usage regulations of ICD-11 should facilitate implementation. Royalties and other charges need to be considered in that context.
• The search engine of the coding tool needs to handle specifics of the different languages.
• The heterogeneity of the coding outcomes likely due to multiple contributors, no international standards for morbidity coding, possible language issues (testing so far only in English also by non-native speakers); and different coding traditions in each country. Assessing the results (some 20%) must be done in taking into account the comments provided by the participants and the context above.
• It was noted that the problem with Main condition definition being different in some countries and not following the international definition as outlined in the reference Guide, impacted on the results. For statistical consistency, it has been agreed that the definition of main condition should be the reason for admission and is to be used for international comparison.
• The structure of ‘diagnosis type’ in relation to main diagnosis in the extension codes should be reviewed to clarify the intended meaning of the different entities.
• Mortality field testing so far has to be conducted without the decision tables for ICD-11. Results were from certificate based line coding. The methodology does not allow to assess if there would be any problems with the selection of a single underlying cause. All findings of the testing are relevant. Users need to be guided on what is postcoordinated and how to get the independent stem codes.
• Digesting and categorizing the feedback from the field testing requires to understand if a resulting suggestion for a change is addressing a real issue of the structure of ICD-11, or if there was a need for more guidance on postcoordination and use of ICD-11, and whether the coding tool has been used.
• It is clear that if there is a term missing in the index, it needs to be added and the most common terms need to be added into iCAT.

Content issues
1. Summary of German special testing by scientific societies)
   • >It looks like the level of detail is different between the different parts of ICD-11. Some explanations would be helpful.
   • Some concepts can’t be coded in ICD-11 - this should be addressed.
   • There are comments related to structure and how ICD-11 is organized - this may not be urgent but should be responded to from a scientific point of view.
   • Codes are hard to memorize. - This is true, but there is no better way to assure sufficient coding space and prevent confusion with ICD-10.
   • Finding a code using the search in the browser of tree browsing is problematic for the coding quality - we need to reiterate that the entry point for coding is always the coding tool. That may resolve many of the mentioned problems
   • Some of the issues could be partly due to primary familiarity with ICD-10.
   • Appropriate feedback should be given to the different scientific groups-- granular feedback would take more time than available, so there should be at least an appreciative feedback.
   • Some comments show the lack of familiarity with cluster coding.

2. The JTF recommended that thanks be passed on to all involved in the German review and acknowledged the amount of work involved.
3. Results of this review work will be published in different journals. It needs to be clarified in the publications that the review work was done on an older version of ICD-11 (April 2107).
4. It was noted that there was an issue of whether a concept was codable or not. However, in all instances it needs to be verified whether this means that the concept is missing in the foundation or whether instructions need to be added on how to code this concept in postcoordination.

5. In view of the wealth of input it will be helpful to have some standard procedures do discriminate between amendments that can be easily done, and changes that may require further discussion by the JTF. It was noted that a single national scientific review cannot simply overrule the work made by the TAGs.

6. As a simple way forward the approach could be:
   - Do not redo the structure
   - Proposals would be prioritized, and JTF could assist with that, with focus also on frequently used areas of ICD.
   - Scientific dissent will be addressed by the MSAC.
   - Issues that cannot be changed after release will be addressed first
   - Summary feedback on issues addressed to process towards addressing them (e.g. via MSAC) will inform the testers. Individual detailed feedback is not possible. It will drain workforce from the finalization of ICD-11.

7. Substance list: A concept paper has been written explaining the work that needs to be done for the inclusion of INN. The INN only includes substances that can be used therapeutically. ICD-10 had more than this. The INN does not have a hierarchy. Some points require discussion with the JTF:
   - Inclusion of brand names:
     - There is a need to map the brand names to the generic codes.
     - The US is working on this issue right now, and how to update them on a regular basis, and may be able to provide some support - not only map the drugs to ICD-10 codes, but to have a method of drilling down to the individual drugs.
     - It was agreed that brand names could be added as a second stage process.
     - Globally, adding brand names could be challenging due to different names in countries.
     - The drug dictionary at the Uppsala Centre could also help with brand names,
     - The substance list is part of the extension codes; so, brand names can be added easily.
   - Drugs that are not therapeutic agents, and not in INN, need to be included in the list.
   - Concerns were raised that just putting the INN names in increases the workload of translation. WHO advised that the INN list exists in the 6 official languages. It was also and it is available with Swedish and Finnish versions.

8. In the discussion on why mapping shows also postcoordination, it was clarified that one version of map is supposed to provide the full correspondence between ICD-10 and ICD-11. In cases where a detail of ICD-10 is not above the shoreline, postcoordination is the way to describe such an entity.

9. The most recent version of representation of dementia was shown. The instructions for postcoordination make sure that both, the aetiology and the resulting dementia are always coded.

**Additional testing (for discussion)**

Have to ensure the rules are clear for postcoordination and clustering concerning the format and the extent of postcoordination.

- Postcoordination is an optional way to add detail to a particular condition. The rules for postcoordination need to be clear for the different usecases. For example, mortality and morbidity
code injuries and external causes differently so this may be a case for a postcoordination rule to be different for the two different use cases. However, the recommendation was and will remain to always code both.

- For Mortality testing it is important to look at the coding results to assess where postcoordination has the potential for changes in rules. Ideally this would be done before the December mortality meeting and a further look at rules can be done following this meeting.
- Additional testing is also necessary for the updated external causes chapter, and for diseases of the skin.

**Action items:**

- James Harrison will start to formulate some rules and examples for clustering
- Will need to do some field trials of the external cause codes in the new structure to see what may need to be revised.
- Some instruction is required in ICD-FiT to assist people in doing the clustering
- Ask other countries other than Australia to also test the external cause codes for morbidity use.

**Sepsis update**

A report was provided from the meeting on the new international definition of sepsis – Sepsis 3 and its incorporation in ICD. The application of this new definition will be added to ICD-11 as a new 4-character code for Sepsis in Chapter 1. It already was added to proposal platform for comment and has now been added to the classification. Issue that has arisen is the terminology sepsis vs septicaemia. In the past, these were considered synonymous. No longer the case. Septicaemia should be a parent to bacteraemia. In discussion, the following points were made:

- Concerns about this change and the effect on epidemiology studies as this will cause a shift in numbers and frequencies.
- Mortality has concerns that the certifiers are using septicaemia to mean sepsis.
- Suggestion that there be a mortality rule in the Reference Guide that if Septicaemia is selected as COD it be recoded to sepsis.
- Decision to go with Option 1 in the discussion paper.

**Action items:**

- MRG to write a coding rule for reselection when ‘Septicaemia’ is COD.
- Send terminology issues to MRG e.g. urosepsis for review

**Coding Rules**

**Cluster coding**

The MRG had compiled a paper on cluster coding in mortality. Comments received from MRG on the paper included:

- No comments excluding cluster coding for mortality.
- No extension codes for UCOD (Single Underlying Cause of Death).
- Concerns about losing information in Diabetes Mellitus coding – maybe add more information to stem codes
- Rules on selecting only one condition for UCOD is now out dated, people are multimorbid at older age.
- Concerns that mortality rules are outdated in a number of areas.
Further discussions to be held at the MRG ICD-11 session during the WHO-FIC meeting.

There are rules already for morbidity and mortality ordering of codes within one cluster. ‘Code also’ and ‘use additional codes’ notes will inform on the type of stem code and priority in primary tabulation in a particular usecase.

Is there an importance in the order within the cluster? Does ordering have to be the same for both mortality and morbidity. MbRG will be discussing this during the WHO-FIC meeting.

Does the ordering need to be determined internationally and could it be different for national cases? Reporting and interoperability between countries need to be considered. However primary code for public health prevention tabulation likely is the same for mortality and morbidity.

For cluster coding in morbidity, the first code has primacy. Also, the first code in a cluster is more likely to survive in the event of truncation.

Concern that underlying because coding could lose information without postcoordination. Suggestion that cluster coding mapping will help and rules to choose a single underlying cause.

Discussion papers need to address the difference between ordering and sequencing and provide 5 examples. High level rules can be added to the Reference Guide. How to do clustering will be in the Reference Guide. The discussion papers will be written in the style of instructions and become part of the annexes to the Reference guide.

**Action item:**
- Mortality group to continue with the work on the cluster paper. Deadline will be to have this work completed by the December Meeting.
- Morbidity group set up (Olafr, Bill, Martti, Jenny, Anne and Vera) to produce an initial draft of the cluster paper to be discussed at next TC in 3 weeks.
- Clinical documentation document was created to be part of the reference guide and comments are invited from the JTF

**Morbidity coding rules**
- MbRG will discuss during the WHO-FIC.

**Mortality coding rules/MRG discussion**
- Acknowledge that the UCOD is not what it used to be and is more complex now. Need however one cause to make tabulations possible – balance needs to be found. A consistent way needs to be retained. It is both an analysis and reporting issue not just a coding issue.
- Single code for UCOD is acceptable and if there are multiple causes then encourage the use of cluster coding. Allowing a cluster for UCOD will cover the multiple causes of death. It is still important to capture the underlying aetiology amongst all the multiple cause.
- Question asked - is there a need to change ICD-11 for mortality or would changes to mortality rules be more beneficial?
- 90% of deaths in the world are done using verbal autopsy – Suggestion that WHO should develop a policy where 2 types of data is collected – verbal autopsy + complicated

**Transition plan and implementation package**
WHO provided an update on the state of the components of the implementation package.
- Transition of revision process from development to maintenance.
- MSAC now working.
• CSAC will be convened during the WHO-FIC Meeting. This will consist of the URC plus the co-chairs of MSAC. Possibility of including some epidemiologist. Countries wishing to join the discussion will need to have a collaborating centre.

• Questions raised:
  – What will happen to the URC?
  – Do we need to have 2 committees in parallel?
  – URC would deal with ICD-11, ICF & ICHI. They would be familiar with the work process.
  – What happens to ICD-10 during the transition period?
  – May also have to consider major updates for ICD-11 sooner than the 5 years.

Discussion:
• URC would finish with the last updates to ICD-10 this year (2017).
• Concerns were raised that any major updates would not be able to be added to ICD-10. Discussed that CSAC could deal with ICD-10 updates as well as ICD-11. ICD-10 updates would be minimised.
• Maintaining 2 classifications will require considerable resources. Next major updates in ICD-10 will be 2019 – should there be any others after this time? Guidance can be given but final decision will be with WHO. Clear message needs to come from WHO as to when ICD-10 is no longer being updated and when ICD-11 should be implemented. Countries with clinical modifications can continue to update.
• Resources to handle ICD-10? It would be good to stop updating ICD-10 if ICD-11 was fit for purpose and could be introduced within 2-3 years.
• Concerns raised that it cannot be left in its current format as there are known crucial updates that need to happen (e.g. sepsis). Proposals could be discussed in parallel with ICD-11 updates.

Recommendations by the JTF:
• There needs to be a clear message as to when ICD-10 updates will end.
• URC is not needed once CSAC starts
• Issues could arise with major clinical/scientific knowledge changes for ICD-10. MbRG and MRG could request a decision by WHO/CSAC to include these.
• MRG does not envisage need for changes to Volume 1. Uptake of updates in mortality is slow. Only corrections to volume 2 (rules) and these are relevant for ICD_11 as well.
• The MbRG would have to provide very strong rationale for any changes. MbRG would bring up topics of significance. Countries using ICD-10 must have an update that is relevant for international statistical reporting.
• Criteria should include whether it matters for ICD-11 – if it does not matter for ICD-11, then it probably should be added to ICD-10.
  – Countries can add items to their clinical modifications, but WHO will not produce an international update.
• Suggestions for major updates would be introduced into ICD-11 rather than ICD-10.
• WHO would no longer publish in browser or book format but give advice on some issues only on the website. This could stop national modifications making different decisions for some of the urgent items that need change.
• Putting updates on the URC platform would cease.
• Need to add a general note that there will be a clear decision by WHO if these proposed updates are really acceptable, important or relevance to international statistical reporting.
ICD-11 will be released in 2018, have an update in 3-5 years and there will be some ongoing work on mortality rules.

(NOTE: The URC recommended later, and the WHOFIC Council agreed, that the last update to ICD-10 shall occur in 2019. After that date, only errors will be corrected and published in the format of errata. The recommendation has been accepted by WHO.)

Feedback from Regional Consultations
Report by WHO on the regional implementation needs of ICD-11.

- Finalisation of Transition paper is necessary– comments need to be sent to Vera Dimitropoulos within 2 weeks.
- Some advocacy texts need to be added at the begin of the paper, but should not become too detailed.
- The paper is intended to inform about what the ICD-11 is. It is important to raise the questions/issues that countries will need to be aware of for their implementation.

Action item:
- WHO to email both papers to members for comment and these to be returned by Nov 6. Jenny and Vera to be cc’d on all. Deadline is November 6, 2017.

Governance and Transition

Governance and proposal workflow
The document describing governance and workflow for maintenance of ICD-11 is looking mature and very close to finality.

Comments:
- JTF supports the proposal workflow paper. Concerns exist about implementation of the proposal workflow particularly in the early days, because there are Imponderables as to how much work and resources will be needed. - Suggestion that Co-chairs of JTF will provide wording for a recommendation on this issue from JTF to the WHO.
- Concerns were raised about number of proposals, expected workload and time available for the work. The first few years will require more updates in ICD-11.
- The ICD-11 proposal mechanism will require more resources (compared to ICD-10) not only at WHO but also at the MbRG and MRG.
- Recommendation from JTF is that WHO devotes sufficient resources to support this more complex system. These resources need to be available long-term.
- WHO staff planning should also cover the expected higher needs in the transition period.
- It was suggested that countries would provide support. Alternatives for improving available staff and ensuring that there is a pool of trained persons, could include rotation of staff from various countries - supplemented by full time staff at HQ.
- Suggested edits to the workflow document include:
  - Addition to paper that this workflow would start at the release for implementation. WHO would need to deal with the backlog of proposals.
  - Changes were made to the document at the time of meeting (version uploaded on the meeting site). Any further comments on the questions should be sent to WHO.
Action items:
- Updates to be included
- Wording by JTF cochairs regarding initial phase to be provided for inclusion

Clinical modification needs.
- ICD-11 is much more suitable for clinical use than ICD-10. The intent was to include as much content from the clinical modifications as possible. It also allows for coding even more detail with the use of postcoordination. It is important to get a robust international ICD-11 and then discuss the national modifications. Points to be considered in the context of the topic ‘national modification’ are:
  - ICD-10 was not fit for purpose for multiple condition coding. License agreements allowed countries to do their own things
  - ICD-11 is quite different and countries should be encouraged to stick with the plan, but will have different forms of implementation.
  - Content of the clinical modifications of ICD-10 will be in the foundation and available for that national use.
  - ICD-11 MMS extension codes are very far reaching and it is not likely that all will be used by any single country.
- Characteristics of a national modification – Suggestion that this be called a national linearization. There will always be specific items that are only needed for one country and implemented only there.
- It is still important that countries keep focus on international comparison while addressing their own needs and use international rules to maintain international standards as much as possible.
- JTF agrees that entities needed specifically for a single country are included in the foundation but that they may be below the shoreline of the international reference version. Extension codes will definitely facilitate the coding of the necessary detail. Extension code could eventually be used for very specific conditions needed by a single country.
- There will be a variety of specific characteristics in the different places that ICD-11 will be implemented. Needs to be some terminology to show these different ‘lists’ based on the place of implementation. JTF agreement that most people are happy with the way this is going.

Where do we go from here?
- ICD-11 version for implementation will be released in June 2018
- JTF needs to determine what urgent steps need to be done now in advising WHO. A summary would be provided at the JTF/WHO plenary session of the WHOFIC meeting.

Discussion:
- It has been a long process to get to this stage of maturity of ICD-11. Now, at the stage of operationalisation, future users will be looking at the ICD-11 in even more detail in how it suits the various usecases. ICD-11 now needs to be used practically, and suggestions of changes will be based that practical experience. The theoretical discussions about the optimal structure have come to an end. It is expected that there will be proposals following implementation,
- There will be about 3 years of more intense updates. For the sets of categories there should be only minor changes after the release – emphasis should be rather on improving user guidance.
It will be important to convey the message that ICD-11 is stable and that projects like Iris and translations have started.

It is likely that countries that start new on implementation of ICD may take ICD up for mortality before countries that have a long-standing tradition in use of ICD.

There needs to be a set of strong visibility activities

- About need of education and training – navigation of political environments.
- Marketing strategy including endorsement by high profile leaders. Australia has been ‘advertising’ ICD-11 at their various meetings and conferences.
- Explaining well how to use ICD-11. JTF can provide some history of the development.
- WHO do more education on the use of ICD-11 the closer we get to the release.

WHO needs to be proactive on publishing and write some journal articles in leading journals. Topics to be addressed in the articles are:

- Technical paper describing the foundation - to JAMIA
- NEJM paper that would reference the technical paper
- Papers can be completely honest about the questions but be excited about the classification, but not too technical, exciting new thing, and why it’s not implemented

In the current planning, there will be no WHA resolution in 2018. The start of the revision process had been announced by the DG, as has been the invitation for Member State comments. It may be helpful to inform Member States about the release in the same way.

At a meeting in March 2018 it will shown that input from Member States and field testing has been addressed.

Summary:

- Endorsement of ICD-11 for implementation acknowledging that there will be edits (mainly improving user guidance)
- After ICD-11 is released, there is a necessity to have more frequent updates in the first 3 years, to be extended, if needed. The need for a translation may delay implementation in some countries.
- ICD-11 is ready to move to the next phase and advise that the process of steps towards implementation be ready to begin.

Future Meetings:

- Continue monthly TC until Oct 2018 - Need to fix calendar for these dates.
- Small editing meeting in December for Mortality Rules.
- March Meeting 5-9 – first few days will be Review Meeting and JTF at the end of the week.

Action item:

WHO to send invitations for March meeting.