WHO-JLMMS Task Force Co-Chairs 2016 Planning Meeting

Date: 12-13 Jan 2016
Time: 9:00 – 17:00 (GVA time)

List of Participants:

<table>
<thead>
<tr>
<th>Co-Chairs:</th>
<th>WHO Participants:</th>
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<tr>
<td>☒ James Harrison</td>
<td>☒ Ties Boerma</td>
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<td>☒ Stefanie Weber</td>
<td>☒ Robert Jakob</td>
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<td></td>
<td>☒ Anneke Schmider</td>
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<td>☒ Nenad Kostanjsek</td>
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<td>☒ Lori Moskal</td>
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<td>☒ Molly Meri Robinson Nicol</td>
<td>☒ Can Celik</td>
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<td>☒ Can Celik</td>
<td>☒ Stephane Espinosa</td>
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List of Documents Requested from the meeting

NOTE: Most will be necessary for the JLMMS TF Meeting in April

1) Use Cases (update) *(Anneke Schmider to lead, with Stefanie Weber, James Harrison, Jenny Hargreaves, Donna Pickett, Robert Anderson, and Robert Jakob)*
2) ICD-11 Business Model *(Anneke Schmider to lead)*
3) ICD-11 Revision Overview, including project scope, the “Four Dimensions”, post-2018 plans *(Stefanie Weber, James Harrison, & Jenny Hargreaves, with Anneke Schmider, Robert Jakob, and Molly Meri Robinson Nicol)*
4) JTF Decision-making process *(Stefanie Weber, James Harrison, & Anneke Schmider)*
5) Sanctioning Rules (update) *(Robert Jakob to lead)*
7) Harmonization of Update and Revision Processes Plan (update) *(Robert Jakob to lead)*
8) ICD Revision Conference Agenda *(Anneke Schmider & Molly Meri Robinson Nicol)*
9) ICD Revision Conference Feedback Plan *(Anneke Schmider)*
10) ICD-11 Terminology Glossary - *(Robert Jakob to lead)*
11) Governance Paper (update) *(Anneke Schmider & Dr Molly Meri Robinson Nicol)*
12) Project Plan (update) *(Anneke Schmider)*
13) Review and Testing Strategy *(Robert Jakob to lead)*
14) ICD-11 Revision Stocktake *(Robert Jakob to lead)*
15) ICD-11 Definitions: Status and Plan *(Dr Robert Jakob to lead)*
16) Linearization Naming Conventions: JLMMS *(Dr Stefanie Weber and Dr James Harrison)*
17) Volume II Morbidity Rules (update) *(Donna Pickett, Ulrich Vogel, and Anne Elsworthy)*
19) JTF April 2016 Meeting Agenda *(Anneke Schmider & Molly Meri Robinson Nicol)*
20) JTF Co-Chair Recommendations *(Stefanie Weber & James Harrison)*
21) Shoreline Document (update) *(Stefanie Weber)*
22) JTF Co-Chairs Planning Meeting Report *(Molly Meri Robinson Nicol)*
Agenda and Notes:

9:00 – 10:00

1. Introduction and Review of Plan for 2016

1.1. Background
- The goal of the meeting was to plan the necessary JLMMS work for 2016, as well as to prepare for 2018

1.2. Key Discussion
- Stakeholders and participants have had legitimate concerns that the project might not be successful, and WHO must now manage expectations accordingly.
- Credit should be given that by the end of 2015, there was consistent feedback that goals now look more feasible
- A key outcome of this meeting and the documentation that will be produced afterwards is to ensure a common understanding of what is being done, how, and by when, as well as a clear list of deliverables for each time period.
- ICD-11 will be a compromise between statisticians and clinicians, and must be a compromise both sides can live with.
- Ensuring that people have a chance to input to the revision is important, though obviously not all ideas can be incorporated
- Use cases must be more clearly defined – Mortality is fairly clear, but Morbidity and Clinical use cases are less so.
- Tasks such as the Sanctioning Rules are very important for the implementation of ICD-11, yet are not intuitive to users of ICD-10. As such, this topic should be revisited.

1.3. Action Items
- For the TF Meeting and ICD Revision Conference:
  - Use Case document update - *(Anneke Schmider to lead, with Stefanie Weber, James Harrison, Jenny Hargreaves, Donna Pickett, Robert Anderson, and Robert Jakob)*
  - ICD-11 Business Model document - *(Anneke Schmider to lead)*
    - Include JLMMS use case, as well as other specialty and national linearizations
    - Also include a risk assessment
      - Include project scope, plans for post-2018, and document components identified in the “four dimensions” outlined later
- For April Task Force Meeting:
    - Include workflows on how decisions will be made and implemented, particularly when consensus is difficult or not possible.
  - Review and Testing Strategy document - *(Robert Jakob to lead)*
    - Include information on the longitudinal process of how and when proposals received after 31 December 2015 will be dealt with.
  - Sanctioning Rules (update) - *(Robert Jakob to lead)*
2. 2016 ICD-11 Planning

2.1. Background

- May 2018 remains fixed as the end date for the project and will not change.
- The ICD Revision Conference in Tokyo on 13-14 October 2016 is a key deliverable for this year, and the agenda will be set in the next few weeks.
- Given key time and resource constraints, prioritization is necessary, and it may be necessary to make some decisions that are not popular in all user groups and stakeholders.

2.2. Key Discussion

- It is important that all stakeholder groups, including internal experts working on project development, have the same understanding of what must be delivered in 2018 as well as how each group and individual will deliver. A plan for what will happen after 2018 is advisable.
- The 2007 Revision Conference resulted in 68 pages of features that were desirable in ICD-11, but not all are possible in the current environment.
- Now is the time to prioritize, deciding how much time is necessary for testing before 2018 as compared to 2018 and beyond, which content model parameters are essential, and other such considerations.
- There are Four Dimensions to be considered in the context of the JLMMS:
  - **State of the Content** - ICD-11 must be at least as complete as ICD-10 and should make efforts to address the known issues from ICD-10 as a minimum component of added value in ICD-11. The content must be at or above a minimum standard of quality, completeness and robustness (as verified in Field Trials, Review, etc.). The JLMMS Task Force will focus on the content of the JLMMS, while the Foundation will continue to be moderated by the RSG.
  - Clarity on the post-2018 update procedures, Verification of backwards compatibility with ICD-10
  - **Clarity of Use Cases**
  - **Business Model**
    - Include the model for implementation in countries, guidance on implementation of JLMMS, key differences from ICD-10 with evidence that all former uses (key country requirements) are still possible, List of known ICD-10 issues that have been corrected, and information about how, information about the “value add” for ICD-11

2.3. Action Items

- Reinforce the desirability of developing information around the “four dimensions” as a part of the ICD-11 Revision Overview document, supporting the ICD-11 Business Model document.
- Test the papers outlined above at the Face to Face meeting of the JTF in April 2016 in preparation for the ICD Revision Conference.
  - Address the requirement to ensure comparable data during the transition period when some countries will be reporting with ICD-11 while others are still on ICD-10
- Harmonization of Update and Revision Processes Plan document (update) - (Dr Robert Jakob to lead)
Include a concrete action plan for implementation
Collaborate with the relevant stakeholders in Member States and the WHO-FIC Network
Link the Harmonization of Update and Revision Processes Plan document with the Review and Testing Strategy document to ensure synergies between the two processes.

3.1. Background
- An additional complication in 2016 is that there will be four different meetings scheduled in the same place at the same time:
  - 10-15 October – IFHIMA
  - 11-14 October – JHIM
  - 8-12 October – WHO-FIC
  - 13-14 October – ICD Revision Conference
- The most significant conflict will be on 13 October between the ICD Revision Conference and the IFHIMA Mortality Conference.
- There is a concern that the parallel sessions will increase the rate of time conflicts and potentially limit the scope for the WHO sessions. Conversations with the meeting hosts in Japan may provide more information.
- The agenda, particularly for the ICD Revision Conference, must be set soon. This may include opportunities for Member State Feedback, such as through the reading of prepared statements as at WHA.

3.2. Key Discussion
- It is essential to ensure that WHO listens to all comments and takes the feedback on board, and that the decision making process is transparent.
- All Member States will be invited, but it is assumed that not all will be able to attend, particularly those Member States with fewer financial resources. Unfortunately, WHO does not have the funding necessary to supplement the cost of attendance.
  - It may be possible to investigate electronic participation
- Key Agenda Topics might include items such as:
  - Content of ICD-11
  - Use Cases
  - Implementation
  - Business Model and Governance
- A full agenda should include, among other things, sessions on:
  - Use cases in the introduction
  - New things – TM, Sexual Health, Sleep
  - Tech – what exists now, what will be in place by 2018, what will be developed afterwards
  - Changes – where major work has been done, what was changed, and why
  - Risk management – outline the desired process and risks, mixed with implementation
  - Governance
  - Pre- and Post-coordination, JLMMS and Foundation
  - Plans for post-2018
- It will be prudent to minimize the “insider” terminology when presenting to Member States (as well as to the public), so this is the time to work on branding, naming, and simplifying how ICD-11 is discussed and presented.
  - Review all of the ICD terminology, simplify where possible, and create a glossary
  - Review the “translation table” document of ICD-10 to 11 terms to inform the above
- It is important to be clear with participants in terms of what each is invited and expected to do, such providing feedback on potential implementation needs

3.3. Action Items
- Agenda and Invitation Process:
Request Network members to prepare their Member State Representatives as much as possible to attend the Revision Conference.

ICD Revision Conference Agenda - (Anneke Schmider to lead)
  - Include list of session chairs and speakers

ICD Revision Conference Feedback Plan document - (Anneke Schmider to lead)

ICD-11 Terminology Glossary document - (Robert Jakob to lead)
  - Include common terms used in ICD-11, such as “linearization”, “post-coordination”, “sanctioning rule”, and others.

**14:30 – 14:55**

4. Governance and Update of ICD-11

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<tr>
<td>The process of harmonizing the revision and update processes to allow seamless handover of ICD development has been a topic under discussion for some years, but must be concretely laid out with buy-in from all stakeholders and a clear implementation plan.</td>
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<th>4.2. Key Discussion</th>
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<tr>
<td>Given that the JLMMS structure is new, it is not necessary to create a new group and governance structure, but this must be a priority for 2017 and beyond.</td>
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<td>The URC harmonization paper has been an agenda item for some years, and the URC is pending, waiting for the next stage of progress.</td>
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<td>Oct 2018 will be the last updates approved for the 2019 ICD-10 release, after which all efforts will be focused on ICD-11.</td>
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<th>4.3. Action Items</th>
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<td>Governance Paper document (update) - (Anneke Schmider to lead)</td>
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**14:55 – 16:15**

5. Review of Project Plan

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<tr>
<td>The Project Plan must be updated as tasks are completed and new decisions are made.</td>
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<td>Three concrete items do not change</td>
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<td>ICD-11 must meet the needs of Member States in terms of statics, clinical use, etc.</td>
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<td>ICD-11 should have a sustainable model for development, implementation, and maintenance (e.g. a business model)</td>
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<td>A key driver of ICD-11 is improvement in health information implementation in 2018 and beyond</td>
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<th>5.2. Key Discussion</th>
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<td>There are different opinions on the level of details that should be included in the project plan. Some prefer extensive detail so everything is clear, while other prefer less detail so things are straightforward and one does not get lost.</td>
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<td>Review of progress: a line-by-line review of the completeness of work tasks that were planned for delivery in 2015.</td>
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<td>From a JTF perspective, which items are on the work list, and should this be a separate workstream?</td>
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<td>There are overlaps with Mortality and Morbidity to be managed</td>
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<td>JTF will not go into the area of traditional medicine, but may consider the impact on data if use of the TM chapter in the JLMMS is made optional</td>
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<td>Testing is a major question for the next phase of work, including:</td>
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<td>What is actually meant by “testing”? What all is being tested, how, and who will do it?</td>
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| How much review / testing is needed, and in what areas? As there may be a time shortage,
what is the essential minimum that must be done before 2018 vs. what could be completed afterwards?
- Definitions could be tested now
- Structure is more difficult as it is still changing
- Index and coding tool could also be tested now
- Chapters must be prioritized, as it is unlikely that all 27 chapters could be completed in one year
  - Chapter 1 should be first, as soon as it is done in terms of structure, inclusions, exclusions. In particular, test post-coordination and determine if the content can be used in terms of the rules.
  - Each chapter should also be accompanied by a list of “known / systemic issues” to make testing more efficient
- There are two streams of work with regard to testing; Fixing the content, such as definitions and testing the structure

5.3. Action Items
- **Project Plan document (update)** - *(Anneke Schmider to lead)*
- **Review and Testing Strategy document** - *(Robert Jakob to lead)*
  - Include 1-page Executive Summary for Member States
  - Also include a concrete action plan for how testing will proceed and what will be accomplished
  - Accompanied by a task list outlining what has been done, and what must be done, in each individual chapter
- **ICD-11 Revision Stocktake document** - *(Robert Jakob to lead)*
  - Include work completed to date and plans for future work
  - Also include known gaps and issues

**16:15 – 16:30**

6. Face to Face Meeting of the JTF

6.1. Background
- It would be useful to have another face to face meeting of the JTF in Tokyo as a part of the WHO-FIC Network Annual Meeting, but also to have one in the first half of the year to progress the work and to prepare for the meeting and the Revision Conference.

6.2. Key Discussion
- An agenda is essential before dates can be identified
- WHO is requested to accommodate for other, related meetings already on the calendar.
- A key focus of the agenda should be the “package” of information for the October Revision Conference.
- At present, several costings have been done, but WHO is not yet aware of available funding.
- It may be possible to host the meeting in Cologne, Germany at DIMDI, which might be a more cost-effective option than Geneva.

6.3. Action Items
- Investigate the possibility of hosting at DIMDI - *(Dr Stefanie Weber)*
- Determine availability for a meeting in the first two weeks of April - *(Molly Meri Robinson Nicol)*
- WHO will investigate possible sources of funding, or of participants’ ability to self-fund and will prepare additional costings based on the new information. - *(Anneke Schmider & Molly Meri Robinson Nicol)*
7. WHO-FIC Network Annual Meeting 2016 / ICD Revision Conference Schedule

7.1. Background

- A tentative DRAFT Theme may be: Health information in the new age: ICD Revision Conference
- Current conversations are ongoing with the local hosts, and a venue with floorplans has been identified

7.2. Key Discussion

- JTF is slated to have 1 full day of meetings, but it may be better to split the sessions across two days to allow for some work time
- Scheduling is difficult with requests that JTF not overlap with URC, mbTAG, mTAG, or MRG due to conflicts with membership, nor with MRG, mTAG, FDC, fTAG, or FDRG due to conflicts for the secretariat.
- The Wednesday schedule, with opening session and social event, is non-negotiable, as this is a shared day and certain individuals (e.g. the Emperor of Japan, WHO DG, etc.) have already been invited.
- JTF members and WHO should not plan to use this day as “preparation” for the Revision Conference out of respect for the meeting hosts.
- It may be possible to either cut or move the poster session(s), and/or to decrease further the amount of time the Council has, including plenary sessions.

7.3. Action Items

- WHO will determine if Japan will host a “local session” during the WHO-FIC meeting, as is typically done. Further options will be investigated for scheduling. - (Anneke Schmider & Molly Meri Robinson Nicol)

10:00 – 11:30 / 12:00 – 14:15
8. To-Do List

8.1. Background

- The “to do list” has been an underpinning task list for JTF work since inception, but there are currently multiple lists in more than one format. It would be better to have a single list that can be maintained and updated easily by all parties necessary in a single, easily accessible location.
- At present, there is one list maintained by WHO with input from the JTF co-chairs which is quite detailed, and a separate, more high-level “to do list”.

8.2. Key Discussion

- More detailed discussion was captured in the “notes” column of the to-do list.
- Key topics and tasks discussed included:
  - **Definitions**
    - Dr Stefanie Weber questioned whether or not definitions were needed for all codes and, indeed, if definitions are desirable
    - Those codes missing definitions should be scanned to determine which are the priority for definition completion
    - Those definitions which are of poor quality should be deleted to ensure that the quality of the classification, as a whole, is not called into question.
  - **Stable Code Values** -
    - At what point will the codes in the output stop changing daily? Can this be done before 2018 to support testing?
  - **Exclusion Notes**
    - More than 3000 have been evaluated, and the work is still ongoing
The “type” of exclusion can be identified in iCAT, but at present, the types are not represented in the browser or other outputs

- Terms and Naming
  - “JLMMS” is quite an awkward title, and should be re-discussed. If a new name will be used, it should be determined well in advance of the Revision Conference.

- National Linearizations
  - Previous decisions about who will manage these and how the process will work may be revisited and reconceptualised.

- Testing
  - As mentioned above, a new testing strategy should be developed with information about how to test, including extensions and the sanctioning rules on how to use them

- Foundation and Other items
  - At present, JLMMS is the focus and other components will be addressed later in the process

- Extension Codes
  - The majority is quite good and complete, but the list is not yet implemented in a usable way in the coding tool or browser.
  - There are known issues with the substances and histopathology lists
  - The import of the anatomy list into iCAT has been problematic.

### 8.3. Action Items

- **ICD-11 Definitions: Status and Plan document** - (Robert Jakob to lead)
  - Include a review of definitions, advisability of retaining definitions, options for how definition review / development should proceed, and feasibility considerations in light of timelines and available resources

- **WHO will investigate updating the ICD-11 Browser and Coding Tool to display “exclusion type(s)”** - (Can Celik)

- **Linearization Naming Conventions: JLMMS document** - (Dr Stefanie Weber & Dr James Harrison)

- Reiterate the desirability of an executive summary as a part of the Review and Testing Strategy document

- All JTF Members will be requested again to read the Volume II Update before the proposed JTF meeting in April 2016 in preparation for detailed work in the meeting
  - **Volume II Morbidity Rules document** (update) - (lead by Donna Pickett, with Ulrich Vogel, and Anne Elsworthy)
  - **Volume II Mortality Rules document** (update) - (lead by James Eynstone-Hinkins, with Stefanie Weber, & Robert Anderson)

- **JTF April Meeting Agenda document** - (Anneke Schmider & Molly Meri Robinson Nicol)
  - Suggested agenda items include: Vol. II, Linearization Naming Conventions: JLMMS document, ICD-11 Business Model document, Shoreline document, Content issues, ICD Revision Conference, Implementation support requirements, the JTF WHO-FIC Network Annual Meeting Agenda document

### 9. Fit for Purpose

#### 9.1. Background

- WHO has committed to the idea that ICD-11 will be “fit for purpose”, but this can mean different things in different contexts. For the JTF, what is required for the JLMMS to be fit for purpose?
9.2. Key Discussion
- What exactly is meant by “fit for purpose”? Is this something that should be asked of the JTF? Is the old “purpose document” still valid and useful? How does one get there?
- Co-Chair Recommendations. Focus on:
  o **Content** – this is the most important thing. Both the text, and the structure.
  o **Vol II** – use of the classification
  o **Sanctioning Rules** – fully outline the model for implementation and use and, at minimum, prepare a few key examples of where and how to use them. It is unlikely that the Sanctioning Rules will all be done by 2018, in which case WHO will need an appropriate caveat for WHA to consider.
  o **Testing** – prepare the status (including the definition paper) for April
  o Update the **Project Plan** as of Jan 2016, including changes outlined above

9.3. Action Items
- JTF Co-Chair Recommendations document - *(Dr Stefanie Weber & Dr James Harrison)*

### 10. Shoreline Doc

10.1. **Background**
- The document is still in drafting, with the most current version as of 11 January 2016.
- At present, one “header” has no accompanying text

10.2. **Key Discussion**
- The document (and all JTF documents) should have a date and a version number
- The shoreline document should also have a cover note that says that it is a JTF document that originated with James Eynstone-Hinkins, the JTF Co-Chairs, and WHO, and is now provided to JTF members for feedback.

10.3. **Action Items**
- **Shoreline** document (update) - *(Dr Stefanie Weber)*
  - The **Shoreline** document will be shared with the JTF in preparation for the 21 January 2016 teleconference - *(Molly Meri Robinson Nicol)*
11. Closing with Director, IER, Dr Ties Boerma

11.1. Background
- The meeting to date has been very productive.
- Outcomes and recommendations will be drafted and shared.

11.2. Key Discussion
- Co-Chairs have a list of recommendations that will be sent to WHO / Director. These include:
  - A need to focus on content, both the text and the structure in which the text is organized. This will be the largest body of work and key priority for the next 1.5-2 years.
  - Limited time and resources may require reconsideration of some of the “new” things in the content model, such as diagnostic criteria.
  - A request for a status report (ICD-11 Revision Overview) of the JLMMS for the proposed April JTF meeting to allow the JTF to give informed recommendations on essential areas of focus, and feasibility, as well as on non-essential or non-immediate components.
- Sanctioning Rules
  - Although very important, the priority level for Sanctioning Rules is slightly lower than for content.
  - Completing all rules by 2018 is impossible given limited time and resources, and it is suggested instead to have a concrete model for implementation and use by 2018 with specific examples.
  - A large amount of work has already been completed is recognized, but it is only many thousands out of the possible 100,000+ necessary to be considered “complete”.
  - The machine-readable format the Sanctioning Rules are currently prepared in is not sufficiently “human reader user friendly”
- Testing
  - Testing is lower priority than content or sanctioning rules, and can be downsized from earlier proposals.
  - The JTF Co-Chairs request an updated Review and Testing Strategy document with clear guidelines for implementation for the proposed April meeting to allow sample testing of a single chapter. This can be used to inform the process that may be planned for 2017.

11.3. Action Items
- Reiterate the desirability for a Review and Testing Strategy document
- JTF Co-Chairs Planning Meeting Report document - (Molly Meri Robinson Nicol)
- JTF Co-Chair Recommendations document - (Dr Stefanie Weber & Dr James Harrison)
Annex 1 – Co-Chair Recommendations (received after the meeting)

Planning Meeting: A primary goal of the planning meeting was to ensure a common understanding of the work to be done and how we will do it given the large volume but short timeline and limited resources. Conclusions and recommendations from the meeting included:

• **What WHO is expected to deliver to the WHA, with the JTF’s assistance** – A classification suitable for international mortality and morbidity statistics which:
  i. builds on and has substantial backward comparability with ICD-10;
  ii. differs from ICD-10 where justified by new knowledge, changes in mortality or morbidity and changed user requirements, and in order to remedy technical deficiencies in ICD-10;
  iii. is developed in a way that responds to and takes advantage of developments in information technology so as to facilitate its use and maintenance;
  iv. is designed to be, or to be a suitable basis for, clinical modifications that may be developed by some Member States;
  v. is expected to be accompanied in future by specialist classifications, based on the same foundation and designed to serve special purposes.

• **The state of development that is essential before submission to the WHA** —
  i. The list of stem codes must be complete and coherent. This implies that ‘shore-lining’, related structural work, content reviews and responses to them are complete.
  ii. The extension codes to be included in this classification must be specified.
  iii. Certain fields in the content model [to be specified] must be complete for the categories in the list of stem codes and for the extension codes.
  iv. Rules must have been specified on which stem codes may, must, and may not be combined with other stem codes and extension codes.
  v. Coding rules for the mortality and morbidity use cases must be complete.
  vi. An electronic index must be available. This must cover all stem terms; it might not yet cover sanctioning rules and post-coordination.
  vii. The classification has been documented (i.e. ‘Vol II’);
  viii. A plan for implementation has been written.
  ix. Some testing has been conducted.

• **The critical component is the content** – both the codable entities and the information associated with each one, and the structure in which they sit.

Sanctioning rules are also very important, but slightly lower priority than the content. What is critical is to ensure we have a clear model and instructions on implementation as well as a functional demo with key examples, such as for a complete chapter or block.

• **The content model is lower priority.** These are not complete across the entities, and not all are of an acceptable level of quality. The JTF may need to consider which parts of the CM are essential for the JLMMS version that will be presented to WHA, recognizing that others can be completed after 2018.

• **Testing is also lower priority.** This was historically done after WHA rather than before, and JTF and WHO should plan for a more modest amount of pre-testing than was suggested earlier, with more testing afterwards, as needed.

• **Communication is key.** Better communication is needed both inside the JTF and with the wider network, revision, and stakeholder groups. The GoogleDocs site has worked well, and this should continue (or something similar).

• **Prioritization is essential.** The task of getting a usable JLMMS out in time for WHA 2018 is only just achievable, and then only if work is very efficient – no spinning wheels or re-hashing decisions once made. Focus must be on essential tasks, and there isn’t latitude for dealing with additional crises that might arise.