**List of Participants:**

<table>
<thead>
<tr>
<th>WHO Participants:</th>
<th>JTF Members:</th>
<th>Observers:</th>
</tr>
</thead>
</table>
| ☑ Ties Boerma  
(apologies) | ☑ James Harrison  
(apologies) | ☒ Solvejg Bang |
| ☒ Lindy Best | ☒ Stefanie Weber | ☒ Robert Chalmers |
| ☑ Can Celik  
(apologies) | ☒ Christopher G. Chute | ☒ Richard Madden |
| ☒ Robert Jakob | ☒ Robert Anderson | ☒ Ayano Otsubo |
| ☒ Nenad Kostanjsek | ☒ Lars Berg | ☒ Yukiko Yokobori |
| ☒ Colin Mathers  
(Monday, only) | ☒ Vincenzo Della Mea | |
| ☒ Lori Moskal | ☒ Vera Dimitropoulos | |
| ☒ Molly Meri  
Robinson Nicol | ☑ Anne Elsworthy  
(apologies) | Additional Discussants: |
| ☒ James Eynstone-Hinkins | ☒ William Ghali (MbRG Co-Chair) | |
| ☒ Jenny Hargreaves | ☑ Francesco Grippo (MRG Co-Chair)  
(apologies) | |
| ☒ Kaori Nakayama | ☒ Olafr Steinum (MbRG Co-Chair)  
(T&W, only) | |
| ☑ Emiko Okawa  
(apologies) | ☒ Naoko Tajima (MSAC Co-Chair) | |
| ☒ Donna Pickett | ☒ Kees Van Boven  
(Monday, only) | |
| ☒ Martti Virtanen | ☒ Ulrich Vogel | |
| ☑ Patricia Wood  
(apologies) | | |
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1. Member State Feedback

1.1. Member State Consultation

- WHO sent the Circular Letter inviting Member States to provide feedback to WHO on 23 January 2017. The deadline for feedback was extended to 30 June 2017 given the delay in sending the letter.
- Member States were invited to provide free-text responses to the generic WHO email inbox
  - 1. ICD-11 Advances:
    - Chapter Updates – including new approaches for cancer, diabetes, hypertension, maternal conditions, dementia, injuries, accidents, and infectious diseases.
    - New Data Options – including the additional coding options for anatomy, histopathology, causal agents, laterality and severity stage; as well as the new chapter for traditional medicine diagnosis.
    - Improved Breadth and Depth of Information – including the use of extension codes or through clustering entities to provide more detail as well as the possibilities for production of different versions that present the diseases from the perspective of a single specialty.
    - ICD-11 Multilingual Features – including the new translation platform.
  - 2. ICD Implementation Needs: country implementation needs, recognizing that better data will be delivered in a modern electronic environment.
  - 3. Data Priorities: In relation to ICD-11 finalization, WHO is seeking comments on future data priorities from Member States, noting even stronger demand for quality country mortality and morbidity statistics at national level.

1.2. Key Discussion Points

- Mechanism for incorporating Member States and role of JTF in this, needs to be clear

1.3. Recommendations

- WHO & JTF – will be working to address the MS feedback at the next face to face meeting of the JTF.

2. Timelines

2.1. Background

- WHO presented the timelines proposed for the work between now and the end of the year.
- The deadlines for the Quality Assurance phases are as follows:
  - Pilot Testing (Phase 1) will be completed by 28 February 2017
  - Structural Integrity quality assurance (QA) (Phase 2) will be completed by 31 May 2017
  - Special use QA (Phase 3) will be completed by 30 September 2017
- These deadlines will allow for the following release versions:
  - The frozen version for quality assurance is released on 31 March 2017.
  - A prefinal version will be released by 30 November 2017. That can be used for information of WHO Governing Bodies, as necessary.
  - The final version will be released in the first half of 2018

2.2. Key Discussion Points

- Education materials should be available during the commenting phase, for Member States that may be new to ICD-11.
- The QA version of ICD-11 will be available for use also from the Field trial platform (FIT).
Past feedback had been submitted in different formats, rather than through the established proposal platform. All feedback received so far will be addressed in the 31 March 2017 version as much as possible. The carry-over would remain to be incorporated in the November 2017 release version.

JTF members agreed that, in future, all comments and submissions must be submitted through the proposal platform. The mechanism will not always result in immediate reaction, but it ensures transparency, and changes can be processed, ensuring that no proposals are lost or overlooked.

JTF members agreed that this applies to all requests for change, including those advocacy efforts that have targeted WHO, JTF, and others involved in the revision. All should be directed to submit their proposals, including rationale, through the platform.

Member States will submit feedback in the format they feel appropriate. While respecting the rules that govern WHO, changes arising from this feedback may also be processed through the proposal mechanism.

The Structural Integrity protocols will be a continuation of the line coding exercises which are already underway but with an additional focus on the priority areas identified. In this way, the short time (two months – April and May) is believed to be sufficient for this part of the quality assurance.

The deadlines will target ‘priority areas’, acknowledging that other work will remain necessary after this time. The November release should include that information as a caveat.

2.3. Recommendations

- JTF – consider suggestions for increasing WHO capacity given current resourcing constraints.
- WHO & JTF – direct all authors submitting proposals to ICD-11 to submit requests for change via the WHO ICD-11 Proposal Platform (http://apps.who.int/classifications/icd11/browse/proposals/f/en#/).
- WHO – consider wording associated with deadlines to manage expectations of external stakeholders.

3. Taxonomy Principles

3.1. Background

- WHO presented a brief outline of the current general guidelines for changes in ICD-11

3.2. Key Discussion Points

- JTF members complimented the clarity of the document and agreed that it should be helpful in supporting discussion and decision making during the meeting, particularly when discussing content issues.
- It was suggested to change the name of the document to “guiding taxonomy principles”.
- It was confirmed that the guiding taxonomy principles in the document are presented in priority order.
- It was noted that on the list of ‘special chapters’, the Neoplasms chapter is missing.
- It was recognised that application of the rules is difficult where ICD legacy is inconsistent, and it is necessary to balance ‘correcting’ the publication with the needs of the primary users – the statistical community.
- It was suggested that the language of the text could be amended:
  - Aetiology is the most important guiding principle, and items are classified by this principle, first.
  - Organization by body system is the second most important guiding principle, and is used in situations when the aetiology is unknown or where there can be multiple aetiologies for the given condition.
  - Exceptions to the above may be made in cases of expediency (such as to keep similar conditions grouped together, regardless of aetiology or body system) or to accommodate for legacy requirements, when necessary, as data continuity is also a legitimate consideration in the ICD-11 MMS.
- The JTF acknowledged that legacy ICD was has some inconsistencies in the tabular list. Given the history of ICD use and the requirements for consistent data over time, it is not possible to make all of the corrections
• It was clarified that ‘strong rationale’ for changes is defined by WHO.
• It was confirmed that it is necessary to have a list of guiding principles on decision making, particularly in light of competing groups advocating for decisions to be made in different, often conflicting ways.
• The JTF suggested that this paper should be widely disseminated, particularly during the quality assurance phases, so individuals understand that identifying a difference of opinion or preference is not the same as identifying an error, and that rationales for changes must be stronger than an opinion.
• The JTF agreed that it should be made clear, that any provider may use a code from any chapter. This appears necessary as there are some professions or advocates who appear to have the mistaken impression that a given profession or specialty ‘owns’ a specific section or chapter, and that they may not be permitted to use a code that is not in ‘their’ chapter.

3.3. Recommendations

- Jenny Hargreaves – Clarify the language for authoring rule 3 and its sub points and submit to WHO
- WHO – Include an introductory note to the text which clarifies that chapters do not correspond to specialties; and add a note explaining that the rules are in order of priority
- WHO – Change the wording of the paper to clarify that ‘rules’ are better termed ‘guiding principles’
- WHO – Add the Neoplasms to the list on page 3 of special groups chapters
- WHO – Widely disseminate the final document, particularly to ensure it is available for quality assurance participants.

4. Interim Proposal Review

4.1. Backgrounds

- WHO provided an update on the number of proposals received and those that have been actioned. In particular, it was noted that 237 proposals have already been received in the first seven weeks of 2017.

Between 1 July 2014 and 14 February 2017:
  - 8479 proposals have been received
    - 2082 in 2014
    - 3075 in 2015
    - 3085 in 2016
    - 237 so far in 2017
  - Of these
    - 5736 have been actioned
    - 1549 have been rejected or are non-applicable
    - 67 are in queue waiting for additional feedback from the author, the TAG, or another respondent
    - 890 remain to be actioned (those received up to December 31 2016)
    - 237 are pending, having been received after the 31 December 2016 deadline
  - Proposal have been submitted in the following distribution
    - 767 proposals to Add New Entity
    - 543 proposals to Delete Entity
    - 5471 proposals for Content Enhancement
    - 1698 proposals submitted as Complex Hierarchical changes

- These numbers will inform discussion about future maintenance, both to look at the volume of proposals and the frequencies of proposals by type.

4.2. Key Discussion Points

- Proposals may have come from individuals not familiar with ICD, its purpose, and how it is organized. It was confirmed that some proposals of this type have been received and are being responded to.
  - The JTF agreed that responses to such proposals should make it clear that WHO cannot and will not consider or accept such proposals.
4.3. Recommendations
- WHO – prepare a breakdown of the proposals still pending by type for the next JTF teleconference
- WHO – continue actioning proposals

Additional Meeting Briefings

5. Primary Care

5.1. Background
- Primary Care task force members met with WHO in Geneva from 9-12 January.
- The meeting worked through 8 ICD chapters, solved many incongruences in structure. It will not always be possible to maintain the ‘telescopic approach’.

5.2. Key Discussion Points
- PC taskforce suggested that ICPC3 will be a linearization drawn from the ICD-11 Foundation, but that it will not be a fully telescopic linearization.
- A primary care linearization from ICD-11 will be larger than the current ICPC

5.3. Recommendations
- WHO – continue to work with the Primary Care working group to support their requirements and report back at next JTF meeting

6. Quality and Safety

6.1. Background
- Quality and Safety TAG met with WHO in Geneva from 9-10 January 2017.
- Postprocedural complications were discussed.
- ‘Grafts and implants’ were added to the section on devices chapters 22 and 23.
- The meeting also suggested a change in language from ‘harmful effect of or exposure to’ to ‘harmful effect of substances’ to clarify that exposure may not always result in harmful effect.
- Quality Assurance currently being done at the University of Calgary in which charts including adverse events are being reviewed to test the ability to code using the ICD-11

7. Neurology

7.1. Background
- A meeting was held on 24 January 2017 with representatives from the former Neurology TAG and internal WHO staff.
- Diseases of the nervous system chapter was reviewed during the meeting of the JTF, held in July 2016 in Queensland, Australia.
- At that time, many of the questions and identified issues were addressed, but there remain several important issues still pending. The specifics of these issues will be reviewed in the context of the Content Issues discussions.
- One specific issue highlighted by WHO includes a re-building of the section of codes including Human Prion Diseases, where there are differences of opinion on the ideal location for primary parenting, the

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1 meeting report available here: [http://who.int/classifications/icd/revision/2016.07.11-14_iSummaryMeetingReportQueensland.pdf?ua=1](http://who.int/classifications/icd/revision/2016.07.11-14_iSummaryMeetingReportQueensland.pdf?ua=1)
exponential increase in codes in the chapter due to extensive use of precoordination, and the outstanding work needed in some areas such as epilepsy and seizures.

- Regarding the increase in codes, WHO confirmed that the meeting participants have been requested to review the precoordinated concepts to advise on the relevancy of including each as a precoordinated, independently codable entity in ICD-11 MMS.

7.2. Key Discussion Points
- The JTF was satisfied with the report, and will examine the specific issues more closely in the context of the Content Issues discussions.

7.3. Recommendations
- WHO – follow-up on the meeting with regard to moving some precoordinated concepts ‘below the shoreline’ to address the issue of granularity within the chapter.

8. Dermatology

8.1. Background
- WHO reported that a meeting was held on 30 January 2017 with a representative from the former Dermatology TAG to review several areas of the Diseases of the skin chapter.
- In particular, WHO highlighted that the meeting recommended retaining Adverse cutaneous reactions to medication in the Diseases of the skin chapter with instructions to post-coordinate the concepts as proposed by the former Quality and Safety TAG members.

8.2. Key Discussion Points
- The JTF was satisfied with the report and made no specific recommendations.

9. Cerebrovascular Diseases, including Stroke

9.1. Background
- A meeting was held on 21 December 2016 with representatives from the former Neurology TAG to discuss primary parenting of the section of codes on cerebrovascular diseases.
- This will be discussed later in the meeting.

9.2. Key Discussion Points
- The JTF was satisfied with the report, and will examine the specific issues more closely in the context of the Content Issues discussions.

10. Neurology (on Dementia)

10.1. Background
- WHO reported that a meeting was held with representatives of the former Neurology TAG and former Mental Health TAG to discuss primary parenting of the section of codes on Dementia.
- WHO confirmed that this will be discussed further in the context of the Content Issues agenda items.

10.2. Key Discussion Points
- The JTF was satisfied with the report, and will examine the specific issues more closely in the context of the Content Issues discussions.
11. Rehabilitation 2030

11.1. Background
- WHO reported that a meeting was organized by the WHO team on Disability and Rehabilitation to discuss the development of a Rehabilitation Research Agenda on 6-7 February 2017.
- ICF and the inclusion of Functioning Properties within ICD-11 were presented. There was interest in how this could be used and when ICD-11 MMS would be available.

11.2. Key Discussion Points
- The JTF was satisfied with the report and requested access to the meeting report, once available.

11.3. Recommendations
- 

12. War Operations

12.1. Background
- Concerns have been raised by the WHO statistical technical unit:
  - The expanded code set related to Operations of War is not mutually exclusive.
  - Significant additional detail has been added
    - The 10 codes available for use in ICD-10 have been expanded to approximately 171 codes related to conflict deaths in ICD-11. The related WHO unit has questioned the need for such an expansion, and if increasing the burden necessary to use the codes would result in improvement of the information collected and the related statistics
  - The split between military and civilian personnel is not applied consistently through the section and may not be the most important or most relevant consideration, at least not at the international level. It was suggested that this information could be better collected through other mechanisms, such as on the death certificate or through the military service record, rather than including such status in the code. The WHO statistical unit suggested that if, indeed, this is a necessary distinction, that combatant vs. non-combatant might be a better distinction than specifically identifying the person as being an active duty member of an official military.

12.2. Key Discussion Points
- The code titles should be changed to say ‘war and armed conflicts’
- The expansion comes from the morbidity use case, which was overshadowed by the mortality use case in ICD-10.
- The Injuries and External Causes TAG considered the needs for ICD-10-CM when developing the expansion and that some of the additional codes are consistent with that model. An example of this included the ability to code injuries due to abandoned land mines after the conflict has ceased. The United States is collecting data using this model and this might help to inform review. This data is not yet available.
- Some of the modelling is based upon the Uppsala database of conflict deaths.
- Inclusion criteria in each category and at the block level will clarify the distinction between similar categories
- Definitions (descriptions) are particularly important in areas where the category is not clear. Such help may not be necessary everywhere, but Operations of War is one location where such guidance could be particularly useful.
- Distinction is necessary between homicide (individual motive) vs conflict death (collective violence for a collective purpose).
- Identifying the difference between ‘assault’ vs ‘collective intent can be difficult given that, for example, homicide can still occur while collective violence is ongoing, either coincidentally or opportunistically.
• Pre- and post-coordination mechanisms might help to allow for greater detail in countries where it is possible to collect such detail, while not setting the barriers to implementation too high for low resources countries.
• The TAG had preserved the top levels of ICD-10 in ICD-11, because they had already been reorganized between ICD-9 and ICD-10
• Summary
  – The JTF agreed that there appeared to be some overlap and ambiguity in this section of codes
  – The JTF recommended that the categories currently represented in the ICD-11 MMS do need to undergo review, and some specific issues addressed as identified in this discussion
  – The JTF recommended that a working group including Colin Mathers, Donna Pickett, and James Harrison, among others, meet together to complete an initial review
  – The JTF recommended that the ICD-11 MMS should take care to avoid new terms or definitions that might cause political or other complications at international level. Specifically, national concerns should continue to be addressed in national clinical modifications, though be included in the ICD-11 Foundation, as well, of course.

12.3. Recommendations
• JTF Workgroup – Review the inclusion and exclusion notes on each category
• JTF Workgroup – Review the definitions (descriptions) in line with the discussion summarized above
• JTF Workgroup – Review the level of granularity in line with the discussion summarized above, including recommendations for items that can, instead, be postcoordinated

13. Primary Parenting of Cerebrovascular Diseases, including Stroke

13.1. Background
• The document prepared by the WHO NMR team was shared before the meeting, and the report of the meeting between WHO, Stroke society, Neurology Society, and JTF.
• In ICD-10, cerebrovascular diseases were classified in different areas, including in different chapters, based on decisions made at that time.
• In ICD-11 MMS, it has been long agreed that these related conditions should be classified together in one group (even if subsets of the group are also secondarily parented elsewhere) to reflect updated scientific perspectives.
• It is generally agreed that the group of cerebrovascular diseases, as a whole, can and should be multiple parented into both the ‘Diseases of the circulatory system’ chapter and the ‘Diseases of the nervous system’ chapter, though there are different opinions on which chapter should be the ‘primary’ chapter.
• It should be noted that the ‘primary’ parent represents the location from which the automatically generated code is derived, and is primarily used for statistical aggregation. The new concept in ICD-11 to have one or more ‘secondary’ parents is often misunderstood.
• Given this, as well as the guiding taxonomy principles that have been discussed earlier and again in this meeting, a previous recommendation of the JTF was to primarily parent the section of codes on cerebrovascular diseases, including stroke, in the circulatory system chapter, consistent with where it was solely parented in the past.
• WHO and the JTF have received a request to revisit the decision again, however, and have been provided with additional information for consideration.

13.2. Key Discussion Points
• From a clinical point of view, the wish to move CVD to the ‘Diseases of the nervous system’ is understandable
• Location in ICD is irrelevant for DRG or delivery of treatment
• New available treatment for stroke is an argument for the move
• Epidemiologically they are seen as vascular, but other cerebrovascular conditions are in other places, e.g. vascular dementia
• There was a ‘stormy discussion’ (Morayama) resulting in the move in 1955 for ICD–8
• The concept of ‘neurovascular unit’ is an argument in support of a move of the CVD to the ‘diseases of the nervous system’
• Vascular dementia should be located close to the stroke
• The logic around ‘infections of the nervous system’ suggests to move strokes to the nervous system chapter
• The aspect of perception by decision makers is important
• In view of the high public health importance, it is important to ensure best possible position in the classification
• **Summary**
  – This is a topic of very high Public Health importance, and it is clear that it is important that patients get the best possible treatment.
  – It is not clear that the treatment will be effected by the chapter from which the condition draws the code, negating this reason as a rationale for change.
  – The argument for updated aetiology is questionable or weak
  – The JTF would not oppose moving CVD to the chapter ‘Diseases of the nervous system’ on condition that new evidence will be presented. However, the final recommendation has to come from WHO and point to the ‘Guiding Principles’

### 13.3. Recommendations

- **WHO & JTF** – Evaluate the guiding taxonomy principles to ensure that the nuances understood in the context of this discussion are correct
- **WHO and JTF** – Consider the evidence provided for an updated aetiology of cerebrovascular diseases, including stroke
- **WHO** - clarify for the neurology community, and other medical disciplines that chapter borders are not defining areas of work of medical specialties.

### 14. Primary Care Questions

#### 14.1. Background

- There is a need for some additional Primary Care codes
- The residuals in primary care may differ from ICD-11 MMS, in case different siblings are included.
- The Primary Care linearization/tabulation requires a higher level grouping in some instances, such as neoplasm of the intestine

#### 14.2. Key Discussion Points

- Primary Care grouping codes in the ICD-11 MMS, could be marked with a ‘P’ or some other marker to denote that these were Primary Care codes different from similar ones in the ICD-11 MMS.
- Any prefix or suffix used with the codes to denote a difference in any linearization/tabulation could make codes very long, and add a layer of complexity for users of the classification and the data.
- MMS codes should be used in any specialty linearization/tabulation; Any entity can be identified through the use of the URI, whether or not that specialty linearization/tabulation uses a different code structure.
- If the residuals are different, they must have different codes and maybe titles. Merely marking them with a ‘P’ or equivalent prefix or suffix would not be sufficient.
- Using the same MMS codes in the Primary Care specialty linearization/tabulation if the content is not the same, is not recommended.
- Using similar codes to the extent possible to facilitates use, but the coding scheme between the ICD-11 MMS and the Primary Care specialty linearization/tabulation should be different if the mapping of overlapping codes will not be a complete one-to-one map.
- This principle would apply to all specialty linearizations/tabulations and not just the one for Primary Care.
• Linearizations/tabulations should, ideally, follow the telescopic principle and the ICD-11 MMS code structure, when possible.
• An ICD-11 Primary Care specialty linearization/tabulation is within the context of ICD-11, and there will be concepts, like procedures, that are not part of ICD, but part of the International Classification of Primary Care (ICPC)
• Avoid mixing two sets of data with information that does not mean the same thing
• Avoid complications and challenges for users who might face a requirement to use two different specialty linearizations/tabulations.
• The ‘marker’ identifying the linearization/tabulation being used could exist on the back-end, mitigating the confusion for users while guiding electronic records systems to not mix up the information collected and this could apply to all linearizations/tabulations except the ICD-11 MMS
• **Summary**
  – The Primary Care linearization/tabulation will not be fully telescopic with the ICD-11 MMS
  – The two linearizations/tabulations should use codes that are somewhat similar, e.g. using a linearization/tabulation marker.
  – The Primary Care linearization/tabulation be drawn from the ICD-11 Foundation, meaning that all Primary Care necessary codes be added to the ICD-11 Foundation, ensuring that they are placed appropriately and correctly placed in the index
  – The work on the Primary Care linearization/tabulation will need to continue.

14.3. **Recommendations**

• **PC Task Force** – determine what codes must be added to the ICD-11 Foundation, create the necessary proposals, and implement the changes in the ICD-11 Foundation and the primary care linearization/tabulation

• **PC Task Force and WHO** – consider the issue of a Primary Care ‘marker’ for the codes and propose a solution to the question of code structure for consideration by the JTF either on a teleconference or at a future face-to-face meeting of the JTF. This solution should consider the recommendation by the JTF that:
  – where the Primary Care linearization/tabulation entity is a one-to-one match with an MMS code (including the same content and residuals), there is no need for a ‘marker’.
  – where the Primary Care linearization/tabulation entity is not a one-to-one match with an MMS code, the JTF recommends using something similar to ‘P-#unique code#’

15. **Primary Care Code Titles**

15.1. **Background**

• WHO reported that a previous decision taken in 2012 eliminated the use of ‘slashes’ and other similar punctuation in preferred term code titles.
• Several codes were structured as ‘XX symptom/complaint’ and where therefore changed to ‘Problem of the XX’
• Members of the Primary Care community have expressed an objection to the use of the term ‘problem’ and a preference for a structure of ‘XX symptom or complaint’

15.2. **Key Discussion Points**

• JTF members noted that there could also be an objection to the use of the term ‘complaint’, particularly in translations.
• The JTF recommended that the title structure be changed to ‘Symptom or complaint of XXX’

15.3. **Recommendations**

• **WHO** – Change all relevant titles to ‘symptom or complaint of XXX’
16. ‘Functional’ Gastrointestinal Disorders

16.1. Background
- The GI Working Group introduced many concepts into ICD-11 that were called ‘Functional XXX’, many of which overlapped with existing symptoms (e.g. Heartburn vs. Functional Heartburn).
- Concerns have been raised about mutual exclusivity, as it is not clear from either the title or the definition (description) what the difference is between the paired concepts.
- WHO has asked the fTAG to review these concepts several years ago given the use of the term ‘functional’. The fTAG felt that the term ‘functional’ was misleading and recommended using the term idiopathic if the term accurately represented the concept being conveyed.
- After consulting also with the GI workgroup, WHO came to the conclusion that the term was being used to avoid the term ‘idiopathic’, though the rationale for avoiding that term was unclear.

16.2. Key Discussion Points
- The term ‘functional’ was being used in place of the term ‘idiopathic’. However, when using these terms, it should be clear that the provider did not know the underlying aetiology and that a structural aetiology had been ruled out. This is different than the standard use of the term ‘idiopathic’ where nothing is known about the aetiology at all. For example:
  - Heartburn, as a symptom is idiopathic with no information at all about the aetiology
  - Functional heartburn is also idiopathic, but one particular aetiology (structural anomaly) has been ruled out.
- In other such cases, terminology such as ‘idiopathic’ or ‘after evaluation’ would be used
- The concept is still a symptom.
- When it is possible to identify aetiology, the cause would be coded.
- It is inconsistent with classification use that ruling out one potential aetiology should make the code more specific or justify classifying it in a different chapter of the classification.
- The term ‘functional’ is used differently elsewhere within the classification, and a same term should not be used to represent multiple different meanings.
- It could be possible to use post-coordination to identify the concept of ‘structural anomaly ruled out’

Summary
- The JTF recommends parenting the ‘functional XXX’ concepts within the existing ‘Symptoms, signs or clinical findings, not elsewhere classified’ chapter, either as synonyms or inclusion terms, as appropriate.
- The JTF recommends that due care is taken to ensure that ‘different’ conditions are not accidentally made equivalent in the merge.

16.3. Recommendations
- WHO – Parent the ‘functional XXX’ concepts within the existing ‘Symptoms, signs or clinical findings, not elsewhere classified’ chapter, either as synonyms or inclusion terms, as appropriate.
- WHO – Add an extension code to allow users to post-coordinate the concept that ‘structural abnormality ruled out’. This needs to be aligned with existing concepts of ‘ruled out’, ‘after diagnosis’ and ‘after study’.

17. Acute Coronary Syndrome

17.1. Background
- The Primary Care task force would like to use ‘Acute Coronary Syndrome’ in the PC linearization, but with two of the current ICD-11 Foundation siblings (acute infarction and unstable angina) as children. In the current structure, this would mean that a concept becomes the parent of its own siblings, so a structural edit may be necessary.
• In ICD-11, this concept is included in the ICD-11 Foundation, but is not above the shoreline, and therefore appears as an index term under Ischaemic heart disease.
• URC in 2003 recommended to add the inclusion term ‘Acute Coronary Syndrome’ in ICD-10

Key Discussion Points
• This proposed change would ‘drop’ a leading cause of death, myocardial infarction, down a level or two, in the classification hierarchy - which is not desirable.
• Perhaps, given the earlier discussion on the level of ‘telescopic compatibility’ between the Primary Care linearization/tabulation and the ICD-11 MMS, this might no longer be an issue.
• Clinically, a person does not die of angina in the absence of a myocardial infarction. The myocardial infarction is coded only if it is confirmed. As a result, angina is frequently found on death certificates.
• Acute Coronary Syndrome is a working diagnosis, and if a more specific diagnosis can be made, it should be recorded as such.
• Acute Ischaemic Heart Disease would be a better grouping title than Acute Coronary Syndrome. As an entity with children, Acute Ischaemic Heart Disease would not be codable. However, it could be the ‘leaf code’ in the Primary Care linearization/tabulation, if desired.
• The above solution should be implemented but then evaluated to determine any further implications or issues that might arise.

17.2. Recommendations
• WHO – Change the preferred term from Acute Coronary Syndrome to ‘Acute Ischaemic Heart Disease’ with Acute Coronary Syndrome as an index term.
• WHO – Parent Unstable angina and Acute myocardial infarction under Acute Ischaemic Heart Disease, but do not include the concept in the ICD-11 MMS. This would allow the Primary Care linearization/tabulation to use the entity, but would not ‘drop’ Acute myocardial infarction down a level in the classification.
• WHO – Add a concept called ‘Chronic ischaemic heart disease’ in parallel to the ‘Acute Ischaemic Heart Disease’
• JTF & WHO – Evaluate this decision after it is implemented for further implications of these changes.
• WHO – Include in the next agenda on where to create the concept of ‘Subsequent myocardial infarction’

18. Primary Parenting of Dementia (Revisited on Wednesday, 22 February 2017 – 9:00)

18.1. Background
• The question of where to primarily parent ‘dementia’ has been the subject of passionate advocacy.
• The Neurology TAG and the Mental Health TAG were requested to provide a rationale for their proposal to create a competing overlapping classification of dementia in the chapter ‘Diseases of the nervous system’ and in ‘mental health’
• Following that discussion, it was requested from the above TAGs to formulate a unified proposal and locate it in one of the above chapters.
• Upon suggestion by the TAGs ‘dementia’ was located in the ‘Nervous system’
• This moving of dementia resulted in protests by the psychiatric community.
• The proposal received previously, includes that ‘dementia as a syndrome’ (as opposed to dementia in diseases, e.g. dementia due to Parkinsonism) be in the ‘Mental, behavioural or neurodevelopmental disorders chapter’ while those that are disease-related be in the ‘Diseases of the nervous system’ chapter.

18.2. Key Discussion Points
• One JTF-member objected strongly to having two competing coding schemes and stated clearly that the perspectives have to be merged into a single hierarchy.
From a morbidity perspective, there is rationale for splitting, similar to what is done in drug intoxication (there is a difference between the mental state caused by the drug and the toxicity of the drug that kills the person). From the mortality perspective, confusion may be caused by splitting the concept into two different areas.

Previously, the two TAGs had recommended putting the group of conditions associated with dementia into the ‘Diseases of the nervous system’ chapter, but this proposal overrules that recommendation and suggests splitting the group again.

Grouping the dementia conditions together is consistent with the guiding taxonomy principles. Moving conditions such as Alzheimer disease to the ‘Mental, behavioural or neurodevelopmental disorders chapter’ does not seem to be logical.

Classifying dementia is similar to classifying stroke. The clinical community is in the phase of learning more about the aetiologies of conditions such as Alzheimer disease. However, in dementia, the majority of aetiologies are not known, which makes the decision on the best ‘primary parent’ more difficult than for stroke.

One of the guiding taxonomy principles does state that keeping a group of subtypes together in one location may override anatomical or aetiological conditions, though this is a lower ranking principle than aetiology or legacy. In dementia (at present) 50% of cases are reported ‘cause unknown’. Splitting the dementia group in two chapters, requires that the data be re-aggregated afterwards which may compromise statistical continuity.

The proposal would place the equivalent of ‘unspecified dementia’ or even ‘functional dementia’ in the MNH chapter, essentially making the diagnosis a symptom, which is not a compelling argument.

Where would ‘dementia in Parkinson’s’ or ‘dementia in Alzheimer’, be tabulated - with dementia, or with Alzheimer or Parkinson?

For tabulation purposes, the dementias should still be a group.

Dementia, as it is represented in ICD-10, is too spread, and it is preferred to have all dementias grouped in one place so that coders can better find the conditions in a single block.

There should be just one code for ‘dementia as a symptom’ (not the actual title) with a requirement to post-coordinate this code with the underlying cause, if known.

The JTF welcomes the consistent addition of ‘severity’ to all dementia codes using post-coordination.

Multiple parenting will ensure that the block of dementia codes is represented in all relevant locations in the classification.

The block of dementia codes should be primarily parented into the ‘Diseases of the nervous system’ chapter with secondary parenting to the ‘Mental, behavioural or neurodevelopmental disorders’ chapter.

‘Dementia syndrome’ as a concept would be eliminated.

This is a topic of increasing interest and there is a desire for clear dementia coding.

Chapter borders do not really matter for treatment or specialties, particularly in ICD-11, though also in ICD-10. Placement in one chapter or another does not restrict patients from accessing necessary care.

The JTF agrees that, whenever possible, post-coordination is the preferred option. In the situation of dementia, the JTF recommends to use post-coordination for ‘dementia in diseases classified elsewhere’ + ‘underlying cause’.

– In situations where the dementia is an essential part of the diagnosis (e.g. in Alzheimer disease dementia), such combinations will be precoordinated.
– In situations, where dementia is not an essential component of the disease, such combinations will be post-coordinated (e.g. dementia in Huntington’s, HIV, Lewy Body, etc.)
– Additional exceptions include those codes that Mortality must have precoordinated.

It is proposed to create a group titled either ‘dementia’ or ‘neurocognitive disorders’, the children of which are:

– Alzheimer’s Dementia (representing a merger of the Alzheimer and Alzheimer disease dementia from ICD-10)
– Vascular Dementia
- Dementia in Diseases classified elsewhere (with a sanctioning rule that mandates use of the underlying cause code and including the list of pre-coordinated concepts included in the ICD-11 Foundation, below the shoreline)
- Dementia, Unspecified
- With severity post-coordinated

• A condition in ICD is placed in a certain chapter for epidemiological reasons. The link to any specialty or reimbursement schemes is secondary. In particular, the reimbursement schemes can be adapted easily. Clinical specialties cannot ‘own’ diagnoses.

• Post-coordination to identify the underlying cause of the dementia might result in the loss of some information. E.g. ‘Dementia due to Huntington disease’ reported on a death certificate and coded with two stem codes, may result in loss of the information ‘Huntington Disease’. However, this is may also happen with ICD-10. Only in multiple cause of death coding and analysis, both pieces of information are collected. Continuing this practice might be desirable from a data-continuity perspective.

• The Neurology TAG has been clear in their recommendation that the pre-coordinated concepts (e.g. Dementia due to … X) should remain in the ICD-11 MMS as independently codable entities

• Vascular dementia is a unique case as it could be post-coordinated. However, this is a legacy category, and that it fits the situation above in which ‘the dementia is an essential part of the diagnosis’.

• Referring again to the guiding taxonomy principles, given the rationale provided and within the guiding principles, there is insufficient evidence to move dementia to the ‘Mental, behavioural or neurodevelopmental disorders’ chapter.

• This suggestion would not preclude the creation of a code specific for Alzheimer disease without dementia. However, the Neurology TAG had suggested that Alzheimer disease without Dementia could be coded in a residual category using index terms.
  – Alzheimer disease is more an impairment of cognitive function rather than real dementia, which is an argument for having multiple entities in ICD-11 that are appropriately parented.

• While moving cerebrovascular diseases, including stroke, to the ‘Diseases of the nervous system’ chapter, similar principles should apply to vascular dementia.

• In the future, the clinical community will know more about dementia, and the classification must be prepared to expand the level of detail that can be coded in this area.

• Some statistics will aggregate dementia cases together regardless of the underlying cause, such as for treatment considerations.

• Summary
  – The JTF did not feel strongly about the placement of the block of codes on dementia, but did agree that for statistical purpose they should be grouped together in an internationally comparable way.
  – The JTF suggested that it was not clear from either the guiding taxonomy principles or from the provided rationale why the codes should be moved in ICD-11, compared to ICD-10, so ‘Dementia of unknown aetiology would reside in the mental health chapter, and known aetiologies that cause dementia would remain in the nervous system chapter. Following these rules, there would be even a rationale to move the vascular dementia to the nervous system.
  – The JTF recommends having the possibility to code Alzheimer disease with OR without dementia, both as pre-coordinated concepts. Other conditions in which ‘dementia due to … X’ will be post-coordinated, with the precoordinated concepts included in the ICD-11 Foundation ‘below the shoreline’.
  – The JTF recommends that, for statistical grouping, there should be clear guidance from the classification on how to classify all dementia cases together so that they can be seen the same way, statistically, world-wide. This could be done in the format of a ‘special tabulation list’.
  – The JTF noted a limitation that in mortality data, where the manifestation (dementia) is reported without the cause (e.g. Huntington disease) the manifestation becomes the cause. However, this is a problem of the reporting that can’t be solved by the classification.

18.3. Recommendations
  • WHO – communicate the recommendations to the relevant stakeholder groups.
• **WHO** – implement the solution in line with the final summary recommendations above.

### 19. Infections of the Central Nervous System

#### 19.1. Background
- In ICD-10, infections were scattered across all of the chapters, with inconsistent application of groupings. For example, meningitis was split between the ‘Certain infectious or parasitic diseases’ chapter and the ‘Diseases of the nervous system’ chapter, with some ‘aetiologies’ in one chapter and other ‘aetiologies’ in the other.
- An argument has been made for bringing the infectious diseases together in one chapter, accepting that, for example, all meningitis will be in the ‘Certain infectious or parasitic diseases’ chapter with multiple parenting to the other relevant chapter, even the rare cases in which the aetiology is not infectious.

#### 19.2. Key Discussion Points
- The JTF recalled that a previous decision was made at the Queensland Meeting in July 2016 ([http://www.who.int/entity/classifications/icd/revision/2016.07.11-iSummaryMeetingReportQueensland.pdf?ua=1](http://www.who.int/entity/classifications/icd/revision/2016.07.11-iSummaryMeetingReportQueensland.pdf?ua=1)) to group similar conditions (e.g. meningitis, encephalitis, etc.) together in the ‘Diseases of the nervous system’ chapter, and confirmed that the current proposal is to overturn that decision.
- The primacy of aetiology, is particularly relevant here.
- The principle of the argument above is sound. The guiding taxonomy principles have already noted that aetiology is a primary consideration. However, ‘similar conditions’ are grouped together, for clinical utility or navigation, even if the similar conditions do not share an aetiology or a body system.
- There must be a ‘not otherwise specified’ residual category for each condition (e.g. meningitis, encephalitis, etc.) to accommodate for diagnoses such as ‘meningitis with agent not known’ or ‘meningitis due to unknown origin’ (which could include non-infectious meningitis).
- The issue of ‘how much information is reported’ is relevant. However, documentation will continue to improve.
- Gastroenteritis includes a category for ‘gastritis of unknown origin’ for ‘non-infectious gastroenteritis’.
- The ICD-10 block of ‘Inflammatory conditions of the CNS’ changed to ‘Infectious diseases of the CNS’ in the ICD-11, as part of the earlier decision, and that in that change, only infectious conditions remained parented into that block. When the subsequent decision was enacted, the inclusions were changed but not the title.
- The vast majority of cases with meningitis are considered to be infectious, even if the clinician cannot or does not identify the specific agent.
- A JTF member noted the presence of a block titled ‘disorders of the meninges excluding infection’, which includes pachymeningitis, and suggested that this should also be reviewed.
- **Summary**
  - The JTF suggests maintaining the decision made at the Queensland meeting to primarily parent the block of ‘Infections of the Nervous System’ in the ‘Diseases of the Nervous system’ chapter, correcting parenting errors such as ‘Measles complicated by meningitis’
  - The JTF rejected a suggestion that ‘Meningitis due to Haemophilus influenza’ should be an exception similar to ‘meningococcal meningitis’
  - The JTF reiterated that special tabulation lists may move the block to the ‘Certain infectious or parasitic diseases’ chapter, but that the chapter borders are otherwise less important than they were in ICD-10.

#### 19.3. Recommendations
- **WHO** – consider the JTF recommendation that the block of ‘Infections of the nervous system’ remain primarily in the ‘Diseases of the Nervous system’ chapter, with the exception of Meningococcal...
meningitis, which will remain in the ‘Certain infectious or parasitic diseases’ chapter, primarily parented to the meningococcal conditions

**Tuesday, 21 February 2017**

**20. Primary Parenting of Human Prion Diseases**

**20.1. Background**
- The Neurology TAG has made an argument that not all Human Prion Diseases are infectious, and the group is therefore more appropriately parented in the ‘Diseases of the nervous system’ chapter than the ‘Certain infectious and parasitic diseases’ chapter given the uncertain or inconsistent aetiology.

**20.2. Key Discussion Points**
- The JTF reviewed the concept in the context of the guiding taxonomy principles, and agreed that this was consistent with the principles.
- The JTF accepts the rationale provided, and recommends that WHO move the block of codes including Human Prion Diseases to be primarily parented to the ‘Diseases of the nervous system’ chapter.

**20.3. Recommendations**
- WHO – move the block of codes including Human Prion Diseases to be primarily parented to the ‘Diseases of the nervous system’ chapter.

**21. Changing Chapter Names**

**21.1. Background**
- WHO has received several proposals to change chapter title names including:
  - Changing ‘Mental or Behavioural Disorders’ to ‘Mental, Behavioural, and Neurodevelopmental disorders’ as proposed by the Paediatrics TAG and supported by the Mental Health TAG
  - Changing ‘Diseases of the eye and adnexa’ to ‘Disorders of the Visual System’ as proposed by the Ophthalmology TAG

**21.2. Key Discussion Points**
- JTF members agreed that chapter titles are meant to be meaningful labels, but it is not practical to include a complete list of everything included in the chapter in the title.

**Diseases of the eye and adnexa**
- How might the change to ‘Disorders of the Visual System’ effect other chapter titles, such as ‘Diseases of the ear or mastoid process’
- ‘Ocular adnexa’ is an older term that is no longer in regular use.
- A block titled ‘Disorders of the visual pathways or centres’ is already included in the chapter, as is a block titled ‘Impairment of visual functions’.
- If the chapter title change does not change the border of the chapter, then the change causes less of an issue.
- Since the previous title was narrower than the content, the proposed change would be more appropriate.
- Some chapters are ‘disorders’ while others are ‘diseases’. This raised a question about the definition of the terms. It was suggested that all chapters should be renamed as ‘disorder’ as this is the broader term.
  - The reason for a revision of ICD is to make changes to ICD that could not be done in a regular maintenance cycle. Historically, ICD was for mortality and that many people died of diseases while few died of disorders. Disorder is a broader term that includes diseases and it might be a useful discussion to allow terminology to be updated.
Advocates may argue passionately for the use of term ‘disorders’ or ‘disease’. DSM uses disease as the ‘highest level, most specific conceptualization of a health condition’, whereas disorder / syndrome has a less rigorous criteria for determination.

The decision of using the term ‘disorders’ instead of ‘diseases’ could be discussed later, if needed.

- JTF members noted that ‘Posterior cortical atrophy’ is still in the ‘Diseases of the nervous system’ chapter, and this is a potential duplication that must be corrected.

Mental and Behaviour Disorders
- The Mental Health TAG is supportive of the Paediatrics TAG proposal to include ‘neurodevelopmental disorders’ in the chapter title.
- The renaming could help to mitigate the stigma associated with ‘Mental health’
- There is potential overlap in terms of neurodevelopmental disorders between the ‘Mental and Behaviour Disorders’ chapter and the ‘Developmental anomalies’ chapter that must be addressed.

Recommendations
- WHO - Change the chapter title from ‘Diseases of the eye and adnexa’ to ‘Diseases of the Visual System’
- WHO – add an exclusion for ‘Posterior cortical atrophy’
- WHO – change the chapter title from ‘Mental or Behavioural Disorders’ to ‘Mental, Behavioural, and Neurodevelopmental disorders’

22. Circulatory System Chapter – Pulmonary Hypertension

22.1. Background
- There is a difference of expert opinion on the topic of Pulmonary Hypertension between the members of the former TAG and the external reviewers that were asked to contribute as a component of the JTF review.
- The difference of opinion stems from a paper, ‘Updated Clinical Classification of Pulmonary Hypertension’, developed following the 5th World Symposium held in Nice, France, in 2013.
- In essence, the primary decision that must be made is between:
  - Keeping the existing categories with the Nice classification embedded
  - Removing the pre-and post-capillary distinction and using the Nice classification order
    - Group 1 – Pulmonary arterial hypertension
    - Group 2 – Pulmonary hypertension due to left heart disease
    - Group 3 – Pulmonary hypertension due to chronic lung disease or hypoxia
    - Group 4 – Chronic thromboembolic pulmonary hypertension
    - Group 5 – Pulmonary hypertension due to unclear multifactorial mechanisms
- A subsequent decision to be made relates to the desired and appropriate level of post-coordination in this block.

22.2. Key Discussion Points
- Clinically, the 5-category Nice distinctions are used rather than the pre- and post-capillary hypertension distinction.
- The pre- and post-capillary distinction could be included in the description, if necessary, though that this is a much older, historical distinction which has been superseded by the more specific designation.
- ‘Pulmonary hypertension due to left heart disease’ could be post-coordinated, but that there is an argument to keep the category precoordinated for several reasons including:
  - The entity is a category description
  - This is not a simple question of laterality, as ‘right heart failure’ and ‘left heart failure’ are very different things, and this condition is particularly relevant in the heart.

22.3. Recommendations
- WHO – Reorganize the block to be consistent with the five Nice groups
- **WHO** – maintain ‘pulmonary hypertension due to left heart disease’ as a precoordinated term in the block
- **WHO** – include the pre- and post-capillary distinction in the definition (description) as well as in the inclusion terms

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### Tuesday, 21 February 2017 – 10:07

#### 23. Circulatory System Chapter – Level of Detail for Secondary Hypertension

**23.1. Background**
- ICD-10 had specific codes for secondary hypertension due to renal, renovascular and endocrine disorders. These entities exist in ICD-11 as well, but below the shoreline.
- Based on feedback from German cardiologist review as well as a proposal from Belgium, the codes have been put back into the ICD-11 MMS (above the shoreline).
- How much detail should be included in the ICD-11 MMS and in which situations should ‘Secondary Hypertension associated with XXX’ be post-coordinated?

**23.2. Key Discussion Points**
- In many cases, post-coordination would be the more appropriate option.
- The rationale for increasing the number of pre-coordinated terms that ‘additional detail is needed’, is not a sufficiently strong to make changes to the ICD-11 MMS.
- Post-coordination makes the ICD-11 MMS more simple and clear. Users should become aware that postcoordination is an option and understand how to use it.
- The JTF acknowledged that there will be situations where secondary hypertension is coded without any information about the underlying condition, either because the user did not know because they did not say, and the entity ‘Secondary hypertension’ must therefore remain in the ICD-11 MMS.

**23.3. Recommendations**
- **WHO** – Remove the conditions under secondary hypertension from the ICD-11 MMS so that conditions of ‘Secondary Hypertension associated with XXX’ will be post-coordinated.
- **WHO** – Retain the precoordinated entities in the ICD-11 Foundation, as per standard practice.

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### Tuesday, 21 February 2017

#### 24. Circulatory System Chapter – Proposed Revision of Heart Valve Disease

**24.1. Background**
- In ICD-10, it was assumed that the main cause of heart valve disease was rheumatic fever. The codes for acute rheumatic fever were the first ones in the Circulatory system chapter, followed closely by the block chronic rheumatic heart diseases which included mitral, aortic and tricuspid valve stenosis and insufficiency.
- In ICD-11, the hierarchy has the valve, then the problem (e.g. stenosis), followed by aetiology.
- A proposal from an external review suggests splitting ‘heart valve insufficiency’ into primary and secondary where primary is due to a primary abnormality of the valve while secondary is due to another cardiac disease, such as coronary heart disease or cardiomyopathy. A secondary component of the proposal is to eliminate the rheumatic and non-rheumatic distinction.

**24.2. Key Discussion Points**
- This proposal is a reflection of the more current distinction that can be made clinically.
- Primary vs secondary is not a required component of the diagnosis.
- The proposal for the above is to equate ‘non-rheumatic’ to ‘secondary heart valve insufficiency’ and ‘rheumatic’ to ‘primary heart valve insufficiency’, while concurrently updating the descriptions.
- Historically, valve disease was tough to diagnose and impossible to treat, this is no longer the case.
• There should be a code for ‘rheumatic valve disease’ and another code for ‘other and unspecified’ valve disease.
• ‘Primary heart valve insufficiency’ and ‘secondary heart valve insufficiency’ is not currently noted on death certificates. It could be inappropriate to replace terminology in the classification with concepts that are not broadly available in the patient record, or on death certificates.
• JTF members agreed that there is benefit to having better options in this area, and it was suggested that post-coordination might be the best way to accomplish. Post-coordination could be used to address:
  – Rheumatic vs non-rheumatic
  – Primary vs secondary
  – Additional complications

Summary
  – The JTF does not recommend taking the suggestion to use primary and secondary, as there is insufficient evidence that this would be of benefit.
  – In the absence of another proposal, the JTF recommends keeping things as they are, with a note to evaluate this during the quality assurance process

24.3. Recommendations
• WHO – Make no changes to the ICD-11 MMS
• WHO – include Heart Valve Disease as a priority area for review during quality assurance.

25. Circulatory System Chapter – Proposed Changes to Pacemakers and Defibrillators

25.1. Background
The WHO team is receiving proposals in the area of pacemaker/defibrillator complications that appear to be contradictory to JTF decisions regarding postprocedural conditions and the Quality and Safety perspective taken at the Glion meeting in 2015\(^2\), and were not actioned by the Cardiology WG. These proposals include topics such as:
  – Pacemaker or implantable cardioverter defibrillator pocket haematoma
  – Pacemaker or implantable cardioverter defibrillator lead extraction related venous perforation;
  – Pacemaker or implantable cardioverter defibrillator phrenic nerve stimulation;
  – change this parent category ‘Implantable cardioverter or defibrillator dysfunction or complication’ to ‘Pacemaker or implantable cardioverter defibrillator dysfunction’

Feedback from German cardiologists review also noted that the codes related to pacemaker dysfunction and complication needed further review that could not be completed at the time the rest of the feedback was submitted. There has not been any further information received.

The taxonomy document notes that:
  – Chronic, specific postprocedural conditions are grouped at the end of the organ system chapter where they manifest (e.g. lymphoedema due to surgery or radiotherapy). Residual categories do not exist for these groups.
  – Acute postprocedural complications are identified by combinations of codes from body system, injury and external causes chapters. (e.g. an accidental puncture during an intervention is classified with a code for the injured organ, a code identifying the accidental puncture as the mode of injury and a code describing what surgery occurred as the mechanism of injury)
  – The Quality and Safety coding rules state that the harm is coded first, followed by codes for mode and mechanism of injury. There are external cause codes for complications caused by a device.
  – All chapters should be used the same way with regard to quality and safety coding
  – ‘Diseases of the circulatory system’ chapter has a significant number of ‘postprocedural / conditions related to devices’ and it is therefore necessary to look at this section in particular detail.
  – Three options are proposed for how to resolve the discrepancy.

\(^2\) [http://who.int/entity/classifications/icd/revision/2015.09.01-4_iSummaryMeetingReportGlion.pdf?ua=1]
Option 1 – follow the Glion decision and treat pacemakers/defibrillators the same as other devices by coding the harm (e.g. Infection due to pacemaker) with a code from the block Mode of injury or harm associated with a surgical or other medical device, implant or graft in the Injuries chapter, followed by external cause codes for mode and mechanism.

Option 2 – pacemakers/defibrillators are not the same as other devices and need to have separate codes in the ‘Diseases of the circulatory system’ chapter. Add the proposals from the Cardiology Working Group.

Option 3 – None of the other options are correct and further feedback should be sought.

25.2. **Key Discussion Points**

- ’Infections associated with devices’ are not limited to cardiac devices. They can apply to all implanted devices.
- Sufficient evidence has not been provided that pacemakers/defibrillators are ‘special’ and must be treated differently than other devices. Therefore option 2 is rejected.
- There is no rationale for option 3 and it is also rejected.
- The JTF recommended going with option 1.
- Additional feedback is to be expected, particularly in the context of the quality assurance work.
- Complications due to prostheses (currently in the ‘Diseases of the musculoskeletal system or connective tissue’ chapter) where a device is coming to the end of its natural life is not a complication of that device, and is therefore coded elsewhere.

25.3. **Recommendations**

- WHO – enact and remain with option 1, following the Glion decision to treat pacemakers and defibrillators in the same way as other devices.

26. **Diabetes**

26.1. **Background**

- At the first meeting of the JTF in March 2015, a decision was made to decrease the granularity of precoordinated concepts in the block on diabetes and to code the complications separately using post-coordination.
- A recent proposal suggests to reintroduce a code for ‘diabetes with multiple complications’ based on the following rationale:
  - There is a need to create subcategories ‘with chronic diabetic complication’ and ‘without (mention of) complication’ for all different types of diabetes mellitus listed in the ICD-11 MMS. Often the clinical record information lists diabetes mellitus with complication(s) without specification of the type of complication. This is particularly the case when the main condition is unrelated to diabetes mellitus, but where at the same time the diabetes mellitus has an important impact as ‘other condition’, for example at surgery where a patient with (multiple) diabetes mellitus complications will have a higher risk of adverse events, a longer length of stay and poorer clinical outcome than a patient with diabetes mellitus without complications. The same considerations may be held for most of serious infections (pneumonia, acute pyelonephritis, meningitis, serious gastroenteritis, abscesses etc.).
  - Post-coordination options have been added to the classification to instruct users to add additional codes for the complications. This is the same process that will be followed for other ‘multiple’ conditions where the instruction is to code all that apply (e.g. in multiple injuries), or to use additional codes for complications of other diseases (e.g. endocarditis due to gonococcal infection).

26.2. **Key Discussion Points**

- The proposal suggests to code the diabetes and then post-coordinate the complications, consistent with the current status of the ICD-11 MMS.
• However, the proposal raises questions about the diabetic hypoglycaemic coma.
  • Diabetic hypoglycaemic coma is a relevant, frequent, and important complication
    – that diabetes is a syndromic condition associated with hyperglycaemia, as well as with many other complications
    – the IM TAG, after long discussion, agreed to post-coordinate the majority of complications to allow for a cleaner, easier-to-use shoreline for the ICD-11 MMS, but that the current list of available complications is insufficient
• There is a short list of acute diabetic complications, but the majority of diabetic complications are chronic and there is no group for these complications.
• ‘Acute complications of diabetes mellitus’ block is a sibling of the diabetes mellitus types, and maybe this would be better represented as a child of each of the types.
• One of the complaints about ICD-10 was that diabetes severity was coded through the inclusion of co-morbidities. However, this system should not be replicated in ICD-11. Instead, it had been agreed that severity should be coded using the severity axis in post-coordination.
• The inclusion of an additional code for ‘diabetes with multiple complications’ would require a number of new rules, as it would be necessary to still code what those complications are, if known. Also, some users may then code ‘diabetes with multiple complications’ without specifying what the complications are, while others coded diabetes and listed the complications.
• The MMS should not be changed to accommodate for this kind of problematic documentation.
• The suggestion to create a code titled ‘diabetes with multiple complications’ was rejected by the JTF.
• The JTF recommended to reject the suggestion to include ‘with’ and ‘without complications’ to each diabetes entity in the ICD-11 MMS
• The JTF considered a proposal to update certain other terminology (retaining the outdated terminology as index terms), namely:
  – ‘Diabetic hyperosmolar hyperglycaemic coma without ketoacidosis’ should be updated to ‘Hyperglycaemic-Hyperosmolar State’
  – ‘Hypoglycaemic coma’ should be updated to ‘Hypoglycaemia in the context of diabetes’
  – ‘Non-diabetic hyperglycaemia’ should be updated to ‘Hypoglycaemia without associated diabetes’
• A request to include the coma status is referred to the MSAC:
  – ‘Hyperglycaemic-Hyperosmolar State with coma’
  – ‘Hyperglycaemic-Hyperosmolar State without coma’
  – ‘Hypoglycaemia in the context of diabetes with coma’
  – ‘Hypoglycaemia in the context of diabetes without coma’
• The recommendation for MSAC review was based on a JTF understanding that the ‘new terminology’ might not be in wide use, and may therefore not be appropriate for use as the ‘preferred terms’.
• The JTF recommended that ‘acute’ and ‘chronic’ be post-coordinated, consistent with earlier decisions.
• The JTF recommended that severity be post-coordinated, consistent with earlier decisions.

26.3. Recommendations
• JTF members to meet and discuss the correct code titles for acute complications of diabetes. Proposals for any changes to be added to the platform for review and comment prior to implementation.
• Do not change the current structure at this point in time

27. Review of Chapters not completed by JTF

27.1. Background
• WHO confirmed that the ‘Diseases of the respiratory system’ chapter and the ‘External causes of morbidity or mortality’ chapter were not reviewed by JTF in a manner similar to what was done with the other chapters.
• Given the lack of time at this meeting, WHO requested feedback from the JTF about how best to address these unreviewed chapters.
27.2. **Key Discussion Points**
- The JTF agreed that there was a need to complete the review, but raised a concern about the ability to obtain, review, and integrate feedback by the 31 March deadline.
- The JTF raised a concern about the reviews done during the quality assurance mechanism, and the fact that there is a difference between the full reviews completed by the JTF and the quality assurance testing with a focus on hot spots.
- The ICD-11 MMS coding tool may struggle with the ‘External causes of morbidity or mortality’ chapter given the length, complexity, and detail included in the preferred term titles.
  - The external causes chapter remains unfinished at this time, and that this is a priority area to address. JTF members agreed that completing the shoreline review should facilitate use of the chapter while improving the structure.
- JTF members agreed that the review of the ‘External causes of morbidity or mortality’ chapter could not be completed by 31 March given the size, complexity, and lack of completeness and that a later deadline would be required.
- Volunteers were requested to do each review
  - The ‘Diseases of the respiratory system’ chapter will be reviewed by Jenny Hargreaves, Vera Dimitropoulos, and Donna Pickett
  - The ‘External causes of morbidity or mortality’ chapter will be reviewed by Stefanie Weber, Bob Anderson, Jenny Hargreaves, and Robert Chalmers

27.3. **Recommendations**
- **WHO** – provide the chapter review files (currently available on the meeting website) with a requested deadline for review of
  - The ‘Diseases of the respiratory system’ by Jenny Hargreaves, Vera Dimitropoulos, and Donna Pickett on or before 25 March 2017
  - The ‘External causes of morbidity or mortality’ by Stefanie Weber, Bob Anderson, Jenny Hargreaves, and Robert Chalmers on or before 30 April 2017
- **JTF** – carry out the reviews

28. **Update on Mapping**

28.1. **Background**
- WHO reported that a mapping of ICD-10 to ICD-11 has been completed and reviewed from multiple perspectives, including bi-directional review to look for ‘orphan’ codes
- One type of review looked at mapping from ICD-10 to ICD-11 and then backwards, to see if there was any change to the mappings after the ‘back-translation’
- WHO suggested that a primary area of review focus should be on those categories where, after back-mapping,
  - something has mapped to a different chapter (306),
  - something was missing a mapping due to a category that has no residual (539), or
  - something had no mapping at all (92).
- A particular focus may also be to address the ‘broken maps’ due to a missing of residual

28.2. **Key Discussion Points**
- The mapping tool should be available for use in Member States looking to map their national clinical modifications, as well.
- Mapping work is essential and great work has been done to date. However, the specific detail of each map should be reviewed in terms of where the case will now be coded recognizing that if there is a possibility that a given case could go to more than one category it would create data discontinuity.
- A table that indicates where each ICD-10 code would be coded in ICD-11 is included in the mapping tables for download on the browser.
- The mapping efforts should include mapping the asterisk combinations.
The browser or coding tool should show the post-coordinated equivalent of the pre-coordinated ICD-11 Foundation item to ensure this is coded in a standard way. WHO confirmed that this is work that remains pending.

28.3. **Recommendations**
- **WHO** – provide a translation table showing the single location in ICD-11 where each ICD-10 should now be coded, including the dagger-asterisk combinations.

## 29. Extension Codes Code Structure

### 29.1. **Background**
- The Extension Codes code structure follows the same model as the rest of the ICD-11 MMS. There are often more items in each Extension Codes parameter than the 34 items that the coding structure can accommodate for.
- WHO has suggested that there are a few potential solutions, each with certain limitations. For example:
  - The URI could be used as the code structure, but this would present some challenges for human coders, as the URIs are long and include special characters.
  - Alternatively, the simple numeric component of the extension code URI could be used, which would eliminate the ‘limit’ on the number of siblings permitted in a given list otherwise imposed by the ICD-11 MMS coding structure, though this would lose the intrinsic hierarchy created by the ICD-11 MMS structure.

### 29.2. **Key Discussion Points**
- A third alternative might be to create a unique coding structure for use in the Extension Codes allowing for a ‘mini-hierarchy’. This was not immediately accepted due to the complexity of creating competing code structures in the ICD-11 MMS, but left for later consideration.
- A ‘hybrid’ alternative, in which the ICD-11 MMS coding structure with inherent hierarchy could be maintained for the ‘short’ lists of values, while the use of the URI numbering could be used for the ‘long’ lists. This was also not immediately accepted, due to the same complexity of competing code structures.
- It might not be necessary to maintain a hierarchy in the Extension Codes, as the extension codes are more ‘word searchable’ than requiring navigation through a hierarchy.
  - This was countered by the suggestion that in some Extension Codes parameters, such as anatomy, such hierarchy would be useful.
  - WHO confirmed that a hierarchy for navigation can still exist, even if that hierarchy is not also represented by the code structure.
- It was noted that the list of drugs is out of date and will be updated to be consistent with the WHO International Nonproprietary Names (INN) list.
  - The JTF recommended that the full INN list be used
  - Licensing may take care of use of codes for business purposes
- As a second aside, a JTF observer raised a concern about ‘residual type’ entities in the Extension Codes, such as ‘laterality unspecified’.
  - This was countered by noting that in some jurisdictions, coding of laterality might be mandatory. As such, when mandatory but not specified in the record, the presence of residual codes would be necessary.

### 29.3. **Recommendations**
- **WHO** – implement the recommendation to use the numeric component of the URI as the coding structure for entities in the Extension Codes.
- **WHO** – consider the recommendation that each axis of the Extension Codes be identified in the ICD-11 MMS coding structure.
- **WHO** - consider review of the Extension Codes as a potential future work item.
• **WHO** – consider the JTF recommendation that the ICD-11 downloadable files include all items, not merely a subset, addressing the protections of intellectual property (including INN concepts) through licensing agreements.

### 30. Ambiguous Terms and a Need for Defaults

#### 30.1. Background

- Pilot testing of the quality assurance mechanism identified several terms that were found to be ambiguous. These included (in the absence of location, aetiology, or other specific detail)
  - Glioblastoma
  - Atherosclerosis
  - bilateral hernia,
  - Sepsis
  - Aspiration
- In particular, the example presented identified that glioblastoma can be of the brain or of the spinal cord in the ICD-11 MMS, but there is not a code for glioblastoma when the location is not identified. Moving the case up to the nearest shared level would result in a code of ‘Neoplasms of brain or central nervous system’, which loses the critical information that it was a glioblastoma.
- The Pilot Testing found that, in many cases, there was not a generic entity to which such cases could be coded, and this problem will continue to arise when coding death certificates.

#### 30.2. Key Discussion Points

- Many of these cases may have a place which is most logical, but not all, and this may therefore require rules or defaulting to ensure consistent usage
- It may not always be necessary to have inclusion terms, but index terms are necessary that point to a correct location addressing the issue of ‘where to put the ambiguous term’. This would then mean that it was no longer necessary to have specific NOS codes for these items.
- At a discussion in March 2012 at a face-to-face meeting of selected Revision Steering Group (RSG) Members the topic of defaulting was raised. It was noted that, at that time, defaulting was seen as an undesirable option while acknowledging that it still might be necessary, and that there should be continued discussion on the topic as the Revision progressed. It is desirable to avoid creating a classification which would engender or permit ‘lack of detail’ in documentation or coding, but necessary to ensure a location for where such ambiguous cases could be coded consistently.
  - A specific example used in the 2012 meeting was that ‘in the absence of further information, appendicitis is assumed to be acute’, caused problems to estimate the number of chronic cases. JTF members agreed with the position taken at that time by the selected RSG members that defaulting is not intolerable, per se, but should not be permitted when such defaulting adds detail to the case being coded that is not truly included in the record.
- JTF requested a complete list of such ambiguous cases that might need to be considered in terms of defaulting, and recommended that these terms be included in the ICD-11 Foundation with correct indexing. The JTF agreed that it would not be possible to action this item without specifically identifying the terms in question one-by-one.
- JTF members agreed that there is no limitation to the size of the ICD-11 Foundation and there should be no resistance to adding additional terms, as a comprehensive index will only support coders and facilitate identifying the correct code to use. All members of the JTF and their networks could contribute through submitting terms identified as missing.

#### 30.3. Recommendations

- **WHO** – collect a list of ‘ambiguous terms’ identified during the Mortality quality assurance exercise to address further, including ensuring that they appear somewhere in the ICD-11 Foundation and are indexed appropriately. Use the direction from the ICD-10 index as much as possible.
WHO & JTF — include a future agenda item related to developing criteria for what could be added to the ICD-11 Foundation. MSAC and CSAC will contribute to these discussions

31. Morbidity Coding Rules & ‘Quick Guide to Coding’

31.1. Background

- WHO had received a request for a ‘short and user-friendly’ guide for morbidity coding that could be used during the quality assurance exercise. Initially, it was suggested that this guide should be just 1-2 pages, though the current excerpt from the Reference Guide is closer to 40 pages. The excerpt needs to be streamlined and still ensure comprehensive guidance.
- Key questions to be addressed include:
  - Will this guide help the many people involved in testing to apply the codes consistently?
  - What additional education is required?
  - Is it complete?
  - Is it too long?

31.2. Key Discussion Points

- A primary use for this document is supporting the quality assurance testing of morbidity coding.
- The document is condensed as compared to the full reference guide and is very readable, but it is too long and might be incomplete.
- The text should be edited to focus on just the things being tested during this phase of quality assurance. Examples included infectious diseases, paediatric conditions, injuries, and similar sections as limits in the first instance.
- The document gives background on the structure and the terms used, but it is not the requested ‘summary of the rules’. It should be approximately 6-10 pages long and include hyperlinks to the full Reference Guide, as needed, for those who might be interested in the full detail.
  - The text should include information about the tools, something not currently included but very important, as they are ‘new’ to the testers.
  - At long term, instructional videos should be produced showing what the tools look like and how to navigate and use them. Resources need to be identified.
- The examples in the morbidity coding guidance read as mortality examples, and should be more morbidity focused.
- MbRG will review this document at their March 2017 midyear meeting.
- It should be made explicit that the quality assurance exercise is about testing the codes, and not the coding guidance. In particular, the focus is on whether or not the needed codes are present and organized in a correct way. The education manual for ICD-11 prepared previously is designed in a modular format to educate users about ICD-11.
- The WHO Collaborating Centre for CTS at the University of Calgary is developing training for their Q&S work, and that this might be a resource to draw upon, as desired.

Summary

- The JTF recommended that the quick guide focus on a summary of morbidity coding rules from the international reporting perspective and the tools to access and navigate them with a focus on the desired outcomes for testing during this phase of the quality assurance exercise. This should include
  - A background guide to orient the users to the ICD-11 MMS, including the new elements different from ICD-10, such as:
    - The definition of main condition has changed
    - Post-coordination and clustering
    - Use of the Extension Codes
    - New ICD-11 tooling
    - Major changes in content
Focus should be on just the information required for testers participating in the quality assurance exercise, specifically the information users might need to know ‘now’ before the end of March.

1 page summarizing the intro information from the first 10 pages of the existing draft to describe the context

- 1 page on ‘what is new in ICD-11’
- 1 page on the desired outcomes of the quality assurance exercise and how the information should be captured, potentially focusing on 5 key priority testing areas
- 1 page specifying the use case (morbidity in this version, including the quality and safety perspective)
- 2 pages, ideally, summarizing the morbidity coding rules with the morbidity-focused examples, possibly up to no more than 6 pages, if needed.

- The JTF recommended that this must be ready and available by 15 March 2017.
- A draft would be prepared by 8 March 2017 for consideration, and that the JTF will provide feedback to the draft by 15 March 2017.
- Any additional suggestions for ‘requirements’ should be submitted to WHO.

31.3. Recommendations

- JTF – submit suggestions to VD for ‘requirements’ to the quick coding guide
- Vera Dimitropoulos – prepare an outline of the document as suggested in the summary above by 8 March 2017
- MbRG – review the Morbidity Quick Guide to Coding with a view to making corrections and edits in line with the discussion above.
- WHO – consider the recommendation to create instructional videos on the ICD-11 tools, including how such work might be resourced.
- WHO – update the browser text to reflect the previous decision that
  - ‘definition’ is now ‘description’
  - ‘long definition’ is now ‘additional information’
- JTF – provide feedback on the outline by 15 March 2017

32. Quality Assurance Mechanisms

32.1. Background

- WHO provided an overview on the status of Phase 1 of the quality assurance exercise, the pilot testing of line coding. WHO reported that this phase included nearly 400 morbidity-related terms and 1000 mortality-related terms released in batches of 100 in both the English and Spanish versions. One of the goals of the pilot testing was to compare interrater reliability of the testers, as well as the reliability between the testers and the ‘gold standard’ results suggested by WHO.
- The quality assurance exercise intends to focus on three key deliverables, namely:
  - Correcting any remaining errors in the classification, the tooling, and the methodology of the quality assurance exercise, itself.
  - To improve and correctly identify the value-add of ICD-11 MMS as compared to ICD-10
  - To build public capacity in terms of ICD-11 MMS knowledge, familiarity, and coding skills
- Timelines for quality assurance are:
  - Pilot Testing (Jan – Feb 2017)
  - Generic Testing of Priority Areas (April – May 2017)
  - Specific Use input including XM versions, Q&S, DRM, TM, etc. (final deadline of September 2017)
- Priority areas for testing include:
  - Frequent and important conditions
  - Issues identified through previous feedback for generic testing
  - Additional areas suggested by the JTF, such as perinatal and neonatal categories
32.2. **Key Discussion Points**

- The most crucial component to the success of the quality assurance exercise will be managing and processing feedback, the expectations of the contributing experts and focusing on what is feasible within the given timelines.
- WHO should draft a structured feedback template to better process results.
- The outcomes of the quality assurance exercise would be put through the proposal mechanism for transparency and accountability.
- How ‘late’ feedback would be addressed, needs to be decided.
- The 1000 terms used for mortality trials are based on the most commonly certified Causes of Death as reported by Australia and Japan, and that these cover approximately 80% of what is reported in Australia. As such, it was suggested that if these 1000 terms can be correctly and consistently coded in ICD-11 MMS, the classification can be considered significantly robust.
- It is often possible to identify the correct code by simply typing the term into the browser. However, sometimes there is no match nor always correct option is identified, when multiple responses are offered by the system. It was recommended moving into coding cases rather than single terms as soon as possible, and that the testing methodology be well-designed to ensure efficient use of limited time.
- ‘Challenging death certificates’ might prove difficult to code given the structural changes in ICD-11 MMS, such as anaphylaxis. It needs to be clear if the underlying cause now should be an injury code, or if it will still remain the causing substance.
- The current ‘priority areas’ were identified based on areas that were subject to change in ICD-11, newly created sections or chapters, and frequency counts of code usage (mortality and morbidity - presented in earlier meetings of the JTF).
- As a part of the standard template for tester feedback, a question could be asked related to what rule the tester had applied in that case. It was suggested that this might be useful in terms of evaluating interrater reliability in terms of the rules applied. It was furthermore recommended that there should remain some space for open-ended feedback.
- The ICDFIT platform for case coding should show the ‘most important and relevant coding rules’ in a sort of hover-box so that users are directed to the rule they should use. This was not immediately accepted, both because it would represent a significant additional burden to program into the system and because it could bias the testers, eliminating issues that might otherwise arise among users that would not have this specific guidance; and public users will not in the future.
- The JTF recommended that they should remain involved in the process and contribute to the consideration and processing of feedback received through the quality assurance exercise and from Member States.
  - The next face-to-face meeting should take place in the second half of July or early August given the 30 June deadline for Member State feedback.
  - A face-to-face meeting in September for the preparation for the November release would also be useful.
- The JTF further discussed how to respond to feedback.
  - The JTF recommended that WHO prepare a standard response to feedback received.
  - Responding to the cardiovascular clinicians from Germany who provided feedback could be an initial exercise. However, there is a significant difference in the workload associated with acknowledging feedback received as compared to providing a response including rationale for each acceptance or rejection.
  - The JTF recommended a standard mechanism and timeline for responses, but acknowledged there needs to be a good balance between time spent on crafting responses and the resources needed for implementing the work. It is not feasible to expect individualized and line-item feedback given the volume, timelines, and limited resources.
  - The JTF noted that when recommendations are accepted, there is typically no need to respond. It is only when a recommendation is rejected or only partially accepted that WHO may be challenged.
  - The JTF recommended that the topic of responding to feedback be included as a continuing agenda item.
32.3. Recommendations
- JTF – Suggest any additional priority areas for testing
- WHO – develop a structured feedback template for testers, including a question about what rule(s) the tester applied in the given case, and if there was any difficulty in applying that rule.
- WHO – consider the JTF recommendation to move into coding cases rather than single terms as soon as possible, and to ensure quality design of testing methodology
- WHO – include discussion of how best to respond to feedback as a future agenda item
- WHO – organize the meetings of the JTF in July/August, and maybe September

Wednesday, 22 February 2017

33. Transition Plan to Maintenance of ICD-11 MMS³

33.1. Background
- There are two different perspectives on transition –
  - transition at the international level from ICD-10 to ICD-11 in terms of maintenance, update, and support, as well as
  - transition in countries, with or without national clinical modifications
- The URC served the purpose of advising WHO on updates successfully and with many identified strengths. However, members drew on their own expertise or on national clinical expertise with the associated and inherent limitations or biases of these perspectives.
- As such, the MSAC was also formed to address these needs of medical and clinical expertise from an ‘international’ rather than ‘national’ perspective.
- The CSAC, which will be the evolution of URC, will continue to serve the statistical and political needs of update, looking at proposals and the related comments by the reference groups and the MSAC.
- The URC will continue until Q2 2018 to address the 2019 update, but would then cease to exist. The CSAC would come into force at the WHO-FIC Network Annual Meeting 2017 to allow a longer lead-in to develop working procedures, etc. to address the requirements moving forward and there is overlap in the transition from URC to CSAC.

33.2. Key Discussion Points
- The currently proposed structure does not make clear which group is responsible for, proposing improvements and working to improve ICD-11. The JTF suggested that MbRG and MRG might take on this role, but that they would be focused on ICD-10 until 2018 and may take time after that to make the transition to ICD-11.
- The current working methods employed by the JTF do seem to generally work well, but recognized that the group is significantly less formal than structures such as the URC. The JTF acknowledged that it would be difficult to maintain the current level of efficacy in the URC/CSAC, because initially there will be members less familiar with the new aspects of ICD-11. This may be a reason for starting the CSAC work earlier and including URC members.
- Proposals for ICD-11 would be submitted by existing proposal authors for ICD-10, such as MRG and MbRG, and external authors many of which have been contributing to ICD-11 already. Shifting the MRG and MbRG agendas from ICD-10 to ICD-11 may impact on motivation of the participants. ICD-11 may not be relevant for all members, yet. Work on ICD-10 may need to continue, to some extent.
- The more important question is whether or not the ‘right’ proposals will be received.
- The addition of a group (MSAC) will change the flow of how proposals are actioned, and it will be useful to start doing this review starting this year so the work flows can be tested.

³ https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVmYXVsdGRvbWFpbmxqbG1tc3Rhc2tmb3jjZXxneDo0N2lzMTMmMmRImZjZjgy
• The fact of having the MSAC will not preclude national clinical feedback such as from specialist societies. Such feedback may require some discussion regarding how to harmonize and balance the feedback from different sources.
• The following statement from the document needs to be clarified: ‘where a proposal is submitted by one of the groups involved in commenting, a separate comment by the submitting committee will not be necessary’.
• The JTF recommended amending the statement in the document which states ‘all official members will participate [emphasis added]’ into ‘all official members will be invited to participate’, to clarify that the process will still move forward even if one or more members have not responded.
• The proposed 5-year update cycle is too long to be practical for Member States, suggesting a 3-year cycle. This was countered by the statement that some Member States do not implement any updates, so the update cycle requirements might differ between different stakeholders. Stability is as important, as are updates.
  – The JTF agreed that it could be possible to have one update cycle in the first few years after ICD-11 MMS release, noting that the ICD-11 MMS is not expected to be ‘done’ by 2018, to address the bulk of issues that will be identified, allowing for a longer period between updates as stability and accuracy improves. It was suggested that there should be annual updates for the first 5 years, followed by a transition to the 3-year or 5-year cycle.
  – The JTF recommended discussing this further on a future agenda.
• The CSAC has primary authority to make recommendations to WHO on the ICD-11 MMS, while MSAC focuses more on issues of scientific appropriateness, asserting relationships, and other work in. The MSAC will improve the currency of information included in ICD-11, and increase credibility with the scientific and clinical communities.
• The MSAC would also play a role in advising on primary parenting, answering questions such as ‘Is the evidence to move stroke based on new information about the aetiology sufficiently strong?’, but the final recommendation to WHO on whether or not to make the move will still come from the CSAC based on their responsibility for the ICD-11 MMS.
• The ‘proposal filter’ is recommended to be a staff member located within WHO rather than a volunteer with limited time as was done with URC, because of the expected workload.

Summary
• The JTF recommends that the MRG and MbRG discuss the updating cycle in their midyear meetings organized for March 2017 and report back to JTF. The updating cycle may differ in the first years of ICD-11 as possibly more changes will be required. It may start with annual updates, progress to every 3 years and then move to a 5-year cycle.
  – The JTF recommends a gradual and phased approach to the transition from ICD-10 maintenance to ICD-11 MMS maintenance in the network with appropriately managed expectations to avoid demotivating experts from the process. No specific guidance on how this should be done was discussed.
  – The JTF recommends a gradual transition from the JTF to the CSAC, trialling the workflow with a joint gathering of the two groups starting after the WHO-FIC Network Annual Meeting 2017. This group may also include URC members (recognizing the already expected overlap between URC and CSAC membership) allowing the JTF members to provide some support to those less familiar with ICD-11 MMS.
  – The JTF recommends that WHO develop proper support for the work flow and working methods for the ICD-11 MMS maintenance process. Of course, the Network will continue to contribute to ICD-11 MMS as they did for ICD-10.

33.3. Recommendations
• WHO - Remove a statement from the document which states ‘where a proposal is submitted by one of the groups involved in commenting, a separate comment by the submitting committee will not be necessary’
• WHO - Replace the statement in the document which states ‘all official members will participate [emphasis added]’ with ‘all official members will be invited to participate’
• **MRG & MbRG** – include a discussion on the update cycle at the upcoming midyear meetings, as well as if the update cycles should/must be synchronized.

• **WHO & JTF** – include the update cycle on a future agenda, including a discussion of whether a 3 or 5-year cycle would best address Member State needs, including the feedback from the MRG and MbRG midyear meeting discussions, as well as if there should be an ‘introductory period’ with more frequent updates.

• **WHO & JTF** – Consider how to develop a gradual and phased approach to the transition from ICD-10 maintenance to ICD-11 MMS maintenance that accounts for volunteer availability and manages expectations. Consider including this topic on a future agenda.

• **WHO** - develop proper support for the work flow and working methods for the ICD-11 MMS maintenance process.

• **WHO** – Consider how best to resource ICD-11 MMS update and maintenance support from within the Organization.

• **WHO** – Organize a joint gathering of the JTF and the CSAC, potentially with additional URC members included as necessary, to trial the ICD-11 MMS update process starting after October 2017.

• **WHO** – Circulate the updated JTF and WHO-FIC Council SEG documents no later than 31 March 2017.

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## 34. Transition to ICD-11 in Countries

### 34.1. Background

- During the WHO-FIC Network Annual Meeting 2016 and ICD-11 Revision Conference, there was discussion around transition in countries and a request for some ideas about how to advise countries on how to transition from ICD-10 to ICD-11 MMS. It was suggested that there should be multiple tracks for transition, acknowledging that the situation might be different in each Member States, with some preferring to be ‘early adopters’, others who have implemented ICD-10 very deeply and who therefore may struggle with the transition, still more who currently use no version of ICD and will implement ICD-11 MMS for the first time, and still more in other unique situations.

- The transition requires extensive forward planning, and some countries may run two revisions in parallel for a period so they can trial ICD-11 MMS.

- It will become increasingly difficult to use ICD-10 once maintenance and update of the classification is finished, due to outdated content.

- A document\(^4\) described the aspects of transitioning from ICD-10 to ICD-11 MMS from a national perspective, information about benefits of implementing ICD-11 MMS, as well as governance.

### 34.2. Key Discussion Points

- The paper on country transition should receive feedback from all members of the JTF.

- There should be a clear document which outlines the benefits of transitioning to ICD-11 MMS, while also including the risks of delayed transition.

- The document should have sections that address common Member State situations, including
  - ‘early adopters’
  - ‘first time classification adopters’
  - Intense ICD-10 users
  - Dual-adopters (e.g. those running ICD-10 and ICD-11 MMS concurrently, either as a temporary measure or as an established practice in different health care environments.)

- There should be information about the ICD-11 multilingual platform (a.k.a. translation tool) as this is an asset already available from WHO that is of specific value to Member States.

- The quality assurance exercise or the previously-completed national surveys could be used to inform the paper, particularly with regard to requirements for and barriers to implementation.

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\(^4\) [https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVmYXVsdGRvbWFpbmxqbgG1tcRhc2tmb3jjZXxneDo2YTlyYjgwZWM4MDEyNTk2](https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVmYXVsdGRvbWFpbmxqbgG1tcRhc2tmb3jjZXxneDo2YTlyYjgwZWM4MDEyNTk2)
This paper is one component of a larger package of information that should be provided to Member States. WHO agreed and recommended that a proposal for what should be included in such a package of information be a future agenda item.

A major contributor to the success of implementation is raising awareness. WHO should draft an announcement to be submitted to an appropriate publication(s) announcing the release of the ICD-11, including the summary of benefits to transitioning in Member States. This could be co-authored by WHO, JTF, MSAC, RSG chair, Network co-chairs, etc.

One barrier to implementation in Member States will be resourcing the transition, and developing institutional knowledge and national capacity.

34.3. Recommendations

- **WHO** – Share the word-version of the transition document with members of the JTF
- **JTF** – Provide comments on the document to the author via track-changes / comments embedded in the text.
- **WHO & JTF** – Develop a short document which clearly outlines the benefits of transitioning to ICD-11 MMS, while also including the risks of delayed transition.
- **WHO & JTF** – Include contents of a ‘transition information package for Member States’ as a future agenda item.
- **WHO** – Consider the JTF recommendation to prepare a publication announcing the release of ICD-11 MMS, including the value-add, to prepare Member States prior to publication.

35. Clinical Modification Needs

35.1. Background

- A document discussed aspects of clinical modification needs, including WHO requirements to consider such modifications and Member State requirements of WHO in terms of support.
- The document includes the agreement that Member State needs with regards to national clinical modifications are particularly relevant in the context of the ICD-11 Foundation within the current ICD-11 model.
- The text also includes suggestions for information that might be required by Member States when considering whether or not to request permission to create a national clinical modification.
- One question raised by the document author relates to the linkages between ICD-11 and SNOMED CT. In particular, the author requests clarification about if and how the linkages will be completed, as well as how.
- The document is clear to draw a distinction between the question of whether or not a Member State will request to create a national clinical modification and the decision of that Member State about if and when to implement ICD-11. However, the author recognizes the potential for overlap, asking the question of the point at which a decision on how to implement national (e.g. choosing which parameters of post-coordination to include or mandate) crosses into being a national clinical modification.

35.2. Key Discussion Points

- It was discussed, whether or not national clinical modifications will also require their own morbidity coding rules, or if general rules developed at the international level will apply and sufficiently address national requirements.
- A small working group should continue to discuss and develop this document composed of representatives of Member States who have had national clinical modifications in the past, or are likely to request them in the future.

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5 https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVmYXVsdGRvbWFpbmNxbG1tc3Rhc2tmb3lkbXxneDooZGlkExYdiMm10ZTliNmFi
The text should be consistent with, and include, the extract from the ICD-11 MMS Reference Guide which relates to national clinical modifications, and the Reference Guide should be updated as necessary to be consistent with the feedback from the working group.

The JTF agreed that national clinical modifications should be developed with the telescopic model, as represented that the requirements allow for the adding of specific detail below the level of depth specified in the ICD-11 MMS, and that they cannot conflict with the international tabulation or with the ICD-11 Foundation.

- It might be necessary for a country to hide codes from the ICD-11 MMS to suit national needs. For example, the external causes chapter, could not be fully implemented nationally due to privacy and data protection.

The JTF agreed that Member States shall be required to update their national clinical modifications to adhere to updates to the ICD-11 MMS international version, as quickly as possible.

Additional content in the ICD-11 Foundation is necessary to allow for Member States to create their national clinical modifications.

- Updates would still require approval by all of the relevant international groups, in particular the CSAC, MSAC, Reference Groups.
- However, Member States will have different update cycles than a 3-year or 5-year update cycle e.g. less than one year, making participation of all the above groups difficult.
- The JTF recommended that all additional terms that will be included in any national clinical modification must also be submitted to the ICD-11 Foundation.
- The JTF recommended that the addition proposed by a Member State for inclusion in their own national clinical modification must be submitted to the ICD-11 Foundation where MSAC can approve the accuracy on a continuous basis to best serve Member State needs with regard to their national clinical modifications. The consideration of whether or not to implement in the ICD-11 MMS, however, can still be done in accordance with the WHO timelines.

All changes to the ICD-11 Foundation could have impact on the ICD-11 MMS, even if just adding an index term, and therefore all changes must be considered by CSAC on the established CSAC timelines, however, such impact is minimal and should not matter, and, CSAC should not object to the addition of an index term in the correct place.

Translations are not considered to be national clinical modifications. Changes beyond translation may be considered national clinical modifications, as choosing to drop certain codes, translate things differently, or even adjust the index to better suit the needs of their national case mix groupings.

The JTF recommended that WHO develop a plan for licensing that includes considerations of national clinical modifications, as well as the issues discussed earlier in the context of intellectual property rights and access.

A rationale used in some Member States to justify the creation of ICD-10 national clinical modifications was that ICD-10 was not detailed enough for use in their morbidity coding. The claim should be made that the ICD-11 MMS can serve now that purpose, and that national clinical modifications would no longer be necessary and allow interested parties to offer proof to the contrary.

Member State governments will follow national needs and may not always be able to wait for a lengthy international process to be completed. In the past, certain issues that have been with the URC for many years due to lack of international consensus.

It was discussed that for rapid approval of additions to the ICD-11 Foundation by the MSAC, the ICD-11 Foundation model could be adjusted to allow MSAC to provisionally approve items that are tagged as ‘not yet validated, available only for use in XM version’. In this way, the proposing country would have immediate access to necessary concepts, other countries could see the entities and choose to use them if desired, but the term would not appear in the index or ICD-11 MMS until duly reviewed by the CSAC. However, then term would remain in the ICD-11 Foundation even if rejected by the CSAC. And changing the ICD-11 Foundation model could have significant implications.

The historic view of the ICD-11 Foundation was that it could and should be updated frequently with low barriers related to Member State requirements. This would imply that the governance of the ICD-11 Foundation is different than the governance of the linearization/tabular list.

**Summary**
The JTF acknowledges the desire to produce an ICD-11 MMS that will sufficiently address the needs of all Member States such that national clinical modifications will no longer be necessary, but recognizes that this claim cannot be made or verified at this time.

– The MbRG is requested to review the text and to propose changes to the text.
– The JTF recommends that both this text and the text of the Reference Guide be updated to be consistent, and take into account the above aspects.

WHO Member States producing national clinical modifications are well-represented on the JTF, but are a minority of Member States, and the discussion is therefore best placed in that context.

**35.3. Recommendations**

- **WHO** – consider the recommendation to organize a small working group to discuss and develop this document composed of representatives of Member States who have had national clinical modifications in the past, or are likely to request them in the future.
- **WHO** – consider the recommendation that the text (5) should be consistent with, and include, the extract from the ICD-11 MMS Reference Guide which relates to national clinical modifications, and that the Reference Guide is updated as necessary to be consistent with the feedback from the working group.
- **WHO** – consider the JTF recommendation that additions proposed by a Member State for inclusion in their own national clinical modification be submitted to the ICD-11 Foundation. The consideration of whether or not to implement in the ICD-11 MMS, however, will still be done in accordance with the WHO timelines.
- **WHO** – develop a licensing strategy for ICD-11 which accommodates for national clinical modifications as well as the aspects of intellectual property rights and access.
- **Document Author** – update the text based on the discussion above and provide to WHO.
- **WHO** – share the updated text with the JTF and MbRG for the next phase of commenting.
- **WHO, JTF, MSAC, and WHO-FIC Council** – include the updated text as a future agenda item for each of the groups.
- **JTF** – include a discussion of necessary Reference Guide updates as related to the discussion above as a future agenda item.

**36. Next Meetings**

- The JTF suggested that the next face-to-face meeting(s) of the JTF could be:
  – A 3-4-day meeting scheduled between mid-July and early August in
    - Canada
    - Cologne
    - Geneva
  – A 2-day meeting schedule in October/November, either the two days before or the two days after the WHO-FIC Network Annual Meeting 2017 in
    - Mexico City

**36.1. Recommendations**

- **WHO** – prepare a doodle to identify participant availability from second week of July through mid-August for the next face-to-face meeting of the JTF.
37. Proposal Workflow

37.1. Background
- During the maintenance phase of ICD-11, all proposals for change must be submitted through the proposal mechanism to ensure a clear and transparent review of the proposed content which is accountable to key stakeholders and actioned according to established working procedures. To that end, it is useful to evaluate the different types of proposals that might be received through the platform, and propose a workflow for how each proposal might move through the process of consideration.
- WHO identified the following proposal types for consideration:
  - Add new entity:
    - to add an entity below the shoreline (becoming an index entry in ICD-11 MMS)
    - to add an entity above the shoreline (becoming a category in ICD-11 MMS)
  - Delete entity:
    - applicable to an entity below the shoreline (removing an index term from the ICD-11 MMS)
    - applicable to an entity above the shoreline (removing a category from the ICD-11 MMS)
  - Content Enhancement:
    - Change of Preferred Term (title) (with no change to meaning)
    - Addition / Deletion of a synonym
    - Addition / Deletion of an exclusion
    - Change of Description (Definition)
    - Correction of a typo (in any field)
    - Addition / Deletion of a post-coordination combination
    - Addition / Deletion of entity rubric content (with no change to meaning)
  - Structural Change:
    - Change a primary parent link
    - Change a secondary parent link
  - Reference Guide Change: applicable to any text of the ICD-11 Reference Guide, including coding rules and defaults, etc. Subtypes include:
    - Correction of a Typo
    - Clarification
    - Change to a rule (that effects data integrity)

37.2. Key Discussion Points
- The ‘proposal filter’, given the increased workload, should be located within WHO rather than a volunteer with limited time as was done with URC. However, much of the workload of the past consisted of preparing the update documents, and this could be automated with the ICD-11 tooling environment, providing more time for the role of the proposal filter.
- Proposal Types:
  - Changes to the ICD-11 Foundation are different than changes to the ICD-11 MMS, in particular when evaluating ‘impact of data collected’. For example, adding a new codable entity to the ICD-11 MMS is clearly a major change, while adding a new entity to the ICD-11 Foundation, which appears only as an index term, if done correctly, would have a minimal impact on the ICD-11 MMS.
  - Adding or deleting an inclusion term is included in the proposal types ‘add new entity’ and ‘delete new entity’, as these apply whether the term will be above or below the shoreline of the ICD-11 MMS.
  - JTF members recommended the addition of a proposal type for ‘change a coding hint’.
  - There should be a proposal type related to moving an entity above or below the shoreline, the effecting outcome of a suggestion to ‘make this entity individually codable’ versus ‘make this entity an index term rather an individually codable.’
  - Impact of changing a description (definition) needs to be clarified. If the change resulted in altering what should be coded to that concept, it would be a major change. However, descriptions

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6 https://sites.google.com/site/jmmstaskforce/meetings/february2017/40.Proposal%20Workflow.pdf?attredirects=0&d=1
(definitions) are not used by coders to make a diagnosis based on what is in the patient record, but merely to clarify the meaning.

– It needs to be made clear that the ‘change of preferred Term (title) (with no change to meaning)’ proposal type does not mean that other changes WITH change to meaning are permitted.

– Impact on data collected using the ICD-11 MMS is one metric by which complexity of a proposal might be measured, while complexity of implementing the change is another. It was furthermore noted that complexity of implementing the change in the ICD-11 Foundation versus in the linearization is yet another perspective to consider.

– The JTF agreed that proposals submitted by authors who do not specify the target of their proposal (e.g. ICD-11 Foundation, ICD-11 MMS, Primary Care linearization/tabulation, National Clinical Modification, etc.) should be defaulted to one of the above. The JTF recommended, however, that the default be the ICD-11 Foundation rather than the ICD-11 MMS.

– The JTF agreed that the barrier to have proposals considered should be low, with simple rules to identify what is receivable/actionable. The JTF recommended that these be based solely on whether or not the proposal is complete and correctly submitted.

• Summary

– The JTF agreed that the list is an acceptable draft of proposal types with the additions outlined above.

– The JTF agreed that not all proposals will need to be reviewed by all parties, but that each proposal type will need to have its own identified workflow to make each track explicit.

– The JTF agreed that full transparency remains essential, and that all proposals must be available and actioned through the proposal platform, but that not every group or committee will need to act on each proposal.

– The JTF agreed that proposal authors should be directed to identify the target of their proposal (e.g. ICD-11 Foundation, ICD-11 MMS, Primary Care linearization/tabulation, National Clinical Modification, etc.), but that in the absence of such specification, the assumption shall be that the proposal targets the ICD-11 Foundation. This does not preclude the CSAC or any other linearization/tabulation holder from considering the change, if desired.

– The JTF was concerned about the workload associated with the proposal filter, and recommended that this could be a group of responsible individuals lead by WHO.

37.3. Recommendations

• WHO – create a new proposal type for ‘change a coding hint’.

• WHO – create a new proposal type for moving an item above or below the shoreline.

• WHO – clarify that changing a preferred term (title), changing entity rubric content, and other similar changes cannot be used to change the meaning of a concept. If a concept is outdated, it should be removed and a new entity added.

• WHO – change the proposal default from the ICD-11 MMS to the ICD-11 Foundation, when no target is specified by the submitting author.

• WHO – consider how a WHO staff member serving in the role of proposal filter could be identified and resourced.

• WHO – update the proposal workflow document in line with the discussion above and circulate to the MSAC, WHO-FIC Council SEG, and JTF for further comments.

• WHO & JTF – include the updated document as an agenda item for the 16 March 2017 teleconference of the JTF.

Wednesday, 22 February 2017 – 14:45
38. **MSAC Governance & Structure**

38.1. **Background**
   - It is proposed to reorganize the current ICD Revision structures towards a longterm maintenance framework for ICD-11. This will include revisiting the governance design and evolving the status quo into a new structure.

38.2. **Key Discussion Points**
   - Given limited time for discussion, the JTF recommended taking this document to the 16 March 2017 teleconference of the JTF, as well.

38.3. **Recommendations**
   - **MSAC** – review the updated Proposal Workflow and MSAC Governance documents on the 2 March 2017 teleconference of the MSAC Co-Chairs.
   - **WHO-FIC Council SEG** - review the updated Proposal Workflow and MSAC Governance documents on the 9 March 2017 teleconference of the Council SEG.
   - **WHO** – circulate the updated documents to the JTF
   - **MSAC** – take into account the comments and update 40 and 41 on the call next week
   - **WHO** – share updated doc in Word for comments with SEG and JTF
   - **JTF** – review the updated Proposal Workflow and MSAC Governance documents on the 16 March 2017 teleconference of the JTF.

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**Wednesday, 22 February 2017 – 14:47**

39. **Chronic Fatigue Syndrome Advocacy Efforts**

39.1. **Background**
   - WHO and JTF members are aware of advocacy efforts related to ‘Postviral fatigue syndrome’ and ‘Benign myalgic encephalomyelitis’, sometimes referred to collectively as aspects of Chronic Fatigue Syndrome.

39.2. **Key Discussion Points**
   - The JTF is an advisory body called by WHO to support finalization of the ICD-11 MMS, but no individual member of the JTF has the authority to speak on behalf of, or to represent WHO, or should feel forced to respond in that role.
   - Individuals seeking changes to ICD-11 should be directed to submit their proposals via the ICD-11 proposal mechanism platform. Adjustments to such proposals, or comments on the proposal, should also be submitted through that mechanism.
   - Responses should reference the proposed timelines so that advocates understand that all proposals will be addressed, but that not everything will be accepted and that there is a priority order to considerations. Reference was made to the URC where certain complicated proposals take years to be either accepted or rejected. This might mitigate the perception by individuals that they are being ignored or ‘brushed off’.
   - The process for updating ICD-11 is not closed, and each deadline is an incremental improvement. It is prudent to manage expectations of the public by explaining clearly that all proposals will be considered, but that this work takes time and that conditions with significant mortality impact will be considered higher priority for consideration.
   - The JTF recommended that WHO prepare a standard response for use by JTF members contacted by individual members of the public or by professional societies making clear that
     - JTF members do not have the authority to represent WHO or respond on behalf of the Organization
No submissions or requests for changes received outside of the proposal platform will be considered

39.3. **Recommendations**

- **WHO & JTF** – Maintain the practice of directing all requests for change to the ICD-11 Proposal Platform.
- **WHO** – consider the JTF recommendation to prepare a standard response for use by JTF members line with the discussions above.

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**40. SNOMED CT**

**40.1. Background**

- The work on mapping is progressing on both sides.

**40.2. Key Discussion Points**

- The JTF requested WHO to continue updating the group as developments progress.

**40.3. Recommendations**

- **WHO** – continue updating interested parties on the progress of work between the two organizations as necessary or requested

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**41. Meeting Report**

**41.1. Background**

- WHO confirmed that the draft report will be prepared as quickly as possible, and shared with the JTF after being reviewed internally by the other members of the team.
- JTF members are requested to review the report carefully and provide comments and feedback through track changes.