Extract from response by Chapman and Dimmock to proposal for ICD-11 submitted by Dr Tarun Dua on November 06, 2017

February 15, 2018

Extract:

4. Compliance with WHO standards and other considerations on relocation

General considerations for potential chapter relocations were discussed at a meeting of the Joint Task Force, in July 2016 (20). According to the meeting Summary Report (**5.2 Key discussion**), a general principle was reiterated that *"...in the absence of compelling evidence mandating a change, legacy should trump with regard to the question of moving certain conditions to new chapters...JTF members confirmed that continuity over time is desirable. Where there is a rationale for change, the changes can be accommodated for, but there was a question about how to justify the effort required to make the changes in data reporting systems in the absence of compelling information indicating that the change makes things better or more accurate."*

Further, the ICD-11 Reference Guide (Draft iteration 2017-10-09, pages 20-22) sets out Guiding Principles, including guidelines on the potential movement of categories or groups between chapters (21). Of particular interest are the following statements from the Reference Guide, listed in the priority order provided in the guide:

1. *"No changes to the classification, including movement of categories or groups between chapters, without rationale and documented change in aetiology or prevention method."*

2. *"Conditions that could arguably be in two or more places of the classification remain in their legacy location."*

3. *"Syndromes, where the aetiology is unknown, are allocated with the most relevant organ system. (e.g. Costen syndrome is in the Digestive chapter)"*

There appears to be no precedent in the Guiding Principles for relegating diseases, disorders or syndromes for which etiologies have yet to be established to the Symptoms, signs chapter until further evidence guides their restoration back to a specific chapter or for assignment under additional parents.

Furthermore, we see no evidence that other diseases with incompletely understood etiopathogenesis have been proposed to be removed from their legacy chapters and dumped into the Symptoms, signs chapter.

Even if an evidence review were to appropriately exclude Oxford studies, a systematic review of the literature as it exists today is unlikely to provide definitive answers on chapter placement.

At most, the review is likely to demonstrate that an immunological parent would be warranted in addition to neurological chapter placement, although evidence may be insufficient to denote where in the immunological chapter the terms should be parented.

The current scientific evidence of neurological impairment and WHO/ICD Revision's position on precedence supports retention of chronic fatigue syndrome, myalgic encephalomyelitis, and postviral fatigue syndrome in Diseases of the nervous system.

Another issue is that of continuity and backward compatibility with ICD-10, which will continue to be used globally for records and reporting for some time. Dr. Dua's proposal does not consider a proposed relocation in the context of data collection and statistical analysis, an important consideration, particularly in a proposal that lacks the scientific justification to support the relocation.

20) Fourth Meeting of the JLMMS Task Force, Queensland, Australia, 11-14 July 2016 http://www.who.int/entity/classifications/icd/revision/2016.07.11-14_iSummaryMeetingReportQueensland.pdf

21) ICD-11 Reference Guide, Draft iteration 2017-10-09, pages 20-22. (Accessed February 12, 2018) https://icd.who.int/dev11/Downloads/Download?fileName=refguide.pdf