Progression of PVFS, ME and CFS through the ICD-11 drafting platforms

Key events in the timeline: tracking the progress of the ICD-10 G93.3 legacy terms through the initial iCAT, Alpha and Beta drafting platforms, from May 2010 to May 2018.

May 2010 Parent class: *Other disorders of brain* retired; change of hierarchy for PVFS; CFS is lead Concept term; BME is Inclusion term; PVFS relocated under Synonyms to CFS.

Feb 2013 ICD Revision (or TAG Neurology) inexplicably remove CFS, BME and PVFS from the public version of the Beta draft. No rationale is provided for their absence.

Feb 2017 Advocates and selected international orgs lobby Joint Task Force to place issue of missing terms on Agenda of Feb Joint Task Force meeting. Discussion is minuted.

March 26 2017 PVFS, BME and CFS restored to Beta under *Other disorders of the nervous system*. PVFS is lead Concept term; CFS and BME both specified Inclusion terms.

ICD Revision posts this caveat: *"While the optimal place in the classification is still being identified, the entity has been put back to its original place in ICD."*

March 27 2017 Dimmock & Chapman submit proposals and rationales for PVFS, ME and CFS via Proposal Mechanism. Submission meets the March 30 2017 proposal deadline.

Nov 6 2017 WHO's Dr Tarun Dua submits a proposal (apparently on behalf of TAG Neurology, which had ceased operations in Oct 2016). Proposal recommends to Delete PVFS from *Diseases of the nervous system* chapter and to relocate *Myalgic encephalitis/ Chronic Fatigue Syndrome (ME/CFS)* [sic] to the Signs and Symptoms chapter as a child of *Symptoms, signs or clinical findings of the musculoskeletal system*. There is no indication of the intention for PVFS, or the proposed hierarchies.

The rationale for the proposal is, *"...lack of evidence regarding any neurological etiopathogenesis of chronic fatigue syndrome...When there is sufficient evidence and understanding of the pathophysiological mechanisms, diagnostic biomarkers, and specific treatments, the syndrome can be appropriately classified within the proper block."*

"...ME/CFS is thus not a disease of the nervous system. It should be categorized in the Signs and Symptoms chapter given the lack of clear evidence pointing to the etiology and pathophysiology of this syndrome until evidence to organ placement is clarified in years to come."

Feb 15 2018 Dimmock & Chapman submit counter analysis to Dua proposal on Feb 15 and submit further evidence on March 10.

Statement, Dr Robert Jakob (June 2015): *"I can be crystal clear, there is no proposal to classify the ICD-10 G93.3 terms under the Mental and behavioural disorders chapter."*

Statement, Dr Robert Jakob (March 2017): *"As discussed earlier, chronic fatigue syndrome will not be lumped into the chapter 'signs and symptoms.'"*

Australian Minister for Health (April 2017): *"WHO has advised that the final classification in the ICD-11 will be decided based on an extensive scientific review."*

Jan 29 2018 "Team WHO" post comment under Dua proposal: *"Any decisions regarding this entity are on hold until the results of a review become available."*

Dec 2017 Mar 2018 Countess of Mar advised to write to WHO's Dr John Grove *(Director, Information, Evidence and Research)* to discuss concerns, in general, and Dr Dua's failure to provide clarifications, in particular.

Dr Grove provides the following: A systematic evidence review will determine if the category needs to be moved to any other specific chapter of ICD-11. The classifications team organizes the review. The review is expected to be completed by mid-April.

The outcomes will be provided for review by the *Medical Scientific Advisory Committee* (MSAC) and will be posted together with the relevant detail on the proposal platform. New proposals posted on the platform will become part of the workflows of the maintenance mechanism of ICD-11 and be processed in an annual cycle. The draft ICD-11 will be frozen for finalization in preparation of the release on 30 May 2018. The relevant category will in any case be kept separate from the generic 'chronic fatigue' (signs and symptoms)*.

(There has been no indication of whether a scientific review was concluded in April, what the outcome was, or whether any potential new proposals are with the MSAC.)

*There is no 'chronic fatigue' concept in Signs and Symptoms. There is a concept "Fatigue" (was "Malaise and fatigue" in ICD-10). On March 26, 2017, a long-standing proposal for Exclusions for CFS and ME under "Fatigue" was Approved by the Beta Admins. A proposal for Deletion of the ICD-10-CM concept term "chronic fatigue, unspecified" from under Synonyms to PVFS has been marked as "Implemented".

Whatever is in the Beta draft at the point at which the draft is frozen at the end of May should go forward to the initial release in June, though not all chapters may include "Description" texts.

After release, ICD Revision might potentially post new proposals for PVFS, ME and CFS via the Proposal Mechanism, which will remain open for submission of new proposals.

PVFS in the ICD-11 Foundation view

PVFS in the ICD-11 Mortality and Morbidity Statistics Linearization

To view or comment on Proposals or to add comments to the Beta listings you will first need to register here https://icd.who.int/dev11/Account/Register

Notes:

1 The retirement, in May 2010, of Parent: *G93 Other disorders of brain* as part of the restructuring of the *Diseases of the nervous system* chapter affected seven other category terms that had sat under the *G93* parent block, in addition to *G93.3 Postviral fatigue syndrome* and its associated terms [1].

2 Part of the remit of the ICD Revision *Topic Advisory Groups (TAGs)*, as set out in the *Terms of Reference*, had been to identify existing ICD-10 terms and new terms intended for inclusion in ICD-11 for which reviews of the literature might be considered and to undertake evidence reviews.

Mindful of this, in July 2015, Dimmock and Chapman had provided substantial evidence, reports and other background materials to Dr Robert Jakob and *TAG Neurology* to inform the Revision process.

3 **ICD-11 precedence on relocation:** General considerations for potential chapter relocations were discussed at a meeting of the *Joint Task Force*, in July 2016 [2].

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."*

Also in *ICD-11 Reference Guide* Draft, 2017-10-09, Page 20-21:

*"**3.4 Guiding Principles:** Allocation of entities in the classification follows a set of rules that serve to maintain the structural and functional integrity of the classification. The core set of rules listed here is complemented by additional rules that address special cases or serve to ensure consistent user guidance (see annex). They are listed in order of priority.*

1. No changes to the classification, including movement of categories or groups between chapters, without rationale and documented change in aetiology or prevention method." [3].

References:

1 iCAT Change Notes:
https://dxrevisionwatch.files.wordpress.com/2010/05/2icatnotegj92cfs.png
https://dxrevisionwatch.files.wordpress.com/2010/05/2icat06vineedingadecisiontobemadenote.png

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

3 Reference Guide Draft 2017-10-09, Pages 20-21
https://icd.who.int/dev11/Downloads/Download?fileName=refguide.pdf