Q & A version 1, April 2017

Proposal for the ICD-10 G93.3 legacy terms for ICD-11, submitted by Suzy Chapman and Mary Dimmock on March 27, 2017

If you have a question relating to our proposal, to the Beta draft as it currently stands, or to the development of ICD-11, please contact me at dxrevisionwatch@page1.myzen.co.uk and I will add your question to the next version of this FAQ.

Q1 addresses the question: *Why did we not propose that CFS should be retired?* If you are also able to read the other Qs, this will help place the decisions we made when drafting our submission in the context of information that could not be included within our proposal.

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Q1: Your proposal for ICD-11 does not recommend retiring CFS. Why is that?

A: Realistically, CFS cannot be retired from the classification at this time.

Some patients and advocates have expressed concerns that our proposal does not recommend retirement of CFS. We share concerns about the CFS term.

However, realistically, chronic fatigue syndrome cannot be removed from ICD at this time because the term will continue to be used clinically, is required for social security, insurance and reimbursement and will still be included in other globally used electronic health record systems.

For example, chronic fatigue syndrome is specified as the preferred concept term in SNOMED CT International Edition and its National Extensions. ICD-11 has been designed to link with SNOMED CT and the cross mapping between the two terminology systems is in preparation.

If ICD Revision could be persuaded to retire the term, the owners of SMOMED CT would need to be convinced, too. SNOMED CT is used in over 80 countries. As mentioned in Q5, SNOMED CT will be adopted in the UK for NHS primary care use by 2018, replacing the Read Codes (CTV3) terminology system and is scheduled for implementation across *all* NHS clinical settings by 2020.

Since ICD Revision was proposing between 2010-2013 that CFS should be elevated to the lead (or "concept title") term, and in the absence of any alternative consensus proposals from the work group since early 2013, we considered it unlikely that a strong enough case for retiring the term, *at this point*, could be built.

Unlike the U.S.'s ICD-10-CM, ICD-11 won't implement, globally, on a specific date – it will be a staggered and lengthy adoption process.

Over a hundred countries use ICD-10, including countries licensed by WHO to develop national modifications, like Canada, the U.S. and Germany, which already have CFS in their Tabular Lists.

WHO requires statistical comparability between one ICD edition to another for data analysis. During the transition period (which will span several years and potentially longer, in the case of Canada and the U.S.), statistics will continue to be collected using ICD-10 alongside data using the new version, until the majority of Member States have implemented the new edition.

Given these considerations, we consider there is a strong possibility that ICD Revision would reject outright any submission that includes a proposal for the retirement of the CFS term, during the early years of the transition process where data collected from two editions will be aggregated for analyses.

At some future point, scientific advances will hopefully provide robust evidence to support a case for retirement of the CFS term and/or for relocation of ME to another chapter, or for parenting ME under multiple chapters, or for creation of a specific parent class for ME, at which point, new proposals can be submitted via the annual update and revision process.

ICD Revision's, Dr Christopher Chute, wrote to me, on February 22: *"What is produced say in 2018 will continue to evolve, ICD11 is designed for graceful evolution. It may differ in substantial ways by the time the first country implements it, say 5-6 years from now from what is put forth in 2018."*

There was uncertainty around ICD Revision's intentions for the three legacy terms while we were drafting our proposal and that uncertainty continues. Given the March 30 deadline for submission of proposals for potential inclusion in the initial 2018 release, *the absence of any proposals from the work group and the non disclosure of the WHO classification experts' and Joint Task Force's position on these terms*, it was considered strategically preferable to propose what we felt stood a chance of consideration than to submit recommendations we felt risked outright rejection.

Q2: Are PVFS, (Benign) ME and CFS classified the same across all versions of ICD-10?

A: No. The classification of the three terms in the national modifications, ICD-10-CA, ICD-10-CM and ICD-10-GM, all differ from each other and from the WHO's ICD-10.

In the WHO's ICD-10: PVFS is the lead (or "concept title") term coded at G93.3 in the Tabular List, in Chapter VI: *Diseases of the nervous system*. (Benign) ME is the inclusion term under PVFS and takes the G93.3 code. CFS is included only in the Index and directs coders and clinicians to G93.3.

In Canada's ICD-10-CA: PVFS is the lead (or "concept title") term coded at G93.3 in the Tabular List, in Chapter VI: *Diseases of the nervous system*. (Benign) ME and CFS are both specified as inclusion terms under PVFS and take the G93.3 code.

In the U.S.'s ICD-10-CM: PVFS is the lead (or "concept title") term coded at G93.3 in the Tabular List, in Chapter 6: *Diseases of the nervous system*. (Benign) ME is the inclusion term under PVFS and takes the G93.3 code. But CFS (as "Chronic fatigue syndrome NOS") is coded in Chapter 18: *Symptoms, signs etc*. as an inclusion term to R53.82 Chronic fatigue, unspecified.

In Germany's ICD-10-GM: Chronisches Müdigkeitssyndrom [Chronic fatigue syndrome] is the lead (or "concept title") term coded at G93.3 in the Tabular List, in Chapter VI: *Diseases of the nervous system*. There are three inclusion terms: Benigne myalgische Enzephalomyelitis; Chronisches Müdigkeitssyndrom bei Immundysfunktion; and Postvirales Müdigkeitssyndrom that take the G93.3 code.

Q3: How is ICD Revision proposing to classify the G93.3 legacy terms?

A: We still don't know.

From 2012 to early 2013, the ICD-11 Beta draft was proposing chronic fatigue syndrome as the lead (or "concept title") term. (Benign) ME was specified as the inclusion term under CFS and took the same code. PVFS was deprecated to synonyms, with 13 associated and historical terms.

In early 2013, all three terms were removed from view in the public version of the Beta draft, with no explanation from ICD Revision for their absence.

Advocates, patient organizations and a parliamentarian attempted to obtain transparency from ICD Revision around the Topic Advisory Group (TAG) for Neurology's intentions for these terms.

For over four years, stakeholders had been disenfranchised from scrutinizing and commenting on proposals, or submitting their own proposals in the context of the TAG's recommendations.

On March 26, the day before we had completed uploading our proposal text and hit the *Submit* button, the three terms were unexpectedly restored to the Beta draft – but with 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. *Team WHO 2017-Mar-26 – 12:46 UTC*

This suggests that despite the March 30 proposal deadline and the need for the Beta draft to be finalized by the end of 2017, the work group has still not reached consensus among its members or reached consensus with the WHO classification experts and the Joint Task Force.

Therefore we should view the restoration of the terms as a "placeholder" only, since the work group might be intending to release further proposals, later this year, *which may be too late for consideration for inclusion in the 2018 release of ICD-11 and may need rolling forward to 2019.*

This could potentially leave the Beta with *no TAG proposals* for these terms when the Beta is finalized, at the end of 2017, in preparation for presentation to the WHA, in May 2018.

It is important to note that the recommendations of the various Topic Advisory Groups (TAGs) are advisory, only. WHO classification experts and the Joint Task Force make the final decisions. So if TAG Neurology did release further proposals later this year, they may not obtain approval.

Dr Christopher Chute is chair of the ICD Revision Steering Group and a member of the Joint Task Force that has oversight of the finalization of ICD-11. On February 22, Dr Chute wrote to me:

> *"[The issue of the missing terms] was discussed today in Köln. Evidently, there are plans to include these terms as index entries. I would advise, that you: a) Create a Beta draft proposal entry for these terms and/or b) Identify an existing draft proposal and add evidence."*

But he added that these terms were not within his personal area of expertise or responsibility, so he could not give me informed answers to my specific questions.

WHO's Dr Robert Jakob and the Joint Task Force co-chairs have been asked to clarify whether Dr Chute had correctly understood the situation, as it had stood at that point, and which of the three terms were being proposed, potentially, as index entries. But they have failed to clarify.

Possibly the TAG had been considering, at one point, making CFS the only "concept title" term and including BME and PVFS as index entries, only; or possibly considering the term "SEID" as a replacement for all three G93.3 terms - but we do not know because they have not clarified.

Q4: Is there any proposal to classify the terms under Mental or behavioural disorders?

A: WHO/ICD Revision has given four written and verbal assurances that there is no proposal and no intention to classify the terms under the *Mental, behavioural or neurodevelopmental disorders* chapter.

Dr Jakob also told me: *"...chronic fatigue syndrome will not be lumped into the chapter 'signs and symptoms'. We certainly will share the rationale for any decision." (personal correspondence: March 17, 2017. Ccd: ICD Revision staff; Countess of Mar)*

Since March 26, all three terms were restored to the public version of the Beta draft in Chapter 08: *Diseases of the nervous system*, under parent: *Other disorders of the nervous system.*

PVFS is currently listed as lead (or "concept title") term. BME and CFS are both specified as inclusion terms to PVFS, which brings CFS into the Tabular List from its ICD-10 location as an index entity, only. All other "Content Model" descriptive content appears much as the Beta had stood in 2009, ie in the early stages of the process before the Alpha draft was launched.

It isn't known whether Dr Jakob or the Joint Task Force decided to restore the terms to the public Beta with their 2009 hierarchy (as opposed to how they had stood in early 2013), or whether this was a decision taken by the Topic Advisory Group for Neurology in response to advocacy approaches or the imminent March 30 proposals deadline, since no rationale has been posted.

But given the caveat, it remains uncertain what the TAG might be considering for these terms, by what date any consensus proposals might be released, and whether any further proposals would be posted in the Proposal Mechanism and subject to the internal ICD Revision review process or entered straight into the Beta listings, as already "Approved/Implemented."

A note on Exclusions: When the three terms were restored to the public Beta draft, on March 26, "Team WHO" also approved and implemented two outstanding proposals which I had submitted in December 2014, proposing exclusions for (Benign) ME and for Chronic fatigue syndrome under Fatigue (Malaise and fatigue in ICD-10) in the *Symptom, signs etc.* chapter.

A third proposal, in December 2014, for an exclusion for PVFS under Fatigue has yet to be approved. I have requested a rationale for this anomaly, since ICD-11 convention suggests that if a concept title's inclusion terms are specified as Exclusions under another ICD-11 entity, the concept title term would also be specified as an Exclusion. Whether this is an oversight or whether the TAG is considering locating PVFS under Fatigue (but not CFS), remains unclarified.

Q5: Will ICD-11 look and function differently to ICD-10?

A: Yes. ICD-11 will be a web based classification designed to be used in electronic health information systems and to link to other computerized health information and terminology systems, like SNOMED CT. It is considerably more complex than ICD-10.

SNOMED CT is used in electronic patient records to capture patient information at the time and point of clinical care. ICD is used to report and summarise an episode of care after the event and in accordance with requirements for data collection for statistical and epidemiological analysis, reimbursement and resource allocation.

The owners of SNOMED CT and WHO have a collaborative agreement to work towards alignment between SNOMED CT and ICD-11 and preparation of cross mappings is in progress.

In the UK, SNOMED CT will have replaced the CTV3 (Read Codes v3) classification system, that is used in NHS primary care settings, by 2018, and is scheduled for adoption across all NHS clinical settings by 2020. It won't replace ICD, which will continue to be used for statistical and epidemiological analyses. The UK is involved in the current field testing of the utility of ICD-11 but no date has yet been set for when the NHS will transition from ICD-10 to ICD-11.

In ICD-10, apart from Chapter V: *Mental and behavioural disorders,* there is very little descriptive content attached to each category term. For ICD-11, *all* categories will potentially have descriptive content, known as the "ICD-11 Content Model" which includes Definitions and other descriptors (though for many terms, definitions have still to be drafted, approved and populated). Coders will be cautioned not to use the definitions to establish a diagnosis.

For ICD-11, additional chapters have been added (there are now 27 chapters); chapters and category blocks have been restructured; the coding structure is different, too (so no more "G93.3"). A computerized system allows parent, child and grandchildren terms to be arranged hierarchically; hundreds more category terms and new parent classes have been added.

There are two views to the ICD-11 platform: a "Foundation" component, which contains all the ICD-11 entities. From this "Foundation" database, various linearizations or sub sets can be generated, for example, for Mortality and Morbidity Statistics (MMS) or for more specialized linearizations. Not all terms listed in the Foundation will be included in the MMS Linearization.

One of the biggest changes between ICD-10 and ICD-11, is the concept of "multiple parenting." Previous editions of ICD have organized diseases into chapters based on aetiology or affected organ or body system and any given category can be assigned under *only one parent*.

But for ICD-11, the new structure allows for categories to be assigned under more than one hierarchical parent; so a single condition may be represented in more than one location. This means that diseases like skin cancers, which belong to both Chapter 02: *Neoplasms* and to Chapter 14: *Diseases of the skin*, can be assigned a "primary" parent location and coded under one chapter but can also be listed under a "secondary" parent class, in another chapter.

This also permits multisystem diseases that belong to or affect multiple body systems, for example, systemic lupus erythematosus (SLE) and Behçet disease, to be listed under two or more parents within the same chapter or listed under two or more chapters.

For ICD-11, the Mortality and Morbidity Statistics (ICD-11 MMS) will be known as Volume 1 (the equivalent of the ICD-10 Tabular List). There will be a Reference Guide (Volume 2); an Index (Volume 3) and the Foundation is expected to be known as Volume 4. A number of specialty editions and an abridged version of the *Mental or behavioural disorders* chapter for use in primary care and low resource settings are also in development.

Q6: What is the implementation date for ICD-11?

A: There will be no mandatory date by which Member States must implement ICD-11.

WHO is currently planning to release a version of ICD-11 at some point in 2018, following presentation at the May 2018 World Health Assembly (WHA). To meet this target, the Joint Task Force will need to have ICD-11 finalized by the end of 2017.

WHO won't be seeking endorsement of the new edition until later, because ICD-11 won't be fully completed by May 2018 and because Member States will need time to evaluate the new edition and prepare their electronic health information systems for implementation. Countries will transition from ICD-10 to ICD-11 at their own pace, with no mandated implementation date.

WHO has committed to supporting ICD-10 until the majority of countries have implemented ICD-11. After the projected 2018 release, data will continue to be collected using ICD-10. Backward comparability between ICD-11 and ICD-10 has been built in and at some point, data will be accepted using the new edition at the same time as continuing to collect data using ICD-10.

Once a finalized version of ICD-11 has been released, it is anticipated that countries will require several years to prepare for transition. So adoption of ICD-11 by Member States will be a staggered process over a number of years and low resource countries and countries that need to develop a modification of ICD-11 will take longer to adopt the new edition. Canada's CIHI has said the earliest Canada could adopt a modification of ICD-11 is 2023. The U.S.'s CDC has said it will take the U.S. at least 6 years from ratification of the codes to adapt, field test, prepare and implement an ICD-11-CM and ICD-11-PCS.

Following release, in 2018, the new edition will be placed on an annual maintenance and update schedule. It is projected that proposals for corrections, revisions and additions submitted by Member States and Collaborating Centres will be considered as they are received and that being an electronic system, the new edition will facilitate a more rapid response to scientific advances.

It is projected that each year's release will be styled "ICD 2018", "ICD 2019", "ICD 2020" etc. The platform is designed for "graceful evolution"; there may never be the need for an "ICD-12."

Q7: Is ICD-11's proposed new category "Bodily distress disorder" the same as Fink's "Bodily distress syndrome"?

A. No. As defined by ICD-11, "Bodily distress disorder" is very close to the DSM-5's Somatic symptom disorder.

For ICD-11, the *Somatic Distress and Dissociative Disorders Working Group (S3DWG)* is proposing to replace ICD-10's F48.0 Neurasthenia and all the F45.0 - F45.9 somatoform disorder categories (with the exception of F45.2 Hypochondriasis) with a new and much simplified, *single* diagnostic category, for which the current suggested name is "bodily distress disorder (BDD)."

As defined for ICD-11, the bodily distress disorder diagnostic construct has strong conceptual, characterization and criteria alignment with DSM-5's somatic symptom disorder, and in the ICD-11 Beta, somatic symptom disorder is listed under Synonyms to bodily distress disorder.

Despite claims by some websites, some practitioners and the media, there has been no adoption of the Fink et al Bodily distress syndrome (BDS) diagnostic construct for ICD-11.

For both bodily distress disorder (as defined for ICD-11) and DSM-5's somatic symptom disorder, the distinction between medically explained and medically unexplained somatic complaints has been abolished. There is no longer the requirement for symptoms to be "medically unexplained" in order to meet the criteria, and the symptoms may or may not be associated with another medical condition: *"If another health condition is causing or contributing to the symptoms, the degree of attention is clearly excessive in relation to its nature and progression."*

ICD-11's proposed BDD diagnosis can be applied to a percentage of patients with any general medical condition like cancer, cardiovascular disease, COPD or diabetes, as well as a percentage of the so-called, functional somatic syndromes, if the clinician considers the patient also meets the criteria for BDD (or meets the very similar criteria for SSD, if using DSM-5).

So there is the potential for all patients diagnosed with medical conditions (or waiting for a diagnosis) to attract an additional diagnosis of BDD or to be misdiagnosed with BDD. Patients diagnosed with chronic fatigue syndrome or myalgic encephalomyeltis, or awaiting a diagnosis, may be particularly vulnerable to misdiagnosis with, or misapplication of, an additional diagnosis of bodily distress disorder.

In our proposal, we have recommended reciprocal exclusions for bodily distress disorder for ME and CFS. I have also separately proposed reciprocal exclusions for bodily distress disorder for all three G93.3 legacy terms.

The Fink et al. (2010) "bodily distress syndrome" disorder construct, that is already in use in Denmark and in several other EU countries, in research and clinical settings, *is differently conceptualized, has a very different criteria set and is intended to capture a different patient population* to DSM-5's SSD and to ICD-11's defining and characterization of BDD.

Fink et al. (2010) consider their "bodily distress syndrome" disorder construct has the ability to capture the ICD-10 somatoform disorders, neurasthenia, "functional symptoms", noncardiac chest pain, chronic pain disorder, MCS and some others, but to **also subsume and replace** chronic fatigue syndrome, myalgic encephalomyeltis, fibromyalgia and irritable bowel syndrome under a **single**, unifying "BDS" diagnosis.

(The various so-called specialty "functional somatic syndromes" are considered by Fink and colleagues to be an artifact of medical specialization and manifestations of a similar, underlying disorder with a common, hypothesized aetiology.)

The Fink et al's BDS diagnosis cannot be applied to distressing bodily symptoms associated with general medical conditions, and the criteria, rather than being based on "excessive psychological responses," are based on symptom clusters from various body or organ systems.

So ICD-11's BDD and Fink et al's BDS are inconsistently defined and characterized, with different criteria sets and they potentially capture different patient populations.

However, the "bodily distress disorder" term has a history of usage in the literature and in the field interchangeably with that of the already operationalized, divergent, Fink et al. (2010) disorder construct.

Since researchers, clinicians and commissioners of services already do not differentiate between

these two terms (and in some cases, one sees the terms conflated as "bodily distress syndrome or disorder" and "bodily distress syndrome/disorder"), some patient groups will be especially vulnerable to being misclassified.

I have raised the alarm, with ICD Revision, for the diagnostic and statistical implications for confusion and conflation between the two diagnoses, and the difficulties for maintaining disorder construct integrity, within and beyond the ICD-11 classification system.

I have separately proposed that BDD should be renamed, or preferably deleted.

For an expanded discussion on BDD and BDS see:
our **Proposal Rationale point 3.3 and 3.4:** http://bit.ly/2mQxWTS
and my **Proposal for Deletion of Bodily distress disorder:** http://wp.me/pKrrB-4dc

Q8: Where can I view the Beta draft and comment on your proposal?

A: You can access the Beta draft here: http://apps.who.int/classifications/icd11/browse/f/en

The current listing for PVFS, (Benign) ME and CFS is here:

Foundation view:
http://apps.who.int/classifications/icd11/browse/f/en#/http://id.who.int/icd/entity/569175314

MMS Linearization: http://apps.who.int/classifications/icd11/browse/l-m/en#/http://id.who.int/icd/entity/569175314

But if you want to view or comment on our proposal, this is located in a section of the Beta draft known as the "Proposal Mechanism". For access to this section you will first need to register an account with the Beta platform. If you prefer, you can register using an existing Google, Yahoo!, Linkedin, Facebook or MS account.

For ease of access, we've put a copy of our Proposal and Rationale into a PDF, which you can download here: http://bit.ly/2mQxWTS

This is the Beta registration page: http://bit.ly/ICD11Registrationpage

There is a WHO tutorial video on how to register, here: http://bit.ly/ICD11regtutorial

Once registered and logged in, to view and Comment on proposal go straight to this page:
http://bit.ly/commentICD11

The **"Agree"** button is located underneath the blue clickable list of References at the end of our proposal. The **"add new comment"** button is located right at the bottom of the web page, directly under the most recent comment.

On my *Dx Revision Watch* site there is a summary of our proposal: http://bit.ly/ICD11proposal

There is a one page **"Key points on current ICD-11 Beta proposals"** here:
http://bit.ly/2oD51DA

For a good overview of the structure and functionality of ICD-11 by NHS Digital see:
https://sway.com/ADbCPTecRhtlDb4U

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