

# Update on classification and coding of PVFS, ME and CFS for ICD-11

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## What is the “ICD”?

The International Classification of Diseases (ICD) is the global classification and diagnostic standard of diseases for use in epidemiology, health management, clinical practice and research. ICD is maintained and published by the World Health Organization (WHO). It is used to classify and monitor causes of injury and mortality (cause of death) and to monitor morbidity (illness and disease) trends for analysing data compiled from many types of health and other records, including death certificates and insurance.

More than 100 countries (WHO Member States) use the ICD system to report mortality statistics. ICD is increasingly used in clinical care and research to define diseases, study disease patterns, manage health care, monitor outcomes and inform policy makers on health related spending and resource allocation.

## What is the current revision of the WHO’s international version of ICD?

The current revision of ICD is the 10th Revision [1]. The WHO has said that the final update for ICD-10 will be the 2019 release but Member States can continue to use ICD-10 until they have prepared their health systems for transition to ICD-11.

## How are the terms: postviral fatigue syndrome; myalgic encephalomyelitis; and chronic fatigue syndrome currently classified in ICD-10?

Image 1: ICD-10 Browser Version: 2019, Accessed February 15, 2020: <https://icd.who.int/browse10/2019/en#/G93.3>

The screenshot shows the ICD-10 Browser interface for the 2019 version. The search bar contains 'Postviral fatigue syndrome'. The left sidebar shows a tree view of categories, with 'G93.3 Postviral fatigue syndrome' highlighted. The main content area displays the details for G93.3, including the term 'Postviral fatigue syndrome' and the sub-term 'Myalgic encephalomyelitis'. Other categories like G93.2 and G93.4 are also visible.

For this final update of ICD-10, the WHO has removed the “Benign” prefix from the Tabular List inclusion term “Benign myalgic encephalomyelitis”. “Benign myalgic encephalomyelitis” has been retained as an Index term. The deprecation of the “Benign” prefix sets a precedent for the various national modifications of ICD-10, and also for ICD-11. In February 2020, I submitted a new proposal for retirement of the “Benign” prefix for ICD-11, which has yet to be processed. You can read a copy of my proposal and rationale here: <http://bit.ly/BenignICD11>

**For ICD-10 Version: 2019, Postviral fatigue syndrome** is specified as the ICD-10 **Concept Title** term. It is classified in **Volume 1: Tabular List** in Chapter VI: *Diseases of the nervous system* (the neurological chapter) at code **G93.3**, under category block G90-G99 *Other disorders of the nervous system* > G93 *Other disorders of brain*.

**Myalgic encephalomyelitis** is the Tabular List **inclusion term** under G93.3 Postviral fatigue syndrome.

There is an exclusion for “postviral fatigue syndrome (G93.3)” under F48.0 Neurasthenia and its inclusion, Fatigue syndrome. There is also an exclusion for “fatigue syndrome • postviral (G93.3)” under R53 Malaise and fatigue [2].

For the WHO’s international version of ICD-10, **Chronic fatigue syndrome** is not included in the Tabular List but is indexed to the G93.3 code in the **Alphabetical Index (Volume 3)**.

## Are all Member States using the same version of ICD-10?

No. Around 25 Member States have been licensed by the WHO to adapt the ICD-10 classification for the collection of morbidity (illness and disease) data. These are known as “national modifications” or “clinical modifications” and their category content and code structure varies from the WHO’s unmodified ICD-10.

Member States which have developed clinical modifications of ICD-10 include: Canada, Germany, the United States (also used by Belgium, Luxembourg and Spain), Australia (also used by Ireland and Slovenia) and Thailand.

## How do Canada, Germany and the United States classify the G93.3 terms?

**Canada (ICD-10-CA):** Postviral fatigue syndrome is the G93.3 Tabular List Concept Title. Benign myalgic encephalomyelitis; and Chronic fatigue syndrome are **both** included in the Tabular List under G93.3.

**Germany (ICD-10-GM):** Chronisches Müdigkeitssyndrom [Chronic fatigue syndrome] is the G93.3 Concept Title. There are **three** inclusions at G93.3 in the Tabular List: Chronisches Müdigkeitssyndrom bei Immundysfunktion; Myalgische Enzephalomyelitis; and Postvirales Müdigkeitssyndrom.

**United States (ICD-10-CM):** Postviral fatigue syndrome is the G93.3 Tabular List Concept Title. Benign myalgic encephalomyelitis is the inclusion term under G93.3 in the Tabular List.

But Chronic fatigue syndrome (as “chronic fatigue syndrome NOS”) is classified in the Tabular List in *Chapter 18: Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified* as an inclusion under code R53.82 Chronic fatigue, unspecified. (NOS = Not Otherwise Specified.)

There is an Excludes1: postviral fatigue syndrome (G93.3) exclusion under the R53.82 code and a reciprocal Excludes1: chronic fatigue syndrome NOS (R53.82) exclusion under the G93.3 code.

**Note: The United States’ ICD-10-CM (which has been adopted for use by Belgium, Luxembourg and parts of Spain) is the only national modification of ICD-10 that classifies chronic fatigue syndrome (as “chronic fatigue syndrome NOS”) under the *Symptoms, signs* chapter — not under G93.3 Postviral fatigue syndrome in the *Diseases of the nervous system* chapter.**

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2 PDF versions of ICD-10 (Fifth edition v 2016) Volume 1: Tabular List and Volume 3: Alphabetical Index are now available as free downloads from the WHO’s IRIS document archive: <https://apps.who.int/iris/handle/10665/246208>

(For listing of PVFS and BME, see p376) ICD-10 (Fifth edition v 2016) Volume 1: Tabular List (9.952 Mb): <https://apps.who.int/iris/bitstream/handle/10665/246208/9789241549165-V1-eng.pdf>

(For indexing of CFS, see p604) ICD-10 (Fifth edition v 2016) Volume 3: Alphabetical Index (3.110 Mb): <https://apps.who.int/iris/bitstream/handle/10665/246208/9789241549165-V3-eng.pdf>

## How are the ICD-10 G93.3 terms being classified for ICD-11?

From 2008, the WHO began assembling external working groups (known as “Topic Advisory Groups” or “TAGs”). Topic Advisory Groups reported directly to the ICD-11 Revision Steering Group and were tasked with reviewing chapter content and hierarchical structure of ICD-10, conducting literature reviews, making recommendations for revisions, proposing additional terms for ICD-11 and drafting description texts.

The role of the TAGs and their sub working groups was advisory and final decisions rested with WHO classification experts and the Revision Steering Group; later with the Revision Task Force, and more recently with the ICD-11 Classifications and Statistics Advisory Committee (CSAC) and the Medical Scientific Advisory Committee (MSAC). Some proposed new categories were subject to field testing.

The TAG with responsibility for the G93.3 terms was **TAG Neurology**, chaired by Prof Raad Shakir.

A full account of the tortuous progression of the G93.3 terms through the 9 year long ICD-11 Alpha and Beta drafting stages and the advocacy undertaken is beyond the scope of this update. But in summary:

- As the ICD-11 Beta draft stood in early 2013, TAG Neurology was recommending that Chronic fatigue syndrome should replace Postviral fatigue syndrome as Concept Title term, with Benign myalgic encephalomyelitis retained as the specified inclusion. Postviral fatigue syndrome was recommended to be relocated under a list of 14 historical and alternative Synonyms/Index terms.
- In early 2013, all three terms were unaccountably removed from view in the public version of the Beta platform, making it difficult for stakeholders to monitor, input or comment on proposals.
- In March 2017, the terms were restored to the public version of the Beta drafting platform under parent block: *Other disorders of the nervous system*, with Postviral fatigue syndrome as the Concept Title. Benign myalgic encephalomyelitis; and chronic fatigue syndrome were **both** specified as inclusion terms. I was informed by Dr Robert Jakob that, *“While the optimal place in the classification is still being identified, the entity has been put back to its original place in ICD.”*
- In March 2017, Chapman & Dimmock submitted a detailed proposal and rationale requesting, among other recommendations, that Postviral fatigue syndrome should be removed as the Concept Title term; that Myalgic encephalomyelitis and Chronic fatigue syndrome should both be elevated to the level of Concept Titles and that a unique code should be assigned to each term.
- In March 2017, Lily Chu MD submitted a proposal on behalf of the IACFS/ME, requesting that all three terms should be elevated to Concept Titles and a unique code assigned to each term.

Dr Tarun Dua is a medical officer working on the *Program for Neurological Diseases and Neuroscience, Management of Mental and Brain Disorders*, Department of Mental Health and Substance Abuse, World Health Organization, and had served as Lead WHO Secretariat and Managing Editor to TAG Neurology. TAG Neurology had ceased operating in October 2016 when a number of TAGs were stood down.

- In November 2017, Dr Dua submitted a proposal which she later clarified was being submitted on behalf of TAG Neurology and which she said, *“reiterates the TAG’s earlier conclusions.”*

Since the WHO had stated that decisions about potential changes to these terms were on hold pending completion of a literature review, it was unclear how this new proposal sat in relation to this review, which was understood to be still in progress. It was also unclear if this submission was supported by the WHO or represented only the position of TAG Neurology and Dr Dua, its former Managing Editor.

**Dr Dua’s proposal recommended that “Myalgic encephalitis/Chronic Fatigue Syndrome (ME/CFS)” [sic] should be removed from the *Diseases of the nervous system* chapter and reclassified in *Chapter 21: Symptoms, signs or clinical findings, not elsewhere classified*, as a child category under parent block: *Symptoms, signs or clinical findings of the musculoskeletal system*.**

- In November 2018, the WHO rejected Dr Dua's proposal. In the brief rationale for their decision, the WHO stated that following completion of their literature review, they had concluded that Postviral fatigue syndrome should remain the indexing target, that there was currently no evidence to suggest a better place to relocate these terms and that the three terms would remain classified within the *Diseases of the nervous system* chapter.

The WHO further confirmed their decision was supported by the ICD-11 Classifications and Statistics Advisory Committee (CSAC) and the Medical Scientific Advisory Committee (MSAC). This decision was also noted in a November 2018 presentation given by the WHO's Dr Robert Jakob and referenced in the Summary Report of the October 2018 WHO-FIC Network Annual Meeting.

**To recap:** Postviral fatigue syndrome remains the **Concept Title** for ICD-11 and remains classified in the *Diseases of the nervous system* chapter (which is renumbered **Chapter 08** for ICD-11).

Postviral fatigue syndrome's new code is **8E49** and its parent block is **Other disorders of the nervous system**. (The ICD-10 G93 legacy parent block "Other disorders of brain" has been retired for ICD-11.)

**Benign myalgic encephalomyelitis** and **chronic fatigue syndrome** are both specified as inclusion terms within the ICD-11 Foundation and ICD-11's equivalent to the Tabular List, and assigned code **8E49**. Code **8E49** maps directly to the ICD-10 **G93.3** code in the ICD-11 to ICD-10 Mapping Tables.

Image 2: ICD-11 for Mortality and Morbidity Statistics (Version: 04/2019), Accessed November 01, 2019: <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2f569175314>

**ICD-11 for Mortality and Morbidity Statistics** (Version : 04 / 2019)

Search  [ Advanced Search ] Browse Coding Tool

- Disorders of consciousness
- Other disorders of the nervous system**
  - 8E40 Disorders of the meninges excluding infection
  - 8E41 Pachymeningitis
  - 8E42 Superficial siderosis of the nervous system
  - 8E43 Pain disorders
  - 8E44 Post anoxic brain damage
  - 8E45 Locked-in syndrome
  - 8E46 Reye syndrome
  - 8E47 Encephalopathy, not elsewhere classified
  - 8E48 Encephalitis, not elsewhere classified
  - 8E49 Postviral fatigue syndrome**
  - 8E4A Paraneoplastic or autoimmune disorders of the nervous system
  - MH10 Brain death
  - 4B20.3 Neurosarcoidosis

Foundation Id : <http://id.who.int/icd/entity/569175314>

### 8E49 Postviral fatigue syndrome

**All ancestors up to top**

- 08 Diseases of the nervous system
- Other disorders of the nervous system
- 8E49 Postviral fatigue syndrome

**Inclusions**

- Benign myalgic encephalomyelitis
- chronic fatigue syndrome

**Exclusions**

- Fatigue (MG22)

The current version of the "Blue Implementation Browser" does not display the list of 14 alternative and historical Synonyms/Index terms. These are viewable in the "Orange Browser" (click on "Show all index terms [14]" to display the Index term list): <https://icd.who.int/dev11/l-m/en#/http://id.who.int/icd/entity/569175314>

The **Coding Tool** serves as ICD-11's electronic Index. All 14 index terms are searchable in the database and direct coders and clinicians to the 8E49 code: [https://icd.who.int/ct11/icd11\\_mms/en/release](https://icd.who.int/ct11/icd11_mms/en/release)

**Exclusions under Fatigue:** For ICD-11, the ICD-10 category R53 Malaise and fatigue has been revised to MG22 Fatigue. For ICD-10, there is an exclusion for the G93.3 code under R53 Malaise and fatigue **but this legacy exclusion had not been carried forward to the ICD-11 Alpha and Beta drafts.**

In December 2014, I submitted proposals for addition of exclusions for Postviral fatigue syndrome; (Benign) myalgic encephalomyelitis; and Chronic fatigue syndrome under MG22 Fatigue. **These were approved and implemented in April 2019 and can be seen at the end of the Exclusions list at:** <https://icd.who.int/dev11/f/en#http%3a%2f%2fid.who.int%2fcd%2fentity%2f1109546957>

In January 2018, I submitted a proposal and rationale for the deletion of the term, “chronic fatigue, unspecified” (which is specific to the US’s ICD-10-CM) which had been included in the Index terms list for 8E49 Postviral fatigue syndrome. This was approved and the term deleted in March 2019.

## Which proposals for ICD-11 have not been approved?

The proposals submitted by Chapman & Dimmock (March 2017) for removing PVFS as Concept Title and assigning two unique Concept Title codes for ME and CFS; and by Lily Chu MD on behalf of IACFS/ME (March 2017) for assigning three unique Concept Title codes for PVFS; ME; and CFS were not approved.

The proposals submitted by Chapman & Dimmock (March 2017) and by Lily Chu MD on behalf of IACFS/ME (March 2017) for removing the word “Benign” from “Benign myalgic encephalomyelitis” were not approved. (Note: the terms “myalgic encephalomyelitis” and “ME - [myalgic encephalomyelitis]” are included under the Synonyms/Index terms list and are assigned the 8E49 code in the Coding Tool.)

The proposals submitted by Chapman (March 2017), Chapman & Dimmock (March 2017) and by Lily Chu MD on behalf of IACFS/ME (March 2017) for exclusions for the three 8E49 terms under 6C20 Bodily distress disorder and for reciprocal exclusion of Bodily distress disorder under 8E49 were not approved.

**In February 2020, I submitted a new proposal for retirement of “Benign” for ICD-11. This has not yet been reviewed and processed. Copy of proposal/rationale here:** <http://bit.ly/BenignICD11>

**In December 2019, I submitted a new proposal for exclusions for the three 8E49 terms under Bodily distress disorder, supported by a [new rationale text](#). WHO approved and implemented my proposal on January 17, 2020. View the implementation of exclusions under Bodily distress disorder here:** <https://icd.who.int/dev11/l-m/en#http://id.who.int/icd/entity/767044268>

## Are definitions for any of the three terms coded to 8E49 included in ICD-11?

In ICD-10, there are no description texts or definitions for any of the G93.3 terms. (For ICD-10, only disorders coded in *Chapter V Mental and behavioural disorders* have description texts.)

For ICD-11, the convention is that Concept Title terms *in all chapters* will have description texts but the textual content for many of these “Description” fields has yet to be authored. At the time of compiling this report, there is no “Description” or “Definition” text proposed by the WHO or by any party for Postviral fatigue syndrome or either of its inclusion terms and the 8E49 Description field remains unpopulated.

## When will Member States start using ICD-11?

The WHO published a stable version of ICD-11 in June 2018. This version was presented as an “advance preview” to enable Member States to undertake consultations with end user stakeholders, evaluate the new system, start planning for implementation, prepare national translations and begin training health professionals. An updated release was published in April 2019. A further release is anticipated this year.

On May 25, 2019, the 72nd World Health Assembly (WHA) voted unanimously to adopt ICD-11. WHA's endorsement of the new edition won't come into effect until **January 01, 2022, which is the earliest date from which Member States can begin using ICD-11 for reporting data.**

Note that there is no mandatory implementation date — Member States will transition from ICD-10 to ICD-11 at their own pace and according to their countries' specific timelines, requirements and resources.

Global adoption of ICD-11 is anticipated to be a prolonged process and during the period of transition, the WHO will be accepting and aggregating data recorded using both ICD-10 and the new ICD-11 code sets.

No countries have announced implementation schedules yet. The WHO anticipates early implementers will take several years to evaluate the new edition, determine how they will use ICD-11, produce training and implementation materials, complete translations and prepare their health systems for migration. The WHO is still formulating policies around licensing for adaptations for country specific morbidity use.

Canada and Australia are in the process of evaluating ICD-11. Australia has launched consultations and published a report: [ICD-11 Review stakeholder consultation report, March 2020](#)

NHS Digital has yet to publish a tentative road-map for implementation of ICD-11. NHS England currently mandates ICD-10 Version: 2016 and the terminology system, SNOMED CT UK Edition. It is understood that a decision has not yet been made as to whether NHS England will be adopting ICD-10 Version: 2019 or skip implementation of Version: 2019 in preference to migrating at some future point directly to ICD-11.

## Where can I view ICD-11?

The "Blue Implementation Browser" for **ICD-11 Mortality and Morbidity Statistics (Version: 04/2019)** can be accessed here: <https://icd.who.int/browse11/l-m/en>

**Mortality and Morbidity Statistics Linearization** (ICD-11 MMS) is the equivalent of the Tabular List. The **ICD-11 Coding Tool** (the electronic index and search engine for coders and clinicians for looking up disease terms and their associated codes) is here: [https://icd.who.int/ct11/icd11\\_mms/en/release](https://icd.who.int/ct11/icd11_mms/en/release)

The ICD-11 "Blue Browser" does not currently display the index terms. These can be seen in the **Update and Maintenance Platform** (the "Orange Browser") or searched for via the Coding Tool:

**Update and Maintenance Platform Foundation Component:** <https://icd.who.int/dev11/f/en/>

**Update and Maintenance Platform MMS Linearization:** <https://icd.who.int/dev11/l-m/en/>

## Has the content of ICD-11 been completed?

No. Many of the Description field texts have still to be completed. There remain hundreds of proposals in the ICD-11 Proposal Mechanism waiting to be processed. None of the specialty or derivative publications, for example, the *ICD-11 Clinical Descriptions and Diagnostic Guidelines for Mental and Behavioural Disorders (CDDG)* or the proposed ICD-11 PHC guideline for 27 mental disorders have been released.

**Update and revision cycle:** Official releases of ICD-11 will be produced annually for international use in mortality and morbidity. Approved proposals for additions and corrections will be incorporated into ICD-11 on an annual or five yearly cycle, according to their potential impact on data collection.

**The WHO stated in February 2020: "The ICD-11 codes are now frozen. Proposed changes to the classification that would result in a code change are not permitted."**

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