

## Comment on proposals: Postviral and Related Fatigue Syndromes

(Page 169–172, Diagnosis Codes agenda, ICD-10-CM Coordination and Maintenance Committee Meeting, September 14-15, 2021)

**November 06, 2021**

---

Thank you for the opportunity to provide public comment.

A request for changes to the G93.3 code was presented by Mary Dimmock on behalf of 7 US organisations: IACFS/ME, #MEAction, Solve M.E., Open Medicine Foundation (OMF), Massachusetts ME/CFS & FM Association, Minnesota ME/CFS Alliance, and Pandora Org. (In this feedback submission I shall refer to this request as “Org Option 1”.)

Following discussions with the requesters in advance of the meeting, NCHS presented an alternative set of proposals for the G93.3 and R53.82 codes, as set out in Diagnosis Codes Agenda, 171–172 [1]. (I shall refer to the NCHS proposals as “NCHS Option 2”.)

### **1 Both sets of proposals request deletion of entity: Benign myalgic encephalomyelitis and replacement with: Myalgic encephalomyelitis:**

In September 2016, WHO-FIC ICD-10 Update & Revision Committee (URC) approved a request submitted in March 2016 by a representative from *Canadian Institute for Health Information* for removal of the “Benign” prefix from “Benign myalgic encephalomyelitis” [2]. This terminology revision was implemented for the final update of the WHO’s international edition of ICD-10 (ICD-10 Version: 2019), released in January 2020 [3].

In February 2020, the author of this public feedback submitted a new proposal and rationale to ICD-11 for removal of the “Benign” prefix, citing *inter alia* the URC’s decision in September 2016 and implementation of that decision for the final release in the life of ICD-10 [4]. This proposal was approved by WHO/ICD Revision in November 2020, for implementation in the next annual release of ICD-11 MMS [5].

**Removal of “Benign” from “Benign myalgic encephalomyelitis” for the final update of the WHO’s International edition of ICD-10 and its implementation in the forthcoming ICD-11 sets a precedent for updating the national modifications of ICD-10.**

**I support the request for deprecation of the “Benign” prefix. I also support retention of the term in the ICD-10-CM index for backward comparability, and for consistency with its retention as an index term in ICD-10 Version: 2019 and ICD-11.**

#### References

1 ICD-10-CM Coordination and Maintenance Committee Meeting, September 14-15, 2021 Diagnosis Agenda, 169–172: <https://www.cdc.gov/nchs/icd/Sept2021-TopicPacket.pdf>

2 Screenshot: Proposal ID: 2211, March 16, 2016, ICD-10 Update and Revision Platform: <https://dxrevisionwatch.files.wordpress.com/2020/11/request-urc-march-2016.png>

3 ICD-10 Version: 2019, January 2020: <https://icd.who.int/browse10/2019/en#/G93.3>

4 ICD-11 Proposal, S Chapman, February 14, 2020: <http://bit.ly/BenignICD11>

5 ICD-11 for Mortality and Morbidity Statistics (Version: 05/2021): <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2fid%2fentity%2f569175314>

## **2 NCHS Option 2 proposal to add: Systemic exertion intolerance disease [SEID] to the ICD-10-CM Alphabetical Index:**

It is six years since the Institute of Medicine (now known as *National Academy of Medicine*) published its report, in early 2015 [1]. The panel's suggested term, "Systemic exertion intolerance disease (SEID)" was one of a number of recommendations included in the report for the consideration of the sponsor agencies.

At the point of release, it would have been prudent for the report's authors to have included a stronger caveat that its list of Recommendations were just that – recommendations drawn up for sponsor agencies to review, test and evaluate for validity, reliability, acceptability and utility.

NCHS could have provided clarity on the status of the panel's various recommendations by circulating a caution note to clinicians and medical bodies while the report was under review.

The "Systemic exertion intolerance disease (SEID)" term has not been adopted by any US federal agencies.

The WHO classifications team, ICD-11 Topic Advisory Group for Neurology, ICD Revision Steering Group, Joint Task Force, Medical Scientific Advisory Committee (MSAC) and Classification and Statistics Advisory Committee (CSAC) elected not to incorporate the term "Systemic exertion intolerance disease (SEID)" within ICD-11 as a unique code, as an inclusion term or as an index term, as either a replacement for one of more of the three G93.3 legacy terms, or in addition to the three legacy terms. Nor was the term added by URC to the final update in the life of ICD-10 International edition (ICD-10 Version: 2019).

As the IOM panel's report and recommendations formed part of the WHO's literature review for the potential revision of the G93.3 legacy terms for ICD-11, one concludes that WHO and its advisory committees and working groups consider there is insufficient evidence to support the inclusion of this term within ICD-11.

A request in November 2019 for addition of "Systemic exertion intolerance disease (SEID)" to SNOMED CT International Edition was rejected by SNOMED International's terminology team, in June 2020, who considered it would be premature to add the term to SNOMED CT.

Donna Pickett (CDC) stated at a previous C & M Committee meeting that because some clinicians had already started to use the SEID term, the term needed to be incorporated into ICD-10-CM in order that it can be coded for [2].

**I am not persuaded that NCHS should be facilitating clinical application and coding of a term that has been *rejected* for adoption and implementation by US federal agencies.**

**I do not support the proposal to add this term to the index, coded to a proposed new ICD-10-CM entity: *G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome*.**

### References:

1 Institute of Medicine. *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. The National Academies Press; May 2015:  
<https://www.nap.edu/catalog/19012/beyond-myalgicencephalomyelitischronic-fatigue-syndrome-redefining-an-illness>

2 ICD-10-CM Coordination and Maintenance Committee Meeting, September 11-12, 2018. Diagnosis Agenda Part 2, 11-12: [https://www.cdc.gov/nchs/data/icd/Topic\\_packet\\_Sept\\_2018\\_part2.pdf](https://www.cdc.gov/nchs/data/icd/Topic_packet_Sept_2018_part2.pdf)

### 3 Creation of a new ICD entity: “Myalgic encephalomyelitis/chronic fatigue syndrome”

Both sets of proposals recommend adding a new entity to ICD-10-CM’s Tabular List: “Myalgic encephalomyelitis/chronic fatigue syndrome” and the acronym “ME/CFS”.

**This hybrid term is not coded for in the WHO’s ICD-10, in ICD-11, or in any national modification of ICD-10. Nor is the term included in SNOMED CT terminology system.**

**The convention for ICD-10 is to classify mutually exclusive, machine readable entities.**

**NCHS Option 2** proposes to **conjoin** two existing ICD entities, “myalgic encephalomyelitis” and “chronic fatigue syndrome” to form a new code title, “Myalgic encephalomyelitis/chronic fatigue syndrome”, whilst retaining the two existing ICD entities as inclusion terms [1].

#### **I question whether conjoining two existing ICD terms aligns with ICD-10 conventions.**

NCHS Option 2 proposes revising the existing code title: *G93.3 Postviral fatigue syndrome* to *G93.3 Postviral and related fatigue syndromes* and to create separate sub-codes for *Postviral fatigue syndrome* and new code title, “Myalgic encephalomyelitis/chronic fatigue syndrome”.

*Chronic fatigue syndrome*; *Myalgic encephalomyelitis*; and conjoined acronym, *ME/CFS* are proposed to be listed as inclusions under the new *G93.32* title code (see also *Fig 3*):

#### **G93.3 Postviral and related fatigue syndromes**

##### **G93.31 Postviral fatigue syndrome**

##### **G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome**

Chronic fatigue syndrome

ME/CFS

Myalgic encephalomyelitis

*Systemic exertion intolerance disease [SEID]* is proposed to be indexed to the *G93.32* code title.

The existing inclusion term: *Chronic fatigue syndrome NOS* under *R53.82 Chronic fatigue, unspecified* is proposed to be deleted from the Tabular List.

**Org Option 1** also proposes revising the existing code title: *G93.3 Postviral fatigue syndrome* to *G93.3 Postviral and related fatigue syndromes* and to create separate sub-codes for *Postviral fatigue syndrome* and *Myalgic encephalomyelitis*, with *Myalgic encephalomyelitis/chronic fatigue syndrome* and *ME/CFS* as inclusions under new sub-code *G93.3x Myalgic encephalomyelitis* [2]:

#### **G93.3 Postviral and related fatigue syndromes**

##### **G93.3x Postviral fatigue syndrome**

##### **G93.3x Myalgic encephalomyelitis**

Myalgic encephalomyelitis/chronic fatigue syndrome

ME/CFS

*‘[Org Option 1] did not make recommendations regarding the term “chronic fatigue syndrome” because of the lack of consensus on earlier proposals on how this should be addressed.’* Nor does Org Option 1 make recommendations for code *R53.82 Chronic fatigue syndrome NOS*.

NCHS is authorised by the WHO to develop and maintain an adaptation of ICD-10 for use in morbidity coding. All modifications to ICD-10 must conform to WHO conventions for ICD.

**Whilst I welcome creation of unique sub-codes for Postviral fatigue syndrome and Myalgic encephalomyelitis (or creation of unique sub-codes for Postviral fatigue syndrome; Myalgic encephalomyelitis; and Chronic fatigue syndrome, were separate sub-codes for all three terms under consideration), I cannot support either of these two proposals.**

**Although the term, “Myalgic encephalomyelitis/chronic fatigue syndrome” and acronym “ME/CFS” are commonly used by some patients, patient organisations and more recently, by some federal agencies, I do not consider conjoining two existing ICD-10 and ICD-11 entities to form a single term to be valid in the context of ICD classificatory conventions.**

I am concerned that coding all the following terms to the same ICD-10-CM sub-code, will result in confusion for existing patients, new patients, clinicians, allied health professionals and coding industry professionals. There will also be implications for data collection, analysis, and data integrity, and for research utility, patient selection etc:

**G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome**

Chronic fatigue syndrome

ME/CFS

Myalgic encephalomyelitis

**Index term:** Systemic exertion intolerance disease [SEID]

**I have particular concerns for the potential for unintended consequences for patients with an existing diagnosis of R53.82 Chronic fatigue syndrome NOS.**

There was no useful discussion at the September meeting about what would happen to those patients currently assigned the R53.82 code if “Chronic fatigue syndrome NOS” is deleted from R53.82: will that leave these patients orphaned under R53.82 Chronic fatigue, unspecified? Will patients need to contact their clinicians to request their diagnosis codes are revised from R53.82 to G93.32? What education will providers receive about implementing a code change?

Has NCHS carried out assessment for unintended consequences for medical insurance, determination of disability benefits, provision of home and workplace adaptations and educational accommodations for those patients already coded to R53.82 or assessed the implications for the types of medical investigations, tests and treatments that clinicians are prepared to consider and which insurers are prepared to fund for those patients with an historical diagnosis of R53.82?

Did NCHS consider relocating *Chronic fatigue syndrome NOS* under the proposed G93.32 sub-code, or creating an additional sub-code under the G93.3 block for *Chronic fatigue syndrome* and *Chronic fatigue syndrome NOS*? If relocation was considered and rejected, what was the rationale for recommending relocating both these terms under a G93.3 sub-code in September 2018, but not doing so for this most recent proposal? (See Section 5.)

References:

1 ICD-10-CM Coordination and Maintenance Committee Meeting, September 14-15, 2021. Diagnosis Agenda, 169–172: <https://www.cdc.gov/nchs/icd/Sept2021-TopicPacket.pdf>

2 Presentation slides: Postviral and Related Fatigue Syndromes: <https://bit.ly/31v1Nq9>

#### 4 Lack of consistency in NCHS Option 2 proposal regarding conventions for acronyms:

The convention for handling acronyms in ICD-11 is: “Acronyms may never be used for titles of categories. They should be added as synonyms to the appropriate spelt out disease entity thus facilitating identification of the relevant cases and categories.” [1].

For example, acronyms in ICD-11 are not listed as code titles, per se, or placed in brackets at the end of an entity but are listed under Synonyms/Index Terms under their respective code titles using this format:

ARC - [aids-related complex]  
COPD - [chronic obstructive pulmonary disease]  
SIDS - [sudden infant death syndrome]  
CFS - [chronic fatigue syndrome]  
ME - [myalgic encephalomyelitis]  
PVFS - [postviral fatigue syndrome]

A very small number of acronyms are included in ICD-10-CM. With reference to the Tabular List and to discussions following presentation of the September 2021 meeting topic: Postural orthostatic tachycardia syndrome (POTS), 167–168 [2], the convention for ICD-10-CM appears to place the acronym in square brackets at the end of the entity, for example:

Human immunodeficiency virus [HIV] disease (B20)  
B20 Human immunodeficiency virus [HIV] disease  
Includes: acquired immune deficiency syndrome [AIDS]  
AIDS-related complex [ARC]

NCHS Option 2 proposes to add the acronym: “ME/CFS” under inclusions to the proposed new five character sub-code: *G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome*.

There is no rationale provided in the Topic Packet text for proposing to add an acronym (or in this case, two conjoined acronyms) as an inclusion term rather than placing the acronym in square brackets at the end of the entity, thus:

**G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome [ME/CFS]**  
Chronic fatigue syndrome  
Myalgic encephalomyelitis

**As the ICD-10-CM convention for handling of acronyms was not discussed by either of the presenters or queried at the end of the presentation by public participants, this needs public discussion before any decision is made regarding approval of these most recent NCHS proposals.**

References:

1 ICD-11 Content Model, World Health Organization, Geneva, January 2011, p59:  
[https://www.who.int/classifications/icd/revision/Content\\_Model\\_Reference\\_Guide.January\\_2011.pdf](https://www.who.int/classifications/icd/revision/Content_Model_Reference_Guide.January_2011.pdf)

2 ICD-10-CM Coordination and Maintenance Committee Meeting, September 14-15, 2021, Day 2  
Recording passcode: \$E33^Cb@ Topic discussion begins 05:05:16 ends 05:23:25.  
[https://cms.zoomgov.com/rec/share/UpsJosGmVMiUSihVCK1EtJee5X5Fwl25r2pZ-fAqlwYh1NWPDVawjzC2CEUjxCg.yHF2Cy\\_7xX0LVdGW](https://cms.zoomgov.com/rec/share/UpsJosGmVMiUSihVCK1EtJee5X5Fwl25r2pZ-fAqlwYh1NWPDVawjzC2CEUjxCg.yHF2Cy_7xX0LVdGW)

**5 Omission of “Chronic fatigue syndrome NOS” from NCHS Option 2 proposed coding structure:**

There is a potential anomaly in the coding structure proposed in **NCHS Option 2** which was not identified and discussed at the meeting and for which no rationale was provided in the Topic Packet text or by presenter Traci Ramirez (NCHS).

The proposed coding structures presented on behalf of NCHS/CDC in September 2011 [1] and September 2018 [2] both recommended relocating existing entity: *Chronic fatigue syndrome NOS* as an inclusion, under a new sub-code in a restructured G93.3 code block:

Fig 1, September 2011, NCHS:

**Option 2 (proposed by NCHS):**

	G93	Other disorders of brain
Revise Delete Delete	G93.3	<u>Postviral and other chronic fatigue syndromes</u> <del>Benign myalgic encephalomyelitis</del> <del>Excludes 1: chronic fatigue syndrome NOS (R53.82)</del>
New code	G93.31	Postviral fatigue syndrome Benign myalgic encephalomyelitis
New code	G93.32	Chronic fatigue syndrome Chronic fatigue syndrome NOS
		Excludes2: chronic fatigue, unspecified (R53.82)

Fig 2, September 2018, NCHS:

	G93	Other disorders of brain
Revise Delete Delete	G93.3	<u>Postviral and related fatigue syndromes</u> <del>Benign myalgic encephalomyelitis</del> <del>Excludes 1: chronic fatigue syndrome NOS (R53.82)</del>
New code	G93.30	Systemic Exertion Intolerance Disease, unspecified SEID, NOS
New code	G93.31	Postviral fatigue syndrome
New code	G93.32	Myalgic encephalomyelitis
New code Add	G93.33	Chronic fatigue syndrome Chronic fatigue syndrome NOS
New code	G93.39	Other postviral and related fatigue syndromes

The structure presented in **NCHS Option 2** at the September 2021 meeting also proposes deletion of *Chronic fatigue syndrome NOS* from under R53.82 but omits to relocate the term as an inclusion under proposed new sub-code title: *G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome*.

Fig 3, September 2021, NCHS:

	<b>G93 Other disorders of brain</b>
Revise	G93.3 Postviral <u>and related</u> fatigue syndromes
Delete	<del>Benign myalgic encephalomyelitis</del>
	Excludes1: chronic fatigue, unspecified (R53.82)
Add	neurasthenia (F48.8)
New code	G93.31 Postviral fatigue syndrome
New code	G93.32 Myalgic encephalomyelitis/chronic fatigue syndrome
Add	Chronic fatigue syndrome
Add	ME/CFS
Add	Myalgic encephalomyelitis
New code	G93.39 Other post infection and related fatigue syndromes

There has been discussion at previous presentations given by Donna Pickett (CDC) around legacy data aggregation/disaggregation issues and the potential for loss of data going forward if an ICD-10-CM entity were to be retired entirely from the classification [1].

**There are potential implications for data analysis going forward. Omission of *Chronic fatigue syndrome NOS* from the NCHS Option 2 proposal may also have implications for patients already assigned the *R53.82 Chronic fatigue syndrome NOS* code. (See Section 3.)**

**Public discussion of how patients already assigned the R53.82 code will be accounted for under the proposed restructure and whether historical R53.82 cases will need mapping to G93.32 going forward, needs to take place before any decision is made regarding these most recent NCHS proposals.**

Note: The submission presented on behalf of 7 organisations makes no recommendations for how the *Chronic fatigue syndrome NOS* inclusion term might be accommodated within the framework of their proposed restructure of the G93.3 categories; nor are any recommendations made on whether or how legacy data for patients already assigned the *R53.82 Chronic fatigue syndrome NOS* code would be mapped to the proposed new conjoined term: *G93.3x Myalgic encephalomyelitis/chronic fatigue syndrome*; nor whether the term: *Chronic fatigue syndrome* should be added to the restructured G93.3x block (with or without retention of a *Chronic fatigue syndrome NOS* term in one of these locations).

**I therefore have no comment to make on this aspect of the Org Option 1 proposal as the proposal is incomplete.**

References:

1 ICD-9-CM Coordination and Maintenance Committee Meeting September 14, 2011 Diagnosis Agenda, 10–11: <https://www.cdc.gov/nchs/data/icd/TopicpacketforSept2011a.pdf>

2 ICD-10-CM Coordination and Maintenance Committee Meeting September 11-12, 2018 Diagnosis Agenda Part 2, 11–12: [https://www.cdc.gov/nchs/data/icd/Topic\\_packet\\_Sept\\_2018\\_part2.pdf](https://www.cdc.gov/nchs/data/icd/Topic_packet_Sept_2018_part2.pdf)

## 6 Lack of consistency regarding proposed exclusions under code R53.82:

NCHS Option 2 proposes *Chronic fatigue syndrome; ME/CFS* and *Myalgic encephalomyelitis* to be added as inclusion terms under a proposed new ICD-10-CM term and sub-code: G93.32 *Myalgic encephalomyelitis/chronic fatigue syndrome* (see Fig 3).

Four entities are proposed to be added as **Excludes1** under R53.82.

Fig 4, September 2021, NCHS Option 2:

	R53	Malaise and fatigue
		R53.8 Other malaise and fatigue
		R53.82 Chronic fatigue, unspecified
Delete		<del>Chronic fatigue syndrome NOS</del>
Add		Excludes1: chronic fatigue syndrome (G93.32)
Add		myalgic encephalomyelitis (G93.32)
Add		post infection and related fatigue syndromes (G93.39)
Revise		postviral fatigue syndrome (G93.31)

There is no rationale provided in the Topic Packet text (nor was it acknowledged or discussed during the presentation) why NCHS is recommending to add two of the proposed G93.32 inclusion terms as **Excludes1** under R53.82 but does not specify the code title: *myalgic encephalomyelitis/chronic fatigue syndrome* (G93.32) as an **Excludes1**.

**Whether an oversight or anomaly, this omission needs rationalising before any decision is made regarding these most recent NCHS proposals.**

## 7 Clarification required for ICD-10-CM conventions for numbering of sub-codes:

I note in September 2011, NCHS's alternative option had proposed creating the five character sub-codes:

G93.3  
G93.31  
G93.32

in September 2018, the NCHS option proposed this sequence:

G93.3  
G93.30  
G93.31  
G93.32  
G93.33  
G93.39

The September 2021 NCHS Option 2 proposes: G93.3; G93.31; G93.32; G93.39 (see Fig 3).

There is no clarification in the Topic Packet text of the circumstances that dictate whether sequential five character sub-codes should begin with **G93.30**, as opposed to **G93.31**.

## 8 Summary

The potential restructure of the ICD-10-CM G93.3 and R53.82 codes has now been discussed at four Coordination and Maintenance Committee meetings (2011, 2012, 2018 and 2021) but no consensus on the various submissions and NCHS's alternative proposals has been reached.

The alternative structure presented by NCHS in September would have benefited from closer scrutiny prior to being added to the agenda.

It was unfortunate that the meeting had an exceptionally full agenda to work through. Queries relating to anomalies and ICD conventions which were not identified or discussed following the presentations but have significance for the safety and utility of both sets of proposals require clarification, in addition to questions around unintended consequences.

These as yet unaddressed concerns may present obstacles to constructive stakeholder feedback. My recommendation would be to consider these issues and public comment and revise and re-present proposals at the March 2022 meeting.

**In the meantime, revision of the term, “Benign myalgic encephalomyelitis” to “Myalgic encephalomyelitis” (approved by URC in September 2016) should be implemented for the next release of ICD-10-CM, to bring the US modification in line with the final update in the life of the WHO’s International edition of ICD-10, and in line with ICD-11.**

Thank you for your consideration of the points raised in this feedback.

---

### **Suzy Chapman, Dorset, UK**

Comment submitted in a personal capacity. No affiliations or COIs to declare. Primary carer of adult family member; owner of *Dx Revision Watch*.

<https://dxrevisionwatch.com>  
[dxrevisionwatch@page1.myzen.co.uk](mailto:dxrevisionwatch@page1.myzen.co.uk)