

To: National Center for Health Statistics  
From: Patient-Led Research Collaborative  
Subject: Feedback on ICD-10-CM proposal for U09.9  
Date: April 9, 2021

We are writing regarding the proposal for U09.9, Post COVID-19 Condition, presented at the March ICD-10-CM Coordination and Maintenance Committee meeting. We are Patient-Led Research Collaborative, a group of Long COVID patients who were the first to conduct research on Long COVID and whose recent survey was taken by over 6,500 Long COVID patients. We are supportive of the introduction of a disease-specific Long COVID code, as we believe the adoption of the code will lead to better research, care, and support for Long COVID patients. To ensure that the proposed code is clear, encompassing, and relevant, we ask that you consider the following recommendations to improve the U09.9 ICD-10-CM proposal presented in March.

1. Inclusion terms:

Because COVID and Long COVID are new, a number of different terms are being used to refer to Long COVID. To ensure that these terms are recognizable, we recommend the following terms be added as inclusions to U09.9:

Long COVID, post-acute sequela of COVID-19, Post-Acute Sequelae of SARS-CoV-2, PASC, sequela of COVID-19, post-COVID syndrome, long-haul COVID-19, and long COVID-19

2. Clarify notes:

Revise the following statement to allow for Long COVID and a SARS-CoV-2 reinfection to coexist: *"This code is not to be used in cases that still are presenting COVID-19."*

As worded, this sentence could be interpreted to mean that a patient cannot have both Long COVID and a reinfection of SARS-CoV-2 at the same time. A modification such as *"This code is not to be used in cases that experienced the onset of their initial SARS-CoV-2 infection less than 28 days ago"* could help clarify this.

3. Expand the list of "Code First" terms:

Add the following additional examples to the list of Code First terms:

Postviral fatigue syndrome (G93.3)

Other specified cardiac arrhythmias (I49.8)

Mast cell activation, unspecified (D89.40)

Unspecified symptoms and signs involving cognitive functions and awareness (R41.9)

Other specified systemic involvement of connective tissue (M35.89)

Orthostatic hypotension (I95.1)

Disorder of the autonomic nervous system, unspecified (G90.9)

The rationale for requesting these specific terms is that these diseases and symptoms are reported to substantially overlap with Long COVID. A growing number of Long COVID patients are being diagnosed with these conditions and/or have these symptoms.

For example, [Patient-Led Research Collaborative](#) (PLRC) found that 72.2% of their survey respondents who have Long COVID symptoms for at least 6 months experience post-exertional malaise, a cardinal symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). While we await the creation of an ME/CFS-specific code, suggesting postviral fatigue syndrome as a sample code will be useful for tracking Long COVID patients who are diagnosed with ME/CFS. The same survey found that 33.9% of respondents who reported tachycardia measured an increase of at least 30 BPM within ten minutes of standing, consistent with one criterium for a POTS diagnosis. [Mast cell activation syndrome \(MCAS\)](#) is also a prevalent diagnosis among this population. Adding these as explicit examples will help doctors identify relevant codes and help clinicians narrow the scope of common differential diagnoses in Long COVID. For a list of common diagnoses see Table S2 in Appendix A of [PLRC's preprint](#). For a list of Long COVID symptoms by prevalence, please see <https://patientresearchcovid19.com/resources-for-long-covid-researchers/>.

4. Expedite implementation as soon as possible

Because of the [prevalence of Long COVID](#), the impact of Long COVID at the personal and societal level, and the planned NIH strategy to use [electronic health records to accelerate research into Long COVID](#), it is essential that mechanisms to track Long COVID be implemented as quickly as possible. There is precedent for accelerating the introduction of COVID-19 diagnostic codes, and the code for Long COVID should be taken as seriously. Until implementation of U09.9, we recommend the use of B94.8: "Sequelae of other and unspecified infectious and parasitic diseases." Once U09.9 is introduced, the B94.8 ICD-10-CM should not be used to indicate Long COVID.

5. Revise Excludes2

To ensure that coders understand that B94.8 is no longer intended to code for Long COVID, we recommend adding to the U09 term an Excludes2 of Sequelae of other specified infectious and parasitic diseases (B94.8). We are recommending this be added to the U09 term with the assumption that this exclusion should apply to any future terms added to the "Post COVID-19 condition" category.

Thank you for your consideration of these revisions to the proposed U09.9 code. We appreciate your understanding of how important the addition of this code is for Long COVID patient wellbeing.

Signed,

Patient-Led Research Collaborative

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