



2033 K Street, NW | Suite 450 | Washington, DC 20006

✉ info@agingresearch.org | www.agingresearch.org



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Donna Pickett, MPH, RHIA, Co-Chair
ICD-10-CM Coordination and Maintenance Committee
National Center for Health Statistics
3311 Toledo Road
Hyattsville, MD20782-2064

Re: Comments to the Proposed New ICD-10-CM Code for “Adverse Effect of COVID-19 Vaccines”

Dear Co-Chair Pickett and the ICD-10-CM Coordination and Maintenance Committee Members,

Thank you for the opportunity to submit public comments on the proposed addition of a COVID-19 vaccine-specific adverse effect code (T50.B25). The Alliance for Aging Research (“Alliance”) is the leading nonprofit organization dedicated to changing the narrative to achieve healthy aging and equitable access to care.

For the past 10 years, the Alliance has led the Our Best Shot educational campaign, which encourages vaccine confidence, aims to increase vaccination rates, and arms older adults with reliable information about vaccines. The Alliance is also a co-convener of the Champions for Vaccine Education, Equity & Progress (CVEEP), a trusted source of information and a leading voice in discussions on vaccines and treatments for infectious respiratory disease.

Vaccines represent one of our most effective tools in preventing disease and improving quality of life, especially for older adults. Recognizing their importance, we respectfully request that the Committee decline to create a new diagnosis code – “Adverse Effects of COVID-19 Vaccines.”

An Unreliable Diagnosis of Exclusion

While a new code to uniquely identify adverse effects from COVID-10 vaccines, distinct from all other vaccines, would theoretically enable clinicians, researchers, and public health professionals to better identify and study these cases, it is also likely to become a catch-all code for symptoms that share one thing in common—not being attributable to other known causes.

Attributing symptoms as adverse events related to vaccine administration for any vaccine is inherently difficult, since those symptoms may have other causes, be coincidental, be caused by the stress of vaccination, and develop days or weeks after vaccination. Co-administration of vaccines can further confound things, making it difficult to ascertain which, if any, vaccine might be the cause of an adverse event.

The proponents for the new code believe that it could be used to track a proposed condition called post-acute COVID vaccination syndrome (PACVS). PACVS is defined as “a proposed clinical condition involving persistent multi-system symptoms that develop weeks, months, or even years after COVID-19 vaccination” and that are not attributable to other diagnoses. Meaning that a diagnosis of PACVS is essentially a diagnosis of exclusion, arrived at after ruling out other reasonable and known possibilities. This makes it especially important for PACVS to either be clinically validated or a widely accepted diagnosis, but this is not the case. It is unclear what the proposed ICD-10-CM codes for adverse events of COVID-19 vaccines would add at this point, until a clearly defined clinical entity exists for PACVS.

PACVS can also be difficult to distinguish from long-COVID due to significant overlap in the associated symptoms. Fatigue, headache, attention deficit, cognitive impairment, muscle pain anxiety, depression, transverse myelitis, Guillain-Barré syndrome, myocarditis, thrombosis, persistent cough, chest pain, and a dozen other symptoms are common to the two disorders. While the pursuit of clinical distinctiveness is important, a new code at this point is not likely to solve the problem of misdiagnosis.

A Significant Departure

The current ICD-10-CM structure captures vaccine-related adverse events. The coding is based on clinical presentation rather than on specific vaccines, and on a current body of scientific evidence and precedent. A new distinct code would represent a departure from the established coding paradigm without evidence that it will improve diagnosis, tracking, and treatment—but WITH evidence that it could result in further confusion and increase unnecessary litigation. This code has the potential to become a catch-all for symptoms that can’t otherwise be explained but that may not be caused by a COVID-19 vaccine, and lead to messy and unreliable data.

Deny the Code Request Until There is More Information

We urge the Committee to deny the request for this new code until there is 1) a clearly defined clinical entity for PACVS, and 2) more information showing that a new code would create more clarity and transparency. Thank you once again for the opportunity to submit these comments.

Sincerely,

A handwritten signature in black ink that reads "Lindsay Clarke". The signature is written in a cursive, flowing style.

Lindsay Clarke, JD
COO & SVP of Health Education
lclarke@agingresearch.org