Formal Proposal for ICD-10-CM Codes for Post-COVID Vaccine Syndrome (PCVS)

Submitted to: CDC/National Center for Health Statistics (NCHS)
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Background

The ICD-10-CM coding system plays a critical role in clinical documentation, billing, epidemiological tracking, and research. While the ICD-10-CM currently includes codes for **post-COVID conditions (U09.9)**, there is no dedicated coding framework for documenting **adverse health conditions following COVID-19 vaccination**. In the US healthcare system currently, a variety of T codes and nonspecific symptoms codes are currently being used. Since the global rollout of COVID-19 vaccines, a subset of individuals has reported persistent, disabling symptoms following vaccination. These cases—commonly referred to by patients and clinicians as **Post-COVID Vaccine Syndrome (PCVS)**—present with multisystem involvement, including neurologic, cardiovascular, autoimmune, dermatologic, gastrointestinal, musculoskeletal, allergic, and hematologic conditions. Currently, these cases are **inadequately captured** in existing ICD-10-CM codes, which prevents accurate documentation, research, resource allocation, and care delivery.

Proposal

We propose the creation of a new code block under the **Uxx** (exact number tbd) **series** to identify and classify **Post-COVID Vaccine Syndrome (PCVS)**. This structure mirrors the current **U09.x** series used for post-COVID conditions and allows for system-based sub-categorization to capture the variability in clinical presentation.

Proposed Code Structure for Post-COVID Vaccine Syndrome (PCVS)

Code	Title	Description
Uxx.0	Post-COVID-19 vaccine syndrome with neurologic manifestations	Includes symptoms such as paresthesia, small fiber neuropathy, POTS, brain fog, or chronic headaches
Uxx.1	Post-COVID-19 vaccine syndrome with cardiovascular manifestations	Includes myocarditis, pericarditis, palpitations, chest pain, and postural tachycardia
Uxx.2	Post-COVID-19 vaccine syndrome with autoimmune features	Includes new-onset autoimmune diseases, exacerbations of existing autoimmune conditions, or positive autoantibody findings
Uxx.3	Post-COVID-19 vaccine syndrome with musculoskeletal symptoms	Includes fatigue, joint pain, myalgias, or musculoskeletal weakness
Uxx.4	Post-COVID-19 vaccine syndrome with dermatologic symptoms	Includes urticaria, rashes, flushing, and persistent skin eruptions
Uxx.5	Post-COVID-19 vaccine syndrome with gastrointestinal symptoms	Includes nausea, bloating, abdominal pain, diarrhea, and gastroparesis
Uxx.6	Post-COVID-19 vaccine syndrome with allergic or anaphylactoid reaction history	For patients with persistent hypersensitivity or mast cell-related symptoms post-vaccination
Uxx.8	Post-COVID-19 vaccine syndrome with multiple system involvement	Involves more than one organ system without a single dominant symptom set
Uxx.9	Post-COVID-19 vaccine condition, with hematologic issues	Involves bleeding or clotting issues
Uxx.10	Post-COVID-19 vaccine condition, unspecified	General code for patients with post-vaccine symptoms not otherwise classified
Uxx.11	Post-COVID-19 vaccine condition, death	

Justification

- **Clinical necessity:** A growing number of patients are presenting with persistent symptoms temporally related to COVID-19 vaccination, which are not adequately documented using existing ICD-10-CM codes.

- **Data integrity:** New codes will enable researchers, clinicians, and public health professionals to identify, track, and study these cases with greater precision.
- **Health equity:** Patients affected by PCVS deserve acknowledgment and access to evidence-based care, which begins with accurate diagnosis coding.
- **Consistency:** These proposed codes parallel the structure of U09.x codes for Long COVID, which enhances uniformity in post-viral and post-vaccine condition tracking.

Request

We respectfully request that the CDC and NCHS:

1. **Review and consider the creation of a new ICD-10-CM code block under Uxx** for Post-COVID Vaccine Syndrome (PCVS).
2. **Engage stakeholders**, including clinicians, patients, researchers, and public health officials, in the refinement of terminology and classification.
3. **Develop guidance** for clinicians on using these codes in documentation and reimbursement practices.

Supporting Documentation

- Case studies and clinical data from organizations such as React19.
- Literature review of peer-reviewed articles on post-vaccination adverse events and persistent symptoms. [3500+ COVID Vaccine Publications and Case Reports - React19.]
- Testimonials from affected patients and treating physicians.
- Existing reporting inconsistencies in VAERS and EHRs due to lack of specific codes.

Conclusion

Establishing ICD-10-CM codes for Post-COVID Vaccine Syndrome are critical for improving patient care, facilitating research, and guiding healthcare resource allocation. This proposal outlines a structured and clinically justified path forward to address a growing public health concern.

We welcome the opportunity to provide additional data or participate in stakeholder discussions as needed.

Respectfully submitted,
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