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Dear Dr. Stanfill:

The American Health Information Management Association (AHIMA) respectfully submits the following comments on the ICD-10-CM code proposals presented at the March ICD-10 Coordination and Maintenance (C&M) Committee meeting and being considered for April 1 or October 1, 2027 implementation.

AHIMA is a global nonprofit association of health information professionals, with over 61,000 members and more than 88,500 credentials in the field. The AHIMA mission of empowering people to impact health® drives its members and credentialed HI professionals to ensure that health information is accurate, complete, and available to patients and clinicians. Leaders within AHIMA work at the intersection of healthcare, technology, and business, occupying data integrity and information privacy job functions worldwide.

Laterality and Disease Stages

We recommend that consideration be given to using seventh characters when code expansion is needed to capture laterality or disease stages, so that available codes at the fourth, fifth, and sixth character levels can be reserved for specifying additional types of a medical condition. This approach would align with ICD-11, which uses extension codes for laterality and staging systems. We realize the approach of using seventh characters for laterality and disease staging could not be applied to existing codes that include laterality or disease stages, but we believe it would be worthwhile to consider this approach for current and future code proposals.

Adverse Effect of COVID-19 Vaccines

AHIMA supports the creation of a unique code for adverse effect of COVID-19 vaccines.

Anatomical Specificity for Eyelid Disorders

We support the addition of ICD-10-CM to capture disorders of the upper and lower eyelids.

Biomarkers for Alzheimer's Disease

We support the revised proposal to capture biomarkers for Alzheimer's disease.

Cardiogenic Shock Staging

We are concerned that the stages of cardiogenic shock will frequently not be documented, resulting in the unspecified code being reported most of the time. We are also concerned that the proposed codes will no longer be accurate or relevant if the staging framework changes in the future.

If ICD-10-CM codes are created for the stages of cardiogenic shock, we recommend using the narrative descriptions of the stages for the code titles (At Risk, Beginning, Classic, Deteriorating, Extremis) and listing the stage letters as inclusion terms. Both the stage descriptions and stage letters should be indexed.

We also recommend that consideration be given to creating seventh characters to identify the stage, rather than expanding the cardiogenic shock code at the fifth character level, in order to preserve the fifth and sixth characters for future expansion of types of cardiogenic shock or other aspects of this condition. **We recommend that CDC/NCHS consider this approach for all future disease staging systems added to ICD-10-CM.**

We recommend adding a guideline to the *ICD-10-CM Official Guidelines for Coding and Reporting* to address proper coding when a patient progresses between stages during a hospitalization. Guidance will also be needed on proper "present on admission" (POA) reporting.

Carotid Web

We support the creation of unique codes for carotid web.

Carrier of Candidiasis

We support the proposal to create a new code for carrier of Candidiasis.

Chronic Hand Eczema

While we support the creation of an ICD-10-CM code for idiopathic chronic dermatitis of hand, with an inclusion term of "chronic hand eczema," we recommend that consideration be given to

creating additional codes to capture idiopathic chronic dermatitis of sites other than the hand as well as that of unspecified site.

Congenital Hyperinsulinism

AHIMA supports the creation of a unique code for congenital hyperinsulinism.

Controlled Obesity

We do **not** support the proposal to establish a new diagnosis code for "controlled obesity." The meaning, purpose, and intended use of this proposed code are unclear.

The term "controlled obesity," as well as the proposed placement of the code within subcategory E66.8 (Other obesity), suggests that the patient is currently obese. This implication is potentially misleading. While the proposal describes controlled obesity as a documented history of obesity in which the underlying pathophysiology remains despite improvement in Body Mass Index (BMI), anthropometric measures, and body composition to levels considered healthy, the distinction between "controlled obesity" and a resolved or past history of obesity is not clearly defined. It is also unclear how, or whether, this distinction could be consistently documented in the medical record.

Additionally, the clinical differentiation between controlled obesity and other forms of obesity is not well articulated. The use of the term "controlled" implies the existence of an "uncontrolled" form of obesity; however, no such category was described by the presenter or included in the supporting materials. This lack of clarity raises concerns about conceptual consistency and clinical applicability.

We are also concerned that "controlled obesity" would not be routinely or consistently documented by healthcare providers. As a result, the proposed code may be infrequently used, used incorrectly, or applied inconsistently, limiting its usefulness and potentially introducing confusion into clinical documentation and coding practices.

Corneal Pseudomicrocysts

We support the establishment of a new sub-subcategory for corneal pseudomicrocysts.

We recommend that the proposed Excludes1 note under sub-subcategory H18.89, Other specified disorders of cornea, be changed to an Excludes2 note, as an individual could have corneal pseudomicrocysts in addition to another corneal disorder that is classified to this sub-subcategory.

We agree with the C&M meeting attendee who stated that "Corneal cysts" should be an inclusion term under code H18.89, not part of the Excludes note.

Dysphotopsia

We support the creation of new codes for dysphotopsia.

As noted in our earlier comments above regarding an alternative approach to capturing laterality, we recommend that consideration be given to creating seventh characters for right, left, bilateral, and unspecified side that would apply to new codes for positive, negative, and unspecified dysphotopsia, rather than expanding new sub-sub-subcategories to create laterality-specific codes.

Encounter for Observation for Suspected Condition: Delirium - EEG Monitoring
Encounter for Observation for Suspected Condition: Status Epilepticus- EEG Monitoring

We do **not** support the proposal to create a new sub-subcategory for encounter for observation for suspected conditions related to continuous EEG monitoring device, ruled out. The concepts described in the proposal – the use of continuous EEG monitoring to evaluate patients for delirium or status epilepticus – are procedural, not diagnostic, concepts.

The proposed code titles are very problematic, as they suggest the EEG monitoring device malfunctioned or otherwise caused a problem that led to delirium or status epilepticus being suspected and necessitated observation.

We recommend that the requester submit an ICD-10-PCS procedure code proposal to the Centers for Medicare and Medicaid Services.

Facial Angiofibroma

We support the creation of a unique ICD-10-CM code for facial angiofibroma.

Floppy Eyelid Syndrome

AHIMA supports the creation of codes for floppy eyelid syndrome (FES). A C&M meeting attendee asked if subcategory H02.5, Other disorders affecting eyelid function, would be a better location than subcategory H0.7, Other and unspecified degenerative disorders of eyelid and periocular area. The code proposal states, "Due to the degeneration of the tarsal plate and decreased elastin found in FES, the new codes should be placed as a subcategory under H02.7-." If it is correct that FES is considered a degenerative disorder, as this statement suggests, we believe subcategory H02.7 is the most appropriate location for the new codes.

We recommend that consideration be given to creating seventh characters to identify laterality (left, right, bilateral, unspecified) rather than creating unique codes in proposed new sub-subcategory H02.74, Floppy eyelid syndrome, to capture this information.

Hypertriglyceridemia

We support the proposed new codes for hypertriglyceridemia level.

We recommend that the word "level" be added to the title of proposed new code E78.A9, Other Hypertriglyceridemia, to be consistent with the subcategory level and make it clear that other types of hypertriglyceridemia should not be classified to this code.

Lipedema and Lipolymphedema

We support the proposed code modifications to identify lipedema and lymphedema.

We agree with the statement in the background material that it would be appropriate to use proposed code E88.838, Other lipedema stage, when the medical record documentation indicates disease severity is intermediate between stages. However, if suspected truncal involvement complicates staging, and this is referring to the fact the clinician is unable to determine the stage, we believe the "unspecified" code would be more appropriate.

Macular Telangiectasia

While we support creating at least one code for macular telangiectasia, it is not clear that it is necessary to create separate codes for each type, since this is an uncommon condition. In particular, type 3 was described as very rare.

If CDC/ NCHS believes separate codes for the different types of macular telangiectasia are warranted, we recommend that consideration be given to titling the codes congenital, acquired, other, and unspecified macular telangiectasia, rather than using the type numbers in the code titles.

We recommend that consideration be given to creating seventh characters to identify laterality for macular telangiectasia rather than creating laterality-specific codes in proposed new sub-subcategory H35.08, Macular telangiectasia.

Metabolic Dysfunction- and Alcohol Associated Liver Disease

We support the proposed code modifications for liver diseases.

Neonatal Supraventricular Tachycardia

We recommend that a new code for neonatal supraventricular tachycardia should be created by expanding code P29.11, Neonatal tachycardia, rather than expanding subcategory P29.1, Neonatal cardiac dysrhythmia.

The proposed "Code also" note should be located under P29.11, Neonatal tachycardia, rather than under category P29, Cardiovascular disorders originating in the perinatal period, since the note refers specifically to tachycardia.

Oral Epithelial Dysplasia

We support the creation of new severity-stratified diagnosis codes for oral epithelial dysplasia.

Pneumothorax that occurs after CPR

We support the creation of a new code for pneumothorax associated with chest compression and cardiopulmonary resuscitation and the related proposed modifications.

The “Code also” note shown under code J95.811, Postprocedural pneumothorax, in the proposal should appear under the proposed new code J93.84, Pneumothorax associated with chest compression and cardiopulmonary resuscitation, rather than under code J95.811.

Post-Intensive Care Syndrome (PICS)

We support the creation of a unique code for post-intensive care syndrome.

There is a typographical error in the “Code also” note under the proposed new code – “intercranial” injury should say “intracranial” injury.

Postprocedural Open Deep Wound Without Disruption

We support the proposed code modifications to report intended postprocedural state whereby the surgical wound is deliberately left open, to be closed at a later time.

We agree with the C&M meeting attendee that the word "intentionally" should be added to the proposed Excludes1 note under subcategory T81.3, Disruption of wound, not elsewhere classified, to be consistent with the proposed new code titles.

Progressive Myopia

We support the expansion of subcategory H44.2, Degenerative myopia, to create codes for degenerative myopia with progression.

We do **not** support the proposal to change the Excludes1 note under subcategory H52.1, Myopia, to an Excludes2 note. Since the H52.1 codes only identify the presence of myopia, and the H44.2 codes also identify myopia, assigning codes from both subcategories does not provide any additional information.

Sepsis

We appreciate the efforts to update the classification of sepsis in ICD-10-CM and the opportunity to provide comments prior to finalization of a more complete code proposal. We understand stakeholders' concerns about incorporating clinical criteria in ICD-10-CM, as well as concerns that not all healthcare providers are using the Sepsis 3 criteria. We fully support the official coding guideline that states, "Code assignment is not based on clinical criteria used by the provider to establish the diagnosis." However, ICD-10-CM must still reflect up-to-date medical knowledge and terminology. The current ICD-10-CM sepsis codes are based on the understanding of sepsis in the Sepsis 2 criteria, and thus can be difficult to use when medical record documentation reflects Sepsis 3 criteria. Therefore, we believe at least some revisions to the sepsis codes are needed.

We agree that codes are needed to identify patients who have serious systemic infections, but do not have organ dysfunction and may not develop organ dysfunction if treated. We recommend titling these codes "Infection with systemic inflammatory response syndrome" (which is listed as an inclusion term in the draft of the code proposal) instead of "Impending sepsis" (impending sepsis could be listed as an inclusion term). While we acknowledge there are a lot of good reasons for this code to be included in the Sepsis categories (e.g., capture of the severity of the condition, patient management is similar because it is aimed at preventing organ dysfunction), since impending sepsis is not actually sepsis, further discussion as to the most appropriate location of this concept in ICD-10-CM would be beneficial. Other potential code locations for consideration are B99, Other and unspecified infectious diseases, and R65, Symptoms and signs specifically associated with systemic inflammation and infection.

If codes for "infection with systemic inflammatory response syndrome" are created in the Sepsis code categories, the category titles should be revised to encompass this concept (e.g., category A41, Other sepsis), in addition to revising subcategory titles.

We do **not** support the addition of an inclusion term for "infection with positive sepsis diagnostic aid" under proposed new codes for impending sepsis. It was noted during the C&M meeting that these new diagnostic technologies can indicate both sepsis and impending sepsis. Therefore,

not all infections with a positive sepsis diagnostic aid should be classified to the codes for impending sepsis. Also, this inclusion term implies that code assignment may be based on a positive test result, which would not be appropriate. Code assignment for impending sepsis should be based on provider documentation.

We fully support the proposed elimination of "severe sepsis" terminology from the classification. We support re-titling subcategory R65.2 to state "Organ dysfunction associated with sepsis." The existing instructional note to code first the underlying infection should be retained.

We do **not** support the proposed new sub-subcategory for "Other specific organ dysfunction associated with sepsis." These codes are vague, confusing, not all that useful, and unnecessary. They also do not include all of the relevant types of organ dysfunction. Instead of creating this sub-subcategory, we recommend retaining both codes R65.20 and R65.21 and re-titling them "Organ dysfunction associated with sepsis without septic shock" and "Organ dysfunction associated with sepsis with septic shock." The "Use additional code" note under subcategory R65.2 should be deleted, and an appropriate "Use additional code" note should be added under codes R65.20 and R65.21. The note under code R65.20 should state "Use additional code to identify specific organ dysfunction." The note under code R65.21 should state "Use additional code, if applicable, to identify other organ dysfunction(s)."

Spontaneous Coronary Artery Dissection

We support the creation of a new ICD-10-CM code for spontaneous coronary artery dissection.

We recommend the proposed "Use additional code, if applicable" note under codes I25.428, Other coronary artery dissection, and I25.429, Coronary artery dissection, unspecified, be changed to a "Code also, if applicable," note, to allow a type 1 myocardial infarction to be sequenced first when appropriate.

Titanium Dioxide Exposure

We support the creation of new codes for toxic effect of titanium dioxide.

An instructional note should be added under the new sub-subcategory that states "Use additional code, if applicable, for contact with and (suspected) exposure to war theater (Z77.3-)."

Toxic Effects of Hexane

AHIMA supports the proposal to create new codes for toxic effect of hexane.

The proposed "Use additional code" note should be revised to state, "Use additional code, if applicable, for contact with and (suspected) exposure to war theater (Z77.3-)." The code number

is missing from this note in the code proposal, and also, contact with and (suspected) exposure to war theater is not a "manifestation" of the toxic effect of hexane.

Toxic Effect of Iron Oxide

We support the creation of new codes for toxic effect of iron oxide.

An instructional note should be added under the new sub-subcategory that states "Use additional code, if applicable, for contact with and (suspected) exposure to war theater (Z77.3-)."

Toxic Effect of N-Butyl Acetate

We support the creation of new codes for toxic effect of n-butyl acetate.

An instructional note should be added under the new sub-subcategory that states "Use additional code, if applicable, for contact with and (suspected) exposure to war theater (Z77.3-)."

Wolff-Parkinson-White (WPW) syndrome

We support the creation of a unique code for Wolff-Parkinson-White syndrome.

Addenda

We support the proposed Addenda modifications. We recommend Addenda changes, if approved, be implemented on the earliest possible effective date. That would mean implementing Addenda changes discussed at the March 2026 C&M meeting on October 1, 2026, and no later than April 1, 2027 (rather than on October 1, 2027 as proposed).

The addition of a "Code also" note was proposed under code P29.11, Neonatal tachycardia, to identify the specific type of tachycardia, if known. In the code proposal for neonatal supraventricular tachycardia, this "Code also" note was proposed at the category level (category P29). **We believe this note should be located as proposed in the Addenda modifications, under code P29.11.**

Organizing Principles for Classification of Ultra-rare and Genetic Conditions

AHIMA appreciates the commitment by CDC/NCHS to establish principles for the classification of ultra-rare and genetic conditions. We have recommended in previous C&M comments that guiding principles or a set of parameters are necessary to apply a consistent and systematic approach to the classification of rare diseases in ICD-10-CM.
We completely agree with the CDC/NCHS that continuing to add precoordinated, gene-specific codes is not sustainable without a defined approach. ICD-10-CM is a classification system and

its structure will not support unique, precoordinated codes for diseases by individual gene or gene variant in the long-term, especially given the volume of singe gene disorders, the fact that gene mutations may cause more than one disorder, and the reality there are many gene-disease relationships yet to be discovered. Medical conditions are expected to be clinically valid and recognized and well-defined by the medical and scientific communities to justify a unique code in ICD-10-CM. The field of genetics is constantly evolving and new discoveries are being made every day, which is challenging for the maintenance of a relatively stable classification system.

Recommendations for consideration as organizing principles for classification of ultra-rare and genetic conditions are developed:

- We believe the best approach is the option described in the C&M topic packet that would involve representing known disorders in ICD-10-CM with additional gene-specific attributes represented in a separate data standard that is updated on an ongoing basis and curated with direct input from geneticists. This approach would be the most comprehensive, consistent, clinically accurate, and sustainable long-term.
- If the above recommendation is not feasible, then we recommend that geneticists and other clinical experts should be involved in vetting the clinical validity of genetic proposals for rare and genetic disorders (including the assessment of whether the current scientific evidence supports creating a unique ICD-10-CM code). These experts should also provide input on code structure and placement. We have reviewed Mondo's proposal for Mondo to serve as the curated upstream source for coordinating expert-vetted genetic and ultra-rare disease concepts and believe it represents a promising approach that warrants further exploration.
- A genetic or rare condition should be recognized as a clinically valid disease by a relevant professional medical association or society before being considered for inclusion in ICD-10-CM. An expression of support for the proposal from the relevant professional medical societies would also be helpful.
- CDC/NCHS should consider requiring code requesters to submit citations for research and scientific evidence to support the clinical validity of a rare or genetic disease.
- Incidence of the disease should be one factor, but not the only factor to consider when evaluating code proposals for rare diseases. Only U.S. incidence data, not global data, should be considered.
- Vetting of code proposals should include an evaluation of the use case(s) for a unique code: Why is a unique code needed? Who needs it? Who is going to use the code? Why is the proposed level of specificity necessary? How likely is it that the necessary information to report the code will be documented?
- Standards for an appropriate and consistent level of gene specificity for inclusion in ICD-10-CM should be developed. We recommend that geneticists be involved in determining the most appropriate and clinically meaningful (from research and statistical perspectives) level of gene specificity for inclusion in ICD-10-CM.

- Options for code clustering should be considered in order to link a gene to a disease without an explosion of precoordinated ICD-10-CM codes. Ideally, a separate data standard to identify the genetic variant could be linked in a code cluster to the related medical condition (see our first recommendation above).
- The classification of rare diseases and genetic conditions in ICD-10-CM should be aligned with the approach used in ICD-11 where possible.
- Alignment across chapters is needed, as currently, genetic disorders are scattered across multiple chapters and sections of ICD-10-CM, including congenital anomalies, genetic disorders, neurodevelopmental disorders, neurological disorders, neoplasms, blood disorders, and endocrine disorders.
    - A more organized thought process around which disease concepts are placed in which chapter and how the related codes in different chapters fit, or do not fit, together is needed.
    - The title of chapter 17 in ICD-10-CM has been revised to include "and genetic disorders," but not all genetic disorders are classified in chapter 17.
    - The distinction between chromosomal disorders and congenital diseases is also confusing, so guidance would be helpful.
    - It is not clear whether multiple codes should be assigned when a congenital malformation syndrome is also a neurodevelopmental disorder (e.g., is it appropriate to assign a code from category QA0, Neurodevelopmental disorders related to specific genetic pathogen variants, with a code from subcategory Q87.8, Other specified congenital malformation syndromes, not elsewhere classified?).
    - Either a modification of the inclusion terms under codes F88, Other disorders of psychological development, and F89, Unspecified disorder of psychological development, or clarification of their interpretation and application is needed. These inclusion terms for "Other specified neurodevelopmental disorder" and "Neurodevelopmental Disorder NOS" are confusing because the distinction between these terms and the codes in category QA0 is not clear.
        - Is it appropriate to assign code F88 or F89 with a code from category QA0? If not, consideration should be given to adding an Excludes1 note for category QA0 under codes F88 and F89.
- A table of genes that are associated with neurodevelopmental disorders to provide direction on the appropriate code to use from category QA0 would be helpful. Alternatively, enhancements to the Alphabetic Index or the addition of inclusion terms could help guide users from a specific gene to the appropriate QA0 code.
    - The Alphabetic Index is limited in the number of genes that it directs to unique QA0 codes.
- While we recognize the "Code also" note under category QA0 is not intended to be all-inclusive, it is not clear what conditions are considered inherent to the QA0 codes (if any) and when a related condition that is not explicitly listed in the "Code also" note should be coded separately.

- Clear guidance is needed to assist coding professionals in consistent use of the genetic susceptibility codes. We do not believe a genetic susceptibility code should be assigned in conjunction with a code for a genetic disease if the genetic disease by definition predisposes an individual to the disease(s) described by the genetic susceptibility code(s).
    - As genomic discoveries continue to advance, category Z15, Genetic susceptibility to disease, could potentially expand significantly, resulting in a substantial increase in these codes. Without identification of the specific gene involved, this information may not be useful.
    - We believe it is redundant and thus unnecessary to assign a Z15 code in conjunction with a code for a condition that is inherently genetic or the code title indicates the condition is genetic.
    - Allowing the use of the Z15 codes with genetic disorder codes causes confusion. For example, it is not clear how to use the Z15 codes if a genetic disorder predisposes an individual to multiple types of malignant neoplasms. Should all of the applicable genetic susceptibility codes always be coded in conjunction with the code for the genetic disorder? Or does it depend on the reason for the encounter (e.g., if the reason for the encounter is a colonoscopy to screen for colon cancer due to a genetic susceptibility, assign code Z15.060, Genetic susceptibility to colorectal cancer, and not codes for other types of genetic susceptibility that may be related to the underlying genetic disorder)?
    - The *ICD-10-CM Official Guidelines for Coding and Reporting* should be revised to indicate when codes from category Z15 are and are not appropriate.
- Instructional notes under codes for genetic and rare conditions should be reviewed and revised if necessary, as some of these notes are confusing and conflicting.
    - For example, the "Code also" note under category QA1, Genetic disorders associated with neoplasms, not elsewhere classified (effective October 1, 2026), is confusing. Genetic susceptibility is not a "condition." The phrase "if applicable" when applied to genetic susceptibility to malignant neoplasm does not make sense, as all of the codes in category QA1 describe genetic disorders associated with neoplasms.
- As part of the process of developing organizing principles, the CDC/NCHS should evaluate existing codes for rare and genetic conditions. This review should consider to what extent these codes are being used; whether or not these conditions are being documented and whether the documentation aligns with the code(s) that were created; who is using this data and how is it being used? Understanding how existing codes for rare and genetic diseases are being used can help inform principles for the future classification of other rare and genetic conditions.

We recommend that the Cooperating Parties collaborate on the development of organizing principles for the classification of ultra-rare and genetic conditions, with additional stakeholder input. A C&M meeting attendee suggested that CDC/NCHS host a special meeting of

stakeholders to brainstorm ideas around the organizing principles. That seems like a reasonable suggestion. The annual AHIMA conference is one possibility for holding a stakeholder brainstorming session.

Thank you for the opportunity to comment on the ICD-10-CM code proposals being considered for April 1 or October 1, 2027 implementation. If you have any questions, please feel free to contact Sue Bowman, Senior Director of Coding Policy and Compliance, at (312) 233-1115 or sue.bowman@ahima.org.

Sincerely,

Lauren Riplinger, JD
Chief Public Policy and Impact Officer