



ICD-10 Coordination and Maintenance Committee Meeting
September 10-11, 2019
Diagnosis Agenda
Part 1 of 2

Welcome and announcements
Donna Pickett, MPH, RHIA
Co-Chair, ICD-10 Coordination and Maintenance Committee

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ICD-10 TIMELINE ONLY

A timeline of important dates in the ICD-10 process is described below:

September 10-11, 2019 ICD-10 Coordination and Maintenance Committee Meeting.

Those who wish to attend the ICD-10 Coordination and Maintenance Committee meeting **must have registered for the meeting online by September 2, 2019**. You must bring an official form of picture identification (such as a driver's license) in order to be admitted to the building.

In compliance to The Real ID Act, enacted in 2005, (<http://www.dhs.gov/real-id-enforcement-brief>) the following states/territories: Maine, Minnesota, Missouri, Montana and Washington State **will not** gain access into any Federal Agencies using the **above states** driver's license or ID. This means CMS visitors from these states/territories will need to provide alternative proof of identification (**such as a passport**) to gain entrance into Baltimore-based and Bethesda CMS buildings, as well as the Humphrey Building in Washington.

September 2019 Webcast of the September 10-11, 2019 ICD-10 Coordination and Maintenance Committee meeting will be posted on the CMS webpage as follows:
<https://www.cms.gov/Medicare/Coding/ICD10/C-and-M-Meeting-Materials.html>

October 1, 2019 **New and revised ICD-10-CM and ICD-10-PCS codes go into effect along with DRG changes. Final addendum available on web pages as follows:**

Diagnosis addendum –
<https://www.cdc.gov/nchs/icd/icd10cm.htm>

Procedure addendum –
<https://www.cms.gov/Medicare/Coding/ICD10/>

October 11, 2019 **Deadline for receipt of public comments on proposed new codes discussed at the September 10-11, 2019 ICD-10 Coordination and Maintenance Committee meetings for implementation on April 1, 2020.**

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- March 17-18, 2020 ICD-10 Coordination and Maintenance Committee Meeting.
- March 2020 Webcast of the March 17-18, 2020 ICD-10 Coordination and Maintenance Committee meeting will be posted on the CMS webpage as follows:
<https://www.cms.gov/Medicare/Coding/ICD10/C-and-M-Meeting-Materials.html>
- April 1, 2020 Any new ICD-10 codes to capture new diseases or technology will be implemented on April 1, 2020.
- April 17, 2020** **Deadline for receipt of public comments on proposed new codes and revisions discussed at the March 17-18, 2020 ICD-10 Coordination and Maintenance Committee meetings for implementation on October 1, 2020.**
- April 2020 Notice of Proposed Rulemaking to be published in the Federal Register as mandated by Public Law 99-509. This notice will include references to the finalized FY 2021 ICD-10-CM diagnosis and ICD-10-PCS procedure codes to date. It will also include proposed revisions to the MS-DRG system based on ICD-10-CM/PCS codes on which the public may comment. The proposed rule can be accessed at:
<https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/index.html?redirect=/AcuteInpatientPPS/PPS/list.asp>
- June 2020 Final addendum posted on web pages as follows:
Diagnosis addendum -
<https://www.cdc.gov/nchs/icd/icd10cm.htm>

Procedure addendum -
<https://www.cms.gov/Medicare/Coding/ICD10/index.html>
- June 12, 2020** **Deadline for requestors: Those members of the public requesting that topics be discussed at the September 2020 ICD-10 Coordination and Maintenance Committee meeting, tentatively scheduled for September 8-9, 2020, must have their requests submitted to CMS for procedures and NCHS for diagnoses.**
- August 1, 2020 Hospital Inpatient Prospective Payment System final rule to be published in the Federal Register as mandated by Public Law 99-509. This rule will also include links to all the final codes to be implemented on October 1, 2020.

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This rule can be accessed at: <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/index.html>

August 2020

Tentative agenda for the Procedure part of the September 2020 ICD-10 Coordination and Maintenance Committee meeting will be posted on the CMS webpage at –

<https://www.cms.gov/Medicare/Coding/ICD10/C-and-M-Meeting-Materials.html>

Tentative agenda for the Diagnosis part of the September 8-9, 2020 ICD-10 Coordination and Maintenance Committee meeting will be posted on the NCHS webpage at -

https://www.cdc.gov/nchs/icd/icd10cm_maintenance.htm

Federal Register notice for the September 2020 ICD-10 Coordination and Maintenance Committee meeting will be published. This will include the tentative agenda.

August 3, 2020

On-line registration opens for the September 2020 ICD-10 Coordination and Maintenance Committee meeting at:

<https://www.cms.gov/apps/events/default.asp>

September 3, 2020

Because of increased security requirements, those wishing to attend the September 2020 ICD-10 Coordination and Maintenance Committee meeting must register for the meeting online at:

<https://www.cms.gov/apps/events/default.asp>

Attendees must register online by September 3, 2020; failure to do so may result in lack of access to the meeting.

September 8-9, 2020
(Tentative date)

ICD-10 Coordination and Maintenance Committee Meeting.

Those who wish to attend the ICD-10 Coordination and Maintenance Committee meeting **must have registered for the meeting online by September 3, 2020**. You must bring an official form of picture identification (such as a driver's license) in order to be admitted to the building.

September 2020

Webcast of the September 8-9, 2020 ICD-10 Coordination and Maintenance Committee meeting will be posted on the CMS webpage as follows:

<https://www.cms.gov/Medicare/Coding/ICD10/C-and-M-Meeting-Materials.html>

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- October 1, 2020 New and revised ICD-10-CM and ICD-10-PCS codes go into effect along with DRG changes. Final addendum available on web pages as follows:
- Diagnosis addendum –**
<https://www.cdc.gov/nchs/icd/icd10cm.htm>
- Procedure addendum –**
<https://www.cms.gov/Medicare/Coding/ICD10/>
- October 9, 2020 **Deadline for receipt of public comments on proposed new codes discussed at the September 8-9, 2020 ICD-10 Coordination and Maintenance Committee meetings for implementation on April 1, 2021.**
- November 2020 Any new ICD-10 codes required to capture new technology that will be implemented on the following April 1 will be announced. Information on any new codes to be implemented April 1, 2021 will be posted on the following websites:
- <https://www.cdc.gov/nchs/icd/icd10cm.htm>
- <https://www.cms.gov/Medicare/Coding/ICD10/>
- November 9, 2020 **Deadline for receipt of public comments on proposed new codes and revisions discussed at the September 8-9, 2020 ICD-10 Coordination and Maintenance Committee meetings for implementation on October 1, 2021.**

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Webcast and Dial-In Information for Listen-only Participants

- Day 1: September 10, 2019: The meeting will begin promptly at 9:00 AM ET and will end at 5:00 PM ET. Lunch will be held from 12:30 PM to 1:30 PM. The meeting will be webcast via CMS at <http://www.cms.gov/live/>.
- Day 2: September 11, 2019: The meeting will begin promptly at 9:00 AM ET and will end at 5:00 PM ET. Lunch will be held from 12:30 PM to 1:30 PM. The meeting will be webcast via CMS at <http://www.cms.gov/live/>.
- Toll-free dial-in access is available for listen-only participants who cannot join the webcast:

Day 1-September 10, 2019: Phone: 1-877-267-1577; Meeting ID: 995 481 510.

Day 2-September 11, 2019: Phone: 1-877-267-1577; Meeting ID: 995 481 510.

We encourage you to join early, as the number of phone lines is limited.

In-Person Attendance

- Day 1: September 10, 2019: The meeting is being held in the CMS Auditorium. The meeting time is listed above. By your attendance, you are giving consent to the use and distribution of your name, likeness and voice during the meeting. You are also giving consent to the use and distribution of any personally identifiable information that you or others may disclose about you during the meeting. Please do not disclose personal health information.

There will be a WebEx option for this meeting. In-person attendees and those participating via WebEx may ask questions, as time permits. Remaining questions, as well as questions from those attending the meeting via the webcast may be submitted via the CMS ICD-10 Procedure Code Request mailbox at ICDProcedureCodeRequest@cms.hhs.gov.

- Day 2: September 11, 2019: The meeting is being held in the CMS Auditorium. The meeting time is listed above. By your attendance, you are giving consent to the use and distribution of your name, likeness and voice during the meeting. You are also giving consent to the use and distribution of any personally identifiable information that you or others may disclose about you during the meeting. Please do not disclose personal health information.

Note: Proposals for diagnosis code topics are scheduled for September 11, 2019 and will be led by the Centers for Disease Control (CDC). Please visit CDC's website for the Diagnosis agenda located at the following address: http://www.cdc.gov/nchs/icd/icd10cm_maintenance.htm

Registration to attend meeting in-person:

Information on registering online to attend the meeting in-person can be found at:

<http://www.cms.hhs.gov/apps/events/> ***If participating via the webcast or dialing in, and not attending in-person, you do NOT need to register on-line for the meeting.** For questions about the registration process, please contact Mady Hue at 410-786-4510 or marilu.hue@cms.hhs.gov or Noel Manlove at 410-786-5161 or noel.manlove@cms.hhs.gov.

Updated Security Information for In-person Attendees:

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Beginning June 1, 2018, Federal Protective Services (FPS) has implemented new security screening procedures at all CMS Baltimore locations to align with national screening standards. Please allow extra time to clear security prior to the beginning of the meeting.

Employees, contractors and visitors must place **all items** in bins for screening, including:

- Any items in your pockets
- Belts, hats, jackets & coats (not suit jackets or sport coats)
- Purses, laptop computers & cell phones
- Larger items (e.g. computer bags) can be placed directly onto the conveyer.

In the event the metal detector beeps when you walk through:

- A security guard will run a hand-held metal detector over you. If the metal detector doesn't alarm, you're cleared to enter.
- If the hand-held metal detector alarms, the guard will pat down the area of the body where the metal detector alarmed.
- If footwear alarms, it will need to be removed and placed in a bin for x-ray screening.
- Employees using a mobility aid (e.g. wheelchair, motorized scooter) will be screened using a hand-held metal detector and/or pat-down.

If you believe that you have a disability that will cause you to require reasonable accommodation to comply with the new process, please contact reasonableaccommodationprogram@cms.hhs.gov as soon as possible.

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Contact Information

Mailing address:

National Center for Health Statistics
ICD-9-CM Coordination and Maintenance Committee
3311 Toledo Road
Hyattsville, Maryland 20782
Fax: (301) 458-4022

Comments on the diagnosis proposals presented at the ICD Coordination and Maintenance Committee meeting should be sent to the following email address: nchsicd10CM@cdc.gov

Donna Pickett	(301) 458-4434
David Berglund	(301) 458-4095
Cheryl Bullock	(301) 458-4297
Shannon McConnell-Lamprey	(301) 458-4612
Traci Ramirez	(301) 458-4454

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Continuing Education Credits

Continuing education credits may be awarded by the American Academy of Professional Coders (AAPC) or the American Health Information Management Association (AHIMA) for participation in CMS/NCHS ICD-10 Coordination and Maintenance (C&M) Committee Meeting.

Continuing Education Information for American Academy of Professional Coders (AAPC)

If you plan to attend or participate via telephone the ICD-10 Coordination and Maintenance (C&M) Committee Meeting, you should be aware that CMS /NCHS do not provide certificates of attendance for these calls. Instead, the AAPC will accept your printed topic packet as proof of participation. Please retain a your topic packet copy as the AAPC may request them for any conference call you entered into your CEU Tracker if you are chosen for CEU verification. Members are awarded one (1) CEU per hour of participation.

Continuing Education Information for American Health Information Management Association (AHIMA)

AHIMA credential-holders may claim 1 CEU per 60 minutes of attendance at an educational program. Maintain documentation about the program for verification purposes in the event of an audit. A program does not need to be pre-approved by AHIMA, nor does a CEU certificate need to be provided, in order to claim AHIMA CEU credit. For detailed information about AHIMA's CEU requirements, see the Recertification Guide on AHIMA's web site.

Please note: The statements above are standard language provided to NCHS by the AAPC and the AHIMA. If you have any questions concerning either statement, please contact the respective organization, not NCHS.

Abnormal Neonatal Screening

Currently throughout the United States there are thirty-four (34) core conditions as part of the Recommended Uniform Screening Panel (RUSP) and an additional twenty-six secondary target conditions¹.

The Recommended Uniform Screening Panel is a list of disorders that are recommended by the Secretary of the Department of Health and Human Services (HHS) for states to screen as part of their state universal newborn screening (NBS) programs². Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments. Most states screen for the majority of disorders on the RUSP. Newer conditions are still in process of being adopted and some states screen for additional disorders.

While every state may vary regarding the specific tests they mandate, there are four (4) main categories of conditions that is screened by every state. Those categories are:

- 1) Metabolic conditions (e.g., PKU, Maple syrup urine disease) Fatty Acid disorders, Organic acid disorders, Amino acid disorders, Other metabolic disorders
- 2) Endocrine conditions (e.g., congenital hypothyroidism)
- 3) Hemoglobin conditions (e.g., sickle cell anemia)
- 4) Other conditions (e.g., critical congenital heart disease)

Under the other conditions category, screening for critical congenital heart disease (CCHD) is performed on all newborns as part of the American Academy of Pediatrics Periodicity Schedule and is currently mandated by law in more than half of the states.³

Neonatal CCHD screening failure (abnormal findings) is a distinct clinical event that clinicians now face. As this screening is performed on asymptomatic newborns, those babies who fail the CCHD screening should have no other signs or symptoms that would justify additional testing, which includes a cardiac echo.

The current ICD-10-CM code set has a single code P09 (Abnormal findings on neonatal screening) as a coding option, which may include any or all newborn screens that may be abnormal or have a positive indicator.

An ICD-10-CM code for failed CCHD screen would allow the cardiology department and cardiologists to accurately report and support their additional clinical evaluations and testing even if no critical illness is identified and when the patient is asymptomatic. Additionally, an ICD-10-CM code for an failed screening (abnormal findings) of CCHD screening would help to identify those babies who had a neonatal CCHD screen failure so that clinicians, health care delivery systems and state departments of health can more accurately assess appropriate follow-up.

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The American Academy of Pediatrics is asking for expansion of this code to specifically show which screening categories were abnormal and to show why there was an increase in healthcare utilization (e.g., echo test from positive CCHD screen) or until a time when a more definitive diagnosis can be made.

The American Academy of Pediatrics request the following tabular modifications:

TABULAR MODIFICATION

Add	P09	Abnormal findings on neonatal screening Abnormal findings on state mandated newborn screens
		Use additional code to identify signs, symptom and conditions associated with the screening
		Excludes2: nonspecific serologic evidence of human immunodeficiency virus [HIV] (R75)
New code	P09.1	Abnormal findings for inborn errors of metabolism
New code Add	P09.2	Abnormal findings for congenital endocrine disease Includes hypothyroidism, congenital adrenal hyperplasia
New code Add	P09.3	Abnormal findings for congenital hematologic disorders Includes: hemoglobinopathies, red cell membrane defects, sickle cell
New code	P09.4	Abnormal findings for cystic fibrosis
New code Add	P09.5	Abnormal findings for critical congenital heart disease Abnormal findings for CCHD
New code Add	P09.6	Abnormal findings for infectious organisms Includes Group B strep, herpes simplex, HIV, Toxoplasmosis, Cytomegalovirus
New code Add	P09.7	Abnormal findings for neonatal hearing loss Excludes1: Z01.110 Encounter for hearing examination following failed hearing screening
New code	P09.8	Other abnormal findings on neonatal screening
New code	P09.9	Abnormal findings on neonatal screening, unspecified

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- 1) <https://www.babysfirsttest.org/newborn-screening/the-recommended-uniform-screening-panel>
- 2) <https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html>
- 3) Glidewell J, Grosse S, Riehle-Colarusso T, et al. Actions in Support of Newborn Screening for Critical Congenital Heart Disease—United States, 2011–2018. MMWR Morb Mortal Wkly Rep 2019;68: 107-111.

Aromatic L-Amino Acid Decarboxylase (AADC) Deficiency

Aromatic L-amino acid decarboxylase (AADC) deficiency is a rare genetic, autosomal-recessive disorder resulting in an inborn error of neurotransmitter biosynthesis (Wassenberg 2017). Pathogenic mutations in the DOPA decarboxylase gene (*DDC*) encoding for the AADC enzyme result in severe combined deficiency of dopamine and serotonin; norepinephrine and epinephrine, which are synthesized from dopamine, are also deficient (Wassenberg 2017; Hwu 2018).

Dopamine is a neurotransmitter responsible for cognitive function, voluntary movement, and emotions while serotonin serves to regulate basal function, mood, sleep, memory and learning, body temperature, and cardiovascular and endocrine functions. Epinephrine and norepinephrine serve to control mood, attention, sleep patterns, cognition, and stress hormones (Himmelreich 2019). Due to the combined deficiency of these neurotransmitters, common signs and symptoms of AADC deficiency include hypotonia, hypokinesia, hypertonia, dystonia, oculogyric crisis, developmental delay/failure to thrive, ptosis, and excessive sweating. Less common signs and symptoms include temperature instability, epileptic seizures, sleep disturbance, irritability, dysphoria, and autism-like symptoms. Further, non-neurologic signs and symptoms include short stature, diarrhea or constipation, nasal congestion, feeding difficulties, hypoglycemia, and gastroesophageal reflux disease (Himmelreich 2019; Wassenberg 2017). In most cases, these signs and symptoms present within the first few months of life and patients often die within their first decade of life (Chen 2014; Wassenberg 2017).

AADC deficiency is a rare disease. The estimated prevalence of AADC deficiency in the United States ranges from 1:32,000 to 1:90,000. The variance is based on the limited population, early age of death, and potential delayed or misdiagnosis (Himmelreich 2019; Wassenberg 2017; Chien 2016; Pons 2004; Helman 2014).

Early diagnosis of AADC deficiency is critical for promoting early use of available management options (Pons 2004; Himmelreich 2019). Guidelines for diagnosis and treatment of AADC deficiency have been published (Wassenberg 2017). From the clinical standpoint, there are a number of specific medications that may be beneficial in particular cases, as well as other types of medications that would be contraindicated (Wassenberg 2017). The average onset of symptoms is around 3 months of age; however, diagnosis of AADC deficiency is often delayed to a mean age of 3.5 years (Wassenberg 2017). In order to diagnose children with unexplained developmental delay and other signs and symptoms of AADC deficiency, in particular oculogyric crisis and autonomic symptoms, consensus guidelines recommend at least 2 of the following 3 core diagnostics (Wassenberg 2017):

- 1) Low cerebral spinal fluid (CSF) levels of 5-hydroxyindoleacetic acid (5-HIAA), homovanillic acid (HVA), and 3-methoxy-4-hydroxyphenylglycol (MHPG); increased CSF levels of 3-O-methyldopa (3-OMD), levodopa, and 5-hydroxytryptophan (5-HTP); and normal CSF pterins
- 2) Decreased AADC enzyme activity in plasma
- 3) Compound heterozygous or homozygous pathologic variants in the *DDC* gene

Creating a unique ICD-10-CM code for AADC deficiency will aid in tracking the disorder, as well as help to promote proper diagnosis and treatment for patients with this condition.

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References

- Chen PW, Lee NC, Chien YH, et al. Diagnosis of aromatic L-amino acid decarboxylase deficiency by measuring 3-O-methyldopa concentrations in dried blood spots. *Clin Chim Acta*. 2014 Apr 20;431:19-22.
- Chien YH, Chen PW, Lee NC, et al. 3-O-methyldopa levels in newborns: result of newborn screening for aromatic l-amino-acid decarboxylase deficiency. *Mol Genet Metab*. 2016 Aug;118(4):259-263.
- Helman G, Pappa MB, Pearl PL. Widening phenotypic specturm of AADC deficiency, a disorder of dopamine and serotoonin synthesis. *JIMD Rep*. 2014;17:23-27.
- Himmelreich N, Montioli R, Bertoldi M, et al. Aromatic amino acid decarboxylase deficiency: molecular and metabolic basis and therapeutic outlook. *Mol Genet Metab*. 2019 Mar 27. pii: S1096-7192(18)30786-8.
- Hwu W-L, Chien Y-H, Lee N-C, Li M-H. Natural history of aromatic l-amino acid decarboxylase deficiency in Taiwan. *JIMD Rep*. 2018;40:1-6.
- Pons R, Ford B, Chiriboga CA, et al. Aromatic l-amino acid decarboxylase deficiency: clinical features, treatment, and prognosis. *Neurology*. 2004;62(7):1058-1065.
- Wassenberg T, Molero-Luis M, Jeltsch K, et al. Consensus guideline for the diagnosis and treatment of aromatic l-amino acid decarboxylase (AADC) deficiency. *Orphanet J Rare Dis*. 2017;12:12:1-21.

TABULAR MODIFICATIONS

E70 Disorders of aromatic amino-acid metabolism

E70.8 Other disorders of aromatic amino-acid metabolism

New Code E70.81 Aromatic L-amino acid decarboxylase deficiency
AADC deficiency

New Code E70.89 Other disorders of aromatic amino-acid metabolism

Chimeric Antigen Receptor T-Cell Therapy (CAR-T) Status

The Alliance of Dedicated Cancer Centers (ADCC) submits a request for tabular modifications to address the need to track patients who have received Chimeric Antigen Receptor T-Cell Therapy (CAR-T). This information is vital to understand the long-term impact and benefits of CAR-T therapy, assess costs and other issues presented by this evolving therapy.

In October 2017, the U.S. Food and Drug Administration (FDA) approved the first CAR-T products for use in the treatment of certain blood cancers. CAR-T therapy has impacted the clinical options for patients who have highly refractory Non-Hodgkin lymphoma (NHL).

These patients are seeing clinicians to assess their status after CAR-T therapy, including treatment response and to address late on-set complications. The typical complications of CAR-T therapy include Cytokine Release Syndrome (CRS) and/or neurotoxicity, which usually occur in the first few weeks after receiving the cell infusion (when the patient is typically still in the hospital.) Sometimes, however, such complications occur post-discharge and can be the reason for additional medical encounters (i.e. visit to a physician or ED).

There is currently no ICD-10-CM code to capture the status of a patient after receiving CAR-T therapy. As a result, neither hospitals nor providers can accurately track patient outcomes. In addition, without a code, CAR-T patient's status cannot be designated as the reason for the additional resources, tests, and/or treatment that may occur as a result of the patient's status as a CAR-T recipient.

TABULAR MODIFICATIONS

Z98 Other postprocedural states

Excludes2: aftercare (Z43-Z49, Z51)
follow-up medical care (Z08-Z09)
postprocedural complication - see Alphabetical Index

Z98.8 Other specified postprocedural states

Z98.89 Other specified postprocedural states

Z98.890 Other specified postprocedural states
Personal history of surgery, not elsewhere

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classified

Z98.891 History of uterine scar from previous surgery
Excludes1: Maternal care due to uterine scar from
previous surgery (O34.2-)

New
sub-subcategory

Z98.892 Gene and cellular therapy status

New code

Z98.8921 Chimeric Antigen Receptor T-cell Status
CAR-T Status

New code

Z98.8928 Gene and cellular therapy status, other

New code

Z98.8929 Gene and cellular therapy status unspecified

Cyclin-dependent kinase-like 5 (CDKL5) Deficiency Disorder

The Loulou Foundation, the International Foundation for CDKL5 Research and the principal investigators of the CDKL5 Centers of Excellence are proposing that a new ICD-10-CM code be created to specifically identify patients with CDKL5 Deficiency Disorder. Currently, there is no unique ICD-10-CM code to identify patients with CDKL5 Deficiency Disorder.

CDKL5 Deficiency Disorder is a developmental encephalopathy caused by pathogenic variants in the gene *CDKL5*. CDKL5 Deficiency Disorder is a unique disorder that presents with early infantile onset refractory epilepsy, hypotonia, developmental intellectual and motor disabilities, and cortical visual impairment¹⁻⁶. CDKL5 Deficiency Disorder also causes autonomic problems and gastrointestinal dysfunction that range from oral adversity, swallow dysfunction, gastroesophageal reflux and constipation¹⁻⁴. Over time, children affected can develop scoliosis¹⁻⁴.

CDKL5 Deficiency Disorder has unique complications and treatment implications. Seizures might become worse with specific anti-convulsant medications¹, requiring neurology expertise and proper identification of the disorder. Unlike other diseases with epilepsy, CDKL5 Deficiency Disorder affects visual function¹⁻², and it is important that the risk/benefit ratio of particular anti-epileptic drugs affecting visual function be considered⁷. Language ability is very limited, requiring speech therapy and augmentative communication¹⁻⁴. Motor function is also strongly affected, and patients need physical therapy, occupational therapy and orthopedics¹⁻⁴. Feeding and swallowing dysfunction are common, and gastrostomy tubes are used to limit the risks from pulmonary aspiration, including mortality due to aspiration pneumonia¹⁻⁴.

CDKL5 is a gene that provides instructions for making a protein called cyclin-dependent kinase-like 5 also known as serine/threonine kinase 9 (STK9) that is essential for normal brain development. Although little is known about the protein's function, it may play a role in regulating the activity of other genes.

The existing ICD-10-CM codes are not specific enough to capture the multisystem effect of CDKL5 Deficiency Disorder. A result of not having a specific ICD-10-CM code can lead to coding inconsistencies, inability to track disease prevalence and mortality, clinical and epidemiological research and can affect treatment and delivery of care.

A specific ICD-10-CM code would make it possible to track outcomes from clinical interventions, and facilitating the development of protocols for standard of care. With the data that would be captured, this will also allow clinicians to understand the severity and risk of the different symptoms and impact on outcomes of different interventions. A unique ICD-10-CM code for CDKL5 Deficiency Disorder will improve care by improving clinical care by ensuring appropriate patient treatment, facilitating access to multidisciplinary treatment and consistency across different treatment specialists, including physical and behavioral therapy, speech therapy, augmentative communication,

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and specific interventions to address sleep, orthopedic and gastrointestinal issues.

The Loulou Foundation, the International Foundation for CDKL5 Research and the principal investigators from the CDKL5 Centers of Excellence support the proposed new code. The American Epilepsy Society, the American Academy of Neurology and Sections of the American Academy of Pediatrics provided clinical input and various recommendations in response to this proposal. NCHS is proposing the following tabular modifications.

The principal investigators of the CDKL5 Centers of Excellence¹² support this proposal. All investigators are specialists in the diagnosis and treatment of CDKL5 Deficiency Disorder, and include:

Dr. Heather Olson, Boston Children's Hospital

Dr. Tim Benke, Children's Hospital Colorado

Dr. Scott Demarest, Children's Hospital Colorado

Dr. Judy Weisenberg, St. Louis Children's Hospital

Dr. Robin Ryther, St. Louis Children's Hospital

Dr. Orrin Devinsky, NYU Langone Health Center

Dr. Elia Pestana-Knight, Cleveland Clinic

Dr. Bernhard Suter, Texas Children's Hospital

Dr. Eric Marsh, Children's Hospital of Philadelphia

Dr. Raj Rajaraman, UCLA Mattel Children's Hospital REFERENCES

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9. NCT03572933

NCT03694275

NCT03861871

<https://www.cdkl5.com/cdkl5-centers-excellence/>

TABULAR MODIFICATIONS

- G40 Epilepsy and recurrent seizures
- G40.4 Other generalized epilepsy and epileptic syndromes
 - Epilepsy with grand mal seizures on awakening
 - Epilepsy with myoclonic absences
 - Epilepsy with myoclonic-astatic seizures
 - Grand mal seizure NOS
 - Nonspecific atonic epileptic seizures
 - Nonspecific clonic epileptic seizures
 - Nonspecific myoclonic epileptic seizures
 - Nonspecific tonic epileptic seizures
 - Nonspecific tonic-clonic epileptic seizures
 - Symptomatic early myoclonic encephalopathy
 - G40.40 Other generalized epilepsy and epileptic syndromes, not intractable
 - Other generalized epilepsy and epileptic syndromes without intractability
 - Other generalized epilepsy and epileptic syndromes NOS
 - G40.401 Other generalized epilepsy and epileptic syndromes, not intractable, with status epilepticus
 - G40.409 Other generalized epilepsy and epileptic syndromes, not intractable, without status epilepticus
 - G40.41 Other generalized epilepsy and epileptic syndromes, intractable
 - G40.411 Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus
 - G40.419 Other generalized epilepsy and epileptic syndromes, intractable, without status epilepticus
 - New code Add G40.42 Cyclin-Dependent Kinase-Like 5 Deficiency Disorder
CDKL5

Fetal Anomalies

The Society for Maternal Fetal Medicine (SMFM) and the American College of Obstetricians and Gynecologists (ACOG) are requesting that the O35 code sections for fetal anomalies (eg. Central Nervous System Anomalies (CNS), Chromosomal Anomalies, and Fetal Abnormalities and Damage), be expanded to provide additional specificity for appropriate diagnosis coding and to assist in measuring the incidence of these specific anomalies. A proposal was presented at the September 2018 Coordination and Maintenance meeting and public comment was not supported. This will enable better tracking, measurement, and ultimately improved treatment modalities for identified fetal anomalies. Assignment of trimesters is not applicable.

The proposed data set will be used primarily by physicians with specialized training and skill in assessing fetal anomalies during pregnancy. These physicians currently document these conditions during patient assessments but have no method of capturing the data with the current code set. These expanded code sets would be reported once the condition has been confirmed.

For most antenatal diagnosis, the currently available ICD-10-CM codes include the O35.0XX- series which provides no specificity as to which CNS abnormality has been diagnosed, O35.1XX- which provides no specificity as to which chromosomal abnormality has been diagnosed, or the O35.2 to O35.7 series which provide specificity to etiology but not to the fetal abnormality. The O35.8 and O35.9 code series are non-specific as well. The proposed new codes represent the most common central nervous system anomalies. Their specificity provides guidance in reviewing and abstracting medical records. For example, during the height of the Zika virus outbreak, having specific codes would have allowed identification of the O35.06X0 code (microcephaly) one of the new codes in the proposal, as opposed to having a non-specific O35.09X0 (other central nervous system) as a default diagnosis.

The advantage of the expanded code set is that the additional codes will provide specificity for fetal conditions during the antepartum. Specific antenatal codes for fetal anomalies currently do not exist although most fetal anomalies are diagnosed during the antepartum with reasonable specificity. This information is documented and available in the patient records with no correspondingly specific ICD-10-CM code.

The aforementioned abnormalities are often captured in the neonatal record with postnatal ICD-10-CM codes but the absence of antenatal ICD-10-CM codes to reflect many of the same diagnoses limits the ability to assess the quality of the antenatal diagnosis as well as the evaluation of the different treatment modalities proposed for some of these diagnoses.

Specificity in fetal anomaly coding has major implications on treatment modality. For example, If the proposed codes were used, the common diagnosis of O35.02X0 (choroid plexus cyst) would be reported for a non-lethal condition, while a diagnosis of O35.01X0 (anencephaly), though less common, is incompatible with life. Hence, the option of terminating the pregnancy should be offered with the latter diagnosis.

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In other examples, would the performance of a Cesarean delivery for certain CNS abnormalities (e.g. spina bifida but not agenesis of the corpus callosum) lead to better outcomes? Are certain drug exposures associated with skeletal, neurologic, and cardiac abnormalities? The proposed codes would allow data tracking to determine the treatments that provide the best outcomes. The existing ICD-10 codes do not provide the specificity to develop the data that would enable further research on these important issues.

With regards to specific chromosomal abnormality codes, the top trisomies are all managed in different ways. They also have varying and different implications as to pregnancy continuation. For example, a diagnosis of trisomy 21, with proposed code O35.12X0 as the diagnosis, may have diametrically opposite outcomes as regards pregnancy continuation or termination. On the other hand, diagnoses of trisomies 13 & 18 are both lethal and pregnancy termination is often recommended.

We favor keeping the “other” categories because the proposed additions or changes include the most common abnormalities but are not comprehensive to ALL abnormalities. We should have the flexibility to allow the identification of rare abnormalities, even though the creation of a specific ICD-10-CM code for every rare abnormality is not possible.

The facial abnormalities series of codes is important because they identify relatively common abnormalities, some of which may be genetic in origin while others may be associated with drug intake (e.g. antiseizure medications). The correct and most specific diagnosis code helps in referring these patients to specialized centers where facial surgery is undertaken. The antenatal diagnosis is important because some of these babies may need specialized mouth suckling devices that are critical soon after delivery and a specific antenatal diagnosis would be helpful to avoid delays in providing proper care and nutrition.

TABULAR MODIFICATION

Remove the first "X" place holder and replace with more specific fetal condition.

O35 Maternal care for known or suspected fetal abnormality and damage

Includes: the listed conditions in the fetus as a reason for hospitalization or other obstetric

care to the mother, or for termination of pregnancy

Code also any associated maternal condition

Excludes1: encounter for suspected maternal and fetal conditions ruled out (Z03.7-)

One of the following 7th characters is to be assigned to each code under category O35. 7th character 0 is for single gestations and multiple gestations where the fetus is unspecified. 7th characters 1 through 9 are for cases of multiple gestations to identify the fetus for which the

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code applies. The appropriate code from category O30, Multiple gestation, must also be assigned when assigning a code from category O35 that has a 7th character of 1 through 9.

- 0 not applicable or unspecified
- 1 fetus 1
- 2 fetus 2
- 3 fetus 3
- 4 fetus 4
- 5 fetus 5
- 9 other fetus

O35.0 Maternal care for (suspected) central nervous system malformation in fetus

Delete ~~Maternal care for fetal anencephaly~~

Delete ~~Maternal care for fetal hydrocephalus~~

Delete ~~Maternal care for fetal spina bifida~~

Excludes2: chromosomal abnormality in fetus (O35.1)

New

subcategory O35.00 Maternal care for (suspected) central nervous system malformation in fetus, Agensis of the Corpus Callosum

Delete ~~O35.0XX0 Maternal care for (suspected) central nervous system malformation in fetus, not applicable or unspecified~~

New code O35.00X0 Maternal care for (suspected) central nervous system malformation in fetus, agensis of the corpus callosum, not applicable or unspecified

Delete ~~O35.0XX1 Maternal care for (suspected) central nervous system malformation in fetus, fetus 1~~

New code O35.00X1 Maternal care for (suspected) central nervous system malformation in fetus agensis of the corpus callosum, fetus 1

Delete ~~O35.0XX2 Maternal care for (suspected) central nervous system malformation in fetus, fetus 2~~

New code O35.00X2 Maternal care for (suspected) central nervous system malformation in fetus, agensis of the corpus callosum, fetus

2

Delete ~~O35.0XX3 Maternal care for (suspected) central nervous system malformation in fetus, fetus 3~~

New code O35.00X3 Maternal care for (suspected) central nervous system malformation in fetus, agensis of the corpus callosum,

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		fetus 3
Delete	O35.0XX4	Maternal care for (suspected) central nervous system malformation in fetus, fetus 4
New code	O35.00X4	Maternal care for (suspected) central nervous system malformation in fetus, agenesis of the corpus, fetus 4
Delete	O35.0XX5	Maternal care for (suspected) central nervous system malformation in fetus, fetus 5
New code	O35.00X5	Maternal care for (suspected) central nervous system malformation in fetus, agenesis of the corpus callosum, fetus 5
Delete	O35.0XX9	Maternal care for (suspected) central nervous system malformation in fetus, other fetus
New code	O35.00X9	Maternal care for (suspected) central nervous system malformation in fetus, agenesis of the corpus callosum, other fetus
New subcategory	O35.01	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly
New code	O35.01X0	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, not applicable or unspecified
New code	O35.01X1	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, fetus 1
New code	O35.01X2	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, fetus 2
New code	O35.01X3	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, fetus 3
New code	O35.01X4	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, fetus 4
New code	O35.01X5	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, fetus 5
New code	O35.01X9	Maternal care for (suspected) central nervous system malformation in fetus, anencephaly, other fetus
New subcategory	O35.02	Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts
New code	O35.02X0	Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts, not applicable or unspecified

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New code	O35.02X1 Maternal care for (suspected) central nervous system malformation in fetus choroid plexus cysts, fetus 1
New code	O35.02X2 Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts, fetus 2
New code	O35.02X3 Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts, fetus 3
New code	O35.02X4 Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts, fetus 4
New code	O35.02X5 Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts, fetus 5
New code	O35.02X9 Maternal care for (suspected) central nervous system malformation in fetus, choroid plexus cysts, other fetus
New subcategory	O35.03 Maternal care for (suspected) central nervous system malformation in fetus, encephalocele
New code	O35.03X0 Maternal care for (suspected) central nervous system malformation in fetus, encephalocele, not applicable or unspecified
New code	O35.03X1 Maternal care for (suspected) central nervous system Malformation in fetus, encephalocele, fetus 1
New code	O35.03X2 Maternal care for (suspected) central nervous system Malformation in fetus, encephalocele, fetus 2
New code	O35.03X3 Maternal care for (suspected) central nervous system malformation in fetus, encephalocele, fetus 3
New code	O35.03X4 Maternal care for (suspected) central nervous system malformation in fetus, encephalocele, fetus 4
New code	O35.03X5 Maternal care for (suspected) central nervous system malformation in fetus, encephalocele, fetus 5
New code	O35.03X9 Maternal care for (suspected) central nervous system malformation in fetus, encephalocele, other fetus
New subcategory	O35.04 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly
New code	O35.04X0 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly, not applicable or unspecified
New code	O35.04X1 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly, fetus 1
New code	O35.04X2 Maternal care for (suspected) central nervous system

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	Malformation in fetus, holoprosencephaly, fetus 2
New code	O35.04X3 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly, fetus 3
New code	O35.04X4 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly, fetus 4
New code	O35.04X5 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly, fetus 5
New code	O35.04X9 Maternal care for (suspected) central nervous system malformation in fetus, holoprosencephaly, other fetus
New subcategory	O35.05 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly
New code	O35.05X0 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, not applicable or unspecified
New code	O35.05X1 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, fetus 1
New code	O35.05X2 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, fetus 2
New code	O35.05X3 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, fetus 3
New code	O35.05X4 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, fetus 4
New code	O35.05X5 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, fetus 5
New code	O35.05X9 Maternal care for (suspected) central nervous system malformation in fetus, hydrocephaly, other fetus
New subcategory	O35.06 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly
New code	O35.06X0 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly, not applicable or unspecified
New code	O35.06X1 Maternal care for (suspected) central nervous system Malformation in fetus, microcephaly, fetus 1
New code	O35.06X2 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly, fetus 2

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New code	O35.06X3 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly, fetus 3
New code	O35.06X4 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly, fetus 4
New code	O35.06X5 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly, fetus 5
New code	O35.06X9 Maternal care for (suspected) central nervous system malformation in fetus, microcephaly, other fetus
New subcategory	O35.07 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida
New code	O35.07X0 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, not applicable or unspecified
New code	O35.07X1 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, fetus 1
New code	O35.07X2 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, fetus 2
New code	O35.07X3 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, fetus 3
New code	O35.07X4 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, fetus 4
New code	O35.07X5 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, fetus 5
New code	O35.07X9 Maternal care for (suspected) central nervous system malformation in fetus, spina bifida, other fetus
New subcategory	O35.08 Maternal care for (suspected) central nervous system malformation in fetus other central nervous system malformation
New code	O35.08X0 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous malformation, not applicable or unspecified
New code	O35.08X1 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous system malformation, fetus 1
New code	O35.08X2 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous system malformation, fetus 2

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New code	O35.08X3 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous system malformation, fetus
New code	O35.08X4 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous system malformation, fetus 4
New code	O35.89X5 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous system malformation, fetus 5
New code	O35.08X9 Maternal care for (suspected) central nervous system malformation in fetus, other central nervous system malformation, other fetus

O35.1 Maternal care for (suspected) chromosomal abnormality in fetus

New subcategory	O35.10 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13
Delete	O35.1XX0 Maternal care for (suspected) chromosomal abnormality in fetus not applicable or unspecified
New code	O35.10X0 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, not applicable or unspecified
Delete	O35.1XX1 Maternal care for (suspected) chromosomal abnormality in fetus, fetus 1
New code	O35.10X1 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 1
Delete	O35.1XX2 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 2
New code	O35.10X2 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 2
Delete	O35.1XX3 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 3
New code	O35.10X3 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 3
Delete	O35.1XX4 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 4
New code	O35.10X4 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 4
Delete	O35.1XX5 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 5
New code	O35.10X5 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, fetus 5

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Delete	O35.1XX9 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, other fetus
New code	O35.10X9 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 13, other fetus
New subcategory	O35.11 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18
New code	O35.11X0 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, not applicable or unspecified
New code	O35.11X1 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, fetus 1
New code	O35.11X2 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, fetus 2
New code	O35.11X3 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, fetus 3
New code	O35.11X4 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, fetus 4
New code	O35.11X5 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, fetus 5
New code	O35.11X9 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 18, other fetus
New subcategory	O35.12 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21
New code	O35.12X0 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, not applicable or unspecified
New code	O35.12X1 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, fetus 1
New code	O35.12X2 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, fetus 2
New code	O35.12X3 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, fetus 3
New code	O35.12X4 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, fetus 4
New code	O35.12X5 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, fetus 5
New code	O35.12X9 Maternal care for (suspected) chromosomal abnormality in fetus, Trisomy 21, other fetus

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New subcategory	O35.13 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome
New code	O35.13X0 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, not applicable or unspecified
New code	O35.13X1 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, fetus 1
New code	O35.13X2 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, fetus 2
New code	O35.13X3 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, fetus 3
New code	O35.13X4 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, fetus 4
New code	O35.13X5 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, fetus 5
New code	O35.13X9 Maternal care for (suspected) chromosomal abnormality in fetus, Turner Syndrome, other fetus
New subcategory	O35.14 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality
New code	O35.14X0 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, not applicable or unspecified
New code	O35.14X1 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, fetus 1
New code	O35.14X2 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, fetus 2
New code	O35.14X3 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, fetus 3
New code	O35.14X4 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, fetus 4
New code	O35.14X5 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, fetus 5
New code	O35.14X9 Maternal care for (suspected) chromosomal abnormality in fetus, sex chromosome abnormality, other fetus

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New subcategory	O35.18 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality
New code	O35.18X0 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality not applicable or unspecified
New code	O35.18X1 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality, fetus 1
New code	O35.18X2 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality fetus 2
New code	O35.18X3 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality fetus 3
New code	O35.18X4 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality fetus 4
New code	O35.18X5 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality fetus 5
New code	O35.18X9 Maternal care for (suspected) chromosomal abnormality in fetus, other chromosomal abnormality, other fetus
	O35.8 Maternal care for other (suspected) fetal abnormality and damage
Delete	Maternal care for damage to fetus from maternal listeriosis
Delete	Maternal care for damage to fetus from maternal toxoplasmosis
New subcategory	O35.80 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies
Delete	O35.8XX0 Maternal care for other (suspected) fetal abnormality and damage, not applicable or unspecified
New code	O35.80X0 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, not applicable or unspecified
Delete	O35.8XX1 Maternal care for other (suspected) fetal abnormality and damage, fetus 1
New code	O35.80X1 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, fetus 1
Delete	O35.8XX2 Maternal care for other (suspected) fetal abnormality and damage, fetus 2
New code	O35.80X2 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, fetus 2
Delete	O35.8XX3 Maternal care for other (suspected) fetal abnormality and damage, fetus 3
New code	O35.80X3 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, fetus 3

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Delete	O35.8XX4 Maternal care for other (suspected) fetal abnormality and damage, fetus 4
New code	O35.80X4 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, fetus 4
Delete	O35.8XX5 Maternal care for other (suspected) fetal abnormality and damage, fetus 5
New code	O35.80X5 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, fetus 5
Delete	O35.8XX9 Maternal care for other (suspected) fetal abnormality and damage, other fetus
New code	O35.80X9 Maternal care for other (suspected) fetal abnormality and damage, fetal facial anomalies, other fetus
New subcategory	O35.81 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, not applicable or unspecified
New code	O35.81X0 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, not applicable or unspecified
New code	O35.81X1 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, fetus 1
New code	O35.81X2 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, fetus 2
New code	O35.81X3 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, fetus 3
New code	O35.81X4 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, fetus 4
New code	O35.81X5 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, fetus 5
New code	O35.81X9 Maternal care for other (suspected) fetal abnormality and damage, fetal cardiac anomalies, other fetus
New subcategory	O35.82 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, not applicable or unspecified
New code	O35.82X0 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, not applicable or unspecified
New code	O35.82X1 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, fetus 1
New code	O35.82X2 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, fetus 2
New code	O35.82X3 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, fetus 3

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New code	O35.82X4 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, fetus 4
New code	O35.82X5 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, fetus 5
New code	O35.82X9 Maternal care for other (suspected) fetal abnormality and damage, fetal pulmonary anomalies, other fetus
New subcategory	O35.83 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies
New code	O35.83X0 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, not applicable or unspecified
New code	O35.83X1 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, fetus 1
New code	O35.83X2 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, fetus 2
New code	O35.83X3 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, fetus 3
New code	O35.83X4 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, fetus 4
New code	O35.83X5 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, fetus 5
New code	O35.83X9 Maternal care for other (suspected) fetal abnormality and damage, fetal gastrointestinal anomalies, other fetus
New subcategory	O35.84 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies
New code	O35.84X0 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, not applicable or unspecified
New code	O35.84X1 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, fetus 1
New code	O35.84X2 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, fetus 2
New code	O35.84X3 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, fetus 3
New code	O35.84X4 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, fetus 4
New code	O35.84X5 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, fetus 5

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	fetal genitourinary anomalies, fetus 5
New code	O35.84X9 Maternal care for other (suspected) fetal abnormality and damage, fetal genitourinary anomalies, other fetus
New subcategory	O35.85 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies
New code	O35.85X0 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, not applicable or unspecified
New code	O35.85X1 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, fetus 1
New code	O35.85X2 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, fetus 2
New code	O35.85X3 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, fetus 3
New code	O35.85X4 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, fetus 4
New code	O35.85X5 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, fetus 5
New code	O35.85X9 Maternal care for other (suspected) fetal abnormality and damage, fetal musculoskeletal anomalies, other fetus
New subcategory	O35.86 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies
New code	O35.86X0 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, not applicable or unspecified
New code	O35.86X1 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, fetus 1
New code	O35.86X2 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, fetus 2
New code	O35.86X3 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, fetus 3
New code	O35.86X4 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, fetus 4
New code	O35.86X5 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, fetus 5
New code	O35.86X9 Maternal care for other (suspected) fetal abnormality and damage, fetal upper extremities anomalies, other fetus

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New
subcategory O35.87 Maternal care for other (suspected) fetal abnormality and damage, fetal lower
extremities anomalies

New code O35.87X0 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, not applicable or unspecified

New code O35.87X1 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, fetus 1

New code O35.87X2 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, fetus 2

New code O35.87X3 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, fetus 3

New code O35.87X4 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, fetus 4

New code O35.87X5 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, fetus 5

New code O35.87X9 Maternal care for other (suspected) fetal abnormality and damage,
fetal lower extremities anomalies, other fetus

New
subcategory O35.88 Maternal care for other (suspected) fetal abnormality and damage, other
non-central nervous system fetal markers or anomalies

Add Maternal care for damage to fetus from maternal listeriosis

Add Maternal care for damage to fetus from maternal toxoplasmosis

New code O35.88X0 Maternal care for other (suspected) fetal abnormality and damage,
other non-central nervous system fetal markers or
anomalies, not applicable or unspecified

New code O35.88X1 Maternal care for other (suspected) fetal abnormality and damage,
other non-central nervous system fetal markers or
anomalies, fetus 1

New code O35.88X2 Maternal care for other (suspected) fetal abnormality and damage,
other non-central nervous system fetal markers or
anomalies, fetus 2

New code O35.88X3 Maternal care for other (suspected) fetal abnormality and damage,
other non-central nervous system fetal markers or
anomalies, fetus 3

New code O35.88X4 Maternal care for other (suspected) fetal abnormality and damage,

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	other non-central nervous system fetal markers or anomalies, fetus 4
New code	O35.88X5 Maternal care for other (suspected) fetal abnormality and damage, other non-central nervous system fetal markers or anomalies, fetus 5
New code	O35.88X9 Maternal care for other (suspected) fetal abnormality and damage, other non-central nervous system fetal markers or anomalies, other fetus

Identification of Specific Synthetic Opioids

The U.S. is grappling with an opioid epidemic with a still-mounting death rate. The Centers for Disease Control and Prevention (Hedegaard, Miniño & Warner, 2018) reports that the drug overdose death rate increased from 6.1 per 100,000 in 1999 to 21.7 in 2017. The large majority of these deaths involved opioids. Rates also have risen for opioid-related inpatient stays (5.7% average annual growth rate between 2005 and 2014) and opioid-related emergency department visits (8.0% average annual growth rate between 2005 and 2014) (Weiss, Elixhauser, Barrett, Steiner, Bailey, & O'Malley, 2017).

Fentanyl and fentanyl analogues are highly potent opioids that are posing a serious threat to the public health. Pharmaceutical fentanyl, prescribed as transdermal patches or lozenges, is approved for treating severe pain. Chemically identical counterfeit fentanyl, as well as carfentanil and other fentanyl analogs not approved for human use, are sold through illegal drug markets for their opioid-like effect. They are often combined with heroin, cocaine, and other substances or mixed with fillers and pressed into counterfeit opioid pills. Law enforcement reports indicate that clandestinely-produced fentanyl/analog products are causing increases in synthetic opioid overdoses.

Overdose deaths attributed to fentanyl began to rise in 2013. A review of medical examiner/coroner reports or death certificate data from six states with a high burden of synthetic opioid deaths (i.e., a 1-year increase in synthetic opioid deaths exceeding two per 100,000 residents, or a 1-year increase of ≥ 100 synthetic opioid deaths) showed that the increase in fentanyl deaths was the primary factor driving increases in synthetic opioid deaths during 2013-2014 (Gladden, Martinez, & Seth, 2016).

Tramadol, an opioid analgesic approved for the treatment of moderate to moderately severe pain in adults, is also reported as synthetic opioid. Misuse of tramadol can cause serious problems, including overdose and death. Despite this knowledge, tramadol is commonly diverted and abused by narcotic addicts, chronic pain patients, and health professionals. In 2016, 1.6 million people in the U.S. aged 12 or older misused tramadol products in the past year (Substance Abuse and Mental Health Services Administration, 2017). The number of misusers increased to over 1.7 million in 2017 (Substance Abuse and Mental Health Services Administration, 2018).

The rapid increases in illicit fentanyl and fentanyl analog deaths and high misuse of diverted pharmaceutical tramadol indicate the need to intensify efforts to reduce overdoses from these opioids.

The death rate from these overdoses has soared from 1.0 per 100,000 in 2013, to 1.8 in 2014, 3.1 in 2015, 6.2 in 2016, and 9.0 in 2017 (Hedegaard, Miniño & Warner, 2018), with hand-counts of death narratives being used to distinguish deaths involving fentanyl and its analogs versus tramadol.

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As public health researchers and practitioners strive to reduce opioid-related mortality and morbidity, surveillance data on synthetic opioid-specific codes, differentiating fentanyl or fentanyl analogs from tramadol, is critical because they require different preventive responses.

Currently ICD-10-CM code, T40.4- Poisoning by, adverse effect of and underdosing of other synthetic narcotics, does not have a specific code for these narcotics thus, specific data are not available for adequate surveillance and efforts to abate this epidemic. Unlike mortality data, drug overdose narratives are not readily available in most hospital and emergency department records coded in ICD-10-CM.

This proposal, submitted by members of the Pacific Institute for Research and Evaluation, Children's Safety Network is requesting coding changes to expand code T40.4- to differentiate fentanyl or fentanyl analogs from tramadol codes.

The Children's Safety Network (www.childrendefenssafetynetwork.org) is a national resource center for the prevention of childhood injuries and violence, provides training and technical assistance to states and jurisdictions in their efforts to reduce fatal and severe injuries. One of the focused topic areas for the Children's Safety Network is poisoning, with emphasis on opioids. The proposed changes would support improved surveillance and health services to inform federal and state-level prevention and intervention programs.

This proposal is supported by NCHS Office of Analysis and Epidemiology.

TABULAR MODIFICATIONS

T40 Poisoning by, adverse effect of and underdosing of narcotics and psychodysleptics
[hallucinogens]

Excludes2: drug dependence and related mental and behavioral disorders due to psychoactive substance use (F10.-F19.-)

The appropriate 7th character is to be added to each code from category T40

A - initial encounter

D - subsequent encounter

S - sequela

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T40.4 Poisoning by, adverse effect of and underdosing of fentanyl or
fentanyl analogs

New sub-subcategory	T40.41 Poisoning by, adverse effect of and underdosing of fentanyl or fentanyl analogs
New code	T40.411 Poisoning by fentanyl or fentanyl analogs, accidental (unintentional)
New code	T40.412 Poisoning by fentanyl or fentanyl analogs, intentional self-harm
New code	T40.413 Poisoning by fentanyl or fentanyl analogs, assault
New code	T40.414 Poisoning by fentanyl or fentanyl analogs, undetermined
New code	T40.415 Adverse effect of fentanyl or fentanyl analogs
New code	T40.416 Underdosing of fentanyl or fentanyl analogs
New sub-subcategory	T40.42 Poisoning by, adverse effect of and underdosing of tramadol
New code	T40.421 Poisoning by tramadol, accidental (unintentional)
New code	T40.422 Poisoning by tramadol, intentional self-harm
New code	T40.423 Poisoning by tramadol, assault
New code	T40.424 Poisoning by tramadol, undetermined
New code	T40.425 Adverse effect of tramadol
New code	T40.426 Underdosing of tramadol
New sub-subcategory	T40.49 Poisoning by, adverse effect of and underdosing of other synthetic narcotics
New code	T40.491 Poisoning by other synthetic narcotics, accidental (unintentional)
Add	Poisoning by other synthetic narcotics NOS

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New code	T40.492 Poisoning by other synthetic narcotics, intentional self-harm
New code	T40.493 Poisoning by other synthetic narcotics, assault
New code	T40.494 Poisoning by other synthetic narcotics, undetermined
New code	T40.495 Adverse effect of other synthetic narcotics
New code	T40.496 Underdosing of other synthetic narcotics

Irregular Eye Movement

The American Optometric Association (AOA) is proposing a revision to code H55.81, Saccadic eye movements and the creation of a new ICD- 10-CM code for anomalies of smooth pursuit movements (eye). In ICD-9-CM a unique code did exist for deficiencies of saccadic eye movements and deficiencies of smooth pursuit movements.

Currently, deficient smooth pursuit eye movements is reported with ICD-10-CM code H55.89, Other irregular eye movement. A unique code for anomalies of smooth pursuit eye movements would allow for more precise reporting.

To better capture these conditions and to help with research and public health, AOA is requesting the following ICD-10-CM tabular revisions and additions.

TABULAR MODIFICATIONS

	H55	Nystagmus and other irregular eye movements
	H55.8	Other irregular eye movements
Revise	H55.81	<u>Deficient</u> saccadic eye movements
New code	H55.82	Deficient smooth pursuit eye movements

Isthmocele

The American College of Obstetricians and Gynecologists (ACOG) and the Society for Maternal Fetal Medicine (SMFM) are proposing a new code to specify isthmocele scarring. An isthmocele is the result of incomplete healing of the isthmic myometrium after a low transverse uterine incision performed for cesarean section.

Although mostly asymptomatic, isthmoceles may cause menstrual abnormalities (typically postmenstrual spotting), chronic pelvic pain, and secondary infertility. Scar tissue dehiscence, scar pregnancy, and abnormally adherent placenta are some of the obstetric complications associated with this defect. No standardized treatment has yet been accepted. Hysteroscopy and laparoscopy are the minimally invasive approaches currently used to repair the defect.

ACOG is requesting the expansion of ICD-10-CM code subcategory O34.2- Maternal care due to uterine scar from previous surgery in order to identify this condition when found. A new code will allow the ability to track the frequency at which this condition occurs, as well as to allow mechanized tracking of the most effective treatment modalities through diagnosis code searches in EMR datasets. The following tabular modifications are being proposed:

TABULAR MODIFICATION

O34 Maternal care for abnormality of pelvic organs

Includes: the listed conditions as a reason for hospitalization or other obstetric care of the mother, or for cesarean delivery before onset of labor

Code first any associated obstructed labor (O65.5)

Use additional code for specific condition

O34.2 Maternal care due to uterine scar from previous surgery

O34.21 Maternal care for scar from previous cesarean delivery

O34.211 Maternal care for low transverse scar from previous cesarean delivery

O34.212 Maternal care for vertical scar from previous cesarean delivery

O34.219 Maternal care for unspecified type scar from previous cesarean delivery

New code O34.22 Maternal care for cesarean scar defect (isthmocele)

O34.29 Maternal care due to uterine scar from other previous surgery

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Juvenile Osteochondrosis of Tibia and Fibula

This proposal was originally presented at the September 2018 and March 2019 Coordination and Maintenance (C&M) meetings and is being represented with recommendations received from public comments. The American Academy of Orthopedic Surgeons (AAOS) is requesting modifications to the category M92.5 Juvenile osteochondrosis of tibia and fibula to adequately represent the clinical significance of this disorder.

The two conditions, Blount Disease and Osgood-Schlatter are very dissimilar both in character, prognosis and treatment. Blount disease is a growth disorder of the tibia (shin bone) that causes the lower leg to angle inward, resembling a bowleg which occurs in growing children. Osgood-Schlatter disease is a characteristic of soreness and swelling at the tibial tuberosity, which occurs in adolescence.

AAOS is requesting modifications to better distinguish the difference between these conditions.

TABULAR MODIFICATIONS

M92	Other juvenile osteochondrosis
Revise	M92.5 Juvenile osteochondrosis of tibia and fibula <u>[Blount]</u>
Delete	Osteochondrosis (juvenile) of proximal tibia [Blount]
Delete	Osteochondrosis (juvenile) of tibial tubercle [Osgood-Schlatter]
Delete	Tibia vara
Revise	M92.50 <u>Unspecified Juvenile</u> osteochondrosis of tibia and fibula; unspecified leg
New code	M92.501 Unspecified juvenile osteochondrosis, right leg
New code	M92.502 Unspecified juvenile osteochondrosis, left leg
New code	M92.503 Unspecified juvenile osteochondrosis, bilateral leg
New code	M92.509 Unspecified juvenile osteochondrosis, unspecified leg
Revise	M92.51 Juvenile osteochondrosis of tibia and fibula, right leg <u>proximal tibia</u>
Add	Blount disease
New code	M92.511 Juvenile osteochondrosis of proximal tibia, right leg
New code	M92.512 Juvenile osteochondrosis of proximal tibia, left leg
New code	M92.513 Juvenile osteochondrosis of proximal tibia, bilateral
New code	M92.519 Juvenile osteochondrosis of proximal tibia, unspecified leg
Revise	M92.52 Juvenile osteochondrosis of tibia <u>tubercle</u> and fibula, left leg
Add	Osgood-Schlatter disease
New code	M92.521 Juvenile osteochondrosis of tibia tubercle, right leg
New code	M92.522 Juvenile osteochondrosis of tibia tubercle, left leg

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New code	M92.523 Juvenile osteochondrosis of tibia tubercle, bilateral
New code	M92.529 Juvenile osteochondrosis of tibia tubercle, unspecified leg
New code	M92.59 Other juvenile osteochondrosis of tibia and fibula
New code	M92.591 Other juvenile osteochondrosis of tibia and fibula, right leg
New code	M92.592 Other juvenile osteochondrosis of tibia and fibula, left leg
New code	M92.593 Other juvenile osteochondrosis of tibia and fibula, bilateral
New code	M92.599 Other juvenile osteochondrosis of tibia and fibula, unspecified leg

Macular Hole

The American Academy of Ophthalmology (AAO) is proposing suggested changes to ICD-10-CM subcategory H35.3, Degeneration of macula and posterior pole. The current scheme merges true macular holes and pseudoholes at code H35.34. This may work for simple descriptions of a diagnosis. This is not appropriate when outcome measures of surgery are contemplated as these stages of macular holes have different prognoses, management decisions and range of outcomes. For instance, large full thickness macular holes have a worse prognosis. Experts have created a staging system which describes the characteristics of macular holes. Loss of the foveal depression and a yellow foveal spot or posterior extension of the pseudocyst with disruption of the outer retinal layer are characteristics of Stage 1. The small full-thickness (<400 microns in diameter) retinal defects indicate Stage 2 macular holes. Stage 3 macular holes consist of a full-thickness hole (>=400 microns in diameter). A full-thickness hole with complete vitreous detachment represents a Stage 4 macular hole. In addition, the presence of a vitreomacular adhesion has an impact on surgical outcomes.

Thus, the proposal is to define the holes based on the widely accepted staging of macular holes, with the chance of the physician or coder to modify the stage by coding of vitreomacular adhesion when present.

AAO is requesting new codes in order to facilitate more accurate coding of full versus partial thickness macular holes.

TABULAR MODIFICATIONS

H35	Category
	H35.3 Degeneration of macula and posterior pole
	H35.34 Macular cyst, hole, or pseudohole
Add	Impending macular hole, lamellar macular hole
Add	Code also associated vitreomacular adhesion (H43.82-)
Add	One of the following 7 th characters is to be assigned to codes in subcategory H35.34 to designate the stage of the macular cyst, hole or pseudohole:
Add	0- stage unspecified
Add	1- impending, stage 1
Add	2- small full-thickness, Stage 2
Add	3- full-thickness, Stage 3
Add	4- full-thickness with complete detachment, Stage 4
Add	9- indeterminate stage

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New code	H35.341X Macular cyst, hole, or pseudohole, right eye
New code	H35.342X Macular cyst, hole, or pseudohole, left eye
New code	H35.343X Macular cyst, hole, or pseudohole, bilateral
New code	H35.349X Macular cyst, hole, or pseudohole, unspecified eye

H35.37 Puckering of macula

Add	Epiretinal membrane, surface wrinkling retinopathy
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Add	One of the following 7 th characters is to be assigned to codes in subcategory H35.37 to designate the cause of disease
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Add	0- stage unspecified
Add	1- idiopathic
Add	2- secondary
Add	9- indeterminate cause

New code	H35.371X Puckering of macula, right eye
New code	H35.372X Puckering of macula, left eye
New code	H35.373X Puckering of macula, bilateral
New code	H35.379X Puckering of macula, unspecified eye

Other Specified Diseases and Conditions Complicating Pregnancy, Childbirth and the Puerperium

The American College of Obstetricians (ACOG) is requesting the expansion of code O99.89 (Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium) to allow clinicians and coders to quickly identify the obstetric-related stage of the patient, e.g. pregnancy, childbirth, puerperium.

Per CMS-1716P, IPPS Proposed Rule FY2020, CMS proposes to make the following changes to ICD-10-CM diagnosis code O99.89 (Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium):

1. Expand O99.89 to become a sub-subcategory that would result in the creation of unique codes with a sixth digit character to specify the obstetric-related stage of the patient, e.g. pregnancy, childbirth, puerperium), and
2. Reclassify proposed new pregnancy sub code under code section O99.89 from a postpartum condition to an antepartum condition under MDC 14.

ACOG agrees that, due to the description of ICD-10-CM code O99.89 (Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium), it is unclear which set of MS-DRGs (antepartum, delivery, postpartum) would be the most appropriate for this code.

ACOG is submitting this code proposal in support of the CMS proposed change to diagnosis code O99.89 to develop a new sub-subcategory O99.89-.

ACOG believes that creating this new sub-subcategory will enable the appropriate assignment of MS-DRGs to the existing obstetric-related diagnosis codes, and therefore improve the accuracy and specificity of data collected during pregnancy, childbirth, and the postpartum period.

TABULAR MODIFICATION

O99	Other maternal diseases classifiable elsewhere but complicating pregnancy, childbirth and the puerperium
O99.8	Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium
O99.89	Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium
New code	O99.891 Other specified diseases and conditions complicating pregnancy

Powassan Virus Disease

Powassan (POW) virus disease is a tick-borne zoonosis caused by a bite of an infected tick, mostly *Ixodes scapularis*. Although many infected persons may not develop symptoms immediately due to a long incubation period of 1 week to 1 month, Powassan virus disease is considered a serious disease that usually results in encephalitis and/or meningitis and may lead to death. Symptoms can include fever, headache, vomiting, weakness, confusion, loss of coordination, speech difficulties, and seizures. (1, 2, 3) Most POW cases have occurred in the Northeastern and Great Lakes regions of the United States during the spring, summer, and mid-fall when ticks and humans are most active. (4, 5) As Powassan infections may be initially asymptomatic, POW virus can also be transmitted by transfusion of blood and blood components collected from an infected donor. (6, 7, 8) Although POW virus disease is considered rare, the number of reported neuroinvasive cases have increased considerably in recent years. (1, 7, 9, 10) CDC has reported a substantial increase of POW disease occurrence in the last decade: from 6 neuroinvasive cases in 2009 to 21 cases in 2018, with about 9% overall mortality. (10) As POW virus disease is transmitted by the commonly found tick species, *Ixodes scapularis*, it is expected that cases of POW virus disease will continue to rise and potentially pose a threat to the safety of blood supply. As such, the introduction of the disease-specific code for Powassan virus disease will allow to monitor the spread of the disease and help to develop prevention strategies and assure the safety of blood supply.

Currently, Powassan virus disease is under A84.8, Other tick-borne viral encephalitis. The objective of the request is to improve coding specificity for Powassan virus disease, and thus allow physicians, after establishing the diagnosis, to code for the Powassan virus disease distinctly. The proposed new code will help FDA and other organizations to monitor the spread of Powassan virus disease in the United States by states and counties of residence using real-world evidence (e.g., large databases). Consequently, the proposed new disease-specific code will enable public health organizations to recommend the appropriate prevention strategies (e.g., deer population control, population education) targeting specific areas of high disease transmission to help reduce the spread of Powassan virus disease and assure public safety.

As Powassan virus disease is transfusion-transmissible, a new code will also allow CDC, FDA and others to evaluate the disease risk to blood supply and if needed to develop donor testing strategies thus helping to prevent transfusion-transmission and assure the safety of blood supply. This will also likely improve provider awareness of this tick-borne disease as well as the availability and further development of diagnostic and donor testing.

In summary, the introduction of a disease-specific code for Powassan virus disease will improve coding accuracy, increase provider and, consequently, population awareness of this serious neuroinvasive disorder, allow to monitor occurrence of the disease locally and nationally, and therefore will help in the development of appropriate prevention strategies to stop spread of the disease and assure safety of blood supply.

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The Food and Drug Administration (FDA) is proposing the creation of a new code for human Powassan virus disease that distinguishes this disease from other tick-borne viral encephalitis disorders.

TABULAR MODIFICATION

A84 Tick-borne viral encephalitis

New subcategory	A84.8 Other tick-borne viral encephalitis
Delete	Louping ill
Delete	Powassan virus disease
New code	A84.81 Powassan virus disease
New code	A84.89 Other tick-borne viral disease
Add	Louping ill

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Problems Related to Upbringing

Today there are a greater variety of family dynamics that are more extended than the traditional nuclear family. A child may be living with a step-parent or non-parental guardian, such as a grandparent, almost as often as living with a biological or adopted parent. A child being cared for by a non-parental relative (kinship care) is not the same as foster care.

The current ICD-10-CM codes identifying problems related to upbringing and parent-child conflict do not cover some of these other family situations. These types of circumstances often present unique situations that frequently contribute to the child being brought to seek medical attention.

The American Academy of Pediatrics (AAP) requests that the code set at Z6.2 Upbringing away from parents, be expanded to better identify and track these situations.

TABULAR MODIFICATIONS

Z62 Problems related to upbringing

Includes: current and past negative life events in childhood

current and past problems of a child related to upbringing

Excludes2: maltreatment syndrome (T74.-)

problems related to housing and economic circumstances (Z59.-)

Z62.2 Upbringing away from parents

Excludes1: problems with boarding school (Z59.3)

Z62.21 Child in welfare custody

Delete

~~Child in care of non-parental family member~~

Child in foster care

Excludes2: problem for parent due to child in welfare
custody (Z63.5)

Z62.22 Institutional upbringing

Child living in orphanage or group home

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New code	Z62.23 Child in custody of non-parental guardian
Add	Child in care of non-parental family member
Add	Child in custody of grandparent
Add	Child in kinship care
Add	Excludes 1: child in welfare custody (Z62.21)
	Z62.29 Other upbringing away from parents
	Z62.8 Other specified problems related to upbringing
	Z62.82 Parent-child conflict
Add	Legal guardian
Add	Other relative
Add	Code also, if applicable: Absence of family member (Z63.3-)
Add	Disappearance and death of family member (Z63.4)
Add	Disruption of family by separation and divorce (Z63.5)
Add	Other stressful life events affecting family and household (Z63.7-)
Add	Other specified problems related to primary support group (Z63.8)
	Z62.820 Parent-biological child conflict
	Parent-child problem NOS
	Z62.821 Parent-adopted child conflict
	Z62.822 Parent-foster child conflict
Add	Group home staff-child conflict
Add	Child living in group home (Z62.22)
Add	Code also, if applicable: Child in welfare custody (Z62.21)
New code	
	Z62.823 Parent-step child conflict
New code	
	Z62.824 Non-parental guardian-child conflict
Add	Grandparent-child conflict

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Add	Other relative-child
Add	Kinship care conflict
New code	Z62.828 Runaway [from current living environment]
Add	Child leaving living situation without permission

Z63 Other problems related to primary support group, including family circumstances

Excludes2: maltreatment syndrome (T74.-, T76)

Delete	Excludes 2: parent-child problems (Z62.-)
Delete	problems related to negative life events in childhood (Z62.-)
Delete	problems related to upbringing (Z62.-)

Pulp Polyp

A pulp polyp, also known as chronic hyperplastic pulpitis, is directly exposed pulp tissue that has developed a granulation tissue ‘epithelium’ and maintains tissue vitality in spite of being totally exposed to the oral cavity. Presence of a pulp polyp means the tooth cannot be restored without root canal therapy, whereas a tooth diagnosed with Reversible Pulpitis (and perhaps Irreversible Pulpitis) may be successfully treated/restored without root canal therapy. (It is understood that, by definition, Irreversible pulpitis (K04.02) will also likely require root canal therapy or extraction. However, there is no potential to successfully restore a tooth with a pulp polyp without providing root canal therapy.)

Neither of the current codes for chronic hyperplastic pulpitis, K04.01 (reversible) and K04.02 (irreversible), refers to or definitively describes the condition of a tooth with a pulp polyp. Reversible (K04.01) and Irreversible (K04.02) pulpitis refer to degrees of indirectly diagnosed pulp tissue inflammation within an unexposed pulp chamber. A new ICD-10 CM (diagnosis) code for Pulp Polyp (chronic, hyperplastic pulpitis) is indicated to differentiate this condition from Reversible and Irreversible Pulpitis.

Terms used in this requested maintenance are included in the “[AAE Consensus Conference Recommended Diagnostic Terminology](#)” that is maintained and published by the American Association of Endodontists. It is the AAE’s position that the pulp polyp condition would be included in the existing irreversible pulpitis diagnosis (K04.02), whether symptomatic or asymptomatic.

The American Dental Association, with contributions and support from the American Association of Endodontists and the Indian Health Service, requests the following new codes and associated modifications to differentiate pulp polyps.

TABULAR MODIFICATIONS

	K04	Diseases of pulp and periapical tissues
	K04	Pulpitis
Delete		Chronic (hyperplastic) (ulcerative) pulpitis
New sub-subcategory	K04.02	Irreversible pulpitis
Add		Chronic (hyperplastic) (ulcerative) pulpitis (pulp polyp)
New code	K04.021	Symptomatic irreversible pulpitis
New code	K04.022	Asymptomatic irreversible pulpitis

Recurrent Caries

Recurrent caries is a specific clinical diagnosis which currently cannot be differentiated within ICD-10-CM category, K02 Dental caries. The following entry: “Includes: recurrent caries (dentine enamel junction) (enamel) (to the pulp)” constrains accurate documentation and reporting of a patient who presents with recurrent caries.

A single code addition is needed as the location of recurrent caries is documented elsewhere on the patient dental record and claim submission with the applicable Tooth Number and Tooth Surface codes published by the American Dental Association and incorporated by reference in the HIPAA standard electronic transaction (837D).

The American Dental Association, with contributions and support from the American Academy of Pediatric Dentistry, requests the following new codes and associated modifications within K00 Disorders of tooth development and eruption.

TABULAR MODIFICATIONS

	K00	Disorders of tooth development and eruption
	K02	Dental caries
		Includes: caries of dentine dental cavities early childhood caries pre-eruptive caries recurrent caries (dentine enamel junction) (enamel) (to the pulp) tooth decay
Delete		
New subcategory	K02.8	Other dental caries
New code	K02.81	Recurrent caries (dentine enamel junction) (enamel) (to the pulp)
New code	K02.89	Other specified dental caries

Refractory Gastro-Esophageal Reflux Disease

Gastroesophageal reflux disease (GERD) is a condition that develops when the reflux of gastric contents into the esophagus results in troublesome symptoms and/or complications. The symptoms of GERD are heartburn and regurgitation. Currently, proton pump inhibitors (PPIs), which reduce the production of acid by the stomach, are the standard of care for GERD. PPIs are highly effective in healing erosive esophagitis. However, PPI therapy does not completely relieve symptoms in a substantial proportion of GERD patients. When GERD patients present with insufficient or little response to PPI therapy, those patients may be referred to as having refractory GERD.

The treatment options for patients with refractory GERD may include endoscopic or surgical interventions such as radiofrequency energy delivery (Stretta procedure), magnetic augmentation of the lower esophageal sphincter (LINX procedure), or laparoscopic fundoplication.

Existing ICD-10-CM codes for GERD do not distinguish patients with refractory GERD, therefore, do not capture the full history and clinical presentation of those patients. For greater specificity in code assignment and supplementing information relevant to ambulatory care delivery systems, a series of codes for refractory GERD would help to provide a more accurate record of the patient experience as well as facilitate medical treatment and research.

This proposal is based on a request for new codes for refractory gastro-esophageal reflux disease, received from Ironwood Pharmaceuticals (a pharmaceutical company).

TABULAR MODIFICATIONS

	K21	Gastro-esophageal reflux disease
New subcategory		K21.0 Gastro-esophageal reflux disease with esophagitis
Delete		Reflux esophagitis
New code		K21.00 Gastro-esophageal reflux disease with esophagitis, not specified as refractory
Add		Gastro-esophageal reflux disease with esophagitis, NOS
Add		Reflux esophagitis
New code		K21.01 Refractory gastro-esophageal reflux disease with esophagitis

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New subcategory	K21.9 Gastro-esophageal reflux disease without esophagitis
Delete	Esophageal reflux NOS
New code	K21.90 Gastro-esophageal reflux disease without esophagitis, not specified as refractory
Add	Gastro-esophageal reflux disease without esophagitis, NOS
Add	Esophageal reflux NOS
New code	K21.91 Refractory gastro-esophageal reflux disease without esophagitis

Superficial Injury of Thorax: Bilateral and Middle

The anterior thorax is one of the most common locations of traumatic injury. Blunt, high energy injuries as seen with vehicle collisions are responsible for upward of 25% of trauma related deaths. Unlike penetrating thorax trauma which may be to one (or both sides) of the anterior or posterior thorax, blunt trauma is usually to the mid-chest region.

Anatomically, the sternum and the underlying heart are in the center of the chest as opposed to one side or the other. Currently there is no way to accurately identify mid-chest or bilateral injuries with the current anterior thorax injury codes.

The American Academy of Pediatrics (AAP) is requesting code expansion to include bilateral and middle anatomical locations to better be able to tract these type of injury details.

TABULAR MODIFICATIONS

S20	Superficial injury of thorax
	S20.2 Contusion of thorax
	S20.20 Contusion of thorax, unspecified
	S20.21 Contusion of front wall of thorax
	S20.211 Contusion of right front wall of thorax
	S20.212 Contusion of left front wall of thorax
New code	S20.213 Contusion of bilateral front wall of thorax
New code	S20.214 Contusion of middle front wall of thorax
	S20.219 Contusion of unspecified front wall of thorax
	S20.22 Contusion of back wall of thorax
	S20.221 Contusion of right back wall of thorax
	S20.222 Contusion of left back wall of thorax
New code	S20.223 Contusion of bilateral back wall of thorax
New code	S20.224 Contusion of middle back wall of thorax
	S20.229 Contusion of unspecified back wall of thorax

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S20.3 Other and unspecified superficial injuries of front wall of thorax

S20.30 Unspecified superficial injuries of front wall of thorax

S20.301 Unspecified superficial injuries of right front wall of thorax

S20.302 Unspecified superficial injuries of left front wall of thorax

New code S20.303 Unspecified superficial injuries of bilateral front walls of
thorax

New code S20.304 Unspecified superficial injuries of middle front wall of thorax

S20.309 Unspecified superficial injuries of unspecified front wall of
thorax

S20.31 Abrasion of front wall of thorax

S20.311 Abrasion of right front wall of thorax

S20.312 Abrasion of left front wall of thorax

New code S20.313 Abrasion of bilateral front wall of thorax

New code S20.314 Abrasion of middle front wall of thorax

S20.319 Abrasion of unspecified front wall of thorax

S20.32 Blister (nonthermal) of front wall of thorax

S20.321 Blister (nonthermal) of right front wall of thorax

S20.322 Blister (nonthermal) of left front wall of thorax

New code S20.323 Blister (nonthermal) of bilateral front wall of thorax

New code S20.324 Blister (nonthermal) of middle front wall of thorax

S20.329 Blister (nonthermal) of unspecified front wall of thorax

S20.34 External constriction of front wall of thorax

S20.341 External constriction of right front wall of thorax

S20.342 External constriction of left front wall of thorax

New code S20.343 External constriction of bilateral front wall of thorax

New code S20.344 External constriction of middle front wall of thorax

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S20.349 External constriction of unspecified front wall of thorax

S20.35 Superficial foreign body of front wall of thorax

Splinter in front wall of thorax

S20.351 Superficial foreign body of right front wall of thorax

S20.352 Superficial foreign body of left front wall of thorax

New code

S20.353 Superficial foreign body of bilateral front wall of thorax

New code

S20.354 Superficial foreign body of middle front wall of thorax

S20.359 Superficial foreign body of unspecified front wall of thorax

S20.36 Insect bite (nonvenomous) of front wall of thorax

S20.361 Insect bite (nonvenomous) of right front wall of thorax

S20.362 Insect bite (nonvenomous) of left front wall of thorax

New code

S20.363 Insect bite (nonvenomous) of bilateral front wall of thorax

New code

S20.364 Insect bite (nonvenomous) of middle front wall of thorax

S20.369 Insect bite (nonvenomous) of unspecified front wall of thorax

S20.37 Other superficial bite of front wall of thorax

Excludes1: open bite of front wall of thorax (S21.14)

S20.371 Other superficial bite of right front wall of thorax

S20.372 Other superficial bite of left front wall of thorax

New code

S20.373 Other superficial bite of bilateral front wall of thorax

New code

S20.374 Other superficial bite of middle front wall of thorax

S20.379 Other superficial bite of unspecified front wall of thorax

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2) Taghavi S, Askari R. Mediastinal Trauma. [Updated 2019 Jan 13]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2019 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK526031/>

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3) Platz J.J., Fabricant L., Norotsky M. Thoracic Trauma: Injuries, Evaluation, and Treatment. (2017) Surgical Clinics of North America, 97(4) , pp. 783-799.

Therapeutic and Rehabilitative Ophthalmic Devices

The American Optometric Association (AOA) is proposing a new external causes of morbidity code be developed to better report contact lens related adverse events. It is important that contact lens wearers follow their eye care professional's recommendation for proper wear and care of contact lens.

Contact lens wearers are at risk for contact lens-related eye infections, especially if they are sleeping or napping in their lenses. Sleeping in contact lenses increases the risk for corneal infection regardless of lens material and frequency of occasional overnight use.

To facilitate better data collection efforts related to contact lens, AOA is requesting the following ICD-10-CM tabular revisions and additions.

TABULAR MODIFICATIONS

Y77 Ophthalmic devices associate with adverse incidents

New

Subcategory

Y77.1 Therapeutic (nonsurgical) and rehabilitative ophthalmic devices associated with adverse incidents

New code

Add

Add

Y77.11 Contact lens associated with adverse incidents
Rigid gas permeable contact lens
Soft (hydrophilic) contact lens

New code

Y77.19 Other therapeutic (nonsurgical) and rehabilitative ophthalmic devices associated with adverse incidents