Child Neurology
Quality Measurement Set

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Invited Organizations

The following organizations were invited to participate, but declined: American College of Emergency Physicians, Tourette Association of America, Muscular Dystrophy Association, American Psychological Association, American Psychiatric Association, American Academy for Cerebral Palsy and Developmental Medicine, American Occupational Therapy Association, American College of Physicians

Improving Outcomes for Patients

Purpose of Measures

In 2016, the American Academy of Neurology (AAN) and Child Neurology Society (CNS) formed a Child Neurology Work Group (Work Group) to review existing guidelines, current evidence, and gaps in care in order to develop a measurement set for pediatric neurology that promotes quality improvement and drives better outcomes for neurologically-ill children.

The AAN and CNS developed these quality measures based on the belief that specialists should play a major role in selecting and creating measures that will drive performance improvement and could possibly be used in future accountability programs. The AAN and CNS formed the Work Group with representatives from professional associations and patient advocacy organizations to ensure any measures developed include input from all members of the healthcare team. All members of the Work Group were required to disclose financial relationships with industry and other entities to avoid actual, potential, or perceived conflicts of interest.

Quality Improvement and Caring for Children with Neurologic Illness

Although the practice of Child Neurology has become significantly more complicated in recent years due to the sheer amount of new information and the ever increasing amount of administrative responsibilities into the patient-family interaction, one thing remains constant- Neurology's commitment to provide the optimal care for each patient. Confronted with the reality of limited Class 1 evidence to guide the vast majority of our clinical decisions, it seems logical to fall back onto individual knowledge and experience with only the best intent in mind. However, in doing so, we will not achieve the advancement of care that we all so desire. An alternative approach is to engage in the process of Quality Improvement (QI) that has been so successful in reducing morbidity and mortality in the domains of cardiology, hypertension and stroke. At the core of QI methodology is the process of reviewing what is known about a problem/disorder, formulating a plan for care, measuring outcomes and then altering the plan to achieve improved outcomes in an iterative manner. Specifically, guidelines are formulated based upon best evidence and consensus and the results determined by prospectively identified, desired outcomes, i.e. quality metrics. The metrics can be categorized into those which reflect processes (e.g. how often did a patient receive a recommended treatment) and those that indicate clinical outcomes (e.g. reduction in seizures).

As medicine has moved away from fee-for-service to 'value-based' reimbursement, quality metrics have become the 'currency' by which we will be judged. Thus, it is incumbent upon the Child Neurology community to create metrics that have meaning for our patients and families to avoid measures being imposed by those external to care delivery. The metrics established by this work group are a first effort in that direction. The topics were chosen based upon clinical importance as well as an existing evidence base that allowed recommendations. The quality metrics proposed are intended to be reasonable to achieve and have high face validity (i.e. agreement that the metric is worthwhile). Undoubtedly there will be changes in the metrics with use, but these can only be discovered with application in a clinical environment. The AAN and CNS strongly encourage constructive feedback that will not only lead to better care for our patients, but also reflect the value we provide to patients and families.

AAN Measure Development Process

Once a topic has been approved, AAN staff seek out a leadership team that consists of two co-chairs who are content experts and two facilitators from the Quality and Safety Subcommittee. Following approval of this topic, the AAN partnered with CNS to develop these measures through the AAN process. AAN then

commissions a multidisciplinary work group to evaluate available evidence and literature around the topics defined by the leadership team and AAN staff. The leadership team and Work Group create draft measure concepts for discussion. An in-person meeting is held to discuss and refine the measure concepts. The Work Group votes to approve or not approve each proposed measure.

Following the meeting, measures are further refined and posted for public comment. The leadership team reviews the public comments and refines the measures accordingly. After the measures have been finalized the Work Group votes to approve or not approve the whole measure set. If approved by the Work Group, AAN staff facilitate internal AAN approvals. A writing group drafts a manuscript which is an executive summary of the measurement set that is submitted for publication in *Neurology*. AAN measures undergo a maintenance review every three years.

Topic Importance

Child neurology does not focus on one disease alone, but encompasses signs, symptoms and conditions spanning the neurological spectrum in the inpatient and outpatient settings. After consideration of a variety of conditions and measures, the leadership team determined this measurement set would focus on infantile spasms, seizures and epilepsy, tic disorder and Tourette syndrome, headache, cerebral palsy, global developmental delay, and transitions in care.

Headache and Migraine

Headache, in particular migraine, is a common pediatric problem worldwide. Approximately 8% of children and adolescents are prone to develop it over at least a 3-month period and it can become a chronic and disabling disorder.[1] The prevalence of migraine for those under 20 years of age is 7.7% with the prevalence in females reported at 9.7% and 6.0% in males.[1] An analysis estimated that 60% of children are at risk for headache with females being affected at a greater rate (67%) than males (58%).[1] Chronic daily headache is defined as "pain localized to the head occurring 15 or more days per month for more than 3 months".[2] While there are many pharmacologic treatments available for migraine and other primary headache disorders, there are limited pediatric randomized controlled trials to provide guidance to an effective and safe medication to use as a preventative treatment. Non-pharmacologic treatment of headache such as psychological interventions have become an integral part of treatment plans.

Tourette syndrome and Tic disorder

Tic disorder, including Tourette syndrome (TS), is a neurologic disorder characterized by repetitive, stereotyped involuntary movements and vocalizations.[3,4] The symptoms typically start in childhood between the ages of 3 and 9 years of age. TS and other tic disorders can last a lifetime or improve with age.[4] The prevalence of TS is estimated to affect between 0.3 and 1% of the population with males being affected at a higher rate (1.06%) than females (0.25%).[3,5] TS and tic disorders are known to have multiple co-morbid conditions such as attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), oppositional defiance disorder (ODD), and mood disorders including depression and anxiety.

Infantile Spasms

Infantile Spasms (IS) is an epilepsy condition that primarily affects those in infancy. The prevalence of IS ranges from 2 to 3.5 per 10,000 live births.[6] A common EEG abnormality noted is hypsarrhythmia.[6] Neurodevelopmental regression often can accompany infantile spasms. Poor developmental outcomes are often associated with this condition when the spasms fail to respond to treatment.[7] First line treatments include ACTH, high dose prednisolone, and vigabatrin.

Status Epilepticus

Status epilepticus (SE) refers to the condition of seizures which exceed a specific time threshold and/or recur without the person returning to his or her baseline level of alertness and cognition. It is estimated that 50,000 to 150,000 people in the United States will have an episode of SE each year.[8] SE can be convulsive (i.e. seizures with either or both tonic or clonic features) or non-convulsive (e.g. absence status). As convulsive SE is the type most associated with morbidity and mortality, it has been the focus of treatment guidelines. The most recent guideline involving children uses a duration >5 minutes to initiate the time-driven therapeutic cascade.[8]

Cerebral Palsy

Cerebral Palsy (CP) is a diagnosis that refers to a life-long and significant impairment of voluntary motor activity due to a brain injury that occurs prior to early childhood.[9] The CDC reports that 3.3 per 1,000 live births are diagnosed with CP.[9] CP can manifest with different degrees of spasticity, dystonia, choreoathetoid movements, ataxia, incoordination, and hypotonia and can affect the limbs in a diplegic, hemiplegic, or tetraplegic pattern. Medical treatments for spasticity and dystonia include oral medications such as baclofen and oral tizanidine, benzodiazepines, dantrolene, and trihexyphenidyl. Invasive treatments include surgical placement of an intrathecal baclofen pump or deep brain stimulator, surgical selective dorsal rhizotomy, and intramuscular injections of botulinum toxin. Supportive measures include the use of orthoses and adaptive equipment and involvement in neurorehabilitative physical, occupational, and speech therapies.[10]

Global Developmental Delay

Global Developmental Delay (GDD) is a diagnosis given to children showing significant delay in acquiring early childhood developmental milestones in more than two of these domains: motor, speech and language, cognitive, social adaptive. It is not synonymous with intellectual disability, which can be difficult to diagnose in children younger than age 5, but suggests a concern for long-term cognitive ability and functional independence. It is estimated that between 1% and 3% of children meet criteria for GDD with autism considered separately.[11] It is estimated that 40% of otherwise unexplained GDD can best be explained by genetic and metabolic disorders rather than by environmental factors.[12, 13] Genetic testing that establishes a specific diagnosis has a number of benefits for patients and families and can result in specific changes in management.[14]

Transition to Adult Neurology

The transition of adolescent patients remains a challenge for all patients with chronic illness in need of adult care. A formal transition process is recommended to address the gaps that currently exist in this process.[15] Neurology conditions often continue into adulthood and should follow a similar treatment format.

Clinical Evidence Base

The co-chairs and facilitators, guided by a medical librarian, conducted a comprehensive search to identify published guidelines, measures, and consensus recommendations in the National Guidelines Clearinghouse, the National Quality Measures Clearinghouse, PubMed, MEDLINE, EMBASE, and the Cochrane Library. The Work Group reviewed existing literature and consulted the following clinical practice guidelines published, which included:

- Evidence-based guideline update: Medical treatment of infantile spasms
- Summary of recommendations for the management of infantile seizures: Task Force for the ILAE Commission of Pediatrics
- An evidence-based guideline for pediatric prehospital seizure management using GRADE methodology

- Guidelines on the management of prolonged acute convulsive seizures in out-of-hospital settings: A gap to be filled
- Benzodiazepine use for emergency treatment of seizures: A review.
- Guidelines for the evaluation and management of status epilepticus
- Evidence-based Guideline: Treatment of Convulsive Status Epilepticus in Children and Adults
- A definition and classification of status epilepticus –Report of the ILAE Task Force on Classification of Status Epilepticus
- Summary of recommendation for the management of infantile seizures: Task Force for the ILAE Commission on Pediatrics
- European clinical guidelines for Tourette syndrome and other tic disorders. Part I: assessment
- Practice Parameter for the Assessment and Treatment of Children and Adolescents with Tic Disorders
- Evidence-based assessment of compulsive skin picking, chronic tic disorders and trichotillomania in children
- European clinical guidelines for Tourette syndrome and other tic disorders. Part III: behavioural interventions.
- Canadian guidelines for the evidence-based treatment of tic disorders: Behavioural therapy, deep brain stimulation, and transcranial magnetic stimulation
- Clinical report – Supporting the health care transition from adolescence to adulthood in the medical home
- Psychological therapies for the management of chronic and recurrent pain in children and adolescents.
- Clinical Answers: Are nonpharmacological interventions for migraine effective in children and adolescents?
- Practice Parameter: Pharmacologic treatment of spasticity in children and adolescents with cerebral palsy (an evidence-based review)
- Spasticity in children and young people with non-progressive brain disorders
- Evidence report: Genetic and metabolic testing on children with global developmental delay
- Consensus statement: Chromosomal microarray is the first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies
- Unexplained developmental delay/learning disability: guidelines for best practice protocol for first line assessment and genetic/metabolic/radiological investigations

Additional Child Neurology Measures

No one measurement set is able to capture all the aspects of treatment needed for the clinically diverse patient population of child neurology. This measurement set is focused on measuring the quality of care provided for a variety of conditions or diseases, and does not address the whole scope of each condition or disease, nor all of pediatric neurology.

In addition to this measurement set, the AAN has additional measures that are applicable to the pediatric population:

- Epilepsy Measurement Set (2014)
    - Percent of all visits for patients with a diagnosis of epilepsy where the seizure frequency of each seizure type was documented
    - Percent of patients with a diagnosis of epilepsy with seizure frequency > 0 for whom an intervention to reduce seizure frequency was offered or discussed with the patient or caregiver.

    - Percent of all visits for patients with a diagnosis of epilepsy with seizure type and epilepsy etiology or syndrome documented OR testing ordered to determine etiology of epilepsy, seizure type, or epilepsy syndrome
    - Percent of all patients with a diagnosis of epilepsy with active anti-seizure therapy side effects for whom an intervention was discussed
    - Percent of all patients with a diagnosis of epilepsy, or their caregivers, who were provided with personalized safety issue and epilepsy education at least once annually.
    - Percent of all visits for patients with a diagnosis of epilepsy where the patient was screened for psychiatric or behavioral disorders.
    - All female patients of childbearing potential (12-44 years old) diagnosed with epilepsy who were counseled or referred for counseling for how epilepsy and its treatment may affect contraception OR pregnancy at least once a year
    - Percent of all patients with a diagnosis of treatment resistant (intractable) epilepsy who were referred for consultation to a comprehensive epilepsy center for additional management of epilepsy.
- Headache Measurement Set (2014)
    - Percentage of patients age 12 years and older with a diagnosis of migraine who were prescribed a guideline recommended medication for acute migraine attacks within the 12 month measurement period.
    - Percentage of patients aged 12 years and older diagnosed with primary headache disorder and taking opioid containing medication who were assessed for opioid containing medication overuse within the 12-month measurement period and treated or referred for treatment if identified as overusing opioid containing medication.
    - Percentage of patients diagnosed with a primary headache disorder, who are actively taking an acute headache medication and experiencing headaches ≥15 days per month for 3 months, who were assessed for medication overuse headache (MOH).
    - Percentage of patients diagnosed with medication overuse headache (MOH) within the past 3 months or who screened positive for possible MOH (measure 6a) who had a medication overuse plan of care created or who were referred for this purpose.
    - Percentage of patients diagnosed with primary headache and who have a normal neurological examination for whom advanced brain imaging (CTA, CT, MRA or MRI) was NOT ordered.
    - Percentage of patients with a diagnosis of primary headache disorder whose health related quality of life (HRQoL) was assessed with a tool(s) during at least two visits during the 12 month measurement period AND whose health related quality of life score stayed the same or improved.
    - Percentage of patients age 6 years old and older who have a diagnosis of migraine headache or cervicogenic headache and for whom the number of headache-related disability days during the past 3 months is documented in the medical record.
    - All patients diagnosed with migraine headache or cervicogenic headache who had a headache management plan of care developed or reviewed at least once during the 12 month measurement period.
- Multiple Sclerosis Measurement Set (2014)
    - Percentage of patients who received a new diagnosis of multiple sclerosis in the past 12 months who fulfilled international criteria.
    - Percentage of patients with MS who had an MRI with and without gadolinium within 24 months of diagnosis compared with a baseline MRI.
    - Percentage of patients with MS who have a MS disability scale score documented in the medical record in the past 12 months.
    - Percentage of patients with MS who were screened for fall risk in past 12 months.
    - Percentage of patients with MS who have had a bladder infection in past 12 months.
    - Percentage of patients with MS who are counseled on the benefits of exercise and appropriate physical activity for patients with MS in the past 12 months.

    - Percentage of patients with MS whose most recent score indicates results are maintained or improved on a validated fatigue rating instrument for patients with MS in past 12 months.
    - Percentage of patients aged 12 years and older with MS who were screened for clinical depression using an age appropriate standardized depression screening tool at least once in past 12 months.
    - Percentage of patients aged 12 years and older with MS whose most recent score indicates results are maintained or improved on a validated depression screening instrument for patients with MS in past 12 months.
    - Percentage of patients with MS whose most recent score indicates results are maintained or improved on an age appropriate Quality of Life tool in past 12 months.
- Muscular Dystrophy Measurement Set (2013)
    - All patients diagnosed with Duchenne muscular dystrophy (DMD) prescribed appropriate DMD disease modifying pharmaceutical therapy.
    - All patients diagnosed with a muscular dystrophy (MD) for whom a MD multi-disciplinary care plan was developed, if not done previously, or the plan was updated at least once annually.
    - All patients diagnosed with a muscular dystrophy (MD) who had a pulmonary status evaluation ordered.
    - Patients diagnosed with a muscular dystrophy (MD) who had a cardiac status evaluation ordered.
    - All visits for patients with a diagnosis of a muscular dystrophy (MD) where the patient had a scoliosis evaluation ordered.
    - All visits for patients diagnosed with a muscular dystrophy (MD) where the patient was referred for physical, occupational, or speech/swallowing therapy.
    - All visits for patients diagnosed with muscular dystrophy (MD) where the patient's nutritional status or growth trajectories were monitored.
    - All visits for patients diagnosed with a muscular dystrophy (MD) where the patient was queried about pain and pain interference with function using a validated and reliable instrument.
    - All patients with a diagnosis of a muscular dystrophy(MD), or their caregivers who were counseled about advanced health care decision making, palliative care, or end-of-life issues at least once annually.

Work Group Recommendations

2016 Child Neurology Measurement Set
Appropriate first line treatment for Infantile Spasms
Rescue seizure therapy for children with epilepsy
Time to third line therapy for refractory convulsive status epilepticus (RCSE)
Neurodevelopmental/neuropsychological screening in epilepsy
Screening for co-morbid conditions of tic disorder or Tourette syndrome
Management of co-morbid symptoms of tic disorder or Tourette syndrome
Behavioral therapy for tic disorder or Tourette syndrome
Transition from pediatric neurology to adult neurology
Psychological interventions for chronic headache
Botulinum Toxin Serotype A (BoNT-A) for spasticity and dystonia
Genetic testing for global developmental delay (GDD)

Definitions and Abbreviations

The Work Group utilized the following definitions and abbreviations in the measurement set:

- ACTH: Adrenocorticotropic hormone
- ADHD: Attention Deficit Hyperactivity Disorder
- BoNT-A: Botulinum Toxin Serotype A
- CBIT: Comprehensive Behavioral Treatment for Tics
- CP: Cerebral Palsy
- CMA: Chromosomal Microarray
- DSM: Diagnostic and Statistical Manual of Mental Disorders
- ED: Emergency Department
- EEG: Electroencephalogram
- ERP: Exposure Response Prevention Therapy
- GDD: Global Developmental Delay
- HCT: Health Care Transitions
- HRT: Habit Reversal Training
- IS: Infantile Spasms
- LGS: Lennox-Gastaut Syndrome
- OCD: Obsessive Compulsive Disorder
- ODD: Oppositional Defiance Disorder
- RCSE: Refractory Convulsive Status Epilepticus
- SLD: Specific Learning Disability
- TD: Tic Disorder
- TS: Tourette Syndrome

The AAN has a Quality Improvement Glossary, which provides more in depth explanations and is available at aan.com/practice/quality-measures/quality-resources.

Desired Outcomes

This list represents the optimal outcomes for pediatric neurology care facing diagnoses epilepsy, seizures, Tourette syndrome or tic disorders, headache, cerebral palsy, global developmental delay, and care transitions. Additional information on how process measures developed by the work group link to desired outcomes is located below in the measure specifications.

Treatment of infantile spasms

- Rapid elimination of seizures
- Elimination of hypsarrhythmia on EEG
- Decrease morbidities
- Optimize developmental outcomes
- Improve quality of life

Pre-hospital rescue medication for seizures

- Decrease morbidity and mortality
- Decrease unnecessary healthcare utilization
- Improve quality of life
- Avoid unnecessary hospitalization
- Avoid emergency service utilization

Third line therapy for seizure cessation

- Increase the probability of medication responsiveness
- Decrease mortality
- Decrease seizure
- Decrease medication morbidities
- Optimize neurological and cognitive outcomes
- Improve quality of life

Screening for neuropsychological testing

- Increase utilization of testing
- Increase developmental attainment
- Improve quality of life

Screening for co-morbid conditions of tics/Tourette's

- Recognize and properly address common co-morbid conditions
- Early diagnosis
- Improve quality of life
- Maximize general function

Referral for co-morbid conditions

- Decrease tic burden
- Improve co-morbid conditions
- Early diagnosis and treatment
- Improve quality of life
- Maximize general function

Behavioral therapy for tics/Tourette's

- Decrease tic burden
- Non-pharmacologic treatment option
- Increase utilization of behavioral therapy
- Improve quality of life
- Maximize general function

Transition to adult neurology

- Improve transitions to outpatient and adult providers
- Increase patient/caregiver satisfaction
- Increase patient/caregiver knowledge of their own diagnosis
- Increase patient/caregiver understanding of the management plan and follow-up
- Increase patient/caregiver engagement in treatment decision process
- Address all patient/caregiver needs and engage patients on a personal level

Psychological intervention for chronic headache

- Reduction of pain and disability
- Reduce the occurrence of adverse effects associated with medication overuse
- Improve quality of life
- Maximize general function

Evaluation for BoNT-A for CP

- Reduction of spasticity and dystonia
- Reduction of pain and disability
- Reduce the need for surgical correction of contractures
- Increase caregiver knowledge of treatment options
- Maximize general function

Genetic testing for GDD

- Provide patients with a definitive etiologic diagnosis
- Reduce unnecessary and invasive testing
- Improve appropriate surveillance for complications
- Increase patient access to treatments and experimental protocols
- Improve patient access to support services and networks
- Improve caregiver knowledge of prognosis
- Improve family understanding of recurrence risk
- Reduce caregiver uncertainty and anxiety

Intended Care Audience, Settings, and Patient Populations

The AAN encourages the use of these measures by physicians and other health care professionals, practices, and health care systems, where appropriate, to achieve improved performance. These measures are intended as steps that providers, practices, and systems can take towards optimized clinical outcomes for children with neurological illness.

	Applicable Care Settings			
2016 Child Neurology Measurement Set	Outpatient	Inpatient	Residential	Emergency Department
Appropriate first line treatment for infantile spasms	X	X		
Rescue seizure therapy for children with epilepsy	X	X	X	X
Time to third line therapy for refractory convulsive status epilepticus (RCSE)		X		X
Neuropsychological/neurodevelopmental screening in epilepsy	X			
Screening for co-morbid conditions of tic disorder or Tourette syndrome	X			
Management of co-morbid symptoms of tic disorder or Tourette syndrome	X			
Behavioral therapy for tic disorder or Tourette syndrome	X			
Transition from pediatric neurology to adult neurology	X			
Psychological interventions for chronic headache	X	X		
Botulinum Toxin Serotype A (BoNT-A) for spasticity and dystonia	X		X	

Genetic testing for global developmental delay (GDD)	X			

Other Potential Measures

The measures developed are a result of a consensus process. Work Group members are given an opportunity to submit new measures in advance of the in-person meeting where all measures are reviewed and edited individually. After each measure has been discussed, each individual on the work group votes to approve, not approve, or abstain from voting on each measure. The Work Group discussed potential measures for development, prior to and during the meeting and the Work Group voted to not approve:

- Education of patient and family on the diagnosis of Tic Disorder or Tourette Syndrome,
- Assessment of medication side effects among patients with Tic Disorder or Tourette Syndrome Treated with Anti-Psychotic Drugs,
- Patients with epilepsy receiving baseline neuropsychological testing,
- Developmental and behavioral screening for pre-school-aged children and infants with epilepsy,
- Follow up visit for headache prophylactic,
- Migraine prophylactic refills and follow-up,
- Follow-up visit for patients taking ADHD medication,
- ADHD medication adherence and follow-up visits
- Disease modifying treatment for children with multiple sclerosis
- Trial dose of pyridoxine for neonates with ongoing seizures
- Appropriate outcome for infantile spasms

The Work Group felt these concepts were not ready for development at this time due to lack of evidence. The Work Group recommends these concepts be revisited when this measurement set is updated in 3 years.

Measure Harmonization

Many existing AAN quality measures, as well as measure developed by others, apply to the child neurology patient population. The Work Group reviewed existing measures on the topics included in this measurement set. Efforts were made to reduce duplicative measures when possible.

Time to third line therapy for seizure cessation for Refractory Convulsive Status Epilepticus
One measure exists in the AAN's Inpatient and Emergency Care measure set on patients with generalized convulsive status epilepticus who are treated with a non-benzodiazepine antiepileptic/anti-seizure medication following the administration of a benzodiazepine. The measure applies to patients aged 16 years of age and older. This existing measure harmonizes with the child neurology measure which captures patients younger than 16 years of age.

Patients with epilepsy receiving screening for neuropsychological or neurodevelopmental deficits
This measure does harmonize with an existing adult measure on screening for psychological co-morbidities as they would be identified on this testing. However, it expands the screening to including other disorders that are commonly seen in children that do not necessarily apply to the adult epilepsy population.

Proper transition of pediatric neurology patients to adult neurology care

This measure harmonizes across all neurology disease states and covers both child and adult neurology providers. Although several existing measures deal with transitioning care, nothing specific exists on the transfer of care from child to adult neurology. Based on the gap and importance in this area, the work group felt a separate measure was warranted for neurological patients.

Technical Specifications Overview

The Work Group developed technical specifications for measures that include data from:

- Electronic Health Record (EHR) Data
- Electronic Administrative Data (Claims)
- Registry

Administrative claims specifications are not provided for measures given the AMA's decision to discontinue the maintenance of CPT II codes. The AAN is in the process of creating code value sets and the logic required for electronic capture of the quality measures with EHRs, when possible. A listing of the quality data model elements, code value sets, and measure logic (through the CMS Measure Authoring Tool) for each of the measures will be made available at a later date. These technical specifications will be updated as warranted.

The measurement set includes measures that require the use of validated screening tools. The Work Group discussed and determined that multiple tools should be offered to allow providers to determine which tool best meets their individual practice needs. Tools may be subject to copyright and require licensing fees.

Measure Exceptions

A denominator exclusion is a factor supported by the clinical evidence that removes a patient from inclusion in the measure population. For example, if the denominator indicates the measure is for all patients aged 0 to 18 years of age, a patient who is 19 years of age is excluded.

A denominator exception is a condition that should remove the patient, procedure or unit of measurement from the denominator only if the numerator criteria are not met. The AAN includes three possible types of exceptions for reasons why a patient should not be included in a measure denominator: medical (e.g., contraindication), patient (e.g., declination or religious belief), or system (e.g., resource limitation) reasons. For each measure, there must be a clear rationale to permit an exception for a medical, patient, or system reason. The Work Group provided explicit exceptions when applicable for ease of use in eMeasure development.

Public Comment Feedback

The draft measurement set was put on the AAN website for public comment from August 30 through September 30. Specific segments of the AAN membership were notified of the opportunity to review and comment. Additionally, over 20 organizations were contacted regarding the opportunity to provide comment. Based on these comments the following major changes were made:

- General:
  - Greater consistency of wording and formatting across the measure set
  - Grammatical errors were identified and fixed
  - Exceptions incorporated into denominator statements across the measure set
- Infantile Spasms:

    - Additional exceptions added
- Abortive Seizure Therapy:
    - Added language regarding non-FDA approved treatments
- Therapy for Refractory Convulsive Status Epilepticus
- Screening for neurodevelopmental or neuropsychological deficits in epilepsy
    - Changed verbiage of the type of testing to more accurately reflect DSM V language
    - Added list of questionnaire-based screening tools
- Screening for co-morbid conditions of Tic Disorder and Tourette Syndrome
    - Changed language from "screened" to "queried"
- Management of Co-Morbid Symptoms of Tic Disorder or Tourette Syndrome
    - Added exception
- Counseling or Referral for Behavioral Therapy for Tic Disorder or Tourette Syndrome
    - Added exception
- Transitions of care:
    - Significant revision to the Transitions of Care measure to provide more guidance on how to conduct a transition
- Psychological Interventions for Chronic Headache
    - None
- Treatment for Spasticity and Dystonia
    - Took out references to CP
- Genetic Testing for Global Developmental Delay
    - Refined denominator verbiage

Testing and Implementation of the Measurement Set

The measures in this set are being made available without any prior testing. The AAN encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so. Select measures will be beta tested once the set has been released, prior to submission to the National Quality Forum for possible endorsement.

First line treatment for infantile spasms

Measure Description	
Percentage of patients receiving appropriate first line treatment for infantile spasms (IS)	
Measure Components	
Numerator Statement	Patients who received any guideline recommended first line therapy* as initial treatment for IS as soon as diagnosed, but no later than 1 week after initial, confirmed diagnosis** *Guideline Recommended Treatments: • Adrenocorticotropic hormone (ACTH) • High dose prednisolone • vigabatrin (VGB) **Diagnosis is usually defined as seizure marked by momentary flexion or extension of the neck, trunk, extremities, or any combination, with onset occurring in first year of life with or without the presence of hypsarrhythmia. Recommended treatments subject to change if approved treatments added after measure approval.
Denominator Statement	All patients aged 2 weeks to 24 months diagnosed with IS
Denominator Exceptions	• Medical provider identified all 3 treatments are contraindicated • Caregiver refuses all 3 treatments • Patient participating in a research trial that precludes use of these medications as first line therapy. • Presence of an inborn error of metabolism disorder (may include, but not limited to: (1) disorders of amino acid metabolism (phenylketonuria, dihydropteridine reductase deficiency, pyridoxine deficiency, pyrodoxal-5-phosphatase deficiency, folinic acid deficiency), (2) organic acidurias (D-glyceric aciduria, methylmalonic aciduria, propionic acidemia, maple syrup urine disease), (3) disorders of fatty acid oxidation (short-chain acyl-coenzyme A dehydrogenase enzyme deficiency), where alternative therapy is recommended and/or more appropriate.[1] • Resective epilepsy surgery is recommended as first line treatment.
Exception Justification	Patients that are surgical candidates may not need medication treatment for their infantile spasms. Parent/caregivers may refuse first line treatments. Provider may have good evidence that all three treatments are contraindicated. There may be times when the medical provider deems the risks of these three treatments to outweigh the benefits as first line therapy. Should the opportunity arise in the future for a trial, patients may need to be excluded from these treatments. Patients with inborn errors of metabolism can have a treatment to correct the error of metabolism and reverse symptomology including the infantile spasms. Therefore, first line infantile spasms treatments may not be necessary.

Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "The evidence is insufficient to recommend the use of prednisolone, dexamethasone, and methylprednisolone as being as effective as ACTH for short-term treatment of infantile spasms"[2] • "ACTH or VGB may be offered for short-term treatment of infantile spasms. Evidence suggests that ACTH may be offered over VGB"[2] • "Hormonal therapy (ACTH or prednisolone) may be considered for use in preference to VGB in infants with cryptogenic infantile spasms, to possibly improve developmental outcomes"[2] • "A shorter lag time to treatment of infantile spasms with either hormonal therapy or VGB may be considered to improve long-term cognitive outcomes"[2] • "VGB is most effective in the first line treatment of infantile spasms when used in children with normal development at the time of diagnosis"[3] • "Children with infantile spasm who respond to VGB first are more likely to undergo seizure resolution over time than those who failed VGB"[3] • "The results show that high dose ACTH appears to be more effective than prednisolone"[4] • "…vigabatrin is most likely to be effective in the first line treatment of infantile spasms, not related to tuberous sclerosis complex in children with normal development at the time of diagnosis"[5] • "Lead time to treatment was 7 days or less in 11, 8-14 days in 16, 15 days to 1 month in 8, 1-2 months in 15, >2 months in 21 and not known in 6. Each month of reduction in age at onset of spasms was associated with a 3.1 [95% confidence interval (CI) 0.64-5.5, p = 0.03] decrease, and each increase in category of lead time duration associated with a 3.9 (95% CI 7.3-0.4, p = 0.014) decrease in VABS, respectively "[6] • "ACTH is preferable in the short-term control of spasms"[7] • "Oral steroids are probably effective in the short-term control of spasms"[7] • "Data are insufficient to comment on the optimal preparation, dosage, and duration of treatment of steroids"[7] • "Vigabatrin is possible effective in the short-term control of spasms, especially in the case of tuberous sclerosis complex"[7] • "Treatment with ACTH/oral steroids may result in better long-term neurodevelopmental outcome than treatment with vigabatrin in children with epileptic spasms due to unknown etiologies"[7] • "A shorter interval from the onset of spasms to treatment initiation may improve the long-term neurodevelopmental outcome, especially in cases where there is no identified etiology"[7] • "The shorter the "lag time" (time from spasms onset to commencement of therapy) the better the developmental outcome"[7] • "Hormone treatment controls spasms better than does vigabatrin initially, but not at 12-14 months of age. Better initial control of spasms by hormone treatment in those with no identified underlying aetiology may lead to improved developmental outcome"[8] • "In particular, the poor response to nonstandard medications and fewer relapses with ACTH over oral steroids were noted"[10]

Measure Importance	
Relationship to Desired Outcome	Patients that receive first line therapy for IS have a greater chance for improved clinical outcomes such as decreased risk for developmental delay and potentially less chance of developing epilepsy such as Lennox-Gastaut Syndrome (LGS).
Opportunity for Improvement	Use of non-standard or evidence based treatment or treatment that has been shown to be ineffective for IS still occurs significantly.[9]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☒ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☒ Outpatient ☒ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
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10. Knupp K, Coryell J, Nickels KC, et al. Response to treatment in a prospective national infantile spasms cohort. Ann Neurol 2016; 79:475-84.

Denominator (Eligible Population)	<u>ICD-10 Code</u> G40.82 Infantile spasms AND <u>CPT E/M Service Code</u> **99221, 99222, 99223** Initial hospital care 30, 50, or 70 minutes, per day, for the evaluation and managem ent of a patient; **99231, 99232, 99233** Subsequent hospital care 15, 25, or 35 minutes, per day, for the evaluation and management of a patient **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Rescue seizure therapy for children with epilepsy

Measure Description	
Percentage of patients who received appropriate and correctly dosed rescue seizure therapy for children with epilepsy	
Measure Components	
Numerator Statement	Patients who receive or have received a prescription for an appropriately dosed* rescue seizure therapy (i.e., midazolam, diazepam) in the pre-hospital^ setting. *Appropriate dose recommendations:[1,2,3,4,5,6,7,8,9] • Intranasal, buccal, or IM midazolam: all ages: 0.1 to 0.4 mg/kg/dose (maximum 10 mg) • Rectal Diazepam: 6 months – 5 years: 0.5 mg/kg/dose; 6-11 years: 0.3 mg/kg/dose; > 12 years: 0.2 mg/kg/dose (maximum 20 mg) ^Pre-hospital setting means outside of the emergency department (ED) and hospital (i.e. ambulance, home, school, etc.). Please note, currently no FDA approved treatment for prolonged seizures in the prehospital setting exist and recommendations are for clinical standard and accepted practice use.
Denominator Statement	Patients aged 6 months and older with documented prolonged convulsive^ seizure $\geq$ 5 minutes ^Convulsive is defined as: Tonic, clonic, tonic-clonic, myoclonic
Denominator Exceptions	• Patient contraindication documented for all abortive medications • Patient/caregiver refuse • IV access established • Undocumented seizure duration recorded • Documentation that supports patients have self-resolving seizures that last more than five minutes
Exception Justification	If a patient has a contraindication, such as an allergy, then they should be excluded due to risk of harm. A patient or caregiver should be allowed to refuse a treatment. As IV access is an acceptable route, it can be utilized and the measure as written would not apply. For patients where the seizure duration is unknown, it would be difficult to assess when the abortive medication should be given. Certain patients will have prolonged seizures self-abort. The intent of an abortive medication is to stop a seizure that otherwise would not stop. Therefore, it may not be needed for all seizures greater than five minutes if it is documented that the patient has seizures that self-abort after five minutes.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • [In the EMS setting] "We recommend that prehospital protocols for seizure management in children utilize alternative (non-IV) routes of drug

	administration as first-line therapy for treating children with status epilepticus"[10] • [In the EMS setting] "We recommend buccal midazolam over rectal (PR) diazepam for prehospital seizure cessation and control"[10] • [In the EMS setting] "We recommend IM midazolam over PR diazepam for prehospital seizure cessation and control"[10] • [In the EMS setting] "We suggest intranasal (IN) midazolam over PR diazepam for prehospital seizure cessation and control"[10] • [In the EMS setting] "We suggest that in children with convulsive status epilepticus requiring medication management in the prehospital setting, trained prehospital personnel should be allowed to administer medication without online medical direction"[10] • "While most families have an emergency seizure rescue plan in place, knowledge gaps exist. Nearly half of responders provided could not correctly verbalize how to administer rescue medication and nearly half were not aware of respiratory depression as a side effect. A standardized training program by nursing, with regular reviews at clinic visits is needed to improve parental proficiency in the home management of acute seizures"[11] • "Of the 32 children who presented in the community, 19 (59%) had evidence that they had been given rescue medication prior to arrival at hospital. This confirms previous reports that appropriate and timely treatment is not being administered in many cases of prolonged seizure"[12] • "Most existing guidelines do not provide practical recommendations to caregivers in out-of-hospital settings on the administration of rescue medication. Filling this gap is critical to ensure that children at risk of prolonged acute convulsive seizures receive their rescue medication quickly and safely regardless of where their seizure occurs, thereby avoiding unnecessary treatment delays, clinical sequelae and costly admission to hospital"[13] • "Published data support the efficacy and safety of nonintravenous routes of administration for midazolam, when compared to diazepam administered via any route in treating patients with status epilepticus, in the doses studied. Midazolam has characteristics that may make it an optimal choice for the treatment of seizing patients"[14] • "There is a perceived need for alternative administration methods that offer fast onset of effect and rapid and convenient administration for different populations with varying needs/preferences. Mounting evidence supports multiple safe and effective alternative routes of BDZ administration for rapid treatment of seizures in children with adults"[15] • "Based on our results, many of the visits of patients to the ED or hospital could have been possibly prevented with appropriate doses of an emergency seizure medication"[16]
Measure Importance	
Relationship to Desired Outcome	It is anticipated that by increasing the number of patients who have abortive medications available when needed will decrease healthcare utilization and decrease episodes of treatment resistant seizures (status epilepticus).[10,16]

Opportunity for Improvement	A study of high utilizers of ED care for seizures had not been prescribed an abortive medication for prolonged convulsive seizures.[17]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☒ Efficient Use of Healthcare Resources ☐ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☒ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☐ System
Care Setting (Check all that apply)	☒ Outpatient ☒ Inpatient ☒ Emergency Departments and Urgent Care ☒ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
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Denominator (Eligible Population)	ICD-10 Code R56.8 Seizures (otherwise unspecified) G40.xx Epilepsy (otherwise unspecified) AND CPT E/M Service Code **99221, 99222, 99223** Initial hospital care 30, 50, or 70 minutes, per day, for the evaluation and management of a patient; **99231, 99232, 99233** Subsequent hospital care 15, 25, or 35 minutes, per day, for the evaluation and management of a patient **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Time to third line therapy for refractory convulsive status epilepticus (RCSE)

Measure Description	
Percentage of patients who received the start of a third line therapy for seizure cessation for refractory convulsive status epilepticus (RCSE)	
Measure Components	
Numerator Statement	Patients who were started on a third line therapy* within 60 minutes of seizure onset (inpatient setting) or after arrival to the emergency department (ED) (outpatient setting) Definitions: *For use in this measure, "third line therapy" means a second non-benzodiazepine anti-epileptic drug (AED)/anti-seizure drug or a continuous IV infusion (benzodiazepine or non-benzodiazepine) of a medication for seizures. Third line therapies include but are not limited to: • Continuous IV infusion: midazolam, pentobarbital, propofol, thiopental • Different non-benzodiazepine AED medications: fosphenytoin, levetiracetam, valproic acid, phenobarbital NOTE: A medicine that is the same but given by a different route is acceptable (ex. Oral then IV)
Denominator Statement	Patients ≥ 1 month old with refractory convulsive status epilepticus (RCSE)^ ^RCSE means ongoing clinical or electrographic seizures despite 2 appropriate medications, one of which is typically not a benzodiazepine.[1]
Denominator Exceptions	• Patient/caregiver refuse • Care team documents goals of treatment are not seizure control • Patient in palliative care setting • Patient is participating in a clinical trial for the treatment of status epilepticus • Intervention is delayed by clinical status such as hypotension precluding intravenous access
Exception Justification	The parent or caregiver may refuse the treatment. The patient's caregivers and care team may have determined that further treatment is futile and no longer impactful; therefore, the goal may not be seizure control or the patient has entered into a palliative care setting. Patients participating in clinical trials should not be included for this measure as the trial protocol will dictate the treatment plan.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "There is international consensus that convulsive seizures lasting more than 30 minutes may cause long-term consequences, including neuronal injury, neuronal death, alteration of neuronal networks, and functional deficits"[2]

	• "Although no evidence-based AED timeline or optimal time window exists for this AED sequence, most current SE treatment protocols recommend that the first AED be administered within 5 minutes of seizure onset. If seizures persist, moving to the next AED class in the sequence should be done by 10 minutes and, if repeated AED doses do not control SE, the initiation of anesthetic dosing via continuous infusions should be started by 30-70 minutes of seizure onset."[3] • "Timely AED administration and rapidly moving along the sequence of AED classes are intended to stop seizures as quickly as possible."[3] • "The algorithm starts with a stabilization phase (0-5 minutes), which includes standard initial first aid for seizures. The initial therapy phase should begin when the seizure duration reaches 5 minutes and should conclude by the 20-minute mark when response (or lack of response) to initial therapy should be apparent. A benzodiazepine (specifically IM midazolam, IV lorazepam, or IV diazepam) is recommended as the initial therapy of choice, given their demonstrated efficacy, safety, and tolerability (level A, four class I RCTs). The second-therapy phase should begin when the seizure duration reaches 20 minutes and should conclude by the 40-minute mark when response (or lack of response) to the second therapy should be apparent. Reasonable options include fosphenytoin (level U), valproic acid (level B, one class II study) and levetiracetam (level U). There is no clear evidence that any one of these options is better than the others. The third therapy phase should begin when the seizure duration reaches 40 minutes. There is no clear evidence to guide therapy in this phase (level U)."[4] • "Definitive control of SE should be established within 60 min of onset. All patients presenting with SE will need emergent initial AED therapy (i.e., 1st line) and urgent control AED therapy (i.e., 2nd line) in addition to AED maintenance therapy, even if SE is immediately controlled."[1]
Measure Importance	
Relationship to Desired Outcome	Patients with status epilepticus have better long term outcomes with cessation of seizures as quickly as possible. Prolonged uncontrolled status epilepticus carries risk of increase morbidity and mortality.
Opportunity for Improvement	A significant gap exists in time to treatment for RCSE.[3] Refractory status epilepticus patients "are not being treated with a third-line anti-epileptic drug until after 2 hours".[3] Although only limited data exists, this is a significant opportunity to improve the care of children with RCSE.
National Quality Strategy Domains	☐ Patient and Family Engagement ☒ Patient Safety ☐Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☐ Clinical Process/Effectiveness

Harmonization with Existing Measures	Harmonizes with AAN's Inpatient and Emergent QM developed for patients >16 years of age. One measure exists addressing patients with generalized convulsive status epilepticus who are treated with a non-benzodiazepine antiepileptic/anti-seizure medication following the administration of a benzodiazepine. The measure applies to patients aged 16 years of age and older. This measure is needed to capture performance for patients younger than 16 years of age.
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☐ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☐ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☐ Outpatient ☒ Inpatient ☒ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
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1. Brophy G, Bell R, Claassen J, et al. Guidelines for the Evaluation and Management of Status Epilepticus. Neurocrit Care 2012; 17:3-23. 2. Trinka E, Cock H, Hesdorffer D, Rossetti AO, Scheffer IE, Shinnar S, Shorvon S, Lowenstein DH. A definition and classification of status epilepticus--Report of the ILAE Task Force on Classification of Status Epilepticus. Epilepsia. 2015 Oct; 56(10):1515-23. 3. Sanchez Fernandez I, Abend NS, Agadi S, et al. Time from convulsive status epilepticus onset to anticonvulsant administration in children. Neurology 2015; 84:2304-2311. 4. Glauser T, Shinnar S, Gloss D, et al. Evidence-Based Guideline: Treatment of Convulsive Status Epilepticus in Children and Adults: Report of the Guideline Committee of the American Epilepsy Society. Epilepsy Currents 2016; 16:48-61.	
Denominator (Eligible Population)	ICD-10 Code G40.001 Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, with status epilepticus G40.011 Localization-related (focal) (partial) idiopathic and epileptic syndromes with seiures of localized onset, intractable, with status epilepticus

	G40.201 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, with status epilepticus. G40.211 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, with status epilepticus. G40.301 Generalized idiopathic epilepsy and epileptic syndromes, not intractable, with status epilepticus. G40.311 Generalized idiopathic epilepsy and epileptic syndromes, intractable, with status epilepticus. G40.401 Other generalized epilepsy and epileptic syndromes, not intractable, with status epilepticus. G40.411 Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus. G40.501 Epileptic seizures related to external causes, not intractable, with status epilepticus G40.901 Epilepsy, unspecified, not intractable, with status epilepticus G40.911 Epilepsy, unspecified, intractable, with status epilepticus AND <u>CPT E/M Service Code</u> **99221, 99222, 99223** Initial hospital care 30, 50, or 70 minutes, per day, for the evaluation and management of a patient; **99231, 99232, 99233** Subsequent hospital care 15, 25, or 35 minutes, per day, for the evaluation and management of a patient

Neuropsychological/neurodevelopmental screening

Measure Description	
Percentage of patients with epilepsy screened for neurodevelopmental or neuropsychological deficits	
Measure Components	
Numerator Statement	Patients who were screened* or referred for screening for neurodevelopmental and/or neuropsychological deficits within 1 year of initial epilepsy diagnosis *Screened is defined as using a validated instrument or querying the patient or caregiver to determine the presence or absence of symptoms.
Denominator Statement	Patients aged 1 month and older diagnosed with epilepsy within the past 12 months without severe or profound intellectual disability who are not currently under the care of a psychiatrist/psychologist
Denominator Exceptions	• Patient/caregiver refuse
Exception Justification	Some children have significant intellectual inability that preclude them for being able to participate adequately in testing. A patient or caregiver have the right to refuse testing. If a patient already has neuropsychological or neurodevelopmental services, they would not need additional screening or referrals.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "Establishing the presence of a deficit in a particular area of cognition that is hypothesized to be related to a deficit in academic achievement (e.g., working memory in reading) should be part of the process of determining the presence of an SLD [specific learning disability] according to some definitions of SLD."[1] • "Given the high rate of neurobehavioral comorbidity in childhood epilepsy and noted under recognition, screening of all children for cognitive and behavioral difficulties would seem warranted, as has been previously recommended."[2] • "Given general brain development and changes/vulnerabilities to seizures and comorbid behavioral health symptoms in puberty, screening should take place at seizure onset and throughout the developmental course of the youth's epilepsy to achieve optimal quality of life."[3] • "Neuropsychological assessment should be considered in children, young people and adults in whom it is important to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory."[4] • "Referral for a neuropsychological assessment is indicated: - When a child, young person or adult with epilepsy is having educational or occupational difficulties - When an MRI has identified abnormalities in cognitively important brain regions - When a child, young person or adult complains of memory or other cognitive deficits and/or cognitive decline"[4]

	• "Screening for developmental delay is important for all young children and especially those with epilepsy."[5] • "Formal screening, as recommended by the American Academy of pediatrics, with a well-validated measure such as the ASQ-3 is ideal and should be done whenever feasible."[5]
Measure Importance	
Relationship to Desired Outcome	Increase the percent of patients who get neuropsychological testing in order to address issues and obtain proper treatment
Opportunity for Improvement	Literature suggests that neuropsychological deficits are present in many children with epilepsy independent from control of seizures.[6,7,8,9,10] Eom et al., discuss the lack of implementation of screening guidelines into clinical practice which results in a gap in high quality care.[5] When interventions are initiated earlier for neuropsychological or neurodevelopmental issues there is an increase in developmental attainment that benefits the patient long term.[11] The Work Group identified the following questionnaire-based tools to assist in screening: • Child Behavior Checklist (CBCL) • Behavior Assessment System for Children, 3rd edition (BASC-3) • Behavior Rating Inventory of Executive Function, 2nd edition (BRIEF-2) • Conners' third edition (Conners-3) (ADHD rating scale) • NICHQ Vanderbilt Assessment Scale • Ages & Stages Questionnaires, Third Edition (ASQ-3) • Strengths & Difficulties Questionnaires (SDQ) • Pediatric Quality of Life Inventory (PedsQL) • Neuro QoL/PROMIS measures • Child Depression Inventory, 2nd edition (CDI-2) • Multidimensional Anxiety Scale for Children, 2nd edition (MASC-2) • Psychosocial Assessment Tool (PAT)
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness
Harmonization with Existing Measures	This measure does harmonize with an existing adult measure on screening for psychological co-morbidities as they would be identified on this testing. This measure is needed as it expands the screening to include other disorders that are commonly seen in children that do not necessarily apply to the adult epilepsy population.
Measure Designation	

Measure Purpose (Check all that apply)	☒ Quality improvement ☐ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☐ System
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry

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2. Reilly C, Atkinson P, Das K, et al. Neurobehavioral comorbidities in children with active epilepsy: a population-based study. Pediatrics 2014; 133(6): e1586-1593.
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Denominator (Eligible Population)	ICD-10 Code R56.8 Seizures (otherwise unspecified) G40.xx Epilepsy (otherwise unspecified) AND CPT E/M Service Code **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Querying for co-morbid conditions of tic disorder (TD) and Tourette syndrome (TS)

Measure Description	
Percentage of patients who were queried for psychological and/or behavioral co-morbid conditions of tic disorder (TD) or Tourette syndrome (TS)	
Measure Components	
Numerator Statement	Patients who were queried^ for symptoms of psychological and/or behavioral co-morbid conditions* at least once per year. Definitions: *Co-morbid conditions (to meet measure requirements must query for all conditions in the list below): • Mood disorders, including depression and anxiety, • Obsessive compulsive disorder (OCD), • Attention Deficit Hyperactivity Disorder (ADHD), AND • Oppositional Defiant Disorder (ODD) ^Queried is defined as asking or inquring about the presence of absence of symptoms
Denominator Statement	All patients aged $\leq$ 18 years with the diagnosis of TD* or TS who do not have an existing diagnosis of a comorbid condition *Tic disorders include:[1] • Chronic or transient (DSM IV) • Persistent or provisional (DSM V) • Motor and vocal • Other tic disorder • Tic disorder not specified
Denominator Exceptions	• Patient/caregiver refuse
Exception Justification	Exception for patient and caregiver declinations needed as patient and caregivers need to be willing to undergo evaluation for results to be meaningful.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "Recommendations are given to assess the most prevalent comorbid conditions, i.e. ADHD and OCD."[2] • "Lastly, due to high rates of comorbidity in children with CTD, global assessment measures like the TODS-CR and TODS-PR may be useful as they assess the severity of tics in addition to common comorbid symptoms."[3] • "The assessment for tic disorders should involve a careful examination for comorbid psychiatric conditions."[4]

Measure Importance	
Relationship to Desired Outcome	Tic disorder is frequently associated with psychiatric conditions and presence of these co-morbid conditions can be worse than the tics itself, can significantly impair function and can affective cognitive performance.[3] Screening for these conditions will lead to early diagnosis and treatment.
Opportunity for Improvement	It is estimated that between 80% to 90% of patients with Tourette syndrome have both tics and psychiatric manifestations.[5] Their quality of life is impacted by these accompanying psychiatric conditions.[5]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☒ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
References	

1. American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C: American Psychiatric Association.

2. Cath DC, Hedderly T, Ludolph AG, et al. European clinical guidelines for Tourette syndrome and other tic disorders. Part I: assessment. European Child & Adolescent Psychiatry 2011; 20:155-71.
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Denominator (Eligible Population)	ICD-10 Code F95.1 tic chronic F95.2 Tourette syndrome AND CPT E/M Service Code **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Management of co-morbid symptoms of tic disorder (TD) or Tourette syndrome (TS)

Measure Description	
Percentage of patients who were treated or referred for treatment for co-morbid symptoms of tic disorder (TD) or Tourette syndrome (TS)	
Measure Components	
Numerator Statement	Patients who were treated* or referred for treatment for comorbid condition(s)** annually. *Treated is an intervention and/or medication implemented for co-morbid conditions **Co-morbid conditions: • Mood disorders, including depression and anxiety, • Obsessive compulsive disorder (OCD), • Attention Deficit Hyperactivity Disorder (ADHD), AND • Oppositional Defiant Disorder (ODD)
Denominator Statement	All patients aged 18 years of age and below with the diagnosis of TD* or TS and co-morbid mood disorder, OCD, ADHD, or ODD diagnosis who are not currently under the care of a psychiatrist/psychologist *Tic disorders include:[1] • Persistent, provisional (DSM V) • Chronic, Transient (DSM IV) • Motor and vocal • Other tic disorder • Tic disorder not specified
Denominator Exceptions	• Patient/caregiver refuse
Exception Justification	Some patients may not be receptive to treatment/intervention. If patient is already under psychiatric or psychological care they would not need a referral for further management.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "80-90% of patients with Tourette syndrome have comorbid disorders such as attention deficit hyper-activity disorder, depression, anxiety, and obsessive-compulsive disorder, which often impair the quality of life more than the tics themselves and are accordingly the main target of treatment."[2] • "It is recommended that psychiatric disorders accompanying Tourette syndrome should be treated in the same way as when they occur in the absence of Tourette syndrome."[2]
Measure Importance	

Relationship to Desired Outcome	There are patients whose tics are mild but have significant symptoms from the co-morbid disorders.[2] Treatment or referral for management of co-morbid conditions will lead to improved quality of life and improve tic frequency as well.
Opportunity for Improvement	Psychiatric manifestations appear in 80-90% of patients.[2] Patient quality of life is severely impaired by the accompanying psychiatric conditions of tic disorders and Tourette's syndrome.[2,3] Patients and their caregivers often find the co-morbid conditions to be more challenging than the tic itself.[4]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☐ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
References	

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<table>
<tr><td colspan="2">2. Ludolph AG, Roessner V, Munchau A, Muller-Vahl K. Review article: Tourette syndrome and other tic disorders in childhood, adolescence and adulthood. Deutsches Arzteblatt International 2012; 48:821-828.
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<tr><td>Denominator (Eligible Population)</td><td><u>ICD-10 Code</u>
F95.1 tic chronic
F95.2 Tourette syndrome

AND
<u>CPT E/M Service Code</u>
99201, 99202, 99203, 99204, 99205 Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient;
99211, 99212, 99213, 99214, 99215 Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient</td></tr>
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Behavioral therapy for tic disorder (TD) or Tourette syndrome (TS)

Measure Description	
Percentage of patients who were counseled or referred for behavioral therapy for management of chronic tic disorder (TD) or Tourette syndrome (TS)	
Measure Components	
Numerator Statement	Patients who were counseled or referred for behavioral therapy* *Behavioral therapy (must provide at least one of the therapies from the below list to meet measure): • Comprehensive behavioral treatment for tics (CBIT), OR • Habit reversal training (HRT), OR • Relaxation training, OR • Exposure and Response Prevention Therapy (ERP)
Denominator Statement	Patients aged 8 years of age and above diagnosed with chronic^ TD or TS without severe or profound intellectual disability who are currently not receiving behavioral therapy ^Chronic is defined as greater than one year
Denominator Exceptions	• Patient/caregiver refuse • Patient has already received a referral in the 12-month measurement year
Exception Justification	Active patient participation is a necessity in behavioral therapy and may not be suitable for extremely young and cognitively disabled patients; and if patient and family refuse to participate. If a referral has already been given in the measurement period, additional referrals should not be required.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "Intervention built on HRT appears to be effective for decreasing tic severity in children and adolescents."[1] • "Based on the current available evidence, we have made strong recommendations for HRT and ERP, preferably embedded within a supportive, psycho-educational program, and with the option of combining either of these approaches with drug treatment."[2] • "In summary, studies indicate that HR is effective for both vocal and motor tics, for children as well as adults, for patients receiving TS medications as well as those not doing so, for tic severity as well as tic frequency, and with no evidence of symptom substitution."[3] • "Preliminary results indicate that ERP is effective for vocal and motor tics, for children as well as adults, for tic severity as well as tic frequency, with no indications of a rebound effect. Since younger children are less aware of premonitory sensory motor phenomena it has to be clarified if there is an age effect respective an age limit for ER but also for HR."[3] • "Preliminary results seem to indicate that cognitive interventions have no specific additive value in the treatment of tics."[3]

	• "This meta-analysis found a medium to large treatment effect for BT across RCTs for TS (SMD=0.67)."[4] • "While TS has traditionally been managed with pharmacotherapy, this quantitative synthesis suggests BT presents an alternative treatment option with comparable treatment effects to psychotropic medications – supporting current treatment recommendations by some professional organizations that BT serve as a first-line treatment for TS."[4] • "When examining treatment response on the CGI-Improvement, participants receiving BT were five times more likely to respond to treatment compared to individuals receiving comparison interventions."[4] • "Behavioral interventions for CTD should be considered when tics cause impairment, are moderate in severity, or if behavioral-responsive psychiatric comorbidities are present."[5]
Measure Importance	
Relationship to Desired Outcome	There is no cure for tics and while pharmacologic agents can reduce tic frequency, there are potential significant side effects from medications. Behavioral treatment does not have adverse effects and its possible advantage is its better long term effects beyond the duration of therapy.[6,7,8] The use of behavioral treatment will improve frequency of tics and increase functioning, adaptation and coping skills to the fluctuating nature of the disorder.
Opportunity for Improvement	The typical treatment for severe tics is antipsychotics, alpha agonists, and anticonvulsants.[1,2] These medications are effective but often have many side effects and rarely eradicate the tics completely.[1,2] Behavioral therapies have been around for a long time, but have recently had a growing interest in the last decade with many RCTs being completed.[2]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☐ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure

Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry

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Denominator (Eligible Population)	<u>ICD-10 Code</u> F95.1 tic chronic F95.2 TS F72 Severe intellectual disability F73 Profound intellectual disability AND <u>CPT E/M Service Code</u> **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Transition to adult neurology care

Measure Description	
Percentage of patients who had a neurological transition plan of care	
Measure Components	
Numerator Statement	Pediatric neurology patients with chronic ongoing neurological condition ≥ 13 years of age that have had a documented neurological transition plan of care* initiated and updated annually with copy given to patient and/or caregiver • *Neurological transition plan of care must include ALL of the following, but not limited to:[1] o Medical plan (pertinent medical and surgical history related to neurological condition, current and past neurological medications with adverse effects, previous and future needed testing) o Discussion of existing office transition policy with expected year of transition given to patient and caregiver o Patient self-management skills assessment[2,3,4] o Transition readiness assessment[2,3] o Patient current and expected legal competency o Patient plan for employment, school, vocation, placement (for profound intellectual disability patients), etc. o Emergency plans (medical power of attorney, living will, DNR, plans for guardianship for patients with profound intellectual disability) o Name of provider providing or accepting care of neurological condition (at time of transition only)
Denominator Statement	Pediatric neurology patients with chronic ongoing neurological conditions ≥ 13 years of age
Denominator Exceptions	• A patient does not need continued care • Patient/caregiver refuses to see the adult provider or participate in the transition planning
Exception Justification	If a patient does not need continued care, there is no need for transition planning to adult care. If a patient or caregiver refuses to see the adult provider or participate in the transition planning, then the provider should not be accountable.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "Transition planning should be a standard part of providing care for all youth and young adults, and every patient should have a transition plan regardless of his or her specific health care needs."[5] • "A key component of supporting the transition process is the primary care medical home having an explicit office policy that describes the practice's approach to health care transition, including the age and process at which youth shift to an adult model of care."[5]

	• "The medical home team members must understand and address patients' and parents' perspectives and needs during transition and recognize that this process is complex and potentially emotional for parents and other caregivers/guardians."[5] • "For transition planning to succeed, providers, and parents/caregivers must view the youth as the driver in the process and encourage the youth to assume increasing responsibility for his or her own health care to the fullest extent possible."[5] • "The population of adults with diseases originating in childhood who are hospitalized at children's hospitals is increasing, with varying disease-specific changes over time. Our findings underscore the need for proactive identification of strategies to care for adult survivors of pediatric diseases."[6] • "Quality of life is an important construct relevant to HCT [Health Care Transitions]. Future research should identify valid measures associated with each outcome and further explore the role that quality of life plays in the HCT process. Achieving consensus is a critical step toward the development of reliable and objective comparisons of HCT outcomes across clinical conditions and care delivery locations."[7] • "Both disease complexity and failure of transition planning appear to have contributed to the increased admission of young adults to the RCH [Royal Children's Hospital]. While greater support of transition planning is needed, there are also concerns about the lack of appropriate services within the adult sector for young adults with complex, multidisciplinary healthcare needs."[8] • "Strengthening the capacity for transitioning from a service that is family focused to one with an individual orientation requires a paradigmatic shift and clear identification of roles and responsibilities in the health care system."[9] • "The child neurologist has a critical role in planning and coordinating the successful transition of youth with neurologic conditions from the pediatric to adult health care system."[1]
Measure Importance	
Relationship to Desired Outcome	Adolescent and young adult neurology patients will be properly transitioned to adult neurology care. No gap will occur. Rate of proper completion will occur with improved patient and caregiver satisfaction with transition, stability or improvement of neurological condition, decrease emergency utilization and improved quality of life.[1]
Opportunity for Improvement	Currently only a minority of practices participate in a formal transition process which has led to poor quality of care, decreased patient satisfaction, and increased healthcare utilization and costs.[10] Tools available: • Got Transition™ a program of The National Alliance to Advance Adolescent Health: www.gottransition.org • Data Resource Center for Child and Adolescent Health: www.childhealthdata.org

	• Institute for Healthcare Improvement: http://www.ihi.org/Topics/TripleAim/Pages/default.aspx • The Transition Readiness Assessment Questionnaire (TRAQ): Its Factor Structure, Reliability, and Validity • National Consensus Document: http://pediatrics.aappublications.org/content/128/1/182 • The National Alliance to Advance Adolescent Health • AES Transition Tools: https://www.aesnet.org/clinical_resources/practice_tools/transition_tools_adolescents • CNF Transition Tools: http://www.childneurologyfoundation.org/patients-or-caregivers/transition-into-adulthood/ • AHRQ: https://www.effectivehealthcare.ahrq.gov/ehc/products/546/1920/children-special-needs-transition-report-140617.pdf https://psnet.ahrq.gov/webmm/case/348/transitions-in-adolescent-medicine
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☒ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☐ Clinical Process/Effectiveness
Harmonization with Existing Measures	This measure harmonizes across all neurology disease states and covers both child and adult neurology providers. Although several existing measures deal with transitioning care, nothing specific exists on the transfer of care from child to adult neurology. Based on the gap and importance in this area, the work group felt a separate measure was warranted for neurological patients.
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☐ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care

	☒ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry

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Denominator (Eligible Population)	<u>ICD-10 Code</u> G00-G99 Diseases of the nervous system AND <u>CPT E/M Service Code</u> **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Psychological interventions for chronic headache

Measure Description	
Percentage of patients who have been counseled to seek psychological or bio-behavioral interventions for management of chronic headache	
Measure Components	
Numerator Statement	Patients ≥ 8 years of age who have been counseled to seek a behavioral health evaluation or are referred for psychological or bio-behavioral interventions* to manage chronic headache^. *Interventions include any of the following: • Cognitive behavioral therapy, OR • Relaxation, OR • Biofeedback ^"Chronic headache" is defined as a headache occurring more than 15 days per month for more than 3 months
Denominator Statement	Patients ≥ 8 years of age diagnosed with chronic headache without severe or profound intellectual disability who is not currently under the care of a psychologist
Denominator Exceptions	• Patient/caregiver refuse
Exception Justification	Active participation is essential in psychological therapy and cannot be enforced to patients and families who do refuse such treatment. Lack of support for such therapy from insurance companies will also be a barrier, and some patients and family may refuse as a result.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "Psychological treatments are effective in reducing pain intensity for children and adolescents (<18 years) with headache and benefits from therapy appear to be maintained."[1] • "There is evidence that psychological treatments are effective in reducing pain intensity in children and adolescents with headache, and that therapies such as relaxation and cognitive behavioural therapy (CBT) may have lasting effect for improving mood and reducing pain for chronic headache; however, it is not possible to distinguish effectiveness for migraine versus other types of chronic headache."[2] • "Children and adolescents with CDH pose a significant problem because of their impairment and of the possible social costs of their headache. Drugs, both used as preventive medications or as pain-killers, are insufficient for

	the management of these patients; a more global approach should be warranted, involving also a psychological support."[3] • "Providers treating pediatric migraine should be routinely recommending CBT as an evidence-based treatment strategy for decreasing pain experience and improving quality of life."[4] • "It can be safety concluded that psychological treatments have proved their efficacy on the top level of evidence, which means that methodological well-designed randomized controlled studies exist, supporting efficacy, and meta-analyses confirm these results on a hierarchically higher level."[5] • "CBT for children with headache is effective both in the short and long term. Especially when standardized treatment programs are used, group sessions are highly effective in terms of headache frequency, headache duration, or headache intensity."[6] • "Biobehavioral management is an essential pillar of pediatric headache management, several principles of which can be integrated into clinical practice."[7] • "There is strong evidence for the efficacy of cognitive behavioral therapy, relaxation treatment, and biofeedback in reducing headache pain."[7] • "As in adults, psychological therapies should be discussed with families of all children with headache as an option or complementary to pharmacological management, especially in the following situations: patients with frequent headache; chronic daily headache with high risk factors for persistence; significant stressors; associated psychiatric disorders; overuse of medication, and intolerance to or lack of benefit from appropriate drugs."[7]
Measure Importance	
Relationship to Desired Outcome	Recurrent headache in children and adolescents is common, can be disabling and associated with co-morbid psychiatric conditions. There is good evidence that psychological and bio-behavioral therapies are essential in the multidisciplinary management of recurrent headache.[1,2] There are also studies showing that isolated medical intervention do not lead to sufficient alleviation of pain.[4,8,9] Hence recommending psychological therapy for headache can lead to reduction of headache frequency, prevent future headache attacks, modify cognitive and behavioral mechanisms aggravating pain which lead to improve function and less disability.
Opportunity for Improvement	Several reviews have showed effectiveness of psychological therapies for children with headache. Despite this evidence, few patients receive this intervention.[4]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness

Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☒ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☐ System
Care Setting (Check all that apply)	☒ Outpatient ☒ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
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Denominator (Eligible Population)	ICD-10 Code G43.7X migraine R51.X headache F72 severe intellectual disability F73 profound intellectual disability AND CPT E/M Service Code **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Botulinum Toxin Serotype A (BoNT-A) for spasticity or dystonia

Measure Description	
Percentage of patients with spasticity or dystonia who were evaluated or referred or treated with BoNT-A	
Measure Components	
Numerator Statement	Patients who were evaluated OR treated OR referred for BoNT-A injection
Denominator Statement	All patients ≤ 18 years of age with moderate to severe localized/segmental spasticity or dystonia in the upper and/or lower extremities
Denominator Exceptions	• Patient/caregiver refuse • BoNT-A is contraindicated • Patient has established care with another neurology or non-neurology provider that can evaluate the need for and/or provide BoNT-A injections
Exception Justification	Not all patients and parents may agree to the procedure. If a patient has a contraindication to BoNT-A, such as prior adverse reaction, then they should be excluded due to risk of harm. The patient may be seeing a different practitioner for their BoNT-A injection needs making additional evaluation redundant and burdensome.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "For localized/segmental spasticity that warrants treatment, botulinum toxin type A should be offered as an effective and generally safe treatment."[1] • "Consider botulinum toxin type A treatment in children and young people in whom focal spasticity of the upper limb is:[2] o Impeding motor function o Compromising care and hygiene o Causing pain o Impeding tolerance of other treatments, such as orthoses o Causing cosmetic concerns to the child or young person" • "Consider botulinum toxin type A treatment where focal spasticity of the lower limb is:[2] o Impeding gross motor function o Compromising care and hygiene o Causing pain o Disturbing sleep

	○ Impeding tolerance of other treatments, such as orthoses and use of equipment to support posture ○ Causing cosmetic concerns to the child or young person" • "Children and young people with spasticity should have access to a network of care that uses agreed care pathways supported by effective communication and integrated team working, and provides access to healthcare professionals experienced in the care of such people. The network team should provide local expertise in paediatrics, nursing, physiotherapy, and occupational therapy. Access to other expertise, including orthotics, orthopaedic surgery (and/or neurosurgery), and paediatric neurology, may be provided locally or regionally."[3] • "After diagnosis, ensure that all children and young people with spasticity are referred without delay to an appropriate member of the network team."[3]
Measure Importance	
Relationship to Desired Outcome	BoNT-A is established as an effective treatment for localized/segmental spasticity and dystonia.[1] While there is conflicting evidence regarding its use to improve motor function, improving spasticity and dystonia can provide better delivery of care and hygiene, improve tolerance to other treatments (such as orthoses and equipment to support posture), reduce pain from spasticity, reduce disturbance of sleep from pain and spasticity.
Opportunity for Improvement	Early referral to services will allow for stimulation of motor development.[3]
National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☒ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☐ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☒ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement	☒ Individual Provider ☒ Practice ☐ System

(Check all that apply)	
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care ☒ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
References	
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Denominator (Eligible Population)	ICD-10 Code R25.2 Spasticity G24.9 Dystonia AND CPT E/M Service Code **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

Genetic testing for global developmental delay

Measure Description	
Percentage of patients who had genetic testing ordered for global developmental delay (GDD)	
Measure Components	
Numerator Statement	Patients for whom chromosomal microarray (CMA) was ordered.
Denominator Statement	All children less than 6 years of age with GDD* of unknown etiology *GDD defined as developmental skills of more than 2 Standard Deviations below age-matched peers in 2 or more aspects of the 5 domains of development (motor, speech and language, cognitive, social, adaptive).[1]
Denominator Exceptions	• Patient/caregiver refuse • Referred to or under the care of a geneticist
Exception Justification	Parental/caregiver approval is necessary in proceeding with genetic testing. If a patient has an established geneticist providing services, additional evaluation is redundant and burdensome.
Supporting Guideline & Other References	The following statements are quoted verbatim from the referenced supporting articles: • "Microarray testing is abnormal on average in 7.8% of subjects with GDD/ID and in 10.6% of those with syndromic features (Class III)."[1] • "Karyotype studies are abnormal in at least 4% of subjects with GDD/ID and in 18.6% of those with syndromic features (Class II and III)."[1] • "StFISH testing is abnormal in at least 3.5% of subjects with GDD/ID, in at least 4.2% of those with syndromic features, in as few as 0.5% of those with mild impairment, and in at least 7.4% of those with moderate/severe impairment (Class I, II, and III)."[2] • "Mutation in X-linked genes may explain up to 10% of all cases of GDD/ID. Testing of XLID genes has a yield of 42% in males from definitely X-linked families and of 17% in males from possibly X-linked families (Class III)."[2] • "MeCP2 mutations are found in 1.5% of girls with moderate/severe GDD/ID and in less than 0.5% of males with GDD/ID (Class III)."[1]

	• "Screening for IEMs in children with GDD/ID has a yield of between 0.2% and 4.6%, depending on the presence of clinical indicators and the range of testing performed (Class III)."[2] • "Testing for CDGs has a yield of up to 1.4%, and testing for creatine synthesis and transport disorders has a yield of up to 2.8% (Class III)."[1] • "…Confirm the clinical diagnosis with the appropriate genetic testing, as warranted by clinical circumstances."[3] • "If a specific diagnosis is suspected, arrange for the appropriate diagnostic studies to confirm including single-gene tests or chromosomal microarray test."[3] • "If diagnosis is unknown and no clinical diagnosis is strongly suspected, begin the stepwise evaluation process: o Chromosomal microarray should be performed in all o Fragile X genetic testing should be performed in all"[3] • "If no diagnosis established: o Male gender and family history suggestive X-linkage, complete XLID panel that contains genes causal of nonsyndromic XLID and complete high-density X-CMA. Consider X-inactivation skewing in the mother of the proband. o Female gender: complete MECP2 deletion, duplication, and sequencing study"[3] • "It is important to emphasize the new role of the genomic microarray as a first-line test, as well as the renewal of efforts to identify the child with an inborn error of metabolism."[3] • "CMA offers a much higher diagnostic yield (15%-20%) for genetic testing of individuals with unexplained DD/ID, ASD, or MCA than a G-banded karyotype (~3%, excluding Down syndrome and other recognizable chromosomal syndromes), primarily because of its higher sensitivity for submicroscopic deletions and duplications."[4] • "Available evidence strongly supports the use of CMA in place of G-banded karyotyping as the first-tier cytogenetic diagnostic test for patients with DD/ID, ASD, or MCA. G-banded karyotype analysis should be reserved for patients with obvious chromosomal syndromes (e.g., Down syndrome), a family history of chromosomal rearrangement, or a history of multiple miscarriages."[4]
Measure Importance	
Relationship to Desired Outcome	While identifying the genetic cause of GDD only occasionally leads to specific therapy, establishing an etiologic diagnosis will a) provide information regarding symptomatic management and/or surveillance for known complications; b) provide validation of the medical problem and empower families to advocate for their child; c) assist family in obtaining services particularly in schools and condition specific family support; d) provide information on the genetic mechanism and recurrence risks; e) prevent unnecessary or redundant diagnostic tests; f) provide access to possible research treatment protocols.
Opportunity for Improvement	At least 30-50% of cases of GDD/ID remain unexplained after an initial clinical evaluation by a neurologist or geneticist.[4]

National Quality Strategy Domains	☐ Patient and Family Engagement ☐ Patient Safety ☐ Care Coordination ☐ Population/Public Health ☐ Efficient Use of Healthcare Resources ☒ Clinical Process/Effectiveness
Harmonization with Existing Measures	N/A
Measure Designation	
Measure Purpose (Check all that apply)	☒ Quality improvement ☐ Accountability
Type of Measure (Check all that apply)	☒ Process ☐ Outcome ☐ Structure
Level of Measurement (Check all that apply)	☒ Individual Provider ☒ Practice ☒ System
Care Setting (Check all that apply)	☒ Outpatient ☐ Inpatient ☐ Emergency Departments and Urgent Care ☐ Residential (i.e., nursing facility, domiciliary, home care)
Data Source (Check all that apply)	☒ Electronic health record (EHR) data ☐ Administrative Data/Claims ☒ Patient Medical Record ☒ Registry
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Denominator (Eligible Population)	ICD-10 Code F88.X Global developmental delay AND CPT E/M Service Code **99201, 99202, 99203, 99204, 99205** Office or other outpatient visit 10, 20, 30, 45, or 60 minutes for the evaluation and management of a new patient; **99211, 99212, 99213, 99214, 99215** Office or other outpatient visit 5, 10, 15, 25, or 40 minutes for the evaluation and management of an established patient

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