

CDC Activities Related to Recommendations of the 2012 IOM Report, *Epilepsy Across the Spectrum*, 2012–2022

Final Progress Report



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OVERVIEW

Epilepsy, which is sometimes called a seizure disorder, is a broad term used for a brain disorder that causes recurring seizures. A seizure is a brief change in normal brain activity that can cause changes in awareness, behavior, or body movement. Seizures are the main sign of epilepsy.

Epilepsy affects an estimated 3.4 million people in the United States.¹ Similar to other chronic diseases, epilepsy affects many aspects of a person's life, including not only their health, but daily activities and life opportunities. CDC received initial funding to address epilepsy in 1994. Since then, CDC has followed epilepsy partner recommendations and national health promotion objectives to guide its agenda on epilepsy surveillance, research, program development, public awareness, and partnerships to address the public health dimensions of epilepsy.²

In 2010, recognizing the ongoing challenges of epilepsy, a coalition of 24 federal and nonprofit professional and advocacy organizations charged the Institute of Medicine (IOM) to

identify progress and gaps in the epilepsy field—and make comprehensive recommendations to reinforce and guide future public health action to improve epilepsy care and quality of life among people with epilepsy.

The IOM assembled two workshops to obtain input from nearly 100 epilepsy experts, researchers, and people with epilepsy and their loved ones. Their collective knowledge, testimonies, and personal stories of lived experience were the bedrock of the 2012 report *Epilepsy Across the Spectrum: Promoting Health and Understanding*.³

Importantly, *Epilepsy Across the Spectrum* identified 13 recommendations to guide public health action on epilepsy. Of the 13 recommendations, 10 were designated for CDC to lead or co-lead with partners (recommendations 1, 2, 3, 4, 8, 9, 10, 11, 12, 13). Although recommendations 5 and 7 were not designated for CDC, the agency made relevant contributions to address them. Recommendation 6 was outside the scope of CDC's work.

Since 2012, CDC has been responsive in addressing the IOM's recommendations through coordination of extramural and intramural activities that incorporated IOM recommendation objectives. Additionally, CDC has provided updated inventories of activities representing progress achieved to the committee that developed the IOM recommendations and to the Epilepsy Leadership Council.

This 10-year progress report serves as the final inventory of CDC extramural and intramural activities. Activities encompass those supported directly by both the National Center for Chronic Disease Prevention and Health Promotion's Epilepsy Program and the National Center on Birth Defects and Developmental Disabilities and indirectly by other CDC centers (e.g., National Center for Health Statistics). References for this report are provided in **Appendix A**.

The IOM recommendations are organized within two established public health frameworks.^{4,5} Select activities, key outcomes, and demonstrations of reach and impact are highlighted for each recommendation. **Appendix B** includes a comprehensive inventory of activities organized by recommendation and year. These activities include those with inconclusive outcomes to demonstrate that an activity was supported by CDC but requires more action. **Appendix C** contains an expanded list of publications, presentations, reports, workshops, and outcomes by recommendation.

This report has several limitations. First, it is an incomplete assessment of outcomes for activities ongoing in 2022. Second, although referenced publications have undergone peer-review, other reported outcomes are derived from awardee-submitted reports. CDC applied a conservative approach regarding selecting awardee outcomes. Therefore, some outcomes may be underestimated relative to assessing overall program reach and impact. Readers are encouraged to review publications for a more comprehensive overview of activities

implemented and outcomes achieved. Third, where activities and outcomes overlapped, they were described where they most closely aligned with the IOM recommendation narrative. Fourth, for simplicity throughout the report, distinctions between CDC's centers and institutes involved in each activity are not made, but most activities described were coordinated and funded by the CDC Epilepsy Program, which is also responsible for this report. Fifth, epilepsy can be characterized as idiopathic (attributed to an unknown cause) or secondary (attributed to known causes such as stroke, brain tumor, or central nervous system infections). Therefore, except where noted, most activities and estimates in this report are associated with both idiopathic and secondary epilepsy. As it was not possible to address all methodological nuances and limitations of various estimates presented in this report, readers are encouraged to review supporting references for these details relative to specific estimates presented.

CDC is grateful to its many partners who helped implement the activities described in this report and remains committed to continued public health action on epilepsy to prevent it and to improve the health and quality of life of people with epilepsy.



EPILEPSY FACTS AND FIGURES: US POPULATION

- About 3 million adults (≥ 18 years) and 470,000 children (≤ 17 years) live with active epilepsy.¹
- The age-standardized incidence of (idiopathic) epilepsy is 47.6 per 100,000 population, representing about 150,000 people who will develop epilepsy each year.⁶
- In 2019, total epilepsy-attributable health care spending for the noninstitutionalized population with epilepsy was estimated to be \$5.4 billion; the cost for seizure was \$19.0 billion, and the cost for epilepsy or seizure was \$25.4 billion.⁷ Total health care costs (epilepsy-attributable and other health-related costs) for noninstitutionalized people with epilepsy or seizure was \$54 billion.⁷
- People with epilepsy of all ages are at higher risk of co-occurring conditions (e.g., depression) that negatively affect health and quality of life.^{8–11}
- Less than half (44%) of people taking epilepsy medications were seizure-free in the past year.¹²

- Among children with intellectual and developmental disabilities, epilepsy/convulsions was the most frequent reason for hospitalizations.¹³
- Children with epilepsy miss more days of school than children without epilepsy.¹⁴
- People with epilepsy are at an increased risk of premature mortality in all age groups.¹⁵
- Males, non-Hispanic Black people, and adults aged 85 years or older with epilepsy are at higher risk of death.¹⁶
- Age-adjusted epilepsy mortality rates (as any listed cause of death) per 100,000 significantly increased from 0.58 in 2005 to 0.85 in 2014 (47% increase).¹⁶
- Sudden unexpected death in epilepsy (SUDEP) occurs in about 1 in 1,000 people with epilepsy.¹⁷
- People with epilepsy are at 22% higher risk of suicide than the general population.¹⁸
- About one-half of adults with active epilepsy and seizures have annual family incomes under \$25,000.¹⁹ In addition:
 - Adults with epilepsy are more likely to report an inability to afford medication and specialty care than adults without epilepsy.²⁰
 - Adults with epilepsy are more likely to report delayed care because of transportation barriers.²⁰
 - Adults with epilepsy are more likely to be in families that have difficulties paying medical bills overall.²⁰
- Epilepsy is common, costly, and complex. Epilepsy is associated with barriers that limit access to timely and effective treatment and life opportunities.

Public Perceptions of Epilepsy

Among US adults in 2017:

- 16% felt knowledgeable about epilepsy.
- 25% knew seizure first aid.
- 20% were confident they could help someone having a seizure with appropriate seizure first aid.
- 56% correctly identified symptoms or signs associated with generalized seizures, but less than 20% correctly identified symptoms or signs associated with focal seizures.
- 33% wanted to learn more about epilepsy.²¹



PUBLIC HEALTH APPROACHES APPLIED TO EPILEPSY

Multiple public health strategies are needed to address this common and complex disorder and the ongoing need to understand:

- Incidence, prevalence, risk factors, co-occurring conditions, quality of life, cost, and related outcomes.
- Facilitators and barriers to timely and appropriate care.
- Optimal coordination of clinical and community services.
- Best practices to improve health literacy and self-management approaches.
- Approaches to improve public understanding of epilepsy and reduce stigma.
- The effectiveness, impact, and support for health equity.

A multifaceted, coordinated public health approach to epilepsy should be grounded in a framework that encompasses the three core public health functions: Assessment, Policy Development, and Assurance.⁴ These core functions (**Figure 1**) provide the foundation for any public health activity and underlie past and ongoing CDC activities on epilepsy.

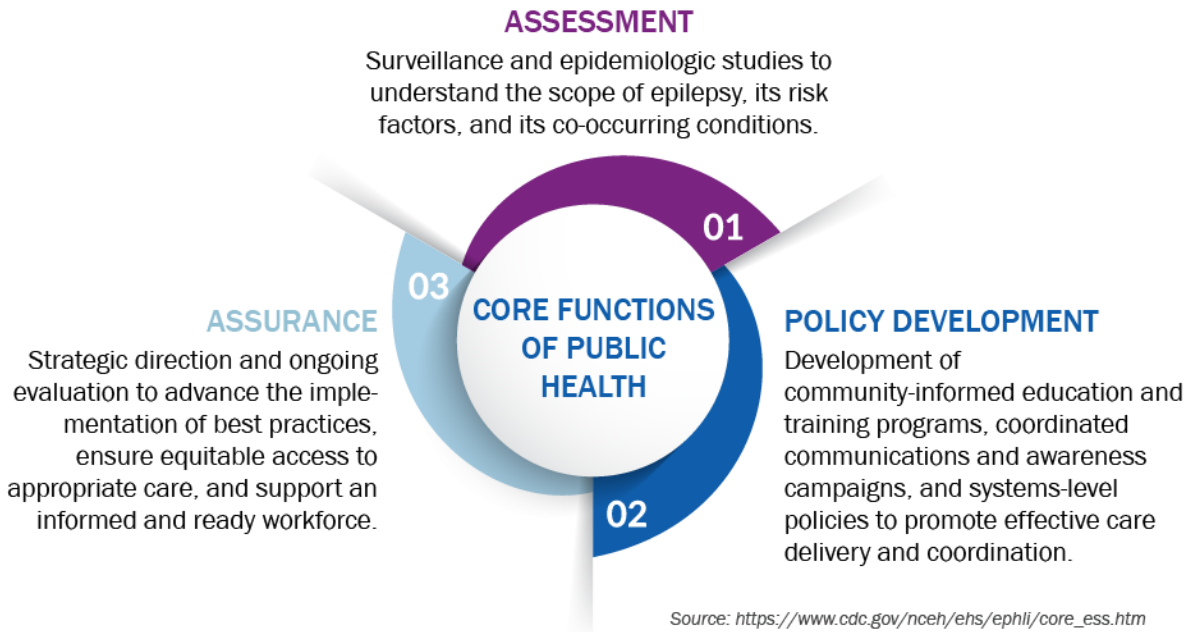


Figure 1. Public health core functions.⁴



CDC PROGRESS ON IOM RECOMMENDATIONS

The CDC Epilepsy Program used the three core public health functions framework (**Figure 2**) and the CDC Science Impact Framework (**Figure 3**) to characterize and evaluate progress across 12 of the 13 IOM recommendations.^{4,5} CDC's activities and accomplishments from 2012 to 2022 were organized by the IOM recommendations and then aligned across one of three core public health functions:

- **Data and Assessment for Insight and Action** (Assessment): includes activities such as data surveillance and epidemiological studies (recommendations 1, 2, 4).
- **Policies and Partnerships to Mobilize and Strengthen** (Policy Development): includes activities such as social media campaigns, education and training programs, and care coordination efforts (recommendations 7, 8, 9, 11, 13).
- **Evaluation and Strategy Toward Effectiveness and Improvement** (Assurance): includes activities such as prevention, quality assurance, standardized performance metrics, community care coordination, and strategic partnerships (recommendations 3, 5, 10, 12).

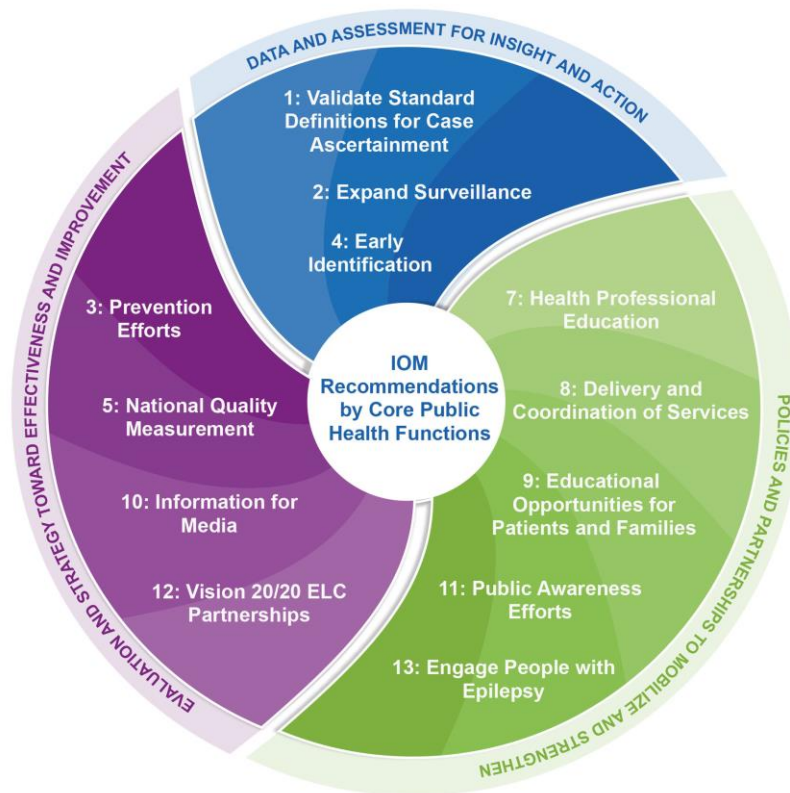


Figure 2. The 12 IOM recommendations CDC has responded to, aligned under each of the three core public health functions.

The **CDC Science Impact Framework** encompasses five domains of scientific influence that define the degree of impact that an activity may have on the public.⁵ The five domains are:

- **Disseminating Science** through scientific or trade publications, professional meetings, social media campaigns, and training courses.
- **Creating Awareness** through continuing education courses, focus groups, and partnerships with professional societies.
- **Catalyzing Action** through funding new research or projects, conducting research and evaluation, forming collaborative agreements, or creating new tools and technologies.
- **Effecting Change** through new surveillance systems, policy changes, social and behavioral changes, guideline creation, and science translation.

- **Shaping the Future** through continuous quality improvement, implementation initiatives, improved prevalence and incidence reporting, health outcomes reporting, reduced economic burden, and improved quality of life and life expectancy.

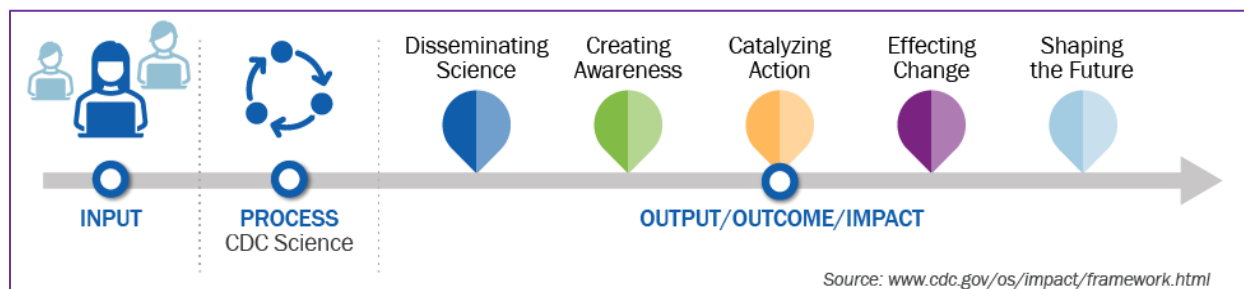


Figure 3. CDC Science Impact Framework.⁵

The CDC Science Impact Framework assumes that the degree of impact of any one activity may not be reflected at every domain. For each IOM recommendation, CDC considered how its activities influenced outcomes and selected one or two domains that best exemplified the effect these activities have had on public health.

The following sections demonstrate CDC progress across each IOM recommendation. Progress is presented through a description of select activities, the outputs of those activities, the impact of those outputs, and select highlighted accomplishments.

Readers are encouraged to review a comprehensive list of activities in **Appendix B**. Readers are also encouraged to review a more comprehensive overview of CDC outcomes in **Appendix C**, which includes a wide representation of peer-reviewed publications (and other reported outcomes derived from awardee-submitted reports directly responsible for data quality); scientific and educational workshops, presentations, and podcasts; and other professional and consumer reports.

DATA AND ASSESSMENT FOR INSIGHT AND ACTION

IOM Recommendation 1: Validate Standard Definitions for Case Ascertainment

The IOM recommended that CDC collaborate with federal agencies and epilepsy organizations to fund projects to validate and implement standard definitions for epilepsy case ascertainment, health care services use and costs, quality of life, and related outcomes for use in different data collection systems to guide surveillance and inform program and policy development.

Since 2012, the CDC Epilepsy Program has addressed this recommendation through several cooperative agreements supporting the use of standardized or validated criteria within multiple epidemiological research studies. (Cooperative agreements are assistance mechanism used when there is substantial agency involvement beyond normal oversight and monitoring activities.) CDC has also conducted intramural research using standardized, validated criteria for epilepsy case ascertainment.

1

Validate and implement standard definitions and criteria for epilepsy case ascertainment, health care and community services use and costs, and quality-of-life measurement.

CDC Epilepsy Program Activities

Issued research cooperative agreements to:

- Expand surveillance and epidemiologic studies using standardized data definitions.
- Examine local, state, and national health care service use and cost.
- Develop and validate case ascertainment criteria and survey questions to identify incident and prevalent cases of epilepsy overall and/or by epilepsy subgroups.
- Examine treatment gaps.

Used multiple data sources to examine:

- Health care costs.
- Seizure burden by type.
- Quality of life and well-being.
- Access to care.
- Links to community care.
- Rare epilepsy burden.
- Mortality.

Output

- Increased use of underutilized tools (e.g., National Institutes of Health Patient Reported Outcomes Measurement Information System [PROMIS] measures) and data sources (e.g., CDC School Health Profiles Survey, Medical Expenditure Panel Survey) to characterize epilepsy burden and costs.
- Improved understanding of:
 - Scope and cost of epilepsy among adults and children.
 - Access to specialists or community services.
 - Gaps in care by subgroups (e.g., race/ethnicity, insurance type).

Impact : Disseminating Science:

Funded research led to multiple published articles in peer-reviewed journals and multiple presentations to professional audiences. These studies documented the availability of standardized epilepsy case ascertainment criteria using multiple underutilized data sources and advanced knowledge in areas such as epilepsy burden, medical costs, treatment gaps, and diagnostic gaps.

For more information, see Appendix B (pages 48–49) and Appendix C (pages 55–56).

Highlights

Healthy People 2020, a national health promotion initiative, called for increasing the proportion of adults who self-report good or better health to 80%. The Patient-Reported Outcomes Measurement Information System (PROMIS) Global Health Survey is a reliable, validated tool for adults to self-report their physical and mental health. Using PROMIS Global Health Survey data from the 2010 National Health Interview Survey, CDC compared the age-standardized prevalence of reporting good or better physical or mental health among adults with epilepsy to adults with other chronic health conditions, such as heart disease, cancer, or hypertension.²²

They found that the percentage of adults with epilepsy reporting good or better physical health (52%) was significantly lower than the percentages of adults with heart disease, cancer, or hypertension.²² Additionally, the percentage of adults with epilepsy reporting good or better mental health (54%) was significantly lower than the percentage of adults with all selected conditions. The percentages of adults with epilepsy who reported either outcome fell dramatically short of the Healthy People 2020 goal (**Figure 4**).²² These findings provided baseline estimates intended to track progress in health services, community programs, and policies to improve the quality of life for people with epilepsy.

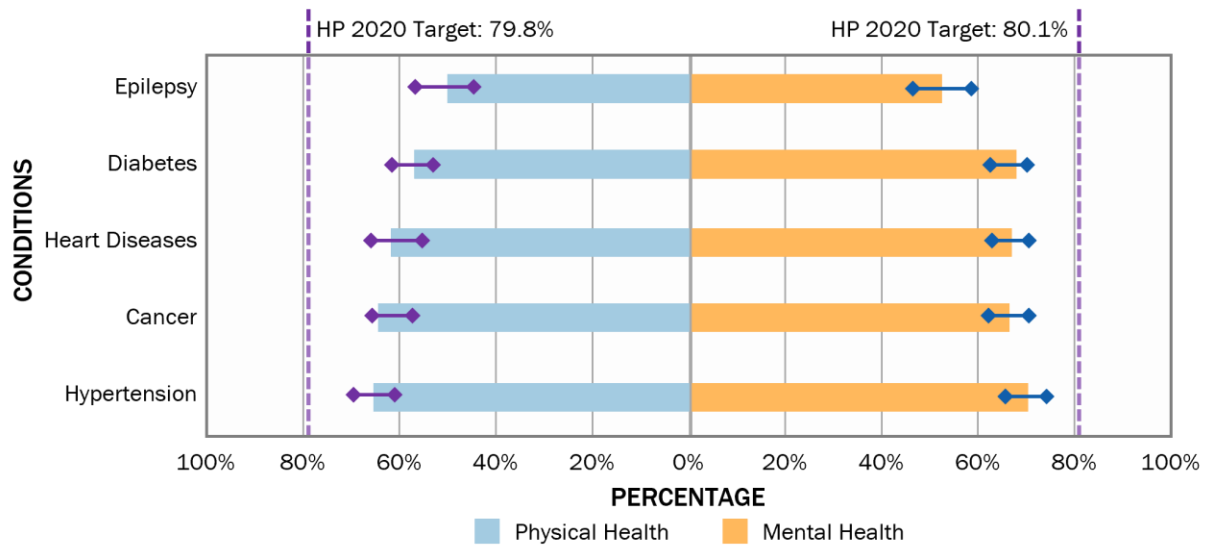


Figure 4. Age-adjusted percentage of adults with select chronic conditions reporting good or better physical and mental health, PROMIS Global Health data.²²

Note: Figure includes Healthy People (HP) 2020 targets for each condition.

The International Classification of Diseases, Ninth Revision (ICD-9) defines multiple types of epilepsy, the distribution of which varies across age, etiology, provider diagnostic capability, and assessment criteria. Diagnostic accuracy is essential for developing an effective treatment plan. CDC used MarketScan data from nearly 400,000 people diagnosed with epilepsy from 2010 to 2015 to estimate the proportion of diagnosed epilepsy types.²³ Findings indicated that “unspecified epilepsy” was the most common diagnosis, highlighting a need for improved training in epilepsy diagnosis and coding (**Figure 5**).²³

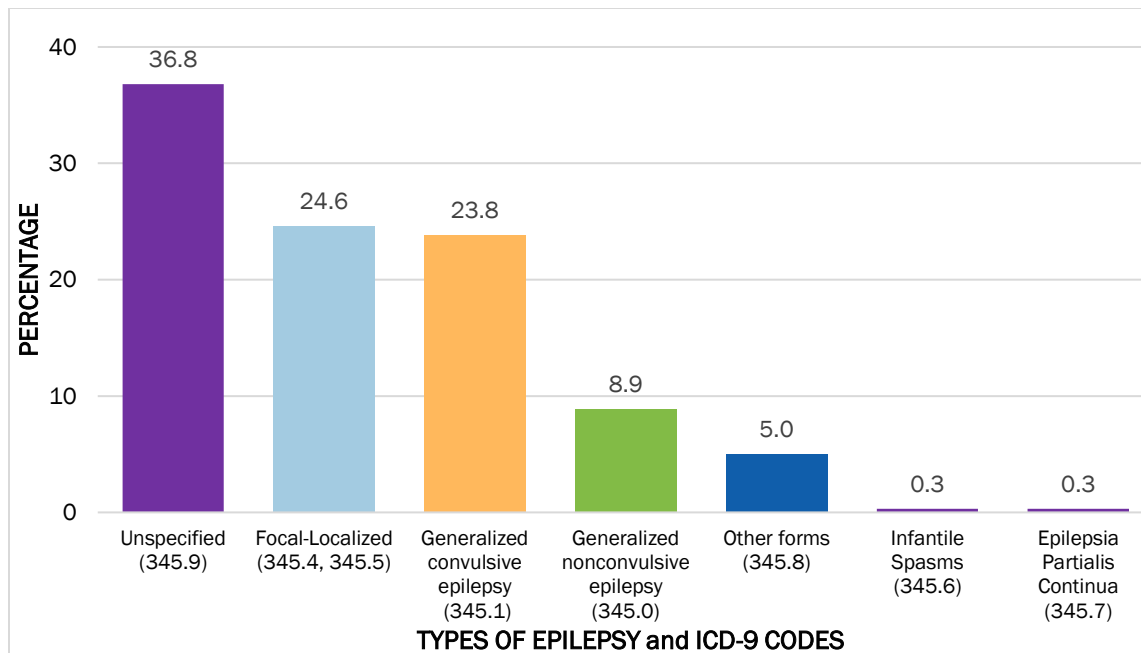


Figure 5. Percentage of epilepsy types among people with epilepsy, MarketScan data, United States, 2010–2015.²³

To update national estimates of health care costs associated with epilepsy and provide the first estimates of costs associated with seizure and epilepsy or seizure, CDC funded researchers to use pool data from Medical Expenditure Panel Survey (MEPS) household component files for 2010–2018 to examine health care spending overall and by site of care and to examine trends in spending growth for people with epilepsy (n=1,078), seizure (n=2,344), or epilepsy or seizure (n=3,422).⁷ (Health care spending represented costs paid from insurers to providers and out of pocket by respondents.) Estimates were adjusted for select sociodemographic factors (e.g., age group, sex, education) and comorbidities (e.g., stroke, diabetes, arthritis). Costs were updated to 2019 US dollars. People with epilepsy incur total health care costs of \$13.4 billion (**Figure 6**). The health care costs attributable to epilepsy, as opposed to other diseases, are \$5.4 billion.

These costs are considered underestimates for three reasons: the MEPS methodology is limited to noninstitutionalized adults; epilepsy and seizure case ascertainment is based on a recent medical encounter or a loss of work or school day attributed to these conditions; and other biases, such as omission of indirect costs, are possible.⁷

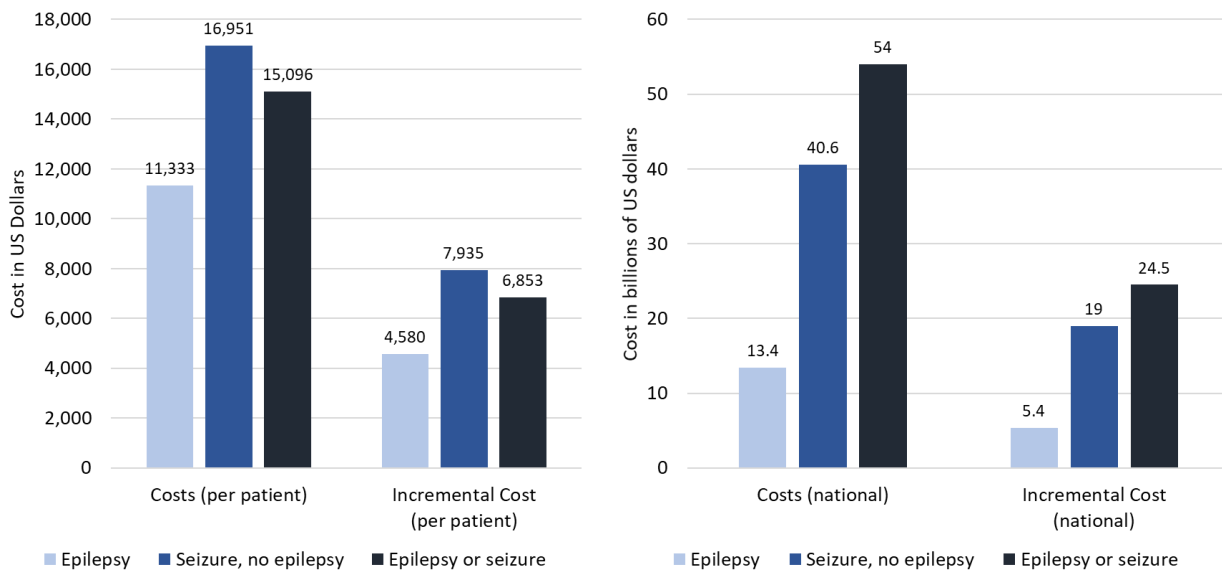


Figure 6. Total burden of epilepsy, seizure, and epilepsy or seizure costs, per patient and nationally.

Note: Estimations of the national burden of epilepsy, seizure, and epilepsy or seizure assume a population of 314 million noninstitutionalized, community-dwelling people and treated prevalence of epilepsy, seizure, and epilepsy or seizure of 0.38%, 0.76%, and 1.14%, respectively. MEPS operationalizes “treated prevalence” as people who attribute a recent medical encounter, prescription drug, or disability day to a particular condition, such as epilepsy or seizure.⁷

IOM Recommendation 2: Expand Surveillance

The IOM recommended that CDC expand its lead in epilepsy surveillance through collaboration with local, state, federal, and academic partners to better understand epilepsy burden (e.g., incidence, prevalence, comorbidity, mortality, health care services use) in representative populations and in subgroups and use novel approaches.

Since 2012, the CDC Epilepsy Program has expanded its surveillance efforts through intramural and extramural activities. These activities include sponsoring validated epilepsy-related questions on the 2010, 2013, 2015, 2017, 2021, and 2022 National Health Interview Survey. These efforts led to multiple *Morbidity and Mortality Weekly Report (MMWR)* articles and other articles published by CDC that garnered media attention to raise visibility of the national burden of epilepsy (**Appendix C**). Since 2010, CDC has funded at least eight academic institutions or contractors to conduct population-based epidemiologic studies of epilepsy, including use of administrative datasets and/or electronic health records. CDC also

co-funded at least 22 states/jurisdictions to expand the SUDEP registry to assess mortality associated with SUDEP and at least 10 states to examine co-occurring conditions among people with intellectual or developmental disability.

2

Continue and expand collaborative surveillance and data collection efforts.

CDC Epilepsy Program Activities

Funded and/or facilitated:

- Epidemiological studies to better understand epilepsy incidence, prevalence, and associated disability across the life span.
- Surveillance across select states and jurisdictions on SUDEP, pediatric rare epilepsy burden, and intellectual and developmental disabilities among specific populations.

Expanded surveillance through:

- Addition of epilepsy-related questions on public health surveys.
- Data collection on epilepsy across specific populations, such as children with autism and/or intellectual and developmental disabilities.
- Data collection to understand knowledge, experiences, and attitudes about epilepsy.
- Data collection to understand co-occurring conditions, morbidity, and mortality.

Output

Multiple publications and national, state, or local presentations on:

- National and state-level estimates of epilepsy prevalence
- Mortality among subgroups of people with epilepsy (e.g., adults, children, veterans).
- Case identification and referrals to supportive services among children with epilepsy in schools.
- Physical and mental co-occurring conditions.
- Race/ethnic disparities in access to care.
- Burden of epilepsy associated with Zika virus.
- SUDEP in infants and children.
- Cost burden of epilepsy.
- Epilepsy stigma.

Impact

Disseminating Science:

Advanced understanding of epilepsy data sources, underutilized epilepsy data sources, and epilepsy burden trends across different populations.

For more information, see Appendix B (page 49–50) and Appendix C (pages 56–58).

Highlights

CDC has been instrumental in the inclusion of epilepsy-related questions in surveillance systems and population surveys and has co-led analysis of epilepsy-related data in other publicly available population or administrative data sets. Some examples of population data sources used to advance epilepsy knowledge include:

- Autism and Developmental Disabilities Monitoring Network.

- Medicaid data (select states and years).
- Medical Expenditure Panel Survey.
- National Child Death Review Case Reporting System.
- National Health Interview Survey.
- National Survey of Children’s Health.
- National Survey of Children with Special Health Care Needs.
- National Violent Death Reporting System.
- School Health Profiles surveys.
- Porter Novelli DocStyles survey.
- Porter Novelli HealthStyles survey.
- Sudden Death in the Young Case Registry (state/jurisdiction level).
- US Zika Pregnancy and Infant Registry.
- Wide-ranging ONline Data for Epidemiologic Research (WONDER) mortality files.

Examples of expanded collaboration within and across CDC include:

- Epilepsy Program and National Center for Injury Prevention collaboration on analysis of suicide burden in epilepsy using the National Violent Death Reporting System.
- Epilepsy Program and the Division of Reproductive Health collaboration with external partners, including the National Center for Child Death Review, to examine causes of death.
- Epilepsy Program and National Center on Birth Defects and Developmental Disabilities collaboration on guidance related to tracking epilepsy burden associated with Zika virus infection.
- Epilepsy Program and School Health Program collaboration for the inclusion of epilepsy questions in the 2014, 2016, 2017, and 2018 CDC School Health Profiles surveys.
- Epilepsy Program and National Center for Health Statistics collaboration for the inclusion of epilepsy questions on the 2010, 2013, 2015, 2017, 2021, and 2022 National Health Interview Survey to examine epilepsy burden.

- Epilepsy Program and CDC Office of Communication collaboration to support data collection from the 2013 HealthStyles survey to examine attitudes toward epilepsy in the US population.
- Epilepsy Program and CDC Office of Communication collaboration to support data collection from the 2017 HealthStyles survey to examine knowledge about epilepsy and seizure first aid in the US population.
- Epilepsy Program and CDC Office of Communication collaboration to support data collection from the 2018 DocStyles survey to examine general practitioners' experiences and attitudes toward referral of epilepsy patients to specialty care.

IOM Recommendation 4: Early Identification

The IOM recommended collaborations between professional organizations and relevant federal agencies, including CDC, to promote and disseminate screening programs or protocols to identify epilepsy in populations at high risk, epilepsy comorbidities, and patients with poorly controlled epilepsy.

Since 2012, the CDC Epilepsy Program has supported cooperative agreements and activities to examine epilepsy risk factors, ascertain co-occurring conditions among children and adults with epilepsy, implement validated screening tools to identify populations at high risk, and develop validated instruments to assess epilepsy self-management behaviors.

4

Improve the early identification of epilepsy and its comorbid health conditions.

CDC Epilepsy Program Activities

Funded and/or facilitated:

- Data collection on epilepsy incidence, co-occurring conditions, and risk factors.
- The inclusion of epilepsy screening among children with Zika virus.
- The Epilepsy Foundation to use the Patient Health Questionnaire-2 for depression screening²⁴ and to implement a behavioral health referral process in its Informational and Referral hotline and across local chapters.
- Small Business Innovation Research projects to develop novel point-of-care neurocysticercosis screening tools.
- The Managing Epilepsy Well (MEW) Network to develop and validate a standardized self-management screening tool.

Analyzed:

- The burden of co-occurring conditions in adults and children with epilepsy.
- The burden of co-occurring conditions and early mortality in Gulf War veterans.
- The burden of psychiatric and physical co-occurring conditions.

Output

- Increased screening and referral for depression.
- Increased number of referrals to epilepsy services and supports.

- Availability of a validated epilepsy self-management screening instrument
- Progress in identifying an aptamer-based screening tool to detect neurocysticercosis.

Impact Catalyzing Action:

The development of screening tools and coordinated screening protocols led to increased identification of common co-occurring conditions and referrals to appropriate services. Implementation pilots demonstrated feasibility for scaling up within other communities.

For more information, see Appendix B (page 51) and Appendix C (pages 62–63).

Highlights

The CDC Epilepsy Program funded the use of multiple, large, population-based data sources to identify physical and mental comorbidities among people with epilepsy. For example, CDC-funded researchers used CDC-supported Medical University of South Carolina Epilepsy Surveillance System data to examine co-occurring conditions among 120,129 people with epilepsy.²⁵ They found that:

- Black adults with epilepsy had significantly higher prevalence of diabetes, cardiovascular diseases, HIV/AIDS, alcoholism, and schizophrenia.
- People with epilepsy residing in rural communities had a significantly higher burden of co-occurring conditions than their counterparts living in urban communities.
- More than half of people with epilepsy had a median household income of less than \$36,000 for a family of four.
- Families of four with a median household income of less than \$36,000 had a 2.5 times higher risk of co-occurring conditions than families of four with a median household income of more than \$54,000.

In another study, CDC-funded researchers from Case-Western Reserve University used five years of Medicaid claims data from 16 states to identify the burden of racial and ethnic disparities among people with epilepsy.²⁶ Among 81,963 people with epilepsy who used Medicaid:

- The most common co-occurring conditions were anxiety and mood disorders (46.5%), hypertension (36.9%), back problems (35.2%), developmental disorders (31.6%), and headache (29.5%).
- American Indian or Alaska Native people with epilepsy had substantially higher prevalence of developmental disabilities.
- Black people with epilepsy had higher prevalence of hypertension.

- High users of Medicaid had much higher disease burden, with 75.8% having an anxiety or mood disorder.
- High users of Medicaid had a higher burden of injuries.

These and other research studies revealed disparities by race and ethnicity, geographical location, income, and Medicaid use among people with epilepsy. These findings can help focus the intervention strategies needed to promote health equity and improve quality of life among populations affected by disparities.

POLICIES AND PARTNERSHIPS TO MOBILIZE AND STRENGTHEN

IOM Recommendation 7: Health Professional Education

The IOM recommended that CDC collaborate with other organizations to support the development and evaluation of educational materials and training approaches that reflect best practices for interdisciplinary health professionals who care for people with epilepsy.

Since 2012, the CDC Epilepsy Program has funded three nonresearch and three research cooperative agreements for the development and dissemination of evidence-based educational materials or training programs designed to reach different professional populations, such as primary care providers, first responders, behavioral health providers, school nurses, community health workers, and other groups. CDC has also supported Project Extension for Community Healthcare Outcomes (ECHO) pilots to train general practitioners on best practices for epilepsy management.²⁷

7 Improve health professional education about the epilepsies.

CDC Epilepsy Program Activities

- Funded three non-research cooperative agreements with the Epilepsy Foundation to:
 - Develop epilepsy education materials for multidisciplinary health care professionals, school nurses, educators, and first responders.
 - Implement a Project ECHO pilot to train general practitioners on epilepsy best practices.
 - Implement a Project ECHO pilot to train school nurses on epilepsy best practices.
- Partnered with national organizations to develop the first community health worker curriculum on epilepsy self-management.
- Funded a research cooperative agreement to determine the efficacy of the integration of community health care workers in epilepsy clinics to improve health and social outcomes.
- Funded three research cooperative agreements to support training of MEW Network program facilitators.
- Supported multiple provider training sessions at national conferences (e.g., American Epilepsy Society) and provider training webinars through partnerships (e.g., National Association of County Behavioral Health and Disability Directors).
- Participated in podcasts and community forums to reach community-based providers with information on epilepsy management.

Output

- Novel, feasible, and effective epilepsy training curriculums for behavioral health providers, community health workers, and other groups.
- Evidence of feasibility and effectiveness of Project ECHO to address gaps in access to epilepsy specialty care for potential scale-up.
- Training for over 270 MEW Network program facilitators.
- Training for at least 150 community health workers.
- Improved awareness and understanding among providers of epilepsy care and unmet medical and social needs.
- Accreditation of the Texas Department of Health Services to carry out the CDC-developed community health worker epilepsy self-management curriculum.

Impact

Effecting Change:

The implementation of education and novel training programs funded and developed by CDC expanded their reach to general and specialized practitioners, community health workers, and other community service providers, such as school nurses and first responders. These programs improved provider knowledge, increased provider confidence, and helped dispel common misconceptions about epilepsy.

For more information, see Appendix B (pages 51–52) and Appendix C (page 64).

Highlights

Epilepsy is a complex disorder that requires specialized medical knowledge to support an accurate diagnosis and an appropriate treatment plan. Unfortunately, the United States has a shortage of epilepsy specialists, and research indicates that more than half of people with active epilepsy who do not take medication for their seizures have only been seen by a primary care provider.²⁷ This shortage of specialists, which is expected to continue, has created an urgent need to train primary care providers on epilepsy best practices in diagnosis, treatment, and referral.^{1,27}

To close this gap, the CDC Epilepsy Program provided support to the Epilepsy Foundation and the University of Cincinnati to assess the effectiveness of a telementoring program to help primary care providers deliver best-in-practice neurology and epilepsy care. This program, called Project ECHO, was originally created to improve the treatment of patients with hepatitis C in rural communities.²⁸ For this pilot program, Project ECHO was adapted to connect primary care providers with a panel of clinical epilepsy specialists using case-based learning delivered through videoconferencing.

Project ECHO for Epilepsy and Neurology consisted of 10 one-hour sessions each month from September 2018 (year 1) to July 2020 (year 2). A total of 164 primary care providers from Ohio and surrounding states participated.²⁷ Each session included an average of 28 participants and the following four components:

- A 20-minute presentation by a neurology expert.
- Case presentations by the participants.
- A discussion period between participants and the specialist panel.
- A briefing to summarize the discussion and identify recommendations for next steps.

Of the 164 primary care providers, nearly 3 in 4 reported seeing at least one patient with epilepsy each week, and 1 in 5 reported seeing 16 or more adult patients with epilepsy each week.²⁷ After completing the program, 97% of participants reported higher interest in improving their care of patients with epilepsy, and more than 98% reported feeling more comfort and self-efficacy for treating epilepsy.²⁷ The primary care providers credited the success of the program to their ability to actively engage in discussions focused on specific topics, such as recommended screening tools and the latest research in epilepsy treatment.

From 2018 to 2021, Project ECHO pilots trained over 900 primary care and advanced practice providers and nearly 250 school nurses (**Appendix C**, page 64). In 2021, the CDC Epilepsy Program provided funding to the Epilepsy Foundation in collaboration with the University of Cincinnati and the American Academy of Pediatrics to adapt Project ECHO for rare epilepsies. By supporting an evidence-based bridge to close the gap in specialty care providers, CDC has promoted a step forward in improving care for all people with epilepsy.

CDC also supported the Epilepsy Foundation to reach school nurses with traditional in-person and online training programs. Through their Managing Students with Seizures and Seizure Training for School Nurses: Caring for Students programs, the Epilepsy Foundation reached over 75,000 school nurses from 2011 to 2021.

IOM Recommendation 8: Delivery and Coordination of Services

The IOM recommended that CDC collaborate with the Epilepsy Foundation and other partners to foster collaboration among community-based organizations in order to enhance access to local educational and community services and resources to meet both the health and social needs of people with epilepsy. This recommendation also called for efforts to develop and disseminate educational and training opportunities for community service providers focused on epilepsy awareness and seizure first aid training.

Since 2012, the CDC Epilepsy Program has funded three 5-year, nonresearch cooperative agreements supporting the Epilepsy Foundation and other community-based organizations to improve the delivery and coordination of services, especially among populations with unmet needs. This funding has had significant influence in expanding access and connection to community service delivery for thousands of people with epilepsy to address unmet social needs and self-management support. Through two 2020 research cooperative agreements, CDC supported intervention research to train and engage clinic-based community health workers to improve health and social outcomes for adults with epilepsy.

In 2021, CDC funded the Epilepsy Foundation and new partners (American Epilepsy Society, National Association of School Nurses, Epilepsy Association of Western and Central Pennsylvania, and Epilepsy Foundation New England) to enhance the delivery and coordination of care, including developing, implementing, and evaluating protocols with bidirectional links between community and clinical providers in select communities.

8

Improve the delivery and coordination of community services.

CDC Epilepsy Program Activities

Funding to the Epilepsy Foundation has:

- Expanded access to community services through a 24/7 referral hotline accessible in English and Spanish and through virtual community networks.
- Trained information specialists and community service providers on assessment and intervention skills, such as suicide prevention, first aid training, and self-management tools.
- Created a Seizure Recognition and First Aid certification for the public.
- Expanded the number and type of epilepsy-related courses in an on-demand Learning Management System.
- Provided education to multiple sectors of the community, including employers, school personnel and students, and transportation providers (in collaboration with the National Association of School Nurses and select Epilepsy Foundation local offices).
- Developed partnerships with faith-based organizations.
- Expanded access to evidence-based epilepsy self-management programs in multiple communities.

Output

- Accredited 24/7 English and Spanish information and referral hotline with updated information on community-based resources.
- First online seizure recognition and first aid certification training for the general public.

- Extended reach to individuals and communities.
- Implementation of at least 70 MEW Network pilots in local communities.
- Increased understanding of the needs of people with epilepsy.

Impact Catalyzing Action:

Funding from the CDC Epilepsy Program resulted in enhanced capacity to provide the following: updated information about local services and resources to people with epilepsy; new research to integrate community health workers into epilepsy care; new community-based partners to expand outreach to people with epilepsy and their families; increased availability of evidence-based epilepsy self-management programs in communities; and increased capacity to reach people with epilepsy, their support persons, and the general public with seizure first aid training and general awareness of epilepsy to improve knowledge and attitudes about epilepsy.

For more information, see Appendix B (page 52) and Appendix C (page 64).

Highlights

Through multiple cooperative agreements from 2011 to 2026 (**Appendix B**, page 52), the CDC Epilepsy Program funded the Epilepsy Foundation to lead efforts to improve the delivery and coordination of community services. With this support, the Epilepsy Foundation:

- Conducted a needs assessment survey of 1,029 adults with epilepsy and their caregivers, resulting in improved understanding of their concerns about personal safety, inability to pay for medical expenses, inadequate health insurance coverage, lack of knowledge about epilepsy medication, and difficulties finding jobs and maintaining personal relationships.
- Helped approximately 100,000 people with epilepsy from 2011 to 2022 through its 24/7 English and Spanish information and referral hotline. These efforts included:
 - Implementing the first depression screening (using the Patient Health Questionnaire-2²⁴) and referral protocol for the 24/7 helpline, providing at least 10,000 mental health referrals.
 - Training information and referral helpline information specialists in the Applied Suicide Intervention Skills program.
- Implemented the Seizures and Youth: Take Charge programs to decrease stigma, reaching more than 103,000 middle and high school students and teachers.
- Implemented the Seizure Training for School Personnel program in person and online, reaching more than 720,000 school personnel across the United States.
- Implemented Signature Programs in person and online to educate more than 47,000 law enforcement personnel, emergency medical service providers, senior caregivers,

and childcare workers about epilepsy and seizure first aid from 2011 to 2021. The Epilepsy Foundation funded 16 of its local offices to enhance its reach in rural and underserved areas, reaching nearly 3,800 emergency medical services providers, law enforcement personnel, and senior caregivers.

- Implemented a faith-based organization educational program in eight local offices, reaching 10,394 people with epilepsy.

IOM Recommendation 9: Educational Opportunities for Patients and Families

The IOM recommended that CDC collaborate with organizations to develop and increase access to accurate, up-to-date, clear, and culturally and linguistically appropriate educational materials for a diverse spectrum of people with epilepsy and their families. This recommendation called for efforts to support the development, evaluation, replication, and expanded use of self-management and educational programs, including those developed through the MEW Network.

Since 2012, the promotion of high-quality educational materials for all people with epilepsy and their families has been the bedrock of CDC activities. Notably, collaborations with the MEW Network and the Epilepsy Foundation have led to increased awareness and effective self-management of epilepsy across multiple communities.

9 Improve and expand educational opportunities for people with epilepsy and their families.

CDC Epilepsy Program Activities

Promoted self-management programs through:

- Funding for the MEW Network to develop, evaluate, and disseminate effective epilepsy programs for different subgroups of people with epilepsy (e.g., based on age group, comorbidity, or race/ethnicity).
- Expanded funding for the MEW Network to replicate effective programs.
- Providing free MEW Network provider training programs to increase program adoption.
- Launching the MEW Network website for patients and providers with information about, resources for, and referral to community-based MEW Network programs.
- Developing a MEW Network webinar series for multiple audiences.
- Funding local Epilepsy Foundation offices to build capacity to implement MEW Network programs to serve people with epilepsy.

Increased epilepsy educational resources and opportunities through:

- Funding for the Epilepsy Foundation to:
 - Develop culturally and linguistically appropriate educational materials for select racial/ethnic communities.
 - Improve epilepsy knowledge and social support among culturally diverse communities through broad and focused activities (e.g., Now I Know!,

#BackToSchool, and StoryDays campaigns; outreach to veterans and Asian Americans).

- Assess epilepsy educational brochures for health literacy and update select documents to meet plain language guidance.
- Enhance capacity of its online Learning Management System with new or updated content (e.g., Epilepsy 101, Seizure First Aid certification) and functionality (e.g., new portal).

Output

- Implementation of multiple campaigns focused on people with epilepsy and their families, caregivers, and communities.
- Expanded access to evidence-based epilepsy self-management tools and resources in multiple communities across the United States.
- Increased number of resources that met health literacy and plain language guidance.
- Increased use of online self-management resources.
- Increased number of providers trained to deliver epilepsy self-management guidance or programs in communities.
- Increased course enrollments in the Epilepsy Foundation Learning Management System.

Impact *Creating Awareness and Effecting Change:*

CDC support for the development, evaluation, and dissemination of evidence-based self-management programs has helped close scientific gaps in the field. The number of evidence-based epilepsy self-management programs supported by the MEW Network increased from three in 2012 to 8 by 2022. Each program is designed to meet the spectrum of needs of people with epilepsy. Providing funding for local program delivery of evidence-based MEW Network programs demonstrated initial feasibility of community, provider, and patient buy-in for these programs as important elements of epilepsy education and care. This has increased the number of communities offering evidence-based epilepsy self-management programs.

Enhanced functionality and content of the Epilepsy Foundation online Learning Management System became a timely resource for reaching people interested in learning more about epilepsy during the COVID-19 pandemic. These efforts have promoted the use of effective self-management tools, increased access to and quality of educational resources, and may have reduced misinformation and stigma surrounding epilepsy.

For more information, see Appendix B (page 53) and Appendix C (page 64).

Highlights

Originally established in 2007 as part of CDC’s Prevention Research Centers (PRC) program, the MEW Network’s mission is to lead the development and evaluation of epilepsy self-management programs to close long-standing gaps in the field.^{29,30} Consistent with community-based research principles that underlie the PRCs, the MEW Network engages with epilepsy patients, providers, and public health professionals to ensure that its programs are patient-driven and meet community needs. Over the years, the MEW Network has included 2 to 8 PRCs. Partners have included local and national organizations, such as the Epilepsy Foundation, the American Epilepsy Society, and since 2021, Epilepsy Alliance America.

MEW Network programs are generally 8 to 29 weeks long. They are delivered by trained and licensed providers and, in some cases, trained peers with epilepsy. The programs are delivered online or by phone to eliminate barriers to care (e.g., transportation, stigma associated with mental health care). Building on the three epilepsy self-management program efficacy studies conducted before 2012 (WebEase, UPLIFT, PEARLS),²⁹ the CDC Epilepsy Program supported 12 randomized controlled trials to determine initial efficacy and later effectiveness of 11 programs from 2012 to 2022 (**Appendix B**, page 53 and **Appendix C**, pages 59–62 and 64). Specifically, the trials assessed efficacy of new programs (e.g., SMART) and program effectiveness in different subgroups (e.g., UPLIFT among African American and Hispanic adults with epilepsy) to determine improvements in knowledge, self-management, self-efficacy, seizure management, seizure frequency, and positive mood.³⁰ Overall, the CDC MEW Network has found eight programs to be effective:

- **HOBSCOTCH** (HOMe-Based Self-management and COgnitive Training CHanges Lives), an online memory and attention program for adults with epilepsy.
- **MINDSET** (Management Information & Decision Support Epilepsy Tool), a tablet-based clinical decision tool for adults with epilepsy available in both English and Spanish.
- **PACES** (Program for Active Consumer Engagement in Epilepsy Self-management), an in-person or phone-based program to help adults with epilepsy learn strategies for emotional and community adjustment.
- **PEARLS** (Program to Encourage Active, Rewarding Lives), a program to manage depression and improve quality of life among older adults.
- **SMART** (Self-Management for People with Epilepsy and a History of Negative Health Events), a phone-based and online program using peer support to teach health-enhancing behaviors and skills to adults with poorly controlled epilepsy.
- **TIME** (Targeted Self-Management for Epilepsy and Mental Illness), a person-centered program for adults with epilepsy with depression.
- **Project UPLIFT** (Using Practice and Learning to Increase Favorable Thoughts), a phone-based program to improve the mental health and quality of life in adults with epilepsy available with both English- and Spanish-speakers.
- **WebEase (Web Epilepsy Awareness Support and Education)**, an online program incorporating elements of behavioral science change theories and motivational interviewing to improve medication adherence, stress management, and sleep management.

Two programs were evaluated among adolescents or young adults with epilepsy (FOCUS on Epilepsy and YESS), but neither study was able to recruit a sufficient sample size to complete

the randomized controlled trial. An additional program, PAUSE (Personalized Internet Assisted Underserved Self-Management of Epilepsy) was found to be promising (**Appendix C**, page 60).

CDC provided support to the Epilepsy Foundation to implement these programs through its network of offices across the United States. From 2013 to 2021, the Epilepsy Foundation implemented 74 MEW Network pilot sites, resulting in over 600 adults who completed a program (i.e., participants who participated in at least 6 of 8 sessions) (**Figure 7**).

In 2022, CDC is continuing its evaluation of MEW Network programs for adaptability across different populations of focus (e.g., rural-dwelling adults, Spanish-speaking adults). CDC also supported the development and dissemination of culturally appropriate educational materials through its cooperative agreements with the Epilepsy Foundation (**Figure 8**). From 2012 to 2021, these efforts reached hundreds of thousands of patients with epilepsy and their family members.

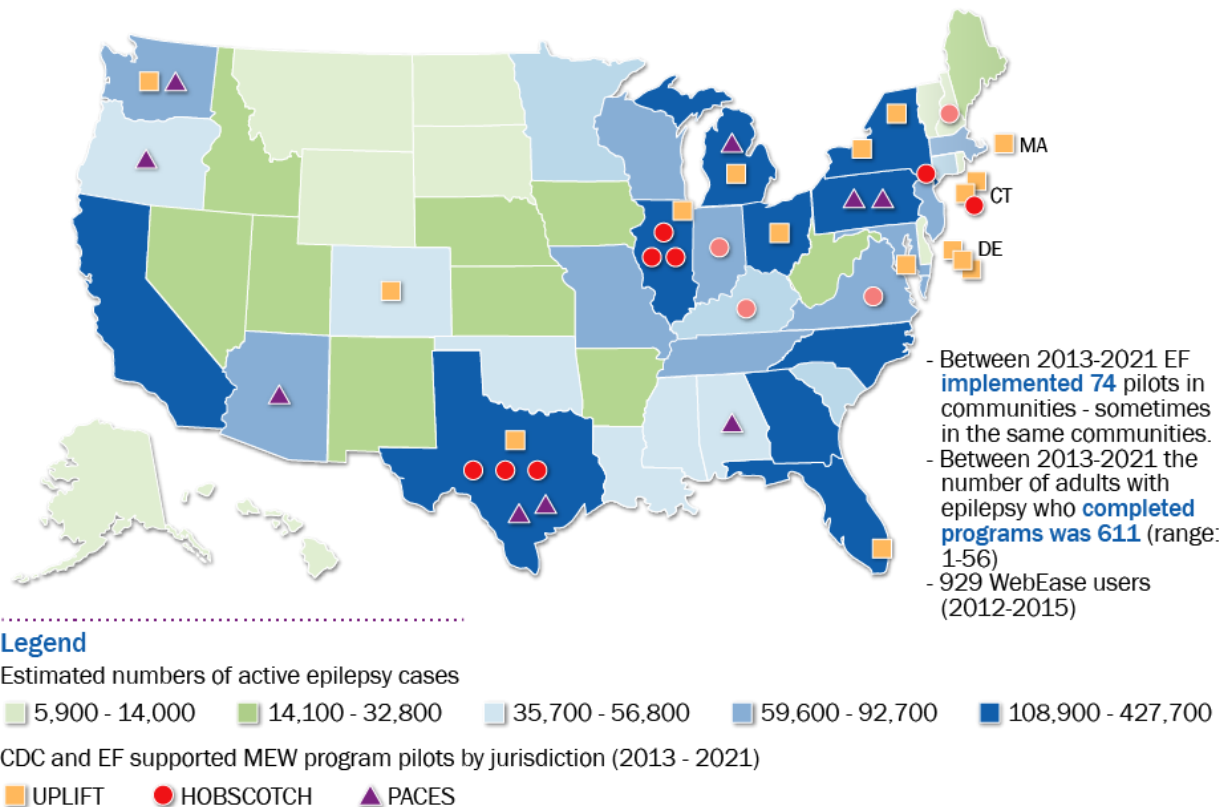


Figure 7. General scope and location of MEW Network program implementation.

Note: Not all 74 pilot programs are represented in this figure.



Figure 8. Select accomplishments from 2011–2016 and 2016–2021 Epilepsy Foundation cooperative agreements.

IOM Recommendation 11: Public Awareness Efforts

The IOM recommended that CDC lead efforts to measure public awareness and knowledge about epilepsy, and collaborate with partners to implement large-scale, multimedia, sustainable public awareness campaigns to improve the public’s understanding of epilepsy and reduce stigma.

Since 2012, CDC has supported several studies to monitor and improve public knowledge and attitudes about epilepsy.^{21,31–33} CDC has also supported the Epilepsy Foundation and its communication partners (e.g., CBS Partnerships Division, Univision, iHeartMedia, NativeAmericaCalling.com) to implement public awareness campaigns, both for the general public and populations of focus (**Appendix B**, page 54). Specifically, the use of diverse communication channels has ensured a wide reach to different age groups and cultures. Additionally, CDC coordinated at least 13 features on epilepsy that were spotlighted on CDC’s home page and disseminated through a listserv of over 50,000 subscribers. CDC also coordinated four CDC radio podcasts featuring results published in the CDC *MMWR* (**Appendix C**, page 65).

11

Coordinate public awareness efforts.

CDC Epilepsy Program Activities

Funded cooperative agreements with the Epilepsy Foundation to:

- Support public awareness campaigns for both the general public and populations of focus (e.g., Asian Americans, youth, seniors, childcare personnel).
- Develop and conduct education, awareness, and first aid campaigns using multiple communication channels, including CBS, iHeartMedia, Univision, and Hispanic Communications Network.

CDC intramural activities included:

- Funding for a research cooperative agreement to develop and test new communication strategies to reduce epilepsy stigma.
- Distribution of press releases to highlight epilepsy burden, prevention, and available resources.
- Promotion of a national epilepsy observance month through multiple communication channels.
- Coordination of a special issue of the *American Journal of Public Health*³⁴ on stigma, featuring an editorial co-authored by former Representative Tony Coehlo, former First Lady Rosalynn Carter, and former US Surgeon General Dr. David Satcher that described epilepsy stigma. Also participated in a media event with Tony Coehlo and Rosalynn Carter at The Carter Center.
- Publication of newsletter for more than 50,000 subscribers, featuring CDC programs, science, and partners.
- Distribution of epilepsy information to teachers and students via CDC’s BAM! Body and Mind website.
- Sharing of informational resources via CDC social media, podcasts, and media interviews.

Output

- An effective intervention shown to improve attitudes about epilepsy.
- A systematic review of strategies and effectiveness of past epilepsy anti-stigma interventions.
- Increased epilepsy content across various media and communications channels.

Impact

Creating Awareness:

Through multiple CDC-supported Epilepsy Foundation public awareness campaigns, efforts resulted in expanded epilepsy and seizure first aid content reaching millions in diverse communities across the nation.

For more information, see Appendix B (page 54) and Appendix C (page 65).

Highlights

CDC supported the development of culturally appropriate public awareness campaigns to raise awareness of epilepsy and seizure first aid through its cooperative agreements with the Epilepsy Foundation. These campaigns were intended to increase understanding of epilepsy, reduce hesitation in responding to a seizure, and reduce negative public perceptions. Examples of these campaigns are shown in **Figures 9 and 10**.

- Through two cooperative agreements with the Epilepsy Foundation from 2011 to 2021, the CDC Epilepsy Program supported multiple public awareness campaigns designed for both the public and populations of focus.
- In 2013, CDC supported a 26 Days of Epilepsy Awareness campaign, encouraging all Americans (and Asian Americans in particular) to learn, discuss, and share stories about epilepsy. This campaign, in both English and Chinese, reached six key communities and nearly 3 million people across the United States.
- In 2014, the CDC supported the Epilepsy Foundation’s #DareTo (Learn More) social media campaign that launched during National Epilepsy Awareness Month. This campaign challenged the public to better understand epilepsy, recognize seizures, and learn proper first aid, with focused efforts to reach Asian American and African American populations.
- In 2015, the Epilepsy Foundation’s MEW Network participated in an American Broadcasting Company (ABC) News Twitter chat that generated nearly 16 million impressions.
- From 2016 to 2021, the Epilepsy Foundation launched a new collaboration with the CBS Community Partnerships Division to create the #ShareMySeizure campaign. This campaign educated the public about seizures and first aid using television, email, and social media platforms. In its first year, the campaign reached more than 18 million people in Chicago and Los Angeles. By 2021, it had reached more than 150 million people in Chicago, Atlanta, Philadelphia, Tampa, and Los Angeles.

The Epilepsy Foundation joins Asian American communities in raising awareness about epilepsy. #DareTo learn, talk, and share your story.

Seizures and Epilepsy in African Americans
 African-American History Month
 Nearly 375,000 African Americans have epilepsy. #DareTo Learn More at epilepsy.com/african-american.

Community Corner: #DareTo Learn More, February 4, 2015
 Wednesday, February 4, 2015
 Seizures and epilepsy occur in 2.8 million Americans and 65 million people worldwide. In the United States, about 375,000 African Americans at a time and over 20,000 each year are diagnosed with epilepsy.

Seizure First Aid
 How to help someone having a seizure

தலைநகர் தலைநகர் தலைநகர்
 தலைநகர் தலைநகர் தலைநகர்
 தலைநகர் தலைநகர் தலைநகர்

Learn more: epilepsy.com/firstaid

EPILEPSY FOUNDATION
 END EPILEPSY TOGETHER

24/7 Helpline: 1-800-332-1000

Figure 9. Public awareness campaigns for select populations.

Seizure First Aid
 How to help someone having a seizure

- 1 STAY** with the person until they are awake and alert after the seizure.
 - Time the seizure
 - Remain calm
 - Check for medical ID
- 2 Keep the person SAFE.**
 - Move or guide away from harm
- 3 Turn the person onto their SIDE** if they are not awake and aware.
 - Keep airway clear
 - Loosen tight clothes around neck
 - Put something small and soft under the head

Call 911 if...

- Seizure lasts longer than 5 minutes
- Person does not return to their usual state
- Person is injured, pregnant, or sick
- Required seizure
- First time seizure
- Difficulty breathing
- Seizure occurs in water

Do NOT

- Do NOT restrain
- Do NOT put anything in the mouth

#ShareMySeizure

He's having a seizure. Would you know what to do?

LEARN FIRST AID

What's Your Story?
 #ShareMySeizure

1 in **26** people in the United States will develop epilepsy at some point in their lives

Figure 10. Campaigns and media products to raise awareness of epilepsy.

- In 2016, CDC supported a literature review to describe misconceptions about epilepsy across Europe, Australia, and North, Central, and South America. The review identified common misconceptions and potential interventions for improving knowledge and attitudes.³¹
- In 2017, CDC supported a pilot study to determine the effectiveness of two brief stigma-reduction videos to reduce stigmatizing attitudes and negative stereotypes. A total of 295 participants watched the videos and completed a web-based survey. The videos were shown to improve knowledge and attitudes about epilepsy.³²
- In 2020, the Epilepsy Foundation translated a Seizure First Aid poster into three Native languages: Cherokee, Navajo, and Lakota. This poster was advertised digitally and in Native American print newspapers, including the *Cherokee Phoenix* and the *Native America Calling*. The foundation also developed social media posts for Native American Heritage Month, using culturally relevant and appropriate Native American and epilepsy images.
- In 2021, CDC supported the Epilepsy Foundation’s partnerships with iHeartMedia, Univision, and Hispanic Communications Network to raise awareness about epilepsy and to promote an English/Spanish Seizure First Aid certification program. The iHeartMedia campaign launched in Alaska, North Carolina, Indiana, Alabama, and the District of Columbia, resulting in an estimated 1.6 million impressions through 386 radio spots within 2 months. An email campaign reached an additional 20,000 people. The Univision campaign promoted 255 radio spots, generating more than 1.6 million impressions in California, Florida, New York, and Arizona. Univision’s digital platform also generated nearly 900,000 impressions. The Hispanic Communications Network promoted radio spots with 210 radio affiliates that generated over 2.3 million impressions and published an article in 16 newspapers that generated more than 1 million impressions. The CDC Epilepsy Program has funded the Epilepsy Foundation to continue these media campaigns through 2026.

IOM Recommendation 13: Engage People With Epilepsy

The IOM recommended that people with epilepsy and their families actively participate in research, surveillance, education, and awareness activities and advocate for improvements in care by sharing their experiences and communicating their needs and preferences.

Community engagement is fundamental to public health practice. Since 2012, the CDC Epilepsy Program has ensured that people with epilepsy and their families have opportunities to engage in the planning, implementation, and evaluation of both research and nonresearch activities and continues to promote inclusiveness across all cultures and communities.

13 Engage in education, dissemination, and advocacy for improved epilepsy care and services.

- CDC Epilepsy Program Activities**
- Funded the Epilepsy Foundation to create Community Action Boards in multiple states.
 - Engaged people with epilepsy, their support persons, and/or their providers in the development and testing of epilepsy self-management programs and community health worker interventions.
 - Developed eight evidence-based epilepsy self-management programs with input from people with epilepsy.

- Output**
- Increased community involvement in the development of research studies and best practices.
 - Improved cultural awareness across specific communities at high risk.

Impact *Shaping the Future and Effecting Change:*

The CDC Epilepsy Program incorporates the lived experiences, needs, and preferences of people with epilepsy and their families into research, education, outreach, and evaluation activities—ensuring that these activities promote community inclusion and reduce isolation and stigma.

For more information, see Appendix B (page 54) and Appendix C (page 66).

EVALUATION AND STRATEGY TOWARD EFFECTIVENESS AND IMPROVEMENT

IOM Recommendation 3: Prevention Efforts

The IOM recommended that CDC partner with other organizations to develop and evaluate prevention efforts focused on risk factors for epilepsy and common outcomes of epilepsy.

Since 2012, the CDC Epilepsy Program has supported three levels of prevention: primary (preventing risk factors), secondary (screening to identify disease early), and tertiary (managing post-diagnosis) prevention.

3 Develop and evaluate prevention efforts for epilepsy and its consequences.

- CDC Epilepsy Program Activities**
- Collaborated with academic or nonprofit partners and other CDC programs to:
- Develop guidance for the management of risk factors for seizures, such as traumatic brain injury.
 - Fund multiple Small Business Innovation Research biomedical contractors to develop and evaluate screening and diagnostic tools for neurocysticercosis, the most common and preventable cause of epilepsy worldwide.
 - Initiate behavioral health screening tools and protocols.
 - Develop and disseminate communication products to raise awareness of primary prevention of epilepsy by reducing known risk factors (e.g., stroke, head injury).
 - Enhance public awareness of and increased community participation for SUDEP prevention.

- Output**
- Increased communication products to prevent known epilepsy risk factors.
 - Development and implementation of systematic depression screening protocols and referral to mental health services.
 - Increased knowledge about aptamer-based screening approaches for neurocysticercosis detection.

Impact Effecting Change:

The CDC Epilepsy Program supported the first community-based depression screening protocol demonstrating feasibility for scale-up, the first depression screening protocol implemented in the Epilepsy Foundation information and referral hotline, and novel approaches to improve screening for neurocysticercosis detection.

For more information, see Appendix B (page 50) and Appendix C (pages 59–62).

Highlights

Since 2012, the CDC Epilepsy Program and Center for Global Health have collaborated to enhance capacity for neurocysticercosis prevention through multiple activities. **Neurocysticercosis (Figure 11)** is a preventable parasitic infection that is a leading cause of adult-onset epilepsy worldwide, accounting for nearly 30% of epilepsy cases in endemic areas³⁵ and up to 10% of emergency room seizure patients in areas of the United States with large immigrant populations.³⁶ **Taenia solium** is a preventable parasitic infection often acquired by eating contaminated food and another primary cause of epilepsy in endemic areas.³⁷

Laboratory tests to identify these infectious diseases have been inadequate. The CDC Epilepsy Program and Center for Global Health leveraged more than \$1 million in Small Business Innovation Research grants to fund researchers to develop and evaluate point-of-care neurocysticercosis screening tools for detecting *Taenia solium*. Their promising results will inform future studies to reduce the burden of neurocysticercosis in the United States and globally.

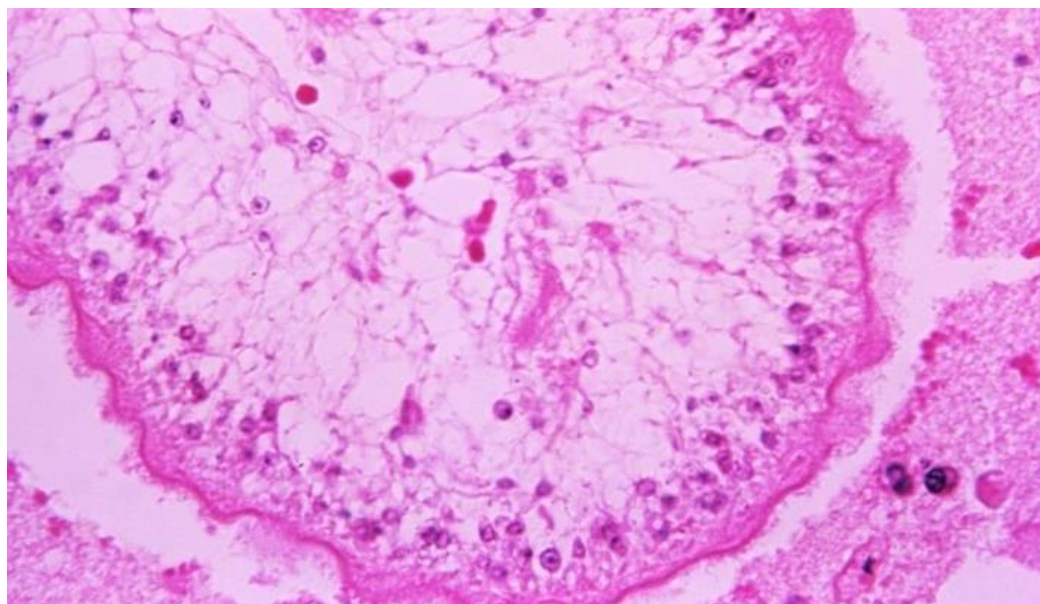


Figure 11. Neurocysticercosis infection in the brain.

*Note: Under a magnification of 400X, this photomicrograph of a brain tissue specimen revealed the presence of cysticerci in a case of cysticercosis, an infection caused by the ingestion of pork tapeworm *Taenia solium* eggs. Infestation of the brain tissue by larval tapeworms is known as neurocysticercosis.*

The CDC Epilepsy Program has also supported prevention strategies for traumatic brain injury—another common cause of epilepsy—through research and development of sports-related guidelines³⁸ and increased outreach to populations at high risk, such as veterans with traumatic brain injury.

IOM Recommendation 5: National Quality Measurement

The IOM recommended the development and implementation of performance metrics to track high-quality health care in epilepsy and to develop accountability and transparency to incentivize change.

Although this recommendation was not directed to CDC, the CDC Epilepsy Program and the National Center on Birth Defects and Developmental Disabilities developed the first Healthy People 2020 national objective for epilepsy focused on tracking access to specialty care and tracked its status through the last decade.

5 Develop and implement a national quality measurement and improvement strategy for epilepsy care.

CDC Epilepsy Program Activities

- Led the development of a Healthy People 2020 objective to increase the number of individuals with epilepsy who receive appropriate care.
- Tracked performance of the Healthy People 2020 epilepsy objective through the National Health Interview Survey.

Output

- First federally approved national objective on epilepsy.
- Data and public reports demonstrating trends in access to specialty care among adults with epilepsy.

Impact

Shaping the Future:

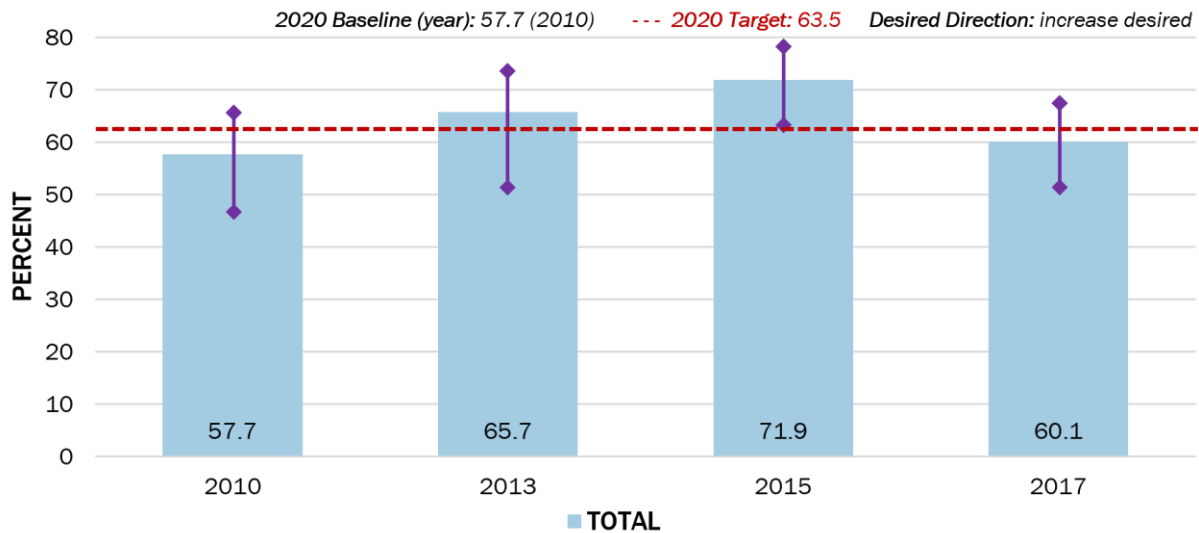
CDC's development of a Healthy People objective ensured that epilepsy was recognized as a public health imperative and that its progress was measured over the decade.

For more information, see Appendix B (page 51) and Appendix C (page 63).

Highlights

The CDC Epilepsy Program and the National Center on Birth Defects and Developmental Disabilities developed the first Healthy People 2020 national objective for epilepsy: to increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.

Using National Health Interview Survey data, CDC has tracked progress on this objective over the last decade. CDC found that the proportion of adults with epilepsy and uncontrolled seizures who received appropriate medical care increased from 57.7% in 2010 to 65.7% in 2013, exceeding the Healthy People 2020 target (**Figure 12**).



Data Source: National Health Interview Survey (NHIS), Centers for Disease Control and Prevention, National Center for Health Statistics (CDC/NCHS)
 Error Bar represents the 95% confidence interval

Figure 12. CDC tracking of progress against the Healthy People 2020 target for people with epilepsy and uncontrolled seizures.

IOM Recommendation 10: Information for Media

The IOM recommended that CDC collaborate with other epilepsy-relevant organizations to provide information to journalists, writers, and producers to help increase public knowledge about epilepsy and combat stigma.

Since 2012, the CDC Epilepsy Program has supported large, coordinated efforts to promote positive storylines about people with epilepsy and to educate the public about the disorder and reduce stigma associated with epilepsy.

10

Inform media to improve awareness and eliminate stigma.

CDC Epilepsy
Program
Activities

Supported cooperative agreements for the Epilepsy Foundation to:

- Design and conduct epilepsy awareness campaigns, including outreach to Spanish-speaking, African American, Native American, and Asian American populations.
- Include high-profile individuals with epilepsy to raise media awareness.

Published epilepsy information such as:

- Multiple press releases and articles for the general public on epilepsy data and research findings in CDC *MMWRs*.
- Annual notices of Epilepsy Awareness Month in *MMWRs*.
- Infographics on epilepsy and access to specialty care in *MMWRs*.
- Bi-monthly messages about epilepsy to 90,000 GovDelivery listserv subscribers.

Output

- National awareness efforts broadly diffused accurate and up-to-date information to populations of focus.

Impact

Creating Awareness:

The CDC Epilepsy Program's support for and development of media campaigns fostered increased visibility of epilepsy burden through multiple national and local media outlets reaching millions.

For more information, see Appendix B (pages 53–54) and Appendix C (page 65).

Highlights

The CDC Epilepsy Program coordinated and partnered with organizations to promote epilepsy awareness through different channels of the media and press.

In 2013, for instance, CDC partnered with The Carter Center to co-sponsor the *American Journal of Public Health's* special issue and commentary on health-related stigma, using epilepsy as a model³⁴ (**Figure 13**). The Carter Center coordinated a press event to promote the special issue, featuring former Representative Tony Coehlo, former First Lady Rosalynn Carter, and CDC staff.

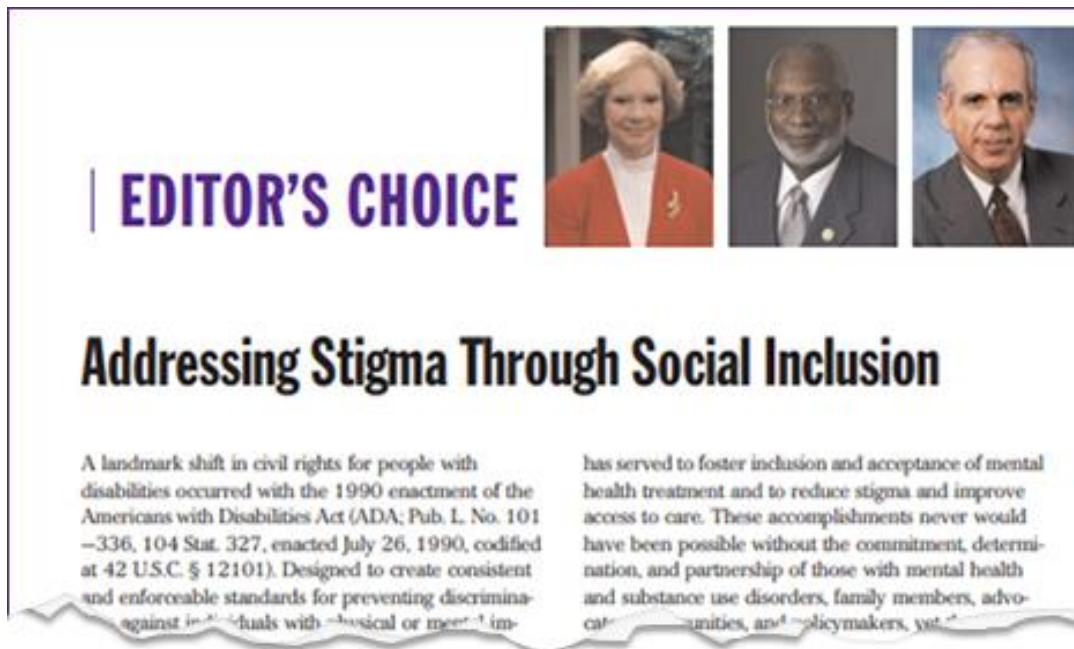


Figure 13. American Journal of Public Health Editor’s Choice article published on The Carter Center website.

In 2017, CDC’s *MMWR* office issued a press release focused on the updated national estimates and first-ever, state-level estimates of epilepsy prevalence among adults and children.¹ The press release highlighted that more Americans had epilepsy than ever before, and that the state-level data showed that its prevalence was widespread across the United States. Multiple media channels featured an article based on the press release, reaching millions (Figure 14).

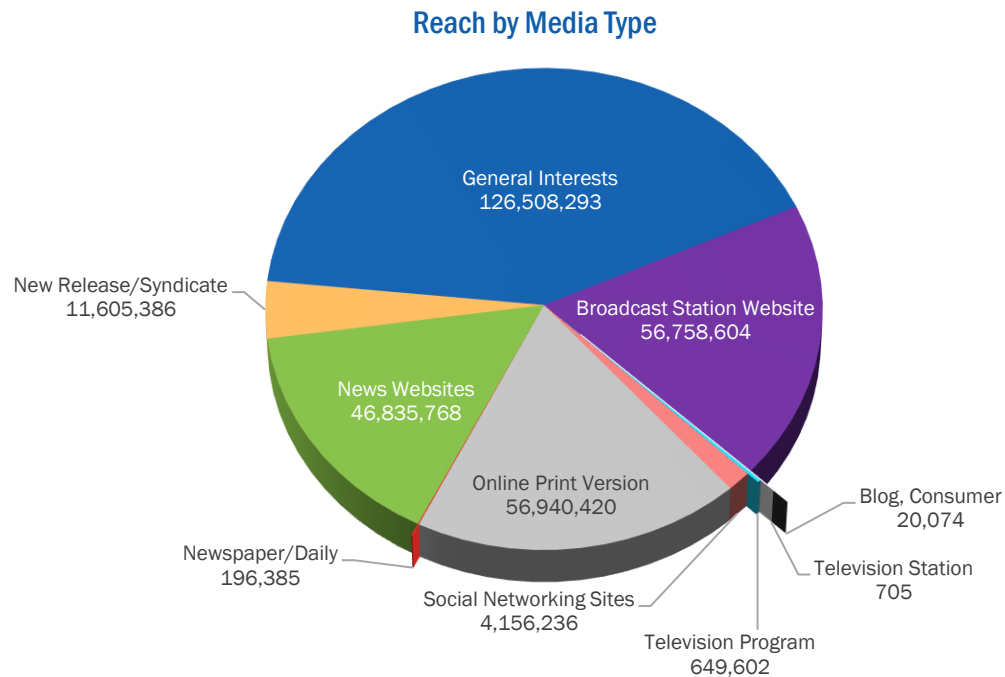


Figure 14. The wide reach across multiple media outlets from August 10 to September 10, 2017, of the CDC press release “Epilepsy prevalence, 2010–2015.”

IOM Recommendation 12: Vision 20-20 and ELC Partnerships

The IOM recommended that member organizations of Vision 20-20, later known as the Epilepsy Leadership Council (ELC), expand their ongoing collaborations and partnerships to align strategic planning and activities.

In the last decade, CDC has kept its collaborative partners regularly informed of programmatic activities and progress on meeting IOM recommendations through participation in ELC meetings, conference presentations, and ad-hoc workshops.

12

Continue and expand Vision 20-20 working groups and collaborative partnerships.

CDC Epilepsy Program Activities

- Participated in Vision 20-20 and ELC meetings to provide updates on CDC activities and research findings.
- Coordinated and finalized the US Department of Health and Human Services (HHS) inventory of activities related to epilepsy.
- Coordinated conference and webinar workshops to focus on underutilized public health resources that could be helpful for epilepsy partners.

Output

- At least five CDC progress reports describing progress on implementing IOM recommendations submitted to Vision 20-20 (now Epilepsy Leadership Council) members.
- A CDC-led article describing multiple HHS agencies' progress in meeting IOM recommendations on epilepsy.
- At least five American Epilepsy Society conference public health workshops and/or webinar presentations to engage partners on opportunities for collaboration.

Impact**Catalyzing Action:**

Ongoing partnerships and collaborations to coordinate strategic direction for epilepsy efforts to promote synergy and reduce redundancy. This ensured that resources are used effectively to advance epilepsy research, program evaluation, intervention development, community services, and—ultimately—improved quality of life for all individuals with epilepsy.

For more information, see Appendix B (page 54) and Appendix C (pages 65–66).

Highlights

In collaboration with the American Epilepsy Society, the CDC Epilepsy Program coordinated a series of public health workshops to raise awareness of underutilized public health resources to address the burden of epilepsy and to foster collaborative partnerships. Some examples of workshop topics in the last decade include:

- **Expanding the use of epilepsy self-management programs.** Programs and resources from the MEW Network. The National Association of Epilepsy Centers annual meeting at the American Epilepsy Society Annual (2013).
- **Putting the “public” back in health.** Resources and opportunities available to help people with epilepsy. Featuring university experts and CDC staff (2016).
- **Strategies to facilitate the transition of youth with epilepsy into adult health care.** Featuring the Health Resources and Services Administration, state agencies and organizations, and CDC staff (2018).
- **Epidemiology Special Interest Group.** Presentation focused on epilepsy disparities (2020).

- **Closing gaps in epilepsy care with provider capacity building models.** A Project ECHO training featuring university experts and CDC staff (2021).
- **Introduction to health services research in the epilepsies.** A joint effort between CDC and the National Institute of Neurological Disorders and Stroke (2021).

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APPENDIX B: CDC ACTIVITIES INVENTORY

IOM RECOMMENDATION 1: VALIDATE STANDARD DEFINITIONS FOR CASE ASCERTAINMENT

Type	Activity	Status
Extramural	Developed population survey questions to ascertain epilepsy cases.	Completed 2012
Extramural	Validated Centers for Disease Control and Prevention (CDC) August 10 through September 10, 2017, International Classification of Diseases, Ninth Revision (ICD-9) survey questions to ascertain prevalent cases of epilepsy in population surveys.	Pre-IOM–2014
Extramural	Developed and validated epilepsy case ascertainment criteria using ICD-9 data.	Pre-IOM–2014
Extramural	Issued fiscal year 2015–2018 (FY15–18) cooperative agreement to use standardized definitions and methods in studies of epilepsy burden.	Completed 2019
Extramural	Issued FY18–19 cooperative agreement “Targeting Treatment Gaps: Describing When, How Quickly, and Why People With Epilepsy Are Referred for Specialty Care.”	Completed 2021
Extramural	Issued FY20 cooperative agreement to examine health care services use and costs with validated case ascertainment criteria.	Ongoing
Extramural	Issued FY21 cooperative agreement “Epilepsy Incidence and Etiology: Important Information for Public Health Prevention and Health Promotion in the US Community.”	Ongoing
Intramural	Used internationally validated measures to examine well-being outcomes in adults with epilepsy.	Completed 2012
Intramural	Used Patient Reported Outcomes Measurement Information System (PROMIS) measures to examine health-related quality of life (HRQOL) in adults with epilepsy to guide Healthy People 2020 objectives on HRQOL.	Completed 2014
Intramural	Used Medical Expenditure Panel Survey (MEPS) data and standard case definitions to assess health care costs among children with epilepsy.	Completed 2016
Intramural	Supported questions on the 2014 School Health Profiles Survey.	Completed 2017
Intramural	Contributed recommendations for the investigation and certification of deaths in people with epilepsy.	Completed 2018
Intramural	Used standard definitions to assess epilepsy burden and access to care outcomes using administrative data and population surveillance systems.	Ongoing
Intramural	Conducted new validation studies in community-based samples, among pediatric cases, using 2014 International League Against Epilepsy (ILAE) epilepsy definition, parent-reported pediatric epilepsy, and epilepsy mortality including sudden unexpected death in epilepsy (SUDEP).	Ongoing

Type	Activity	Status
Intramural	Developed and evaluated instruments addressing health care, community services, and costs.	Ongoing
Intramural	Developed methods for case identification and data extraction from electronic health records (EHRs).	Ongoing
Intramural	Conducted comparative validation of ICD-code based algorithms to identify epilepsies from commercial claim databases.	Ongoing
Intramural	Validate nonspecific epilepsy-related terms for case ascertainment.	Ongoing

IOM RECOMMENDATION 2: EXPAND SURVEILLANCE

Type	Activity	Status
Extramural	Funded ongoing and new cooperative agreements (2012–2021) with academic institutions and contractors to conduct population-based epidemiologic studies.	Ongoing
Extramural	Co-funded CDC Division of Reproductive Health cooperative agreements with at least 22 states/jurisdictions (2013–2021) to expand SUDEP surveillance.	Ongoing
Extramural	Funded cooperative agreements with 10 states to initiate or expand activities to examine Medicaid data for people with intellectual and developmental disabilities (IDD).	Select states/ select years
Extramural	Funded a cooperative agreement to use EHRs and a text processing algorithm to examine pediatric rare epilepsy burden.	Completed 2019
Extramural	Collected data on epilepsy as a co-occurring condition in children identified through the Autism and Developmental Disabilities (ADDM) Network.	Select states/select years
Extramural	Tracked epilepsy/seizure as outcome in US Zika Pregnancy and Infant Registry.	Ongoing
Extramural	Issued FY22 cooperative agreement to use data to promote health and wellness in people with disabilities.	Ongoing
Intramural	Collaborated with National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and National Center for Health Statistics (NCHS) to analyze epilepsy data in National Survey of Children with Special Health Care Needs.	Completed 2015
Intramural	Supported epilepsy questions on 4 years of the School Health Profiles Survey.	Completed 2017
Intramural	Analyzed suicide burden in epilepsy using National Violent Death Reporting System (NVDRS).	Completed 2016
Intramural	Collaborated with National Center for Child Death Review on causes of death.	Completed 2015

Type	Activity	Status
Intramural	Collaborated with NCCDPHP and National Center on Birth Defects and Developmental Disabilities (NCBDDD) on epilepsy burden in Zika infection.	Completed 2017
Intramural	Included epilepsy questions on 6 years of the National Health Interview Survey (NHIS).	Ongoing
Intramural	Used the 2013 HealthStyles survey to examine US attitudes towards epilepsy.	Completed 2021
Intramural	Used the 2017 HealthStyles survey to examine knowledge about epilepsy first aid.	Completed 2021
Intramural	Used the 2018 DocStyles survey to examine general practitioners' attitudes towards referral of epilepsy patients to specialty care.	Completed 2021
Intramural	Reviewed CDC epilepsy surveillance/epidemiologic studies (1994–2020).	Completed 2020
Intramural	Provided latest national and first state-level estimates of epilepsy burden.	Completed 2017
Intramural	Examined trends in epilepsy mortality using CDC Wonder Mortality files.	Completed 2017

IOM RECOMMENDATION 3: PREVENTION EFFORTS

Type	Activity	Status
Extramural	Collaborated with American Academy of Neurology to develop guidelines for mild sports traumatic brain injury (TBI).	Completed 2013
Extramural	Collaborated with Center for Global health to reduce epilepsy burden from cysticercosis and taeniasis.	2012–2022
Extramural	Developed and evaluated 11 epilepsy self-management programs via the Managing Epilepsy Well (MEW) Network.	Ongoing
Extramural	Issued funding announcements to support MEW Network replication of programs.	2014–2019
Extramural	Implemented Patient Health Questionnaire (PHQ-2) depression screening and behavioral health referral protocol in collaboration with Epilepsy Foundation (EF) Central South Texas.	Completed 2021
Extramural	Enhanced public awareness of SUDEP through webinars and participation in Partners Against Mortality in Epilepsy Planning.	Completed 2017
Extramural	Collaborated with the EF in outreach to veterans addressing TBI and epilepsy.	Completed 2016
Extramural	Issued FY18 cooperative agreement to inform interventions on stigma reduction.	Completed 2016

IOM RECOMMENDATION 4: EARLY IDENTIFICATION

Type	Activity	Status
Extramural	Issued cooperative agreement to fund the South Carolina Epilepsy Surveillance System.	Pre-IOM–2015
Extramural	Issued cooperative agreement with EF to facilitate depression screening and referrals.	Completed 2021
Extramural	Supported awardees to examine epilepsy comorbidity and mortality in intervention and administrative data sets.	Ongoing
Extramural	Supported development and validation of standardized epilepsy self-management screening tool through several cooperative agreements.	Completed 2021
Extramural	Supported epilepsy screening in children with congenital Zika virus infection.	Ongoing
Intramural	Analyzed NHIS 2010 data to examine comorbidity burden in adults with epilepsy.	Completed 2014
Intramural	Analyzed NHIS 2010–2014 data to examine comorbidity in children with seizures.	Completed 2015
Intramural	Collaborated with Veterans Affairs Environment of Care to examine comorbidity and mortality in Gulf War Veterans with epilepsy.	Completed 2016
Intramural	Analyzed NHIS 2010–2017 data to examine burden of psychiatric and physical comorbidities of epilepsy.	Completed 2021

IOM RECOMMENDATION 5: NATIONAL QUALITY MEASUREMENT

Type	Activity	Status
Intramural	NCCDPHP led development of first Healthy People 2020 national objective on epilepsy.	2012–2021

IOM RECOMMENDATION 6: ACCREDITATION OF EPILEPSY CENTERS

Not applicable to the CDC Epilepsy Program.

IOM RECOMMENDATION 7: HEALTH PROFESSIONAL EDUCATION

Type	Activity	Status
Extramural	Supported EF-led professional education for school staff, first responders, and other health care professionals through two cooperative agreements.	Completed 2021
Extramural	Implemented a neurology/epilepsy Extension for Community Healthcare Outcomes (ECHO) pilot to train general practitioners on best practices for epilepsy care.	Completed 2021
Extramural	Implemented School Nurse ECHO pilot to train school nurses in epilepsy care.	Completed 2021
Extramural	Trained 270+ providers in MEW Network program delivery.	Ongoing

Type	Activity	Status
Extramural	Developed virtual training curriculum and conference for behavioral health specialists in Texas and 12 partner organizations.	Completed 2021
Extramural	Initiated cooperative agreement to require training of community health workers to deliver epilepsy care.	Ongoing
Extramural	Initiated cooperative agreement to strengthen health systems to improve epilepsy care.	Ongoing
Extramural	Coordinated CDC Medscape feature on 2017 ILAE definitions of epilepsy focused on reaching primary care providers.	Completed 2018
Intramural	Developed community health care worker curriculum on epilepsy self-management and offered technical assistance in collaboration with several stakeholders.	Completed 2018

IOM RECOMMENDATION 8: DELIVERY AND COORDINATION OF SERVICES

Type	Activity	Status
Extramural	Through 2011–2016 EF cooperative agreement, supported development of referral services hotline; training of information specialists in the Association of Surgeons in Training (ASIT) program; development of Epilepsy Awareness Management (EAM) collaborative and Nationwide Volunteer Program; performance of needs assessments; and dissemination of epilepsy awareness and seizure first aid materials.	Completed 2016
Extramural	Through 2016–2021 EF cooperative agreement, supported development and dissemination of epilepsy awareness and seizure first aid training for students, school staff, and general public; development of information and referral services hotline; expansion of online Learning Management System; implementation of pilot programs to link to self-management support; education for transportation providers; and performance of needs assessment.	Completed 2021
Extramural	Funded cooperative agreement to examine pediatric rare epilepsy burden using EHRs and text processing algorithm.	Completed 2021
Extramural	Funded MEW Network and EF collaboration to improve program delivery.	Ongoing
Extramural	Issued FY20 funding announcement to coordinate linkage with community health workers.	Ongoing
Intramural	Collaborated with Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau on National Center for Project Access Advisory Committee.	Completed 2012
Intramural	Developed epilepsy self-management curriculum for community health workers.	Completed 2018

IOM RECOMMENDATION 9: EDUCATIONAL OPPORTUNITIES FOR PATIENTS AND FAMILIES

Type	Activity	Status
Extramural	Expanded MEW Network funding for program development, testing, and dissemination.	Completed 2014
Extramural	Expanded MEW Network funding for program development, replication, and dissemination.	Completed 2019
Extramural	Developed MEW Network website with patient resources and checklists.	Completed 2019
Extramural	Developed and conducted MEW Network webinar series on self-management.	Completed 2012
Extramural	Created and launched redesigned WebEase program public portal.	Completed 2018
Extramural	Supported EF cooperative agreement “Development and Implementation of Programs to Enhance Epilepsy Public Awareness, Knowledge, and Partnership.”	Completed 2016
Extramural	Issued cooperative agreement “Improving Epilepsy Programs, and Outcomes through National Partnerships.”	Completed 2021
Extramural	Issued special interest project funding announcement for MEW Network 2.0.	Ongoing
Extramural	Issued funding announcement to improve epilepsy education, systems of care, and health outcomes through national and community partnerships.	Ongoing
Extramural	Maintained Epilepsy Program website with resources and educational materials.	Ongoing
Intramural	Collaborated with HRSA Project Access grantee program.	Completed 2012

IOM RECOMMENDATION 10: INFORMATION FOR MEDIA

Type	Activity	Status
Extramural	Supported annual Epilepsy Awareness Month media campaigns, supported social media channels, and conducted outreach to Spanish-speaking communities through 2011–2016 cooperative agreement with EF.	Completed 2016
Extramural	Supported partnership with CBS Community Partnership Division on epilepsy awareness campaigns through 2016–2021 cooperative agreement with EF.	Completed 2021
Extramural	Funded cooperative agreement to examine pediatric rare epilepsy burden using EHRs and text processing algorithm.	Completed 2021
Extramural	Collaborated with The Carter Center to co-sponsor <i>American Journal of Public Health</i> issue on health-related stigma through an epilepsy lens.	Completed 2017
Intramural	Published yearly notices of Epilepsy Awareness month in <i>Morbidity and Mortality Weekly Report (MMWR)</i> .	2012–2016

Type	Activity	Status
Intramural	Issued press release on updated national and state estimates of epilepsy.	Completed 2021
Intramural	Collaborated with <i>Epilepsy & Behavior</i> on press release for suicide burden study.	Completed 2016
Intramural	Developed and disseminated bi-monthly GovDelivery messages on epilepsy.	Ongoing

IOM RECOMMENDATION 11: PUBLIC AWARENESS EFFORTS

Type	Activity	Status
Extramural	Through 2011–2016 cooperative agreement with EF, supported public awareness campaigns for general public and specific cultural communities.	Completed 2016
Extramural	Through 2016–2021 cooperative agreement with EF, supported collaboration with CBS Partnerships Division and partnered with several organizations to promote English and Spanish Seizure First Aid certification programs.	Completed 2021
Intramural	Developed Communications Corner on website with social media widgets.	Ongoing
Intramural	Developed epilepsy content for CDC’s BAM! Body and Mind website for teachers and students.	Ongoing

IOM RECOMMENDATION 12: VISION 20-20 AND ELC PARTNERSHIPS

Type	Activity	Status
Extramural	Participated in Vision 20-20 conference calls regarding the Institute of Medicine (IOM) epilepsy report.	Ongoing
Extramural	Participated in Interagency Collaborative to Advance Research in Epilepsy (ICARE) meetings with the National Institute of Neurological Disorders and Stroke (NINDS) and other Vision 20-20 partners.	Ongoing
Extramural	Presented and collaborated with American Epilepsy Society (AES) to lead CDC Public Health Workshop.	Ongoing

IOM RECOMMENDATION 13: ENGAGE PEOPLE WITH EPILEPSY

See Recommendations 8, 9, 10.

APPENDIX C: SELECT PUBLICATIONS, PRESENTATIONS, AND REPORTS

IOM RECOMMENDATION 1: VALIDATE STANDARD DEFINITIONS FOR CASE ASCERTAINMENT

Bensken W, Fernandez-Baca Vaca G, Jobst BC, et al. Burden of chronic and acute conditions and symptoms in people with epilepsy. *Neurology*. 2021;97(24):e2368–e2380.

Bensken W, Navale SM, Andrew AS, Jobst B, Sajatovic M, Koroukian SM. Delays and disparities in diagnosis for adults with epilepsy: Findings from U.S. Medicaid data. *Epilepsy Res*. 2020;166:106406. doi: 10.1016/j.epilepsyres.2020.106406

Bensken W, Suparna N, Angeline A, Jobst B, Sajatovic M, Koroukian S. Markers of quality care for newly diagnosed people with epilepsy on Medicaid. *Med Care*. 2021;59(7):588–596. doi: 10.1097/MLR.0000000000001541

Brooks DR, Avetisyan R, Jarrett KM, et al. Validation of self-reported epilepsy for purposes of community surveillance. *Epilepsy Behav*. 2012;23(1):57–63. doi: 10.1016/j.yebeh.2011.11.002

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Holden EW, Grossman E, Thanh Nguyen H, et al. Developing a computer algorithm to identify epilepsy cases in managed care organizations. *Dis Manag*. 2005;8(1):1–14. doi: 10.1089/dis.2005.8.1

Ip Q, Malone DC, Chong J. An update on the prevalence and incidence of epilepsy among older adults. *Epilepsy Res*. 2017;139:107–112. doi: 10.1016/j.epilepsyres.2017.11.022

Ip Q, Malone DC, Chong J, et al. Economic impact of epilepsy and the cost of nonadherence to antiepileptic drugs in older Medicare beneficiaries. *Epilepsy Behav*. 2018;80:208–214. doi: 10.1016/j.yebeh.2018.01.009

Kobau R, Cui W, Zack M. Adults with an epilepsy history fare significantly worse on positive mental and physical health than adults with other common chronic conditions—Estimates from the 2010 National Health Interview Survey and Patient Reported Outcome Measurement System (PROMIS) Global Health Scale. *Epilepsy Behav*. 2017;72:182–184. doi: 10.1016/j.yebeh.2017.04.047

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IOM RECOMMENDATION 4: EARLY IDENTIFICATION

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IOM RECOMMENDATION 5: NATIONAL QUALITY MEASUREMENT

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IOM RECOMMENDATION 6: ACCREDITATION OF EPILEPSY CENTERS

Not applicable to CDC.

IOM RECOMMENDATION 7: HEALTH PROFESSIONAL EDUCATION

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IOM RECOMMENDATION 8: DELIVERY AND COORDINATION OF SERVICES

See Recommendation 3.

IOM RECOMMENDATION 9: EDUCATIONAL OPPORTUNITIES FOR PATIENT AND FAMILIES

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IOM RECOMMENDATION 10: INFORMATION FOR MEDIA

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IOM RECOMMENDATION 11: PUBLIC AWARENESS EFFORTS

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IOM RECOMMENDATION 12: VISION 20-20 AND ELC PARTNERSHIPS

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IOM RECOMMENDATION 13: ENGAGE PEOPLE WITH EPILEPSY

See Recommendations 8, 9, 10.