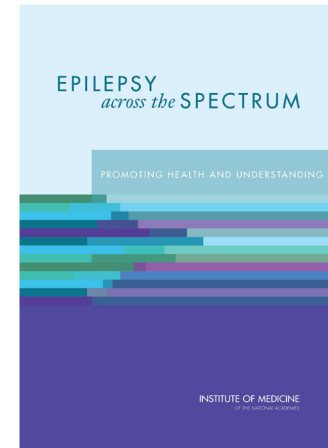


Epilepsy Across the Spectrum

Promoting Health and Understanding



Much can be done to improve the lives of people with epilepsy. The IOM report offered 13 evidence-based recommendations and 46 research priorities in order to present realistic, feasible, and action-oriented steps that a variety of stakeholders can take to enable short- and long-term improvements for people with epilepsy and their families. This document is designed to present the full text of the report's recommendations and research priorities.

Increasing the Power of Data and Preventing Epilepsy

Recommendation 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

The Centers for Disease Control and Prevention (CDC), in collaboration with professional organizations (e.g., the American Epilepsy Society [AES] and International League Against Epilepsy [ILAE]) and other federal entities, including the Centers for Medicare and Medicaid Services, Department of Defense, Veterans Administration, and National Institutes of Health (NIH), should fund demonstration projects to validate and implement standard definitions for epilepsy case ascertainment, health care and community services use and costs, and measures of quality of life for use in different data collection systems and for different specific objectives. Once validated, these definitions and criteria should be adopted by funding agencies and used in surveillance and research, which is the basis for planning and policy making.

Recommendation 2

Continue and Expand Collaborative Surveillance and Data Collection Efforts

The CDC should continue and expand its leadership in epilepsy surveillance and work with state and local public health researchers, academic researchers, and other relevant stakeholders (including other agencies within the Department of Health and Human Services). Surveillance efforts should be funded that use large, representative samples to determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations (e.g., different types of epilepsy, ages, genders, races/ethnicities, socioeconomic statuses). Data collection efforts should include the following:

- Population health surveys should expand their questions about epilepsy, its comorbidities, and health care services use and include these questions more frequently and consistently.
- Existing registries for comorbid conditions, such as the Surveillance, Epidemiology, and End Results program and state-based cancer registries, state-based Alzheimer's registries, and the Interactive Autism Network, should collect data on epilepsy.
- Efforts should be expanded to standardize the practices of coroners and medical examiners in evaluating and recording cause of death in people with epilepsy with the goal of working toward a national epilepsy-related death registry.

- Pilot projects should explore the linkage and use of emerging data collection and sharing partnerships using electronic health records and other electronic repositories (e.g., all-payer claims databases, regional health information organizations, the Health Maintenance Organization Research Network, NIH's Health Care Systems Research Collaboratory, the Health Care Cost Institute) for epilepsy surveillance and research.
- Epilepsy-specific data should be included in the NIH National Children's Study and future longitudinal studies.

Recommendation 3

Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences

The CDC should partner with the World Health Organization, ILAE, NIH, the Action Alliance for Suicide Prevention, and other stakeholders to develop and evaluate culturally appropriate and health literate prevention efforts that focus on

- preventing neurocysticercosis in high-risk populations;
- continuing prevention efforts for established risk factors of epilepsy (e.g., traumatic brain injury, stroke, brain infections, such as meningitis);
- preventing continued seizures in people with epilepsy and depression;
- reducing felt stigma; and
- preventing epilepsy-related causes of death, including accidents and injuries, SUDEP, and suicide.

Research Priorities for Improving Surveillance and Prevention

To improve surveillance and prevention of epilepsy and its consequences, the following areas should be considered priorities for future research:

- Studies to identify effective interventions for epilepsy accompanied by mental health comorbidities
- Studies that test whether treatment of comorbid mental health conditions ameliorates adverse outcomes
- Case-control studies of risk factors for injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy (SUDEP)
- Population-based studies using existing data resources that have included epilepsy, such as the National Survey of Children's Health
- Studies to examine the capacity of data systems to link seizure medication use and birth outcomes
- Continued research on the risk factors for epilepsy of unknown, genetic, or presumed genetic cause*
- Studies on the directionality of the relationship between epilepsy and its comorbidities, risk factors for developing an epilepsy comorbidity, and prognosis of epilepsy in people with comorbidities present before the onset of epilepsy
- A longitudinal study that examines epilepsy's outcomes (for example, a study of cognition in people with different syndromes, seizure types, and seizure frequencies that includes a sufficient number of older adults to enable studies of risk factors for cognitive deterioration)
- Long-term prospective studies that examine the effects of epilepsy surgery on cognitive function and that include appropriate control groups
- Studies or analyses that inform new approaches to randomized controlled trials in epilepsy, in order to minimize the time spent on placebo or on a study drug that is ineffective and thus minimize the risk for SUDEP
- Studies that develop and evaluate educational programs to improve the knowledge of coroners and medical examiners about SUDEP and other epilepsy-related deaths
- Evaluation of behavioral interventions on health outcomes and quality of life for people with epilepsy
- Development of screening methods and criteria to identify children with epilepsy and cognitive comorbidities through the use of educational records

* Previously known as idiopathic or cryptogenic

Improving Health Care

Recommendation 4

Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions

The AES and the American Academy of Neurology (AAN) should lead a collaborative effort with the wide range of relevant professional organizations (including primary care professional organizations) and federal agencies (including the CDC and Health Resources and Services Administration), and others that promote and disseminate screening programs to

- develop and validate screening tests for the early identification of epilepsy in at-risk populations (e.g., people with developmental disabilities; people with mental health conditions; people who have had a traumatic brain injury, brain tumor, or stroke);
- establish and disseminate a standard screening protocol for people with epilepsy that implements screening on a regular basis for comorbidities with currently approved screening tests (e.g., for bone disease, depression, generalized anxiety disorder); and
- establish and disseminate a screening tool for the early identification of patients with persistent seizures that would lead to earlier referral to an epileptologist for further diagnosis and treatment.

Recommendation 5

Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care

The AES, in conjunction with other professional organizations involved in epilepsy care, education, and advocacy (including primary care professional organizations) should initiate the development of a national quality measurement and improvement strategy for epilepsy care. An independent organization with expertise in quality measurement and care should assist in the development of the national strategy, particularly the development of performance metrics. The national quality improvement strategy should

- develop and implement a plan to disseminate existing clinical guidelines and educate health professionals and people with epilepsy and their families about them;
- define performance metrics for epilepsy with specific attention to access to care for underserved populations, access to specialized care, co-management of care among all health care epilepsy providers, and coordination of care with other health care providers and community services organizations;
- continue the development and implementation of a set of performance metrics that includes patient-generated measures; and
- develop demonstration projects to validate performance metrics and test the feasibility of tracking outcomes of care.

Recommendation 6

Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network

The National Association of Epilepsy Centers and the AES should collaborate with relevant organizations to establish accreditation criteria and processes with independent external review mechanisms for the accreditation of epilepsy centers. Accredited epilepsy centers should work together to form an Epilepsy Care Network that includes data sharing, clinical trial and other research networking, professional education, and other collaborative activities.

Independently accredited epilepsy centers should

- emphasize patient-centered care that focuses on co-management approaches with primary care providers, mental health care providers, and other specialists;
- ensure that community service providers are an integral part of the centers and actively collaborate with them to link people with epilepsy to services for all facets of the individual's health and well-being;
- use standardized performance metrics for quality epilepsy care;
- publicly report on a standard set of quality, outcome, and health services data;
- provide onsite education and training for epilepsy specialists (e.g., technicians, nurses, researchers, physicians) as well as educational opportunities, particularly continuing education, for other health and human services professionals in the community; and
- serve as sites for pilot projects on innovative approaches to improving co-management and coordination of care, as well as health care quality, access, and value for people with epilepsy.

The Epilepsy Care Network of Accredited Epilepsy Centers should

- conduct collaborative clinical and health services research;
- collect, analyze, and disseminate quality, outcome, and health services data from all of the accredited centers; and
- collaborate and partner with state health departments and other health care providers to ensure coverage across rural and underserved areas through telemedicine, outreach clinics, and other mechanisms.

Research Priorities for Improving Health Care

To improve health care for people with epilepsy, the following areas should be considered priorities for future research:

- Development of methods for early identification of and new treatment approaches for refractory epilepsy
- Development of screening tools (useful in clinic settings) for the early identification of people with epilepsy who have potential cognitive impairments
- Development of decision-support tools for electronic health records for use by primary care and emergency room providers regarding care of persons with epilepsy, the use of screening tests, and referral steps for further evaluation and care
- Comparisons of the efficacy of brand and generic formulations of seizure medications
- Comparative effectiveness studies of epilepsy therapies and of treatments used to manage epilepsy (including reducing medication side effects) and comorbidities, with initial attention to setting priorities for this research
- Health services research on the provision and effectiveness of epilepsy care by primary care providers, neurologists, and epileptologists, including referrals to epilepsy centers and to specialists for care of comorbidities
- Assessment of differences in the utilization of epilepsy health care services, particularly for underserved populations
- Studies of the capacity of the workforce that cares for people with epilepsy
- Studies that examine value measures for epilepsy care as well as potential reductions in health care costs through changes in access to specialized care and improved coordination with providers caring for comorbid health conditions
- Analysis of cost savings by reducing emergency department use and hospitalizations
- Assessment of incentive strategies for the participation of clinical staff in collaborative service models and co-management of complex cases, including strategies to promote timely referral to surgery, mental health services, and higher levels of care

Recommendation 7

Improve Health Professional Education About the Epilepsies

The AES and AAN should collaborate with relevant professional organizations that are involved in the education of the wide range of health professionals who care for people with epilepsy to ensure that they are sufficiently knowledgeable and skilled to provide high-quality, patient-centered, interdisciplinary care. In their efforts to improve health professional education, these organizations should do the following:

- Define essential epilepsy knowledge and skills for the range of health professionals who care for people with epilepsy and their families.
- Conduct surveys of the relevant health professionals to identify knowledge gaps and information needs.
- Evaluate the efficacy and reach of existing educational materials and learning opportunities (e.g., websites, continuing education courses).
- Develop engaging and interactive educational tools, such as online modules, that meet specific learning needs and could be easily integrated into existing curricula and education programs.
- Ensure that educational materials and programs for health professionals reflect current research, clinical guidelines, and best practices. These educational materials and programs also should convey positive messages that reduce stigma and reinforce the need for (and skills associated with) clear health communication, which takes into account the culture and health literacy of the target audience.
- Explore and promote opportunities to expand the use of innovative interdisciplinary educational approaches, such as high-fidelity simulation.
- Disseminate educational materials and tools widely to health professional educators and other relevant professional associations and organizations.

Research Priorities for Improving Health Professional Education

To improve health professional education about epilepsy, the following areas should be considered priorities for future research:

- Identification of knowledge gaps across health professions that relate to areas such as seizure recognition and classification; new treatment options; SUDEP; and appropriate treatment modalities for specific subpopulations, including infants and children, women, individuals with severe epilepsy syndromes, people with complex comorbidities, and older adults
- Development and testing of educational interventions and incentives that will expand the reach of education and training opportunities about epilepsy and its associated comorbidities for health professionals outside of the epilepsy field (e.g., primary care, psychiatry, psychology, nursing)
- Assessment of current attitudes and beliefs of U.S. health professionals about epilepsy and the impact of these beliefs and attitudes on stigma and on access to and quality of care
- Evaluation of curricula and content of advanced training programs for physicians, nurses, and physician assistants for epilepsy-specific content and identification of specific opportunities and strategies for improving these types of programs
- Evaluation of innovative teaching strategies, such as online epilepsy education and simulation programs, to determine their suitability as models for a range of health professionals and others who interact with people with epilepsy, including teachers, daycare workers, coaches, and social workers
- Assessment of the format and frequency of educational and training opportunities existing within epilepsy centers in order to establish best practices for engaging clinicians in continuous, interdisciplinary learning
- Development and assessment of educational interventions and resources focused on communication skills and strategies for discussing sensitive topics (e.g., SUDEP, suicide, risks associated with medication nonadherence, treatment preferences)

Improving Community Resources and Quality of Life

Recommendation 8

Improve the Delivery and Coordination of Community Services

The CDC, state health departments, and the Epilepsy Foundation, in collaboration with state and local Epilepsy Foundation affiliates and other relevant epilepsy organizations, should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy that encompass the range of health and human services needed for epilepsy, its comorbid conditions, and optimal quality of life. These services include support groups; vocational, educational, transportation, transitional care, and independent living assistance; and support resources, including respite care for family members and caregivers. Specific attention should be given to identifying needs and improving community services for underserved populations. These efforts should

- support and expand efforts by the Epilepsy Foundation's state and local affiliates and other organizations to link people with epilepsy and their families to local and regional resources, emphasizing active collaboration among affiliates in the same region or with similar interests;
- develop innovative partnerships and incentives to collaborate with organizations and public-private partnerships focused on other neurological and chronic diseases or disorders;
- conduct and evaluate pilot studies of interventions to improve the academic achievement of students with epilepsy;
- maintain effective private, state, and national programs that assist people with epilepsy regarding transportation, employment, and housing;
- develop and disseminate evidence-based best practices in employment programs for people with epilepsy;
- identify and disseminate best practices for the coordination of health care and community services, including programs using patient and parent navigators;
- provide a 24/7 nonmedical help line offering information on epilepsy and links to community resources (this effort should involve collaboration with similar efforts for related health conditions); and
- develop, disseminate, and evaluate educational and training opportunities (including interactive web-based tools) for community service providers focused on epilepsy awareness and seizure first aid training.

Research Priorities for Improving Quality of Life and Community Resources

To improve quality of life and community resources for people with epilepsy, the following areas should be considered priorities for future research:

- Development of interventions to identify academic problems and improve academic achievement in students with epilepsy
- Identification of factors that increase the resiliency of the individual and family and of behaviors that improve quality of life
- Evaluations of community programs that go beyond process measures and assess outcomes for people with epilepsy and their families
- Evaluations of the effectiveness of vocational rehabilitation programs
- Identification of creative and innovative models of funding community service providers and collaborations
- Development of performance indicators for vocational and other community services and independent living programs

Raising Awareness and Improving Education

Recommendation 9

Improve and Expand Educational Opportunities for People with Epilepsy and Their Families

To ensure that all people with epilepsy and their families have access to accurate, clearly communicated educational materials and information, the Epilepsy Foundation, the Epilepsy Therapy Project, the CDC, and other organizations involved in Vision 20-20 should collaborate to do the following:

- Conduct a formal evaluation of currently available epilepsy websites and their educational resources to ensure that they meet requirements of clear health communication and are linguistically and culturally appropriate for targeted audiences. This requires thorough testing of content with target audiences, including underserved groups, and revision as necessary.
- Develop a central, easily navigated website (“clearing house”) that provides direct links to websites containing current, accurate epilepsy-related information for individuals and their families. This centralized resource should be comprehensive; it should include concise, easy-to-understand descriptions of the information available on the linked websites and up-to-date contact information for epilepsy organizations; and it should be widely disseminated to health care providers and people with epilepsy and their families.
- Ensure that educational resources are up to date, are effective, and reflect the latest scientific understanding of the epilepsies and their associated comorbidities and consequences.
- Engage a wide and diverse spectrum of people with epilepsy and their families in the development of online educational resources to ensure that the content meets the specific needs of target audiences at the outset.
- Support the development, evaluation, replication, and expanded use of self-management and educational programs, including those developed through the Managing Epilepsy Well Network.
- Engage state and local Epilepsy Foundation affiliates, epilepsy centers, and health care systems and providers to expand the dissemination of available educational resources and self-management tools to people with epilepsy and their families.
- Explore the development of a formal, standardized certificate program for epilepsy health educators.

Research Priorities for Improving Patient and Family Education

To improve the education of people with epilepsy and their families, the following areas should be considered priorities for future research:

- Assessment of the information needs of specific subpopulations, including women, men, older adults, children and adolescents, youths transitioning to adulthood, racial/ethnic minorities, people with low socioeconomic status, individuals with more severe forms of epilepsy or comorbidities and their families, individuals with cognitive limitations, and individuals with seizure-like events with a psychological basis
- Assessment of information needs associated with epilepsy-related risks such as injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy
- Identification of best practices, effective strategies and preferred formats, and innovative mechanisms for educating patients and families, especially individuals in underserved populations

- Development of a knowledge base to support comprehensive educational programs that feature content for epilepsy-specific self-management as well as relevant aspects of the chronic care management models
- Testing of methods for developing educational programs and resources that appropriately reflect health literacy, cultural diversity, developmental stage, cognitive ability, and gender
- Examination of the role that educational materials and programs, support groups, and counseling resources may play in helping individuals and their families successfully cope with stigma and related concerns, such as the fear of having a seizure in public

Recommendation 10

Inform Media to Improve Awareness and Eliminate Stigma

The CDC and other Vision 20-20 and relevant organizations should support and bolster programs that provide information to journalists and to writers and producers in the entertainment industry to improve public knowledge about epilepsy and combat stigma. Efforts to collaborate and engage with the media should include the following:

- Promote more frequent, accurate, and positive story lines about and depictions of characters with epilepsy.
- Continue to encourage high-profile individuals with epilepsy (or high-profile individuals who have family members with epilepsy) to openly discuss their experiences and act as spokespeople.
- Establish partnerships with stakeholders that represent related conditions associated with stigma (e.g., mental health). Efforts could include the development of fellowships or integration of epilepsy information into existing education programs for journalists.
- Continue to work with national and local news media on breaking news about epilepsy research and human interest stories.
- Disseminate regular updates on research and medical advances to journalists and policy makers through a variety of mechanisms, including e-mail updates, listserv messages, social media, and face-to-face meetings.

Recommendation 11

Coordinate Public Awareness Efforts

The Epilepsy Foundation and the CDC should lead a collaborative effort with relevant stakeholder groups, including other members of Vision 20-20, to continue to educate the public through awareness efforts, promotional events, and educational materials and should collaborate to do the following:

- Establish an advisory council of people with epilepsy and their families, media and marketing experts, private industry partners, and health care experts to meet regularly and to inform future efforts.
- Develop shared messaging that emphasizes the common and complex nature of the epilepsies and the availability of successful seizure therapies and treatments.
- Explore the feasibility and development of an ongoing, coordinated, large-scale, multimedia, multiplatform, sustainable public awareness campaign that would start by targeting key audience segments to improve information and beliefs about the epilepsies and reduce stigma.
- Ensure that all awareness campaigns include
 - consideration of health literacy, cultural appropriateness, and demographics of target audiences (e.g., age, gender);
 - rigorous formative research and testing of materials throughout the campaign; and
 - appropriate evaluation and follow-up tools and efforts.

Research Priorities for Improving Public Awareness and Knowledge

To improve public awareness and knowledge, the following areas should be considered priorities for future research:

- Surveys (e.g., General Social Survey, HealthStyles Survey) that capture trends in knowledge and awareness and attitudes and beliefs about epilepsy over time and in specific subpopulations
- Evaluations of websites seeking to promote accurate knowledge about epilepsy (e.g., Talk About It) to determine effective strategies for educating the public through online resources
- Evaluation of public awareness campaigns that include documentation and analysis of pre- and post-campaign data to assess changes in public understanding of and beliefs about epilepsy and to establish best practices in developing public awareness efforts



Strengthening Stakeholder Collaboration

Recommendation 12

Continue and Expand Vision 20-20 Working Groups and Collaborative Partnerships

The member organizations of Vision 20-20 should continue their collaborative endeavors and further these efforts by expanding ongoing working groups that aim to advance the field, support people with epilepsy and their families, and educate the public. They should explore partnerships with other organizations as well as with stakeholders who represent related conditions (e.g., mental health, traumatic brain injury, stroke, autism spectrum disorders). The working groups should communicate regularly, identify common goals, develop strategic plans, and, when possible, carry out joint activities. The working groups should focus on, but not limit their efforts to, the following areas:

- health policy, health reform, and advocacy;
- surveillance and epidemiologic and health services research;
- health care and community resources and services;
- education of health professionals;
- education of people with epilepsy and their families; and
- public education and awareness.

Engaging People with Epilepsy and Their Families

Recommendation 13

Engage in Education, Dissemination, and Advocacy for Improved Epilepsy Care and Services

People with epilepsy and their families should, to the extent possible, work to educate themselves and others about the epilepsies, participate in research, and be active advocates for improvements in care and services for themselves, their family members, and other people with epilepsy. Given their interests and to the extent possible, people with epilepsy and their families should

- become informed about epilepsy and actively participate in and advocate for quality health care and community services with policy makers at the local, state, and national levels;
- discuss best options for care with health care providers, including exploring referrals to epileptologists or epilepsy centers and learning about available community resources and services as needed;
- consider participation in available research and surveillance opportunities;
- engage with teachers, school officials, daycare workers, coaches, and other professionals to educate them about epilepsy and ensure that necessary services and accommodations are provided;
- talk openly, when possible, with family, friends, and colleagues about epilepsy and the impact it has on daily living and quality of life;
- actively participate in support networks to share experiences with other people with epilepsy and their families; and
- work with nonprofit organizations to raise awareness and educate others about epilepsy and participate in advocacy efforts.