

INSTITUTE OF MEDICINE
**EPILEPSY ACROSS THE SPECTRUM:
PROMOTING HEALTH AND UNDERSTANDING**

Selected recommendations and priorities relevant to biomedical research

To view the full report, see: IOM.edu/epilepsy

INCREASING THE POWER OF DATA AND PREVENTING EPILEPSY

Research Priorities

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^a
- 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

^aPreviously known as *idiopathic or cryptogenic*.

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, Department of Veterans Affairs, 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 [TBI], 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, sudden unexpected death in epilepsy, and suicide.

IMPROVING HEALTH CARE

Research Priorities

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 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 TBI, 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.