

Epilepsy Across the Spectrum: Promoting Health and Understanding

**IOM Committee on the
Public Health Dimensions of the Epilepsies**



INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

IOM Committee

MARY JANE ENGLAND (*Chair*), Boston University

JOAN KESSNER AUSTIN, Indiana University School of Nursing

VICKI BECK, Beck Communications, Carlsbad

CHARLES E. BEGLEY, University of Texas Health Science Center

MALACHY L. BISHOP, University of Kentucky

LIONEL CARMANT, University of Montreal

CAROLYN COCOTAS, F·E·G·S Health and Human Services System

SANDRA CUSHNER-WEINSTEIN, Children's National Medical Center

RAMON DIAZ-ARRASTIA, Uniformed Services University of the Health Sciences

DAVID GRANT, University of California, Los Angeles

CHRISTIANNE N. HECK, University of Southern California

DALE C. HESDORFFER, Columbia University

GREGORY L. HOLMES, Dartmouth Medical School

PAUL E. JARRIS, Association of State and Territorial Health Officials

DILIP V. JESTE, University of California, San Diego

PATRICIA OSBORNE SHAFER, Beth Israel Deaconess Medical Center

JOSEPH I. SIRVEN, Mayo Clinic Arizona

Study Sponsors

Department of Health and Human Services (HHS) sponsors:

- Administration on Developmental Disabilities
- Center for Devices and Radiological Health (FDA)
- Center for Drug Evaluation and Research (FDA)
- National Center for Chronic Disease Prevention and Health Promotion (CDC)
- National Center on Birth Defects and Developmental Disabilities (CDC)
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (NIH)
- National Institute of Mental Health (NIH)
- National Institute of Neurological Disorders and Stroke (NIH)
- National Institute on Aging (NIH)
- Office of the Assistant Secretary for Health
- Office of the Assistant Secretary for Planning and Evaluation
- Office on Women's Health

Vision 20-20 nonprofit organization sponsors:

- American Epilepsy Society (AES)
- Citizens United for Research in Epilepsy (CURE)
- Dravet.org
- Epilepsy Foundation
- Epilepsy Therapy Project (ETP)
- Finding a Cure for Epilepsy and Seizures (FACES)
- Hemispherectomy Foundation
- International League Against Epilepsy (ILAE)
- National Association of Epilepsy Centers (NAEC)
- Preventing Teen Tragedy
- Rasmussen's Encephalitis (RE) Children's Project
- Tuberous Sclerosis Alliance (TSA)

Statement of Task Highlights

The IOM committee was asked to conduct a study and prepare a report to recommend priorities in public health, health care and human services, and health literacy and public awareness for the epilepsies and to propose strategies to address these priorities. The study focused on the following four topic areas:

- public health surveillance, collection, and data integration;
- population and public health research;
- health policy, health care, and human services; and
- patient, provider, and public education.

Timeline

- January 2011 – First committee meeting
- March 2011 – Committee meeting and public workshop on public health surveillance, population health research, and data collection
- June 2011 – Committee meeting and public workshop on health care quality and access and education of patients, families, and providers
- September and November 2011 – Committee meetings
- January to March 2012 – National Academies' Report Review
- March 30, 2012 - Report release

Recommendations

Surveillance and Prevention

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
2. Continue and expand collaborative surveillance and data collection efforts
3. Develop and evaluate prevention efforts for epilepsy and its consequences

Health Care

4. Improve the early identification of epilepsy and its comorbid health conditions
5. Develop and implement a national quality measurement and improvement strategy for epilepsy care
6. Establish accreditation of epilepsy centers and an Epilepsy Care Network

Health Professional Education

7. Improve health professional education about the epilepsies

Recommendations (cont'd.)

Quality of Life

8. Improve the delivery and coordination of community services

Education for Patients and Families

9. Improve and expand educational opportunities for patients and families

Public Awareness

10. Inform media to improve awareness and eliminate stigma
11. Coordinate public awareness efforts

Stakeholder Collaboration

12. Continue and expand Vision 20-20 working groups and collaborative partnerships
13. Engage in education, dissemination, and advocacy for improved epilepsy care and services

Areas of Research Priorities

1. Increase the power of data & prevent epilepsy (13)
(General, Risk Factors, Comorbidities, & Outcomes)
2. Improve health care (11)
(Quality, Screening/Early Identification, Access, & Value)
3. Improve health professional education (7)
(Current Knowledge & Educational Programs)
4. Improve quality of life (6)
(Interventions & Community Services)
5. Improve education for patients & families (6)
(Current Knowledge & Educational Programs)
6. Raise public awareness (3)
(Current Knowledge & Campaigns)

Research Priorities:

Increase the Power of Data and Prevent Epilepsy

GENERAL

- Population-based studies using existing data resources that include epilepsy
- Capacity of data systems to link seizure medications and birth outcomes
- New approaches to RCTs to minimize the time spent on placebo/ineffective study drug
- Educational programs for coroners and medical examiners about SUDEP and other epilepsy-related deaths

RISK FACTORS

- Risks for epilepsy of unknown, genetic, or presumed genetic cause

Research Priorities: Increase the Power of Data and Prevent Epilepsy

COMORBIDITIES

- Interventions for people with mental health comorbidities
- Tests of whether treatment of mental health comorbidities improves outcomes
- Directionality between epilepsy and its comorbidities, risk factors for comorbidities, and prognosis of epilepsy in people with comorbidities before epilepsy
- Screening methods and criteria to identify children with epilepsy and cognitive comorbidities in educational records

Research Priorities: Increase the Power of Data and Prevent Epilepsy

OUTCOMES

- Risk factors for injuries, suicide, status epilepticus, and SUDEP
- Longitudinal study that examines epilepsy's outcomes
- Effects of epilepsy surgery on cognitive function
- Evaluation of behavioral interventions on health outcomes and quality of life

Research Priorities: Improve Health Care

QUALITY OF CARE

- EHR decision-support tools for care, screening tests, and referrals
- Comparisons of the efficacy of brand and generic formulations
- Comparative effectiveness of therapies and treatments used to manage epilepsy and comorbidities
- Provision and effectiveness of epilepsy care, including referrals to epilepsy centers and to specialists for care of comorbidities
- Incentive strategies for the participation of clinical staff in collaborative service models and co-management of complex cases

Research Priorities: Improve Health Care

SCREENING AND EARLY IDENTIFICATION

- Methods for early identification and new treatments for refractory epilepsy
- Screening tools for early identification of cognitive impairments

ACCESS TO CARE

- Assessment of differences in health care services use, particularly for underserved populations
- Evaluation of the capacity of the workforce

VALUE OF CARE

- Value measures for epilepsy care and reductions in costs through improved access and coordination with care for comorbidities
- Analysis of cost savings by reducing ED use and hospitalizations

Research Priorities: Improve Health Professional Education

CURRENT KNOWLEDGE

- Identification of knowledge gaps across health professions
- Assessment of attitudes and beliefs of health professionals about epilepsy and the impact on stigma and care access and quality

EDUCATIONAL PROGRAMS

- Interventions and incentives to expand the reach of education and training outside the epilepsy field
- Curricula and content of advanced training programs for physicians, nurses, and physician assistants
- Innovative teaching strategies
- Educational and training opportunities in epilepsy centers
- Interventions and resources focused on communication skills

Research Priorities: Improve Quality of Life

INTERVENTIONS

- Interventions to identify academic problems and improve achievement
- Factors that increase the resiliency of the individual and family and of behavior that improves quality of life

COMMUNITY SERVICES

- Evaluations of programs that assess outcomes
- Effectiveness of vocational rehabilitation programs
- Creative and innovative models of funding community service providers and collaborations
- Performance indicators for vocational and other community services and independent living programs

Research Priorities:

Improve Education for Patients and Their Families

CURRENT KNOWLEDGE

- Information needs of specific subpopulations
- Information needs associated with epilepsy-related risks

EDUCATIONAL PROGRAMS

- Best practices, strategies, formats, and mechanisms for educating people with epilepsy and their families
- Knowledge base to support comprehensive programs including epilepsy-specific and chronic care management models
- Programs and resources that reflect health literacy, cultural diversity, developmental stage, cognitive ability, and gender
- Examination of the role that materials and programs, support groups, and counseling resources may play in helping cope with stigma and related concerns

Research Priorities: Raise Public Awareness

CURRENT KNOWLEDGE

- Trends in knowledge and awareness and attitudes and beliefs over time and in subpopulations
- Evaluation of websites seeking to promote accurate knowledge about epilepsy to determine effective strategies for educating the public through online resources

CAMPAIGNS

- Evaluation of public awareness campaigns

For More Information

- Free PDFs of the report are available:
www.iom.edu/epilepsy
- Twitter hashtag:
#IOMepilepsy
- Questions:
epilepsy@nas.edu

