

# **ACQUIRED BRAIN INJURY in MASSACHUSETTS**

a report generated in response to and requested by the

## **Brain Injury Commission**



**Massachusetts Department of Public Health**



**Massachusetts Rehabilitation Commission**

**October 2014**

# **ACQUIRED BRAIN INJURY in MASSACHUSETTS**



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**John Polanowicz, Secretary of Health and Human Services**

**Cheryl Bartlett, Commissioner of Public Health**

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**October 2014**

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## EXECUTIVE SUMMARY

### Introduction

In fiscal year 2011, a Brain Injury Commission was established by legislative action. Governor Deval L. Patrick appointed the members of this Commission, who included persons with acquired brain injury, state agency representatives, family members of persons with ABI, and providers of community-based brain injury services within the Commonwealth of Massachusetts. The Commission, which held monthly public meetings, identified gaps in service delivery, and other needs, as well as challenges, experienced by Massachusetts residents who had experienced an ABI. These service needs and associated recommendations are detailed in the Commission's final report, which may be accessed at [www.mass.gov/hhs/braininjurycommission](http://www.mass.gov/hhs/braininjurycommission).

One recommendation prioritized by the Commission was to complete an epidemiological study of ABI in Massachusetts. The findings of the proposed study were judged to be critical to informing the development of long-term community-based support services for both adults and children living with acquired brain injury. To this end, the Executive Office of Health and Human Services (Disability Policies and Programs) requested that the Massachusetts Rehabilitation Commission, in collaboration with the Massachusetts Department of Public Health, design and complete an epidemiological study of the ABI population in Massachusetts, including an estimate of the magnitude of the population; affected age groups; region of residence; and other pertinent descriptive information for the major subcategories of ABI, including traumatic, neoplastic, infectious, vascular, and metabolic causes of acquired brain injury.

This report entitled *Acquired Brain Injury in Massachusetts* is intended for use by state agency administrators and program staff; legislators and other policymakers; educators; clinicians and other providers of brain injury rehabilitation and other services; brain injury advocacy groups; persons living with acquired brain injury, their families and significant others. In addition to fulfilling the Brain Injury Commission's recommendation to complete this epidemiological study, it is hoped that the findings included in this report will serve to improve and inform programs and services designed to enhance the quality of life of persons living with ABI in Massachusetts.

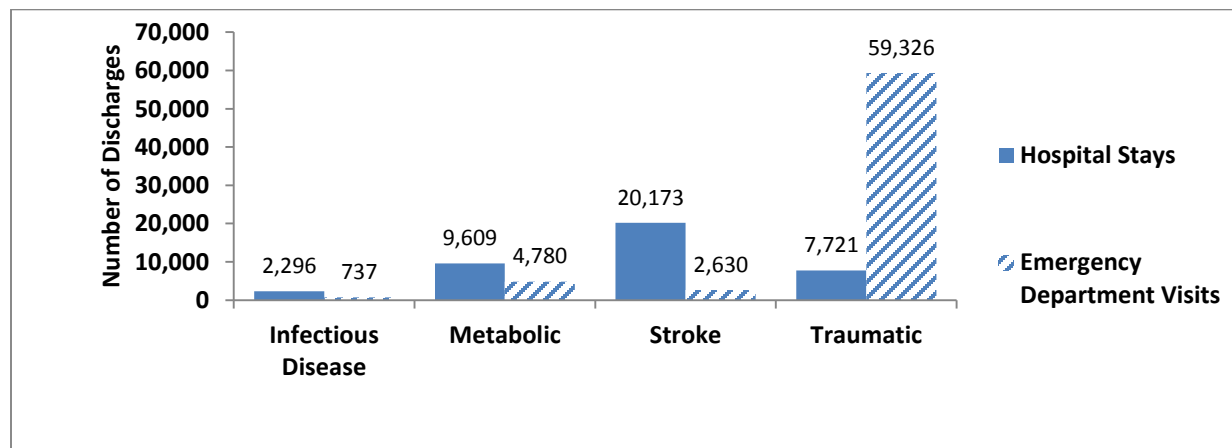
## Methodology

The Massachusetts data sources selected and methodology utilized in this report were established through joint meetings between the epidemiology staff at the Massachusetts Department of Public Health (MDPH) and authors from the Massachusetts Rehabilitation Commission (MRC). For traumatic, infectious, vascular, and metabolic causes of acquired brain injury, the Massachusetts statewide inpatient hospital discharge, outpatient observation stay and emergency department discharge databases were utilized. The Massachusetts Cancer Registry (MCR) was utilized to quantify neoplastic causes of acquired brain injury. National consensus definitions were used to define particular conditions where they existed. Where they did not (i.e., infectious and metabolic disorders associated with ABI), the MDPH epidemiologists worked with authors from the MRC to identify the most appropriate inclusion criteria. Since no data sources were able to be identified for developing statewide estimates of Massachusetts residents with neurodegenerative or neurotoxic conditions (with the exception of childhood lead exposure), only national estimates were provided for these subcategories.

## Summary of Data Findings

Acquired brain injury (ABI), as defined in Chapters III A- III H in this report, is a substantial public health problem in Massachusetts. Figure A summarizes the average annual number of hospital stays and emergency department visits (2008-2010), associated with selected categories of ABI, including traumatic brain injury, stroke, ABI-related infectious diseases, and metabolic disorders affecting the central nervous system. During the same time period, 1,272 primary brain tumors were newly diagnosed in Massachusetts residents on average, annually.

**Figure A. Average Annual Number of Hospital Stays and Emergency Department Visits Associated with Select Categories of ABI, MA Residents, 2008-2010**



Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis

Note: Categories are not mutually exclusive.

The findings in this report indicate that all demographic subgroups and geographic regions of MA are impacted. By age group, the majority of hospital stays for metabolic disorders affecting the central nervous system, stroke, and TBI were among persons 60 years of age or older. These older adults represented 50% of hospital stays for TBI; 84% for stroke; and 58% for metabolic disorders affecting the CNS. In addition, approximately 50% of both malignant and benign brain tumors are newly diagnosed in adults 60 years or older. Children and young adults (i.e., ages 0-21 years of age) accounted for an average of 17% of the hospital stays and 40% of the emergency department visits for ABI associated with traumatic brain injury annually.

A substantial proportion of individuals with acquired brain injury are covered by public payer sources (i.e., Medicaid, Medicare, Free Care/Health Safety Net, Other Government Payment, and Commonwealth Care). Further, the majority of inpatient hospitalizations associated with TBI, infectious-disease related ABI, metabolic disorders affecting the CNS and stroke did not result in the individuals being transferred to either a rehabilitation hospital or rehabilitation unit within a hospital. Most resulted in the individual being discharged home without services or with in-home services (i.e., IV therapy services), including 54% of those with a diagnosis of TBI; 50% of those with a diagnosis of stroke; and 70% of those with an infectious disorder affecting the CNS.

## Limitations of Findings

These data are subject to numerous limitations, including but not limited to:

- The MA inpatient hospital, outpatient observation stay and emergency department discharge databases do not provide information on the initial encounter for a given problem. Individual people are also difficult to separate out using these databases as there are no names and limited identifiers. **Therefore, hospitalization and emergency department visit counts presented in the tables do not necessarily represent unique individuals or incident (new) cases of a specific condition.** Note: This differs from the counts presented in the chapter on central nervous system neoplasms, which *do* reflect incident (new) cases.
- For all of the Massachusetts data presented, the severity and long-term outcomes of the brain insult/injury are not known. While the “discharge disposition” is available through the hospital databases, for individuals who die or who are not discharged to home, the factors contributing to this status may or may not be related to the brain injury.
- Massachusetts residents receiving care at an out-of-state hospital are not included in the totals for traumatic brain injury, stroke, and infectious diseases and metabolic disorders affecting the central nervous system. This may particularly impact the number and rates of individuals who reside in cities and towns which closely border neighboring states.

- Data from federal (including the Veteran's Health Administration-VHA), freestanding psychiatric or rehabilitation hospitals and freestanding emergency departments are not included.
- The data on traumatic brain injury, stroke, and infectious diseases and metabolic disorders affecting the central nervous system are based on billing and other administrative purposes. Although the codes utilized to identify a case were submitted by hospitals with trained medical records coders, cases receiving a diagnosis code for any particular condition have not been validated with the actual medical record.
- The Massachusetts Cancer Registry is a population-based surveillance database which captures nearly all incident cases of brain and central nervous system (CNS) tumors among Massachusetts residents in addition to primary cancers from all other parts of the body. Other than matching annually with the Massachusetts death file to determine cases that died, the MCR is not a follow-up database, and therefore, does not track the metastasis of disease, such as lung cancer that spread to the brain. Brain and CNS tumor data are only for primary tumors originating in the brain and central nervous system.

## **CHAPTER I: BRAIN INJURY COMMISSION HISTORY**

The Brain Injury Commission (BIC) was established during the Fiscal Year 2011 budget process in order to identify the gaps in service delivery for Massachusetts residents who exhibit a history of acquired brain injury (ABI). The BIC was co-chaired by State Senator Harriette Chandler and Representatives Thomas Conroy and Kimberly Ferguson. The membership, appointed by Governor Deval L. Patrick, consisted of representatives of the Executive Office of Health and Human Services (EOHHS) and other Massachusetts human services agencies; individuals who experienced an ABI and family members; and community-based brain injury service providers, including representatives from acute care and rehabilitation hospitals.

The Commission began its work in February of 2011 and met monthly through September, 2011. During the initial meetings of the Brain Injury Commission, members developed and reached consensus regarding the intent and focus of the Commission, which is summarized in the following Mission Statement:

To advance the present scope of community-based long-term supports and services available to individuals with brain injury in Massachusetts by providing an analysis of current services, quality of service delivery, the related needs and gaps relative to access, capacity and resources, and to subsequently develop a series of prioritized recommendations for system change with a focus on positive outcomes for affected individuals.

Over the course of the Commission meetings, community-based long-term supports and services were operationally defined to encompass a wide range of post-acute services and program models, including but not limited to, rehabilitative and other day programs (e.g., recreation/social programs); residential supports and programs; case management; respite and other family support services. The target population identified by the Commission membership was adults, ages 18 to 59 years of age. However, there was recognition by all Commission members that individuals with ABI in both the pediatric and older adult populations exhibit significant needs that was determined to be outside the BIC's focus and scope of activities.

Strategies for accomplishing the BIC's goals included an investigation of currently available services, both private and public, for persons with ABI in Massachusetts; identification of obstacles and challenges to accessing needed services; and review of current and potential funding sources. In addition, the Commission convened regional meetings in an effort to reach out to a diverse group of providers, as well as individuals and family members impacted by brain injury, to ensure that individuals representing all the regions of the Commonwealth were involved in discussions. All Commission meetings were open to the public and included opportunities for public input and more specifically, segments of two meetings were designated as community forums. The content of presentations made to the Commission and other information were also posted on the Executive Office of Health and Human Services website to ensure broad public access. A comprehensive report summarizing the Brain Injury Commission's activities, membership, invited presentations, summary of findings and recommendations can be accessed at [www.mass.gov/hhs/braininjurycommission](http://www.mass.gov/hhs/braininjurycommission).



With respect to the purposes and scope of this report, the BIC recognized the need for current information regarding the epidemiology of acquired brain injury in Massachusetts, which had not been comprehensively ascertained and analyzed since 1988. The Commission, therefore, recommended that an epidemiological study of ABI in Massachusetts be developed and completed by the Massachusetts Department of Public Health (MDPH), in collaboration with the Massachusetts Rehabilitation Commission (MRC). The scope of this study was to determine the magnitude of the ABI population in Massachusetts, including affected age groups, their region of residence, as well as racial and ethnic distribution, for all major categories of acquired brain injury, which are defined in Chapter II and comprehensively discussed in Chapters III B through III H of this report.

## CHAPTER II: ACQUIRED BRAIN INJURY: AN OVERVIEW

Acquired brain injury (ABI) refers to a wide range of disorders and diseases affecting the central nervous system (CNS), and specifically the cerebral cortex or hemispheres, cerebellum, and subcortical structures, including the diencephalon and brain stem (see diagram A). While an ABI can occur at any age beginning in the newborn or perinatal period, most individuals who sustain an ABI are adults. The sequelae, or consequences, of ABI are also related to their severity and the sites within the brain, and other sites within the CNS, that are affected which may be focal, multifocal and in some instances diffuse. The acute presentation and long-term outcome are also disease-specific and related to etiology, described below.

### Acquired Brain Injury Subtypes

More detailed information regarding the causes and related epidemiology of each of the types of acquired brain injuries is included in Chapters III B through III H of this report. The major subcategories of ABI include:

**Infectious:** This category includes infectious diseases affecting the CNS.

**Metabolic:** Refers to disorders affecting the brain, which may be related to systemic disease (e.g., cardiovascular), nutritional deficiencies, and endocrine disorders. One of the leading causes of metabolic disorders of the CNS is anoxia (diminished oxygen levels).

**Neoplastic:** This category includes primary (i.e., arising within the CNS) and secondary tumors of the brain. Secondary tumors represent metastases (spread) of cancer from a primary site (e.g., lung) to the brain.

**Neurotoxic:** Refers to brain injury related to toxins, poisons, alcohol and illicit drug abuse.

**Neurovascular:** The leading cause of neurovascular insults to the brain is stroke, the second leading cause of ABI. This category also includes other diseases and conditions affecting the blood supply to the brain.

**Traumatic:** Traumatic brain injury (TBI), an externally caused ABI, is the leading cause of acquired brain injury. The most common cause of TBI is falls. Other external mechanisms include, but are not limited to, motor vehicles, firearms, and strikes by an object or person.

Individuals who sustain an ABI may experience residual disorders and impairments. Over time, and with the benefit of rehabilitation, recovery and improvement may occur. However, within each ABI subcategory certain diseases and disorders may be progressive, evidenced in a typically gradual decline in cognitive status (dementia) and functional capacity (see Chapter III H for discussion of Progressive Disorders associated with ABI).

## Consequences of Acquired Brain Injury

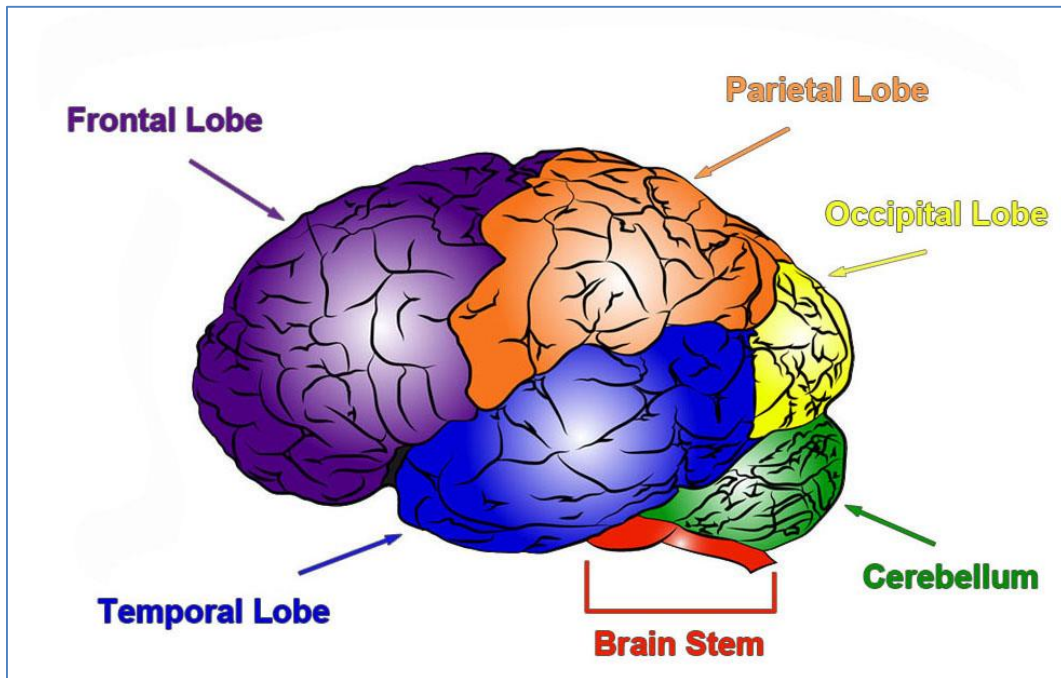
Individuals who sustain an ABI may exhibit residual disabilities which necessitate timely recognition and rehabilitation, as well as long-term supports and services to facilitate optimal independent functioning and quality of life, and to prevent secondary disabilities (e.g., muscle contractures related to lack of physical therapy) and in some instances, inappropriate placement in institutionalized settings. The reader is referred to the references cited at the end of this chapter for a more comprehensive review of the neurological, neurocognitive and neurobehavioral consequences of ABI and their treatment. However, detailed below are descriptions of some of the common disorders and impairments associated with ABI (areas of the brain referenced are depicted in Diagrams A and B).

**Motor Impairments:** Acquired brain injuries affecting the area of the brain that controls voluntary movement (i.e., *precentral gyrus* in the frontal lobe), or the descending pathway (*pyramidal tract*) arising from that area, result in contralateral paralysis (i.e., paralysis on the opposite side of the body). Injury and diseases affecting other parts of the brain, including the basal ganglia, cerebellum, and brain stem structures (e.g., *substantia nigra* and dopamine pathway) are associated with disturbances in the regulation and control of motor movements, or *extrapyramidal* disorders. Extrapyramidal symptoms include tremor; abnormal muscle tone; ataxia (incoordination); involuntary movement (e.g., chorea); gait disorder; slowness (*bradykinesia*) and decreased movement (*akinesia*); and *dysarthria* (inarticulate verbal output). Cerebral palsy (CP) is the most common motor disability in childhood, affecting an estimated 1 in 323 children in the United States. Cerebral palsy, which may result in paralysis and other disorders of movement (i.e., extrapyramidal symptoms), is associated with several risk factors (e.g., prematurity, low birth weight) and ABI, including anoxia (lack of oxygen) and stroke in the newborn or early developmental period.<sup>1</sup>

Physical and occupational therapy are critical in addressing the motor disorders described above; for optimizing function and capacity for independently performing activities of daily living, or ADLs (e.g., bathing and other self-care); and for preventing secondary physical disabilities (e.g., muscle contractures; skin breakdown) in the acute and post-acute stages of recovery. For some individuals, orthopedic treatment (e.g., serial casting to improve and maintain range of motion: ROM) and surgical intervention (e.g., implantation of a Baclofen pump to address spasticity) may be required. Ongoing physical medicine and rehabilitation services and therapeutic interventions are also important, with respect to maintaining functional capacity in the years following an ABI. When indicated, an assessment for assistive technology needs (e.g., mobility devices) should be explored, and for some, long-term neurological follow-up, monitoring, and medication management may be required (e.g., individuals with Parkinson Disease).

**Neurocognitive Disorders:** Persons who sustain an ABI may experience a generalized impairment of cognitive capacity, which in adults may present as a progressive dementia. Children rarely exhibit progressive dementia, but moderate/severe ABI sustained at an early age may result in intellectual disability, or developmental disorder, evidenced in mild to profound impairment of intellectual and adaptive functioning in the conceptual, social and practical domains (e.g., Shaken Baby Syndrome or abusive head trauma). Most commonly,

**Diagram A: Lateral Surface of Brain**



**Associated Functions**

- Frontal Lobe:** Voluntary motor movement; eye gaze; working memory; organization of sequential movement; ability to establish, maintain and shift cognitive set; regulation of behavior; executive skill; expressive language (Broca's area)\*
- Parietal Lobe:** Processing of sensory information (e.g., touch) and proprioception (e.g., position sense); ability to perform mathematical calculations and cognitive-linguistic skill (e.g., reading)\*; spatial orientation and perception; constructional skill
- Temporal Lobe:** Verbal and non-verbal memory and learning; primary auditory cortex; emotional responses to stimuli; processing and recognition of auditory stimuli; comprehension of language (Wernicke's area)\*
- Occipital Lobe:** Primary visual cortex; processing and recognition of visual stimuli
- Cerebellum:** Coordination, accuracy and timing of voluntary movement; muscle tone
- Brain Stem:** Includes the midbrain, pons and medulla; motor nuclei of cranial nerves which innervate muscles which control facial expression, tongue, swallowing, verbal output, mastication, eye movement, and the thoracic and abdominal viscera (e.g., heart, lungs); sensory nuclei of cranial nerves for hearing, vestibular information (position and movement of head), taste, and sensory input from face and viscera; sleep-wakefulness

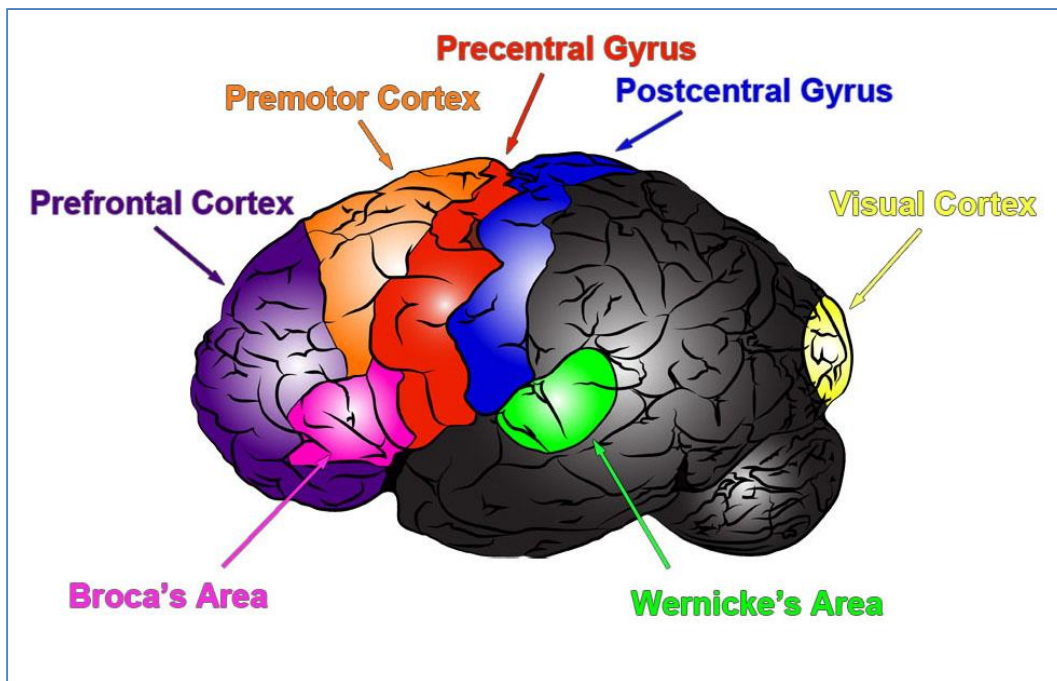
*\* Left Hemisphere*

however, individuals who experience ABI exhibit specific, acquired neurocognitive impairments related to the etiology of the ABI, and the sites and severity of injury within the brain. While individuals who sustain moderate/severe acquired brain injury are at greater risk for exhibiting residual neurocognitive impairment, certain subpopulations of persons with ABI may exhibit mild cognitive deficits which impact functioning and necessitate targeted assessment. With respect to the latter, notable subgroups include individuals living with HIV who may exhibit HIV-associated neurocognitive disorder (HAND); and individuals who exhibit persistent post-concussion syndrome, which may be related to the cumulative effects of repeated head trauma (e.g., sports concussion) or other exposures (e.g., blast injuries sustained in military combat).








Comprehensive neuropsychological evaluation is the recommended approach for identifying, characterizing, and quantifying the neurocognitive impairments associated with ABI. In addition to testing of general intellectual ability, neuropsychological evaluation includes assessment with respect to the following domains:

- *Attentional Capacity/Arousal* including assessment of verbal and non-verbal attention span and vigilance; resistance to interference from irrelevant stimuli and response inhibition; mental tracking; and capacity for divided attention.
- *Executive Skill* including ability to establish, maintain and shift cognitive set; planning and sequencing; problem-solving skill; verbal and non-verbal conceptualization skill and abstract reasoning; and social judgment.
- *Constructional Skill* including the ability to draw or assemble two and three-dimensional designs. Impairment of constructional skill, which may impact adaptive functioning, is most often associated with injury to the right hemisphere.
- *Mathematical Skill* including administration of auditory and written calculation tests. Impairment of capacity to perform mathematical operations and calculations is referred to as *dyscalculia* and is usually associated with injury to the left side of the brain. Injury to the right hemisphere may also result in *spatial dyscalculia* evidenced in the impaired ability to accurately compute written calculations, secondary to spatial deficits. Spatial dyscalculia is often associated with impairment of constructional skill.
- *Language and Cognitive Linguistic Skill* including assessment of expressive and receptive language skill; naming; verbal fluency; reading and spelling skill. An ABI with lateralized injury to the left hemisphere (side) of the brain may result in *aphasia* or *dysphasia*, an acquired disorder of language and verbal output, which may be fluent (e.g., *Wernicke's aphasia*) or non-fluent (e.g., *Broca's aphasia*). In addition to fluency, other qualities of verbal output may be affected by ABI, including impaired articulation (*dysarthria*) and abnormalities in the pitch, rhythm and melody of speech, referred to as *dysprosodia*. These disorders may occur in association with injury to other sites within the brain, as well as the left hemisphere. Difficulty with naming (*anomia* or *dysnomia*) and word retrieval are common language disorders associated with ABI. Aphasia and left hemisphere injury may also be associated

**Diagram B: Primary Sensory, Motor and Other Selected Functional Areas of the Brain (Left Lateral Surface)**



**Impairment related to site and potentially associated with ABI**

	<b>Prefrontal Cortex:</b>	Personality change; executive skill deficits; diminished cognitive flexibility; compromised capacity to initiate and sustain goal-directed behavior; behavioral disinhibition; attentional deficits; diminished verbal and non-verbal fluency
	<b>Premotor Cortex:</b>	Dyspraxia; difficulty with establishing motor set and/or intention
	<b>Precentral Gyrus:</b>	Contralateral (opposite side) paralysis of voluntary movement
	<b>Broca's Area:</b>	Broca's (non-fluent) aphasia
	<b>Postcentral Gyrus:</b>	Contralateral (opposite side) loss of sensation
	<b>Wernicke's Area:</b>	Wernicke's (fluent) aphasia
	<b>Visual Cortex*:</b>	Visual field impairment

*\*NB: visual cortex includes areas surrounding calcarine sulcus on medial surface of cerebral hemisphere-not shown*

with impairment of reading skill (*dyslexia*) and/or spelling skill. Individuals who exhibit aphasia and other disorders of language and verbal output also necessitate evaluation by a speech and language pathologist to elucidate the nature of the acquired language impairment, as well as to develop and provide appropriate therapeutic interventions.

- *Learning and Memory* includes administration of verbal and non-verbal measures of immediate (short-term), working and long-term memory, as well as tests of verbal and non-verbal learning and recall, retrieval, and/or recognition tasks. Individuals with ABI may exhibit difficulty with remembering events experienced, or information learned, prior to sustaining an ABI (retrograde amnesia) and/or difficulty with making new memories following injury (anterograde amnesia). Some memory disorders are associated with progressive disorders, while others are transient, such as loss of memory associated with seizure activity (transient epileptic amnesia: TEA) or transient global amnesia (TGA), which may be associated with a history of migraine headaches, mild traumatic brain injury and other factors, though the exact cause is unknown. Depending upon the cause of the ABI and associated sites and severity of injury to the brain, a range of amnesic disorders may occur, including impairment of semantic memory (facts, concepts and symbols); autobiographical memory (self-knowledge); episodic memory (events, plans); and/or procedural memory (temporally-ordered motor sequences or habits).
- *Orientation* includes an individual's knowledge of general, personal, and temporal information, as well as topographical (e.g., orientation to home and neighborhood) and directional (right-left orientation) ability.
- *Perception* includes performance on auditory, visual and tactile (haptic) tasks. Individuals with ABI may also exhibit disorders of complex processing, or *agnosias*, referring to the loss of the ability to recognize or comprehend perceived stimuli, which cannot be explained on the basis of a primary sensory loss, aphasia, dementia, delirium or other mental status changes. For example, individuals with *prosopagnosia*, a type of visual *agnosia*, are unable to recognize familiar faces or learn to recognize new faces; they may also fail to recognize stimuli within a class of objects (e.g., specific types of birds among a class of birds).
- *Praxis* refers to the ability to correctly execute motor commands and other purposeful actions. *Dyspraxia* refers to impairment of these functions, which cannot be explained on the basis of a primary motor impairment (i.e., paralysis), aphasia, dementia, delirium or other mental status disturbance.

Based upon comprehensive assessment of the neurocognitive, and when indicated, acquired language disorders associated with ABI, cognitive rehabilitation therapy may be recommended to promote recovery and to assist in developing appropriate compensatory strategies for individuals with persistent neurocognitive impairments. When indicated and applicable, assistive technology devices may be utilized to address the neurocognitive deficits associated with ABI, and to optimize performance of instrumental activities of daily living (IADL) tasks (e.g., adhering to prescribed medical directives and medications, such as insulin regimen and other aspects of diabetes management).

**Neuropsychiatric Disorders:** The same range and types of psychiatric disorders exhibited among the general population may also be diagnosed in persons who sustain an ABI. One of the leading types of psychiatric conditions is mood disorder, which affects approximately 21 million Americans, or 9.5% of the U.S. population.<sup>2</sup> Depression, which in part may be correlated with the neuropathological changes evidenced in certain neurological diseases (e.g., frontal lobe stroke), is the most common mood disorder associated with ABI. Personality change, common among individuals who experience a traumatic brain injury, is associated with injury to the prefrontal cortex (PFC) of the brain (See Diagram B). The neurobehavioral symptoms associated with PFC injury are varied in their clinical presentation and may be evidenced in disinhibition (e.g., impulsivity, aggression); difficulties initiating and maintaining goal-directed behavior (*abulia* or apathy); sexual and social inappropriateness; suspiciousness or paranoia; attentional disorder and other neurocognitive impairments (e.g., executive skill deficits).

Mania and psychotic disorder, evidenced in delusions and hallucinations, are less commonly observed in persons with ABI, but may be associated with certain diseases, including the progressive, degenerative disorders (e.g., HIV-associated dementia). Individuals who sustain an ABI in certain psychologically-traumatizing contexts (e.g., combat-related TBI) are also at particular risk for developing Posttraumatic Stress Disorder (PTSD). The presence of a premorbid (i.e., prior to ABI) psychiatric or developmental disorder; predisposing genetic factors or family history of mental illness; and substance abuse may complicate and/or increase the risk for developing a neuropsychiatric disorder in persons who have experienced an ABI. Individuals who exhibit neurobehavioral/neuropsychiatric sequelae of ABI necessitate evaluation and, when indicated, ongoing treatment by neuropsychologists, behavioral psychologists, psychiatrists or neuropsychiatrists. When undiagnosed and unaddressed, the neurobehavioral consequences of ABI place individuals and others at risk (e.g., suicide attempt or aggression), including risk for institutionalization and incarceration.

**Sensory Impairment:** Acquired brain injuries affecting the primary sensory areas of the brain (See Diagram B), associated cranial nerves or ascending sensory pathways to these areas, may result in permanent sensory loss. Sensory deficits may include:

- Contralateral (opposite side of body) loss of touch, vibration sense, perception of movement and the position of limbs and other body parts (i.e., conscious proprioception) may occur with injury to the primary sensory cortex (*post-central gyrus*) in the parietal lobe or ascending sensory pathways.
- Blindness may result from injury to the retina or optic nerve (Cranial Nerve II), which partially crosses (decussates) in the brain. Injury to the nerve after it crosses, or injury to the visual (*calcarine*) cortex in the occipital lobe may result in visual field impairments, evidenced in contralateral loss of vision in half or a quarter of the visual field. Common causes of visual field impairments include stroke and traumatic brain injury, while the most common cause of acquired blindness in adults is diabetic retinopathy. Blindness, secondary to retinal hemorrhages, may also be a consequence of abusive head trauma (i.e., Shaken Baby Syndrome). Acquired loss of color vision (*achromatopsia*) may also be associated with ABI.



- Hearing loss and other auditory disorders may occur as a result of damage to the auditory nerve (Cranial Nerve VIII), ascending auditory pathway, or auditory cortex within the temporal lobe of the brain (i.e., *transverse gyri of Heschl*). Acquired hearing loss may be a consequence of abusive head trauma in infants and children, exposure to neurotoxins, brain infection or a brain stem tumor affecting CN VIII (e.g., acoustic neuroma).
- *Anosmia*, or the loss of sense of smell, is associated with injury to the olfactory nerve (Cranial Nerve I). A common cause of unilateral or bilateral anosmia is traumatic brain injury.

Depending upon the nature of the sensory impairments associated with ABI clinical evaluation by several specialists may be indicated, including a neurologist, audiologist, or neuro-ophthalmologist.

**Other Sequelae Associated with ABI:** Other consequences of ABI may include seizures, chronic pain, sleep, and headache disorders. One of the most common comorbid disorders exhibited by individuals who sustain ABI is substance abuse which, undiagnosed and unaddressed, serves to compromise recovery and functional capacity. Some individuals who sustain severe ABI fail to recover and exhibit persistent disorders of consciousness. It is estimated that approximately 315,000 individuals in the United States, 40% of whom are children, are living with a disorder of consciousness.<sup>3</sup> Common causes include traumatic brain injury and anoxia.

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## **CHAPTER III A: DATA SOURCES, METHODS and TECHNICAL NOTES**

### **Introduction:**

The Massachusetts data sources selected and methodology utilized in this report were established through joint meetings between the epidemiology staff at the Massachusetts Department of Public Health (MDPH) and authors from the Massachusetts Rehabilitation Commission (MRC). Epidemiologists who had expertise in a specific area identified the best available data sources to analyze for this report and the case inclusion criteria. National consensus definitions were used to define a particular condition where they existed. Where they did not, the MDPH epidemiologists worked with authors from the MRC to identify the most appropriate inclusion criteria. They began with a list of International Classification of Disease Ninth Revision, Clinical Modification codes (ICD-9-CM codes) <sup>1</sup> that had been used in the previous report regarding the status of people with brain injuries in Massachusetts.<sup>2</sup> These ICD-9-CM codes were subsequently adopted and are currently utilized by the Massachusetts Office of Medicaid (OOM) to determine eligibility for the Acquired Brain Injury Home and Community Based Services (HCBS) waiver programs. This list of codes was then modified in the individual chapters to reflect conditions that were specific to brain injury and conditions which impacted populations which are not covered under the waiver programs. According to the National Center for Health Statistics, CDC, ICD-9-CM is the official system of assigning codes to diagnoses and procedures associated with hospital utilization in the United States. The data sources and a more detailed description of the case definition criteria used for any specific chapter are provided in the respective data chapters.

It is important to note that for all of the Massachusetts data presented, the severity and long-term outcomes of the brain insult/injury are not known. While the “discharge disposition” is available through the hospital databases, for individuals who die or who are not discharged to home, the factors contributing to this status may or may not be related to the brain injury.

### **Data Sources and Case Definitions:**

Data sources and case definitions used for data tables in the chapters “Infectious Diseases Associated with the Central Nervous System,” “Metabolic Disorders Affecting the Central Nervous System,” “Neurovascular Diseases and Conditions,” and “Traumatic Brain Injury” include:

#### ***Inpatient Hospitalizations***

Source: Massachusetts Inpatient Hospital Discharge Database, Center for Health Information and Analysis.

#### ***Outpatient Observation Stays***

Source: Massachusetts Outpatient Observation Stay Database, Center for Health Information and Analysis.

**“Hospital Stays”** represent a sum total of inpatient hospitalizations and observation stays.

### ***Emergency Department Visits***

Source: Massachusetts Emergency Department Discharge Database, Center for Health Information and Analysis

#### Case Definitions:

*An inpatient hospitalization, observation stay and emergency department discharge associated with a traumatic brain injury* was defined as any case having an International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis code in the range listed in Appendix B-5, in any of the diagnosis fields in the database (15 fields for inpatient, 6 fields for observation stay and 6 fields for emergency department visits).

*An inpatient hospitalization, observation stay and emergency department discharge associated with an infectious disease-related acquired brain injury* was defined as any case having an International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis code in the range listed in Appendix B-2, in any of the diagnosis fields in the database (15 fields for inpatient, 6 fields for observation stay and 6 fields for emergency department visits).

*An inpatient hospitalization, observation stay and emergency department discharge associated with a metabolic disorder affecting the central nervous system* was defined as any case having an International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis code in the range listed in Appendix B-3, in any of the diagnosis fields in the database (15 fields for inpatient, 6 fields for observation stay and 6 fields for emergency department visits).

*An inpatient hospitalization, observation stay and emergency department discharge associated with a stroke and other neurovascular conditions* was defined as any case having an International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis code in the range listed in Appendix B-4, in any of the diagnosis fields in the database (15 fields for inpatient, 6 fields for observation stay and 6 fields for emergency department visits).

Additional methodology applied to above case definitions: In order to reduce duplication, inpatient cases with a discharge disposition indicating that the individual was “transferred to another short stay general hospital for inpatient care” were deleted from all tables except the table describing discharge disposition. Only Massachusetts residents are included.

Note: Since all diagnosis fields were examined for an ICD-9-CM code meeting the case definition, the counts presented in the tables in one chapter are not necessarily mutually exclusive of the counts presented in another chapter. For instance, an individual may have two types of conditions associated with a single hospital event.

Data source and case definition used for data tables in the chapter on “Central Nervous System Neoplasms” include:

### ***Tumor Counts***

Source: Massachusetts Cancer Registry, Massachusetts Department of Public Health

#### **Case Definition**

*An incident case of a tumor of the brain and CNS* was defined as any case having an International Classification of Diseases for Oncology, 3<sup>rd</sup> Edition<sup>3</sup> topography code (ICD-O) in the range listed in Appendix B-1.

#### **Population Data:**

Massachusetts population data, including totals and by sex, age groups, race/ethnicity is from the Missouri Census Data Center, accessible at: [http://mcdc.missouri.edu/websas/estimates by age.shtml](http://mcdc.missouri.edu/websas/estimates%20by%20age.shtml).<sup>4</sup> Population estimates for Executive Office of Health and Human Services Regions (EOHHS) were calculated using totals from the Missouri Census Data Center and a linear interpolation of the population distribution by EOHHS regions on the Massachusetts Community Health Information Profile (MassCHIP), an interactive downloadable query system maintained by the Massachusetts Department of Public Health.

#### **Years of Data:**

The hospital and cancer registry data presented in the data tables represents the latest three calendar years of data that were available at the time development began on the report (2008-2010).

#### **Table Groupings:**

The statistics and the demographic groupings presented in the tables across the chapters were identified as being the most relevant for service planning.

General statistics presented include: annual counts, average annual counts, percentages, and average annual crude rates. Average annual counts were rounded to the nearest whole number. As such, column numbers may not add up to the total number and column percentages may not add up to 100 due to rounding.

Average annual crude rates, which are rounded to the first decimal place, were calculated as follows:

$$\text{Average Annual Crude Rate} = \frac{\text{Average annual count of the event for 3 years}}{\text{Average annual population size for 3 years}} \times 100,000$$

The tables present crude rates, which are the actual rates and were determined to be the most useful for service planning. In some instances, “age adjusted” rates are reported in the accompanying bullets. These are not true rates but rates that adjust for age differences between different populations. These rates answer the question, “what would the rate of these events be if the populations being compared had similar age distributions?” Differences in the age distribution of populations can occur across geographic regions and racial and ethnic populations. The age adjusted rates attempt to control for these differences. All age-adjusted rates in this report have been calculated using the 2000 U.S. standard population.

Methods for grouping the cause and intent of traumatic brain injuries, displayed in Table G6, follow the recommended framework of E-code (external cause of injury code) groupings for presenting morbidity data put forth by the Centers for Disease Control and Prevention.<sup>5</sup> This can be found at [http://www.cdc.gov/injury/wisqars/ecode\\_matrix.html](http://www.cdc.gov/injury/wisqars/ecode_matrix.html)

Average annual counts, percents, and crude rates by select racial and ethnic groups are included in the data chapters. These groups include: White, non-Hispanic, Black, non-Hispanic, Hispanic, and Asian non-Hispanic. “Other and unknown” counts include discharges among patients listed as Native Hawaiian, Pacific Islander, American Indian, Alaska Native, and “other” and “unknown” race. These categories are not presented separately due to the small numbers. Executive Office of Health and Human Services administrative regions were utilized to present statistics by geographic region of residence. A geographic depiction of the cities and towns represented in each region can be found in Appendix C.

Primary payer type “categories,” shown in subchapters III C, D, F and G are based on grouping similar primary payer types (for the inpatient hospital database) or their corresponding information from the primary source of payment (for the observation stay and emergency department discharge databases).

### **Discharge Disposition:**

Discharge disposition categories for the inpatient hospital cases are displayed in the chapters “Infectious Diseases Associated with Disorders of the Central Nervous System,” “Metabolic Disorders Affecting the Central Nervous System,” “Neurovascular Diseases and Conditions,” and “Traumatic Brain Injury.” Since the level of detail on discharge disposition that is available in the inpatient hospital database is much greater than that available in either the observation stay database or the emergency department discharge database, discharge disposition tables for these chapters only provide data for inpatient hospital discharges.

The age categories presented in the disposition tables differ from the age categories presented in the demographic tables to reduce the amount of cells requiring suppression and to provide detail for the population traditionally covered by Medicare. The in-hospital death counts presented in the disposition tables do not include deaths that occur outside of

the hospital. Also, as previously stated, the deaths that occur during the hospitalization may not necessarily be related to the brain injury.

The individual discharge disposition categories that were available in the inpatient hospital database were grouped in the following manner:

<b>Disposition Category</b>	<b>Text of the Dispositions Included in this Category from the Inpatient Hospital Database</b>
In-Hospital Death	Expired (or did not recover - Christian Science Patient)
Home with or without Services	Discharged/transferred to home or self-care (routine discharge); Discharged/transferred to home under the care of organized home health service organization; Discharged/transferred to home under care of a Home IV Drug Therapy Provider; Discharged to Hospice - Home
Medicare Long Term Hospital	Discharged/transferred to a Medicare certified long term care hospital
Psychiatric Hospital	Discharged/transferred to a psychiatric hospital or psychiatric distinct part unit of a hospital
Rehabilitation Hospital or Unit	Discharged/transferred to a rehab hospital; Discharged/transferred to an inpatient rehabilitation facility (IRF) including rehabilitation distinct part units of a hospital
Rest Home	Discharged/transferred to rest home
Shelter	Discharged to Shelter
Skilled Nursing Facility	Discharged/transferred to Skilled Nursing Facility (SNF)
Short Stay Hospital	Discharged/transferred to another short-term hospital for inpatient care; Discharged/transferred to a Critical Access Hospital (CAH)
Other Facility	Discharged/transferred to an Intermediate Care Facility; Discharged/transferred to another type of institution not defined elsewhere; Discharged/transferred to a federal healthcare facility; Discharged to Hospice Medical Facility
Other	Left against medical advice; Discharge other



## Statistical Significance:

Where statistical significance is reported, the methods from the National Center for Health Statistics (NCHS) were used. These methods are presented in the following document: <sup>6</sup>

National Vital Statistics Reports, Volume 52, Number 10

Births: Final Data for 2002

By Joyce A. Martin, MPH, Brady E. Hamilton, PhD; Paul D. Sutton, PHD; Stephanie J. Ventura, MA; Fay Menacker, DrPH; and Martha L. Munson, MS;  
From the Division of Vital Statistics, NCHS.

This document is available from the following website:

<http://www.cdc.gov/nchs/products/pubs/pubd/nvsr/52/52-23.htm>

Non-overlapping 95% confidence intervals were used to determine statistical significance. When two or more statistics are determined to differ significantly they are referred to in the text with language such as “higher,” “highest,” “lower” and “lowest.” The lack of statistical significance does not mean that the differences between two statistics are not clinically or socially significant.

## Technical Notes Pertaining to the Acute Care Hospital and Emergency Department Data:

- These are population-based administrative databases which provide information on all inpatient hospital, observation stay and emergency department discharges that occur within an acute care hospital in Massachusetts. Observation stays are generally stays involving less than 24 hours of care, and may involve similar care as inpatient hospitalization; however classification may vary across hospitals and conditions.
- These databases do not provide information on the initial encounter for a given problem. Individual people are also difficult to separate out using these databases as there are no names and limited identifiers. **Therefore, hospitalization and emergency department visit counts presented in the tables do not necessarily represent unique individuals or incident (new) cases of a specific condition.**

Note: This differs from the counts presented in the chapter on central nervous system neoplasms, which *do* reflect incident (new) cases.

- Inpatient hospitalizations with a discharge disposition “Discharged/Transferred to another short-term general hospital for inpatient care” were deleted from the counts in all tables except for the disposition table, in an attempt to limit the double counting of cases.
- Transfers were not deleted from the observation stay or emergency department counts, as these databases possess a less specific discharge indicator (which may include transfers to institutions not later captured by the database such as psychiatric hospitals or other treatment facilities).

- Massachusetts residents receiving care at an out-of-state hospital are not included in the totals. This may particularly impact the number and rates of individuals who reside in cities and towns which closely border neighboring states.
- Data from federal, including the Veteran's Health Administration (VHA), freestanding psychiatric or rehabilitation hospitals and freestanding emergency departments are not included.
- These data are collected primarily for billing and other administrative purposes. They contain demographic information as well as primary and associated discharge diagnoses for the patient's condition, which are coded to the International Classification of Disease's Ninth Revision, Clinical Modification (ICD-9-CM). These databases are commonly used by states for public health surveillance.
  - Although all ICD-9-CM codes are submitted by hospitals with trained medical records coders, cases receiving a diagnosis code for any particular condition have not been validated with the actual medical record.
- The Massachusetts acute care hospital databases are mutually exclusive for single episodes of care within a particular hospital. The highest level of care for a given episode of care is the one reported. For instance, if a person is treated at the emergency department of Hospital A, and then is admitted as an inpatient to Hospital A, the patient's data would only be reported by Hospital A to the inpatient hospital database, not to the emergency department database. However, the data for a patient transferred from the emergency department of Hospital A to the emergency department of Hospital B, and released to home from the emergency department of Hospital B, would be reported by both Hospital A and Hospital B to the emergency department database.

#### **Other Technical Notes:**

- The data release guidelines, including suppression standards, are developed by the data stewards of each database. Hospital and emergency department discharge counts of 1-10 are required to be suppressed. Where row and column totals are provided, "complementary suppression" may also be applied to protect the back calculation of suppressed values.
- The statistics provided in the subsections of Chapter III under "national epidemiology," are presented in accordance with the scientific reports from which they are referenced. As such, the terminology used in presenting national race and ethnicity data in these subsections may differ from the racial and ethnic groupings and terminology used for the Massachusetts data.
- Since no data sources were able to be identified for developing statewide estimates of Massachusetts residents with neurodegenerative or neurotoxic conditions (with the exception of childhood lead exposure), these chapters largely provide national estimates.

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## CHAPTER III B: CENTRAL NERVOUS SYSTEM NEOPLASMS

### Overview:

#### National Epidemiology

Neoplastic disorders of the central nervous system (CNS) include both primary and secondary tumors:

**Primary** tumors originate from cells within the brain and other sites within the CNS and may be benign (non-cancerous) or malignant. They can also be of uncertain behavior.

**Secondary** neoplasms, all malignant, represent metastases from a primary cancer in another part of the body (most commonly lung and breast), which has invaded the nervous system. Incidence rates for secondary neoplasms vary significantly, and there is currently no mandated reporting mechanism or systematic method for ascertaining the incidence of secondary neoplasms, which are estimated to occur in 20-40% of individuals diagnosed with cancer.<sup>1</sup> In addition, the treatment and prognosis, with respect to metastatic CNS neoplasms, is significantly different than that for primary CNS neoplasms, which are the focus of this report.

While exposure to cranial radiation therapy, immunodeficiency (e.g., increased risk of lymphoma), and genetic/familial factors (e.g., neurofibromatosis, NF1 and NF2) have been linked to an increased risk for developing a brain tumor, or type of CNS neoplasm, most brain tumors are not associated with a specific etiology or known risk factors. Documented cases of malignant CNS neoplasms are found to be higher in Europe, North America and New Zealand/Australia; however, the incidence is likely underestimated in developing countries. While the incidence of brain tumors increases with advancing age, primary CNS neoplasms are the most common solid tumors observed in children, historically accounting for 15-20% of all tumors among children in developed countries, and 27% of all childhood cancers.<sup>2</sup>

The Central Brain Tumor Registry of the United States (CBTRUS), established in 1992, is the designated organization responsible for reviewing and analyzing data for all primary brain and other CNS tumors. The epidemiological data analyzed by CBTRUS is provided by the National Program of Cancer Registries (NPCR)/Centers for Disease Control and Prevention (CDC); and the Surveillance, Epidemiology and End Results (SEER) program/ National Cancer Institute (NCI). According to the most recent statistical report issued by CBTRUS in 2013, it is estimated that 66,240 new cases of primary brain and other CNS tumors will be diagnosed in 2014, of which 22,810 cases will be malignant and 43,430 will be non-malignant.<sup>3</sup> It is important to note that CBTRUS estimates include lymphomas, other hematopoietic neoplasms (e.g., leukemia), and tumors of the nasal cavity and spinal cord, in accordance with the Consensus Conference on Brain Tumor Definition.<sup>4</sup>

During the 2006-2010 time period reviewed in the CBTRUS report, the average annual age-adjusted incidence rates for primary CNS tumors were 21.0 per 100,000 population, with regional incidence rates ranging from 15.2 to 26.5 per 100,000 population. Average

annual rates for malignant tumors ranged from 5.0-8.8 per 100,000, while rates for non-malignant primary tumors ranged from 9.0 to 19.1 per 100,000 population. Females (58%) were more likely than males (42%) to be diagnosed with a primary CNS neoplasm. However, males (55%) were more likely to be diagnosed with malignant CNS neoplasms than females, who account for 64% of non-malignant primary tumors. While the median age at time of diagnosis was 59 years, persons 75 years or older had the highest incidence rate for CNS neoplasms (81.0 per 100,000 population). Children, ages 0-14 years, had the lowest incidence rate (5.1 per 100,000 population).

## CNS Tumor Subtypes

Primary tumors of the central nervous system (CNS) are classified, or coded, with reference to:

**Topography:** referring to location, or site of origin, within the central nervous system

**Behavior:** which may be benign, uncertain or malignant. Malignant CNS neoplasms rarely metastasize to structures/organs outside the CNS.

**Morphology:** which includes the cell type (histology); degree of differentiation as compared to normal tissue; and grade or degree of malignancy. Meningiomas, which arise within the coverings of the brain (meninges), and gliomas of varying grades, comprised of glial (support) or precursor (blast) cells are the most common types of brain tumors.<sup>5</sup>

According to the recent CBTRUS report, meningioma, a principally benign tumor, was the most common tumor type in the United States, accounting for approximately one third of all tumors and 53.8 % of all non-malignant tumors. Glioblastoma was the second most frequently reported tumor subtype and most common malignant tumor, accounting for 45.2% of cases; the highest incidence rate was observed in adults, 75 to 84 years of age. Overall, incidence rates for most histological subtypes were significantly higher for Whites than those observed for Blacks, American Indians/Alaskan Natives (AI/AN), and Asian/Pacific Islanders. However, Blacks had the highest incidence rates compared to other racial groups for tumors of the pituitary gland, meningiomas, and craniopharyngiomas, which arise from embryonic tissue adjacent to the pituitary gland, and are observed in both adults and children. Adults and children of Hispanic ethnicity also had significantly higher incidence rates, in comparison to non-Hispanics, for pituitary tumors. Asian/Pacific Islander and White children/adolescents (ages 0-19) had the highest incidence rates, while AI/AN children exhibited the lowest rate.

## Outcome and Potential Long-Term Consequences

Prognosis, outcome and survival for individuals diagnosed with primary CNS neoplasms are related to tumor subtype and all the associated variables reviewed above. Availability and efficacy of treatment options, including neurosurgical intervention, chemotherapy and radiotherapy are also key prognostic indicators. Regarding prevalence, the American Brain Tumor Association estimates that more than 688,000 people in the U.S. are living with a diagnosis of primary brain or other CNS tumor, and that the majority (approximately 550,000) have been diagnosed with a non-malignant CNS neoplasm.<sup>6</sup>

National survival rates for individuals with malignant brain tumors are based on the Surveillance, Epidemiology and End Results (SEER) data from 18 registries for the years 1995 to 2010. According to SEER, five-year relative survival for individuals diagnosed with malignant brain tumors from 2004 to 2010 was 35%. Individuals with glioblastomas had the poorest survival with 35% of cases alive after one year and only 4.7% after five years. Individuals with pilocytic astrocytomas had the best survival with 97.9% alive after one year and 94.4% alive after five years.<sup>1</sup>

## **Methodology:**

The data source used for most of the Massachusetts data presented in this chapter is from the Massachusetts Cancer Registry for the time period 2008-2010. Massachusetts death data are from the Registry of Vital Records and Statistics, MDPH. Additional data notes are available in Chapter III A.

The Massachusetts Cancer Registry (MCR) collects reports of newly diagnosed cancer cases from health care facilities and practitioners throughout Massachusetts, including acute care hospitals, radiation centers, endoscopy centers, surgical centers, independent laboratories, medical practice associations, radiation/oncology centers and private practice physicians, as required by Massachusetts law. Additionally, the MCR has reciprocal reporting agreements with 34 states and territories to obtain data on Massachusetts residents diagnosed out of state. Currently the MCR collects information on *in situ* and invasive cancers and benign tumors of the brain and associated tissues. Each year, the North American Association of Central Cancer Registries (NAACCR) reviews cancer registry data for quality, completeness, and timeliness. For 2008-2010, the MCR's annual case count was estimated by NAACCR to be more than 95% complete each year. The MCR has achieved the gold standard for this certification element as well as for six other certification elements for each diagnosis year since 1997.

A slightly modified version of the national ICD-O-based (International Classification of Diseases for Oncology, 3<sup>rd</sup> edition) consensus definition of topography codes defining central nervous system tumors was utilized for the purposes of this report (see Appendix B-1 for a detailed listing of these codes). Topography codes for the spinal cord, *cauda equina*, spinal meninges, nasal cavity and meninges (NOS) were excluded from the case definition in order to present data specific to brain and CNS tumors. The data analyzed were limited to brain and CNS tumors whose behavior was benign, of uncertain behavior (which includes borderline malignant, low malignant potential, uncertain malignant potential), or malignant. For the purpose of these analyses, tumor behaviors were categorized as non-malignant (including benign and uncertain) and malignant. Age group, race/ethnicity, and gender by tumor behavior were also analyzed. All counts were rounded to the nearest whole number.

**Table B1: Malignant and Non-malignant\* Brain and CNS Tumors by Anatomic Site, MA Residents, 2008-2010**

	Annual Counts			Average Annual Count***	Average Annual Percent of Total***	Average Annual Crude Rate per 100,000 persons
Site:	2008	2009	2010	2008-2010	2008-2010	2008-2010
Cerebral Meninges	448	504	432	461	34.4	7.0
Cerebrum	25	28	28	27	2.0	0.4
Frontal Lobe	154	142	122	139	10.4	2.1
Temporal Lobe	106	98	101	102	7.6	1.5
Parietal Lobe	76	66	71	71	5.3	1.1
Occipital Lobe	16	8	12	12	0.9	**
Ventricle, NOS	23	22	23	23	1.7	0.3
Cerebellum, NOS	29	35	30	31	2.3	0.5
Brain Stem	29	20	21	23	1.7	0.4
Overlapping Lesion of Brain	76	51	45	57	4.3	0.1
Brain, NOS	69	78	87	78	5.8	1.2
Olfactory Nerve	0	0	0	0	0	0
Optic Nerve	4	6	10	7	0.5	**
Acoustic Nerve	74	88	72	78	5.8	1.2
Cranial Nerves, NOS	13	10	13	12	0.9	**
Overlapping Lesion of Brain and CNS	1	1	1	1	0.1	**
Nervous System, NOS	6	4	5	5	0.4	**
Pituitary Gland	118	144	154	139	10.4	2.1
Craniopharyngeal Duct	1	1	0	1	<0.1	**
Pineal Gland	3	3	8	5	0.4	**
<b>Total</b>	<b>1,271</b>	<b>1,309</b>	<b>1,235</b>	<b>1,272</b>	<b>100</b>	<b>19.6</b>

Source: Massachusetts Cancer Registry

Notes: \*Non-malignant tumors include benign tumors and tumors of uncertain behavior. Tumors of the spinal cord/meninges, *cauda equina*, and nasal cavity are excluded.

\*\*Rates based on average annual counts 1-19 are suppressed.

\*\*\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Please note that the following statistics do not include tumors of the spinal cord, *cauda equina*, spinal meninges, nasal cavity and meninges (NOS). The most common site for a brain and CNS tumor was in the cerebral meninges (34.4% of all sites), with a crude rate significantly higher than other sites.
- Brain tumors in the lobes of the cerebrum comprised 26.2% of all tumors, making the cerebrum as a whole the second most common site. Tumors located in the frontal and temporal lobes were the most common.
- The pituitary gland was the third most common site for a brain and CNS tumor. The histology of nearly all of these tumors was benign pituitary tumors.
- Meningioma, a predominantly benign tumor found in the meninges, was the most common histological type of brain and CNS tumor diagnosed in Massachusetts from 2008 to 2010. There were 1,378 meningiomas of the brain diagnosed during this period, or 36% of all brain tumors. (Data by histology not shown in table.)

- Glioblastoma, a malignant tumor, was the second most common histological type of brain and CNS tumor with 795 cases diagnosed from 2008 to 2010, or 20.9% of all brain tumors. Most were located in the lobes of the cerebrum (81%) followed by overlapping lesion of the brain and the CNS (16%). (Data by histology not shown in table.)
- From 2008 to 2010, there were on average 421 deaths per year in Massachusetts with either malignant or non-malignant brain and CNS tumor (excluding spinal cord) as the underlying cause of death. Of these deaths, 52% were males and 48% were females (data not shown).

**Table B2: Brain and CNS Tumors by Age Group, MA Residents, 2008-2010**

<b>Non-malignant Tumors*</b>	<b>2008-2010 Average Annual Values</b>		
<b>Age Group (Years)</b>	<b>Average Annual Count***</b>	<b>Percentage of Total***</b>	<b>Average Annual Crude Rate per 100,000 persons</b>
0-2	3	0.3	**
3-5	2	0.3	**
6-18	24	3.2	2.2
19-21	8	1.0	**
22-29	32	4.2	4.5
30-39	50	6.6	6.1
40-49	110	14.6	11.1
50-59	152	20.1	16.6
60-69	157	20.8	25.8
70+	217	28.7	34.1
<b>Total</b>	<b>755</b>	<b>100</b>	<b>11.7</b>
<b>Malignant Tumors</b>	<b>2008-2010 Average Annual Values</b>		
<b>Age Group (Years)</b>	<b>Average Annual Count***</b>	<b>Percentage of Total***</b>	<b>Average Annual Crude Rate per 100,000 persons</b>
0-2	11	2.2	**
3-5	9	1.8	**
6-18	33	6.7	3.1
19-21	6	1.1	**
22-29	21	4.2	3.0
30-39	27	5.5	3.3
40-49	53	10.6	5.3
50-59	98	18.8	10.7
60-69	93	18.0	15.3
70+	164	31.2	25.7
<b>Total</b>	<b>517</b>	<b>100</b>	<b>7.9</b>

Source: Massachusetts Cancer Registry

Note: \*Non-malignant tumors include benign tumors and tumors of uncertain behavior. Tumors of the spinal cord/meninges, *cauda equina*, and nasal cavity are excluded.

\*\*Rates based on average annual counts 1-19 are suppressed.

\*\*\*Column counts may not add to total and column percentages may not add to 100 due to rounding.



- The overall crude rate of non-malignant brain tumors was statistically significantly higher compared to malignant brain tumors.
- Both non-malignant and malignant brain tumors were most common among people aged 70 years and older, with statistically significantly elevated rates compared to other age groups in both categories.
- Nearly 50% of malignant and non-malignant brain tumors occurred among people aged 60 years and older.

**Table B3: Brain and CNS Tumors by Race/Ethnicity, MA Residents, 2008-2010**

<b>Non-malignant Tumors*</b>			
<b>2008-2010 Average Annual Values</b>			
<b>Race/Ethnic Group</b>	<b>Average Annual Count**</b>	<b>Percentage of Total**</b>	<b>Average Annual Crude Rate per 100,000 persons</b>
White, non-Hispanic	641	84.9	12.6
Black, non-Hispanic	48	6.4	11.3
Asian, non-Hispanic	22	2.9	6.4
Hispanic	36	4.8	6.1
Other/Unknown	8	1.0	***
<b>Total</b>	<b>755</b>	<b>100</b>	<b>11.7</b>
<b>Malignant Tumors</b>			
<b>2008-2010 Average Annual Values</b>			
<b>Race/Ethnic Group</b>	<b>Average Annual Count**</b>	<b>Percentage of Total**</b>	<b>Average Annual Crude Rate per 100,000 persons</b>
White, non-Hispanic	466	90.1	9.0
Black, non-Hispanic	16	3.1	***
Asian, non-Hispanic	10	1.9	***
Hispanic	24	4.6	4.0
Other/Unknown	1	0.1	***
<b>Total</b>	<b>517</b>	<b>100</b>	<b>7.9</b>

Source: Massachusetts Cancer Registry

Note: \* Non-malignant tumors include benign tumors and tumors of uncertain behavior. Tumors of the spinal cord/meninges, *cauda equina*, and nasal cavity are excluded.

\*\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

\*\*\*Rates based on average annual counts 1-19 are suppressed.

- Both White and Black, non-Hispanics had significantly elevated crude rates of non-malignant brain tumors compared to malignant brain tumors.
- White, non-Hispanics had significantly elevated crude rates of malignant brain tumors compared to Hispanics. The counts for Black, non-Hispanics and Asian, non-Hispanics were too small to compare rates.

**Table B4: Brain and CNS Tumors by Sex, MA Residents, 2008-2010**

Non-malignant	2008-2010 Average Annual Values		
Sex	Average Annual Count	Percentage of Total**	Average Annual Crude Rate per 100,000 persons
Male	276	36.6	8.8
Female	479	63.4	14.2
<b>Total</b>	<b>755</b>	<b>100</b>	<b>11.7</b>
Malignant Tumors	2008-2010 Average Annual Values		
Sex	Average Annual Count	Percentage of Total**	Average Annual Crude Rate per 100,000 persons
Male	274	52.9	8.6
Female	243	47.1	7.2
<b>Total</b>	<b>517</b>	<b>100</b>	<b>7.9</b>

Source: Massachusetts Cancer Registry

Notes: \*Non-malignant tumors include benign tumors and tumors of uncertain behavior. Tumors of the spinal cord/meninges, *cauda equina*, and nasal cavity are excluded.

\*\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- While there was no statistically significant difference in sex for malignant brain tumors, females had a significantly elevated crude rate for non-malignant brain tumors.

**Table B5: Insurance at Diagnosis for All Brain and CNS Tumors, MA Residents, 2008-2010**

<b>Payer Type Category</b>	<b>Percent**</b>
Medicaid***	7.4
Medicare***	30.2
Medicare/Medicaid	3.2
Private Insurer	44.2
Insurance, NOS	9.2
Other Government Payment	0.2
Free Care or Health Safety Net	0.8
Commonwealth Care Plans*	Unknown
Self Pay	0.3
Unknown	4.6

Source: Massachusetts Cancer Registry

Notes: \*Commonwealth Care was not collected as an insurance category from 2008-2010.

Tumors of the spinal cord/meninges, *cauda equina*, and nasal cavity are excluded.

\*\*Percentages may not add up to 100 due to rounding.

\*\*\*Exclusive of cases listed as Medicare/Medicaid.

- The most common payer at diagnosis for brain tumor cases was private insurance (44.2%), followed by Medicare (30.2%). Medicare includes Medicare alone, Medicare administered through a private insurance, and Medicare with a private supplement.

### **Summary of Findings:**

- During the period 2008 to 2010, the average annual number of brain and CNS tumors outside of the spinal cord diagnosed and reported to the MCR was 517 for malignant tumors and 755 for non-malignant tumors.
- While the majority of these non-malignant brain and CNS tumors were located in the meninges, the acoustic nerve, or the pituitary gland, the majority of malignant tumors were located in the lobes of the cerebrum.
- Nearly half of all these brain and CNS tumors were diagnosed among people age 60 years and older. Approximately four percent of non-malignant brain tumors and ten percent of malignant brain tumors were diagnosed among those ages 18 years and younger.
- While there was no statistically significant difference in sex for these malignant brain and CNS tumors, females had a statistically significantly elevated crude rate for non-malignant brain tumors.
- From 2008 to 2010, there were on average 421 deaths per year in Massachusetts with either malignant or non-malignant brain and CNS tumor (outside the spinal cord) as the underlying cause of death. Of these deaths, 52% were males and 48% were females.

## Limitations:

While the MCR is a population based surveillance database which captures nearly all incident cases of brain and CNS tumors among Massachusetts residents, it is not a follow up database. The only follow up that occurs is an annual match with death data from the Massachusetts Registry of Vital Records and Statistics to determine if a case has died. As a result of this lack of follow up, it is not possible to track metastases to the brain from other primary sites, the most common being lung, breast, colorectal, and skin.

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## CHAPTER III C: INFECTIOUS DISEASES ASSOCIATED WITH DISORDERS OF THE CENTRAL NERVOUS SYSTEM

### Overview:

#### National Epidemiology

This category of acquired brain injury (ABI) includes diseases caused by a variety of infectious agents (e.g., bacteria, viruses), which invade the central nervous system (CNS) and produce an inflammatory response in the brain. Disorders are generally categorized as:

**Meningitis** referring to an inflammation of the coverings (meninges) of the brain

**Encephalitis** referring to an inflammation of the brain

**Meningoencephalitis** referring to an inflammation of both the brain and meninges

**Encephalomyelitis** referring to an inflammation of both the brain and spinal cord

CNS infectious disorders may be classified as primary, resulting from an agent that causes primary infection of the brain, or secondary, a systemic infection that also affects the brain. Some secondary agents affecting the CNS (e.g., neurosyphilis), which may become manifest after a prolonged incubation period, are also progressive and associated with dementia (see chapter regarding Progressive Disorders of the CNS). Other infectious processes may be chronic or recurrent (e.g., infection of shunt placed in the brain for treatment of hydrocephalus) or circumscribed, causing focal neurological deficits (e.g., tuberculoma of the CNS, abscess). Certain CNS and peripheral nervous system (PNS) inflammatory disorders also represent reactivation of an infectious agent, such as the varicella-zoster virus (VZV) which causes chickenpox and may later cause herpes zoster (shingles), most commonly diagnosed in persons ages 60 years and older.

The epidemiology of CNS infectious disorders varies with respect to the infectious agent, age, season, gender, and geography. The route of infection is also varied (i.e., respiratory, body fluids, fecal-oral, mosquito-transmitted, etc.), as is the likelihood of acquisition of infection, which may also be related to an individual's living situation (e.g., students in college dormitories who have higher risk for meningococcal meningitis). Historically, the incidence of infectious disorders has also fluctuated and, in part, has been related to epidemics, as well as the availability of effective preventative measures, prophylactic treatment and vaccines (e.g., syphilis, tuberculosis meningitis, polio, *Haemophilis influenzae b*). For example, prior to the 1960s and the development of the measles vaccine, approximately 4 million cases of measles were reported annually in the U.S. Of these, 400-500 died; 48,000 were hospitalized; 1,000 developed encephalitis; and 7,000 developed post-infectious seizure disorders. Currently and contrastingly, there has been an average of approximately 60, mostly imported, reported cases annually in the U.S., although recently there have been several outbreaks. It is important to note, in this regard, that 20 million cases of measles continue to be reported worldwide, resulting in 164,000 deaths per year. <sup>1</sup>

Individuals who are immunocompromised (e.g., individuals on cancer chemotherapy or with uncontrolled HIV infection; transplant recipients) are at greater risk for secondary opportunistic CNS infections, as well as direct infection of the brain that may occur with the human immunodeficiency virus (HIV). It is estimated that more than 1.1 million individuals (13 years of age and older), including an approximate 16% who are unaware of their infection, are living with HIV in the U.S. It is estimated that 50% of adults who develop acquired immune deficiency syndrome (AIDS), as a result of HIV infection, will exhibit HIV-related neurological complications, in addition to increased risk for other CNS infections and conditions, including neoplasms (e.g., lymphoma), degenerative spinal cord disease (e.g., vacuolar myelopathy), neuropsychiatric disorders and dementia: i.e., AIDS dementia complex (ADC) or HIV-associated dementia (HAD). Children with HIV infection are also at risk for exhibiting developmental disorders, smaller than normal skull size (microcephaly) and vacuolar myelopathy.<sup>2</sup> Since the introduction and availability of highly active antiretroviral therapy (HAART), also known as combination antiretroviral therapy (CART), mortality, medical morbidity and the incidence of dementia (ADC/HAD) related to HIV infection has been reduced significantly. However, HIV-associated neurocognitive disorders (HAND), evidenced in disorders of memory, learning and executive skill, have been documented to persist at high rates in individuals in all stages of HIV disease, including those who are medically asymptomatic and have viral suppression and improved immune status achieved in response to HAART.<sup>3</sup>

### CNS Infection Subtypes

The categories of infectious agents affecting the CNS include the following:

**Viral:** Aseptic meningitis is usually caused by enteroviruses, but many other viruses and other agents can cause aseptic meningitis. Causes of viral encephalitis include rabies, arboviruses (e.g., West Nile virus) and herpes simplex (types 1 and 2). In Massachusetts, the arbovirus, eastern equine encephalitis virus, is a rare but catastrophic cause of brain injury. Herpes simplex encephalitis (HSE) is the most commonly documented sporadic (non-epidemic) cause of encephalitis and accounts for 10% of all cases of encephalitis. As noted above, HIV, a type of retrovirus, may also be a cause of primary CNS infection. It is important to note, however, that up to 70-75% of encephalitis cases remain undiagnosed, as to specific cause.

**Bacterial:** Pneumococcal meningitis is the most common and most severe form of bacterial meningitis, with 6,000 cases reported annually in the United States. Meningococcal meningitis, a highly contagious disease, affects 2,600 individuals annually, with higher risk observed in college students living in dormitories, infants, and persons with compromised immunity.<sup>4</sup> Lyme disease, a bacterial infection, may also cause meningitis and encephalitis. Approximately 30,000 cases of Lyme disease are reported to the CDC annually, and thirteen states, including Massachusetts, account for 95% of Lyme disease cases.<sup>5</sup>

**Fungal:** The most common fungal meningitis and encephalitis are caused by *Cryptococcus neoformans*, which is most often diagnosed in persons with immune compromise, but can also occur in healthy individuals. There are other fungi which can cause CNS infections that occur in specific geographic regions. Fungal meningitis is frequently recurrent (50% of individuals).

**Parasitic:** The one-celled parasite *Toxoplasma gondii* can cause CNS and eye infections in neonates and other individuals. Other parasites include cysticercosis, caused by larval cysts of the pork tapeworm, and cerebral malaria. While these disorders are rare among the U.S. population, exposure may occur when traveling outside the U.S.

**Prions:** Prion diseases, also referred to as transmissible spongiform encephalopathies (TSEs), are rare degenerative, fatal disorders of the CNS, caused by an abnormal proteinaceous infectious agent (i.e., prion protein or PrP). Prion diseases primarily occur sporadically, but may also be inherited or acquired through exposure to contaminated instruments or biologic products (e.g., transplant tissue or organs). Examples of human prion diseases include classic Creutzfeldt-Jakob disease (CJD) and variant (vCJD), resulting from exposure to beef products affected by bovine spongiform encephalopathy (BSE), or “mad cow” disease. From 1979 through 2006, there have been approximately 7,000 deaths in the U.S. related to classic CJD, with most cases occurring in persons 65 and older.<sup>6,7</sup>

### Outcome and Potential Long-Term Consequences

Mortality and residual neurological sequelae exhibited in individuals who experience CNS infection are disease-specific and also dependent upon age; severity of infection; timeliness of diagnosis; availability of effective treatment options; general health and, in particular, immunocompetence. The prevalence of permanent neurological, neurobehavioral, and neuropsychological impairments among survivors has not, for the most part, been quantified or systematically documented. For some categories of CNS infection (e.g., viral meningitis), most individuals will not experience significant residual disabilities; however, a small percentage may exhibit post-infectious neurocognitive disorders, which serve to diminish functional capacity.<sup>8</sup> As noted above, persons living with HIV infection, and others with compromised immunity (e.g., persons receiving chemotherapy or prescribed steroids) are at greater risk for developing neurological consequences related to CNS infection.

### Methodology:

The data sources used for most of the Massachusetts data provided in this chapter are from the Massachusetts Inpatient Hospital Discharge, Outpatient Observation Stay, and Emergency Department Discharge Databases which are described in detail in Chapter IIIA. Although the etiologic agents associated with many of the conditions examined in this chapter are reportable to the Massachusetts Department of Public Health under Massachusetts Law, CNS manifestations associated with these infections are not directly reportable and not completely ascertained.

The ICD-9-CM codes utilized to define infectious diseases associated with disorders of the CNS are listed in detail in Appendix B-2. Since there was no available national consensus definition on which to base the analyses, authors began with the list of ICD-9-CM diagnostic codes specific to infectious conditions utilized in the previous MRC-MDPH epidemiology study of ABI. These were subsequently adopted and currently utilized by the Massachusetts Office of Medicaid (OOM) to determine eligibility for the Acquired Brain Injury Home and Community-Based Services (HCBS) waiver programs. The HCBS ABI diagnostic code list was modified for the purposes of this report to also include ICD-9-CM codes representing infectious-related progressive disorders associated with dementia. Codes representing peripheral neuropathies and unspecified or specified complications of

infectious disease (e.g., chickenpox with unspecified complication) were excluded, as documentation of an ABI could not be determined in the absence of a comprehensive review of the medical record or post-acute follow-up assessment, which is the process utilized for eligibility determination for the HCBS waivers.

The resulting list of ICD-9-CM codes was used to develop counts and rates of inpatient hospitalizations, observation stays and emergency department discharges associated with infectious disease-related ABI among Massachusetts residents. A discharge with any of these codes in any discharge diagnosis field of the state databases represented a case associated with infectious disease-related acquired brain injury.

**Table C1. Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with Infectious Disease-related Acquired Brain Injury, MA Residents, 2008-2010**

<b>Data Source</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>Average Annual Count**</b>	<b>Average Annual Percent of Total Events**</b>	<b>Average Annual Crude Rate per 100,000 persons</b>
Inpatient Hospitalizations	2,311	2,173	2,014	2,166	71.4	33.2
Observation Stays	148	143	100	130	4.3	2.0
<b>Total Hospital Stays (Inpatient + Observation)</b>	<b>2,459</b>	<b>2,316</b>	<b>2,114</b>	<b>2,296</b>	<b>75.7</b>	<b>35.2</b>
Emergency Department Visits	743	976	491	737	24.3	11.3
<b>Total Events (Hospital Stays, ED Visits)</b>	<b>3,202</b>	<b>3,292</b>	<b>2,605</b>	<b>3,033</b>	<b>100</b>	<b>46.5</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Over the three year period analyzed, there was an average of 2,296 hospital stays and 737 emergency department discharges annually for infectious disease-related ABI among MA residents.
  - Observation stays made up 5.7% of the total average annual hospital stays. These are generally short duration stays, averaging 33.2 hours.
- The mean and median lengths of stay for inpatient hospitalizations in 2010 were 8.5 days and 4 days, respectively (data not shown).
- Approximately one third of hospital stays associated with infectious disease-related ABI were for viral meningitis, which is less likely to be associated with long term neurologic impairments and need for supportive services (data not shown).



**Table C2. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Infectious Disease-related Acquired Brain Injury, by Age Group, MA Residents, 2008-2010**

Age Group (Years)	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
0 to 2	214	9.3	97.2	38	5.2	17.3
3 to 5	55	2.4	24.7	23	3.2	10.4
6 to 18	268	11.7	24.8	125	17.0	11.6
19 to 21	82	3.6	27.4	61	8.3	20.5
22 to 29	212	9.2	29.8	140	19.0	19.7
30 to 39	259	11.3	31.2	106	14.4	12.8
40 to 49	324	14.1	32.6	99	13.4	9.9
50 to 59	323	14.1	35.3	67	9.1	7.3
60 to 69	241	10.5	39.4	39	5.2	6.3
70+	320	13.9	50.2	39	5.3	6.1
<b>Total</b>	<b>2,296</b>	<b>100</b>	<b>35.2</b>	<b>737</b>	<b>100</b>	<b>11.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- The rate of hospital stays for infectious disease-related ABI among children from birth through two years of age (97.2 per 100,000 persons) was significantly higher than the rate in any other age group.
  - Residents ages 70 years and older had the second highest rate with 50.2 hospital stays per 100,000 persons.
- Nearly half (46.8%) of the emergency department visits for infectious disease-related ABI were among residents 22-49 years of age.

**Table C3. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Infectious Disease-related Acquired Brain Injury by Sex, MA Residents, 2008-2010**

Sex	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
Male	1,134	49.4	36.9	358	48.6	11.3
Female	1,163	50.6	33.7	379	51.4	11.3
<b>Total</b>	<b>2,296</b>	<b>100</b>	<b>35.2</b>	<b>737</b>	<b>100</b>	<b>11.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Males and females represent nearly equal proportions of both hospital stays and emergency department visits associated with infectious disease-related ABI.

**Table C4. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Infectious Disease-related Acquired Brain Injury, by Race/Ethnicity, MA Residents, 2008-2010**

Race/Ethnic Group	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
White, NH	1,604	69.8	31.5	509	69.1	10.0
Black, NH	255	11.1	58.3	65	8.8	14.9
Hispanic	262	11.4	43.0	99	13.4	16.2
Asian, NH	64	2.8	17.6	24	3.3	6.6
Other/Unknown	112	4.9		40	5.4	
<b>Total</b>	<b>2,296</b>	<b>100</b>	<b>35.2</b>	<b>737</b>	<b>100</b>	<b>11.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis. Column percent totals may not add up to 100 due to rounding.

Notes: Other and unknown race counts include discharges among patients listed as Native Hawaiian, Pacific Islander, American Indian or Alaska Native, "other" race and unknown race; rates are not able to be calculated for this category.

'NH' indicates non-Hispanic.

\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Black, non-Hispanics had the highest crude rate of hospital stays associated with infectious disease-related ABI (58.3 per 100,000 persons), followed by Hispanics (43.0 per 100,000 persons). Asian, non-Hispanics had the lowest crude rate.
  - There was no difference in the rankings of rates by race and ethnicity after age-adjustment (data not shown).
- Hispanics and Black, non-Hispanics also had higher crude rates of emergency department visits for these conditions, 16.2 and 14.9 per 100,000 persons, respectively, compared with White, non-Hispanics and Asian, non-Hispanics.

**Table C5. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Infectious Disease-related Acquired Brain Injury, by Executive Office of Health and Human Services (EOHHS) Region of Residence, MA Residents, 2008-2010**

EOHHS Region of Residence	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
I. Western	278	12.1	33.4	54	7.3	6.5
II. Central	290	12.6	33.9	84	11.4	9.8
III. Northeast	435	18.9	33.8	139	18.9	10.8
IV. MetroWest	500	21.8	33.1	204	27.8	13.5
V. Southeast	430	18.7	33.9	133	18.1	10.5
VI. Boston Region	364	15.9	47.5	122	16.6	15.9
<b>Total</b>	<b>2,296</b>	<b>100</b>	<b>35.2</b>	<b>737</b>	<b>100</b>	<b>11.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding. Totals may include cases of unknown region of residence.

- Residents of the Boston region had the highest average annual crude hospital stay rate for infectious disease-related ABI, 47.5 per 100,000 persons. There was no significant difference between annual hospital stay rates across all other regions, where rates were approximately 33 per 100,000 persons.
  - After age adjustment, hospital stay rates remained highest in Boston region residents.
- More than one quarter (27.8%) of the emergency department visits for infectious disease related ABI were among residents of the MetroWest region.

**Table C6. Average Annual Primary Payer Type Category for Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with Infectious Disease-related Acquired Brain Injury, MA Residents, 2008- 2010**

<b>Payer Type Category</b>	<b>Percent of Inpatient Hospitalization Total</b>	<b>Percent of Observation Stay Total</b>	<b>Percent of Emergency Department Visit Total</b>
Medicaid	19.8	24.6	21.0
Medicare	22.6	12.8	10.8
Commercial Insurer	50.6	54.2	52.8
Other Government Payment	0.8	**	**
Free Care or Health Safety Net	3.1	**	6.2
Worker's Comp	**	0.0	**
Auto Insurance	**	**	**
Commonwealth Care Plans	2.0	**	2.3
Self Pay	0.9	**	5.3

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes:\*\* denotes suppressed values reflecting a percentage based on a count of 1-10.

- Commercial insurers were the primary payers listed for at least half of inpatient hospitalizations (50.6%), observation stays (54.2%), and emergency department visits (52.8%) associated with infectious disease-related ABI.
- Medicare was the second most common primary payer category for inpatient hospitalizations (22.6%), while Medicaid ranked second for observation stays (24.6%) and emergency department visits (21%).
- The percent of discharges where the primary payer was Free Care or Health Safety Net was 6.2% for emergency department visits and 3.1% for inpatient stays.

**Table C7. Average Annual Inpatient Hospitalizations Associated with Infectious Disease-related Acquired Brain Injury by Discharge Disposition Category and Age Group, MA Residents, 2008-2010**

Disposition Category	Age Category				
	0-21 years	22-49 years	50-64 years	65+ years	Total
In-Hospital Death	1-10	**	25	40	88
Home with or without Services	536	616	273	163	1,588
Medicare Long Term Hospital	1-10	**	14	16	43
Other†	1-10	16	1-10	1-10	24
Other Facility‡	13	1-10	1-10	1-10	32
Psychiatric Hospital	1-10	1-10	0	1-10	1-10
Rehabilitation Hospital or Unit	1-10	**	62	56	177
Rest Home	0	0	0	1-10	1-10
Shelter	0	0	0	0	0
Skilled Nursing Facility	1-10	**	48	128	204
Short Stay Hospital	34	35	25	23	117
Total	<b>607</b>	<b>778</b>	<b>459</b>	<b>437</b>	<b>2,281</b>

Source: MA Inpatient Hospital Discharge Database, Center for Health Information and Analysis.

Notes:\*\* denotes complementary suppressed values to protect calculation of values in the cells with a count of 1-10. Total includes all dispositions except cases of unknown disposition.

† “Other” includes “left against medical advice” and “discharge other.”

‡ “Other Facility” includes intermediate care facility, hospice medical facility, federal healthcare facility and “another type of institution not defined elsewhere.” Additional detail on disposition categories can be found in Chapter III A.

- The majority (69.6%) of inpatient hospitalizations resulted in patients being discharged to home, with or without services; 8.9% were discharged to a skilled nursing facility, 7.8% were discharged to a rehabilitation hospital, and 5.1% were discharged to a short stay hospital.
- Approximately four percent (3.9%) of inpatient hospitalizations associated with infectious disease-related ABI during this period resulted in the patient dying during the hospitalization.

### Summary of Findings:

- Infectious disease-related ABI accounted for an average of 2,296 hospital stays and 737 emergency department discharges annually in MA for the time period studied.
- Many infectious disease-related ABI discharges resulted from infections not likely to cause long-term impairment (data not shown).
- The sizable discrepancy between mean (8.5 days) and median (4 days) length of stay reflects high degree of variability in severity and duration of illness among individuals with infectious disease-related ABI.

- Hospital stay rates were highest in the youngest (0-2 years of age) and oldest (70 years and older) age groups.
- Black, non-Hispanics and Hispanics had higher crude rates of hospital stays and emergency department visits associated with infectious disease-related ABI compared with White, non-Hispanics and Asian, non-Hispanics.
- Boston region residents had the highest crude rate of hospital stays associated with infectious disease-related ABI compared with other regions.
- Commercial insurers were the primary payer for inpatient hospitalizations (50.6%), observation stays (54.2%) and emergency department visits (52.8%) associated with infectious disease-related acquired brain injury.
- Most persons with discharges associated with infectious disease-related acquired brain injury treated in the inpatient setting were discharged home; 7.8% were discharged to rehabilitation hospitals; and another 16% were discharged to facilities providing specialized care, such as skilled nursing facilities, short stay hospitals, and Medicare long-term hospitals.

#### **Limitations:**

- Although the etiologic agents associated with many of the included discharge codes are reportable to the Massachusetts Department of Public Health under Massachusetts Law, CNS manifestations associated with these infections are not directly reportable. Supplemental clinical information gathered on reported cases does not comprehensively cover all possible complications, and surveillance data may be incomplete due to a variety of factors. In addition, some of the included conditions manifest after the initial infection and after MDPH follow-up is complete. For these reasons, infectious disease surveillance data were determined not to be sufficient for this report.
- These data provide only an estimate of total discharges for infectious disease-related ABI, with limited information in regards to severity or duration of impairment. As noted above, the high degree of variability in patient outcomes presents a challenge for assessment of services required by patients with a discharge for infectious disease-related ABI.
- As there are no ICD-9-CM codes which specify HIV or Lyme Disease encephalopathy, data related to these disorders are not included in the discharge data analyzed.

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## **CHAPTER III D: METABOLIC DISORDERS AFFECTING THE CENTRAL NERVOUS SYSTEM**

### **Overview:**

#### National Epidemiology

Acquired metabolic disorders of the central nervous system (CNS) are associated with systemic conditions (e.g., organ failure), as well as endocrine, nutritional and toxic disorders. The neurological consequences are often generalized and referred to as metabolic encephalopathies, although for some disorders focal neuropathological changes, or lesions may occur in the context of a diffuse insult to the brain.

With the exception of studies conducted on selected clinical populations, currently in the U.S. there is no centralized or mandated reporting mechanism, with respect to the metabolic encephalopathies. Thus, national incidence and prevalence estimates, and other population-based demographics are not available with respect to individuals who exhibit acquired metabolic disorders affecting the CNS. However, the leading cause of metabolic encephalopathy is anoxia or hypoxia, referring to an absent or diminished oxygen supply to the brain. The brain accounts for 2% of body weight, but utilizes 20% of the oxygen supply, most of which is used by the gray matter, or cell bodies of cerebral neurons (nerve cells). The brain is exquisitely sensitive to the absence of oxygen, and cell death resulting in significant brain injury may occur after only several minutes of oxygen deprivation. Heart disease is the leading cause of death in the U.S. (approximately 600,000 annually), and cardiovascular events are also a significant cause of anoxic brain injury. In 2013 more than 568,000 individuals sustained a cardiac arrest, while 720,000 experience a myocardial infarction (heart attack) annually.<sup>1, 2</sup> While most individuals who sustain an out-of-hospital cardiac arrest are over the age of 60 years, adolescents and young adults 15 to 34 years of age have been demonstrated to be at increasing risk, particularly African American youth who participate in sports activities.<sup>3, 4</sup>

#### Acquired Metabolic Encephalopathy Subtypes

The major categories of acquired metabolic disorders affecting the CNS are reviewed below:

##### **A. Anoxic Encephalopathy**

Anoxic/hypoxic disorders and asphyxia (diminished oxygen and excess carbon dioxide, or hypercapnia) may be associated with acute events (e.g., cardiac arrest) or chronic medical conditions (e.g., chronic obstructive pulmonary disease-COPD); may be caused accidentally or intentionally (e.g., suicide attempt by hanging); and may result in permanent neurological consequences (e.g., persistent disorder of consciousness), or reversible neurological and neurobehavioral findings. The anoxic/hypoxic disorders are categorized as follows:

**Anoxic Anoxia:** This type of anoxia/hypoxia occurs when environmental oxygen is diminished, as can occur at high altitudes, resulting in cognitive and mental status changes, which are often reversible, but dependent upon duration and severity, may result in anoxic brain injury.



## Anoxic – Ischemic Encephalopathy:

Diminished oxygen levels and blood flow to the brain (ischemia) characterize this disorder. Causes include cardiac arrest, heart attack (myocardial infarct), congestive heart failure, severe anemia, and peripheral circulatory failure (shock). Anoxic-ischemic encephalopathy can also occur in response to respiratory compromise or arrest; traumatic asphyxia, intentional (e.g., strangulation) or accidental; diseases which paralyze the respiratory muscles (e.g., Guillain-Barre syndrome); pulmonary disease (e.g., COPD); complications of anesthesia; and choking incidents. With respect to the latter, adults who are elderly, prescribed psychiatric medications, intoxicated or edentulous, as well as persons with neurological disorders, are at greater risk for asphyxiation by choking on food, or a so-called “café coronary.” Children under the age of one year who ingest small, round cylindrical foods (e.g., hot dog pieces) are also at greater risk for food-related asphyxia.

Suffocation can also occur in children who are accidentally entrapped in refrigerators; ingest uninflated balloons; or are subjected to intentional and unintentional strangulation or suffocation. At least 1600 deaths related to infant suffocation occur annually in the U.S., and infants who sleep with their parents are estimated to be 20 times more at risk for suffocation than infants who sleep alone.<sup>5</sup> Older children and youth (ages 6-19 years), who are predominantly male (87%), are also at risk for death and significant hypoxic brain injury secondary to the “choking game,” and each year more than 1,000 people die accidentally from engaging in controlled strangulation during sexual activity, or autoerotic asphyxia.<sup>6, 7</sup>

**Histotoxic Hypoxia/Anoxia:** This category includes anoxia/hypoxia associated with toxic exposure (e.g., cyanide; carbon monoxide), which may be accidental or intentional (e.g., suicide attempt). (See chapter regarding Neurotoxic Disorders for discussion of toxic encephalopathy).

**Hypoxic Ischemic Encephalopathy (HIE):** This type of anoxic/ischemic disorder is associated with intrapartum asphyxia and hypoxia. The incidence of HIE at term is estimated to be 2.5 per thousand live births in developed countries.<sup>8</sup> Significant sequelae may include intellectual disability, seizures and cerebral palsy.

**Overutilization Anoxia:** This type of anoxia is related to prolonged seizure activity (i.e., status epilepticus).

## B. Endocrinopathies

Approximately 26 million people, representing 8.3% of the population, have diabetes, the most common endocrine disease, and it is anticipated that the incidence of diabetes will double in the next 25 years. Currently, 10-15% of diabetics have Type I (“juvenile onset”) diabetes, which is usually diagnosed before age 20 years, but can occur at any age. Type I diabetes is caused by a lack of insulin due to destruction of insulin-producing cells in the pancreas. Type II diabetes is related to insulin resistance and associated with obesity and other risk factors (e.g., race). Neurological consequences of diabetes include peripheral neuropathy, stroke, and retinopathy, the leading cause of acquired blindness in persons, aged 20 to 74 years.<sup>9</sup> Metabolic encephalopathy may also occur and be associated with an accidental or intentional overdose of insulin or anti-diabetic agent resulting in low blood sugar and hypoglycemic encephalopathy, which may also be caused by other conditions

(e.g., protracted intoxication). Hyperglycemic encephalopathy may result from elevated blood sugar. Both hyperglycemia and hypoglycemia may result in diffuse brain injury, coma and other disorders of consciousness.

Other diseases affecting the endocrine organs, including the thyroid, adrenal, and parathyroid glands, as well as the neuroendocrine system (i.e., pituitary gland and hypothalamus within the brain), may result in a range of neuropsychiatric and neurocognitive disorders.

### **C. Nutritional Disorders Associated with Encephalopathy**

Malnutrition and vitamin deficiencies may result in developmental disorders, polyneuropathies, optic neuropathy, and degenerative neurological disorders associated with dementia. For example, Combined Systems Disease, which results from an acquired defect in the intestinal absorption of Vitamin B12, results in degenerative spinal cord disease and progressive neurocognitive impairment. A common disorder associated mostly, but not exclusively, with chronic alcoholism, malnutrition, and thiamine deficiency, is Wernicke's disease, or encephalopathy, associated with oculomotor abnormalities, gait disorder, mental status changes and residual amnesic disorder (Korsakoff psychosis).

### **D. Systemic Diseases Associated with Encephalopathy**

Organ diseases may also result in metabolic encephalopathy, which includes hepatic encephalopathy associated with Reye Syndrome in children and adolescents; and in adults, cirrhosis of the liver, and other chronic liver diseases. Uremic encephalopathy is associated with acute or chronic renal disease. Metabolic encephalopathy may also be associated with electrolyte abnormalities (e.g., elevated or diminished sodium levels), dialysis treatment (dialysis encephalopathy or dementia) and systemic infection (sepsis). <sup>10</sup>

### **Outcome and Potential Long-Term Consequences**

Mortality and outcome related to the metabolic encephalopathies are disease-specific and also dependent upon the severity of the metabolic disturbance, general health, underlying cause, timely diagnosis and intervention, which in some cases may result in reversal of symptoms (e.g., intervention to correct hypoglycemia). The neuropathological findings and residual neurobehavioral, neurocognitive, and sensorimotor impairments associated with the metabolic disorders affecting the CNS are also disease/disorder-specific. Metabolic encephalopathies are also associated with mental status changes, including psychosis, and disorders of consciousness, which may be transient (e.g., confusion, delirium) or permanent (e.g., irreversible coma). In some instances, individuals may exhibit progressive neurological deficits (see chapter on Progressive Disorders of the CNS) after a period of apparent recovery (e.g., delayed post-anoxic encephalopathy). <sup>11</sup>

**Methodology:**

Massachusetts does not possess a registry of all persons identified with metabolic conditions affecting the central nervous system. To estimate the magnitude of this category of ABI in Massachusetts, the statewide inpatient hospital, outpatient observation stay and emergency department discharge databases were analyzed. These databases are described in detail in Chapter III A.

The ICD-9-CM codes utilized to define metabolic conditions associated with disorders of the CNS are listed in Appendix B-3. Since there was no available national consensus definition on which to base the analyses, authors began with the list of ICD-9-CM diagnostic codes specific to metabolic conditions utilized in the previous MRC-MDPH epidemiology study of ABI. These were subsequently adopted and currently utilized by the Massachusetts Office of Medicaid (OOM) to determine eligibility for the Acquired Brain Injury Home and Community-Based Services (HCBS) waiver programs. The HCBS ABI diagnostic code list was modified for the purposes of this report to also include ICD-9-CM codes representing metabolic disorders with onset in childhood (e.g., respiratory arrest of the newborn); metabolic conditions associated with coma (e.g., secondary diabetes mellitus with coma); hepatic encephalopathy; and diagnoses known to be associated with anoxia (e.g., cardiac arrest). ICD-9-CM codes associated with neurotoxic disorders of the CNS and codes associated with toxic metabolic encephalopathy or encephalitis were excluded, and these disorders are discussed in Chapter III E (Neurotoxic Disorders).

**Table D1. Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with Metabolic Disorders Affecting the Central Nervous System, MA Residents, 2008-2010**

<b>Data Source</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>Average Annual Count*</b>	<b>Average Annual Percent of Total Events*</b>	<b>Average Annual Crude Rate per 100,000 persons</b>
Inpatient Hospitalizations	8,565	9,316	10,234	9,372	65.1	143.8
Observation Stays	218	228	267	238	1.7	3.7
<b>Total Hospital Stays (Inpatient + Observation)</b>	<b>8,783</b>	<b>9,544</b>	<b>10,501</b>	<b>9,609</b>	<b>66.8</b>	<b>147.5</b>
Emergency Department Visits	4,865	4,767	4,707	4,780	33.2	73.3
<b>Total Hospital-treated Events (Hospital Stays, ED Visits)</b>	<b>13,648</b>	<b>14,311</b>	<b>15,208</b>	<b>14,389</b>	<b>100</b>	<b>220.8</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- On average, there were 9,609 hospital stays and 4,780 emergency department visits for a total of 14,389 hospital-treated events annually related to metabolic disorders affecting the central nervous system among MA residents during the period 2008-2010.
- Fewer than two percent (1.7%) of total hospital stays for these conditions were discharged from an observation stay bed. These were generally short duration stays.
- The average annual inpatient hospitalization rate associated with metabolic conditions affecting the central nervous system was approximately twice the average annual emergency department discharge rate (143.8 vs. 73.3 per 100,000 persons).

**Table D2. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Metabolic Disorders Affecting the Central Nervous System by Age Group, MA Residents, 2008-2010**

Age Group (Years)	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
0 to 2	110	1.1	50.0	81	1.7	37.0
3 to 5	17	0.2	7.6	18	0.4	7.9
6 to 18	95	1.0	8.8	120	2.5	11.1
19 to 21	44	0.5	14.9	74	1.5	24.8
22 to 29	162	1.7	22.9	251	5.2	35.3
30 to 39	306	3.2	36.9	301	6.3	36.2
40 to 49	1,145	11.9	115.3	520	10.9	52.3
50 to 59	2,139	22.3	234.1	754	15.8	82.6
60 to 69	1,805	18.8	295.4	742	15.5	121.4
70+	3,786	39.4	594.4	1,919	40.1	301.3
<b>Total</b>	<b>9,609</b>	<b>100</b>	<b>147.5</b>	<b>4,780</b>	<b>100</b>	<b>73.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding. Totals include cases with unknown age.

\*\*Rates based on counts <20 are considered unstable.

- The highest rate of hospitalization stays were among residents 70 years of age and older, with a rate more than four times as high of the population as a whole.
  - The leading diagnoses associated with these hospital stays in this age group were associated with metabolic encephalopathy (37.6%) and cardiac arrests (30.2%) (data not shown).
  - Adults aged 60 to 69 years and 50 to 59 years had the second and third highest rates, respectively.
- Similar to the hospital stay rate, the highest rate of emergency department discharges were among residents 70 years or older, with a rate more than four times as high as the general population.
  - The vast majority (93.7%) of these emergency department discharges were associated with cardiac arrests (data not shown).
  - Adults aged 60 to 69 years and 50 to 59 years had the second and third highest rates, respectively.

**Table D3. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Metabolic Disorders Affecting the Central Nervous System by Sex, MA Residents, 2008-2010**

Sex	Average Annual Hospital Stay Count*	Percent of Total Hospital Stay*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
Female	4077	42.4	121.2	1750	36.6	52.0
Male	5532	57.6	175.5	3029	63.4	96.1
<b>Total</b>	<b>9,609</b>	<b>100</b>	<b>147.5</b>	<b>4,780</b>	<b>100</b>	<b>73.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding. Totals include cases with unknown gender.

- Overall, males had a higher rate of hospital stays and emergency department visits for these conditions compared to their female counterparts.

**Table D4. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Metabolic Disorders Affecting the Central Nervous System by Race and Ethnicity, MA Residents, 2008-2010**

Race/Ethnic Group	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
White, NH	7,814	81.3	153.3	3,997	83.6	78.5
Black, NH	652	6.8	149.3	287	6.0	65.7
Hispanic	651	6.8	106.9	225	4.7	36.9
Asian, NH	168	1.8	46.6	50	1.0	13.8
Other/Unknown	324	3.4		221	4.6	
<b>Total</b>	<b>9,609</b>	<b>100</b>	<b>147.5</b>	<b>4,780</b>	<b>100</b>	<b>73.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes: Other and unknown race counts include discharges among patients listed as Native Hawaiian, Pacific Islander, American Indian or Alaska Native, "other" race and unknown race; rates are not able to be calculated for this category.

'NH' indicates non-Hispanic.

\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Crude hospital stay rates among White, non-Hispanics and Black, non-Hispanics were higher than Asian, non-Hispanics and Hispanics.

- After age adjustment, Black, non-Hispanics and Hispanics had higher age-adjusted rates compared to White, non-Hispanics and Asian, non-Hispanics (data not shown).
- White, non-Hispanics had the highest crude rate of emergency department visits for these conditions compared to Black, non-Hispanics, Hispanics, and Asian, non-Hispanics.
  - After adjustment for age, Black, non-Hispanics had the highest rates compared to other racial/ethnic groups (data not shown).

**Table D5. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with Metabolic Disorders Affecting the Central Nervous System by Executive Office of Health and Human Services (EOHHS) Region of Residence, MA Residents, 2008-2010**

EOHHS Region	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
I. Western	1,301	13.5	156.6	730	15.3	87.8
II. Central	1,076	11.2	126.0	646	13.5	75.7
III. Northeast	1,963	20.4	152.7	926	19.4	72.1
IV. MetroWest	1,721	17.9	113.8	946	19.8	62.6
V. Southeast	2,451	25.5	193.4	1113	23.3	87.8
VI. Boston Region	1,093	11.4	142.7	415	8.7	54.2
<b>Total</b>	<b>9,609</b>	<b>100</b>	<b>147.5</b>	<b>4,780</b>	<b>100</b>	<b>73.3</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding  
Totals include cases with unknown EOHHS region.

- Residents of the Southeast region had the highest average annual crude rate of hospital stays related to these conditions while residents of the Central and MetroWest regions had the lowest crude rate of hospital stays.
  - After age adjustment, residents of the Southeast and Boston regions had the highest average annual rate of hospital stays, while residents of the Metro West region had the lowest rate of hospital stays (data not shown).
- Residents of the Southeast and Western regions had the highest average annual crude rate of emergency department visits, while residents of the Boston region had the lowest crude rate of emergency department visits.

- After age adjustment, residents of the Southeast and Western regions had the highest rate of emergency department visits, while residents of the MetroWest region had the lowest age-adjusted rate of emergency department visits (data not shown).
- Regional differences in rates may reflect differences not controlled for during age adjustment and/or care provided outside the state and not captured by these databases.

**Table D6. Average Annual Primary Payer Type Category for Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with Metabolic Disorders Affecting the Central Nervous System, MA Residents, 2008-2010**

Payer Type Category	Percent of Inpatient Hospitalization Totals	Percent of Observation Stay Totals	Percent of Emergency Department Visit Totals
Medicaid	15.8	28.6	12.4
Medicare	59.3	39.8	50.3
Commercial Insurer	19.7	23.3	23.9
Other Government Payment	1.2	0.7	1.1
Free Care or Health Safety Net	1.4	1.4	1.8
Worker's Compensation	0.2	3.0	2.8
Auto Insurance	0.2	0.0	1.2
Commonwealth Care Plans	1.4	2.0	1.3
Self Pay	0.8	1.3	5.2

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column percentages may not add to 100 due to rounding and unknown values excluded from the table.

- Medicare was the primary payer listed for more than half (59.3%) of inpatient hospitalizations related to metabolic disorders affecting the central nervous system, while commercial insurers and Medicaid ranked second and third (19.7% and 15.8%, respectively).
- Medicare was also the leading primary payer for observation stays (39.8%) and for emergency department visits (50.3%) with Medicaid (28.6%) and commercial insurers (23.9%) ranked second for each, respectively.



**Table D7. Average Annual Inpatient Hospital Discharges Associated with Metabolic Disorders Affecting the Central Nervous System, by Discharge Disposition Category and Age Group, MA Residents, 2008-2010**

Disposition Category	Age Category				
	0-21 years	22-49 years	50-64 years	65+years	Total
In- Hospital Death	63	326	628	1,468	2,484
Home with or without Services	146	771	1,445	1,107	3,469
Medicare Long Term Hospital	1-10	**	82	99	234
Psychiatric Hospital	1-10	46	30	**	110
Rehabilitation Hospital or Unit	14	98	172	279	564
Rest Home	1-10	1-10	1-10	1-10	1-10
Shelter	1-10	1-10	1-10	1-10	1-10
Skilled Nursing Facility	1-10	**	499	1,459	2,126
Short Stay Hospital	19	94	159	147	419
Other Facility‡	12	32	72	109	226
Other†	1-10	62	64	**	141
<b>Total</b>	275	1,644	3,161	4,711	9,791

Sources: MA Inpatient Hospital Discharge Database, Center for Health Information and Analysis.

Notes:\*\* denotes complementary suppressed values to protect calculation of values in the cells with a count of 1-10. Total includes all dispositions except cases of unknown disposition.

† "Other" includes "left against medical advice" and "discharge other"

‡ "Other Facility" includes intermediate care facility, hospice medical facility, federal healthcare facility and "another type of institution not defined elsewhere".

Additional detail on disposition categories can be found in Chapter III A.

- Approximately one-third (35.4%) of inpatient hospitalizations resulted in patients being discharge to home, with or without services; 5.8% were discharged to a rehabilitation hospital or unit, and 4.3% of patients were discharged to a short stay hospital.
- Of the inpatient hospitalizations for metabolic disorders affecting the central nervous system during this period, 25.4% resulted in the individual dying during the hospitalization.
- The mean and median lengths of stay for metabolic disorders affecting the central nervous system related inpatient hospitalizations in 2010 were 8.2 days and 5 days, respectively (data not shown).

## Summary of Findings:

- Metabolic conditions affecting the central nervous system pose a substantial public health problem with an average of 9,609 hospital stays and 4,780 emergency department visits, annually, among MA residents related to these conditions for the time period studied.
- Hospital stay and emergency department visit rates were highest among adults 70 years of age and older.
- Although 35% of persons with metabolic diseases affecting the central nervous system treated in the inpatient setting were discharged to home, many were also discharged to skilled nursing facilities (21.7%).
- Approximately one quarter (25.4%) of the total hospital stays for these conditions, resulted in death during the hospitalization.
- Medicare and Medicaid were the primary payer categories for the majority (75.1% combined) of inpatient hospitalizations and emergency department visits (62.7% combined) for these conditions.

## Limitations:

- In addition to the limitations described in Chapter III A, these data provide only crude metabolic acquired brain injury severity indicators (i.e., level of care and length of stay). More sophisticated measures, often present in statewide surveillance registries, can be useful in understanding the long-term impact of these conditions, however, Massachusetts currently does not have a registry to specifically track metabolic acquired brain injuries.
- Cases with toxic metabolic encephalopathy were excluded from this chapter since these cases encompass a broad range of disorders and conditions, described in Chapter III E regarding neurotoxic disorders affecting the CNS.
- Cases of encephalopathy related to renal, endocrine and nutritional disorders are not included in the discharge data analyzed, as no ICD-9-CM codes specifically identify these conditions.

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## CHAPTER III E: NEUROTOXIC DISORDERS

### Introduction:

This category of acquired brain injury includes a wide range of disorders associated with exposure to toxins, poisons, and infectious agents, as well as medicinal and other biological substances. Exposure may be accidental or intentional (e.g., suicide attempt), and may occur in an occupational, residential, or environmental context. The route of exposure is varied (e.g., inhalation, dermal contact, or ingestion) and for certain disorders prenatal exposure may occur (e.g., maternal exposure to lead).

Currently, there is no established centralized or mandated reporting system with respect to the majority of toxic disorders affecting the CNS. Therefore, the incidence and prevalence of neurotoxic disorders in the United States, as well as Massachusetts, is unknown. It is also important to note that for most disorders, analysis of hospital and emergency department discharge data would not adequately capture the neurological consequences of exposure to toxins as most of the International Classification of Diseases (ICD-9-CM) codes are not specific to encephalopathy and other CNS effects related to toxic exposure. Therefore, this chapter is largely descriptive of this category of neurological diseases and conditions and does not follow the format of most of the other subchapters in Chapter III.

### Neurotoxic Disorder Subtypes:

While moderate exposure to a multitude of substances may potentially result in injury to the CNS, delineated below are the major categories of toxins associated with ABI and other neurological consequences:

**Bacterial Toxins:** This category includes tetanus, which affects approximately one per million individuals annually in the United States. Exposure may be related to injection of contaminated heroin, but primarily transmitted via scratches and puncture wounds sustained in the home or garden. Less common bacterial toxins include diphtheria and botulism.

**Illicit Drugs and Alcohol:** Alcoholism and addiction to stimulants (e.g., cocaine, amphetamines); opioid drugs (e.g., heroin); and hallucinogens (e.g., mescaline, ecstasy), as well as misuse of prescribed medications (e.g., analgesics) may result in a range of neurological complications and consequences. These include brain hemorrhages; systemic disease and metabolic encephalopathy (e.g., liver failure and associated hepatic encephalopathy); and neurocognitive impairment, including dementia. Individuals who engage in IV drug abuse are also at risk for HIV infection, and if infected, transmission of the HIV to non-addicted sexual partners, as well as prenatal transmission to offspring. Drug overdose deaths have more than tripled since 1990, with the majority of the approximate 36,000 deaths in 2008 caused by prescription drugs, most commonly opioid analgesics (e.g., OxyContin). <sup>1</sup>

**Metals:** One of the leading and preventable causes of toxic encephalopathy in children, as well as adults, is lead poisoning, or plumbism. The leading cause of plumbism among children is exposure to lead paint within the home. Due to the historic implementation of statutory and regulatory initiatives associated with childhood lead poison prevention strategies, and screening and treatment guidelines established by the U.S. Centers for

Disease Control and Prevention (CDC), the incidence of significantly elevated rates of lead poisoning among young children living in Massachusetts has declined since 1995. However, in 2013, 8,263 children aged 0-72 months had lead levels higher than the most current CDC reference value of 5 µg/dL. The CDC reference value represents a level above which presents significant health concerns. This value is based on the U.S. population of children ages 1-5 years who are in the highest 2.5% of children when tested for lead in their blood as part of the National Health and Nutrition Examination Survey (NHANES). The CDC reference value will be updated every four years. It is important to note that 25% of children aged 9-48 months, including children mandated by law for screening (i.e., at 9-12, 24 and 36 months of age), were not screened for lead poisoning.<sup>2</sup> These data suggest that lead exposures still have a significant impact on public health, including the potential for toxic encephalopathy.

Other so-called “heavy” metals include mercury, thallium, cadmium, manganese and zinc, as well as inorganic phosphorous and organophosphorous compounds used in insecticides and other pesticides. Some metals are also radioactive (e.g., uranium, plutonium), and in some instances, metals have been utilized for medicinal purposes with resultant CNS consequences. For example, arsenic had been historically prescribed for the treatment of syphilis; however, currently arsenic encephalopathy is more likely to occur with accidental exposure or intentional ingestion (i.e., suicide attempt) of rodenticides or other pesticides. Other metals used for medicinal purposes include gold for treatment of arthritis, lithium, and Cisplatin, an antineoplastic agent.

**Prescribed Medications:** Prescribed medications, if taken for nonmedical purposes (e.g., abuse of prescription analgesics) or in excess, and in some instances chronically at therapeutic levels, may result in reversible or permanent neurological sequelae. These include antineoplastic agents, antipsychotics, sedative-hypnotics, and antidepressants. Treatment of psychosis with phenothiazines (e.g., Thorazine), for example, may result in extrapyramidal symptoms, such as parkinsonism and tardive dyskinesia (abnormal involuntary movements), while treatment with Haldol and phenothiazines may result in neuroleptic malignant syndrome (NMS), a potentially fatal disorder, more commonly observed in young adult males.<sup>3</sup>

**Radiation Exposure:** Injury to the CNS, which may be acute or delayed, may occur as a complication of cranial radiation treatment of brain neoplasms. Environmental exposure to radiation may also occur accidentally (e.g., nuclear plant incident) or intentionally (e.g., exposure to radioactive weapons).

**Toxic Gas Exposure:** Exposure to carbon monoxide, an odorless exogenous toxin, may result in transient neurological symptoms, but when exposure is prolonged results in anoxic encephalopathy (see Chapter III D for discussion of anoxic disorders). A wide range of other gasses may result in toxic encephalopathy, with exposure occurring in the context of the workplace (e.g., exterminators exposed to cyanide gas); inhalant abuse (e.g., glue sniffing); military combat and acts of terrorism (e.g., weaponized nerve agents; Sarin).

**Venom and Other Neurotoxins:** Central and peripheral neurotoxic disorders may also result from bites and stings inflicted by a variety of animal and marine species, including snakes, ticks, scorpions, spiders, jellyfish, and octopi. Neurotoxic effects may also occur as a result of ingesting certain plants (e.g., wild mushrooms) or fish (e.g., blowfish-induced paralysis). Ingesting fish from mercury contaminated industrial wastewater may also result

in toxic encephalopathy, or Minamata disease, a notable and particularly profound example of industrial contamination of the food supply. <sup>4, 5</sup>

### **Outcome and Potential Long-Term Consequences:**

The acute and long-term neurological consequences related to neurotoxins are dependent upon multiple exposure variables, including the specific toxic agent, as well as the duration, magnitude, and age at time of exposure. Other factors affecting outcome include: accurate differential diagnosis; identification and removal, when indicated, of the source of toxic exposure (e.g., lead paint); prevention of re-exposure; and the availability of an effective antidote or other treatment option, such as a chelating agent to facilitate excretion of lead or other metals from the body. Pharmacologic re-evaluation and treatment of unintended negative side effects may be of benefit in addressing the neurotoxic symptoms associated with prescribed medication. Treatment for addiction and ongoing supports to maintain abstinence are indicated for neurotoxic disorders associated with substance abuse.

It is important to note, however, that many neurotoxic exposures result in permanent neurological sequelae, neurobehavioral disorders, and neurocognitive impairment, including dementia and persistent disorders of consciousness. Some neurotoxins are also carcinogenic, and maternal exposure may result in teratogenic effects, or birth defects, and compromised intellectual capacity (e.g., fetal alcohol syndrome).

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## CHAPTER III F: NEUROVASCULAR DISEASES and CONDITIONS

### Overview:

#### National Epidemiology

Acute stroke, referring to the sudden disruption of blood flow carrying oxygen and nutrients to the brain, is the most common neurovascular disorder and second leading cause of acquired brain injury. Each year more than 795,000 people in the U.S. experience a stroke, approximately 130,000 of whom have a fatal outcome. Men are at greater risk for stroke in most age groups; however, women are more likely to die from stroke. In comparison to Whites, Blacks exhibit approximately twice the risk of having a first stroke and are also more likely to die following a stroke. American Indians and Alaskan Natives are also at greater risk for stroke, in comparison to Hispanics and Asians. The prevalence of and highest death rates from stroke are in the southeastern United States, or so-called “Stroke Belt.” However, these regional disparities are related to an unequal Black/White racial distribution, socioeconomic status, and the prevalence of chronic disease and other risk factors.

Medical conditions associated with an increased risk for stroke include: hypertension; abnormally high cholesterol and triglyceride levels; diabetes mellitus; coronary artery disease (CAD); and arrhythmia (abnormal heart beat). Individuals who experience a previous stroke or a transient ischemic attack (TIA) are also at greater risk for suffering a stroke. A TIA occurs when blood flow to the brain is briefly interrupted, and may be caused by blood clots or fat deposits (plaques) within the cerebral arteries. TIAs result in temporary neurological signs and symptoms, without confirmed evidence (e.g., neuroimaging) of acute infarction, meaning cell death or necrosis secondary to vascular insufficiency. While no permanent residual impairments are associated with TIAs, approximately one third of those who experience a TIA will experience a stroke, particularly in the absence of medical treatment for the underlying cause with medication (e.g., anti-clotting medication) or in some instances, surgical intervention (e.g., carotid endarterectomy to remove fatty plaque). Personal modifiable risk factors associated with stroke include smoking, obesity, physical inactivity, high sodium intake, drug and alcohol abuse.<sup>1-3</sup> Women who use birth control pills; who have a history of migraine with aura (visual disturbances); and those who experience pregnancy-related complications, including a history of multiple miscarriages, preeclampsia (hypertension and excess protein) and eclampsia (uncontrolled preeclampsia and seizures), are at greater risk for stroke.<sup>4</sup>

The majority of individuals who sustain a stroke are 60 years of age and older, but stroke may occur at any age, beginning in the perinatal period. Perinatal stroke occurs in one per 3,500 live births, and children with certain medical conditions are also at greater risk for stroke, including those with sickle cell disease, congenital heart defects, and cerebral arteriopathy, or arterial disease. Some arteriopathies are genetic, such as the condition known as CADASIL, or cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy. Children also exhibit many of the same risk factors associated with adult stroke, including obesity, hypertension, smoking, Type 1 and Type 2 diabetes. Boys have a 1.28 fold higher risk for stroke than girls; and Black children have a two-fold higher risk for stroke, in comparison to White children.<sup>5, 6</sup>

## Neurovascular Disorder Subtypes

Neurovascular disorders may be classified as:

**Hemorrhagic:** referring to the non-traumatic disruption of cerebral blood flow caused by bleeding from or rupture of blood vessels, often associated with hypertension. Hemorrhages may occur within brain tissue (i.e., ICH: intracerebral hemorrhage); in the space between the arachnoid and pia mater, or coverings (meninges) of the brain (i.e., SAH: subarachnoid hemorrhage); or within the ventricles, or cavities within the brain where cerebrospinal fluid (CSF) is stored and made. Intraventricular hemorrhages (IVH), which primarily occur in premature infants, may result in cerebral palsy, hydrocephalus (i.e., excessive CSF in brain), and neurodevelopmental disorders. The neurological consequences of IVH are related to the severity and magnitude, or grade, of the hemorrhage.

Brain hemorrhages are also associated with structural vascular abnormalities or malformations, such as aneurysms. An aneurysm is a balloon-like dilation and weakness of the arterial wall, which may be familial, but is usually acquired with age and occurs more frequently in females than in males. In the U.S. more than 30,000 individuals experience SAHs related to aneurysms annually, and 60-65% will die before reaching a hospital or within the first 30 days of their stroke.<sup>7,8</sup> An arteriovenous malformation (AVM), another type of vascular malformation of presumed prenatal origin, affects the capillaries between arteries and veins, which become entangled and compromise blood flow. It is estimated that approximately 300,000 individuals in the U.S. are living with AVMs of the brain and spinal cord. Of these, an estimated 12% will experience neurological consequences associated with the size and site of the AVM within the CNS, including seizures, headache disorders, cognitive impairment, and a wide range of other neurological sequelae. Approximately 50% of neurologically symptomatic AVMs are also associated with the development of aneurysms and risk of hemorrhage.<sup>9</sup> Moyamoya disease, a rare progressive disorder in which the walls of the internal carotid arteries become constricted, is also associated with hemorrhagic strokes and TIAs in both adults and children.

**Ischemic:** referring to the disruption of the normal blood flow to the brain resulting from obstruction (occlusion) or narrowing (stenosis) of the arteries that supply the brain, most commonly caused by atherosclerosis (i.e., fatty deposits or plaque). Other causes of ischemia include thrombi, or blood clots, formed within the arteries of the brain and emboli, which include blood clots and other debris from sites outside the CNS, most commonly the heart, that travel to the brain via the bloodstream and block an artery within the brain.



Overall, most strokes (85%) are classified as ischemic and caused by cerebral infarction resulting in a constellation of neurological signs and symptoms, or clinical stroke. It is important to note, however, that not all individuals who experience a stroke will present with these signs and symptoms, but more subtle, somatic or atypical symptoms, such as headache, fatigue, malaise. Others may present as so-called “silent strokes” resulting from CNS infarction, particularly within the right hemisphere (side) of the brain that may result in mild cognitive impairment, behavioral and other symptoms that may not be recognized as cerebrovascular-related events. “Silent infarcts” are more prevalent in women and also in Blacks.<sup>10</sup> Children with sickle cell disease and congenital heart defects are at greater risk for ischemic stroke.

### Outcome and Potential Long-term Consequences

Mortality and outcome with respect to the neurovascular disorders are dependent upon subtype (i.e., ischemic vs. hemorrhagic); degree of cerebrovascular compromise (e.g., severity of atherosclerotic disease); age; general health; and genetic predisposition. Timeliness of intervention in response to an acute neurovascular event may also influence outcome. For example, intravenous treatment with either tissue plasminogen activator (tPA) or recombinant tissue plasminogen activator (rt-PA), has been demonstrated to reduce morbidity and improve recovery when administered within three hours, to individuals who experience ischemic stroke caused by blood clots and meet clinical eligibility criteria for this treatment.<sup>11,12</sup> The residual focal neurological, neurobehavioral and neurocognitive consequences of stroke and other neurovascular events are also related to the perfusion territory, or areas of the brain supplied by the involved blood vessels, and the associated site(s) of neurovascular injury.

Identification and treatment of underlying medical conditions and risk factors (e.g., hypertension, atrial fibrillation, hypercholesterolemia) is critical to reducing the incidence of stroke. It is also important to note that although men and women share many of the same stroke risk factors, there are risks that are unique, or as noted above occur more frequently in women, which have recently been incorporated into prevention guidelines that address these gender-specific healthcare needs.<sup>13</sup> With respect to vascular malformations, comprehensive clinical assessment, diagnostic neuroradiology, intervention for risk factors, and when indicated, neurosurgical intervention (e.g., surgical clipping of aneurysms; endovascular embolization for AVMs), may also serve to prevent or diminish the risk of hemorrhagic stroke.

## **Methodology:**

Massachusetts does not possess a registry of all persons identified with neurovascular conditions. To estimate the size of this health problem in Massachusetts, the statewide inpatient hospital, outpatient observation stay and emergency department discharge databases were analyzed. These databases are described in detail in Chapter IIIA. Two other data sources were considered for this purpose: the MA Paul Coverdell Acute Stroke Registry (Coverdell) and data from the Primary Stroke Service (PSS) hospitals in MA. The Coverdell Registry was not used because it does not account for all stroke cases across the state; it only represents up to 58 of the 70 primary stroke service hospitals in MA and is collected primarily for quality improvement purposes. PSS data was not used because it does not include diagnoses of hemorrhagic stroke. Additionally, neither Coverdell nor PSS data includes diagnoses of other neurovascular conditions discussed in this chapter.

A nationally developed ICD-9-CM-based consensus definition of stroke was applied to the statewide databases listed above to develop the counts and rates of discharges associated with these conditions among Massachusetts residents. This definition (detailed in Appendix B-4) is from the Joint Commission on Disease-specific Care<sup>14</sup>. For the development of a full operational definition of neurovascular conditions beyond stroke that can lead to acquired brain injury, (i.e., including categories listed in this chapter as “other cerebrovascular disease or condition” and “fetal/neonatal hemorrhage”) the authors began with the list of ICD-9-CM diagnostic codes specific to neurovascular conditions utilized in the previous MRC-MDPH epidemiology study of ABI. These were subsequently adopted and are currently utilized by the Massachusetts Office of Medicaid (OOM) to determine eligibility for the Acquired Brain Injury Home and Community-Based Services (HCBS) waiver programs. The HCBS ABI diagnostic code list was modified for the purposes of this report to also include ICD-9-CM codes for conditions related to the perinatal and neonatal period. A discharge with an ICD-9-CM code reflecting any of these conditions in any discharge diagnosis field of the state databases mentioned above represented a discharge associated with a neurovascular disease or condition.

Acute stroke is the primary focus of this chapter, as it makes up the majority of discharges among neurovascular conditions. Tables F1 - F7 provide counts and rates of stroke diagnoses, which may include individuals with diagnoses of other neurovascular conditions.

**Table F1. Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Stroke, MA Residents, 2008-2010**

<b>Data Source</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>Average Annual Count*</b>	<b>Average Annual Percent of Total Events*</b>	<b>Average Annual Rate per 100,000 persons</b>
Inpatient Hospitalizations	19,133	19,232	19,769	19,378	85.0	297.4
Observation Stays	787	789	810	795	3.5	12.2
<b>Total Hospital Stays (Inpatient + Observation)</b>	<b>19,920</b>	<b>20,021</b>	<b>20,579</b>	<b>20,173</b>	<b>88.5</b>	<b>309.6</b>
Emergency Department Visits	2,468	2,687	2,736	2,630	11.5	40.4
<b>Total Hospital-treated Events (Hospital Stays, ED Visits)</b>	<b>22,388</b>	<b>22,708</b>	<b>23,315</b>	<b>22,804</b>	<b>100</b>	<b>349.9</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- On average, there were 20,173 hospital stays and 2,630 emergency department discharges annually related to a diagnosis of stroke among MA residents. This includes both hemorrhagic and ischemic strokes.
- Of the emergency department discharges during this period, on average, annually, 1,714 (65.2%) of these were transferred to another, unspecified facility (data not shown). These cases may have been later admitted and may be represented in the hospital stay counts.
- Only 3.5% of total hospital-treated events for stroke were discharged from an observation stay bed. These are generally short duration stays.
- From 2008-2010, of the ischemic stroke patients reported to the MA Coverdell Stroke Registry who arrived at the hospital within 2 hours of the time they were last known to be without stroke symptoms ("last known well time") and were eligible for intravenous (IV) thrombolytic therapy, 75.4% received IV tissue plasminogen activator (IV tPA) within 3 hours of last known well time. (Source: MA Coverdell Stroke Registry, MDPH. Data not shown.)
- In addition to the counts presented in Table F1, there were 5,689 hospital stays and 1,458 emergency department visits associated with a transient ischemic attack (TIAs); and 7,455 hospital stays and 1,522 emergency department visits associated with other cerebrovascular conditions on average annually, which were not associated with a diagnosis of a stroke (data not shown).

- There were 410 hospital discharges on average, annually, associated with neurovascular conditions occurring primarily in the perinatal and neonatal period, and which were not associated with a diagnosis of a stroke (data not shown).

**Table F2. Average Annual Counts and Crude Rates of Stroke-related Hospital Stays and Emergency Department Discharges by Age Group, MA Residents, 2008-2010**

Age Group (Years)	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
0 to 2	42	0.2	19.1	1-10	NA	NA
3 to 5	1-10	NA	NA	1-10	NA	NA
6 to 18	42	0.2	3.9	17	0.6	1.6
19 to 21	**	**	**	12	0.5	4.0
22 to 29	84	0.4	11.9	47	1.8	6.6
30 to 39	228	1.1	27.5	103	3.9	12.4
40 to 49	790	3.9	79.5	240	9.1	24.1
50 to 59	2,035	10.1	222.8	422	16.1	46.2
60 to 69	3,772	18.7	617.2	487	18.5	79.7
70+	13,156	65.2	2,065.3	1,295	49.2	203.3
<b>Total</b>	<b>20173</b>	<b>100</b>	<b>309.6</b>	<b>2630</b>	<b>100</b>	<b>40.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes:\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

\*\*Denotes complementary suppressed values to protect calculation of values in the cells with a count of 1-10.

NA indicates that percents and rates are not shown for suppressed values.

Rates based on counts less than 20 are considered unstable.

- The highest rate of hospital stays for stroke was among residents 70 years of age and older, with a rate more than six times that of the population as a whole.
  - Persons age 50 years and older cumulatively made up 94.0% of hospital stays.
- The highest rate of emergency department discharges for stroke was also among persons 70 years of age and older, approximately five times that of the general population.

**Table F3. Average Annual Counts and Crude Rates of Stroke-related Hospital Stays and Emergency Department Discharges by Sex, MA Residents, 2008-2010**

Sex	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
Male	9,854	48.8	312.7	1,321	50.2	41.9
Female	10,319	51.2	306.6	1,308	49.8	38.9
<b>Total</b>	<b>20,173</b>	<b>100</b>	<b>309.6</b>	<b>2,630</b>	<b>100</b>	<b>40.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes: \*Column counts may not add to total and column percentages may not add to 100 due to rounding. Totals may include cases of unknown sex.

- Overall, males and females had statistically similar rates of hospital stays and emergency department visits for stroke.
- On average, females 70 years of age and older had 7,386 stroke-related hospital stays, the subgroup with the highest stroke rates, versus 5,770 for males in the same subgroup (data not shown).
- In the 70 years and older subgroup, females had 715 emergency department visits on average annually, while males had 580 visits (data not shown).

**Table F4. Average Annual Counts and Crude Rates of Stroke-related Hospital Stays and Emergency Department Discharges by Race and Ethnicity, MA Residents, 2008-2010**

Race/Ethnic Group	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
White, NH	17,518	86.8	343.8	2,271	86.4	44.6
Black, NH	1,044	5.2	239.0	122	4.7	28.0
Hispanic	736	3.7	121.0	113	4.3	18.5
Asian, NH	351	1.7	97.3	50	1.9	13.9
Other/Unknown	524	2.6		74	2.8	
<b>Total</b>	<b>20,173</b>	<b>100</b>	<b>309.6</b>	<b>2,630</b>	<b>100</b>	<b>40.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes: Other and unknown race counts include discharges among patients listed as Native Hawaiian, Pacific Islander, American Indian or Alaska Native, "other" race and unknown race; rates are not able to be calculated for this category. 'NH' indicates non-Hispanic.

\*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- White non-Hispanics had a higher crude rate of hospital stays for stroke, compared with Black non-Hispanics, Hispanics, and Asian non-Hispanics. However, after adjusting for age, Black non-Hispanics had the highest rate of hospital stays. The lowest crude and age adjusted rates of hospital stays were among Asian, non-Hispanics (age adjusted data not shown).
- White non-Hispanics had the highest crude rate of emergency department visits for stroke, compared with Black non-Hispanics, Asian non-Hispanics, and Hispanics.
  - After adjusting for age, only Asian, non-Hispanics had a statistically different (lower) rate of emergency department visits compared with all other races.

**Table F5. Average Annual Counts and Crude Rates of Stroke-related Hospital Stays and Emergency Department Discharges by Executive Office of Health and Human Services (EOHHS) Region of Residence, MA Residents, 2008-2010**

EOHHS Region of Residence	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
I. Western	2,854	14.1	343.4	265	10.1	31.9
II. Central	2,577	12.8	301.6	305	11.6	35.7
III. Northeast	4,291	21.3	333.8	562	21.4	43.7
IV. MetroWest	4,178	20.7	276.2	540	20.5	35.7
V. Southeast	4,332	21.5	341.8	754	28.7	59.5
VI. Boston Region	1,938	9.6	253.1	204	7.7	26.6
<b>Total</b>	<b>20,173</b>	<b>100</b>	<b>309.6</b>	<b>2,630</b>	<b>100</b>	<b>40.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding and/or inclusion of cases of unknown region.

- Residents of the Western, Northeast, and Southeast regions had the highest average annual crude rates of hospital stays for stroke.
  - The age-adjusted hospital stay rate for residents of the MetroWest region was significantly lower than for all other regions (data not shown).
- Average annual emergency department visit rates were highest in residents of the Southeast region, even after age adjustment.
- Regional differences in rates may reflect differences not controlled for during age adjustment and/or care provided outside the state and not captured by these databases.

**Table F6. Average Annual Primary Payer Type Category for Stroke-related Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges, MA Residents, 2008-2010**

<b>Payer Type Category</b>	<b>Percent Inpatient Hospitalizations</b>	<b>Percent Observation Stays</b>	<b>Percent Emergency Department Visits</b>
Medicaid	4.9	4.8	8.2
Medicare	73.0	64.9	57.6
Commercial Insurer	18.8	27.7	28.0
Other Government Payment	0.7	**	0.8
Free Care or Health Safety Net	1.0	**	2.0
Worker's Compensation	0.1	**	**
Auto Insurance	0.1	**	**
Commonwealth Care Plans	0.9	**	1.2
Self Pay	0.4	**	1.6

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note:\*\* denotes suppressed values reflecting a percentage based on a count of 1-10. Column percentages may not add up to 100% due to missing and invalid values.

- Medicare was the primary payer listed for nearly three-quarters (73%) of inpatient hospitalizations, while commercial insurers and Medicaid ranked second and third (18.8% and 4.9%, respectively).
- Medicare was also the leading primary payer category for emergency department visits for stroke, accounting for 57.6% of all visits. Commercial insurers and Medicaid ranked second and third (28.0% and 8.2%, respectively).

**Table F7. Average Annual Stroke-related Inpatient Hospitalizations by Discharge Disposition Category and Age Group, MA Residents, 2008-2010**

Disposition Category	Age Category				
	0-21 years	22-49 years	50-64 years	65+years	Total
In- Hospital Death	1-10	**	212	1,283	1,583
Home with or without Services	74	668	2277	7,080	10,099
Medicare Long Term Hospital	1-10	**	69	257	349
Psychiatric Hospital	1-10	1-10	1-10	33	42
Rehabilitation Hospital or Unit	12	213	600	2,016	2,841
Rest Home	1-10	1-10	1-10	**	**
Shelter	1-10	1-10	1-10	1-10	1-10
Skilled Nursing Facility	1-10	**	262	3638	3944
Short Stay Hospital	1-10	**	144	420	639
Other Facility‡	1-10	**	46	331	396
Other†	1-10	**	36	51	103
Total	112	1,124	3,655	15,123	20,014

Source: MA Inpatient Hospital Discharge Database, Center for Health Information and Analysis.

Notes:\*\* denotes complementary suppressed values to protect calculation of values in the cells with a count of 1-10. Total includes all dispositions except cases of unknown disposition.

† “Other” includes “left against medical advice” and “discharge other.”

‡ “Other Facility” includes intermediate care facility, hospice medical facility, federal healthcare facility and “another type of institution not defined elsewhere.”

Additional detail on disposition categories can be found in Chapter III A.

- Fifty percent of inpatient hospitalizations resulted in individuals being discharged to home, with or without services; 19.7% were discharged to a skilled nursing facility; 14.2% were discharged to a rehabilitation hospital; and 3% were discharged to a short stay hospital.
- Among those discharged to home, an average annual of 6,192 (61.3%) were listed as discharged to home with no services. Of the 38.7% discharged with services, those services included time-limited home health care, IV therapy, or hospice (data not shown).
- Eight percent of inpatient hospitalizations for stroke during this period resulted in death during the hospitalization.
- The mean and median lengths of stay for stroke-related inpatient hospitalizations in 2010 were 5.7 days and 4.0 days, respectively (data not shown).
- Of the inpatient discharges associated with neurovascular conditions occurring primarily in the perinatal and neonatal period, and which were not associated with a diagnosis of a stroke (482 on average annually), 71.7% were discharged to home, and 15.1% were discharged to a short-stay hospital (data not shown).



## **Summary of Findings:**

- Stroke is a substantial public health problem, resulting in an average annual number of over 20,000 hospital stays and over 2,600 emergency department visits among MA residents for the time period studied. TIAs contributed nearly 5,700 additional hospitalization events annually during this period.
- Hospital-treated event rates for stroke are highest among adults 70 years of age and older.
- Publicly-funded payers (Medicaid, Medicare, Free Care/Health Safety Net, Other Government Payment, Commonwealth Care) were the primary payers for at least 80.5%, 69.7%, and 69.8% of the inpatient hospitalizations, observation stays, and emergency department visits, respectively (on average, annually) for hospital-treated stroke events in MA.

## **Limitations:**

- In addition to the limitations described in Chapter III A, these data provide only crude stroke severity indicators (i.e., level of care and length of stay). More sophisticated measures, such as the National Institute of Health's Stroke Scale and treatment with IV thrombolytics, can be useful in understanding the long-term impact of stroke.
- Individuals transferred to another, unspecified facility from an emergency department visit (65.2%) may have been transferred and admitted to an inpatient setting, and therefore may be included in inpatient hospitalization counts.

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## CHAPTER III G: TRAUMATIC BRAIN INJURY

### Overview:

#### National Epidemiology

Traumatic brain injury (TBI) is the leading cause of acquired brain injury (ABI), and the Centers for Disease Control and Prevention estimates that approximately 1.7 million persons sustain TBI annually in the United States. The majority (80.7%) of individuals are examined, treated and released from emergency departments (ED), while 16.3 % are hospitalized and 3% (52,000 annually) die of their injuries. In contrast to other types of ABIs, the causes of TBI are due to external mechanisms such as falls, motor vehicles, firearms, and strikes by an object or person. These events can be further classified as unintentional (or “accidental”) or intentional, which include interpersonal violence and suicide. Traumatic brain injuries can also occur during activities of daily living, in occupational contexts, or during sports and recreation.

Overall, falls are the leading cause of TBI, accounting for more than 50% of TBIs in children 0 to 14 years of age. The highest percentage (60.7%) of TBIs associated with falls is observed in adults 65 years of age or older. Adults 75 years of age or older exhibit the highest rates for TBI necessitating hospitalization, as well as the highest TBI-related death rates. It is also important to note that from 2002-2006, ED visits for TBI related to falls increased by 46% in adults 65 and older, while hospitalization for TBI related to falls increased by 34%, and deaths increased by 27% in this age group.

Motor vehicle/traffic-related events are the second leading cause of TBI (17.3%). The highest number and rate for TBI-related ED visits for motor vehicle/traffic-related injury is observed in adults 20-24 years of age, while the highest number and rate for hospitalization is observed in the 15-19 age group. Events in which an individual is struck by/against an object is the second leading cause of TBI in children, ages 0 to 14. Assaults account for 10% of TBIs.

Overall, males are 1.4 times more likely than females to sustain a TBI. However, gender disparities become less pronounced with advancing age, and among adults ages 75 or older, the number and population rates for TBI-related ED visits for females exceeds that for males. With respect to race, Whites exhibit the highest percentage of persons with TBI (>78 %). However, Blacks exhibit the highest rate for TBI-related hospitalizations and ED visits.<sup>1</sup> Among American Indians and Alaskan Natives (AI/AN), motor vehicle-related events and assaults are the leading causes of TBI.<sup>2</sup> Risk factors associated with both the occurrence and severity of TBI include non-use of prevention strategies (e.g., seatbelt); premorbid psychiatric disorders; and substance use/abuse at time of injury.<sup>3</sup>

## TBI Subtypes

Traumatic brain injuries, which may be mild, moderate or severe, are also classified as follows:

**Closed Head Injury (CHI)** occurs when a blunt force is applied to the head or the head strikes an object (e.g., fall to hard surface). These injuries may be associated with skull fractures.

**Penetrating Head Injury** is most often associated with intentional causes of TBI (e.g., homicide or suicide attempt) and results from a missile-like object (e.g., bullet) or sharp instrument (knife), which forcefully enters the skull and brain.

**Crush Injury** can occur when large, heavy objects compress the head. These injuries may occur in industrial/occupational settings when the head is crushed by equipment or building materials, and may also occur when the head is compressed (rolled over) in a motor-vehicle/traffic-related injury.

**Blast Injury** is a complex TBI, which results from close exposure to an explosion (e.g., Improvised Explosive Device-IED). This type of injury may result in both CHI and penetrating TBI and is most commonly observed in military service members who served in the Iraq/Afghanistan conflicts (i.e., OIF/OEF veterans). It is important to note that individuals who sustain these combat-related injuries are not included in the TBI counts and statistical analyses reported by the CDC. Blast TBI is considered the “signature injury” sustained by OIF/OEF veterans, and is estimated to occur in approximately 20% of those who served. <sup>4</sup>

## Outcome and Potential Long-Term Consequences

The acute and primary consequences of TBI may include loss of consciousness (LOC), which may be brief or prolonged (coma); contusions (bruising) and lacerations of the brain; injury to the connecting fibers within the brain (e.g., axons), referred to as diffuse axonal injury (DAI); and other structural injuries related to mechanical forces. Secondary complications may also occur, such as anoxia associated with cardiac and/or respiratory arrest; hemorrhages and hematomas (blood mass or clot); elevated intracranial pressure; and swelling of the brain (cerebral edema). Recovery and long-term outcome exhibited by survivors are related to all the variables described above, as well as age at time of injury, and the specific residual neurocognitive, neurobehavioral, sensory and functional impairments associated with the sites and severity of injury. <sup>5</sup>

## Methodology:

Massachusetts does not possess a registry of all persons identified with traumatic brain injury. To estimate the magnitude of this health problem in Massachusetts, the statewide inpatient hospital, outpatient observation stay and emergency department discharge databases were analyzed. These databases are described in detail in Chapter III A. A national ICD-9-CM-based consensus definition <sup>6</sup> was applied to these data to develop the

counts and rates of discharges for traumatic brain injury among Massachusetts residents. This definition (detailed in Appendix B-5) includes diagnosis of fracture of the vault or base of the skull; other and unqualified or multiple fractures of the skull; concussion; intracranial injury, including contusion, laceration and hemorrhage; injury to the optic chiasm, optic pathways or visual cortex; head injury, unspecified; and/or shaken infant syndrome. A discharge with an ICD-9-CM code reflecting any of these conditions in any discharge diagnosis field of the state databases mentioned above represented a TBI-related case. The causes and intents of these injuries are based on the first listed external cause of injury code, which is contained in the data for the vast majority of cases related to injury.

**Table G1. Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury, MA Residents, 2008-2010**

<b>Data Source</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>Average Annual Count*</b>	<b>Average Annual Percent of Total Events*</b>	<b>Average Annual Rate per 100,000 persons</b>
Inpatient Hospitalizations	6,054	6,359	6,450	6,287	9.4	96.5
Observation Stays	1,352	1,465	1,484	1,434	2.1	22.0
<b>Total Hospital Stays (Inpatient + Observation)</b>	<b>7,406</b>	<b>7,824</b>	<b>7,934</b>	<b>7,721</b>	<b>11.5</b>	<b>118.5</b>
Emergency Department Visits	52,494	63,039	62,446	59,326	88.5	910.4
<b>Total Hospital-treated Events (Hospital Stays, ED Visits)</b>	<b>59,900</b>	<b>70,863</b>	<b>70,380</b>	<b>67,048</b>	<b>100</b>	<b>1,028.9</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- On average, there were 7,721 hospital stays and over 59,000 emergency department visits annually related to a diagnosis of TBI among MA residents.
- Over eighteen percent (18.6%) of total hospital stays for TBI were discharged from an observation stay bed. These generally represent short duration stays.

**Table G2. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury by Age Group, MA Residents, 2008-2010**

Age Group (Years)	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
0 to 2	320	4.1	145.6	5,343	9.0	2,430.6
3 to 5	87	1.1	39.0	2,568	4.3	1,145.6
6 to 18	636	8.2	58.9	12,247	20.6	1,134.2
19 to 21	294	3.8	98.5	3,591	6.1	1,204.6
22 to 29	527	6.8	74.2	6,738	11.4	948.7
30 to 39	468	6.1	56.4	5,426	9.1	653.8
40 to 49	717	9.3	72.2	6,150	10.4	619.4
50 to 59	812	10.5	88.9	5,181	8.7	567.2
60 to 69	772	10.0	126.4	3,321	5.6	543.5
70+	3,089	40.0	484.9	8,760	14.8	1375.3
<b>Total</b>	<b>7,721</b>	<b>100</b>	<b>118.5</b>	<b>59,326</b>	<b>100</b>	<b>910.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- The highest rate of hospital stays for TBI were among residents 70 years of age and older, with a rate four times that of the population as a whole.
  - The vast majority (88%) of the TBI-related hospital stays in this age group were associated with an unintentional fall (data not shown).
  - Infants and children 0-2 years and persons 60-69 years of age had the second highest rates (these two age groups were statistically comparable).
- The highest rate of emergency department discharges for TBI was among children 0-2 years of age, over two times that of the general population.
  - The vast majority (81%) of the TBI-related emergency department discharges in this age group were associated with an unintentional fall (data not shown).

**Table G3. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury by Sex, MA Residents, 2008-2010**

Sex	Average Annual Hospital Stay Count*	Percent of Total Hospital Stay*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
Female	3,352	43.4	99.6	27,401	46.2	814.3
Male	4,369	56.6	138.6	31,924	53.8	1012.9
<b>Total</b>	<b>7,721</b>	<b>100</b>	<b>118.5</b>	<b>59,326</b>	<b>100</b>	<b>910.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Overall, males had a higher rate of hospital stays and emergency department visits for TBI than females.
  - Average annual hospital stays associated with TBI were higher in males compared with females for individuals ages 0-69 years; however, among individuals ages 70 years and older, females predominated (data not shown).
  - Average annual emergency department visits associated with TBI were higher among males compared with females for individuals ages 0-59 years; females outnumbered males for all residents ages 60 years and older (data not shown).



**Table G4. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury by Race and Ethnicity, MA Residents, 2008-2010**

Race/Ethnic Group	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
White, NH	6,239	80.8	122.5	46,254	78.0	907.8
Black, NH	462	6.0	105.9	4,209	7.1	964.0
Hispanic	536	6.9	88.1	5,353	9.0	879.4
Asian, NH	167	2.2	46.2	1,188	2.0	329.0
Other/Unknown	317	4.1		2,322	3.9	
<b>Total</b>	<b>7,721</b>	<b>100</b>	<b>118.5</b>	<b>59,326</b>	<b>100</b>	<b>910.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes:\*Column counts may not add to total and column percentages may not add to 100 due to rounding. Other and unknown race counts include discharges among patients listed as Native Hawaiian, Pacific Islander, American Indian or Alaska Native, "other" race and unknown race; rates are not able to be calculated for this category.

'NH' indicates non-Hispanic.

- White, non-Hispanics had the highest crude rate of hospital stays for TBI, while Asian, non-Hispanics had the lowest.
  - After adjusting for age, there was no statistical difference in rates among White, non-Hispanics, Black, non-Hispanics, or Hispanics.
- Black, non-Hispanics had the highest crude rate of emergency department visits for TBI, while Asians had the lowest.
  - After adjusting for age, rates among White and Black non-Hispanics were statistically similar.

**Table G5. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury, by Executive Office of Health and Human Services (EOHHS) Region of Residence, MA Residents, 2008-2010**

EOHHS Region	Average Annual Hospital Stay Count*	Percent of Total Hospital Stays*	Average Annual Hospital Stay Rate per 100,000 persons	Average Annual Emergency Department Visit Count*	Percent of Total Emergency Department Visits*	Average Annual Emergency Department Visit Rate per 100,000 persons
I. Western	1,065	13.8	128.1	6,146	10.4	739.5
II. Central	1,083	14.0	126.8	7,852	13.2	919.2
III. Northeast	1,563	20.2	121.6	13,267	22.4	1032.0
IV. MetroWest	1,668	21.6	110.3	13,560	22.9	896.5
V. Southeast	1,335	17.3	105.4	11,679	19.7	921.5
VI. Boston Region	1,004	13.0	131.1	6,796	11.5	887.3
<b>Total</b>	<b>7,721</b>	<b>100</b>	<b>118.5</b>	<b>59,326</b>	<b>100</b>	<b>910.4</b>

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Note: \*Column counts may not add to total and column percentages may not add to 100 due to rounding.

- Residents of the MetroWest and Northeast regions had the highest average annual numbers of hospital stays for TBI.
  - MetroWest and Southeast region residents had the lowest age adjusted rates per 100,000 residents (data not shown).
- Average annual emergency department visits were also highest in residents of the MetroWest and the Northeast regions.
  - Age adjusted rates of emergency department visits for TBI per 100,000 residents were highest in residents of the Northeast region and lowest in residents of the Western region (data not shown).
- Note: The regional differences in rates may reflect differences not controlled for during age adjustment and/or care provided outside the state and not captured by these databases.

**Table G6. Average Annual Counts and Crude Rates of Hospital Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury, by Mechanism/Intent of Injury, MA Residents, 2008-2010**

<b>Mechanism and Intent</b>	<b>Average Annual Hospital Stay Count</b>	<b>Percent of Total Hospital Stays</b>	<b>Average Annual Hospital Stay Rate per 100,000 persons</b>	<b>Average Annual Emergency Department Visit Count</b>	<b>Percent of Total Emergency Department Visits</b>	<b>Average Annual Emergency Department Visit Rate per 100,000 persons</b>
Unintentional Fall	4,527	58.6	69.5	27,830	46.9	427.1
Unintentional Struck by/Against	272	3.5	4.2	11,823	19.9	181.4
Unintentional Motor Vehicle Traffic	1,314	17.0	20.2	8,230	13.9	126.3
Unintentional (All Other Mechanisms not listed above and Unspecified Mechanism)	481	6.2	7.4	3,644	6.1	55.9
Suicide/Self-Inflicted (All mechanisms)	39	0.5	0.6	85	0.1	1.3
Homicide/Assault (All mechanisms)	498	6.5	7.6	5,299	8.9	81.3
Other Intents	23	0.3	0.3	1,126	1.9	17.3

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes: "Other intents" includes undetermined intent and other intent. Column percentages and totals may not add up to 100% of cases (N= 7,721 hospital stays and N= 59,326 emergency department visits) due to missing cause and intent information.

- The majority of hospital stays (58.6%) for TBI were related to an unintentional fall. Motor vehicle traffic crashes accounted for 17% of these hospital stays.
- Among emergency department visits for TBI, 46.9% were related to a fall, while almost 20% were related to a strike by/against an object or person. At least 30% of the strike by/against injuries occurred in sports (data not shown).

**Table G7. Average Annual Primary Payer Type Category for Inpatient Hospitalizations, Observation Stays and Emergency Department Discharges Associated with a Discharge Diagnosis of Traumatic Brain Injury, MA Residents, 2008-2010**

<b>Payer Type Category</b>	<b>Percent of Inpatient Hospitalization Totals</b>	<b>Percent of Observation Stay Totals</b>	<b>Percent of Emergency Department Visit Totals</b>
Medicaid	10.5	15.6	17.9
Medicare	47.9	27.0	18.5
Commercial Insurer	24.8	38.0	42.9
Other Government Payment	1.0	**	0.9
Free Care or Health Safety Net	3.0	2.6	2.5
Worker's Compensation	1.5	1.7	4.0
Auto Insurance	8.0	9.5	7.0
Commonwealth Care Plans	1.5	**	1.6
Self Pay	1.7	3.2	4.7

Sources: MA Inpatient Hospital, Outpatient Observation Stay, and Emergency Department Discharge Databases, Center for Health Information and Analysis.

Notes:\*\* denotes suppressed values reflecting a percentage based on a count of 1-10. Column percentages may not add up to 100% due to missing and invalid values.

- Medicare was the primary payer category listed for almost half (47.9%) of inpatient hospitalizations associated with TBI, while commercial insurers and Medicaid ranked second and third (24.8% and 10.5%, respectively).
- Commercial insurance was the leading primary payer type category for emergency department visits for TBI, accounting for 42.9% of all visits. Medicare and Medicaid ranked second and third (18.5% and 17.9%, respectively).

**Table G8. Average Annual Inpatient Hospitalizations Associated with a Discharge Diagnosis of Traumatic Brain Injury, by Discharge Disposition Category and Age Group, MA Residents, 2008-2010**

Disposition Category	Age Category				
	0-21 years	22-49 years	50-64 years	65+years	Total
In-Hospital Death	20	58	52	249	378
Home with or without Services	809	944	620	1,113	3,485
Medicare Long Term Hospital	1-10	17	**	58	96
Psychiatric Hospital	1-10	15	**	14	47
Rehabilitation Hospital or Unit	51	176	153	433	814
Rest Home	0	0	0	1-10	1-10
Shelter	0	0	1-10	0	1-10
Skilled Nursing Facility	1-10	35	97	1,129	1,267
Short Stay Hospital	1-10	**	23	69	118
Other Facility‡	1-10	1-10	13	59	90
Other†	1-10	53	28	**	104
Total	922	1,325	1,015	3,141	6,403

Sources: MA Inpatient Hospital Discharge Database, Center for Health Information and Analysis.

Notes:\*\* denotes complementary suppressed values to protect calculation of values in the cells with a count of 1-10. Total includes all dispositions except cases of unknown disposition.

† “Other” includes “left against medical advice” and “discharge other.”

‡ “Other Facility” includes intermediate care facility, hospice medical facility, federal healthcare facility and “another type of institution not defined elsewhere.”

Additional detail on disposition categories can be found in Chapter III A.

- The majority (54%) of inpatient hospitalizations resulted in individuals being discharged to home, with or without services; 19.7% were discharged to a skilled nursing facility, and 12.7% were discharged to a rehabilitation hospital.
- Among individuals discharged to home, only 23% were listed as discharged to home with services such as home health care, IV therapy, or hospice services.
- Almost six percent of inpatient hospitalizations for TBI during this period resulted in the individual dying during the hospitalization.
- The mean and median lengths of stay for TBI-related inpatient hospitalizations in 2010 were 5.3 days and 3 days, respectively (data not shown).

## **Summary of Findings:**

- There were an average of over 7,700 hospital stays and over 59,000 emergency department visits associated with a traumatic brain injury annually among MA residents for the time period studied.
- Hospital stay rates were highest among adults 70 years of age and older, while children 0-2 years of age had the highest rates of emergency department-treated TBI.
- Although most persons with TBI treated in the inpatient setting were discharged home, a sizable proportion of individuals were discharged to facilities providing specialized care, such as skilled nursing facilities, and Medicare long term hospitals.
- Only 12.7% of all individuals were discharged to a rehabilitation hospital or unit. Among children and youth 0-21 years of age, only 6% were discharged, on average, annually to a rehabilitation hospital or unit.
- Medicare and Medicaid were the primary payer for the majority (58.4% combined) of inpatient hospitalizations and over one third of emergency department visits for TBI.

## **Limitations:**

- In addition to the limitations described in Chapter III A, these data provide only crude TBI severity indicators (i.e., level of care and length of stay). More sophisticated measures, often present in trauma registries can be useful in understanding the long term impact of these injuries. Massachusetts is in the early development of a statewide trauma registry which will provide more detail on injury severity to inform resource planning and evaluation.

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## CHAPTER III H: PROGRESSIVE DISORDERS of the CENTRAL NERVOUS SYSTEM

### Introduction:

Currently, there is no established centralized or mandated reporting system, with respect to the progressive disorders of the CNS. It is also important to note that the onset of a neurodegenerative disease is usually insidious, and would not result in an acute hospitalization or emergency department visit. Thus, analysis of hospital discharge data would not adequately capture the magnitude of these diseases and associated conditions. Therefore, this chapter is largely descriptive of this category of neurological diseases and conditions and does not follow the format of most of the other subchapters in Chapter III.

The degenerative diseases of the central nervous system (CNS) are characterized by a gradually progressive course, which may be evidenced in:

- Deterioration of cognitive capacity, or dementia
- Progressive movement disorder including ataxia, involuntary movements, dyskinesia, and/or other neurological abnormalities (e.g., Parkinson Disease)
- Motor weakness or paralysis of voluntary muscles (e.g., Amyotrophic Lateral Sclerosis, or Lou Gehrig's Disease)
- Sensory impairment (e.g., progressive blindness)
- Neurobehavioral symptoms including hallucinations, psychosis, disinhibition
- Diminished capacity to independently care for oneself <sup>1</sup>

Progressive disorders may occur in the context of acquired disorders of the CNS, which are the primary focus of this chapter and discussed below.

### Progressive Disorders Associated with Acquired Brain Injury:

The progressive disorders associated with ABI result in a wide range of neurological impairments and span all etiological categories. Progression of disease is for most disorders slow, and for some diseases, symptoms may not become manifest for years, and after a prolonged period of incubation, such as the progressive disorders associated with infection. Some rare neurological diseases may be rapidly progressive once symptoms become manifest. Detailed below are descriptions of representative examples of acquired progressive disorders of the CNS:

**AIDS Dementia Complex (ADC) or HIV-Associated Dementia (HAD)** is a dementing disorder associated with the advanced stages of HIV infection and severe immunosuppression, which may be complicated by opportunistic CNS infection and other HIV-related CNS conditions. ADC/HAD is an acquired dementia, associated with motor



impairment, mental status changes and vacuolar myelopathy (spinal cord pathology). Since the introduction of combination highly active antiretroviral therapy (HAART), the incidence of ADC/HAD in adults with HIV infection has been significantly reduced. A similar disorder occurs in children with AIDS, but this disorder occurs more frequently and results in progressive encephalopathy and reversal of developmental milestones associated with microcephaly, or developmental delay associated with static encephalopathy. <sup>2</sup>

**Chronic Traumatic Encephalopathy (CTE)** is a progressive degenerative disease associated with repetitive head trauma and evidenced in cognitive impairment, confusion, behavioral disinhibition, depression and suicidal behavior. Originally described in boxers and referred to as dementia pugilistica or “punch drunk” syndrome, CTE has primarily been confirmed on post-mortem examination of the brains of deceased professional and amateur athletes, including college and high school athletes, who have experienced multiple symptomatic concussions and/or subconcussive hits. Other causes of CTE include traumatic brain injuries sustained in military combat and as a result of interpersonal violence or self-injurious behavior (e.g., head banging). Onset of symptoms of CTE can become manifest within months or years after concussive events. <sup>3</sup>

**Creutzfeldt-Jakob Disease (CJD)** is a fatal degenerative disorder caused by an infectious prion protein (see Chapter III C regarding Infectious Diseases associated with Disorders of the CNS). Onset may be progressive or sudden, and associated with diffuse loss of neurons (nerve cells) within the brain; profound and rapid dementia; and stimulus-sensitive myoclonus (abnormal muscle contractions).

**Delayed Postanoxic Encephalopathy and Leukoencephalopathy** is a rare and poorly understood disorder characterized by a period of recovery (1-4 weeks) after an anoxic episode, followed by deterioration of mental status and cognitive capacity. While some may recover from this second episode, others exhibit progressive deterioration, associated with neuropathological changes in the white matter of the brain (leukoencephalopathy) and the basal ganglia resulting in parkinsonian symptoms. This syndrome is most often observed in individuals who have experienced carbon monoxide poisoning, but may occur after other types of anoxic events reviewed in the chapter on metabolic disorders (Chapter III D) of the CNS. <sup>4</sup>

**Multi-infarct Dementia (MID)** results from the cumulative effects of multiple strokes, which may present with observable neurological findings or more subtle symptoms (i.e., so-called “silent strokes”). Binswanger Disease, a type of vascular dementia, is associated with diffuse degeneration of the subcortical white matter within the brain (leukoaraiosis), hypertension, and small vessel atherosclerosis resulting in ischemic changes or strokes. Progressive neurocognitive impairment may occur in a gradual or step-like fashion, and other clinical symptoms associated with Binswanger Disease include gait disorder, personality changes, and depression <sup>5, 6</sup> (see Chapter III F regarding neurovascular disorders for detailed review of stroke).

**Neurosyphilis** refers to invasion of the CNS by *Treponemapallidum*, which causes syphilis, a sexually-transmitted disease (STD). Since World War II and the introduction of treatment with penicillin, the incidence of syphilis has declined significantly. The CDC

estimates that, on average, 55,400 people are diagnosed with syphilis in some stage in the U.S., and therefore at risk for acute brain injury as a result of the infection. While historically syphilis primarily occurred among heterosexual men and women of racial and ethnic minority groups, since 2000 the largest numbers of cases have been documented among men who have sex with men (MSM).<sup>7</sup> The most common initial neurological manifestation of syphilis within the CNS is meningitis. Approximately 15-20 years after an original, untreated syphilis infection, individuals may present with parietic neurosyphilis, also referred to as general paresis or dementia paralytica, a progressive disorder. Associated findings include ocular abnormalities, seizures, neuropsychiatric symptoms, and lesions of the spinal cord (tabes dorsalis or tabetic neurosyphilis).

**Paraneoplastic Disorders** include a group of rare neurological conditions representing the remote effects of cancers outside the CNS (e.g., small cell cancer of the lung) and an autoimmune response. Paraneoplastic disorders are characterized by the relatively rapid development of a broad range of neurological symptoms, which may include seizures; mental status changes (e.g., confusion, hallucinations, delusions); polyneuropathy; retinopathy; cerebellar degeneration; and dementia.<sup>8</sup>

**Progressive Multifocal Leukoencephalopathy (PML)** is a degenerative white matter disease (leukoencephalopathy) caused by a human polyomavirus, designated as the JC virus (JCV). Individuals living with immunocompromising conditions, including HIV infection, are most commonly diagnosed with PML, and other at-risk populations include individuals treated with immunosuppressive chemotherapy for autoimmune disorders, including multiple sclerosis, systemic lupus erythematosus and rheumatoid arthritis. Clinical symptoms associated with PML include progressive paralysis, mental status changes, visual impairment (e.g., cortical blindness), aphasia, and neurocognitive impairment.<sup>9</sup>

**Subacute Combined Degeneration (Combined System Disease)** is a degenerative disorder affecting the white matter (myelin) of the spinal cord and brain, which results from Vitamin B<sub>12</sub> (cobalamin) deficiency or malabsorption. Clinical presentation includes progressive muscle weakness, paresthesias (e.g., “pins and needles” sensation), sensory loss (e.g., visual impairment secondary to optic neuropathy), neurocognitive impairment and neuropsychiatric disorder. Persons at risk for this disorder include individuals diagnosed with pernicious anemia, prolonged use of antacid medication (e.g., proton pump inhibitors: PPIs), small intestine disease, and other nutritional absorption disorders.<sup>10, 11</sup>

**Subacute Sclerosing Panencephalitis (SSPE)** is a fatal, progressive neurological disorder related to measles (rubeola), primarily affecting children and young adults, with a higher incidence in males than females. Clinical presentation includes cognitive deterioration, uncontrollable jerking movements (myoclonic jerks), and mental status changes. The incidence of SSPE in the United States has declined significantly as a result of widespread immunization with the measles vaccine.<sup>12</sup>

**Wernicke-Korsakoff Syndrome** refers to two neurological disorders associated with Vitamin B<sub>1</sub> (thiamine) deficiency. Wernicke disease, or encephalopathy, (reviewed in the chapter on metabolic disorders affecting the CNS) is characterized by oculomotor abnormalities, confusion and ataxia. The memory disorder which occurs subsequent to the occurrence of Wernicke disease is referred to as Korsakoff amnesia or psychosis, and when neurocognitive impairment persists, Wernicke-Korsakoff syndrome. This disorder primarily, but not exclusively, occurs in alcoholics. Other at risk groups include the elderly

who are malnourished, individuals with anorexia nervosa, and women who experience extreme vomiting during pregnancy (hyperemesis gravidarum), as well as those who have undergone bariatric surgery or who require long-term dialysis or treatment with diuretics. Untreated, Wernicke disease is potentially fatal, while the neurocognitive and neurological symptoms associated with Wernicke-Korsakoff syndrome are progressive and associated with degenerative lesions within the CNS.<sup>13</sup>

## **Other Progressive Disorders of the CNS**

Most progressive disorders of the CNS occur spontaneously, while some are hereditary (e.g., Huntington Disease or Chorea) or familial (heredodegenerative). Some neurodegenerative disorders are associated with multiple risk factors (e.g., multiple sclerosis: MS). The majority of individuals diagnosed with progressive disorders of the CNS are older adults (i.e., 60 years or older), but degenerative disorders of the CNS can occur at any age.

The most common degenerative disease associated with dementia is Alzheimer's Disease. It is estimated that 5.2 million individuals, two-thirds of whom are women, are currently living with Alzheimer's Disease in the United States. In Massachusetts, approximately 120,000 people, age 65 and older, are estimated to have Alzheimer's Disease.<sup>14</sup> Another leading degenerative disorder is Parkinson's Disease, an extrapyramidal disorder associated with depletion of the neurotransmitter dopamine. An estimated 500,000 individuals in the U.S. are living with Parkinson's Disease, and 50,000 new cases are reported annually.<sup>15</sup>

## **Outcome and Potential Long-Term Consequences**

The majority of degenerative disorders of the CNS are irreversibly progressive and fatal, secondary to the lack of efficacious treatment interventions. However, the natural history, survival rates, and manifestations of these disorders vary with the etiology; the presence and severity of the underlying disease (e.g., stage of HIV infection); the specific nerve cells (neurons) affected, and their functional relationship to other cells and systems within the CNS. For certain progressive disorders intervention with medication may provide symptomatic relief (e.g., L-dopa for Parkinson's Disease); may serve to halt the progression of disease (e.g., antibiotics for treatment of neurosyphilis); or may result in remission (e.g., treatment of PML with combination highly active antiretroviral therapy).

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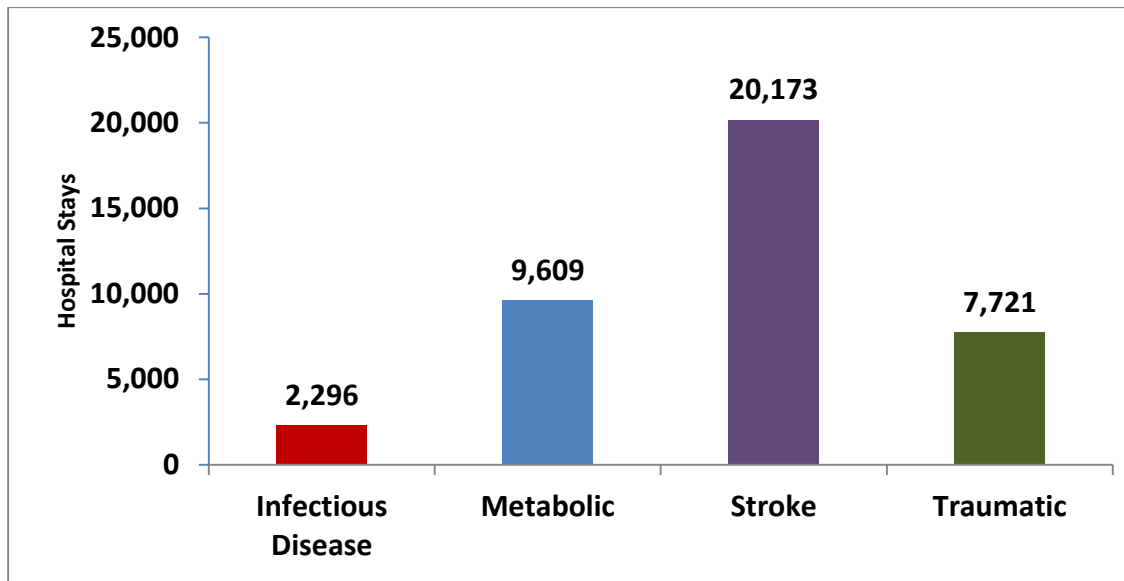
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## CHAPTER III I: SUMMARY of DATA FINDINGS

1. Acquired brain injury (ABI), as defined in Chapters III A- III H in this report, is a substantial public health problem in Massachusetts. Figure B summarizes the average annual number of hospital stays and Figure C, the average annual number of emergency department visits (2008-2010), associated with selected categories of ABI, including traumatic brain injury, stroke, ABI-related infectious diseases, and metabolic disorders affecting the central nervous system. During the same time period, 1,272 primary brain and CNS tumors (excluding the spinal cord) were newly diagnosed in Massachusetts residents on average, annually.
2. Consistent with national epidemiological data, the leading causes of ABI-related hospitalization and ED visits in Massachusetts, for the categories quantified in this report, were traumatic brain injury (TBI) and stroke.
3. Individuals who sustain an ABI associated with many metabolic diseases and conditions (see Chapter III D for discussion); most neurotoxic disorders (see Chapter III E for discussion); and progressive/neurodegenerative disorders of the central nervous system (CNS) reviewed in Chapter III H are not represented or underestimated in the discharge data analyzed for this report. As noted in the methodology sections of the chapters referenced, as well as the data considerations reviewed in Chapter III A, these disorders/diseases are not captured due to the lack of a specific ICD-9-CM code for the disorder (e.g., HIV encephalopathy), or because an acute hospitalization or emergency department visit would not have been necessitated at the time the diagnosis was made (e.g., diagnosis of Alzheimer's Disease).
4. The majority of hospital stays for metabolic disorders affecting the central nervous system, stroke, and TBI were among persons 60 years of age or older. These older adults represented 50% of hospital stays for TBI; 84% for stroke; and 58% for metabolic disorders affecting the CNS. In addition, approximately 50% of both malignant and benign brain and CNS tumors (excluding the spinal cord) are newly diagnosed in adults 60 years or older.

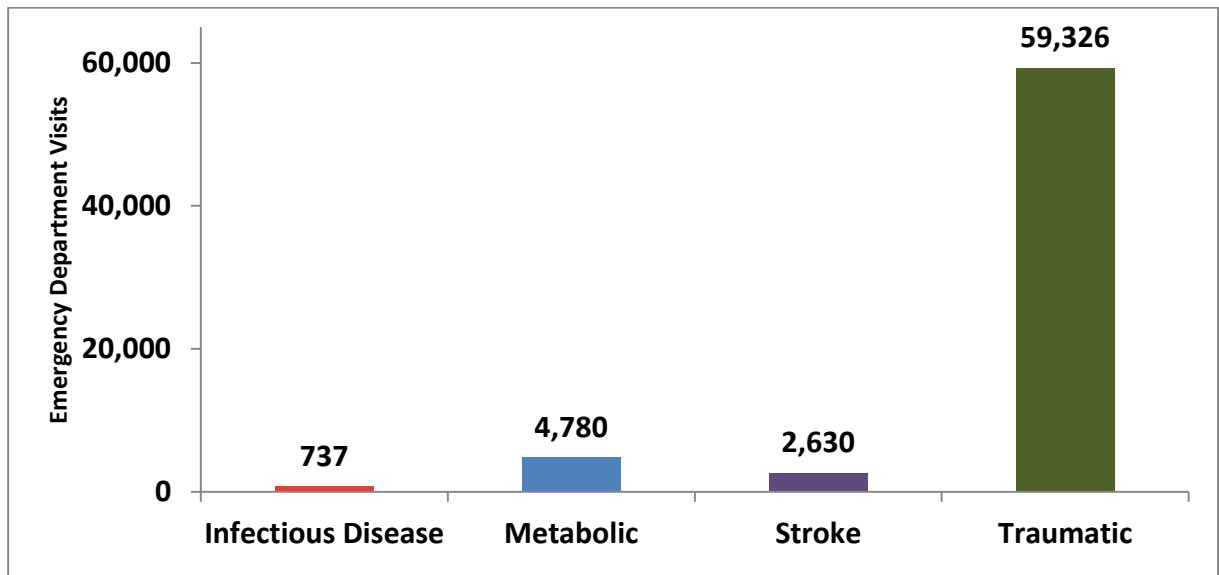
**Figure B. Average Annual Number of Hospital Stays  
Associated with Select Categories of ABI, MA Residents, 2008-2010**



Sources: MA Inpatient Hospital and Outpatient Observation Stay Databases, Center for Health Information and Analysis

Note: Categories are not mutually exclusive.

**Figure C. Average Annual Number of Emergency Department Visits  
Associated with Select Categories of ABI, MA Residents, 2008-2010**



Source: MA Emergency Department Discharge Database, Center for Health Information and Analysis

Note: Categories are not mutually exclusive.

5. With respect to sex, analyses revealed that:

- Females had an elevated average annual rate of non-malignant brain and CNS tumors (excluding the spinal cord) compared with males. The rates by sex for malignant brain tumors were similar.
- Males had a higher average annual rate of hospital stays and emergency department visits for metabolic disorders affecting the CNS compared with females.
- Average annual hospital stay and emergency department visit rates for stroke were comparable for males and females.
- Males had a higher average annual rate of hospital stays and emergency department visits for TBI than females.

6. Regarding differences related to race/ethnicity, analyses revealed that:

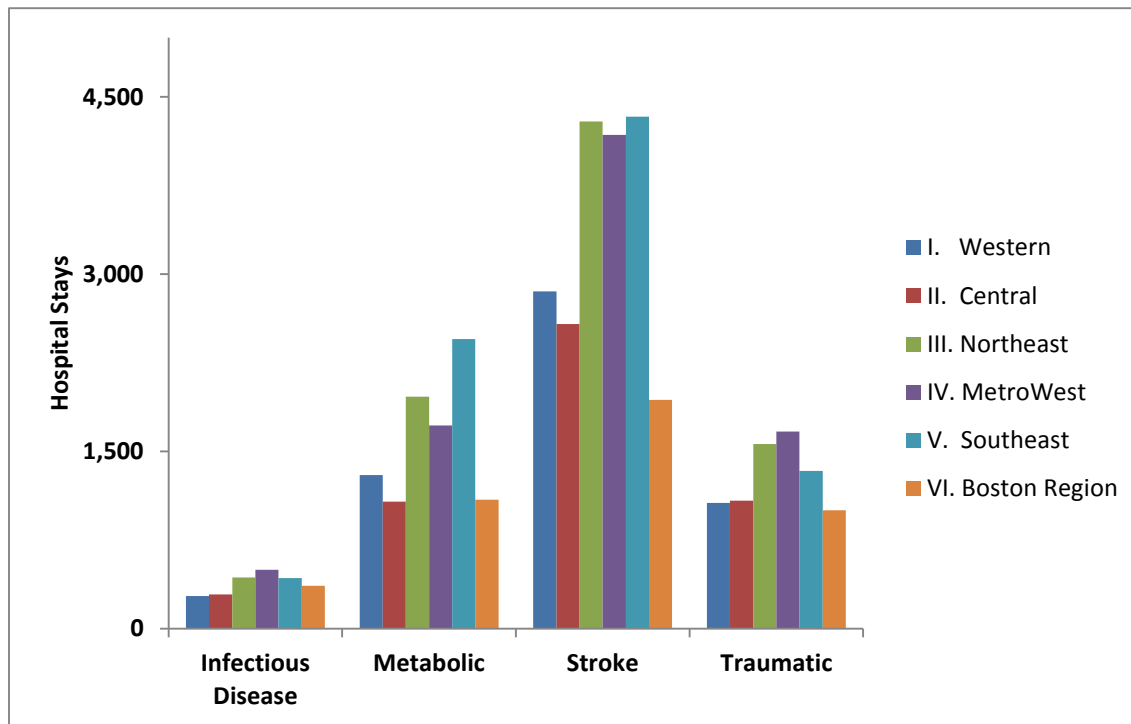
- White, non-Hispanics had elevated crude rates of malignant brain and CNS tumors (excluding the spinal cord), when compared to Hispanics.
- Black, non-Hispanics and Hispanics had higher crude rates of hospital stays and emergency department visits for infectious disease-related ABI, compared with White and Asian non-Hispanics.
- White, non-Hispanics and Black, non-Hispanics had the highest crude rates of hospital stays for metabolic disorders affecting the CNS compared with other racial/ethnic groups, while White, non-Hispanics had the highest crude rates of emergency department visits for these conditions.
- White, non-Hispanics had the highest crude rate of hospital stays and emergency department visits for stroke, in comparison to all other racial/ethnic groups.
- White, non-Hispanics had a higher average annual crude rate of TBI-related hospital stays, while Black, non-Hispanics had a higher crude rate of emergency department visits, when compared with other racial/ethnic groups.

7. Children and young adults (i.e., ages 0-21 years of age) accounted for an average of 17% of the hospital stays and 40% of the emergency department visits for ABI associated with traumatic brain injury annually. Infants and children ages 0-2 years had the highest rate for TBI-related emergency department visits and the second highest rate for hospital stays. Among children and youth 0-18 years of age, infants and children ages 0-2 years also exhibited the highest rates for both emergency department visits and hospital stays for metabolic disorders affecting the CNS and for infectious disease-related ABI. Children and young adults, ages 0-21 years of age also represented 27% of hospital stays and 34% of emergency department visits for infectious disease-related ABIs.

8. Figures D and E depict the average annual number of hospital stays and emergency department visits for select categories of ABI by Executive Office of Health and Human Services region of residence. Please see respective chapters for a listing of the counts. Note, as previously mentioned, these categories are not necessarily mutually exclusive.



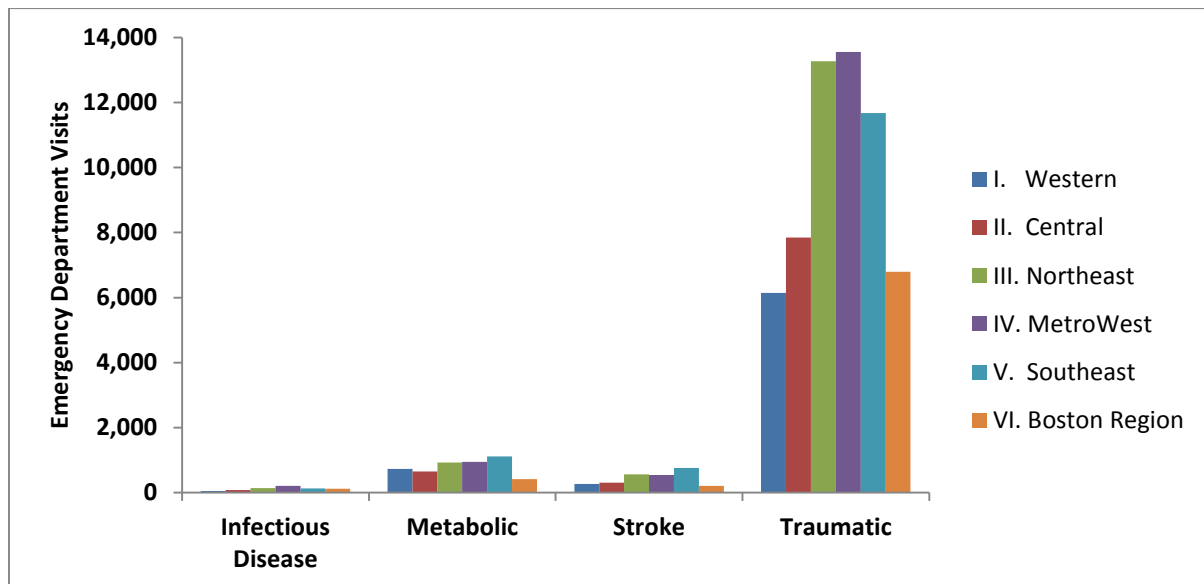
**Figure D. Average Annual Number of Hospital Stays Associated with Select Categories of ABI by Executive Office of Health and Human Services Region of Residence, 2008-2010, MA Residents**



Sources: MA Inpatient Hospital and Outpatient Observation Stay Databases, Center for Health Information and Analysis

Note: Categories are not mutually exclusive.

**Figure E. Average Annual Number of Emergency Department Visits Associated with Select Categories of ABI by Executive Office of Health and Human Services Region of Residence, 2008-2010, MA Residents**



Source: MA Emergency Department Discharge Database, Center for Health Information and Analysis  
 Note: Categories are not mutually exclusive.

9. Analyses of data by primary payer and insurance at diagnosis for primary brain and CNS tumors (excluding the spinal cord) found that public payer sources (i.e., Medicaid, Medicare, Free Care/Health Safety Net, Other Government Payment, and Commonwealth Care) accounted for at least:
  - 48.3%, 37.4%, and 40.3% of inpatient hospitalizations, observation stays and emergency department visits, respectively, associated with infectious disease-related ABI.
  - 41.8% of primary brain and CNS tumor cases (excluding the spinal cord).
  - 79.1%, 72.5%, and 66.9% of inpatient hospitalizations, observation stays and emergency department visits, respectively, associated with metabolic conditions affecting the CNS.
  - 80.5%, 69.7%, and 69.8% of inpatient hospitalizations, observation stays and emergency department visits, respectively, associated with stroke.
  - 63.9%, 45.2%, and 41.4% of inpatient hospitalizations, observation stays and emergency department visits, respectively, associated with a traumatic brain injury.

10. The majority of inpatient hospitalizations associated with TBI, infectious-disease related ABI, metabolic disorders affecting the CNS and stroke did not result in the individuals being transferred to either a rehabilitation hospital or rehabilitation unit within a hospital. Most resulted in the individual being discharged home without services or with in-home services (i.e., IV therapy services), including 54% of those with a diagnosis of TBI; 50% of those with a diagnosis of stroke; and 70% of those with an infectious disorder affecting the CNS. Approximately 20% of inpatient hospitalizations associated with a diagnosis of TBI resulted in the individuals being discharged/transferred to a skilled nursing facility, compared with 19.7% associated with stroke, 21.7% of discharges for metabolic conditions associated with ABI, and 8.9% of for infectious disorders associated with ABI. Fourteen percent of stroke-related inpatient hospitalizations resulted in individuals being discharged to a rehabilitation hospital/unit compared with 12.7% of hospitalizations associated with TBI.

11. The majority of inpatient hospitalizations associated with TBI, stroke, infectious-disease related ABI, and metabolic disorders affecting the CNS, resulted in individuals surviving their hospitalization (94.1%, 92.1%, 96.1%, and 74.6%, respectively).

Final Note: As stated in the preceding subchapters, these data provide only estimates of total discharges for select causes of ABI, with limited information in regards to severity or duration of impairment. The high degree of variability in patient outcomes presents a challenge for assessment of services required by individuals with a discharge for a condition associated with ABI.

## **CHAPTER IV: PREVENTION of ACQUIRED BRAIN INJURY - CURRENT STRATEGIES and INITIATIVES**

### **Traumatic Brain Injury Prevention**

#### *Fall-related Traumatic Brain Injury Prevention Initiatives:*

Falls are the leading cause of traumatic brain injuries in Massachusetts and nationally. The Massachusetts Department of Public Health's Division of Violence and Injury Prevention has had a strong role in promoting the prevention of older adult falls, beginning as a co-founder of the statewide MA Falls Prevention Coalition in 2007. In the early years, the Coalition received funding to host three Falls Prevention symposia, and initiated a Keys to Your Independence social marketing campaign, which included a toll-free information line within MDPH that is still active today (1-800-227-SAFE). The current Coalition is chaired by representatives from MDPH, the MA Senior Care Association, and the Home Care Alliance of MA and maintains a broad-based voluntary membership of over 100 that includes members from the Brain Injury Association of MA and injury prevention/rehabilitation hospital communities. The Coalition holds an annual Falls Prevention Awareness Day event at the MA State House each September, joining a national effort that occurs each fall season to recognize the importance of raising awareness about preventing falls, sponsored by the National Council on Aging.

MDPH is also responsible for facilitating the work of the MA Commission on Falls Prevention; MDPH chairs this 11 member statutory body of stakeholders (created by a health care reform law passed in 2010) that is charged with studying the impact of falls on older adults in MA and recommending strategies to legislators and state policymakers on how to reduce the injuries and health care costs associated with them. The Commission's first report: "Phase 1 Report: The Current Landscape" was submitted in September 2013.<sup>1</sup>

MDPH's Division of Violence and Injury Prevention is also the recipient of a 5-year CDC Core Injury grant, under which reduction of falls among older adults is a focal area and part of a strategic plan for prevention of unintentional injury in the state. In the past year, the grant has afforded MDPH the opportunity to sponsor an evidence-based "Tai-Chi for Healthy Aging" instructor program in three regions of the state to help proliferate availability of these programs to older adults in their communities.

Finally, fall injury prevention in older adults is one of four priority health conditions being addressed through the distribution of more than \$40 million in grants, which were awarded to nine community-based partnerships in Massachusetts. This effort, the Prevention and Wellness Trust Fund, which was created by the Legislature and administered by the MDPH, aims to help fight chronic illness and improve health outcomes while reducing health care costs. Funding to these communities will be used to improve clinical screening of fall risk factors, referrals for and management of these risks and for the development of community-based fall prevention activities, such as tai chi and other methods aimed at improving strength and balance among older adults.

### *Prevention of Falls Related to Work in Construction:*

Falls to a lower level are also a leading cause of work-related injury deaths in Massachusetts. There are also hundreds of non-fatal work-related falls to lower levels each year. The majority of these work-related falls occur in the construction industry. The prevention of falls in construction has been identified by MDPH as an occupational health priority. MDPH's occupational Fatality Assessment and Control Evaluation (FACE) Project, funded by CDC, conducts in-depth investigations of work-related falls to identify contributing factors and uses these case reports to disseminate prevention recommendations to contractors, construction workers and other stakeholders through the state.<sup>2</sup> FACE has also developed a series of education materials (available in multiple languages) on preventing falls from ladders, scaffolding and roofs in residential construction that are disseminated through city and town building permit offices, and other venues. In 2013-14, MDPH collaborated with the Massachusetts Department of Labor Standards (DLS), other state agencies and the Occupational Health and Safety Administration (OSHA) in promoting the "Safety Pays, Falls Cost" national campaign to prevent falls in construction.<sup>3</sup> Campaign posters were displayed throughout the state on public buses, the MBTA subway and the digital billboards along the state highways. Emails with links to resources on fall prevention in construction went out to over 28,000 Massachusetts licensed residential construction contractors, and DLS and OSHA held multiple fall prevention trainings for contractors.

### *Sports-related Traumatic Brain Injury Prevention Initiatives:*

Following passage of state legislation on sports concussions in 2010, the Massachusetts Department of Public Health, in partnership with key stakeholders, has worked extensively to ensure that these injuries are recognized as soon as possible and managed appropriately. The state has developed regulations requiring standardized procedures for students, coaches, school, parents and medical professionals on prevention, training, management and return to activity decisions, and is actively implementing these policies within Massachusetts middle and high schools to reduce the long term health impact of sports-related concussions for student athletes.

### *Motor Vehicle-related Traumatic Brain Injury Prevention Initiatives:*

The Massachusetts Department of Public Health is involved in a number of prevention initiatives to reduce motor vehicle injuries. These include a project, in partnership with the Registry of Motor Vehicles (RMV), examining and improving the effectiveness of the statutorily required two-hour training class for parents of novice teen drivers. Evidence shows that parents are the best enforcers of Junior Operator License (JOL) restrictions. The JOL law has been shown to reduce motor vehicle occupant injuries in this high-risk group.

Belts Ensure a Safer Tomorrow (BEST) is a statewide coalition of concerned stakeholders working to change the state's seat belt law from secondary to primary enforcement. The MDPH supports this effort by providing technical support and data sharing. Additionally, since research shows that ignition interlocks decrease injuries related to driving under the influence of alcohol, the MDPH plans to increase awareness around this to policymakers.

MDPH also provides data and technical assistance to a variety of MA transportation partners and to policymakers on issues related to other forms of transportation---including bicycle and pedestrian safety – all in an effort to reduce injuries in the Commonwealth.

*Traumatic Brain Injury Prevention – Surveillance Initiatives:* The Massachusetts Department of Public Health’s Injury Surveillance and Prevention Program utilizes numerous statewide databases to provide data on traumatic brain injuries to public health professionals involved in strategic planning (for priority setting and establishment of performance measures), policy makers, researchers, and advocates. These data have been incorporated into the MDPH Strategic Plan for Unintentional Injury Prevention, the Massachusetts Strategic Highway Safety Plan (SHSP),<sup>4</sup> and the Massachusetts Falls Commission’s Phase I Report (referenced above). In addition, these data are used by numerous advisory boards and are incorporated into local, state and national presentations.

## **Stroke Prevention**

The Massachusetts Department of Public Health’s Division of Prevention and Wellness supports state and local efforts to promote a heart-healthy, stroke-free environment to help everyone in Massachusetts reach their full potential for optimal health. Work within the division contributes to several statewide and national programs and initiatives that aim to reduce disparities, disease, disability, and death related to heart disease, stroke and corresponding risk factors through evidence-based policy and environmental changes, education, quality improvement, and partnerships. Programs and initiatives include:

- *Massachusetts Coordinated Health Promotions and Chronic Disease Prevention Plan:* Among the goals outlined in this plan is to prevent 20,000 heart attacks and strokes by 2017 through coordination of chronic disease prevention strategies that focus on shared barriers and risk factors.
- *FAST (Face, Arm, Speech, Time):* This campaign provides awareness of common signs and symptoms of stroke to the public.
- *Paul Coverdell Acute Stroke Registry:* Data are submitted to the Massachusetts Department of Public Health from 51 of the 70 Primary Stroke Service hospitals in the state in order to identify opportunities for quality improvement in the treatment of stroke patients.
- *Million Hearts Campaign:* Million Hearts aims to prevent 1 million heart attacks and strokes by 2017 through improved access to effective, quality care; promotion of a heart-healthy lifestyle; and focusing clinical attention on prevention of these events.
- *Prevention and Wellness Trust Fund:* The Trust, described in the section on Traumatic Brain Injury Prevention, supports community-based partnerships including municipalities, healthcare systems, businesses, regional planning organizations, and schools. These groups work together to provide research-based interventions that will reduce rates of the most prevalent and preventable health conditions, including hypertension, a major risk factor for stroke.

## **Prevention of Infectious Disease Affecting the Central Nervous System**

Historically, the major vaccine preventable diseases of childhood were significant causes of CNS injury. On a worldwide basis, diseases such as measles, continue to cause significant neurological damage, but vaccines for most of the serious childhood diseases have almost eliminated these conditions in the United States. Meningococcal meningitis and meningitis due to *Haemophilus influenzae* type b have been made rare diseases with the use of effective vaccines. Massachusetts has had, and continues to have, the highest levels of childhood immunization in the country and this translates into a rarity of CNS complications of vaccine preventable diseases. The Commonwealth has an effective public-private collaboration among public health and pediatric care providers, a universal vaccine distribution system, and an expanding immunization registry that will contribute to assuring the highest possible immunization rates.

CNS complications from non-vaccine preventable infections have been reduced by effective surveillance and disease control programs and by antimicrobial agents. The public health programs involve monitoring disease trends, outbreak investigation, case finding and treatment, and application of isolation and quarantine. For example, effective tuberculosis control programs have depended on case finding and treatment, and rates of tuberculosis in Massachusetts are low, with only a small number of CNS tuberculosis cases identified. Future success will not only depend on continuing efforts to render active tuberculosis cases non-infectious, but also on identifying people with latent tuberculosis infection before they progress to active disease and treating them to prevent active disease from developing. Likewise, identification and treatment of active syphilis cases needs to be combined with efforts to screen those at higher risk and treat them before infection manifests as disease. Early antibiotic therapy of Lyme disease can reduce the risk of subsequent CNS involvement.

Vector-borne diseases, such as viral encephalitis transmitted by mosquitoes (e.g., eastern equine encephalitis, West Nile virus infection) and tick borne infections (e.g., Lyme disease), require promotion of preventive behaviors by the public to take action to avoid mosquitoes and ticks. Promoting safer behaviors has resulted in significant decreases in the incidence of HIV infection, and near universal access to effective antiviral therapy has resulted in a marked reduction in the complications of HIV infection, including AIDS-related opportunistic infections of the CNS and HIV dementia.

## **Prevention of Metabolic Conditions Affecting the Central Nervous System**

Several of the metabolic conditions affecting the central nervous system are related to cardiac arrest and diabetes, two conditions that share many of the same risk factors such as family history, overweight and obesity, poor diet, and lack of physical activity.

In response to rising obesity rates statewide, the Mass in Motion (MiM) initiative was launched in January 2009 under the leadership of Governor Deval Patrick, to promote wellness and to prevent overweight and obesity in Massachusetts. The purpose of this multifaceted campaign is to promote the importance of healthy eating and active living at

home, at work, and in communities throughout the Commonwealth. In particular, the goals of MiM are to decrease the number and percentage of both adults and children who are overweight and obese; and decrease the prevalence of chronic disease associated with unhealthy eating and lack of physical activity. These goals will be accomplished by making the promotion of wellness and prevention of overweight and obesity a top public health priority; and creating conditions that encourage, nurture, and promote wellness. The Municipal Wellness and Leadership program, a component of MiM, provides grant funding, training and technical assistance to cities and towns across the Commonwealth to implement community-based healthy eating/active living interventions. Mass in Motion Website: <http://www.mass.gov/eohhs/gov/departments/dph/programs/community-health/mass-in-motion/>

### **Lead Poisoning Prevention**

The MDPH Bureau of Environmental Health's Childhood Lead Poisoning Prevention Program (BEH/CLPPP) was established for the prevention, screening, diagnosis, and treatment of childhood lead poisoning, including the elimination of sources of poisoning through research, educational, epidemiologic, and clinical activities. BEH/CLPPP provides a range of both primary and secondary prevention services to the children of the Commonwealth of Massachusetts, their families and others with an interest in the prevention of lead poisoning. BEH/CLPPP has developed linkages with a wide array of professionals and programs that provide services to children in order to accomplish the fundamental goals of identifying lead poisoned children and ensuring that they receive medical and environmental services, as well as preventing further cases of lead poisoning. The BEH is currently developing a strategic plan to address the new CDC reference value. The new value suggests that childhood exposure to lead at significantly lower levels are at greater risk of health impacts than previously understood.



**Additional prevention information and resources are available through:**

**American Geriatrics Society**

Falls Prevention in Older Adults (website)

*2010 American Geriatrics Society/British Geriatrics*

*Society Clinical Prevention of Falls in Older Persons*

[http://americangeriatrics.org/health\\_care\\_professionals/clinical\\_practice/clinical\\_guidelines\\_recommendations/2010/](http://americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/2010/)

**Centers for Disease Control and Prevention**

National Center for Injury Prevention and Control

1600 Clifton Rd. Atlanta, GA 30333

1-800-CDC-INFO <http://www.cdc.gov/injury/>

**Massachusetts Department of Public Health:**

**Childhood Lead Poisoning Prevention Program**

250 Washington Street

Boston, MA 02108

(617) 624-5759

**Division of Violence and Injury Prevention**

Bureau of Community Health and Prevention

250 Washington St., 4<sup>th</sup> Floor

Boston, MA 02108

(617) 624-6060

**Division of Prevention and Wellness**

Bureau of Community Health and Prevention

250 Washington St., 4<sup>th</sup> Floor

Boston, MA 02108

(617) 624-6060

**Bureau of Substance Abuse Services**

250 Washington St., 3<sup>rd</sup> Floor

Boston, MA 02108

**Massachusetts Substance Abuse Information and Education Help Line**

800-327-5050

[www.helpline-online.com](http://www.helpline-online.com)

## References:

1. Massachusetts Commission on Falls Prevention. Phase 1 Report: The Current Landscape. Massachusetts Department of Public Health website.  
<http://www.mass.gov/eohhs/docs/dph/injury-surveillance/falls-prevention-phase-1-report.pdf> Published September 2013.
2. Fatal Work-related Injuries. Massachusetts Department of Public Health website.  
<http://www.mass.gov/eohhs/gov/departments/dph/programs/health-stats/ohsp/fatal-injury/>
3. The Center for Construction Research and Training website.  
<http://stopconstructionfalls.com/> 2014.
4. Massachusetts Strategic Highway Safety Plan. Massachusetts Executive Office of Public Safety and Security website.  
<http://www.mass.gov/eopss/docs/oqr/mastrategichighwaysafetyplansept2013.pdf> September 2013.

## **CHAPTER V: ORGANIZATIONS FOR PERSONS WITH ACQUIRED BRAIN INJURY, FAMILIES and CARETAKERS**

Listed below are non-profit, charitable and other organizations which provide education and promote awareness; advocacy for the prevention and development of services for persons with ABI and associated diseases/disorders; and support for acquired brain injury survivors, their families, caregivers and significant others.

### **AIDS Action Committee of Massachusetts**

75 Amory St.  
Boston, MA 02119  
617-437-6200  
<http://www.aac.org/>

### **Alzheimer's Association**

Alzheimer's Association National Office  
225 N. Michigan Ave., Fl. 17  
Chicago, IL 60601  
<http://www.alz.org/>

Alzheimer's Association Massachusetts/New Hampshire  
480 Pleasant Street  
Watertown, MA 02472  
<http://www.alz.org/manh/>  
800-272-3900

### **American Brain Tumor Association (ABTA)**

8550 W. Bryn Mawr Ave.  
Suite 550  
Chicago, IL 60631  
800-886-2282  
<http://www.abta.org/>

### **American Heart Association**

20 Speen St.  
Framingham, MA 01701  
508-620-1700  
[http://www.framingham.com/org/am\\_heart.htm](http://www.framingham.com/org/am_heart.htm)

### **American Lyme Disease Foundation, Inc.**

P.O. Box 466  
Lyme, CT 06371  
<http://www.aldf.com/>

**American Parkinson Disease Association**

135 Parkinson Avenue  
Staten Island, NY 10305  
<http://www.apdaparkinson.org>

American Parkinson Disease Association Massachusetts Chapter  
72 East Concord Street  
Boston, MA 02118  
800-651-8466

**American Stroke Association**

7272 Greenville Ave.  
Dallas, TX 75231  
888-4-STROKE  
<http://www.strokeassociation.org/STROKEORG/>

**Brain Aneurysm Foundation**

269 Hanover St., Building 3  
Hanover, MA 02339  
781-826-5556  
888-BRAIN02 (272-4602)  
<http://www.bafound.org>

**Brain Injury Association of America (BIAA)**

1608 Spring Hill Rd., Suite 110  
Vienna, VA 22182  
703-761-0750  
<http://www.biausa.org/>

**Brain Injury Association of Massachusetts (BIA-MA)**

30 Lyman St.  
Westborough, MA 01581  
508-475-0032  
800-242-0030  
<http://www.biama.org/>

**Children's Hemiplegia and Stroke Association (CHASA)**

4101 W. Green Oaks, Suite 305, #149  
Arlington, TX 76016  
<http://www.chasa.org/>

**Children's Neurobiological Solutions (CNS) Foundation**

1223 Wilshire Blvd. #937  
Santa Monica, CA 90403  
866-CNS-5580 (267-5580)  
<http://www.cnsfoundation.org>

**Healthy Homes Collaborative**

P.O. Box 31796

Los Angeles, CA 90031

323-221-8320

<http://www.healthyhomescollaborative.org>

**Lyme Disease Association, Inc.**

P.O. Box 1438

Jackson, NJ 08527

888-366-6611

<http://www.lymediseaseassociation.org>

**Meningitis Angels**

P.O. Box 448

Porter, TX 77365

281-572-1998

<http://www.meningitis-angels.org>

**Meningitis Foundation of America, Inc.**

P.O. Box 1818

El Mirage, AZ 85335

480-270-2652

<http://www.musa.org>

**National Brain Tumor Society**

Boston Office

55 Chapel St., Suite 200

Newton, MA 02458

617-924-9997

<http://www.braintumor.org/>

**National Meningitis Association, Inc.**

P.O. Box 725165

Atlanta, GA 31139

<http://www.nmaus.org/>

**National Multiple Sclerosis Society**

Greater New England

101A First Ave.

Waltham, MA 02451

800-344-4867

<http://www.nationalmssociety.org/>

**National Organization for Rare Disorders (Massachusetts Office)**

1900 Crown Colony Dr., 4<sup>th</sup> Floor

Quincy, MA 02169

617-249-7300

<http://www.rarediseases.org/>

**National Stroke Association**

9707 E. Easter Lane, Suite B  
Centennial, CO 80112  
800-STROKES (787-6537)  
<http://www.stroke.org/>

**Sports Legacy Institute**

230 Second Ave., Suite 200  
Waltham, MA 02451  
<http://www.sportslegacy.org>

**The Aneurysm and AVM Foundation (TAAF)**

3636 Castro Valley Blvd, Suite 3  
Castro Valley, CA 94546  
<http://www.taafonline.org/>

**United Cerebral Palsy (UCP)**

Berkshire County Office  
208 West St.  
Pittsfield, MA 01201  
413-442-1562  
<http://www.ucpberkshire.org>

MetroBoston Office  
71 Arsenal St.  
Watertown, MA 02702  
617-926-5480  
<http://www.ucpboston.org>

United Cerebral Palsy  
1825 K Street NW Suite 600  
Washington, DC 20006  
<http://www.ucp.org/>

## **APPENDIX A**

### **GLOSSARY of ACRONYMS and INITIALISMS**

## **GLOSSARY of ACRONYMS and INITIALISMS**

ABI:	Acquired brain injury
ABTA:	American Brain Tumor Association
ADC:	AIDS dementia complex
ADL:	Activities of daily living
ADRC:	Aging and Disability Resource Center
AHA:	American Heart Association
AI/AN:	American Indian/Alaskan Native
ALS:	Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease)
ANS:	Autonomic nervous system
ASA:	American Stroke Association
ASAP:	Aging Services Access Points
AVM:	Arteriovenous malformation
BIA-MA:	Brain Injury Association of Massachusetts
BIC:	Brain Injury Commission
BI&SSCSD:	Brain Injury and Statewide Specialized Community Services Department
CAD:	Coronary artery disease
CART:	Combination antiretroviral therapy
CBTRUS:	Central Brain Tumor Registry of the United States
CDC:	Centers for Disease Control and Prevention
CHI:	Closed Head Injury
CHIA:	Center for Health Information and Analysis



CJD:	Creutzfeldt-Jakob disease
CL:	Community Living Division of the Massachusetts Rehabilitation Commission
CLPPP:	Childhood Lead Poisoning Prevention Program
CMS:	Centers for Medicare and Medicaid Services
CN:	Cranial Nerve
CNS:	Central nervous system (brain and spinal cord)
COA:	Councils on Aging
COPD:	Chronic obstructive pulmonary disease
CP:	Cerebral palsy
CT:	Computed (computerized) tomography
CTE:	Chronic traumatic encephalopathy
DAI:	Diffuse axonal injury
DCF:	Department of Children and Families
DDS:	Department of Developmental Services
DMH:	Department of Mental Health
DYS:	Department of Youth Services
ED:	Emergency Department
EEC:	Department of Early Education and Care
EEG:	Electroencephalogram
EOE:	Executive Office of Education
EOEA:	Executive Office of Elder Affairs
EOHHS:	Executive Office of Health and Human Services
ESE:	Department of Elementary and Secondary Education
HAART:	Highly active antiretroviral therapy
HAD:	HIV-associated Dementia

HAND:	HIV-associated neurocognitive disorder
HCBS:	Home and Community-Based Services
HIV:	Human Immunodeficiency virus
HRSA:	Health Resources and Services Administration
IADL:	Instrumental activities of daily living
ICD-9-CM:	International Classification of Diseases, 9 <sup>th</sup> revision, Clinical Modification
ICH:	Intracerebral hemorrhage
ICD-O:	International Classification of Diseases for Oncology
ILC:	Independent Living Center
IED:	Improvised explosive device
IVH:	Intraventricular hemorrhage
LOC:	Loss of consciousness
LTSS:	Long Term Support Services
MassCHIP:	Massachusetts Community Health Information Profile
MCB:	Massachusetts Commission for the Blind
MCDHH:	Massachusetts Commission for the Deaf and Hard of Hearing
MCR:	Massachusetts Cancer Registry
MDPH:	Massachusetts Department of Public Health
MID:	Multi-infarct Dementia
MMWR:	Morbidity and Mortality Weekly Report
MRC:	Massachusetts Rehabilitation Commission
MRI:	Magnetic resonance imaging
MS:	Multiple sclerosis
mTBI/MTBI:	Mild traumatic brain injury
NAACCR:	North American Association of Central Cancer Registries

NCI:	National Cancer Institute
NFI:	Neurofibromatosis
NH:	Non-Hispanic
NIH:	National Institutes of Health
NINDS:	National Institute of Neurological Disorders and Stroke
NLM:	National Library of Medicine
NMS:	Neuroleptic malignant syndrome
NPCR:	National Program of Cancer Registries
OEF/OIF:	Operation Enduring Freedom/ Operation Iraqi Freedom
OOM:	Office of Medicaid
PFC:	Prefrontal cortex
PML:	Progressive multifocal leukoencephalopathy
PNS:	Peripheral nervous system
PrP:	Prion protein
PSS:	Primary stroke service
PTA:	Post-traumatic amnesia
PTSD:	Post-traumatic stress disorder
ROM:	Range of motion
rt-PA:	Recombinant tissue plasminogen activator
SAH:	Subarachnoid hemorrhage
SAMHSA:	Substance Abuse and Mental Health Services Administration
SBS:	Shaken Baby Syndrome
SEER:	Surveillance, Epidemiology and End Results program
SHIP:	Statewide Head Injury Program of the Massachusetts Rehabilitation Commission
TBI:	Traumatic brain injury

TEA:	Transient epileptic amnesia
TGA:	Transient global amnesia
TIA:	Transient ischemic attack
TPA:	Tissue plasminogen activator
TSE:	Transmissible spongiform encephalopathy
VAMC:	Veterans Administration Medical Center
vCJD:	Variant Creutzfeldt-Jakob disease
VZV:	Varicella zoster virus
WHO:	World Health Organization

## **APPENDIX B**

### **DIAGNOSTIC CODES USED FOR DEFINITIONS of ACQUIRED BRAIN INJURY**

## **APPENDIX B-1**

## ICD-0 (Third Edition) Topography Codes used for Definition of Brain Neoplasms

CODE	SITE
<b>C70.0</b>	Cerebral Meninges
<b>C71.0</b>	Cerebrum
<b>C71.1</b>	Frontal Lobe
<b>C71.2</b>	Temporal Lobe
<b>C71.3</b>	Parietal Lobe
<b>C71.4</b>	Occipital Lobe
<b>C71.5</b>	Ventricle, NOS
<b>C71.6</b>	Cerebellum, NOS
<b>C71.7</b>	Brain Stem
<b>C71.8</b>	Overlapping Lesion of Brain
<b>C71.9</b>	Brain, NOS
<b>C72.2</b>	Olfactory Nerve
<b>C72.3</b>	Optic Nerve
<b>C72.4</b>	Acoustic Nerve
<b>C72.5</b>	Cranial Nerves, NOS
<b>C72.8</b>	Overlapping Lesion of Brain and CNS
<b>C72.9</b>	Nervous System, NOS
<b>C75.1</b>	Pituitary Gland
<b>C75.2</b>	Craniopharyngeal Duct
<b>C75.3</b>	Pineal Gland

## **APPENDIX B-2**



**ICD-9-CM Codes Used for Definition of Infectious Diseases associated with Disorders of the CNS**

<b>CODE</b>	<b>ICD-9-CM CODE DESCRIPTION</b>
<b>003.21</b>	Salmonella meningitis
<b>006.5</b>	Amebic brain abscess
<b>013.0-013.3</b>	Tuberculosis of meninges and central nervous system
<b>013.6-013.9</b>	Tuberculosis of meninges and central nervous system
<b>036.0</b>	Meningococcal meningitis
<b>036.1</b>	Meningococcal encephalitis
<b>036.81</b>	Meningococcal optic neuritis
<b>047.0</b>	Meningitis due to coxsackie virus
<b>047.1</b>	Meningitis due to ECHO virus
<b>047.8</b>	Other specified viral meningitis
<b>047.9</b>	Unspecified viral meningitis
<b>048</b>	Other enterovirus diseases of central nervous system
<b>049.0</b>	Non-arthropod-borne lymphocytic choriomeningitis
<b>049.1</b>	Meningitis due to adenovirus
<b>049.8</b>	Other specified non-arthropod-borne viral diseases of central nervous system
<b>049.9</b>	Unspecified non-arthropod-borne viral diseases of central nervous system
<b>052.0</b>	Postvaricella encephalitis
<b>053.0</b>	Herpes zoster with meningitis
<b>053.11</b>	Geniculate herpes zoster
<b>053.12</b>	Postherpetic trigeminal neuralgia
<b>054.3</b>	Herpetic meningoencephalitis
<b>054.72</b>	Herpes simplex meningitis
<b>055.0</b>	Postmeasles encephalitis
<b>056.00</b>	Rubella with unspecified neurological complication
<b>056.01</b>	Encephalomyelitis due to rubella
<b>056.09</b>	Rubella with other neurological complications
<b>062.0</b>	Japanese encephalitis
<b>062.1</b>	Western equine encephalitis
<b>062.2</b>	Eastern equine encephalitis
<b>062.3</b>	St. Louis encephalitis

**ICD-9-CM Codes Used for Definition of Infectious Diseases associated with Disorders of the CNS**

<b>CODE</b>	<b>ICD-9-CM CODE DESCRIPTION</b>
<b>062.4</b>	Australian encephalitis
<b>062.5</b>	California virus encephalitis
<b>062.8</b>	Other specified mosquito-borne viral encephalitis
<b>062.9</b>	Mosquito-borne viral encephalitis, unspecified
<b>063.0</b>	Russian spring-summer [taiga] encephalitis
<b>063.1</b>	Louping ill
<b>063.2</b>	Central European encephalitis
<b>063.8</b>	Other specified tick-borne viral encephalitis
<b>063.9</b>	Tick-borne viral encephalitis, unspecified
<b>064</b>	Viral encephalitis transmitted by other and unspecified arthropods
<b>066.2</b>	Venezuelan equine fever
<b>072.1</b>	Mumps meningitis
<b>072.2</b>	Mumps encephalitis
<b>091.81</b>	Acute syphilitic meningitis (secondary)
<b>094.2</b>	Syphilitic meningitis
<b>094.3</b>	Asymptomatic neurosyphilis
<b>094.81</b>	Syphilitic encephalitis
<b>094.82</b>	Syphilitic Parkinsonism
<b>094.84</b>	Syphilitic optic atrophy
<b>094.85</b>	Syphilitic retrobulbar neuritis
<b>094.86</b>	Syphilitic acoustic neuritis
<b>094.89</b>	Other specified neurosyphilis
<b>094.9</b>	Neurosyphilis, unspecified
<b>098.82</b>	Gonococcal meningitis
<b>100.81</b>	Leptospiral meningitis (aseptic)
<b>112.83</b>	Candidal meningitis
<b>115.01</b>	Histoplasma capsulatum meningitis
<b>115.11</b>	Histoplasma duboisii meningitis
<b>115.91</b>	Histoplasmosis meningitis
<b>130.0</b>	Meningoencephalitis due to toxoplasmosis

**ICD-9-CM Codes Used for Definition of Infectious Diseases associated with Disorders of the CNS**

<b>CODE</b>	<b>ICD-9-CM CODE DESCRIPTION</b>
<b>320.0</b>	Hemophilus meningitis
<b>320.1</b>	Pneumococcal meningitis
<b>320.2</b>	Streptococcal meningitis
<b>320.3</b>	Staphylococcal meningitis
<b>320.7</b>	Meningitis in other bacterial diseases classified elsewhere
<b>320.81</b>	Anaerobic meningitis
<b>320.82</b>	Meningitis due to gram-negative bacteria, not elsewhere classified
<b>320.89</b>	Meningitis due to other specified bacteria
<b>320.9</b>	Meningitis due to unspecified bacterium
<b>321.0</b>	Cryptococcal meningitis
<b>321.1</b>	Meningitis in other fungal diseases
<b>321.2</b>	Meningitis due to viruses not elsewhere classified
<b>321.3</b>	Meningitis due to trypanosomiasis
<b>321.4</b>	Meningitis in sarcoidosis
<b>321.8</b>	Meningitis due to other nonbacterial organisms classified elsewhere
<b>322.0</b>	Nonpyogenic meningitis
<b>322.1</b>	Eosinophilic meningitis
<b>322.2</b>	Chronic meningitis
<b>322.9</b>	Meningitis, unspecified
<b>323.01</b>	Encephalitis and encephalomyelitis in viral diseases classified elsewhere
<b>323.1</b>	Encephalitis, myelitis, and encephalomyelitis in rickettsial diseases classified elsewhere
<b>323.2</b>	Encephalitis, myelitis, and encephalomyelitis in protozoal diseases classified elsewhere
<b>323.41</b>	Other encephalitis and encephalomyelitis due to other infections classified elsewhere
<b>323.51</b>	Encephalitis and encephalomyelitis following immunization procedures
<b>323.61</b>	Infectious acute disseminated encephalomyelitis (ADEM)
<b>323.62</b>	Other postinfectious encephalitis and encephalomyelitis
<b>323.81</b>	Other causes of encephalitis and encephalomyelitis
<b>323.9</b>	Unspecified causes of encephalitis, myelitis, and encephalomyelitis
<b>324.0</b>	Intracranial abscess

**ICD-9-CM Codes Used for Definition of Infectious Diseases associated with Disorders of the CNS**

<b>CODE</b>	<b>ICD-9-CM CODE DESCRIPTION</b>
<b>324.9</b>	Intracranial and intraspinal abscess of unspecified site
<b>325</b>	Phlebitis and thrombophlebitis of intracranial venous sinuses

## **APPENDIX B-3**

## ICD-9-CM Codes used for Definition of Metabolic Disorders Affecting the CNS

<b>CODE</b>	<b>ICD-9-CM CODE DESCRIPTION</b>
<b>070.0</b>	Viral hepatitis A with hepatic coma
<b>070.20</b>	Viral hepatitis B with hepatic coma acute or unspecified without hepatitis delta
<b>070.21</b>	Viral hepatitis B with hepatic coma acute or unspecified with hepatitis delta
<b>070.22</b>	Chronic viral hepatitis B with hepatic coma without hepatitis delta
<b>070.23</b>	Chronic viral hepatitis B with hepatic coma with hepatitis delta
<b>070.41</b>	Acute hepatitis C with hepatic coma
<b>070.43</b>	Hepatitis E with hepatic coma
<b>070.44</b>	Chronic hepatitis C with hepatic coma
<b>070.49</b>	Other specified viral hepatitis with hepatic coma
<b>070.6</b>	Unspecified viral hepatitis with hepatic coma
<b>070.71</b>	Unspecified viral hepatitis C with hepatic coma
<b>249.20</b>	Secondary DM with hyperosmolarity (non-ketotic coma)
<b>249.30</b>	Secondary DM with other coma
<b>250.20</b>	Diabetes with hyperosmolarity (non-ketotic coma)
<b>250.30</b>	Diabetes with other coma, Type II or unspecified type, not stated as uncontrolled
<b>250.31</b>	Diabetes with other coma, Type I [juvenile type], not stated as uncontrolled
<b>250.32</b>	Diabetes with other coma, Type II or unspecified type, uncontrolled
<b>250.33</b>	Diabetes with other coma, Type I [juvenile type], uncontrolled
<b>251.0</b>	Hypoglycemic coma
<b>348.1</b>	Anoxic brain damage
<b>348.31</b>	Metabolic encephalopathy
<b>427.5</b>	Cardiac arrest
<b>572.2</b>	Hepatic encephalopathy

**ICD-9-CM Codes used for Definition of Metabolic Disorders Affecting the CNS**

CODE	ICD-9-CM CODE DESCRIPTION
<b>768.5</b>	Severe birth asphyxia
<b>768.6</b>	Mild or moderate birth asphyxia
<b>768.7</b>	Hypoxic-ischemic encephalopathy (HIE)
<b>768.9</b>	Severe hypoxic-ischemic encephalopathy
<b>770.87</b>	Respiratory arrest of newborn
<b>774.7</b>	Kernicterus not due to isoimmunization (bilirubin encephalopathy)
<b>779.85</b>	Cardiac arrest of newborn
<b>799.01</b>	Asphyxia
<b>799.1</b>	Respiratory arrest
<b>994.7</b>	Asphyxia and strangulation
<b>994.8</b>	Electrocution

## **APPENDIX B-4**



## ICD-9-CM Codes Used for Definition of Neurovascular Diseases and Conditions

CODE	ICD-9-CM CODE DESCRIPTION
<b>430*</b>	Subarachnoid hemorrhage
<b>431*</b>	Intracerebral hemorrhage
<b>432.0</b>	Nontraumatic extradural hemorrhage
<b>432.1</b>	Subdural hemorrhage
<b>432.9</b>	Unspecified intracranial hemorrhage
<b>433.00</b>	Occlusion and stenosis of basilar artery, without mention of cerebral infarction
<b>433.01*</b>	Occlusion and stenosis of basilar artery, with cerebral infarction
<b>433.10*</b>	Occlusion and stenosis of carotid artery without cerebral infarction
<b>433.11*</b>	Occlusion and stenosis of carotid artery, with cerebral infarction
<b>433.20</b>	Occlusion and stenosis of vertebral artery, without mention of cerebral infarction
<b>433.21*</b>	Occlusion and stenosis of vertebral artery, with cerebral infarction
<b>433.30</b>	Occlusion and stenosis of multiple and bilateral precerebral arteries, without mention of cerebral infarction
<b>433.31*</b>	Occlusion and stenosis of multiple and bilateral precerebral arteries, with cerebral infarction
<b>433.80</b>	Occlusion and stenosis of other specified precerebral artery, without mention of cerebral infarction
<b>433.81*</b>	Occlusion and stenosis of other specified precerebral artery, with cerebral infarction
<b>433.90</b>	Occlusion and stenosis of unspecified precerebral artery, without mention of cerebral infarction
<b>433.91*</b>	Occlusion and stenosis of unspecified precerebral artery, with cerebral infarction
<b>434.00*</b>	Cerebral thrombosis, without mention of cerebral infarction
<b>434.01*</b>	Cerebral thrombosis, with cerebral infarction
<b>434.10</b>	Cerebral embolism, without mention of cerebral infarction
<b>434.11*</b>	Cerebral embolism, with cerebral infarction

## ICD-9-CM Codes Used for Definition of Neurovascular Diseases and Conditions

CODE	ICD-9-CM CODE DESCRIPTION
<b>434.90</b>	Cerebral artery occlusion, unspecified, without mention of cerebral infarction
<b>434.91*</b>	Cerebral artery occlusion, unspecified, with cerebral infarction
<b>435.0</b>	Basilar artery syndrome
<b>435.1</b>	Vertebral artery syndrome
<b>435.2</b>	Subclavian steal syndrome
<b>435.3</b>	Vertebrobasilar artery syndrome
<b>435.8</b>	Other specified transient cerebral ischemias
<b>435.9</b>	Unspecified transient cerebral ischemia
<b>436*</b>	Acute, but ill-defined, cerebrovascular disease
<b>437.0</b>	Cerebral atherosclerosis
<b>437.1</b>	Other generalized ischemic cerebrovascular disease
<b>437.2</b>	Hypertensive encephalopathy
<b>437.3</b>	Cerebral aneurysm, nonruptured
<b>437.4</b>	Cerebral arteritis
<b>437.5</b>	Moyamoya disease
<b>437.6</b>	Nonpyogenic thrombosis of intracranial venous sinus
<b>437.7</b>	Transient global amnesia
<b>437.8</b>	Other ill-defined cerebrovascular disease
<b>437.9</b>	Unspecified cerebrovascular disease
<b>348.2</b>	Benign Intracranial Hypertension
<b>997.02</b>	Iatrogenic cerebrovascular infarct/hemorrhage
<b>772.10</b>	Intraventricular hemorrhage-Unspecified Grade
<b>772.11</b>	Intraventricular hemorrhage-Grade I
<b>772.12</b>	Intraventricular hemorrhage-Grade II

### ICD-9-CM Codes Used for Definition of Neurovascular Diseases and Conditions

CODE	ICD-9-CM CODE DESCRIPTION
<b>772.13</b>	Intraventricular hemorrhage-Grade I
<b>772.14</b>	Intraventricular hemorrhage-Grade II
<b>772.20</b>	Subarachnoid hemorrhage from any perinatal cause
<b>767.0</b>	Subdural and cerebral hemorrhage

**\*Codes used to define stroke, in accordance with Joint Commission on Disease-specific Care**

## **APPENDIX B-5**

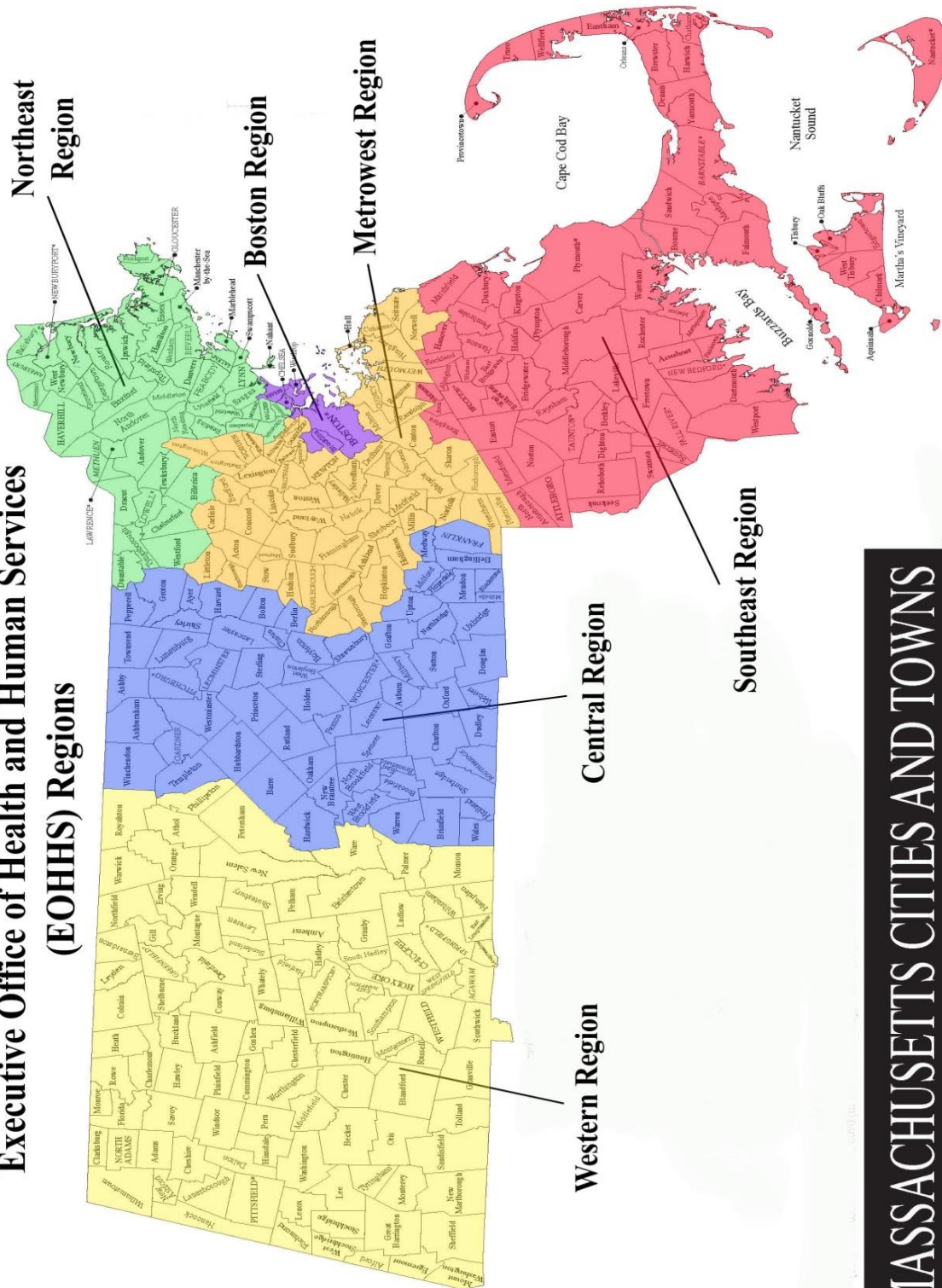
## ICD-9-CM Codes Used for Definition of Traumatic Brain injury

CODE	ICD-9-CM CODE DESCRIPTION
<b>800.0-800.9</b>	Fracture of vault of skull
<b>801.0-801.9</b>	Fracture of base of skull
<b>803.0-803.9</b>	Other and unqualified skull fractures
<b>804.0-804.9</b>	Multiple fractures involving skull or face with other bones
<b>850.0-850.9</b>	Concussion
<b>851.0-851.9</b>	Cerebral laceration and contusion
<b>852.0-852.5</b>	Subarachnoid, subdural and extradural hemorrhage following injury
<b>853.0-853.1</b>	Other unspecified intracranial hemorrhage following injury
<b>854.0-854.1</b>	Intracranial injury of other and unspecified nature
<b>950.1</b>	Injury to the optic chiasm
<b>950.2</b>	Injury to the optic pathways
<b>950.3</b>	Injury to the visual cortex
<b>959.01</b>	Head injury unspecified
<b>999.55</b>	Shaken Infant Syndrome

## **APPENDIX C**

### **MAP OF EOHHS REGIONS & TOWNS**

# Executive Office of Health and Human Services (EOHHS) Regions



## MASSACHUSETTS CITIES AND TOWNS

