## Massachusetts

### Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
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</thead>
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<tr>
<td>MA</td>
<td>STATUTE: Chapter 111, Section 67E. Children born with congenital anomaly, birth defect, birth injury or mental retardation: reports.</td>
<td>Section 67E. (a) Within 30 days after the diagnosis in the commonwealth of a congenital anomaly, birth defect or birth injury which may lead to an incapacity or disability, the physician making the diagnosis shall report the anomaly, defect or injury to the department on a form to be furnished by the department. The commissioner shall require the submission of such information on reported cases up to the age of 3 years as he considers necessary and appropriate for the prevention and early detection of such anomalies, defects and injuries. …</td>
<td>Authorized officials or agents of the department may abstract and record information that is required for reporting from the medical records of children under the age of 3 years and their parents. … (b) The contents of such reports, records and information shall be solely for the use of the department and such reports, records and information shall not be open to public inspection or constitute a public record.</td>
<td>Section 67E. (a) Before abstracting or recording any additional information from an individual’s medical records, department officials shall obtain the approval of a duly constituted institutional review board that reviews and approves, and thereafter annually re-approves, a research protocol submitted to it by the department. The research protocol shall specify how such records shall be reviewed, how information from them shall be abstracted and reported, the exact information to be recorded, and how the information will be used, maintained and kept confidential. The department shall collect no more information than it considers necessary and appropriate in order to conduct epidemiological surveys and to develop appropriate preventative treatment and control measures.</td>
<td>NO</td>
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### 105 CMR 300.000 REPORTABLE DISEASES, SURVEILLANCE AND ISOLATION AND QUARANTINE REQUIREMENTS.

**300.020: Definitions.** Disease. An abnormal condition or functional impairment resulting from infection, metabolic abnormalities, physical or physiological injury or other cause, marked by subjective complaints, associated with a specific history, and clinical signs and symptoms, and/or laboratory or radiographic findings.

Illness. An abnormal condition or functional impairment resulting from infection, metabolic abnormalities, physical or physiological injury or other cause, marketed by subjective complaints and clinical signs.

**105 CMR 300.191: Access to Medical Records and Other Information.** (A) The Department and local boards of health are authorized to obtain, upon request, from health care providers and other persons subject to the provisions of 105 CMR 300.000 et seq., medical records and other information that the Department or the local board of health deems necessary to carry out its responsibilities to investigate, monitor, prevent and control diseases dangerous to the public health...
## Cancer Surveillance System

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<tr>
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<td>MA</td>
<td>STATUTE: M.G.L. c. 111, § 3 and 111B. RULE: 105 CMR 301.000 to 301.040</td>
<td>TITLE XVI. PUBLIC HEALTH, CHAPTER 111. PUBLIC HEALTH: DANGEROUS DISEASES Chapter 111: Section 111B. Malignant disease and benign brain-related tumor registry: reports</td>
<td>301.020: Persons, Facilities, and Agencies Required to Report Information. Every health care facility shall report to the Cancer Registry every case of malignant disease and benign brain-related tumor disease diagnosed, evaluated, treated, medically supported or palliated at that health care facility. Every health care provider shall report to the cancer registry every case of malignant disease and benign brain-related tumor disease diagnosed, evaluated, treated, medically supported or palliated by that health care provider which has not been previously diagnosed, evaluated or treated at a health care facility. All health care facilities and health care providers who provide diagnosis, evaluation, treatment, medical support or palliative services to patients with malignant disease or benign brain-related tumor disease shall report to the Cancer Registry any further demographic, diagnostic, or treatment information requested by the Cancer Registry concerning any person now or formerly receiving services, diagnosed as having or having had a malignant disease, or benign brain-related tumor disease. Additionally, the Cancer Registry shall have physical access to all records which would identify cases of malignant disease or benign brain-related tumor disease, treatment of the malignant disease or benign brain-related tumor disease, or medical status of any identified malignant disease or benign brain-related tumor disease patient.</td>
<td>301.040: Confidentiality of Reports … (E) The Commissioner of the Department of Public Health may release information maintained by the Cancer Registry to the authorized representative of a study or research project authorized by the Commissioner. However, 105 CMR 301.040(E) shall not apply to, and the Department shall not release, any part of a patient's medical record obtained pursuant to 105 CMR 301.035, or 105 CMR 301.036, nor to any participant's Social Security number obtained pursuant to 105 CMR 301.015(A).</td>
<td>NO</td>
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### 301.010: Cases Required to be Reported
Each case of malignant disease and benign brain-related tumor disease diagnosed, evaluated, treated, medically supported or palliated within the Commonwealth of Massachusetts is required to be reported to the Department of Public Health Cancer Registry together with information specified in 105 CMR 301.015 and in accordance with the current procedure manual as specified in 105 CMR 301.017.

### 301.015: Information Required to be Reported
Each report required by 105 CMR 301.010 shall include the following data categories:

- **A** Patient identifiers and demographics
- **B** Provider and facility identifiers
- **C** Cancer identification
- **D** Extent of disease at diagnosis
- **E** First course of treatment
- **F** Other information as necessary to ensure completeness

No such study or research project shall publish the name of any individual who is or was the subject of a report submitted to the Cancer Registry nor shall any such study or research project release any identifying number, mark or description which can be readily associated with an individual who is or was the subject of a report submitted to the Cancer Registry.
Newborn Genetic Testing & Surveillance System

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<tr>
<td>MA</td>
<td>STATUTE: Title XVI, Chapter 111, Sections 110A and 70G RULE: 105 CMR</td>
<td>Chapter 111: Section 110A. Tests of newborn children for treatable disorders or diseases. The physician attending a newborn child shall cause said child to be subjected to tests for phenylketonuria, cretinism and such other specifically treatable genetic or biochemical disorders or treatable infectious diseases which may be determined by testing as specified by the commissioner. The commissioner may convene an advisory committee on newborn screening to assist him in determining which tests are necessary. The department shall make such rules pertaining to such tests as accepted medical practice shall indicate…</td>
<td>Section 110A. …The provisions of this section shall not apply if the parents of such child object thereto on the grounds that such test conflicts with their religious tenets and practices.</td>
<td>Chapter 111: Section 70G. Genetic information and reports protected as private information; prior written consent for genetic testing. a)…For purposes of this section, the term genetic information shall not include any information about an identifiable person that is taken as a newborn screening pursuant to section 110A… [emphasis added] (c) No facility, as defined in section 70E, and no physician or health care provider shall: (1) test any person for genetic information without first obtaining the prior written consent; (2) disclose the results of a genetic test to any person other than the subject thereof without first obtaining the informed written consent except where the results disclosed will be used only as is confidential research information for use in epidemiological or clinical research conducted for the purpose of generating scientific knowledge about genes or learning about the genetic basis of disease or for developing pharmaceutical and other treatments of disease; or identify the person being tested to any other person without first obtaining informed written consent or upon proper judicial order. Organizations conducting pharmaco-economic studies in systematic research to determine the cost benefits of specific treatment for genetic based disease shall be exempted from the need to re-obtain informed written consent.</td>
<td>NO</td>
<td>YES</td>
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## Vaccination Surveillance System

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<td>MA</td>
<td>STATUTE: M.G.L. 111, Section 24M RULE 105 CMR 300 RELATED RULE: 105 CMR 220</td>
<td>Section 24M. The department shall establish, maintain and operate a computerized immunization registry. The immunization registry shall record immunizations and immunization history with identifying information and shall include appropriate controls to protect the security of the system and the privacy of the information. The department shall promulgate rules and regulations to implement the immunization registry.</td>
<td>Section 24M. Licensed health care providers administering vaccinations shall discuss the reporting procedures of the immunization registry with the persons receiving the vaccinations and their parents or guardians, when appropriate, and advise them of their right to object to the disclosure of such information as set forth in this section.</td>
<td>NO</td>
<td>NO</td>
<td></td>
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In 1993, the Boston Immunization Information System (BIIS) was introduced as an electronic registry, tracking, and recall system. BIIS is used in community health centers, hospitals, and private practices.” – APHA conference, Cost-effectiveness and cost-efficiency of an urban immunization registry. Abstract #6187, Thursday, Nov 16, 2000, found at: http://apha.confex.com/apha/128am/techprogram/paper_6187.htm

An Insider’s View of the New Massachusetts Immunization Information System (MIIS)…The team [of public health professionals, data management consultants, clinical informaticians, and software developers] has spent the past two years designing and developing a statewide immunization registry, the Massachusetts Immunization Information System (MIIS), based on the already developed and widely used Wisconsin Immunization Registry…The MIIS is an easy-to-use, yet powerful website developed to support a wide variety of immunization-related functions. It will be linked to Massachusetts Vital Records to ensure that the largest possible number of children is loaded into the system.

Clinicians and nurses will be able to view, update, and print immunization data and reports from any web-enabled computer. Recall and reminder of children in need of immunizations will be supported through easy generation of postcards, letters, or phone lists. Clinicians will also be able to review their practice’s immunization coverage rates. The MIIS will support the exchange of immunization data from existing electronic systems—for example, electronic medical records—and will have a built-in vaccine management system to ease vaccine ordering and accountability.” – SHOTCLOCK, Vol. 10, No. 1, 2004.

“The Massachusetts Department of Public Health is developing a new immunization tracking and vaccine management system. The Massachusetts Immunization Information System (MIIS) is expected to pilot test in the spring of 2005.” – Communicable Disease UPDATE, MA Dept. of Public Health, Fall 2004


“Selecting Records, Maintaining Uniqueness, and Minimizing Duplication in an Immunization Registry.

The Massachusetts Immunization Information System (MIIS) obtains and matches data from multiple sources, including the health department’s birth registry & WIC program, provider sites, and local immunization registries.”

Presentation abstract by Robert Rosofsky, Director, Massachusetts Immunization Information System (MIIS), Jonathan Mosley, Senior Data Analyst, MIIS. Taken from All Kids Count (no date) at http://www.allkidcount.org/iz/ppoin/t/profsksv2/abstract.html

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MIS Massachusetts WIC was among the first states to develop and implement a decentralized computer system—with microcomputers at local programs—to automate participant demographic and health data, and to produce and account for over half-a-million food checks a month. This system provides nutrition and immunization surveillance data to CDC to identify and monitor health trends of mothers and children.”

(Taken from Massachusetts WIC program Women, Infants and Children Nutrition Program, dated 9/98.)

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Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008. Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature.