### NEW YORK

**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>
</tr>
</thead>
<tbody>
<tr>
<td>NY</td>
<td>STATUTE: Public Health Laws, Article 27-C, Section §2733</td>
<td>§ 2500. Maternal and child health; duties of commissioner. 1. The commissioner shall act in an advisory and supervisory capacity, in matters pertaining to the safeguarding of motherhood, the prevention of maternal, perinatal, infant and child mortality, the prevention of diseases, low birth weight, and defects of childhood and the promotion of maternal, prenatal and child health, including care in hospitals, and shall administer such services bearing on the health of mothers and children for which funds are or shall hereafter be made available. [emphasis added] <strong>§ 2733. Reporting of birth defects; confidentiality of information.</strong> 1. Birth defects and genetic and allied diseases shall be reported by physicians, hospitals, and persons in attendance at births in the manner and on such forms as may be prescribed by the commissioner. 2. Such reports and information shall be kept confidential and shall not be admissible as evidence in an action or proceeding in any court or before any other tribunal, board, agency or person. The commissioner may, however, publish analyses of such reports and information from time to time for scientific and public health purposes, in such a manner as to assure that the identities of the individuals concerned cannot be ascertained.</td>
<td><strong>§ 22.3. Supplementary reports of certain congenital anomalies for epidemiological surveillance; filing.</strong> Every physician and hospital in attendance on an individual diagnosed within two years of birth as having one or more of the congenital anomalies listed in this section shall file a supplementary report with the State Commissioner of Health within 10 days of diagnosis thereof. Such report shall be on such forms as may be prescribed by the commissioner to facilitate epidemiological investigation and surveillance. <strong>§ 2731. Birth defects institute.</strong> The commissioner shall establish within the department a birth defects institute for the purposes of initiating and conducting investigations of the causes, mortality, methods of treatment, prevention and cure of birth defects and genetic and allied diseases. <strong>§ 2732. Commissioner; functions, powers and duties.</strong> The commissioner shall have the following powers and duties: <em>(a)</em> To conduct scientific investigations and surveys of the causes, mortality, methods of treatment, prevention and cure of birth defects and genetic and allied diseases. <em>(b)</em> To publish from time to time the results of such investigations and surveys for the benefit of the public health and from time to time collate such publications for distribution to scientific organizations and qualified scientists and physicians…</td>
<td>NO</td>
<td>NO</td>
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## Cancer Surveillance System

<table>
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<tr>
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<tr>
<td>NY</td>
<td>STATUTE: Public Health Laws Article 24, §2401, Title 2</td>
<td>§ 2401. Cancer; duty to report. 1. Every physician, dentist and other health care provider shall give notice immediately but not later than one hundred eighty days of every case of cancer or other malignant disease coming under his or her care, to the department, except as otherwise provided.</td>
<td>Section 1.31. Disclosure of confidential cancer information for research purposes. (a) The identity of any person contained in a report of cancer made pursuant to the provisions of section 2401 of the Public Health Law, or cancer data collected for other specific research studies, shall not be disclosed except to governmental or government-sponsored research projects for the purpose of scientific studies and research when the State Commissioner of Health determines that substantial knowledge may be gained by such disclosure leading toward the reduction of morbidity and mortality…</td>
<td>§ 2421. Cancer institute; functions; powers and duties. 1. The state institute for the study of malignant diseases shall conduct investigations of the cause, mortality, treatment, prevention and cure of cancer and allied diseases. 2. Persons afflicted with cancer or allied diseases, may be received free of charge in the said state institute for study, experimental or other treatment, under regulations established by the commissioner. 3. The direction of related research work in whole or in part toward malignant diseases in connection with conditions other than cancer shall not be a violation of the conditions of the grants made pursuant to the provisions of chapter one hundred twenty-eight of the laws of nineteen hundred eleven.</td>
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<td>RULE: 10 NYCRR 1.31</td>
<td>§ 2420. Cancer institute; continued. The state institute for the study of malignant diseases, known as the Roswell Park Cancer Institute, is hereby continued under the management and control of the department. “As mandated by the Public Health Law, all NYS licensed health care providers/practitioners treating cancer patients, and all licensed facilities at which they are treated (e.g., hospitals, radiation centers), as well as laboratories holding permits to conduct pathology testing (be they independent or hospital based), and managed care organizations are required to report cancer cases to the New York State Department of Health, Cancer Registry. The New York State Cancer Registry (NYSCR) is a population-based cancer incidence registry responsible for the collection of demographic, diagnostic and treatment information on patients diagnosed and/or treated in New York State. Reports on cancer cases are checked for quality and completeness. The data are then used to produce New York State cancer statistics.” (Cancer Reporting Requirements, NYSDOH website - <a href="http://www.health.state.ny.us/professionals/reportable_conditions/cancer/index.htm">http://www.health.state.ny.us/professionals/reportable_conditions/cancer/index.htm</a>)</td>
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CCHF REPORT 2013: Patient Privacy and Public Trust: How Health Surveillance Systems Are Undermining Both

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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. www.cchfreedom.org

New York
### Newborn Genetic Testing & Surveillance System

<table>
<thead>
<tr>
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<th>Exemption</th>
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<tbody>
<tr>
<td>NY</td>
<td>Statute: Public Health Law, Article 25, §2500-G, Title 1 Civil Rights Law, Article 7, § 79-l 10 NYCRR 69-6.1</td>
<td>§ 2500. Maternal and child health; duties of commissioner. 1. The commissioner shall act in an advisory and supervisory capacity, in matters pertaining to the safeguarding of motherhood, the prevention of maternal, perinatal, infant and child mortality, the prevention of diseases, low birth weight, and defects of childhood and the promotion of maternal, prenatal and child health, including care in hospitals, and shall administer such services bearing on the health of mothers and children for which funds are or shall hereafter be made available. [emphasis added]</td>
<td>§ 2500-a. …(b) The provisions of this section shall not apply in the case of any infant or child whose parent or guardian is a member of a recognized religious organization whose teachings and tenets are contrary to the testing herein required and who notifies the person charged with having such test administered of his objection thereto.</td>
<td>79-l. Confidentiality of records of genetic tests. 2. (a) No person shall perform a genetic test on a biological sample taken from an individual without the prior written informed consent of such individual as provided in paragraph (b) of this subdivision, except as otherwise provided in paragraph (e) of subdivision two and by subdivision nine of this section. (b) Written informed consent to a genetic test shall consist of written authorization that is dated and signed and includes at least the following: (1) a general description of the test; (2) a statement of the purpose of the test; 2-a. a statement indicating that the individual may wish to obtain professional genetic counseling prior to signing the informed consent. (3) a statement that a positive test result is an indication that the individual may be predisposed to or have the specific disease or condition tested for and may wish to consider further independent testing, consult their physician or pursue genetic counseling; (4) a general description of each specific disease or condition tested for; (5) the level of certainty that a positive test result for that disease or condition serves as a predictor of such disease. If no level of certainty has been established, this subparagraph may be disregarded; (6) the name of the person or categories of persons or organizations to whom the test results may be disclosed; (7) a statement that no tests other than those authorized shall be performed on the biological sample and that the sample shall be destroyed at the end of the testing process or not more than sixty days after the sample was taken, unless a longer period of retention is expressly authorized in the consent; and (8) the signature of the individual subject of the test or, if that individual lacks the capacity to consent, the signature of the person authorized to consent for such individual. (c) A general waiver, wherein consent is secured for genetic testing without compliance with paragraph (b) of this subdivision, shall not constitute informed consent. Notwithstanding the provisions of this section, for purposes of research conducted in accordance with the provisions of subdivision nine of this section, a general waiver for the use of samples for research may be granted which would authorize the use of samples for these research purposes.</td>
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<tr>
<td>NY</td>
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§ 2500-a. Test for phenylketonuria and other diseases and conditions. (a) It shall be the duty of the administrative officer or other person in charge of each institution caring for infants twenty-eight days or less of age and the person required in pursuance of the provisions of section forty-one hundred thirty of this chapter to register the birth of a child, to cause to have administered to every such infant or child in its or his care a test for phenylketonuria, homozygous sickle cell disease, hypothyroidism, branched-chain ketonuria, galactosemia, homocystinuria and such other diseases and conditions as may from time to time be designated by the commissioner in accordance with rules or regulations prescribed by the commissioner. Testing, the recording of the results of such tests, tracking, follow-up reviews and educational activities shall be performed at such times and in such manner as may be prescribed by the commissioner…

Section 69-1.3. Responsibilities of the chief executive officer… The chief executive officer shall ensure that…

(a) The infant’s parent is informed of the purpose and need for newborn screening, and given newborn screening educational materials provided by the testing laboratory.

4. (a) Notwithstanding the provisions of subdivision two of this section, genetic tests may be performed on anonymous samples for research or statistical purposes, pursuant to a research protocol approved by an institutional review board which assures the anonymity of the sources of the samples… [emphasis added]

9. (a) Notwithstanding the provisions of subdivisions two and ten of this section, samples may be used for tests other than those for which specific consent has been obtained, for purposes of research conducted in accordance with applicable law and regulation and pursuant to a research protocol approved by an institutional review board, provided that the individuals who provided the samples have given prior written informed consent for the use of their sample for general research purposes and did not specify time limits or other factors that would restrict use of the sample for the test, and (1) the samples have been permanently stripped of identifying information; or (2) a coding system has been established to protect the identity of the individuals who provided the samples, and an institutional review board has reviewed and approved the procedures for the coding system.

(b) If consent to storage of the tissue sample is withdrawn at any time, the entity storing the sample shall promptly destroy the sample or portions thereof that have not already been used for research purposes.

(e) In no event shall family members of an individual who provided a stored tissue sample be contacted for clinical, research, or other purposes without consent from the individual who provided the tissue sample with respect to the specific family members who will be contacted and the specific purpose of the contact…

(e) Written informed consent for use of stored human tissue for general research purposes shall consist of written authorization that includes at least the following: [emphasis added]

(1) a statement that the sample will be used for future genetic tests;
(2) the time period during which the tissue will be stored, or if no time limit is specified, a statement that the tissue will be stored for as long as deemed useful for research purposes;
(3) a description of the policies and procedures to protect patient confidentiality;
(4) a statement of the right to withdraw consent to use of the tissue for future use at any time and the name of the organization that should be contacted to withdraw consent;
(5) a statement allowing individuals to consent to future contact for any or all purposes, including the following:
Section 69-1.3. Responsibilities of the chief executive officer...(b) Specimen collection forms are properly stored in a cool and dry environment prior to use. Such forms shall be legibly and fully completed, and shall include all information required by the testing laboratory for processing specimens, and conducting tracking and follow-up activities, including, but not limited to, information identifying: 

(1) the infant's name; sex; whether single birth or, if twin birth, sequence of birth; ethnicity; date of birth; birth weight; medical record number; and whether premature and/or transfused, with transfusion date;

(2) the specimen, including identification number, the date collected, infant's age in hours at time of collection; and whether initial or repeat specimen;

(3) the mother's name, address, county of residence, telephone number, social security number, age in years and test result for hepatitis B surface antigen (HBs Ag);

(4) the hospital or responsible institution's name and city; permanent facility identifier (PFI) code; and whether hospital of birth, or home birth; and

(5) the responsible physician's name, address, telephone number and license number.

(i) research purposes;

(ii) provision of general information about research findings; and

(iii) information about the test on their sample that may benefit them or their family members in relation to their choices regarding preventive or clinical care; and

(6) a statement explaining the benefits and risks of consenting to future contact for the purposes set forth in subparagraph five of this paragraph. In no event shall information about specific test results on stored human tissue donated for general research purposes be disclosed to an individual without obtaining informed consent for the disclosure as required by paragraph (b) of subdivision two of this section….

10. Notwithstanding the provisions of subdivision two of this section, DNA samples may be stored for up to ten years in the absence of genetic testing, if authorized in writing by the subject. Prior to the performance of any genetic test upon stored samples, informed consent must be obtained as provided in subdivision two of this section… [emphasis added]
(c) The above information shall also be submitted to the department in an electronic format which is consistent with the technical specifications established by the department.

**Section 69-1.8 Follow-up review, tracking and educational activities.** The testing laboratory shall:

(a) record requested diagnoses and case follow-up information submitted by health care providers and specialty care centers;
(b) maintain tracking records on identified cases; and
(c) provide educational activities and materials.
### Vaccination Surveillance System

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<td>NY</td>
<td>STATUTE: Public Health Law Section 2168</td>
<td>§ 2168. Statewide immunization registry. 1. The department is hereby directed to establish a statewide automated and electronic immunization registry that will serve, and shall be administered consistent with, the following public health purposes:</td>
<td>NO RULE FOUND</td>
<td>§ 2168. Statewide immunization registry. …3. (a) Any health care provider who administers any vaccine to a person less than nineteen years of age or, on or after September first, two thousand nine, conducts a <strong>blood lead analysis</strong> of a sample obtained from a person under eighteen years of age in accordance with paragraph (b) of subdivision two of this section; and immunizations received by a person less than nineteen years of age in the past if not already reported, shall report all such immunizations to the department in a format prescribed by the commissioner within fourteen days of administration of such immunizations or of obtaining the results of any such blood lead analysis. Health care providers administering immunizations to persons less than nineteen years of age in the city of New York shall report, in a format prescribed by the city of New York commissioner of health and mental hygiene, all such immunizations to the citywide immunization registry. The commissioner, and for the city of New York the commissioner of health and mental hygiene, shall have the discretion to accept for inclusion in the system information regarding immunizations administered to individuals nineteen years of age or older with the express written consent of the vaccine. <strong>[emphasis added]</strong></td>
<td>NO</td>
<td>NO</td>
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(c) The term "citywide immunization registry" shall mean the computerized database maintained by the city of New York department of health and mental hygiene capable of collecting, storing, and disclosing the electronic and paper records of vaccinations received by persons less than nineteen years of age. The term "citywide immunization registry" shall not include the childhood blood lead registry established pursuant to the health code of the city of New York. For the purposes of this section the term New York city department of health and mental hygiene shall mean such agency or any successor agency responsible for the citywide immunization registry.

4. (c) Any data collected by the department may be included in the statewide immunization information system and the statewide registry of lead levels of children if collection, storage and access of such data is otherwise authorized. Such data may be disclosed to the statewide immunization information system only if provided for in statute or regulation, and shall be subject to any provisions in such statute or regulation limiting the use or redisclosure of the data. Nothing contained in this paragraph shall permit inclusion of data in the statewide immunization information system if that data could not otherwise be accessed or disclosed in the absence of the system. For the city of New York the commissioner of health and mental hygiene may include data collected in the citywide immunization registry as provided in this paragraph.

(c-1) The department may require the collection of, maintenance and access to newborn infant hearing screening data and results through the statewide immunization information system in accordance with section twenty-five hundred-g of this chapter.

11. The commissioner, or in the city of New York, the commissioner of the department of health and mental hygiene, may provide registrant specific immunization records to other state registries pursuant to a written agreement requiring that the foreign registry conform to national standards for maintaining the integrity of the data and will not be used for purposes inconsistent with the provisions of this section.

12. Information that would be provided upon the enrollment in the statewide immunization information system of a child being vaccinated, from birth records of all infants born in New York state on or after January first, two thousand four shall be entered into the statewide immunization information system, except in the city of New York, where birth record information shall be entered into the citywide immunization registry.