# New Hampshire

## Birth Defects Surveillance System

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<td>NH</td>
<td>STATUTE: Title X Chapter 141-J NEW RULE PROPOSED D: Chapter He-P 3000, Part He-P 3012 (Public hearing 1/20/09)</td>
<td><strong>141-J:1 Birth Conditions Program Authorized.</strong> The department of health and human services may establish and maintain a statewide, population-based public health surveillance program on birth conditions, to be known as the New Hampshire birth conditions program if established… <strong>141-J:5 Election Not to Participate in the Program.</strong> I. An individual who is the subject of individually identifiable health information may elect not to participate in the program. If the individual is a minor or is legally incompetent, the individual’s parent or legal guardian may so elect on the individual’s behalf. II. The program shall notify each individual with a confirmed birth condition diagnosis whose individually identifiable health information it proposes to include in the program of the <strong>election prior to obtaining any individually identifiable health information relating to the individual, other</strong></td>
<td><strong>141-J:3 Program Access to Health Information.</strong> I. Health care providers, health care facilities, clinics, laboratories, medical records departments, and state offices, agencies, and departments shall allow the program to have access to individually identifiable health information relating to the occurrence of birth conditions in children, infants, or stillborn fetuses. The program may</td>
<td><strong>141-J:1…The program shall:</strong> I. Determine the prevalence and trends of birth conditions among New Hampshire residents. II. Develop and assess prevention strategies relating to</td>
<td>NO</td>
<td>NO – only identifiable data not collected</td>
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than name and address and diagnosis. The program shall not obtain any individually identifiable health information for any individual who does not have a confirmed birth condition diagnosis and shall retain the name and address only of any such individual for a period not to exceed 2 years.

V. If the program has notified an individual pursuant to paragraph II or III, and within 60 days of providing such notice has not received the individual’s election not to participate in the program, the program may obtain access to, or retain, as the case may be, individually identifiable health information relating to the individual.

VI. The program shall not acquire, retain, use, or disclose individually identifiable health information, including birth condition, with respect to those individuals who have elected not to participate in the program under paragraph I or RSA 141-J:6, I. The program shall retain a list of those individuals who have elected not to participate in the program and the dates of such elections but shall not disclose this information to any other entity.

141-J:6 Rights of Individuals. An individual with respect to whom the program retains individually identifiable health information acquire the same information relating to New Hampshire residents from health care facilities, birth conditions surveillance programs, and other sources in other states. The program shall not provide individually identifiable health information relating to New Hampshire residents to any similar program operated by any other state or the federal government.

II. Except as otherwise provided in this chapter, no health care provider, health care facility, clinic, laboratory, medical birth conditions.

III. Promote scientific collaboration through data analysis, investigations, and epidemiological studies on the public health impact of birth conditions and possible cause of birth conditions, including exposure to environmental or
may:
I. Elect at any time not to participate in the program. Upon such election, the program shall remove any individually identifiable health information relating to the individual.
II. Review any individually identifiable health information in program records relating to the individual.
III. Upon payment of any reasonable costs involved, obtain a copy of any individually identifiable health information in program records relating to the individual.
IV. Request amendments or corrections to the individual’s individually identifiable health information in program records.
V. Prohibit the release of individually identifiable health information in program records relating to the individual.
VI. Review and, upon payment of any reasonable costs involved, obtain a copy of the list of persons given access to individually identifiable health information relating to the individual.

He-P 3012.03 Program Access to Health Information.
(a) In accordance with RSA 141-J:3 and this section, health care providers and facilities records department, or state office, agency, or department shall be held liable in any action for civil damages for providing the department or the program with access to individually identifiable health information authorized by paragraph I.

Any individually identifiable health information acquired, used, disclosed, or retained by the program shall not constitute a public record. The names occupation hazards, maternal and stillborn fetal conditions, and illnesses or complicatio ns during pregnancy, labor, or delivery.
shall allow the NHBCP to have access to health information and individually identifiable health information relating to the occurrence of birth conditions in children, infants, and stillborn fetuses.

(b) At least annually, the NHBCP shall direct health care providers and facilities to generate a list of presumed cases of birth conditions. This list shall include only the information allowed by (d)(1) below.

(c) The NHBCP medical records abstractor shall conduct on-site reviews of medical records to determine which cases identified in (b) above are confirmed cases as outlined in the “Guidelines for Conducting Birth Defects Surveillance” (June 2004) established by the National Birth Defects Prevention Network.

(d) For confirmed cases determined in accordance with (c) above, the medical records abstractor:

(1) Shall collect the diagnosis, the health care provider’s name and address, and only the following individually identifiable information about the child, infant, or stillborn fetus:
   a. Name; and
   b. Address, including town or city, state and postal code at the time of birth; and

(2) May collect additional non-

and addresses of individuals who have elected not to participate in the program shall not be a public record. No individually identifiable health information retained by the program shall be discoverable or compelled to be produced pursuant to subpoena or compelled testimony in any legal proceeding without the written authorization of the person about whom the information relates. Analyses and compilations of data that do not disclose individually identifiable health information shall be
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|   | individually identifiable health information about the child, infant, or stillborn fetus in accordance with the “Guidelines for Conducting Birth Defect Surveillance” (June 2004) established by the National Birth Defects Prevention Network. (e) If the NHBCP has not received a completed opt out form from the individual in accordance with He-P 3012.04, the medical records abstractor shall return to the health care provider or facility to conduct a second on-site visit and perform on-site medical record abstraction to collect only that information described in (f) through (i) below. This visit shall be conducted no earlier than 60 days after the opt out packet was mailed. (f) For those cases allowed under (e) above, the following additional individually identifiable health information shall be collected for the child, infant, or stillborn fetus:
   (1) Date of birth and death, if applicable;
   (2) Results of any genetic testing related to the birth condition; and
   (3) Medical record number. (g) For those cases allowed under (e) above, the following individually identifiable information shall be collected for the mother: available to the public under RSA 91-A. 141-J:8 Privacy and Confidentiality Protections. I. Any person allowed access to individually identifiable health information in program records shall sign a confidentiality agreement, in a form specified by the department, requiring adherence to privacy and security protections equivalent to or greater than the protections provided in this chapter. III. Individually identifiable health information in the Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature. |   |
(1) First, middle and last name; (2) Date of birth;

(h) For those cases allowed under (e) above, the following individually identifiable health information shall be collected for the father: : (1) First, middle and last name; and (2) Date of birth.

…(j) The NHBCP shall acquire health information and individually identifiable health information relating to New Hampshire residents with birth conditions only from those health care facilities, birth conditions surveillance programs, or other sources in other states with which the department has entered into an interstate memorandum of agreement for those purposes.

(k) The NHBCP shall not obtain any individually identifiable health information for any individual who does not have a confirmed birth condition diagnosis and shall only retain the name and address of any such individual for a period not to exceed 2 years.

He-P3012.04 Election Not to Participate in the NHBCP.

(a) If an individual, or the parent or guardian of a minor or an individual who is legally incompetent, objects to the collection of individually identifiable health information by records of the program may be retained for 18 years or, if the information relates to a minor, until the individual reaches the age of 18. Thereafter, the program may use and retain the information only in a form where an individual’s identity cannot be discerned.

[AMENDS GENETIC PRIVACY LAW TO ALLOW REPORTING TO BIRTH DEFECTS SURVEILLANCE]:

186:2 Conditions of Genetic Testing. Amend RSA 141-H:2, III to read as
the NHBCP, the individual or a parent or guardian of a minor, may elect not to participate in the program, in accordance with RSA 141-J:5 and RSA 141-J:6,1.

(b) Within 7 business days of collecting data from a confirmed case per He-P 3012.03(d), the NHBCP shall send an opt out information packet which shall include:

(1) A letter to the individual, or the parent or guardian of a minor or an individual who is legally incompetent, explaining the collection of the birth condition data by the NHBCP under RSA 141-J;
(2) A NHBCP fact sheet about the nature and purpose of the program including the telephone number, fax number, mailing address, and email address of the NHBCP;
(3) Information about state-supported early intervention and prevention services; and
(4) An opt out form with:
   a. A statement that the failure to complete and return the opt out form within 60 calendar days of the date of the letter means that their individually identifiable health information as listed in He-P 3012.03 shall be collected by the NHBCP;
   b. A statement that the individual, or

follows: III. Except as provided in paragraph II, or authorized by RSA 141-J, no person shall disclose to any other person that an individual has undergone genetic testing, and no person shall disclose the results of such testing to any other person, without the prior written and informed consent of the individual, the parent, guardian, or custodian if the individual is a minor under the age of 18, or the legal guardian or conservator if the individual is an incompetent person. Discussion and disclosure of
the parent or guardian of a minor or an individual who is legally incompetent, may elect not to participate at any time in the future in accordance with RSA 141-J:6,I and He-P 3012.06(a); and  

(c) Information on what will occur as a result of opting out of the program.  

If information packets described in (b) above are returned to the NHBCP as undeliverable, the program shall contact the individual’s health care provider for the individual’s most current address. The provider shall disclose that information solely for the purpose of the NHBCP contacting the individual regarding the opt out procedures.  

(d) The NHBCP shall send letters to acknowledge the individual’s decision to opt out of the NHBCP within 7 business days of receipt of the completed opt out form.  

(e) The NHBCP shall develop a list of individuals who have confirmed birth conditions but who have elected to opt out of the program, and the dates of such elections, to be used only as a means to verify that an individual or the parent or guardian of a minor has opted out should that individual’s record be encountered again through routine case finding. This list shall not be disclosed to genetic testing for a patient, requested of a physician by a patient, by appropriate professionals within a physician’s medical practice or hospital shall not be a violation of this chapter.
any entity or individual outside of the NHBCP.