### Colorado Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>Statute/Rule</th>
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<th>Research Authority</th>
<th>Consent Required?</th>
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<td><strong>CO STATUTE:</strong> 25-1.5-101. Powers and duties of department.</td>
<td>(1) The department has, in addition to all other powers and duties imposed upon it by law, the powers and duties provided in this section as follows:…(r) To operate and maintain a program for children with disabilities to provide and expedite provision of health care services to children who have congenital birth defects or who are the victims of burns or trauma or children who have acquired disabilities.</td>
<td>Regulation 1. Reportable Diseases. For the purpose of these regulations, the diseases named in the lists below and any epidemic of environmental or chronic disease are declared to be dangerous to the public health and shall be reportable in accordance with the provisions of these regulations.</td>
<td>NO</td>
<td>NO</td>
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<td><strong>RULE:</strong> 6 CCR 1009 – 7</td>
<td>25-1.5-105. Detection of diseases – powers and duties of the department.</td>
<td>List B…Birth defects, developmental disabilities, and medical risk factors for developmental delay in Colorado residents diagnosed prenatally, at birth, or through the third birthday*, with the exception of muscular dystrophies, which shall be reported without age limit…</td>
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<td>May result in birth defects, damage to tissues and organs, and chronic illness…</td>
<td>Regulation 2. Manner of Reporting and Information To Be Submitted. …The information to be submitted shall consist of the diagnosis; the patient's name, age, sex, race/ethnicity, and address; the name and address of responsible physician; the employer (for reportable work-related conditions); and such other information as is needed by the Department to locate the patient for follow-up. With regard to birth defects, developmental disabilities, chromosomal abnormalities, and neural tube defects reported pursuant to regulation 1, the department shall collect no additional information about pregnancy outcome other than what is required for the vital record form. When hospitals and laboratories transmit disease reports electronically using systems and protocols developed by the department that ensure protection of confidentiality, such reporting is acceptable and is considered good faith reporting…The Department shall develop systems and forms for reporting for physicians, other health care providers, hospitals, and laboratories. For birth defects and developmental disabilities, hospitalized head injuries, and spinal cord injuries, hospital reporting shall be through a central computerized data system operated by or for the department.</td>
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**CCHF REPORT 2013: Patient Privacy and Public Trust: How Health Surveillance Systems Are Undermining Both**

**COLORADO**

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<table>
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<th>Regulation 6. Confidentiality.</th>
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<tr>
<td>All personal medical records</td>
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<td>and reports held by the state</td>
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<td>or local health department in</td>
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<td>compliance with these regulations shall be confidential information subject to C.R.S. 25-1-122(4).</td>
</tr>
<tr>
<td>In addition, trade secrets and confidential commercial, geological, or geophysical data submitted to or held by the Colorado Department of Health in compliance with these regulations shall be confidential. This information is to be used by the Department as source material for necessary disease control efforts and the development of prevention programs. Reasonable efforts shall be made by the Department to consult with the attending physician or medical facility caring for the patient prior to any further follow-up by State or local health departments or health agencies.</td>
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</tbody>
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## Cancer Surveillance System

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| CO    | STATUTE: CRS 25 – 1.5-102. (Formerly CRS 25-1-107 (z)) | 25-1-122. Named reporting of certain diseases and conditions - access to medical records - confidentiality of reports and records. (1) With respect to investigations of epidemic and communicable diseases, morbidity and mortality, cancer in connection with the statewide cancer registry, environmental and chronic diseases, sexually transmitted infections, tuberculosis, and rabies and mammal bites, the board has the authority to require reporting, without patient consent, of occurrences of those diseases and conditions by any person having knowledge of such to the state department of public health and environment and county, district, and municipal public health agencies, within their respective jurisdictions. Any required reports shall contain the name, address, age, sex, diagnosis, and such other relevant information as the board determines is necessary to protect the public health. The board shall set the manner, time period, and form in which such reports are to be made. The board may limit reporting for a specific disease or condition to a particular region or community or for a limited period of time. Nothing in this subsection (1) shall be construed to apply to cases of AIDS, HIV-related illness, or HIV infection, which shall be governed solely by the reporting requirements set forth in part 14 of article 4 of this title. [emphasis added]

(2) When investigating diseases and conditions pursuant to subsection (1) of this section, authorized personnel of the state department of public health and environment and county, district, and municipal health agencies, within their respective jurisdictions, may, without patient consent, inspect, have access to, and obtain information from pertinent patient medical, coroner, and laboratory records in the custody of all medical practitioners, veterinarians, coroners, institutions, hospitals, agencies, laboratories, and clinics, whether public or private, which are relevant and necessary to the investigation...

|          | 25-1-122...(3) Any report or disclosure made in good faith pursuant to subsection (1) or (2) of this section shall not constitute libel or slander or a violation of any right of privacy or privileged communication.

(5) No officer or employee or agent of the state department of public health and environment or county, district, or municipal public health agency shall be examined in any judicial, executive, legislative, or other proceeding as to the existence or content of any individual's report obtained by such department pursuant to subsection (1) or (2) of this section without that individual's consent. However, this provision shall not apply to individuals who are under isolation or quarantine, school exclusion, or other restrictive action taken pursuant to section 25-1.5-102 (1) (c) or part 4, 5, 6, or 9 of article 4 of this title.

(6) Any officer or employee or agent of the state department of public health and environment or a county, district, or municipal public health agency who violates this section by releasing or making public confidential public health reports or records or by otherwise breaching the confidentiality requirements of subsection (4) or (5) of this section commits a class 1 misdemeanor and, upon conviction thereof, shall be punished as provided in section 18-1.3-501 (1), C.R.S.

|          | 25-1-122...(4) Reports and records resulting from the investigation of epidemic and communicable diseases, environmental and chronic diseases, reports of morbidity and mortality, reports of cancer in connection with the statewide cancer registry, and reports and records resulting from the investigation of sexually transmitted infections, tuberculosis, and rabies and mammal bites held by the state department of public health and environment or county, district, or municipal public health agencies shall be strictly confidential. Such reports and records shall not be released, shared with any agency or institution, or made public, upon subpoena, search warrant, discovery proceedings, or otherwise, except under any of the following circumstances:

(a) Release may be made of medical and epidemiological information in a manner such that no individual person can be identified.

(b) Release may be made of medical and epidemiological information to the extent necessary for the treatment, control, investigation, and prevention of diseases and conditions dangerous to the public health; except that every effort shall be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose.

(c) Release may be made to the person who is the subject of a medical record or report with written authorization from such person.

|          | NO |
25-1.5-102. Epidemic and communicable disease – powers and duties of the department: (a)(II) For the purposes of this paragraph (a), the board shall determine, by rule and regulation, those epidemic and communicable diseases and conditions that are dangerous to the public health. The board is authorized to require reports relating to such designated diseases in accordance with the provisions of section 25-1-122 and to have access to medical records relating to such designated diseases in accordance with the provisions of section 25-1-122. (III) For the purposes of this paragraph (a), "epidemic diseases" means cases of an illness or condition, communicable or non-communicable, in excess of normal expectancy, compared to the usual frequency of the illness or condition in the same area, among the specified population, at the same season of the year.

6 CCR 1009-3. II. CANCER REGISTRY ESTABLISHED... The registry shall provide a free flow of information relative to the incidence, characteristics, geographical location and control of cancer essential to the protection of the public health from which the Department may disclose general, non-individual identifying information, numerical and statistical data developed therefrom or related thereto, and upon proof of proper written authorization therefore by the patient or the patient’s representative, the entire registry record of such patient.

(d) An officer or employee of the county, district, or municipal health agency or the state department of public health and environment may make a report of child abuse to agencies responsible for receiving or investigating reports of child abuse or neglect in accordance with the applicable provisions of the "Child Protection Act of 1987" set forth in part 3 of article 3 of title 19, C.R.S. However, in the event a report is made by the state department of public health and environment, only the following information shall be included in the report:...
## Newborn Genetic Testing & Surveillance System

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</table>
| CO    | STATUTES: Title 25, Article 4 CRS 24-4-25-4-801 – 804 CRS 1001 – 1006 CRS 25-1-122 RULE: 5 CCR 1005-4 | **25-4-802. Tests for metabolic defects.**
(1) It is the duty of either the chief medical staff officer or other person in charge of each institution caring for newborn infants… to cause to be obtained from every such infant a specimen of the type designated by the state board of health, which specimen shall be forwarded to the department of public health and environment or other laboratory approved by it for testing for phenylketonuria and testing for such other metabolic defects which may be prescribed from time to time by the state board of health to be conducted with respect to such specimen. | **25-4-1002. Legislative declaration.**
(1) The general assembly hereby finds and declares that: (a) State policy regarding newborn screening and genetic counseling and education should be made with full public knowledge, in light of expert opinion, and should be constantly reviewed to consider changing medical knowledge and ensure full public protection; (b) Participation of persons in genetic counseling programs in this state should be *wholly voluntary* and that all information obtained from persons involved in such programs or in newborn screening programs in the state should be held strictly confidential. | **25-4-1003. (2)(e) All information gathered by the department of public health and environment, or by other agencies, entities, and individuals conducting programs and projects on newborn screening and genetic counseling and education, other than statistical information and information which the individual allows to be released through his informed consent, shall be confidential. Public and private access to individual patient data shall be limited to data compiled without the individual's name;** | NO | YES |

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(2) The department of public health and environment shall furnish all physicians, public health nurses, hospitals, maternity homes, county departments of social services, and the state department of human services available medical information concerning the nature and effects of phenylketonuria and other metabolic disorders and defects found likely to cause mental retardation.

25-4-1001. Short title. This part 10 shall be known and may be cited as the "Newborn Screening and Genetic Counseling and Education Act."

25-4-1003. Powers and duties of executive director - newborn screening programs - genetic counseling and education programs – rules. (b) Promulgate rules, regulations, and standards for the provision of newborn screening programs and genetic counseling and education programs;

25-4-1004. Newborn screening. …(b) On or after April 1, 1989, all infants born in the state of Colorado shall be tested for the following conditions: Phenylketonuria, hypothyroidism, abnormal hemoglobins, galactosemia, cystic fibrosis, biotinidase deficiency, and such other conditions as the board of health may determine meet the criteria set forth in paragraph (c) of this subsection (1). Appropriate specimens for such testing shall be forwarded by the hospital in which the child is born to the laboratory operated or designated by the department of public health and environment for such purposes….The results of the testing shall be forwarded directly to the physician or other primary health care provider for the provision of such information to the parent.

25-4-1005. Exceptions. Nothing in the provisions of this part 10 shall be construed to require the testing or medical treatment for the minor child of any person or of any person who is a member of a well-recognized church or religious denomination and whose religious convictions in accordance with the tenets or principles of his church or religious denomination are against medical treatment for disease or physical defects or has a personal objection to the administration of such tests or treatment.

(3) Any report or disclosure made in good faith pursuant to subsection (1) or (2) of this section shall not constitute libel or slander or a violation of any right of privacy or privileged communication.

(4) … Such reports and records shall not be released, shared with any agency or institution, or made public, upon subpoena, search warrant, discovery proceedings, or otherwise, except under any of the following circumstances:

(a) Release may be made of medical and epidemiological information in a manner such that no individual person can be identified;

(b) Release may be made of medical and epidemiological information to the extent necessary for the treatment, control, investigation, and prevention of diseases and conditions dangerous to the public health; except that every effort shall be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose;…
or parents of the child. The results of any testing or follow-up testing pursuant to section 25-4-1004.5 may be sent to the immunization tracking system authorized by section 25-4-2403 and accessed by the physician or other primary health care provider. [emphasis added]

(c) The board of health shall…determine whether or not to test infants for conditions which are not specifically enumerated in this subsection.

25-4-1006. Cash funds…(2) Notwithstanding any provision of this section to the contrary, for the fiscal year beginning July 1, 1988, the state treasurer shall transfer to the general fund out of any unappropriated moneys in the newborn screening and genetic counseling cash funds the sum of five hundred thousand dollars.

5 CCR 1005-4…1.4 Testing and Reporting:…The [Colorado Department of Public Health and Environment] Laboratory shall report as follows:…1.4.4 The submitting agency that originated the specimen shall forward the Newborn Screening results to the health care provider responsible for the newborn’s care…
### Vaccination Surveillance System

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<td>STATUTE: Title 25, Article 4  RULE: 6 CCR 1009-2</td>
<td>C.R.S. 25-4-2401. Short title. This part 24 shall be known and may be cited as the &quot;Immunization Registry Act&quot;. 25-4-2403. Department of public health and environment – powers and duties – immunization tracking system. ...(2) To enable the gathering of epidemiological information and investigation and control of communicable diseases, the department of public health and environment may establish a comprehensive immunization tracking system with immunization information gathered by state and local health officials from the following sources:  (a) Practitioners;  (b) Clinics;  (c) Schools;  (d) Parents, legal guardians, or persons authorized to consent to immunization pursuant to section 25-4-1704;  (e) Individuals;  (f) Managed care organizations or health insurance plans in which an individual is enrolled as a member or insured, if such managed care organization or health insurer reimburses or otherwise financially provides coverage for immunizations;  (g) Hospitals;  (h) The department of health care policy and financing with respect to individuals who are eligible for coverage under the &quot;Colorado Medical Assistance Act&quot;, articles 4, 5, and 6 of title 25.5, C.R.S.; and  (i) Persons and entities that have contracted with the state pursuant to paragraph (d) of subsection (9) of this section.</td>
<td>25-4-2403. -- immunization tracking system... 6. ...(b) A notice given to an individual or a parent or legal guardian of an individual under eighteen years of age pursuant to this subsection (6) shall also inform the individual, parent, or legal guardian of the option to refuse an immunization on the grounds of medical, religious, or personal belief considerations pursuant to section 25-4-903. 25-4-2403. (7) An individual or a parent or legal guardian who consents to the immunization of an infant, child, or student pursuant to part 9 or 17 of this article or this part 24 may exclude immunization information from the immunization tracking system. The individual, parent, or legal guardian may remove such immunization information from the immunization tracking system at any time. The department of public health and environment shall ensure that the process to exclude immunization information from the system is readily available and not burdensome.</td>
<td>NO</td>
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25-4-1705. Department of public health and environment – powers and duties – rules. (1) The department shall negotiate for the purchase of and shall purchase vaccines to achieve the purposes of this part 17…

(4) The department shall collect epidemiological information and shall establish a system for recording such information pursuant to rules and regulations adopted by the board of health…

(8) County, district, and municipal public health agencies and the department shall use the birth certificate of any infant to enroll such infant in an immunization tracking system established in section 25-4-2403. Such use of the infant's birth certificate shall be considered an official duty of county, district, and municipal health agencies and the department…

(10) Physicians, licensed health care practitioners, clinics, schools, licensed child care providers, hospitals, managed care organizations or health insurers in which a student, as defined in section 25-4-901 (3), or an infant is enrolled as a member or insured, persons that have contracted with the department pursuant to subsection (7) of this section, and public health officials may release any immunization records in their possession, whether or not such records are in the immunization tracking system established in section 25-4-2403, to the persons or entities specified in section 25-4-2403 (1) to provide an accurate and complete immunization record for the child in order to verify compliance with state immunization law.

In addition, the physician, licensed health care practitioner, clinic, hospital, or county, district, or municipal public health agency shall inform such parent or legal guardian of a minor individual of the option to refuse an immunization on the grounds of medical, religious, or personal belief considerations pursuant to section 25-4-903.

Neither refusing an immunization on the grounds of medical, religious, or personal belief considerations pursuant to section 25-4-903 nor opting to exclude immunization notification information from the immunization tracking system shall, by itself, constitute child abuse or neglect by a parent or legal guardian.

25-4-906 Certificate of immunization – forms. (1) The department of public health and environment shall provide official certificates of immunization to the schools, private physicians, and county, district, and municipal public health agencies. Upon the commencement of the gathering of epidemiological information pursuant to section 25-4-2403 to implement the immunization tracking system, such form shall include a notice that informs a parent or legal guardian that he or she has the option to exclude his or her infant's, child's, or student's immunization information from the immunization tracking system created in section 25-4-2403.

25-4-1004. Newborn screening. …(b) On or after April 1, 1989, all infants born in the state of Colorado shall be tested for the following conditions: Phenylketonuria, hypothyroidism, abnormal hemoglobins, galactosemia, cystic fibrosis, biotinidase deficiency, and such other conditions as the board of health may determine…

The results of any testing or follow-up testing pursuant to section 25-4-1004.5 may be sent to the immunization tracking system authorized by section 25-4-2403 and accessed by the physician or other primary health care provider…

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