# Wisconsin

## Birth Defect Surveillance System

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<tr>
<td>WI</td>
<td>STATUTE: Wisconsin Statutes and Annotations (W.S.A.), Chapter 253 RULE: Wisconsin Administrative Code, (W.A.C.) Chapter HFS (Department of Health and Family Services) 116</td>
<td><strong>253.12 Birth defect prevention and surveillance system.</strong> (1) DEFINITIONS. In this section: (a) “Birth defect” means any of the following conditions affecting an infant or child that occurs prior to or at birth and that requires medical or surgical intervention or interferes with normal growth and development: 1. A structural deformation, disruption or dysplasia. 2. A genetic, inherited or biochemical disease. …(3) DEPARTMENT DUTIES AND</td>
<td><strong>253.12 …(2) REPORTING.</strong> (a) Except as provided in par. (b), all of the following shall report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect in an infant or child: 1. A pediatric specialty clinic in which the birth defect is diagnosed in an infant or child or treatment for the birth defect is provided to the infant or child. 2. A physician who diagnoses the birth defect or provides treatment to the infant or child for the birth defect. (am) Any hospital in which a birth defect is diagnosed in an infant or child or</td>
<td><strong>253.12 …(5) CONFIDENTIALITY.</strong> …(b) The department may also release confidential information to a person proposing to conduct research if all of the following conditions are met: 1. The person proposing to conduct the research applies in writing to the department for approval to perform the research and the department approves the application. The application for approval shall include a written protocol for the proposed research, the person's professional qualifications to perform the proposed research and any other information requested by the department. 2. The research is for the purpose of studying birth defects surveillance and</td>
<td>NO</td>
<td>NO – partial (only name and perhaps address not reported)</td>
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POWERS.  (a) The department shall do all of the following: 1. Establish and maintain an up-to-date registry that documents the diagnosis in this state of any infant or child who has a birth defect, regardless of the residence of the infant or child. The department shall include in the registry information that will facilitate all of the following: a. Identification of risk factors for birth defects. b. Investigation of the incidence, prevalence and trends of birth defects using epidemiological surveys. c. Development of primary preventive strategies to decrease the occurrence of birth defects without treatment is provided to the infant or child may report the birth defect in the manner prescribed by the department under sub. (3) (a) 3. (b) No person specified under par. (a) need report under par. (a) if that person knows that another person specified under par. (a) or (am) has already reported to the department the required information with respect to the same birth defect of the same infant or child. (c) If the department determines that there is a discrepancy in any data reported under this subsection, the department may request a physician, hospital or pediatric specialty clinic to provide to the department information contained in the medical records of patients who have a confirmed or suspected birth defect diagnosis. The prevention. 3. If the research will involve direct contact with a subject of a report made under sub. (2) or with any member of the subject's family, the department determines that the contact is necessary for meeting the research objectives and that the research is in response to a public health need or is for the purpose of or in connection with birth defects surveillance or investigations sponsored and conducted by public health officials. The department must also determine that the research has been approved by a certified institutional review board or a committee for the protection of human subjects in accordance with the regulations for research involving human subjects required by the federal department of health and human services for projects supported by that agency. Contact may only be made
increasing abortions. **d.** Referrals for early intervention or other appropriate services…  

**HFS 116.04(2)(d)**

**d.** The department may monitor the data contained in the reports submitted under **sub. (2)** to ensure the quality of that data and to make improvements in reporting methods.  

**HFS 116.05 Confidentiality.**  

**Access to Information…(2) Access to Information…(c) 1.** The department may release child-identifiable information to a person requesting, in writing, information for the purpose of demographic, epidemiological, health or social services research specific to birth defects prevention and surveillance… **[emphasis added]**

**HFS 116.04(2)(d)**

**d.** The department may not require a reporter under **par. (a), (b) or (c)** to provide the name of a child to the department if the physician, hospital or pediatric specialty clinic shall provide that information within 10 working days after the department requests it.  

**HFS 116.05 Confidentiality.**  

**Access to Information…(2) Access to Information…(c) 1.** The department may release child-identifiable information to a person requesting, in writing, information for the purpose of demographic, epidemiological, health or social services research specific to birth defects prevention and surveillance… **[emphasis added]**

**HFS 116.04(2)(c)**

**The department shall, not more than 10 years from the date of receipt of a report under **sub. (2)**, delete from any file of the department the name of an infant or child that is contained in the report.**

**HFS 116.05 Confidentiality.**  

**Access to Information…(2) Access to Information…(c) 1.** The department may release child-identifiable information to a person requesting, in writing, information for the purpose of demographic, epidemiological, health or social services research specific to birth defects prevention and surveillance… **[emphasis added]**
| child's parent or guardian does not consent in writing to the release of the name or address of the child to the department. [emphasis added] |  |  |  |