## Arizona Birth Defects Surveillance System

<table>
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<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Data Sharing</th>
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<th>Consent Required?</th>
<th>Dissent Allowed?</th>
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<tr>
<td>AZ</td>
<td>STATUTE: Arizona Revised Statutes, Title 36, Chapter 1, Article 1, §36-133</td>
<td>ARS 36-133. Chronic disease surveillance system; confidentiality; immunity; violation, classification. A. A central statewide chronic disease surveillance system is established in the department. Diseases in the surveillance system shall include cancer, birth defects and other chronic diseases required by the director to be reported to the department. [emphasis added]</td>
<td>ARS 36-133. Chronic disease surveillance system …C. A person who provides a case report to the surveillance system or who uses case information from the system authorized pursuant to this section is not subject to civil liability with respect to providing the case report or accessing information in the system. D. The department may authorize other persons and organizations to use surveillance data: 1. To study the sources and causes of cancer, birth defects and other chronic diseases. 2. To evaluate the cost, quality, efficacy and appropriateness of diagnostic, therapeutic, rehabilitative and preventive services and programs related to cancer, birth defects and other chronic diseases.</td>
<td>ARS 36-133. Chronic disease surveillance system …D. The department may authorize other persons and organizations to use surveillance data: 1. To study the sources and causes of cancer, birth defects and other chronic diseases. 2. To evaluate the cost, quality, efficacy and appropriateness of diagnostic, therapeutic, rehabilitative and preventive services and programs related to cancer, birth defects and other chronic diseases.</td>
<td>NO</td>
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birth defects and other diseases included in the surveillance system. 5. Monitor the incidence patterns of diseases included in the surveillance system.
6. Pursuant to rules adopted by the director, establish procedures for reporting diseases included in the surveillance system.
7. Identify population subgroups at high risk for cancer, birth defects and other diseases included in the surveillance system.
8. Identify regions of this state that need intervention programs or epidemiological research, detection and prevention.
9. Establish a data management system to perform various studies, including epidemiological studies, and to provide biostatistics and epidemiologic information to the medical community relating to diseases in the surveillance system.

**ARTICLE 5. BIRTH DEFECTS MONITORING**

persons and organizations to use surveillance data…

**ARS 36-133…E.** The department of health services and the Arizona early intervention program in the department of economic security may use surveillance data to notify the families of children with birth defects regarding services that are available to them and provide these families with information about organizations that provide services to these children and their families.

including epidemiological studies, and to provide biostatistic and epidemiologic information to the medical community relating to diseases in the surveillance system…

**ARS 12-2802. Confidentiality of genetic testing results; disclosure.**
A. Except as otherwise provided in this article, genetic testing and information derived from genetic testing are confidential and considered privileged to the person tested and shall be released only to…4. A researcher for medical research or public health purposes only if the research is conducted pursuant to applicable federal or state laws and regulations governing clinical and biological
| PROGRAM. R9-4-501. Definitions … | 42. “Patient” means an individual, regardless of current age: a. Who, from conception to one year of age, was clinically evaluated for a possible birth defect or a medical condition that may be related to a birth defect… b. Whose mother was clinically evaluated during her pregnancy with the individual… c. Who, from conception to one year of age, was tested by a genetic testing facility or other clinical laboratory; d. Whose mother was tested during her pregnancy with the individual… e. Who, from conception to one year of age, was provided treatment or whose mother during her pregnancy with the individual was provided treatment by a hospital, clinic, physician, registered nurse practitioner, or other person… | F. Information collected on individuals by the surveillance system that can identify an individual is confidential and may be used only pursuant to this section. A person who discloses confidential information in violation of this section is guilty of a class 3 misdemeanor. | research or if the identity of the individual providing the … 9. The authorized agent of a federal, state or county health department to conduct activities specifically authorized pursuant to the laws of this state for the birth defects registry, children's rehabilitative services, newborn screening and sickle cell diagnosis and treatment programs and chronic, environmentally provoked and infectious disease programs. [emphasis added] |