## Arizona

### 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>
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</table>
| AZ    | AZ STATUTE: Arizona Revised Statutes, Title 36, Chapter 1, Article 1, §36-133 | 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]  
B. The department, in establishing the surveillance system, shall:  
1. Provide a chronic disease information system.  
2. Provide a mechanism for patient follow-up.  
3. Promote and assist hospital cancer registries.  
4. Improve the quality of information gathered relating to the detection, diagnosis and treatment of patients with cancer, 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.  
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.  
ARS 36-133...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.  
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. | 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... | 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. | NO | NO |
ARTICLE 5. BIRTH DEFECTS MONITORING 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.

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]
## Cancer Surveillance System

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<td>§36-133 Chronic disease surveillance system: B. 8. Identify regions of this state that need intervention programs or epidemiological research, detection and prevention.</td>
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### R9-4-404. Requirements for Submitting Case Reports and Allowing Review of Hospital Records.

A. The cancer registry of a hospital with a licensed capacity of 50 or more inpatient beds shall ensure that:

1. An electronic case report is submitted to the Department within 180 calendar days from the date a patient is first released from the hospital; and
2. An electronic follow-up report, including a change of patient address, if applicable, a summary of additional first course preventive services and programs related to cancer, birth defects and other chronic diseases, is submitted to the Department at least annually for: a. All living analytic patients in the hospital’s cancer registry database; and b. All analytic patients in the hospital’s cancer registry database who have died since the last follow-up report.

B. The cancer registry or other designee of a hospital with a licensed capacity of fewer than 50 inpatient beds shall either report as specified in subsection (A), or shall at least once every six months:

1. Prepare and submit a written report to the Department: a. For all individuals: i. Released by the hospital since the last report was prepared; and ii. Whose medical records include ICD-9-CM diagnosis codes specified in a list provided to the hospital by the Department, b. Containing ICD-9-CM diagnosis codes that are arranged in numeric order, and c. Including the following information associated with each ICD-9-CM diagnosis code: i. The individual’s medical record number assigned by the hospital; ii. The individual’s age; iii. The individual’s admission and discharge dates, and iv. Whether the diagnosis code reflects the individual’s principal or secondary diagnosis, and 2. Allow the Department to review the records listed in R9-4-405(A) to obtain the information specified in R9-4-403 about a patient.

### §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: ...5. A third person if approved by a human subjects review committee or a human ethics committee, with respect to persons who are subject to an Arizona cancer registry. 

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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.cchffreedom.org
Newborn Genetic Testing & Surveillance System

| State | Statute/Rule | Language Specific to Genetic Testing and Surveillance System | Exemption | Research Authority | Consent Required? | Dissent Allowed?
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<td>AZ</td>
<td>STATUTE: ARS, Title 36, Article 5 RULE: AAC, Title 9, Chapter 13, Article 2</td>
<td>A.R.S. §36-694. Report of blood tests; newborn screening program; committee; fee; definitions</td>
<td>NONE FOUND</td>
<td>R9-13-206. Reporting Requirements for Specimens...D. Bloodspot test results are confidential subject to the disclosure provisions of 9 A.A.C. 1, Article 3 [R9-1-302 &amp;R9-1-303 - Disclosure of Medical Records, Payment Records, and Public Health Records], and A.R.S. §§ 12-2801 and 12-2802. [Genetic Testing]</td>
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ARTICLE 2. NEWBORN AND INFANT SCREENING

R9-13-203. General Requirements for Newborn and Infant Bloodspot Tests A. When a bloodspot test is ordered for a newborn or an infant, a health care facility's designee, a health care provider, or the health care provider's designee shall:

1. Only use a specimen collection kit supplied by the Department;
2. Collect a blood sample from the newborn or infant on a specimen collection kit;
3. Complete the following information on the specimen collection kit: [emphasis added]

Title 39, Chapter 1, Article 2 governs the Department’s disclosure of public health records, except for:...

3. At the direction of the Human Subjects Review Board, disclosure of public health records that are not de-identified when:

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<tr>
<td>a.</td>
<td>The newborn's or infant's name, gender, race, ethnicity, medical record number, and if applicable, AHCCCS identification number;</td>
<td>b.</td>
<td>The newborn's or infant's type of food or food source;</td>
<td>c.</td>
<td>Whether the newborn or infant is from a single or multiple birth;</td>
<td>d.</td>
<td>If the newborn or infant is from a multiple birth, the birth order of the newborn or infant;</td>
<td>e.</td>
<td>Whether the newborn or infant has a medical condition that may affect the bloodspot test results;</td>
<td>f.</td>
<td>Whether the newborn or infant received antibiotics or a blood transfusion and, if applicable, the date of the last blood transfusion;</td>
<td>g.</td>
<td>The method of blood sample collection;</td>
<td>h.</td>
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## Vaccination Surveillance System

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<tr>
<td>AZ</td>
<td>ARS Title 36, Article 2</td>
<td>36-135. Child immunization reporting system; requirements; access; confidentiality; immunity; violation; classification; definitions. A. The child immunization reporting system is established in the department to collect, store, analyze, release and report immunization data. B. A health care professional who is licensed under title 32 to provide immunization, except as provided in subsection I of this section, shall report the following information: 1) The health care professional’s name, business address and business telephone number. 2. The child’s name, address, social security number if known and not confidential, gender, date of birth and mother’s maiden name. 3. The type of vaccine administered and the date it is administered. C. The health care professional may submit this information to the department on a weekly or monthly basis by telephone, facsimile, mail, computer or any other method prescribed by the department.</td>
<td>36-135 Child Immunization Reporting System… D. Except as provided in subsection I, the department shall release identifying information only to the person, the person's health care decision maker, parent or guardian, a health care provider, an entity regulated under title 20, the Arizona health care cost containment system and its providers as defined in chapter 29 of this title, a school official who is authorized by law to receive and record immunization records or a person or entity that provides services to a health care provider and with whom the health care provider has a business associate agreement that requires the person or entity to protect the confidentiality of the information, as required by the health insurance portability and accountability act privacy standards, 45 Code of Federal Regulations part 164, subpart E. The department may also release identifying information to an entity designated by the person or the person's health care decision maker, parent or guardian. The department may, by rule, release immunization information to persons for a specified purpose. The department may release non-identifying summary statistics.</td>
<td>NO</td>
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