# Arizona

## Newborn Genetic Testing & Surveillance System

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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 …B. When a birth is reported the attending physician or person who is required to make a report on the birth shall order or cause to be ordered tests for certain congenital disorders. The results of tests for these disorders must be reported to the department of health services... D. The director of the department of health services shall establish a newborn screening program within the department to assure that the testing for congenital disorders and the reporting of hearing test results required by this section are conducted in an effective and efficient manner. The newborn screening program shall include an education program for the general public, the medical community, parents</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>
<td>NO</td>
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and professional groups. The director shall designate the state laboratory as the only testing facility for the program.

E. The newborn screening program shall establish and maintain a central database of newborns and infants who are tested for hearing loss and congenital disorders that includes information required in rule…

G. The director shall establish a committee to provide recommendations and advice to the department on at least an annual basis regarding tests that the committee believes should be included in the newborn screening program.

**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;

§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 research or if the identity of the individual providing the …
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]
   a. The newborn's or infant's name, gender, race, ethnicity, medical record number, and if applicable, AHCCCS identification number;
   b. The newborn's or infant's type of food or food source;
   c. Whether the newborn or infant is from a single or multiple birth;
   d. If the newborn or infant is from a multiple birth, the birth order of the newborn or infant;
   e. Whether the newborn or infant has a medical condition that may affect the bloodspot test results;
   f. Whether the newborn or infant received antibiotics or a blood transfusion and, if applicable, the date of the last blood transfusion;
   g. The method of blood sample collection;
   h. The date and time of birth, and the newborn's or infant's weight at birth;

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]
|   |   | i. The date and time of blood sample collection, and the newborn's or infant's weight when the blood sample is collected; j. The name and identification code of the health care facility or health care provider submitting the specimen collection kit; k. The name, identification code, and address of the health care provider responsible for the management of medical services provided to the newborn or infant; l. Except as provided in subsection (A)(3)(m), the mother's first and last names, date of birth, name before first marriage, mailing address, phone number, and if applicable, AHCCCS identification number; and m. If the newborn's or infant's mother does not have physical custody of the newborn or infant, the first and last names, mailing address, and phone number of the person who has physical custody of the newborn or infant. | R9-1-302. Medical Records or Payment Records Disclosure. A. Except as provided in subsection (B), an employee or volunteer shall not disclose to a third person medical records or payment records containing individually identifiable health information that the employee or volunteer obtained or accessed as a result of the employment or volunteering. B. Unless otherwise prohibited by law, an employee or volunteer may disclose to a third person medical records or payment records containing individually identifiable health information:… |
6. At the direction of the Human Subjects Review Board, if the medical records or payment records are sought for research and the disclosure meets the requirements of 45 CFR 164.512(i)(2) [federal HIPAA rule research access provision]...

A. A.R.S. 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:
   a. The public health records are sought for research, and
   b. The disclosure meets the requirements of 45 CFR 164.512(i)(2).