

Virginia

**Birth Defects Surveillance System**

State	Statute/Rule	Language Specific to Surveillance System	Data Sharing	Research Authority	Consent Required?	Dissent Allowed?
VA	<p>STATUTE: Code of Virginia, Title 32.1 Chapter 2</p> <p>RULE: Virginia Administrative Code, Title 12, Agency 5, Chapter 191,</p>	<p><b>§ 32.1-69.1. Virginia Congenital Anomalies Reporting and Education System. A.</b> In order to collect data to evaluate the possible causes of birth defects, improve the diagnosis and treatment of birth defects and establish a mechanism for informing the parents of children identified as having birth defects and their physicians about the health resources available to aid such children, the Commissioner shall establish and maintain a Virginia Congenital Anomalies Reporting and Education System using data from birth and death certificates and fetal death reports filed with the State Registrar of Vital Records and data obtained from hospital medical records. The chief administrative officer of every hospital, as defined in § <a href="#">32.1-123</a>, shall make or cause to be made a report to the Commissioner of any person under two years of age diagnosed as having a congenital anomaly. The Commissioner may appoint an advisory committee to</p>	<p><b>§ 32.1-69.2. Confidentiality of records; publication; authority of Commissioner to contact parents and physicians.</b> The Commissioner and all other persons to whom data is submitted pursuant to § <a href="#">32.1-69.1</a> shall keep such information confidential. For the purpose of only complying with the provisions of § <a href="#">32.1-69.1</a>, hospitals required to report birth defects to the</p>	<p><b>§ 32.1-69.2.</b> ...No publication of information shall be made except in the form of statistical or other studies which do not identify individuals. However, the Commissioner may contact the parents of children identified as having birth defects and their physicians to collect relevant data and to</p>	NO	NO

		<p>assist in the design and implementation of this reporting and education system with representation from relevant groups including, but not limited to, physicians, geneticists, personnel of appropriate state agencies, persons with disabilities and the parents of children with disabilities.</p> <p><b>B.</b> The Commissioner shall provide for a secure system, which may include online data entry that protects the confidentiality of data and information for which reporting is required, to implement the Virginia Congenital Anomalies Reporting and Education System. At a minimum, data collected shall include, but need not be limited to, the following:</p> <p><b>(i)</b> the infant's first and last name, date of birth, gender, state of residence, birth hospital, physician's name, date of admission, date of discharge or transfer, and diagnosis;</p> <p><b>(ii)</b> the first and last names of the infant's mother and father;</p> <p><b>(iii)</b> the first and last name of the primary contact person for the infant; and</p>	<p>Virginia Congenital Anomalies Reporting and Education System and provide patient follow-up may view personally identifiable information in the system as approved by the Commissioner and upon receipt by the Commissioner of sworn affirmation from each such person that the confidentiality of the information will be preserved. No publication of information shall be made except in the form of statistical or other studies which do not identify individuals.</p>	<p>provide them with information about available public and private health care resources.</p> <p><b>2VAC5-191-280. Scope and content of the Virginia Congenital Anomalies Reporting and Education System ...D. Goals.</b></p> <p><b>1.</b> Children with birth defects will receive early diagnosis and assistance in finding and accessing health care services.</p>		
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		<p>(iv) data pertaining to birth defects reported by hospitals and derived from birth and death certificates and fetal death reports filed with the State Registrar of Vital Records and such other sources as may be authorized by the Commissioner. The Commissioner, as he deems necessary to facilitate the follow-up of infants whose data and health record information have been entered into the system, <b>may authorize the integration or linking of the Virginia Congenital Anomalies Reporting and Education System with other Department of Health population-based surveillance systems.</b></p> <p>In addition, to minimize duplication and ensure accuracy during data entry, the Commissioner may authorize hospitals required to report birth defect data to the system to view such existing data and information as may be designated by the Commissioner.</p>	<p>However, the Commissioner may contact the parents of children identified as having birth defects and their physicians to collect relevant data and to provide them with information about available public and private health care resources.</p>	<p><b>2. Birth defect surveillance data will be used in making decisions regarding health services planning and to promote scientific collaboration for the prevention of birth defects.</b></p>		
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