

# State Immunization Information System Laws—Demographic Data Collection

Immunization information systems (IIS), or vaccine registries, are "confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geopolitical area."<sup>1</sup> In general, when healthcare providers<sup>2</sup> administer a vaccine, they enter information about the patient and the vaccine into the medical record and report to an IIS database that a health department administers. Providers, schools, and other entities can access information in the database to get accurate information about an individual patient's vaccination status. Population-level data can also be used to track vaccination rates in communities and may be shared with other agencies.

State laws establish the standards for IIS. Many laws require the collection or reporting of data about vaccine recipients, including demographic data.<sup>3</sup> Demographic data are the characteristics of individuals within a population, such as age, race, sex, pregnancy status, employment status, or occupation.<sup>4</sup> Demographic data, or sociodemographic data, help identify populations that experience disproportionate

<sup>4</sup> <u>Weber SB, Moreland A, Hulkower R, et al. Examining sociodemographic data reporting requirements in state</u> <u>disease surveillance systems. *St. Louis University Journal of Health Law & Policy* 2021;14(2):571-86, *available at* <u>https://scholarship.law.slu.edu/jhlp/vol14/iss2/16</u>.</u>



<sup>&</sup>lt;sup>1</sup> <u>CDC. About Immunization Information Systems [website]. Updated June 7, 2019</u>, *available at* <u>www.cdc.gov/vaccines/programs/iis/about.html</u>.

<sup>&</sup>lt;sup>2</sup> Physicians and their staff, pharmacists, and other healthcare professionals are authorized to administer vaccines based on state law. *See* Washington State Department of Health List of Providers Authorized to Administer Vaccines, *available at* <u>https://doh.wa.gov/sites/default/files/legacy/Documents/Pubs//698-001-</u> <u>ProvidersAuthorizedVaccineAdministration.pdf</u>

<sup>&</sup>lt;sup>3</sup> For simplicity, this menu uses forms of the word "collect" to encompass all the ways that data are entered or reported into immunization information systems.

vaccination rates<sup>5</sup> and may help provide indicators of the social, environmental, economic, and other conditions in which those populations live.<sup>6</sup>

The Centers for Disease Control and Prevention's (CDC's) Public Health Law Program (PHLP)—within the Center for State, Tribal, Local, and Territorial Support—assessed state statutes and regulations (collectively referred to as "laws") governing IIS. This assessment builds on a study conducted by CDC's Immunization Information Systems Support Branch, through the Public Health Informatics Institute, and published in the *Journal of Public Health Management & Practice* in 2015.<sup>7</sup> PHLP collected the laws examined for the current assessment in 2020. This assessment did not include policies or other materials produced by health departments, such as websites or forms. Each section of the menu below provides examples of state laws on IIS addressing the collection of demographic data. The appendices provide data on laws from all jurisdictions collected in the 2020 assessment. PHLP plans to release menus about other aspects of state IIS laws in the future.

For questions related to this document or to request updates to relevant immunization laws for your state, please email PHLP at <u>PHLawProgram@cdc.gov</u>. Note that the information contained in this document was collected for research and educational purposes. Please contact your state or local health department for requirements that may apply to your individual circumstances.

# State Immunization Information System Laws

PHLP researched statutes and regulations for 50 states and the District of Columbia. Researchers identified laws for all the jurisdictions, except Pennsylvania<sup>8</sup>, regarding collection of immunization data in IIS.

The mechanisms for collecting demographic data vary by jurisdiction. Most states collect demographic data by requiring reports from healthcare providers. For example, in **New York**, healthcare providers are required to report specific information to the state or New York City IIS.<sup>9</sup> Some states require birth certificate system directors to report information to IIS; in **Connecticut**, the administrator of the birth registry is required to report some demographic information to the immunization registry for all children

<sup>&</sup>lt;sup>5</sup> <u>Gostin LO, Lazzarini Z. Childhood immunization registries: a national review of public health information systems</u> and the protection of privacy. *JAMA* 1995;274(22):1793-9, *available at* <u>https://jamanetwork.com/journals/jama/fullarticle/392638</u>.

<sup>&</sup>lt;sup>6</sup> Weber, *supra* note 4.

<sup>&</sup>lt;sup>7</sup> Martin DW, Lowery NE, Brand B, et al. <u>Immunization information systems: a decade of progress in law and policy</u>. *Journal of Public Health Management and Practice* 2015:21(3):296–303, *available at* doi:10.1097/PHH.00000000000040.

<sup>&</sup>lt;sup>8</sup> Although researchers did not identify an applicable law, Pennsylvania operates an IIS. See <u>PA-SIIS</u>. There may be other instances where states are collecting demographic data although the law in that jurisdiction does not have an explicit requirement.

<sup>&</sup>lt;sup>9</sup> N.Y. COMP. CODES R. & REGS. tit. 10, § 66-1.2 ([T]the patient's name (first, middle and last); date of birth; gender; race; ethnicity; address, including zip code; telephone numbers; birth order (if multiple birth); birth state/country; mother's maiden name; mother's or other responsible party's name (first, middle and last); vaccines for children program eligibility; Medicaid number; and vaccine administration date, type, lot number and manufacturer ....")

born since 1999.<sup>10</sup> Uniquely, clinical laboratories must enter demographic data from childhood blood lead tests into the IIS in **Ohio**.<sup>11</sup>

## **Collection of Demographic Data**

This assessment focused on five demographic data elements. State laws were coded on whether laws required collection of:

- Date of birth
- Address/zip code
- Sex/gender
- Citizenship/place of birth
- Race/ethnicity<sup>12</sup>

Twenty-seven state laws require collection of demographic data. Six of those states collect all the demographic data elements identified for this assessment: Alabama, Alaska, Iowa, Nevada, New Hampshire, and New York.

### **Date of Birth Collection**

All 27 states that require collection of demographic data require date of birth.

- In Arizona, a "health care professional" shall report the date of birth.<sup>13</sup>
- Idaho law states the "registry shall contain" the birth date for each child.<sup>14</sup>
- Alabama collects the date of birth for the child's mother and father, in addition to the child's date of birth.<sup>15</sup>

## Address/Zip Code Collection

In 24 states, the law requires address/zip code to be collected.

- In Florida, the "information included in the immunization registry must include the child's name, date of birth, [and] address. ...<sup>16</sup>
- New York specifies that "address, including zip code" is required.<sup>17</sup>

<sup>15</sup> Ala. Admin. Code r. 420-6-2-.05(2).

<sup>&</sup>lt;sup>10</sup> CONN. AGENCIES REGS. § 19a-7h-2(a)-(b). ("The administrator of the Connecticut electronic birth registry system shall submit an electronic data file to the immunization registry administrator within 7 days of the information being received at the department. Identifying and locating information shall be: (1) the infant's name, birthdate, hospital of birth, birth certificate number, birth document control number, and address, and, if available, social security number. ...")

<sup>&</sup>lt;sup>11</sup> OHIO ADMIN. CODE 3701-30-05 (Any clinical laboratory that performs any analysis of human blood on a child under sixteen years of age and residing in Ohio to detect or determine levels of lead shall collect and report to the director all of the following information on a form prescribed by the director: (1) Child's name and parent's or guardian's name; (2) Child's street and mailing address, including the city, state, county and zip code; (3) Child's social security number, date of birth, gender, race and ethnicity; (4) Telephone number. ...)

<sup>&</sup>lt;sup>12</sup> CDC provides IIS Functional Standards and has a set of Core Data Elements it endorses as the data elements needed by an IIS to record patient demographics and vaccination events. <u>CDC Core Data Elements for IIS Functional</u> <u>Standards v4.0 [website]</u>. <u>Updated Nov 21, 2018</u>. Some states cite the CDC Core Data Elements for Immunization Information Systems to define the collected data elements. *See, e.g.*, N.H. CODE R. HE-P 307.05(b).

<sup>&</sup>lt;sup>13</sup> Ariz. Rev. Stat. Ann. § 36-135.

<sup>&</sup>lt;sup>14</sup> Idaho Code Ann. § 39-4803.

<sup>&</sup>lt;sup>16</sup> Fla. Stat. Ann. § 381.003(1)(e)(4).

<sup>&</sup>lt;sup>17</sup> N.Y. COMP. CODES R. & REGS. tit. 10, § 66-1.2(c)(1).

 Alabama collects "immunization registry information derived from birth certificates" including mother's address.<sup>18</sup>

## **Sex/Gender Collection**

Laws in 19 states require the collection of sex/gender.

- Alaska requires healthcare providers to submit vaccine information which "shall include the . . . sex . . . of a patient."<sup>19</sup>
- California allows many entities, including health care providers, to disclose information including "patient's or client's gender" to immunization information systems.<sup>20</sup>
- In Oregon, providers who administer "state-supplied vaccine" and pharmacists who administer any vaccine must report the gender of a patient.<sup>21</sup>

### **Citizenship/Place of Birth Collection**

In 13 states, laws require collection of place of birth. Researchers did not identify any jurisdictions that require collection of citizenship information.

- Iowa requires the collection of "birth state and birth country."<sup>22</sup>
- Under Louisiana law, immunization records include the "place of birth of the client."<sup>23</sup>
- Under Virginia law, the patient demographic information that "shall" be reported to the immunization information system includes "birth place."<sup>24</sup>

#### **Race/Ethnicity Collection**

In 11 states, the law requires the collection of race and/or ethnicity.

- Under Arkansas law, providers must collect "race."<sup>25</sup>
- In Ohio, the data collected in the IIS includes "race and ethnicity."<sup>26</sup>
- Under New Jersey law, "ethnicity/race" are collected by providers.<sup>27</sup>

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<sup>&</sup>lt;sup>18</sup> Ala. Admin. Code r. 420-6-2-.05(2).

<sup>&</sup>lt;sup>19</sup> Alaska Admin. Code tit. 7, § 27.650(c)(1).

<sup>&</sup>lt;sup>20</sup> CAL. HEALTH AND SAFETY CODE § 120440(c)(9).

<sup>&</sup>lt;sup>21</sup> OR. ADMIN. R. 333-049-0050(5)(a); OR. ADMIN. R. 855-019-0290(2)(a).

<sup>&</sup>lt;sup>22</sup> IOWA ADMIN. CODE r. 641-7.11(22)(3).

<sup>&</sup>lt;sup>23</sup> LA. STAT. ANN. § 40:31.12(3)(b).

<sup>&</sup>lt;sup>24</sup> VA CODE ANN. § 32.1-46.01(B)(6); 12 VA. ANN. CODE § 5-115-60(d)(1).

<sup>&</sup>lt;sup>25</sup> 007.15.10 Ark. Code R. § IV(A)(3).

<sup>&</sup>lt;sup>26</sup> Ohio Admin. Code **3701-30-05**.

<sup>&</sup>lt;sup>27</sup> N.J. ADMIN. CODE § 8:57–3.16(d)(3).

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PHLP provides technical assistance and public health law resources to advance the use of law as a public health tool. PHLP cannot provide legal advice on any issue and cannot represent any individual or entity in any matter. PHLP recommends seeking the advice of an attorney or other qualified professional with questions regarding the application of law to a specific circumstance. The findings and conclusions in this summary are those of the authors and do not necessarily represent the official views of CDC.

# Appendix A: IIS Demographic Data Required to be Collected by State Law

	Date of Birth Address/Zip Sex/Gender Citizenship/ Race/Ethnicity						
	Date of Birth	Code	Sex/Gender	Place of Birth	Race/Ethnicity		
State							
Alabama	Х	Х	Х	Х	Х		
Alaska	Х	Х	Х	Х	Х		
Arizona	Х	Х	Х				
Arkansas	Х	Х	Х		Х		
California	Х	Х	Х	Х			
Colorado							
Connecticut	Х	Х		Х			
Delaware							
Florida	Х	Х					
Georgia	Х	Х		Х			
Hawaii	Х						
Idaho	Х	Х					
Illinois	Х	X	Х	Х			
Indiana	Х	Х	X		Х		
lowa	Х	X	Х	Х	Х		
Kansas							
Kentucky							
Louisiana	Х			Х			
Maine	Х	Х					
Maryland	Х	Х	Х	Х			
Massachusetts	Х	Х					
Michigan							
Minnesota							
Mississippi							
Missouri							
Montana							
Nebraska	Х	Х	Х		Х		
Nevada	Х	Х	Х	Х	Х		
New Hampshire	Х	X	Х	Х	Х		
New Jersey	X	X	Х		Х		
New Mexico	X	X	Х				
New York	Х	X	Х	Х	Х		
North Carolina							
North Dakota							
Ohio	Х	X	Х		Х		
Oklahoma							
Oregon	Х	X	Х				
Pennsylvania							
Rhode Island							
South Carolina	X		Х				
South Dakota							
Tennessee							
Texas							

Utah					
Vermont					
Virginia	Х	Х	Х	Х	
Washington					
West Virginia					
Wisconsin					
Wyoming					

*Legend: "X" = yes; blank = state law does not require collection of demographic data* 

#### Appendix B: Citations to Statutes and Regulations Requiring Collection of Five Priority Data Elements

#### References for Table Data: Statutes and Regulations by State<sup>i</sup>

STATE	STATUTES AND REGULATIONS			
Alabama	Ala. Admin. Code r. 420-6-205(2) (1997)			
Alaska	Alaska Admin. Code tit. 7, § 27.650(c)(1) (2020)			
Arizona	Ariz. Rev. Stat. Ann. § 36-135(B)(2) (2021)			
Arkansas	007.15.10 Ark. Code R. § IV(A)(3) (2015)			
California	CAL. HEALTH AND SAFETY CODE § 120440(c)(9) (2020)			
Colorado	N/A			
Connecticut	CONN. AGENCIES REGS. § 19a-7h-2(a)-(b) (2000)			
Delaware	N/A			
Florida	Fla. Stat. Ann. § 381.003(1)(e)(4) (2021)			
Georgia	GA. CODE ANN. § 31-12-3.1(b) (2021)			
Hawaii	Haw. Rev. Stat. Ann. § 325-123(b) (2012)			
Idaho	Ідано Code Ann. § 39-4803(2) (2015)			
Illinois	ILL. ADM. CODE tit. 77, 689.40(a)(1) (2021)			
Indiana	IND. CODE ANN. 16-38-5-2(d) (2014)			
lowa	IOWA ADMIN. CODE r. 641-7.11(22)(3) (2017)			
Kansas	N/A			
Kentucky	N/A			
Louisiana	LA. STAT. ANN. § 40:31.12(3)(b) (2019)			
Maine	10-144-274 ME. CODE R. § 3 (2021); 10-144-274 274 ME. CODE R. § 4 (2021); 10-144-274 CMR § 10(B)			
	(2021)			
Maryland	MD. CODE REGS. 10.06.03.04(A)-(B) (2015)			
Massachusetts	105 Mass. Code Regs. 222.100(D) (2022)			
Michigan	N/A			
Minnesota	N/A			
Mississippi	N/A			
Missouri	N/A			
Montana	N/A			
Nebraska	NEB. REV. STAT. ANN. § 71-541 (2011); 173 NEB. ADMIN. CODE § 8-003.01A (2021)			
Nevada	N.R.S. 439.265(2)(c) (2007); NAC § 439.893 (2021)			
New	N.H. CODE R. HE-P 307.05(b) (2021)			
Hampshire				
New Jersey	N.J. ADMIN. CODE § 8:57–3.16(d)(3) (2021)			
New Mexico	N.M. CODE R. § 7.5.5.9(C)(2) (2018)			

STATE	STATUTES AND REGULATIONS			
New York	10 NYCRR 66-1.2 N.Y. COMP. CODES R. & REGS. tit. 10, § 66-1.2 (2021)			
North Carolina	N/A			
North Dakota	N/A			
Ohio	Ohio Admin. Code 3701-30-05 (2021)			
Oklahoma	N/A			
Oregon	OR. ADMIN. R. 333-049-0050(5)(a) (2021); OR. ADMIN. R. 855-019-0290(2)(a) (2021)			
Pennsylvania	[No law identified]			
Rhode Island	N/A			
South Carolina	S.C. CODE ANN. REGS. 61-120(C)(5) (2019)			
South Dakota	N/A			
Tennessee	N/A			
Texas	N/A			
Utah	N/A			
Vermont	N/A			
Virginia	VA CODE ANN. § 32.1-46.01(B)(6) (2021); 12 VA. ANN. CODE § 5-115-60(d)(1) (2015)			
Washington	N/A			
West Virginia	N/A			
Wisconsin	N/A			
Wyoming	N/A			

<sup>&</sup>lt;sup>i</sup> The citations in the table in Appendix B are state statutes and regulations relied upon for the tables in Appendix A. For states with N/A, researchers did not identify a law requiring collection of demographic data. The list of state laws is not exhaustive; other statutes and regulations may be relevant. If you would like additional information about these state documents, please contact PHLP at <u>PHLawProgram@cdc.gov</u>.