## OREGON

**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>
</tr>
</thead>
</table>

---

*Birth Defects Surveillance System*

Lorena Barck, Ph.D., J.D., Program Manager, Oregon Department of Human Services, Environmental and Occupational Epidemiology, Environmental Public Health Tracking: We don’t have a birth defects registry in Oregon, and one of the arguments that people have against it is that we have such small numbers of individual types of birth defects that it wouldn’t do much good in terms of tracking for causes and other kinds of things. I’m wondering, if people classically think of birth defects registry as what shows up at birth, maybe what we can do is try to promote a registry that goes farther in years, so that the structural defects show up later and the functional defects show up later.” – Forum Question, *Birth Defects and Environmental Contaminants, June 30, 2004*
432.520 Reporting requirement; review of records; special studies. (1) Except as provided in subsection (2) of this section, any health care facility in which patients are diagnosed or provided treatment for cancer or benign tumors of the brain and central nervous system shall report each case of cancer or benign tumors of the brain and central nervous system to the Oregon Health Authority within a time period and in a format prescribed by the authority. The authority shall provide, at cost, reporting services to any health care facility at the option of the health care facility. Health care facilities may also purchase reporting services from another facility or commercial vendor.

If a health care facility is unable to report in conformance with the format and standards prescribed by the authority, the authority may, after consultation with the health care facility, elect to activate its reporting service for the facility. When activated, the authority may enter the facility, obtain the information and report it in conformance with the appropriate format and standards. In these instances, the facility shall reimburse the authority or its authorized representative for the cost of obtaining and reporting the information...

432.530 Confidentiality of information... (2) All additional information reported in connection with a special study shall be confidential and privileged and shall be used solely for the purposes of the study, as provided by ORS 432.060. Nothing in this section shall prevent the Oregon Health Authority from publishing statistical compilations relating to morbidity and mortality studies that do not identify individual cases or prevent use of this data by third parties to conduct research as provided by ORS 432.540 (1).
| 432.550 Action for damages; license; disciplinary action prohibited for good faith participation in reporting of data. (1) | No action for damages arising from the disclosure of confidential or privileged information may be maintained against any person, or the employer or employee of any person, who participates in good faith in the reporting of registry data for cancer or benign tumors of the brain and central nervous system or data for cancer morbidity or mortality studies in accordance with ORS 432.510 to 432.540 and 432.900.  
(2) No license of a health care facility or practitioner may be denied, suspended or revoked for the good faith disclosure of confidential or privileged information in the reporting of registry data for cancer or benign tumors of the brain and central nervous system or data for cancer morbidity or mortality studies in accordance with ORS 432.510 to 432.540 and 432.900.  
(3) Nothing in this section shall be construed to apply to the unauthorized disclosure of confidential or privileged information when such disclosure is due to gross negligence or willful misconduct. |
| 333-010-0050 Confidentiality and Access to Data (1)… | Except as required in connection with the administration or enforcement of public health laws or rules, no public health official, employee, or agent shall be examined in an administrative or judicial proceeding as to the existence or contents of data collected under the cancer registry system. | 432.540 Use of confidential data; rules. (2) The authority may enter into agreements to exchange information with other registries for cancer and benign tumors of the brain and central nervous system in order to obtain complete reports of Oregon residents diagnosed or treated in other states and to provide information to other states regarding the residents of other states diagnosed or treated in Oregon. Prior to providing information to any other registry, the authority shall ensure that the recipient registry has comparable confidentiality protections. |
### Newborn Genetic Testing & Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Genetic Testing and Surveillance System</th>
<th>Exemption</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>OR</td>
<td>STATUTE: ORS Title 36, Chapter 433</td>
<td>433.285 Policy to control metabolic diseases; testing; fees; exemptions; waiver of fees; rules. (1) It hereby is declared to be a matter of public policy of the State of Oregon that in the interest of public health and the prevention of mental retardation, every infant, shall be given tests approved by the Oregon Health Authority for the detection of the disease of phenylketonuria and other metabolic diseases. (2) The authority by rule shall specify the diseases for which infants shall be tested under subsection (1) of this section, the appropriate time following delivery for collecting specimens, the manner in which the specimens are to be submitted, the persons responsible for submitting the specimens, the methods of testing and the manner of payment of the fees…(5) The authority by rule shall prescribe the form of the statement.</td>
<td>433.285 (3) The testing required by subsection (1) of this section shall not be required if the infant is being reared as an adherent to a religion the teachings of which are opposed to such testing. The person responsible for submitting specimens under the rules of the authority shall be responsible for submitting a statement signed by the infant’s parent that the infant is being so reared. The department by rule shall prescribe the form of the statement.</td>
<td>Unclear.</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>

#### Oregon Genetic Privacy LAW:

192.535 Informed consent for obtaining genetic information. (1) A person may not obtain genetic information from an individual, or from an individual’s DNA sample, without first obtaining informed consent of the individual or the individual’s representative, except:

... (b) For anonymous research or coded research conducted under conditions described in ORS 192.537 (2), after notification pursuant to ORS 192.538 or pursuant to ORS 192.547 (7)(b);

... (d) As permitted by rules of the Health Authority for newborn screening procedures;

192.537 Individual’s rights in genetic information; retention of information; destruction of information. …(2)(a) A person may use an individual’s DNA sample or genetic information that is derived from a biological specimen or clinical individually identifiable health information for anonymous research or coded research only if the individual:

(A) Has granted informed consent for the specific anonymous research or coded research project;

(B) Has granted consent for genetic research generally;

(C) Was notified in accordance with ORS 192.538 that the individual’s biological specimen or clinical individually identifiable health information may be used for anonymous research or coded research and the individual did not, at the time of notification, request that the biological specimen or clinical individually identifiable health information not be used for anonymous research or coded research; or

(D) Was not notified, due to emergency circumstances, in accordance with ORS 192.538 that the individual’s biological specimen or clinical individually identifiable health information may be used for anonymous research or coded research and the individual died before receiving the notice.
| 433.295 Report of cases required; forms to be furnished. (1) All physicians, public health nurses and the administrators of hospitals shall report the discovery of cases of phenylketonuria to the Oregon Health Authority. | 192.538 Notice by health care provider regarding anonymous or coded research. (1) A health care provider that is a covered entity as defined in ORS 192.519 (2)(c) and that obtains an individual’s biological specimen or clinical individually identifiable health information shall notify the individual that the biological specimen or clinical individually identifiable health information may be disclosed or retained by the provider for anonymous research or coded research....(3) The notice must contain a place where the individual may mark the individual’s request that the specimen or information not be disclosed or retained for anonymous research or coded research before returning the notice to the health care provider. | 333-025-0140 Informed Consent Procedures (1) Unless exempted by ORS 192.535(1)(a)-(f), all persons collecting genetic information must conform to standards of informed consent… | 333-025-0155 Retention for the Purpose of Newborn Screening Procedures Oregon Health Authority may retain the blood samples of newborns collected for the control of metabolic diseases, as provided in ORS 433.285, for up to one year. |
333-090 Purpose of ORS 433.090 to 433.102; waivers of consent to release certain medical information.

The purpose of ORS 433.090 to 433.102 is to waive the requirement of consent for release of information from, or providing information to, the immunization record of a client of any immunization registry and to waive issues of confidentiality in regard to this information.

333-049-0120 Deletion of Information in the Registry and Tracking and Recall System. A client who is 18 years of age or older may request to have their record sealed or removed from the registry. The election of whether to seal the record or remove the record is at the sole discretion of the client.

(1) Process. A client requesting sealing or removal of their registry record must submit a form approved by the Manager for that purpose. The client may elect to have their record sealed or removed from the registry. If the client does not elect either option then their record will be removed from the registry.

(2) The request for sealing or removal of a client’s record must also include a legible photocopy of one piece of photo identification. Acceptable identification includes any of the following: a valid state-issued driver’s license or identification card; a passport; or a U.S. military identification card.

(3) If a client elects to have their registry record sealed, the information will remain in the registry but will not be released to authorized users. In the case of a declared public health emergency, the Manager may release the information to public health officials for the sole purpose of responding to the declared emergency. A client may request that their record be unsealed by submitting the form approved by the Manager along with a photocopy of an approved document that verifies the client’s identity. A record that is removed from the registry cannot be recovered.

(4) When an immunization record is removed from the registry, certain pieces of demographic information, including a client’s name and date of birth, must be kept on file in order to keep the immunization record from being repopulated. [emphasis added]

433.100 Parental consent not required for enrollment in registry; rules; fees. (1) The Oregon Health Authority shall adopt rules pertaining to the development and implementation of the immunization registries and their associated tracking and recall systems. The rules shall include a process that allows a client who is 18 years of age or older, a custodial parent or guardian to control the transfer of information from the immunization record or the immunization tracking and recall record when such control is necessary to protect the health or safety of the family or the client.

(2) Nothing in this section requires the consent of a parent or guardian prior to enrolling the child in the registry or restricts the registry from providing tracking and recall information to a custodial parent or guardian.

433.098 Non-liability for disclosing or using information; confidentiality of information; removal of information. (1) An authorized user and the employees or agents of an authorized user are not liable for sharing information from the immunization record or using information from the immunization tracking and recall record for purposes of tracking immunizations of clients and for outreach to clients who have missed immunizations.

Vaccination Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Exemption</th>
<th>Data Sharing</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>OR</td>
<td>STATUTE: ORS, Title 36, Chapter 433</td>
<td>433.094 Development of immunization registry and tracking and recall system; standards.</td>
<td>433.092 Purpose of ORS 433.090 to 433.102; waivers of consent to release certain medical information. The purpose of ORS 433.090 to 433.102 is to waive the requirement of consent for release of information from, or providing information to, the immunization record of a client of any immunization registry and to waive issues of confidentiality in regard to this information.</td>
<td>433.100 Parental consent not required for enrollment in registry; rules; fees. (1) The Oregon Health Authority shall adopt rules pertaining to the development and implementation of the immunization registries and their associated tracking and recall systems. The rules shall include a process that allows a client who is 18 years of age or older, a custodial parent or guardian to control the transfer of information from the immunization record or the immunization tracking and recall record when such control is necessary to protect the health or safety of the family or the client.</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>