Oregon Revised Statues – Oregon State Cancer Registry Confidentiality Provisions

432.530 Confidentiality of information. (1) All identifying information regarding individual patients, health care facilities and practitioners reported pursuant to ORS 432.520 shall be confidential and privileged. 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 registry system for cancer and benign tumors of the brain and central nervous system.

(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 Department of Human Services 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). [1995 c.585 §5; 2003 c.269 §4]

Note: See note under 432.500.

432.540 Use of confidential data; rules. (1) The Department of Human Services shall adopt rules under which confidential data may be used by third parties to conduct research and studies for the public good. Research and studies conducted using confidential data from the statewide registry must be reviewed and approved by the Committee for the Protection of Human Research Subjects established in accordance with 45 C.F.R. 46.

(2) The department 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 department shall ensure that the recipient registry has comparable confidentiality protections. [1995 c.585 §6; 2003 c.269 §6]

Note: See note under 432.500.

Oregon Administrative Rules - Oregon State Cancer Registry Confidentiality Provisions

333-010-0050
Confidentiality and Access to Data

(1) All identifying information regarding individual patients, cancer reporting facilities, clinical laboratories, and health care providers reported pursuant to ORS 432.510 and 432.520, OAR 333-010-0020, 333-010-0030 and 333-010-0032 shall be confidential and privileged. 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.

(2) The information collected and maintained by OSCaR must be stored in secure locations, must be used solely for the purposes stated in ORS 432.510 and 432.520 and must not be further disclosed unless required by law, with the following exceptions:
(a) When OSCaR has entered into reciprocal cooperative agreements with other states to exchange information on resident cases, as provided for in ORS 432.540. Such agreements must provide for obtaining data on Oregon resident cases diagnosed or treated out of state, and for reciprocal rights of other states to receive information on residents of those states diagnosed or treated in Oregon. Before entering into an agreement with any other state, OSCaR must determine that the other state has comparable confidentiality protections;
(b) When disclosure to officers or employees of federal, state, or local government public health agencies is necessary to investigate or avoid a clear and immediate danger to other individuals or to the public generally;
(c) When the Authority elects to contract with another agency for performance of a registry function the Authority will require the contractor to agree to use the information only for the purposes of the central cancer registry, to maintain the information securely, and to protect the information from unauthorized disclosure as referred to in OAR 333-010-0050(1). Before entering into any contract with another agency the Authority must determine the agency has comparable confidentiality protections; and
(d) When the Authority deems that the information is necessary for others to conduct research in conformance with the purposes for which the data are collected.

(3) Cancer reporting facilities shall have access to confidential and privileged data on any case submitted by that facility. When a patient has been seen for care of a case of cancer by multiple cancer reporting facilities, OSCaR may share information on treatment and follow-up among the facilities, provided that all participating facilities have signed agreements with OSCaR to do so.

(4) Health care providers shall have access to confidential and privileged data on any case submitted by that health care provider. When a patient has been seen for care of a case of cancer by multiple health care providers, OSCaR may share information on treatment and follow-up among the health care providers, provided that all participating health care providers have signed agreements with OSCaR to do so.

Stat. Auth.: ORS 432.510, 432.520
Stats. Implemented: ORS 432.530, 432.540

333-010-0055
Research Studies
(1) Requirements for Research Studies. Before any confidential data may be disclosed to a researcher, OSCaR must:
(a) Approve a submitted protocol for the proposed research, which describes how the research will be used to determine the sources of cancer among the residents of Oregon or to reduce the burden of cancer in Oregon, in accordance with ORS 432.510 and OAR 333-010-0010;
(b) Agree that the data requested are necessary for the effective and efficient conduct of the study;
(c) Approve the researcher's submitted protocol and procedures for:
(A) Identifying patients to be contacted;
(B) Protecting against inadvertent disclosure of confidential and privileged data;
(C) Providing secure conditions to use and store the data;
(D) Assuring that the data will only be used for the purposes of the study; and
(E) Assuring that confidential and privileged data will be destroyed upon conclusion of the research;
(d) Determine that the researcher has access to sufficient resources to carry out the proposed research before releasing any confidential data;
(e) Facilitate appropriate review of the research, including peer review for scientific merit, and review by the body used by the Authority as the Committee for the Protection of Human Research Subjects and established in accordance with 45 C.F.R. 46; and
(f) Determine the need for and require the researcher to implement other safeguards which, in the judgment of OSCaR, may be necessary for protecting confidential and privileged data from inadvertent disclosure due to unique or special characteristics of the proposed research.
(2) Contacting Patients for Research. As outlined in OAR 333-010-0035(2)(e) & (f), participation in research is voluntary and patients may choose whether or not they want to participate in research studies.
(a) Before disclosing confidential patient information to a researcher, OSCaR must determine whether any of the patients meeting the criteria for the research study have previously informed OSCaR that they do not wish to participate in research. Such patients will be excluded from the list of patients provided to the researcher or contacted by OSCaR regarding research.
(b) Unless OSCaR determines it to be impracticable, OSCaR and/or the researcher must contact the patient's current treating physician to inform them of the study prior to any contact with a patient. In situations where the treating physician of record is no longer the patient's physician, OSCaR and/or the researcher must make a good faith effort to find the patient's current physician.
(c) When contacted, the patient’s physician must be informed of the study and the identity of the eligible patient. Within three weeks the physician must:
(A) Agree that direct contact by the researcher would be appropriate; or
(B) Indicate the presence of a medical, psychological or social situation in the patient's life that would make contact inappropriate at that time. The physician is under no obligation to disclose the specifics of the medical, psychological or social situation.
(d) If a researcher does not receive a response from the physician within one month, the researcher may contact the patient directly.
(e) Researchers are strictly prohibited from redisclosing patient names or other confidential information to other researchers, individuals, or institutions not specifically identified in the approved study protocol as outlined above.
Stat. Auth.: ORS 432.510, 432.530, 432.540
Stats. Implemented: ORS 432.510, 432.530, 432.540