

VIII. DATA USES

Providing data for cancer prevention and control is a fundamental purpose of the Oregon State Cancer Registry. Early Registry efforts were focused on planning and implementation. The initial objective was to establish a system through which the Registry could collect complete and accurate data on all reportable cancers diagnosed or treated in Oregon. The Registry is now in a position to support use of the cancer data for cancer prevention and control. The Registry produces annual reports containing general, descriptive epidemiologic data on cancer in Oregon and facilitates research efforts to better understand the natural history

of specific cancers and to improve cancer-related care. Cancer control programs within the Department of Human Services, Oregon Public Health Division, and independent researchers have used OSCaR's database.

In addition to funded research, OSCaR fulfills data requests on a regular basis from the media, legislators, and policy makers, individual physicians, collaborative partners (such as the American Cancer Society and Northwest Portland Area Indian Health Board), and concerned citizens. OSCaR responds to over 200 such public access data requests annually.

RESEARCH PROTOCOL

Research Protocol – The Registry has provided data to outside researchers on a variety of approved cancer projects. Before the release of any confidential data, the following criteria must be reviewed for compliance:

1. The proposed research will be used to determine the sources of cancer among the residents of Oregon or to reduce the burden of cancer in Oregon;
2. the data requested are necessary for the efficient conduct of the study;
3. adequate protections are in place to provide secure conditions to use and store the data;
4. assurances are given that the data will only be used for purposes of the study, and that confidential data will be destroyed at the conclusion of the study (*See Researcher Assurances Form in Appendix D.*);
5. the researcher has adequate resources to carry out the proposed research;
6. the proposal has been reviewed and approved by the Committee for the Protection of Human Subjects or is exempt from such review;
7. any additional safeguards needed to protect the data from inadvertent disclosure due to unique or special characteristics of the proposed research have been required of the researcher;
8. the research methodology has been reviewed for scientific excellence by a nationally recognized peer group, or if such a review has not taken place, that an ad hoc peer review subcommittee of the OSCaR Advisory Committee containing appropriately qualified scientists has performed a peer review of the research.

PATIENT NOTIFICATION

Patient Notification – OSCaR has a unique system of patient notification to inform patients that their information has been reported to OSCaR and to identify patients who are willing to participate in case study research. At the time of notification, patients receive a patient notification letter. (*See Appendix E.*) Oregon is the only state to notify patients of their inclusion in the cancer registry and the only state to give patients the opportunity to inform the Registry of their preference regarding participation in research projects. A form accompanies the letter asking if they are willing to participate in research projects. Those who decide “yes” will be contacted if a research project for which they

are eligible becomes available. Those who decide “no” will never be contacted. If the form is not returned, researchers will consult with the patient’s physician before contacting the patient.

This “pre-consent” identifies potential study participants for researchers. Consent is still required as is stipulated by each project’s Institutional Review Board (IRB) approval, and the patient is not required to participate in a study even if they are eligible. However, patients do not have an option to opt out of the Registry database. The entire database is available for approved academic research that does not require patient contact.