
VIII. Data Uses

Using 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 as well as epidemiologic studies on specific areas of interest. Cancer control programs within the Department of Human Services, Oregon Health Services, and the state of Oregon have also used OSCaR data.

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.

A. Research Protocol

The Registry has provided data to outside researchers on a variety of approved cancer projects. Before the release of any data, all research proposals requesting the use of confidential cancer registry data, must be reviewed by Oregon Health Services for compliance with the following criteria, in addition to complying with researcher assurances. (See *Researcher Assurances Form, Appendix C.*):

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 the purposes of the study, and assurances that confidential data will be destroyed at the conclusion of the study (See *Researcher Assurances Form – Appendix C.*);
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.

B. 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, each patient receives a form 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. The form is accompanied by a patient notification letter. (*See Appendix D.*) Oregon is one of a few states 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.

C. Current Research Projects

An investigation of the burden of cancer in a sample of factory workers exposed to TCE-contaminated drinking water

Michael Heumann, PhD, Oregon Environmental and Occupational Epidemiology Program;
Donald Austin, MD, MPH, Oregon Health & Science University; and Jan Semenza, PhD, Portland State University School of Community Health

Beginning in the mid-1960’s, trichloroethylene (TCE) was used to degrease metal parts in the assembly of the Stereo View-Master viewers and projectors at a toy factory in Beaverton, Oregon. The TCE was discarded onto the ground outside the plant where it seeped into the well that pumped drinking and cooking water for the employees. By 1970, approximately 200 gallons of TCE per month were being used and discarded. In March 1998, high levels of the solvent were identified in the well of the Beaverton factory. The well supplied drinking water to the facility from 1951-1998 and an estimated 13,500 employees drank water contaminated with TCE as high as over 1,500 micrograms per liter ($\mu\text{g/L}$) (300 times EPA maximum allowable contaminant level).

This study will reconstruct the cohort of 20,000+ former factory workers and determine the health effects of TCE consumption among the former workers. This study provides a unique opportunity to investigate cancers that are associated with exceptionally high and long-term oral exposure to TCE alone, thus, can clarify several questions concerning the carcinogenicity of TCE.

Breast cancer survivor fracture risk study

Kerri Winters, PhD, Oregon Health & Science University

It is important to evaluate long-term adverse effects of cancer treatment, so that the quality of life of cancer survivors can be optimized. A common outcome of adjuvant chemotherapy in breast cancer survivors is ovarian failure among premenopausal women. Hormone replacement therapy is contraindicated due to risk of relapse or development of secondary breast cancer. Studies have demonstrated that estrogen depletion during natural menopause leads to reduced skeletal, cardiovascular, and brain function and contributes to osteoporosis. Recent data show that vertebral and perhaps hip fracture rates are elevated among women treated for breast cancer. This study determines the fracture risk profile in a population-based cohort of recently treated young breast cancer survivors.

Pilot study for evaluating a clinical breast exam training program

Donald Austin, MD, MPH, Oregon Health & Science University

This project is a pilot for a larger study that will determine whether physicians trained by the Clinical Breast Exam Training Program (CBETP) at Oregon Health and Science University are better able to detect breast cancers at an early stage through clinical breast exams (CBE). The program retrains practicing providers around Oregon to perform improved CBE. This pilot study will compare and evaluate several methods of collecting cancer data for the purpose of determining how effectively breast cancers are detected by CBETP and non-CBETP graduates.

National Program of Cancer Registries Indian Health Services record linkage

Coordinated by Centers for Disease Control and Prevention, Division of Cancer Prevention and Control, and the Indian Health Service National Epidemiology Program

Misclassification of American Indians has been found to be as high as 40% in some cancer surveillance systems. Local linkages between Oregon tribal registries and OSCaR have identified a 27% misclassification. This racial misclassification could lead to faulty program planning for cancer prevention activities in Indian populations since they would be based on inaccurate estimates of cancer risk. Therefore, cancer registries supported by the National Program of Cancer Registries will be linked with national patient registration records from the Indian Health Services to identify extent of misclassification, correct such errors in participating registries, evaluate usefulness of the linkage, and calculate adjusted cancer rates for American Indians and Alaskan Natives.

Similar activities are undertaken annually with the local Northwest Tribal Registry.