

# **Oregon State Cancer Registry (OSCaR)**

## **Confidentiality Talking Points**

### **What is the purpose of the Oregon State Cancer Registry?**

- The Oregon State Cancer Registry (OSCaR) was established by the 1995 Oregon Legislature under Oregon public health laws (ORS 432.510), which made cancer a mandatory reportable disease for purposes of conducting statewide cancer surveillance.
- Under ORS 432.520, all cancer providers, hospitals, cancer treatment facilities and pathology labs are required to submit reports of cancer diagnosis and treatment to OSCaR.
- OSCaR's mission is to provide accurate data on cancer in Oregon for cancer control activities, public health policy-making and epidemiological research.
- Having a central registry is one of the best ways to learn more about cancer and its progression, to be able to determine possible environmental or occupational causes of cancer, and to evaluate cancer clusters.
- OSCaR data also shows the effectiveness of screening tests that can identify cancers early, when there is the best chance for a cure. For example, the numbers show that screenings for colorectal and breast cancers are working, and that lung cancer rates are dropping due to smoking cessation efforts.
- There are central registries in every state, but Oregon is the only state that notifies patients about the state registry.

### **Why do you need patient names and personal identifiers?**

- If we did not have patient names and other personal identifiers, Oregon would appear to have a 30% higher incidence rate. Approximately a third of all cases of cancer are diagnosed and treated in two or more hospitals. Since cancer cases are reported by all of the facilities at which a patient is seen, without patient names and personal identifiers, one cancer case would be counted as many times as it was reported by different facilities. In order to have accurate and complete data, we need to be able to identify duplicate reports and combine those reports into a single case.

### **How confidential are the data?**

- Paper documents are kept in a restricted area in locked files and are shredded as soon as they are processed.
- All stored electronic data are password protected and can be accessed only by OSCaR staff.
- OSCaR uses a highly secure CDC-developed internet-based application (Web Plus) for the transmission of electronic cancer data from hospitals and providers to the registry.
- Under Oregon Statutes and Administrative Rules, OSCaR is required to maintain the confidentiality of all identifying information reported to OSCaR pursuant to ORS 432.520. (See attached: ORS 432.530 and OAR 333-010-0050; statutory and regulatory provisions addressing confidentiality of OSCaR data, including provisions for limited release of confidential data in connection with research studies having administrative authorization following appropriate scientific review).

### **Can OSCaR release patient information to insurance companies?**

- OSCaR does not release identifiable cancer data to insurance companies. In fact, except where Oregon law requires the release of the data in the case of a public health emergency, the cancer data reported to OSCaR is not obtainable by outside parties, even with a subpoena from a court of law.
- OSCaR does not publish identifiable cancer data online or in any report. The only cancer data published by OSCaR is aggregate statistical data that is carefully prepared so no individual can be identified through any cancer report published by OSCaR.