

**PRELIMINARY STAFF MEASURE SUMMARY****CARRIER:**

Senate Committee on Senate Health Care

**REVENUE: No revenue impact****FISCAL: May have fiscal impact, statement not yet issued****Action:****Vote:****Yeas:****Nays:****Exc.:****Prepared By:** Zena Rockowitz, Administrator**Meeting Dates:** 3/2

**WHAT THE MEASURE DOES:** Requires that personally identifiable information in the statewide cancer and benign tumor registry may not be reported to the Oregon Health Authority no later than January 1, 2016. Requires Oregon Health Authority to adopt rules and remove personally identifiable information no later than January 1, 2016. Declares emergency, effective on passage.

**ISSUES DISCUSSED:****EFFECT OF COMMITTEE AMENDMENT:**

**BACKGROUND:** The Oregon Health Authority manages a uniform, statewide, population-based registry system to determine the incidence of cancer and benign tumors of the brain and central nervous system. This is known as the Oregon State Cancer Registry (OSCAR). OSCAR was established in 1999 and made cancer a mandatory reportable disease. The purpose is to evaluate the causes and reduce the burden of cancer and tumors. Data is used to target populations in need of cancer screening, support the operation of hospital registries in monitoring and upgrading the care and results of treatment, investigate suspected cluster or excess of cancer and tumors in occupational settings and the environment, conduct studies to identify cancer hazards, and project costs and benefits of policies regarding prevention and treatment .

All identifying information regarding individual patients, health care facilities, and practitioners is confidential and privileged (ORS 432.520). The Oregon Health Authority adopts rules (ORS 432.540) to determine circumstances in which confidential data may be used by third parties to conduct research and requires that studies are reviewed and approved by the Committee for the Protection of Human Research Subjects. If a study is being conducted, the physician of the patient must be notified. The Oregon Health Authority may also enter into agreements to exchange OSCAR information with other registries that have comparable confidentiality protections in order to obtain 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.

Oregon Administrative Rules specifies criteria for confidential and privileged data in OSCAR. Cancer reporting facilities have access to cases submitted by that facility. When a patient has been seen for care by multiple cancer reporting facilities, OSCAR may share information on treatment and follow-up, providing facilities have signed agreements with OSCAR. Health care providers also have access to data on cases submitted by that provider. When a patient has been to multiple providers, the data on treatment and follow-up may be shared with other participating providers who have signed agreements with OSCAR.