



March 2, 2015

The Senate Committee on Health Care
c/o The Honorable Senator Monnes Anderson, Chair
Oregon State Legislature
Salem, Oregon 97301

RE: Oppose SB 564 relating to the registry system for the collection of information related to cancer

Dear Chair Monnes Anderson and Members of the Committee:

Thank you for hearing SB 564 and inviting testimony from the American Cancer Society Cancer Action Network (ACS CAN).

The American Cancer Society Cancer Action Network (ACS CAN) is the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society. We support evidence based policy and legislative solutions designed to eliminate cancer as a major health problem and to identify health care processes to improve cancer patients and their caregivers' experience.

SB 564 will have detrimental consequences to the credibility and future use of the registry if passed with the prohibition on personally identifiable information. Proposed legislation such as SB 564 is not needed when the Health Insurance Portability Accountability Act (HIPAA) and Oregon Revised Statutes (ORS) are properly enforced and followed.

The registry's mission is to provide accurate data on cancer in Oregon for cancer control activities, public health policy-making, and epidemiological research.

Patient names and other personal identifiers ensure accurate and complete data for the registry. Approximately a third of all cases of cancer are diagnosed and treated in two or more hospitals. Therefore, 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.

Any identifiable data reported to the registry is maintained under strict confidentiality standards and procedures, and is only released in compliance with the **Health Insurance Portability Accountability Act (HIPAA)** and other laws and regulations established to protect the confidentiality of this 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 Oregon State Cancer Registry (OSCaR) staff. The registry uses a highly secure Center for Disease Control (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**.

The registry 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.

The registry does not publish identifiable cancer data online or in any report. The only cancer data published by the registry is aggregate statistical data that is carefully prepared so no individual can be identified through any cancer report published by the cancer registry.

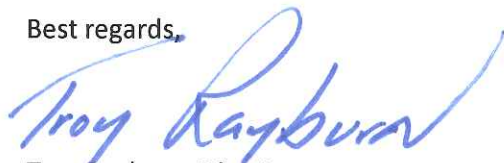
Having a statewide registry is the best way to learn more about cancer and its progression, to be able to determine possible environmental or occupational causes of cancer, and to evaluate cancer clusters within a state, community or population.

Data from the registry also confirm the effectiveness of screening tests used to identify cancers early and whether prevention efforts are working. For example, data show that high screening rates for breast cancers is finding 4 of 5 cancers at early stages, late stage colorectal cancers are dropping as screening rates increase, and that lung cancer rates are dropping due to smoking cessation efforts.

The Oregon cancer registry is funded by CDC's National Program of Cancer Registries. A failure to comply with national standards would likely result in a loss of funding from the CDC, which is the only funding source for the Oregon cancer registry.

Again, thank you for the opportunity to voice our objection to SB 564 and the associated reasons for concern.

Best regards,



Troy Rayburn, Director
Oregon Government Relations
American Cancer Society Cancer Action Network