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PROVIDENCE
Health & Services

March 3, 2015

The Honorable Monnes Anderson
Chair, Senate Committee on Health Care
State Capitol
Salem, Oregon 97301

RE: Senate Bill 564, Cancer registry data collection

Dear Senator Monnes Anderson and members of the committee:

Providence Health & Services takes our commitment to patient privacy very seriously. We believe that current cancer registry reporting mechanisms maintain a patient's right to privacy while ensuring that dependable data informs the world-class cancer research happening here in Oregon, and across the nation. Senate Bill 564 will reduce the efficacy of cancer registries and we urge you to oppose.

Currently Providence provides information to cancer registries as required by state law and national accreditation requirements. All reporting is in accordance with federal laws governing the privacy and security of protected health information. Oregon law requires reporting of cancer diagnoses to the Oregon State Cancer Registry by hospitals, labs and independent practitioners. Providence complies with the statute by uploading files to the state server per the specifications provided to us; generally this occurs at least twice a month.

In addition to state reporting, we also provide data to the National Cancer Database. NCDB reporting is required of any facility accredited by the Commission on Cancer, a program of the American College of Surgeons which recognizes cancer care centers for their commitment to providing comprehensive, high-quality and multidisciplinary patient-centered care. As required by HIPAA, Providence has a fully executed Business Associates Agreement with the Commission on Cancer.

Participation in both the state and national registries require that, in addition to reporting information about new cancer cases, we follow-up on existing cases on an annual basis to determine whether a patient is alive, and if so, has evidence of their cancer. In order to reduce the burden on patients, Providence attempts to acquire this information directly from the patient's physicians or through access to medical records. If information is not available from any other source, it is possible that patients will receive a letter from the hospital of record asking about their current cancer status.

Of approximately 5,000 new cases we enter each year and the 50,000 patients we are currently following in the registries – Providence receives one to two inquiries a year about reporting. We take these questions seriously and respond in a timely manner with the information we've outline above. In our experience, the vast majority of patients are happy knowing their experience has provided information that informs cancer research and will ultimately lead to a cure.

Thank you for the opportunity to share more about our reporting processes and our concerns with SB 564.

Sincerely,

Laurie Skokan

Laurie Skokan, PhD, CIP
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