

ACT 117

S.B. NO. 2040

A Bill for an Act Relating to Cancer Surveillance.

Be It Enacted by the Legislature of the State of Hawaii:

SECTION 1. The legislature finds that surveillance of cancer incidence and survival to assist individuals to make informed decisions is but one of eight goals of the Hawaii comprehensive cancer control coalition to advance cancer control in Hawaii. The other seven goals revolve around the following issues:

- (1) Prevention, primarily through education and behavioral change;
- (2) Early detection and assurance of coordination with cancer management services;
- (3) Treatment with the most current and effective treatments available;
- (4) Quality-of-life enhancement for all cancer survivors;
- (5) Research to advance the capabilities in Hawaii for prevention, early detection, treatment, and quality of life;
- (6) Uniform access to cancer services; and
- (7) Adequate insurance.

However, several obstacles impede the fulfillment of the goal of cancer incidence and survival surveillance. First, the Hawaii Tumor Registry is currently unable to contact cancer survivors in Hawaii directly to educate them on the work of the Hawaii Tumor Registry for cancer research. Second, it is unclear under existing law that the collection of data on pre-cancerous conditions is permissible. Third, the collection of biological specimens that may assist in cancer prognosis and outcome is also uncertain under existing law.

The purpose of this Act is to remove the obstacles impeding the fulfillment of the goals of cancer incidence and survival surveillance by:

- (1) Allowing a cancer patient to be contacted directly, without initial physician contact, to inform the patient that the patient is registered in the state cancer surveillance and registration program;
- (2) Adding “pre-cancerous” to the conditions about which data collection is authorized to monitor cancer screening activities and the efficacy of cancer vaccines; and
- (3) Adding “biological specimens” to the materials that may be collected to assist in research efforts to reduce, mitigate, and ameliorate the morbidity and mortality of cancer in Hawaii.

SECTION 2. Section 321-43, Hawaii Revised Statutes, is amended to read as follows:

“§321-43 Statistical activities. The department of health shall engage in the collection and analysis of statistical information on the morbidity and mortality of cancer in the [State.] state. The morbidity data may be collected in cooperation with the [~~Hawaii state medical association~~] University of Hawaii, Hawaii Medical Association, and the Hawaii cancer society. All data collected by a cooperating agency may be shared with the department of health in the form specified by the department of health. The mortality data as collected from death certificates shall be analyzed by the staff of the department in order to determine the significance of cancer in the [State] state by race, sex, age, occupation, site in the body, and in any other way found desirable for the purpose of determining the areas where greatest emphasis should be laid in the statewide cancer control program. The morbidity data shall be used [in]:

- (1) In determining the prognosis and chance of cure, as well as the number of persons cured of cancer in the [~~State; for~~] state;
- (2) For assisting in the direction of tumor research; [~~for~~]
- (3) For determining, if possible, the tendencies of benign tumors to become malignant; [~~and for~~]
- (4) For assisting in the follow-up of diagnosed or treated tumor cases as requested by attending physicians[-]; and
- (5) For improving the reporting of the cause of death on death certificates.

All statistical material collected under this section shall be considered confidential as to the names of persons or physicians concerned, except that researchers may use the names of [~~such~~] those persons when requesting additional information for research studies when [~~such~~] the studies have been approved by the cancer commission of the [~~Hawaii medical association.~~] Hawaii Medical Association and the appropriate federally authorized human subjects protection board.”

SECTION 3. Section 324-21, Hawaii Revised Statutes, is amended by amending subsection (a) to read as follows:

“(a) Any person, public or private medical facility, or social or educational agency, may provide information, interviews, reports, statements, memoranda, biological specimens, or other data or relevant material relating to individuals with

cancer or pre-cancerous conditions to the Hawaii Tumor Registry. This information may be used in the course of any cancer research study approved by the cancer commission of the Hawaii Medical Association[-] and the appropriate federally authorized human subjects protection board.”

SECTION 4. Section 324-22, Hawaii Revised Statutes, is amended by amending subsections (b) and (c) to read as follows:

“(b) The identity[;] or any group of facts [~~which~~] that tends to lead to the identity[;] of any person whose condition or treatment has been studied shall be confidential and shall not be revealed in any report or any other matter prepared, released, or published. Researchers [~~may~~], however, may use the names of persons when requesting additional information for research studies after being approved by the cancer commission[; ~~provided that when a request for additional information is to be made directly from a patient, the researcher shall first obtain approval for such request from the patient’s attending physician.~~] of the Hawaii Medical Association and the appropriate federally authorized human subjects protection board.

(c) The use of [~~such~~] additional information obtained by researchers shall also be governed by subsection (a) and, in addition, where the patient is still living and the information is to be obtained directly from the patient, the researcher shall first obtain the approval of the patient[;] or the patient’s immediate family, including a reciprocal beneficiary [~~or attending physician~~], in that order of priority.”

SECTION 5. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored.

SECTION 6. This Act shall take effect upon its approval.

(Approved May 27, 2008.)