
A BILL FOR AN ACT

RELATING TO CANCER SURVEILLANCE.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

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

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



1 However, several obstacles impede the fulfillment of the
2 goal of cancer incidence and survival surveillance. First, the
3 Hawaii Tumor Registry is currently unable to directly contact
4 cancer survivors in Hawaii to educate them on the work of the
5 Hawaii Tumor Registry for cancer research, including clinical
6 trials they may be eligible to participate in, to assist in the
7 fight against cancer. Second, it is unclear under existing law
8 that collection of data on pre-cancerous conditions is
9 permissible. Third, the collection of biological specimens that
10 may assist in cancer prognosis and outcome is also uncertain
11 under existing law.

12 The purpose of this Act is to remove the obstacles impeding
13 the fulfillment of the goal of cancer incidence and survival
14 surveillance by:

- 15 (1) Allowing a cancer patient to be contacted directly,
16 without initial physician contact, to inform the
17 patient that the patient is registered in the state
18 cancer surveillance and registration program;
- 19 (2) Adding "pre-cancer" to the diseases about which data
20 are authorized for collection in order to monitor
21 cancer screening activities and the efficacy of cancer
22 vaccines; and



1 (3) Adding "biological specimens" to the materials that
2 may be collected to assist in research efforts to
3 reduce, mitigate, and ameliorate the morbidity and
4 mortality of cancer in Hawaii.

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

7 **"§321-43 Statistical activities.** The department of health
8 shall engage in the collection and analysis of statistical
9 information on the morbidity and mortality of cancer in the
10 State. The morbidity data may be collected in cooperation with
11 the University of Hawaii, the Hawaii state medical association,
12 and the Hawaii cancer society. The mortality data as collected
13 from death certificates shall be analyzed by the staff of the
14 department in order to determine the significance of cancer in
15 the State by race, sex, age, occupation, site in the body, and
16 in any other way found desirable for the purpose of determining
17 the areas where greatest emphasis should be laid in the
18 statewide cancer control program. The morbidity data shall be
19 used [~~in~~]:

20 (1) In determining the prognosis and chance of cure, as
21 well as the number of persons cured of cancer in the
22 State; [~~for~~]



1 (2) For assisting in the direction of tumor research;
2 [~~for~~]

3 (3) For determining, if possible, the tendencies of benign
4 tumors to become malignant; and [~~for~~]

5 (4) For assisting in the follow-up of diagnosed or treated
6 tumor cases as requested by attending physicians.

7 All statistical material collected under this section shall be
8 considered confidential as to the names of persons or physicians
9 concerned, except that researchers may use the names of [~~such~~]
10 those persons when requesting additional information for
11 research studies when [~~such~~] the studies have been approved by
12 the cancer commission of the Hawaii medical association."

13 SECTION 3. Section 324-21, Hawaii Revised Statutes, is
14 amended by amending subsections (a) and (b) to read as follows:

15 "(a) Any person, public or private medical facility, or
16 social or educational agency, may provide information,
17 interviews, reports, statements, memoranda, biological
18 specimens, or other data or relevant material relating to
19 individuals with cancer to the Hawaii Tumor Registry. This
20 information may be used in the course of any cancer research
21 study approved by the cancer commission of the Hawaii Medical
22 Association.



1 (b) Hospitals, skilled nursing homes, intermediate care
2 homes, free-standing radiation oncology facilities, and other
3 treatment or pathology facilities shall submit a report of any
4 person admitted with or diagnosed as having cancer or pre-cancer
5 to the Hawaii Tumor Registry or participating hospital registry
6 according to a format approved by the cancer commission of the
7 Hawaii Medical Association. Physicians who diagnose or treat a
8 patient for cancer shall also submit a report to the Hawaii
9 Tumor Registry or participating hospital registry unless the
10 patient has previously been admitted or treated at a hospital,
11 skilled nursing home, intermediate care home, or free-standing
12 radiation oncology facility for that particular cancer[+] or
13 pre-cancer. The Hawaii Tumor Registry staff or their
14 representative or hospital-based registry staff may assist the
15 hospitals, institutions, treatment or pathology facilities, and
16 physician offices in the preparation of the reports."

17 SECTION 4. Section 324-22, Hawaii Revised Statutes, is
18 amended to read as follows:

19 **"§324-22 Identity of persons studied and material,**
20 **restrictions.** (a) The material collected under this part shall
21 be used or published only for the purpose of advancing medical
22 research, medical education, or education of the public in the



1 interest of reducing morbidity or mortality; provided that the
2 Hawaii Tumor Registry may reveal all relevant information to [a
3 ~~patient's attending physician.~~] appropriate human subject
4 protection boards.

5 (b) The identity[~~]~~ or any group of facts [~~which~~] that
6 tends to lead to the identity[~~]~~ of any person whose condition
7 or treatment has been studied shall be confidential and shall
8 not be revealed in any report or any other matter prepared,
9 released, or published. Researchers [~~may~~], however, may use the
10 names of persons when requesting additional information for
11 research studies approved by the cancer commission; provided
12 that when a request for additional information is to be made
13 directly from a patient, the researcher shall first obtain
14 approval for [~~such~~] the request from the [~~patient's attending~~
15 ~~physician.~~] patient.

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



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

3 SECTION 6. This Act shall take effect on January 1, 2050.



Report Title:

Cancer Surveillance and Research; Data Collection

Description:

Allows a cancer patient to be contacted directly without initial physician contact for purposes of cancer surveillance. Adds pre-cancer to diseases about which data are authorized for collection. Adds biological specimens to the materials that may be collected to assist cancer research. (SD1)

