A BILL FOR AN ACT

RELATING TO CANCER SURVEILLANCE.

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

1	SECT	ION 1. The legislature finds that surveillance of	
2	cancer in	cidence and survival to assist individuals to make	
3	informed	decisions is but one of eight goals of the Hawaii	
4	comprehensive cancer control coalition to advance cancer control		
5	in Hawaii	. The other seven goals revolve around the following	
6	issues:		
7	(1)	Prevention, primarily through education and behavioral	
8		change;	
9	(2)	Early detection and assurance of coordination with	
10		cancer management services;	
11	(3)	Treatment with the most current and effective	
12		treatments available;	
13	(4)	Quality-of-life enhancement for all cancer survivors;	
14	(5)	Research to advance the capabilities in Hawaii for	
15		prevention, early detection, treatment, and quality of	
16		life;	
17	(6)	Uniform access to cancer services; and	

S.B. NO. S.D. 1

1	(/)	Adequate insurance.	
2	However, several obstacles impede the fulfillment of the		
3	goal of c	ancer incidence and survival surveillance. First, the	
4	Hawaii Tumor Registry is currently unable to contact cancer		
5	survivors in Hawaii directly to educate them on the work of the		
6	Hawaii Tumor Registry for cancer research. Second, it is		
7	unclear under existing law that the collection of data on pre-		
8	cancerous conditions is permissible. Third, the collection of		
9	biological specimens that may assist in cancer prognosis and		
10	outcome is also uncertain under existing law.		
11	The purpose of this Act is to remove the obstacles impedin		
12	the fulfillment of the goal of cancer incidence and survival		
13	surveillance by:		
14	(1)	Allowing a cancer patient to be contacted directly,	
15		without initial physician contact, to inform the	
16		patient that the patient is registered in the state	
17		cancer surveillance and registration program;	
18	(2)	Adding "pre-cancer" to the diseases about which data	
19		are authorized for collection to monitor cancer	
20		screening activities and the efficacy of cancer	
21		vaccines; and	

S.B. NO. S.D. 1

. 1	(3) Adding "blological 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.] state. The morbidity data may be collected in
11	cooperation with the <u>University of Hawaii</u> , the Hawaii state
12	medical association, and the Hawaii cancer society. All data
13	collected by the cooperating agency may be shared with the
14	department of health in the form specified by the department of
15	<u>health</u> . The mortality data as collected from death certificates
16	shall be analyzed by the staff of the department in order to
17	determine the significance of cancer in the [State] state by
18	race, sex, age, occupation, site in the body, and in any other
19	way found desirable for the purpose of determining the areas
20	where greatest emphasis should be laid in the statewide cancer
21	control program. The morbidity data shall be used $[\frac{in}{2}]$:

1	(1)	<u>In</u> determining the prognosis and chance of cure, as	
2		well as the number of persons cured of cancer in the	
3		[State; for] state;	
4	(2)	For assisting in the direction of tumor research;	
5		[for]	
6	(3)	For determining, if possible, the tendencies of benign	
7		tumors to become malignant; [and for]	
8	(4)	For assisting in the follow-up of diagnosed or treated	
9		tumor cases as requested by attending physicians $[-]$;	
10		and	
11	(5)	For improving the reporting of the cause of death on	
12		death certificates.	
13	All stati	stical material collected under this section shall be	
14	considere	d confidential as to the names of persons or physicians	
15	concerned	, except that researchers may use the names of [such]	
16	those persons when requesting additional information for		
17	research studies when $[\frac{\text{such}}{\text{studies}}]$ the studies have been approved by		
18	the cance	r commission of the Hawaii [medical association.]	
19	Medical Association and the appropriate federally authorized		
20	human subjects protection board."		
21	SECTION 3. Section 324-21, Hawaii Revised Statutes, is		
22	amended by	y amending subsection (a) to read as follows:	

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         "(a) Any person, public or private medical facility, or
    social or educational agency, may provide information,
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    interviews, reports, statements, memoranda, biological
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    specimens, or other data or relevant material relating to
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    individuals with cancer or pre-cancerous conditions to the
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6
    Hawaii Tumor Registry. This information may be used in the
    course of any cancer research study approved by the cancer
7
    commission of the Hawaii Medical Association [-] and the
8
    appropriate federally authorized human subjects protection
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10
    board."
11
         SECTION 4. Section 324-22, Hawaii Revised Statutes, is
    amended by amending subsections (b) and (c) to read as follows:
12
         "(b) The identity [\tau] or any group of facts [\frac{\text{which}}{\text{that}}]
13
    tends to lead to the identity [\tau] of any person whose condition
14
15
    or treatment has been studied shall be confidential and shall
    not be revealed in any report or any other matter prepared,
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    released, or published. Researchers [may], however, may use the
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    names of persons when requesting additional information for
18
    research studies after being approved by the cancer commission [+
19
    provided that when a request for additional information is to be
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    made directly from a patient, the researcher shall first obtain
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22
    approval for such request from the patient's attending
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- 1 physician.] and the appropriate federally authorized human
- 2 subjects protection board.
- 3 (c) The use of [such] additional information obtained by
- 4 researchers shall also be governed by subsection (a) and, in
- 5 addition, where the patient is still living and the information
- 6 is to be obtained directly from the patient, the researcher
- 7 shall first obtain the approval of the patient $[\tau]$ or the
- 8 patient's immediate family, including a reciprocal beneficiary
- 9 [ror attending physician], in that order of priority."
- 10 SECTION 5. Statutory material to be repealed is bracketed
- 11 and stricken. New statutory material is underscored.
- 12 SECTION 6. This Act shall take effect upon its approval.

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. (SB2040 HD1)