

AMENDED IN ASSEMBLY AUGUST 25, 2000

AMENDED IN ASSEMBLY AUGUST 7, 2000

AMENDED IN ASSEMBLY JUNE 20, 2000

AMENDED IN SENATE MAY 3, 2000

AMENDED IN SENATE MARCH 23, 2000

SENATE BILL

No. 1596

**Introduced by Senator Ortiz
(Principal coauthor: Senator Alpert)**

February 18, 2000

An act to amend Sections 100330, 103850, and 103885 of the Health and Safety Code, relating to health.

LEGISLATIVE COUNSEL'S DIGEST

SB 1596, as amended, Ortiz. Health reporting: confidentiality of information.

Existing law provides for the confidentiality of certain records and other information procured by the State Department of Health Services in connection with morbidity and mortality studies, the Birth Defects Monitoring Program, and the statewide cancer reporting system. Existing law requires an authorized disclosure of this information to be made pursuant to an agreement that the information will be kept confidential.

This bill would revise and recast these provisions to expand the types of records to which these provisions apply to include medical and pathology records and records of health status,

and to require that this information be used solely for statistical, scientific, and medical research purposes relating to the cause of condition of health, except as specified, in accordance with prescribed procedures. The bill would require the confidentiality agreement to be in writing. It would also provide that any person who violates these provisions would be subject to civil and criminal penalties and other actions, and that further access to confidential information maintained by the department may be denied. By creating new crimes, this bill would impose a state-mandated local program.

This bill would incorporate additional changes in Section 103885 of the Health and Safety Code, proposed by AB 48, to be operative only if AB 48 and this bill are both chaptered and become effective January 1, 2001, and this bill is chaptered last.

The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act for a specified reason.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: yes.

The people of the State of California do enact as follows:

1 SECTION 1. (a) *The Legislature finds and declares*
 2 *that researchers continue to make critical advances in the*
 3 *detection and treatment of cancer and other diseases, and*
 4 *more is now known than ever before about risk factors*
 5 *and prevention. For example, since 1988, the overall*
 6 *cancer mortality rate in California has decreased 13*
 7 *percent, and tobacco-related cancers have decreased*
 8 *even more. In the early 1900's, few cancer patients had*
 9 *any hope of long-term survival, and as recently as the*
 10 *1960's only one of three cancer patients could expect to*
 11 *survive for five years. Today, through improved early*
 12 *detection and treatment, two out of three cancer patients*
 13 *are alive five years after diagnosis, illustrating the value*



1 *and rewards of research and public health intervention.*
2 *Emerging research tools offer great promise, but the*
3 *complex nature of disease in our diverse population*
4 *requires continued aggressive research efforts.*

5 *(b) With these challenges in mind, it is the intent of*
6 *the Legislature to ensure continued access to those*
7 *resources. Voluntary participation by human subjects is*
8 *absolutely necessary in research against cancer and many*
9 *other diseases and conditions. To ensure continued*
10 *participation by individuals, both victims of disease and*
11 *healthy individuals acting as control subjects, privacy of*
12 *personal information is imperative. Thus, it is the intent*
13 *of this act to expand legal protection against unwarranted*
14 *invasion into the privacy of people who have come*
15 *forward to willingly participate in efforts to prevent or*
16 *cure devastating diseases.*

17 *SEC. 1.5.* Section 100330 of the Health and Safety
18 Code is amended to read:

19 100330. (a) All data including, but not limited to,
20 medical and pathology records, records of health status,
21 records of interviews, questionnaires, written reports,
22 statements, notes, and memoranda procured by the
23 department or by any other person, agency, or
24 organization acting jointly with the department,
25 including public or private colleges and universities, in
26 connection with morbidity and mortality studies and
27 research investigations to determine any cause or
28 condition of health shall be confidential and shall be used
29 solely for statistical, scientific, and medical research
30 purposes relating to the cause or condition of health,
31 except as otherwise provided in this section.

32 (b) Before the department discloses confidential data
33 to any other person, agency, or organization acting jointly
34 with the department, the requesting entity shall
35 demonstrate to the department that the entity has
36 established procedures and the ability to maintain the
37 confidentiality of the information.

38 (c) All confidential data may be used by the
39 department when necessary for the purpose of
40 controlling nuisances dangerous to the public health



1 including, but not limited to, communicable, contagious,
2 and infectious diseases.

3 (d) Confidential data may be disclosed by the
4 department to other local, state, or federal public health
5 or environmental agencies, or to collaborating medical
6 researchers, when the confidential information is
7 necessary to carry out the duties of the agency or
8 researcher in the investigation, control, or surveillance of
9 disease, as determined by the department.

10 (e) Any disclosure authorized by this section shall
11 include only the information necessary for the stated
12 purpose of the requested disclosure, and shall be made
13 only upon written agreement that the information will be
14 kept confidential and will not be further disclosed
15 without written authorization of the department.

16 (f) The furnishing of confidential data to the
17 department or its authorized representative or to any
18 other cooperating individual, agency, or organization in
19 any study in accordance with this section shall not expose
20 any person, agency, or entity furnishing data to liability
21 and shall not be considered to be the violation of any
22 privileged or confidential relationship.

23 ~~(g) No part of the confidential data shall be available
24 for subpoena nor shall it be disclosed, discoverable, or
25 compelled to be produced in any civil, criminal,
26 administrative, or other proceeding, nor shall these data
27 be deemed admissible as evidence in any civil, criminal,
28 administrative, or other tribunal or court for any reason.~~

29 (g) (1) *There shall be a rebuttable presumption that
30 the necessity for preserving the confidentiality of the data
31 outweighs the necessity for disclosure. The confidential
32 data may only be subject to discovery or subpoena if the
33 party seeking the disclosure rebuts the presumption. This
34 presumption may only be overcome if the court finds that
35 the disclosure of the information will serve to protect
36 public health or safety.*

37 (2) *If the court finds that the presumption has been
38 rebutted and the confidential data is subject to discovery
39 or subpoena, certain confidential information shall be
40 redacted. This information includes personal names,*



1 *addresses, telephone numbers, social security numbers,*
2 *personal identification numbers, insurance policy*
3 *numbers, specific places of employment and education,*
4 *any other data that identifies or accesses the participant*
5 *or any friends, employers, or associates of the participant,*
6 *and any other data the court deems appropriate. The*
7 *party requesting the data shall be responsible for all costs*
8 *associated with the production of the data, including costs*
9 *attributable to any time required to redact the*
10 *confidential information. The party requesting the data*
11 *shall demonstrate the ability to ensure data security and*
12 *confidentiality.*

13 (h) (1) Notwithstanding any other provision of law,
14 any person who violates this section shall be subject to
15 civil and criminal penalties and other actions in
16 accordance with Section 56.36 of the Civil Code.

17 (2) Any person who intentionally discloses
18 confidential data to any third party, except as authorized
19 in this section, may be denied further access to
20 confidential data maintained by the department.

21 (i) Nothing in this section shall prohibit the
22 publication by the department of reports and statistical
23 compilations relating to morbidity and mortality studies
24 that do not identify individual cases and sources of
25 information or religious affiliations.

26 SEC. 2. Section 103850 of the Health and Safety Code
27 is amended to read:

28 103850. (a) All information collected pursuant to this
29 chapter shall be confidential and shall be used solely for
30 the purposes provided in this chapter. Access to the
31 information shall be limited to the department,
32 authorized program staff, and persons with a valid
33 scientific interest, who meet qualifications as determined
34 by the director, who are engaged in demographic,
35 epidemiological, or other similar studies related to health,
36 and who agree, in writing, to maintain confidentiality,
37 except as otherwise provided in this section.

38 (b) Confidential information may be disclosed to
39 other local, state, or federal public health or
40 environmental agencies, or to collaborating medical



1 researchers, when the confidential information is
2 necessary to carry out the purposes of this chapter.

3 (c) The department shall maintain an accurate record
4 of all persons who are given access to the information in
5 the system. The record shall include: the name of the
6 person authorizing access; name, title, and organizational
7 affiliation of persons given access; dates of access; and the
8 specific purpose for which information is to be used. The
9 record of access shall be open to public inspection during
10 normal operating hours of the state department.

11 (d) All research proposed to be conducted by persons,
12 agencies, or organizations other than the department and
13 program staff, using the information in the system, shall
14 first be reviewed and approved by the director and the
15 State Committee for the Protection of Human Subjects.
16 Satisfaction of the terms of the director's rules for data
17 access shall be deemed to establish a valid scientific
18 interest for purposes of subdivision (a), entitling the
19 researcher to review records collected pursuant to
20 Section 103830 and to contact case subjects and controls.
21 Before confidential information is disclosed to any other
22 person, agency, or organization, the requesting entity
23 shall demonstrate to the department that the entity has
24 established the procedures and ability to maintain the
25 confidentiality of the information.

26 (e) Any disclosure authorized by this section shall
27 include only the information necessary for the stated
28 purpose of the requested disclosure, and shall be made
29 only upon written agreement that the information will be
30 kept confidential and will not be further disclosed
31 without written authorization of the department.

32 (f) The furnishing of confidential information to the
33 department or its authorized representative or to any
34 other cooperating individual, agency, or organization in
35 any study in accordance with this section shall not expose
36 any person, agency, or entity furnishing information to
37 liability and shall not be considered to be the violation of
38 any privileged or confidential relationship.

39 (g) Whenever the department, pursuing program
40 objectives, deems it necessary to contact case subjects and



1 controls, the department shall submit a protocol
2 describing the research to the director and to the State
3 Committee for the Protection of Human Subjects. Once
4 a protocol is approved by that committee, the
5 department shall be deemed to have established a bona
6 fide research purpose, and shall be entitled to complete
7 the approved project and contact case subjects and
8 controls without securing any additional approvals or
9 waivers from any entity.

10 ~~(h) No part of the confidential information shall be~~
11 ~~available for subpoena nor shall it be disclosed,~~
12 ~~discoverable, or compelled to be produced in any civil,~~
13 ~~criminal, administrative, or other proceeding, nor shall~~
14 ~~this information be deemed admissible as evidence in any~~
15 ~~civil, criminal, administrative, or other tribunal or court~~
16 ~~for any reason.~~

17 *(h) (1) There shall be a rebuttable presumption that*
18 *the necessity for preserving the confidentiality of the data*
19 *outweighs the necessity for disclosure. The confidential*
20 *data may only be subject to discovery or subpoena if the*
21 *party seeking the disclosure rebuts the presumption. This*
22 *presumption may only be overcome if the court finds that*
23 *the disclosure of the information will serve to protect*
24 *public health or safety.*

25 *(2) If the court finds that the presumption has been*
26 *rebutted and the confidential data is subject to discovery*
27 *or subpoena, certain confidential information shall be*
28 *redacted. This information includes personal names,*
29 *addresses, telephone numbers, social security numbers,*
30 *personal identification numbers, insurance policy*
31 *numbers, specific places of employment and education,*
32 *any other data that identifies or accesses the participant*
33 *or any friends, employers, or associates of the participant,*
34 *and any other data the court deems appropriate. The*
35 *party requesting the data shall be responsible for all costs*
36 *associated with the production of the data, including costs*
37 *attributable to any time required to redact the*
38 *confidential information. The party requesting the data*
39 *shall demonstrate the ability to ensure data security and*
40 *confidentiality.*



1 (i) Nothing in this section shall prohibit the
2 publication by the department of reports and statistical
3 compilations relating to birth defects, stillbirth, or
4 miscarriage that do not in any way identify individual
5 cases or individual sources of information.

6 (j) (1) Notwithstanding any other provision of law,
7 any person who violates this section shall be subject to
8 civil and criminal penalties and other actions in
9 accordance with Section 56.36 of the Civil Code.

10 (2) Any person who discloses confidential data, in
11 violation of a written agreement to maintain
12 confidentiality, to any third party, except as authorized in
13 this section, may be denied further access to confidential
14 data maintained by the department.

15 SEC. 3. Section 103885 of the Health and Safety Code
16 is amended to read:

17 103885. (a) The director shall establish a statewide
18 system for the collection of information determining the
19 incidence of cancer, using population-based tumor
20 registries modeled after the Cancer Surveillance
21 Program of Orange County. As of the effective date of this
22 section, the director shall begin phasing in the statewide
23 cancer reporting system. By July 1, 1988, all county or
24 regional registries shall be implemented or initiated. By
25 July 1, 1990, the statewide cancer reporting system shall
26 be fully operational. Within 60 days of the effective date
27 of this section, the director shall submit an
28 implementation and funding schedule to the Legislature.

29 (b) The department may designate any demographic
30 parts of the state as regional cancer incidence reporting
31 areas and may establish regional cancer registries, with
32 the responsibility and authority to carry out the intent of
33 this section in designated areas. Designated regional
34 registries shall provide, on a timely basis, cancer
35 incidence data as designated by the state department to
36 the department. The department may contract with an
37 agency, including, but not limited to, a health systems
38 agency, single county health department, multicounty
39 health department grouping, or nonprofit professional
40 association, representing a designated cancer reporting



1 region for the purposes of collecting and collating cancer
2 incidence data.

3 (c) The director shall designate cancer as a disease
4 required to be reported in the state or any demographic
5 parts of the state in which cancer information is collected
6 under this section. All cancers diagnosed or treated in the
7 reporting area shall thereafter be reported to the
8 representative of the department authorized to compile
9 the cancer data, or any individual, agency, or
10 organization designated to cooperate with that
11 representative.

12 (d) (1) Any hospital or other facility providing
13 therapy to cancer patients within an area designated as
14 a cancer reporting area shall report each case of cancer
15 to the department or the authorized representative of the
16 department in a format prescribed by the department. If
17 the hospital or other facility fails to report in a format
18 prescribed by the department, the department's
19 authorized representative may access the information
20 from the hospital or the facility and report it in the
21 appropriate format. In these cases, the hospital or other
22 health facility shall reimburse the state department or the
23 authorized representative for its cost to access and report
24 the information.

25 (2) Any physician and surgeon, dentist, podiatrist, or
26 other health care practitioner diagnosing or providing
27 treatment for cancer patients shall report each cancer
28 case to the department or the authorized representative
29 of the department except for those cases directly referred
30 to a treatment facility or those previously admitted to a
31 treatment facility for diagnosis or treatment of that
32 instance of cancer.

33 (e) Any hospital or other facility that is required to
34 reimburse the department or its authorized
35 representative for the cost to access and report the
36 information pursuant to subdivision (d) shall provide
37 payment to the department or its authorized
38 representative within 60 days of the date this payment is
39 demanded. In the event any hospital or other facility fails
40 to make the payment to the department or its authorized



1 representative within 60 days of the date the payment is
2 demanded, the department or its authorized
3 representative may, at its discretion, assess a late fee not
4 to exceed 1¹/₂ percent per month of the outstanding
5 balance. Further, in the event that the department or its
6 authorized representative takes a legal action to recover
7 its costs and any associated fees, and the department or
8 its authorized representative receives a judgment in its
9 favor, the hospital or other facility shall also reimburse the
10 department or its authorized representative for any
11 additional costs it incurred to pursue the legal action.
12 Late fees and payments made to the department by
13 hospitals or other facilities pursuant to this subdivision
14 shall be considered as reimbursements of the additional
15 costs incurred by the department.

16 (f) All physicians and surgeons, hospitals, outpatient
17 clinics, nursing homes and all other facilities, individuals
18 or agencies providing diagnostic or treatment services to
19 patients with cancer shall grant to the department or the
20 authorized representative access to all records that would
21 identify cases of cancer or would establish characteristics
22 of the cancer, treatment of the cancer, or medical status
23 of any identified cancer patient. Willful failure to grant
24 access to those records shall be punishable by a fine of up
25 to five hundred dollars (\$500) each day access is refused.
26 Any fines collected pursuant to this subdivision shall be
27 deposited in the General Fund.

28 (g) (1) All data including, but not limited to, medical
29 and pathology records, records of health status,
30 interviews, questionnaires, reports, statements, notes,
31 and memoranda collected pursuant to this section shall be
32 confidential. Access shall be limited to the department
33 and any regional registry designated by the department
34 except as otherwise provided in this subdivision.

35 (2) The department and any regional cancer registry
36 designated by the department may enter into
37 agreements to furnish confidential data to other states'
38 cancer registries, federal cancer control agencies, local
39 health officers, or health researchers for the purposes of
40 determining the sources of malignant neoplasms and



1 evaluating measures designed to eliminate, alleviate, or
2 ameliorate their effect. Before confidential data are
3 disclosed to those out-of-state registries, agencies,
4 officers, or researchers, the requesting entity shall agree
5 in writing to maintain the confidentiality of the
6 information, and, in the case of researchers, shall do both
7 of the following:

8 (A) Obtain approval of their committee for the
9 protection of human subjects established in accordance
10 with Part 46 (commencing with Section 46.101) of Title
11 45 of the Code of Federal Regulations.

12 (B) Provide documentation to the department that
13 demonstrates to the department's satisfaction that the
14 entity has established the procedures and ability to
15 maintain the confidentiality of the information.

16 (3) Confidential data may be disclosed to other local,
17 state, or federal public health or environmental agencies,
18 or to collaborating medical researchers, when the
19 confidential data are necessary to carry out the duties of
20 the agency or researcher in the investigation, control, or
21 surveillance of disease, as determined by the department.

22 (4) Any disclosure authorized by this section shall
23 include only the information necessary for the stated
24 purpose of the requested disclosure and shall be made
25 only upon written agreement that the information will be
26 kept confidential and will not be further disclosed
27 without written authorization of the department.

28 (5) The furnishing of confidential data to the
29 department or its authorized representative or to any
30 other cooperating individual, agency, or organization in
31 any study in accordance with this subdivision shall not
32 expose any person, agency, or entity furnishing data to
33 liability and shall not be considered to be the violation of
34 any privileged or confidential relationship.

35 ~~(6) No part of the confidential data shall be available~~
36 ~~for subpoena nor shall it be disclosed, discoverable, or~~
37 ~~compelled to be produced in any civil, criminal,~~
38 ~~administrative, or other proceeding, nor shall these data~~
39 ~~be deemed admissible as evidence in any civil, criminal,~~
40 ~~administrative, or other tribunal or court for any reason.~~



1 (6) (A) *There shall be a rebuttable presumption that*
2 *the necessity for preserving the confidentiality of the data*
3 *outweighs the necessity for disclosure. The confidential*
4 *data may only be subject to discovery or subpoena if the*
5 *party seeking the disclosure rebuts the presumption. This*
6 *presumption may only be overcome if the court finds that*
7 *the disclosure of the information will serve to protect*
8 *public health or safety.*

9 (B) *If the court finds that the presumption has been*
10 *rebutted and the confidential data is subject to discovery*
11 *or subpoena, certain confidential information shall be*
12 *redacted. This information includes personal names,*
13 *addresses, telephone numbers, social security numbers,*
14 *personal identification numbers, insurance policy*
15 *numbers, specific places of employment and education,*
16 *any other data that identifies or accesses the participant*
17 *or any friends, employers, or associates of the participant,*
18 *and any other data the court deems appropriate. The*
19 *party requesting the data shall be responsible for all costs*
20 *associated with the production of the data, including costs*
21 *attributable to any time required to redact the*
22 *confidential information. The party requesting the data*
23 *shall demonstrate the ability to ensure data security and*
24 *confidentiality.*

25 (7) (A) *Notwithstanding any other provision of law,*
26 *any person who violates this subdivision shall be subject*
27 *to civil and criminal penalties and other actions in*
28 *accordance with Section 56.36 of the Civil Code.*

29 (B) *Any person who intentionally discloses*
30 *confidential data to any third party, except as authorized*
31 *in this subdivision, may be denied further access to*
32 *confidential data maintained by the department.*

33 (8) *Nothing in this subdivision shall prohibit the*
34 *publication by the department of reports and statistical*
35 *compilations relating to the causes of malignant*
36 *neoplasms or measures to eliminate, alleviate, or*
37 *ameliorate the effect of malignant neoplasms that do not*
38 *identify individual cases and sources of information or*
39 *religious affiliations.*



1 (h) For the purpose of this section, “cancer” means all
2 malignant neoplasms, regardless of the tissue of origin,
3 including malignant lymphoma, Hodgkins disease, and
4 leukemia, but excluding basal cell and squamous cell
5 carcinoma of the skin.

6 (i) Nothing in this section shall preempt the authority
7 of facilities or individuals, providing diagnostic or
8 treatment services to patients with cancer, to maintain
9 their own facility-based tumor registries.

10 (j) It is the intent of the Legislature that the
11 department, in establishing a system pursuant to this
12 section, maximize the use of available federal funds.

13 SEC. 4. Section 103885 of the Health and Safety Code
14 is amended to read:

15 103885. (a) The director shall establish a statewide
16 system for the collection of information determining the
17 incidence of cancer, using population-based cancer
18 registries modeled after the Cancer Surveillance
19 Program of Orange County. As of the effective date of this
20 section, the director shall begin phasing in the statewide
21 cancer reporting system. By July 1, 1988, all county or
22 regional registries shall be implemented or initiated. By
23 July 1, 1990, the statewide cancer reporting system shall
24 be fully operational. Within 60 days of the effective date
25 of this section, the director shall submit an
26 implementation and funding schedule to the Legislature.

27 (b) The department may designate any demographic
28 parts of the state as regional cancer incidence reporting
29 areas and may establish regional cancer registries, with
30 the responsibility and authority to carry out the intent of
31 this section in designated areas. Designated regional
32 registries shall provide, on a timely basis, cancer
33 incidence data as designated by the state department to
34 the department. The department may contract with an
35 agency, including, but not limited to, a health systems
36 agency, single county health department, multicounty
37 health department grouping, or nonprofit professional
38 association, representing a designated cancer reporting
39 region for the purposes of collecting and collating cancer
40 incidence data.



1 (c) The director shall designate cancer as a disease
2 required to be reported in the state or any demographic
3 parts of the state in which cancer information is collected
4 under this section. All cancers diagnosed or treated in the
5 reporting area shall thereafter be reported to the
6 representative of the department authorized to compile
7 the cancer data, or any individual, agency, or
8 organization designated to cooperate with that
9 representative.

10 (d) (1) Any hospital or other facility providing
11 therapy to cancer patients within an area designated as
12 a cancer reporting area shall report each case of cancer
13 to the department or the authorized representative of the
14 department in a format prescribed by the department. If
15 the hospital or other facility fails to report in a format
16 prescribed by the department, the department's
17 authorized representative may access the information
18 from the hospital or the facility and report it in the
19 appropriate format. In these cases, the hospital or other
20 health facility shall reimburse the state department or the
21 authorized representative for its cost to access and report
22 the information.

23 (2) Any physician and surgeon, dentist, podiatrist, or
24 other health care practitioner diagnosing or providing
25 treatment for cancer patients shall report each cancer
26 case to the department or the authorized representative
27 of the department except for those cases directly referred
28 to a treatment facility or those previously admitted to a
29 treatment facility for diagnosis or treatment of that
30 instance of cancer.

31 (e) Any hospital or other facility that is required to
32 reimburse the department or its authorized
33 representative for the cost to access and report the
34 information pursuant to subdivision (d) shall provide
35 payment to the department or its authorized
36 representative within 60 days of the date this payment is
37 demanded. In the event any hospital or other facility fails
38 to make the payment to the department or its authorized
39 representative within 60 days of the date the payment is
40 demanded, the department or its authorized



1 representative may, at its discretion, assess a late fee not
2 to exceed 1¹/₂ percent per month of the outstanding
3 balance. Further, in the event that the department or its
4 authorized representative takes a legal action to recover
5 its costs and any associated fees, and the department or
6 its authorized representative receives a judgment in its
7 favor, the hospital or other facility shall also reimburse the
8 department or its authorized representative for any
9 additional costs it incurred to pursue the legal action.
10 Late fees and payments made to the department by
11 hospitals or other facilities pursuant to this subdivision
12 shall be considered as reimbursements of the additional
13 costs incurred by the department.

14 (f) All physicians and surgeons, hospitals, outpatient
15 clinics, nursing homes and all other facilities, individuals
16 or agencies providing diagnostic or treatment services to
17 patients with cancer shall grant to the department or the
18 authorized representative access to all records that would
19 identify cases of cancer or would establish characteristics
20 of the cancer, treatment of the cancer, or medical status
21 of any identified cancer patient. Willful failure to grant
22 access to those records shall be punishable by a fine of up
23 to five hundred dollars (\$500) each day access is refused.
24 Any fines collected pursuant to this subdivision shall be
25 deposited in the General Fund.

26 (g) (1) All data including, but not limited to, medical
27 and pathology records, records of health status,
28 interviews, questionnaires, reports, statements, notes,
29 and memoranda collected pursuant to this section shall be
30 confidential. Access shall be limited to the department
31 and any regional registry designated by the department
32 except as otherwise provided in this subdivision.

33 (2) The department and any regional cancer registry
34 designated by the department may enter into
35 agreements to furnish confidential data to other states'
36 cancer registries, federal cancer control agencies, local
37 health officers, or health researchers for the purposes of
38 determining the sources of malignant neoplasms and
39 evaluating measures designed to eliminate, alleviate, or
40 ameliorate their effect. Before confidential data are



1 disclosed to those out-of-state registries, agencies,
2 officers, or researchers, the requesting entity shall agree
3 in writing to maintain the confidentiality of the
4 information, and, in the case of researchers, shall do both
5 of the following:

6 (A) Obtain approval of their committee for the
7 protection of human subjects established in accordance
8 with Part 46 (commencing with Section 46.101) of Title
9 45 of the Code of Federal Regulations.

10 (B) Provide documentation to the department that
11 demonstrates to the department's satisfaction that the
12 entity has established the procedures and ability to
13 maintain the confidentiality of the information.

14 (3) Confidential data may be disclosed to other local,
15 state, or federal public health or environmental agencies,
16 or to collaborating medical researchers, when the
17 confidential data are necessary to carry out the duties of
18 the agency or researcher in the investigation, control, or
19 surveillance of disease, as determined by the department.

20 (4) Any disclosure authorized by this section shall
21 include only the information necessary for the stated
22 purpose of the requested disclosure and shall be made
23 only upon written agreement that the information will be
24 kept confidential and will not be further disclosed
25 without written authorization of the department.

26 (5) The furnishing of confidential data to the
27 department or its authorized representative or to any
28 other cooperating individual, agency, or organization in
29 any study in accordance with this subdivision shall not
30 expose any person, agency, or entity furnishing data to
31 liability and shall not be considered to be the violation of
32 any privileged or confidential relationship.

33 ~~(6) No part of the confidential data shall be available~~
34 ~~for subpoena nor shall it be disclosed, discoverable, or~~
35 ~~compelled to be produced in any civil, criminal,~~
36 ~~administrative, or other proceeding, not shall these data~~
37 ~~be deemed admissible as evidence in any civil, criminal,~~
38 ~~administrative, or other tribunal or court for any reason.~~

39 (6) (A) *There shall be a rebuttable presumption that*
40 *the necessity for preserving the confidentiality of the data*



1 *outweighs the necessity for disclosure. The confidential*
2 *data may only be subject to discovery or subpoena if the*
3 *party seeking the disclosure rebuts the presumption. This*
4 *presumption may only be overcome if the court finds that*
5 *the disclosure of the information will serve to protect*
6 *public health or safety.*

7 (B) *If the court finds that the presumption has been*
8 *rebutted and the confidential data is subject to discovery*
9 *or subpoena, certain confidential information shall be*
10 *redacted. This information includes personal names,*
11 *addresses, telephone numbers, social security numbers,*
12 *personal identification numbers, insurance policy*
13 *numbers, specific places of employment and education,*
14 *any other data that identifies or accesses the participant*
15 *or any friends, employers, or associates of the participant,*
16 *and any other data the court deems appropriate. The*
17 *party requesting the data shall be responsible for all costs*
18 *associated with the production of the data, including costs*
19 *attributable to any time required to redact the*
20 *confidential information. The party requesting the data*
21 *shall demonstrate the ability to ensure data security and*
22 *confidentiality.*

23 (7) (A) *Notwithstanding any other provision of law,*
24 *any person who violates this subdivision shall be subject*
25 *to civil and criminal penalties and other actions in*
26 *accordance with Section 56.36 of the Civil Code.*

27 (B) *Any person who intentionally discloses*
28 *confidential data to any third party, except as authorized*
29 *in this subdivision, may be denied further access to*
30 *confidential data maintained by the department.*

31 (8) *Nothing in this subdivision shall prohibit the*
32 *publication by the department of reports and statistical*
33 *compilations relating to the causes of malignant*
34 *neoplasms or measures to eliminate, alleviate, or*
35 *ameliorate the effect of malignant neoplasms that do not*
36 *identify individual cases and sources of information or*
37 *religious affiliations.*

38 (h) *For the purpose of this section, “cancer” means*
39 *either of the following:*



1 (1) All malignant neoplasms, regardless of the tissue
2 of origin, including malignant lymphoma, Hodgkins
3 disease, and leukemia, but excluding basal cell and
4 squamous cell carcinoma of the skin.

5 (2) All primary intracranial and central nervous
6 system (CNS) tumors occurring in the following sites,
7 irrespective of histologic type: brain, meninges, spinal
8 cord, caudae equina, cranial nerves and other parts of the
9 CNS, pituitary gland, pineal gland, and craniopharyngeal
10 duct.

11 (i) Nothing in this section shall preempt the authority
12 of facilities or individuals, providing diagnostic or
13 treatment services to patients with cancer, to maintain
14 their own facility-based cancer registries.

15 (j) It is the intent of the Legislature that the
16 department, in establishing a system pursuant to this
17 section, maximize the use of available federal funds.

18 SEC. 5. Section 4 of this bill incorporates amendments
19 to Section 103885 of the Health and Safety Code proposed
20 by both this bill and AB 48. It shall only become operative
21 if (1) both bills are enacted and become effective on or
22 before January 1, 2001, (2) each bill amends Section
23 103885 of the Health and Safety Code, and (3) this bill is
24 enacted after AB 48, in which case Section 3 of this bill
25 shall not become operative.

26 SEC. 6. No reimbursement is required by this act
27 pursuant to Section 6 of Article XIII B of the California
28 Constitution because the only costs that may be incurred
29 by a local agency or school district will be incurred
30 because this act creates a new crime or infraction,
31 eliminates a crime or infraction, or changes the penalty
32 for a crime or infraction, within the meaning of Section
33 17556 of the Government Code, or changes the definition
34 of a crime within the meaning of Section 6 of Article
35 XIII B of the California Constitution.

