SENATE COMMITTEE ON HEALTH
Senator Dr. Akilah Weber Pierson, Chair

BILL NO:	SB 1150
AUTHOR:	Jones
VERSION:	March 25, 2026
HEARING DATE:	April 22, 2026
CONSULTANT:	Reyes Diaz

SUBJECT: Cancer data: notifications

SUMMARY: Requires an entity that reports a patient's case of cancer to the California Department of Public Health to notify the patient by mail, within five business days of the report, that they reported the patient's case and that the information may be used to add the patient to a registry of cancer cases.

Existing law:

1) Requires the California Department of Public Health (CDPH) to establish a statewide system for the collection of information determining the incidence of cancer, using population-based cancer registries (known as the Ken Maddy California Cancer Registry, or CCR). [HSC §103885(a)]

2) Requires any hospital or other facility providing therapy to cancer patients, within an area designated as a cancer reporting area, to report each case of cancer to CDPH in a format prescribed by CDPH. If the hospital or other facility fails to report as prescribed, CDPH is permitted to access the information from the hospital or facility and report it in the appropriate format. In these cases, the hospital or other health facility is required to reimburse CDPH or its authorized representative for the cost to access and report the information. [HSC §103885(d)(1)]

3) Requires any physician, dentist, podiatrist, or other health care practitioner diagnosing or providing treatment for cancer patients to report each cancer case to CDPH, except for cases directly referred to a treatment facility or those previously admitted to a treatment facility for diagnoses or treatment of that instance of cancer. [HSC §103885(d)(2)]

4) Requires all physicians, hospitals, outpatient clinics, nursing homes and all other facilities, individuals, or agencies providing diagnostic or treatment services to patients with cancer to grant CDPH access to all records that would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient. Willful failure to grant access to those records is punishable by a fine of up to $500 each day access is refused. [HSC §103885(f)]

5) Requires all information collected pursuant to the CCR to be confidential, except to persons with a valid scientific interest engaged in demographic, epidemiological, or other similar studies related to health who meet qualifications determined by CDPH. Requires CDPH to maintain an accurate record of all persons who are given access to confidential information. Prohibits any confidential information from being available for subpoena, or from being disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding, or from being deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason. [HSC §103885(g)]

6) Requires cancer reporting facilities and physicians to employ a mechanism to ensure that their patients are informed that cancer has been designated a reportable disease and that the facility will report each patient with cancer to CDPH as required by law. [17 CCR §2593(b)(18)]

This bill: Requires an entity, under the CCR, that is required to report a patient's case of cancer to CDPH, to notify the patient by mail, within five business days of reporting, that they reported the patient's case to CDPH and that the information may be used to add the patient to a registry of cancer cases.

FISCAL EFFECT: This bill is keyed nonfiscal.

COMMENTS:

1) *Author's statement.* According to the author, California collects comprehensive cancer data through the CCR to support public health and research. While existing regulations require providers to notify patients that their information will be reported, these requirements are not evenly implemented and lack a clear enforcement mechanism. Evidence from practitioners across specialties indicates that many providers are unaware of the notification requirement or associated materials, indicating that compliance is uneven in practice. As a result, patients are not being informed that their identifying and medical information has been submitted and could later be used for research purposes, sometimes only learning of the registry through third-party outreach. Given that existing regulatory requirements are not being consistently followed, codifying these obligations in statute is necessary to ensure uniform implementation statewide. This bill would establish a clear, enforceable standard by requiring the diagnosing physician or facility to provide written notification upon a confirmed cancer diagnosis, using existing CDPH materials. In doing so, this bill strengthens patient awareness and aligns California's data collection practices with basic expectations of informed participation in public health systems.

2) *Patient notification.* The CCR website states that patient notification is required by law. At the time patients are informed of their cancer diagnosis, they must also be informed that their data will be reported to CCR. State law requires CCR to provide informational materials to help inform cancer patients about the statewide reporting requirements. CCR developed materials to assist in the patient notification process and makes electronic PDFs of these materials available to download on its website. A form is also available to allow entities to order free materials to be delivered to them.

3) *CCR.* AB 136 (Connelly, Chapter 841, Statutes of 1985) established the CCR. There are three regional registries: the Greater Bay Area Cancer Registry (administered by the UC San Francisco); the Los Angeles County Cancer Surveillance Program (administered by the University of Southern California); and, the Cancer Registry of Greater California (administered by the Public Health Institute, which covers all other counties). According to CDPH's website, the state has collected information on every cancer diagnosed in the state, except for two common types of skin cancer (basal cell and squamous cell) and a non-invasive form of cervical cancer. CCR is the statewide cancer surveillance system, which collects all the data from the regional registries into a statewide database. The CCR and regional registries use the data to write summary reports that inform the public, local health workers, educators, and legislators about the status of cancer. Researchers may examine the data to identify areas that have high cancer rates and areas where people might benefit from cancer screening and education programs, or to look at trends in cancer

diagnosis. Other uses include measuring the success of cancer screening programs; examining disparities in cancer risk, treatment, and survival; examining treatment choices and other predictors of survival; responding to public concerns and questions about cancer; and, conducting research to find the causes and cures of cancer.

4) *Surveillance, Epidemiology, and End Results (SEER) Program and the National Program of Cancer Registries (NPCR)*. According to the National Cancer Institute (NCI) website, the SEER Program is an authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 45.9% of the U.S. population, including 39.6% of Whites, 43.5% of African Americans, 64.9% of Hispanics, 59.3% of American Indians and Alaska Natives, 68.2% of Asians, and 69.9% of Hawaiian/Pacific Islanders. NCI staff work with the North American Association of Central Cancer Registries to guide all state registries to achieve data content and compatibility acceptable for pooling data and improving national estimates. Use of surveillance data for research is being improved through web-based access to the data and analytic tools, and linking with other national data sources. The NPCR was established by the Centers for Disease Control and Prevention to provide funding and technical assistance to statewide, population-based cancer registries. NPCR supports states and territories to improve existing cancer registries; plan and implement registries where none existed; develop model legislation and regulations for states to enhance the viability of registry operations; set standards for data completeness, timeliness, and quality; provide training for registry personnel; and, help establish a computerized reporting and data processing system. In 2006, NPCR launched the Electronic Pathology (ePath) Implementation Project to test a model for automated electronic capture and reporting of cancer registry data to central cancer registries. Following initial pilot programs, ePath has expanded to all 50 states and includes many more national and regional laboratories. In California, AB 2325 (Bonilla, Chapter 354, Statutes of 2016) required pathologists to use ePath to report cancer diagnoses beginning January 1, 2019.

5) *Prior legislation.* SB 717 (Richardson of 2025) would have required CDPH to maintain statewide and regional infrastructures and systems for collecting information on and reporting cancer incidence through regional cancer registries, and deleted past dates regarding the establishment of the CCR. *SB 717 was vetoed by Governor Newsom who stated: "I appreciate the author's intent to maintain the integrity and effectiveness of California's cancer surveillance system in the face of federal funding cuts [that mandate] a 15% cut in contracts, including those funding the CCR. Unfortunately, by locking a regional cancer surveillance model in statute, this bill would constrain CDPH's ability to update its infrastructure, respond to evolving public health needs, and implement cost-saving strategies to sustain the program. The state needs flexibility to adapt to reduced federal funding, which is not provided for by this bill."*

   SB 344 (Rubio, Chapter 867, Statutes of 2023) revises provisions of the CCR, including to permit individuals who are authorized to access the confidential data in cancer registries to participate in data sharing with other authorized individuals.

   SB 452 (Jones of 2019) would have required CDPH to send an informational brochure about the CCR to every patient when the patient is entered into the CCR. *SB 452 was held on the Assembly Appropriations Committee suspense file.*

AB 2174 (Jones of 2016) would have required CDPH to ensure a cancer patient was notified with specified information about the CCR before a researcher contacted the patient to ask about research participation. Notification to the patient required under this bill would have been distributed in a cost-effective manner, including, but not limited to, by e-mail. *AB 2174 was held on the Assembly Appropriations Committee suspense file.*

AB 2325 (Bonilla, Chapter 354, Statutes of 2016) requires pathologists diagnosing cancer to report diagnoses to CDPH utilizing electronic means in a standardized format approved by CDPH.

AB 972 (Jones of 2015) and AB 1683 (Jones of 2014) would have required CDPH to undertake patient notification, rather than the entities required to report the information to CDPH, including specified information such that their data may be used by researchers. All notifications to the patient required under this bill would have been distributed in a cost-effective manner, including, but not limited to, by e-mail. *AB 972 was not heard in the Assembly Health Committee. AB 1683 was held on the Assembly Appropriations Committee suspense file.*

AB 136 (Connelly, Chapter 841, Statutes of 1985) established the CCR.

6) *Letter of concerns.* The Public Health Institute, the University of Southern California, and the University of California, which operate California's three designated regional cancer registries, and the American Cancer Society Cancer Action Network express concerns in a group letter about the last amended version of this bill and would like to work with the author's office to amend the bill to better clarify how and when patients are notified when their cancer case is reported. While the group supports informing patients about how their information can be used, they argue this bill imposes a new and duplicative requirement. In practice, this approach would create significant problems for patients, providers, facilities, and the CCR. The group further argues the bill risks causing unnecessary confusion and distress for patients at one of the most sensitive moments in care. A cancer diagnosis is often not confirmed and communicated in a single step and can require more testing before a treating clinician is prepared to discuss the diagnosis and next steps. All of these discovery activities leading to the final cancer diagnostic are reportable and patients could receive multiple mailed notices indicating that a cancer case has been reported before they have had that conversation with their doctor. That would create unnecessary psychological distress and could undermine the clinician-patient relationship and their cancer outcome. The group further states this bill could cause confusion for patients in cases where the underlying report does not align with what they understand about their condition. For example, certain benign brain and central nervous system tumors are reportable to the registry even though they are not invasive cancers. Some initial pathology findings are later revised. In other cases, historic cancers may be re-reviewed as part of current care. Additionally, this bill would impose substantial administrative and financial burdens on reporting entities without improving patient care. California has approximately 200,000 new cancer diagnoses each year, and each cancer diagnosis may involve multiple providers and facilities to generate multiple reports. Lastly, the group states this bill introduces new confidentiality concerns by requiring sensitive notices to be sent through the mail, which can be misdirected, opened by others in the household, or delivered to outdated addresses. These risks are especially concerning given the highly sensitive nature of cancer-related information and the importance of preserving confidentiality in all aspects of care and public health reporting. The group says they recognize that the current approach to notify patients can be improved, but this bill may

have unintended consequences. The California Hospital Association also shares these concerns.

SUPPORT AND OPPOSITION:

Support:	None received
Oppose:	None received

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