



PHYSICIAN REQUIREMENTS FOR CANCER REPORTING IN CALIFORNIA

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VOLUME IV



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BACKGROUND

In 1985 the California legislature enacted a law that established the California Cancer Registry (CCR), and since 1987, the California Health and Safety Code, Section 103885 has required hospitals, physicians, and certain other health-care providers to report all new diagnoses of cancer. Beginning January 1, 2001, diagnoses of borderline and benign primary intracranial and central nervous system (CNS) tumors are also reportable, as well as borderline ovarian cancer and Newly Reportable Hematopoietic Diseases (NRHD) described in the Reporting Requirements section below. Physicians¹ must report diagnoses in those patients who do not undergo diagnostic procedures or treatment of their malignancies or brain tumors at a hospital or other cancer-reporting facility² in California. The regional cancer registries, operating under the authority of the Department of Public Health (CDPH), have the responsibility for abstracting the required data from the reporting physician's records. Confidentiality of data collected is strictly maintained in accordance with Health and Safety Code Sections 100330 and 103885; Civil Code, Sections 56.05 and 1798; Government Code Sections, 6250-6265; and Federal Law PL 104-191.

REPORTING REQUIREMENTS

Physicians are to report cancer diagnoses within 30 days of first seeing the patient for the cancer. Reporting is required of all diagnoses that meet the following criteria:

1) Invasive and *in situ* malignancies including leukemia and lymphoma. Beginning January 1, 2001, borderline and benign primary intracranial and CNS tumor data are also reportable as well as borderline ovarian cancer and Newly Reportable Hematopoietic Diseases (NRHD). Report only NRHD cases diagnosed January 1, 2001 forward. If disease is known prior to 2001, do not report the case. NRHD cases diagnosed prior to January 1, 2001, undergoing active treatment are also not reportable cases. NRHD include the following :

Chronic Myeloproliferative Diseases

- Polycythemia vera
- Chronic myeloproliferative disease
- Myelosclerosis with myeloid metaplasia
- Essential thrombocythemia
- Chronic neutrophilic leukemia
- Hypereosinophilic syndrome

Myelodysplastic Syndromes

- Refractory anemia
- Refractory anemia with sideroblasts
- Refractory anemia with excess blasts
- Refractory anemia with excess blasts in Transformation
- Refractory cytopenia with multilineage Dysplasia
- Myelodysplastic syndrome with 5q-syndrome
- Therapy-related myelodysplastic syndrome

Other New Diagnoses

- Langerhans cell histiocytosis, disseminated
- Acute biphenotypic leukemia
- Precursor lymphoblastic leukemia

- Aggressive NK cell leukemia
- Chronic neutrophilic leukemia
- Hypereosinophilic syndrome
- Leukemias with cytogenetic abnormalities
- Dendritic cell sarcoma.

Reporting of the following items are exempted: i) basal or squamous cell carcinoma of the skin unless it occurs on the genitalia; and ii) carcinoma *in situ* or intraepithelial neoplasia grade III (CIN III) of the cervix diagnosed January 1, 1996 and later. Adopted by the CCR, the morphology section of the International Classification of Diseases for Oncology delineates the list of reportable neoplasms. A diagnosis must be reported even if it has not been microscopically confirmed; and 2) The patient was not previously admitted as an inpatient or outpatient to a California cancer reporting facility for **this tumor**; and 3) The patient is not being referred to a hospital or other cancer reporting facility for diagnosis or treatment of **this tumor**. If a patient is referred to a cancer reporting facility for a condition other than **this tumor**, the case must be reported by the physician.

If you are in doubt about whether the diagnosis is reportable, please submit a report.

The Health Information Portability and Accountability Act (HIPAA) does not change or affect the mandate for reporting cancer in California. The California Cancer Registry and its Regional Cancer Registries are considered Public Health authorities and disclosure of protected health information to the registries is permitted by HIPAA without patient signed consent. HIPAA federal regulations citation: 45 CFR 164.512.

CALIFORNIA LAW DOES NOT REQUIRE WRITTEN OR VERBAL PATIENT CONSENT TO REPORT, AND SPECIFICALLY EXEMPTS PHYSICIANS FROM ANY LEGAL ACTION OR DAMAGES FROM MEETING THEIR LEGAL OBLIGATION TO REPORT CANCER CASES OR TO PROVIDE ACCESS TO THOSE PATIENT'S MEDICAL RECORDS.

¹ The reporting requirements for physicians also apply to dentists, podiatrists, and other health-care practitioners, primary-care clinics (as defined in Section 1204 of the California Health and Safety Code), and acute-care psychiatric hospitals (as defined in Section 1250 of the Code) for cases they diagnose or treat without referring the patients to a cancer-treatment facility.

² Under Title 17 of the California Code of Regulations, 2593 (a)(7), cancer-reporting facility is defined as a hospital or other facility that diagnoses or treats cancers and is either

(a) Licensed as a health facility under the provisions of the Health and Safety Code (commencing with Section 1250); or

(b) A surgical clinic licensed under the Health and Safety Code, Section 1204; or

(c) Covered by the provisions of Section 1206, except for subsection (f), of the Code and even though it is not licensed as a clinic, is operated for the predominant purpose of diagnosing or treating cancer or where 100 or more cancer cases are diagnosed or treated in a year.

REPORTING PROCEDURES

To report a diagnosis, please complete the Confidential Physician Cancer Reporting form inserted in this publication, which is also available on the CCR web site (http://www.ccrca.org/PAQC_Pubs/V4_2013/Form-Vol-IV-12.pdf). A separate form is required for each primary tumor. For example, if a patient is diagnosed with leukemia and melanoma, a form must be submitted for each diagnosis. Send the completed forms to the regional cancer registry in your area. Regional registries are listed at the end of this document. Please complete the Confidential Physician Cancer Reporting as **ACCURATELY** and **COMPLETELY** as possible. The Confidential Morbidity Report (CMR) form (PM110), which is available from your local health department, may also be used to report cancer.

In filling out the Confidential Physician Cancer Reporting form please type or print the following information:

Patient Information Section: Report complete name, social security number, date of birth, race, ethnicity, gender, and telephone numbers as accurately and completely as possible so that any other reports for the same person can be identified and cancer incidence can be accurately tabulated. Enter the patient's usual residence *on the date of the initial diagnosis* — that is, where the patient was living and sleeping most of the time, which is not necessarily the same as the legal or voting address.

Vital Status, Date of Last Contact: If the patient is still alive, check "Alive" and enter date patient was last known to be alive in the "Date of Last Contact" section. If the patient died of any cause, check "Dead," and enter the date of death in the "Date of Last Contact" section. If you do not know the exact date, enter as much information as is known (month and/or year of death). If the date is completely unknown, enter "date unknown."

Cancer Diagnosis Section: *Primary site, histology and laterality:* Enter whatever is known. Examples are: "adenocarcinoma of the descending colon," "malignant melanoma of the right calf," "chronic lymphocytic leukemia," and "cancer of the left breast."

Date of Diagnosis: Enter exact date the diagnosis was first made. This can be the date of the first clinical diagnosis, not necessarily the date of the microscopic confirmation.

Diagnostic Work-up At Time of Diagnosis Section: *Physical Findings:* Please record clinical findings of pre-biopsy/pre-surgery masses or lesions. Include description of mass/lesion: hard, fixed, indurated, ulcerated, enlarged, firm, freely mobile etc; size; and location of mass/lesion. Please indicate whether or not there are palpable lymph nodes. If no abnormal findings are noted, please indicate this information on the form. These findings are helpful in properly staging each tumor.

X-rays, scans and scopic findings: Enter the test date, type of test and the results. If you prefer, copies of the reports are sufficient.

PSA and ERA/PRA: Enter the date of the test and the results of test performed just prior to the biopsy, if available.

Treatment At Time of Diagnosis Section: If you are aware of any treatment given, please record the information in the appropriate section. If the patient was referred to another physician for any of the treatment options, please record the physician's name, address and phone number. If patient or family refuses treatment or requests "Observation Only," please record this on the form.

REGIONAL REGISTRY'S PROCEDURES

Within about six months of the submission of the Confidential Physician Cancer Reporting or CMR report, the regional registry will contact you for the required reporting information. The regional registry will not contact your

office for information on cases that have been received from another source.

Physicians are legally obligated to make pertinent medical records available to the registry.³

3. California Health and Safety Code, Section 103885 - (f) All physicians and surgeons, hospitals, outpatient clinics, nursing homes and all other facilities, individuals, or agencies providing diagnostic or treatment services to patients with cancer shall grant to the department or the authorized representative 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.

CONFIDENTIALITY

Data collection under the cancer reporting system is subject to the specific confidentiality provisions in the Health and Safety Code, Section 100330. This law protects from legal damages anyone who furnishes such information to CDPH or its authorized representative. Information about individual

patients is never released to unauthorized persons or agencies, and safeguards have been established throughout the cancer reporting system to maintain confidentiality.

PATIENT INFORMATION SHEET

It is the reporting physician's responsibility to inform patients that their cancer diagnosis has been reported to CCR as required by law. CDPH has developed a "Patient Information Sheet," which you may use to inform your patients. A copy is included as an insert and additional copies can be obtained

through your Regional Registry or at CCR web page under Volume IV: http://www.ccrca.org/PAQC_Pubs/V4_2013/Vol-IV-2013.pdf. If you so choose, you may create your own information sheet to distribute and post in your office.

CALIFORNIA'S CANCER REPORTING SYSTEM

The State's cancer reporting system developed from a successful study initiated in 1947 to determine the feasibility of basing a central cancer registry on data obtained from hospitals. Gradually, reporting was extended from nine hospitals to 55 plus a private cancer clinic, then to the entire San Francisco-Oakland Standard Metropolitan Statistical Area. Because of the medical and epidemiological value of the data reported, the state legislature in 1985 authorized CDPH to establish "a statewide system for the collection of information concerning the incidence of cancer."

Hospitals still have the primary responsibility for reporting the information. However, since an increasing number of people with cancer are not hospitalized at the time of diagnosis, a supplemental reporting mechanism is essential to assure that the data accurately reflect the incidence of cancer in the state. Therefore, Section 103885 of the Health and Safety Code states:

Any physician, dentist, podiatrist, or other health care practitioner diagnosing or providing treatment for cancer patients shall report each cancer case to the department [of Public Health] or the authorized representative of the department except for those cases directly referred to a treatment facility or those previously admitted to a treatment facility for diagnosis or treatment of that instance of cancer.

CCR has developed into one of the most prestigious cancer registries in the world, making significant contributions to our understanding and control of cancer. This valuable resource enables Californians to know incidence trends of cancer in the state, evaluate risk factors in the occurrence of the disease, ascertain variations in risks among different ethnic groups and social classes, identify changes in the incidence of various forms of cancer in subgroups of the population, and study long-term changes in the interrelationship of incidence, early diagnosis, treatment, length of survival, and mortality for a greater understanding of cancer. In addition, it has greatly increased the number of cases available to researchers for epidemiological studies of human cancer and its relationship to the environment and our genetic profile. These achievements have been made possible by the cooperation of California's health-care institutions and professionals in the nation's premier cancer-reporting system.

REGIONAL CANCER REGISTRIES

As of March 2013

- Region 1/8: Cancer Prevention Institute of California**
2201 Walnut Avenue, Suite 300, Fremont, CA 94538; (510) 608-5120, FAX: (510) 608-5100
- Counties:** *Region 1:* Santa Clara Region (Monterey, San Benito, Santa Clara and Santa Cruz Counties).
Region 8: Bay Area Region (Alameda, Contra Costa, Marin, San Francisco and San Mateo Counties).
- Region 2: Cancer Registry of Central California**
1680 W. Shaw Avenue, Fresno, CA 93710, (530) 345-2483; Fax: (530) 345-3214
- Counties:** Central Region (Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare and Tuolumne Counties).
- Region 3: Sacramento and Sierra Cancer Registry**
1825 Bell Street, Suite 102, Sacramento CA 95825, (916) 779-0300, FAX: (916) 779-0264
Fax number for sending confidential data is (916) 564-9300
- Counties:** Sacramento Region (Alpine, Amador, Calaveras, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Solano, Sutter, Yolo and Yuba Counties).
- Region 4: Central Coast Cancer Registry**
1825 Bell Street, Suite 102, Sacramento CA 95825, (916) 779-0300, FAX: (916) 779-0264
Fax number for sending confidential data is (916) 564-9300
- Counties:** Tri-County Region (San Luis Obispo, Santa Barbara and Ventura Counties).
- Region 5: Desert Sierra Cancer Surveillance Program**
11306 Mountain View Ave., Suite B-100, Loma Linda, CA 92354-3834, (909) 558-6174, FAX (909) 558-6178
- Counties:** Inland Empire Region (Inyo, Mono, Riverside and San Bernardino Counties).
- Region 6: Cancer Registry of Northern California**
25 Jan Court, Suite 130, Chico, CA 95928, (530) 345-2483, FAX: (530) 345-3214
- Counties:** North Region (Butte, Colusa, Del Norte, Glenn, Humboldt, Lake, Lassen, Mendocino, Modoc, Napa, Plumas, Shasta, Siskiyou, Sonoma, Tehama and Trinity Counties).
- Region 7/10: Cancer Registry of San Diego and Imperial Counties**
1825 Bell Street, Suite 102, Sacramento CA 95825, (916) 779-0300, FAX: (916) 779-0264
Fax number for sending confidential data is (916) 564-9300
- Counties:** *Region 7:* San Diego Region (Imperial and San Diego Counties). *Region 10:* Orange County.
- Region 9: Cancer Surveillance Program**
Univ. of Southern California
Soto Street Building, Suite 305
2001 N. Soto Street, MC 9238
Los Angeles, CA 90089-9238*
(323) 442-2334, FAX (323) 442-2301
*Use zip 90032 for UPS/GSO/FedEx
- Counties:** Los Angeles County.

CONFIDENTIAL PHYSICIAN CANCER REPORTING FORM

(Please complete all sections and correct any inaccurate printed information)

PHYSICIAN NAME	PHONE	LICENSE
REFERENCE SOURCE		

PATIENT INFORMATION

NAME	SSN	SEX: <input type="checkbox"/> MALE <input type="checkbox"/> FEMALE
ADDRESS AT DIAGNOSIS (include zip code)	DATE OF BIRTH	MARITAL STATUS
	RACE/ETHNICITY	
PHONE	INSURANCE	LONGEST HELD OCCUPATION
VITAL STATUS: <input type="checkbox"/> ALIVE <input type="checkbox"/> DEAD	DATE OF LAST CONTACT OR DEATH	PLACE OF DEATH

CANCER DIAGNOSIS

PRIMARY SITE	LATERALITY <input type="checkbox"/> RIGHT <input type="checkbox"/> LEFT	HISTOLOGY
STAGE AT DIAGNOSIS	DATE OF DIAGNOSIS	CURRENT CANCER STATUS <input type="checkbox"/> FREE <input type="checkbox"/> NOT FREE <input type="checkbox"/> UNKNOWN

DIAGNOSTIC WORK-UP AT TIME OF DIAGNOSIS

Please record any pertinent findings regarding the location, size and extent of tumor at time of diagnosis.

PHYSICAL FINDINGS	DATE	
X-RAY/SCANS/SCOPIC FINDINGS (OR ATTACH COPIES OF REPORTS)	DATE	
PATHOLOGY FINDINGS (OR ATTACH COPY OF REPORTS)	DATE	
PSA LEVEL (PRE-BX, PROSTATE CA ONLY)	ERA/PRA (BREAST ONLY)	DATE
BIOPSY SITE <input type="checkbox"/> INCISIONAL <input type="checkbox"/> EXCISIONAL <input type="checkbox"/> OTHER: _____	DATE	

TREATMENT AT TIME OF DIAGNOSIS

SURGICAL TREATMENT: <input type="checkbox"/> SHAVE/PUNCH BX <input type="checkbox"/> EXCISIONAL BX <input type="checkbox"/> WIDE/RE-EXCISION <input type="checkbox"/> ORCHIECTOMY <input type="checkbox"/> TURP <input type="checkbox"/> TURBT <input type="checkbox"/> POLYPECTOMY <input type="checkbox"/> LASER ABLATION/CRYOSURGERY <input type="checkbox"/> OTHER:	
FACILITY	DATE
TUMOR SIZE AND LOCATION OF TUMOR (FOR MELANOMA RECORD CLARK'S AND DEPTH OF INVASION)	
RADIATION THERAPY: SITES TREATED	DATE STARTED
FACILITY	TOTAL cGy
DRUG TREATMENT: <input type="checkbox"/> CHEMOTHERAPY <input type="checkbox"/> HORMONE THERAPY <input type="checkbox"/> IMMUNOTHERAPY	OTHER TREATMENT
AGENTS (SPECIFY)	DATE STARTED
REFERRAL TO HOSPITAL OR OTHER PHYSICIAN FOR THIS CANCER? <input type="checkbox"/> YES <input type="checkbox"/> NO	MD NAME AND ADDRESS
IF ADMITTED, HOSPITAL NAME AND ADDRESS	DATE OF ADMISSION
NAME OF PERSON COMPLETING FORM	PHONE

PLEASE RETURN COMPLETED FORM TO:

CALIFORNIA CANCER REPORTING SYSTEM

PATIENT INFORMATION SHEET

Cancer is a Reportable Disease

Most people are aware that many types of infectious diseases, such as rabies, measles, and tuberculosis, must be reported to public health officials. However, many Californians are not aware that California state law (Health and Safety Code, Section 103885) also requires that all cases of cancer diagnosed in the state be reported to the California Department of Public Health. This law was passed in 1985; statewide reporting of cancer cases began in 1988 and has continued ever since.

The California Cancer Registry, within the California Department of Public Health (CDPH), is the program that collects and maintains information on all cancer cases diagnosed in California, including demographic information (such as age, sex, race, and ethnicity), diagnostic information (such as the type of cancer, the stage at diagnosis, and the location), and treatment information.

The California Cancer Registry (CCR) uses this data to:

- Monitor the number of new cancer cases and cancer deaths over time.
- Examine inequalities in cancer risk, treatment, and survival.
- Examine treatment choices and other factors which affect survival.
- Measure the success of cancer screening programs.
- Respond to public concerns and questions about cancer.
- Support research to find the causes and cures of cancer.

Data Confidentiality

The information collected by the CCR is vital for understanding cancer, and for developing successful ways to reduce cancer risk and improve outcomes. For the program to be useful, it must obtain complete and accurate counts of all new cancers that occur. Therefore the law requires hospitals and physicians to notify the cancer registry of each new case of cancer. The patient case information collected is confidential under California Health and Safety Code Sections 100330 and 103885, Civil Code, Sections 56.05 and 1798, Government Code, Sections 6250-62-65, and Federal Law PL 104-191. CDPH has more than 50 years' experience in handling confidential records. Laws, regulations and programmatic safeguards are in place throughout the system to assure that the identities of patients are not revealed.

Cancer Research

Cancer patients should be aware that State law allows the CCR to release patient case information to qualified cancer researchers, but only under strictly controlled circumstances. Researchers must have their plans approved by the California Committee for the Protection of Human Subjects (CPHS) before any CCR data on individual cancer patients can be released. Researchers must describe a detailed plan on how they will use and protect the data. The researcher may request approval from the CPHS to contact the patient to ask if he or she will consider participation in a cancer research study. Patients have the right to decline participation in any study.

State law requires that cancer registry data may ONLY be released to cancer researchers. The CCR never releases any patient information to any other entity, including legal, marketing and commercial organizations. State law also specifies that personal information may not be subject to subpoena.

Many cancer patients welcome the opportunity to participate in cancer research that might make a contribution towards improved knowledge of the causes and potential treatments for cancers. Other cancer patients decline participation due to their individual circumstances. Again, if a cancer patient is contacted by a researcher and does not want to participate in that study they can simply decline.

For more information, please visit the California Cancer Registry's website at: www.ccrca.org. If you have any additional questions, please contact the California Cancer Registry at 916-731-2500.

Brochures available on the California Cancer Registry web site www.ccrca.org:

- The California Cancer Registry: California's Cancer Reporting System
- The California Cancer Registry and Cancer Research in California: Searching for Causes and Cures



REGIONAL CANCER REGISTRIES MAP

