



## Fighting Cancer with Data: Enabling the California Cancer Registry to Measure and Improve Care

### Introduction

From the moment a cancer diagnosis is made, the patient and the primary care physician face crucial choices about cancer specialist provider referrals and the facilities where care is to be received. Moreover, the difficulty of these choices is increasing as both the range of treatment options and the complexity of care grows. Despite the significant number of people affected, (see “Cancer’s Burden on California and the Nation,”) there is a lack of accessible information about the quality of cancer care that could inform decisions about where to get that care.<sup>1</sup> Such information could also assist providers’ efforts to improve the quality of the care they deliver. The quality of cancer care is a concern because unwarranted variation is well documented.<sup>2</sup>

The sheer size of cancer’s population burden and associated costs has generated a serious need for the health care system to focus on the measurement and reporting of quality of cancer care metrics that are meaningful for patient and provider decisionmaking as well as to payers and policymakers.<sup>9</sup> To meet this need, the Institute of Medicine, an independent, nonprofit organization that works outside of government to provide unbiased advice to decisionmakers

### Cancer’s Burden on California and the Nation

Cancer’s scope and impact on the nation and the state is staggering. The disease is currently the second leading cause of death in the United States, responsible for nearly 600,000 deaths per year, and by 2030 it is projected to become the leading cause of death.<sup>3</sup> Nationally, more than 2.3 million people will be newly diagnosed with cancer each year.<sup>4</sup> In California, there will be an estimated 155,920 new cases in 2014 and 56,000 deaths from cancer.<sup>5</sup> National expenditures for cancer care are projected to increase to \$173 billion by 2020, up from \$72 billion in 2004.<sup>6</sup> Medi-Cal (California’s Medicaid program) costs related to cancer care are estimated to exceed \$28.3 billion in 2020.<sup>7</sup>

On the positive side, there are now 14 million cancer survivors nationally; that number is projected to increase to 18 million by 2022.<sup>8</sup> This growing number of survivors is partially due to earlier detection, which has allowed for more effective treatment, and underscores the need for comprehensive measurement and public reporting of the quality of care provided. Such information would help inform newly diagnosed patients, their providers, payers, policymakers, and others in making care decisions and improving care.

and the public, has called for development of “a national quality reporting program for cancer care as part of a learning health care system”.<sup>10</sup> Addressing this issue, the California HealthCare Foundation convened a workgroup of experts to explore a first step in this direction: the leveraging of the well-established California Cancer Registry (CCR) to produce quality of care metrics for cancer care in California that are accessible to and meaningfully usable by patients, referring and specialist providers, payers, and policymakers.

After thorough examination of the issue, the workgroup proposes a new quality of care reporting system for California, based on the CCR, that would include three elements:

- ▶ Expanded use of the registry’s data to include quality measurement and public reporting, including provider identification
- ▶ Linkage of the registry to administrative claims and utilization data, in order to supply information not currently captured by the registry
- ▶ Linkage of the registry to systems of electronic health records (EHR), in order to further supplement registry data.

This brief provides some background information and outlines the workgroup’s conclusions and recommendations regarding this new vision for the registry.

## Cancer Registries

An established national system of state-based cancer registries, plus recent advances in health information technology, means that much data already exist that could be useful for improving cancer care. However, these data are not currently available in a way that can assist with decisionmaking by patients, providers, payers, and policymakers because, under current state law, registries do not publicly report, or allow others to publicly report, performance metrics by named provider (e.g., hospital or medical group) using cancer registry data.<sup>11</sup>

### The Basics of Cancer Registries

Health care providers in all 50 states are required by law to report new cases of cancer to their state’s cancer registry. Also, two national cancer registry programs have been developed by the federal government: the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI), and the National Program of Cancer Registries of the Centers for Disease Control and Prevention (CDC). Together, these two registry programs collect data for the entire US population and report annual cancer incidence rates for the nation.<sup>12</sup> Historically, reporting to the state registries has been done largely by hospitals and their certified cancer registrars, who identify new cases of cancer from hospital pathology, radiation oncology, imaging, and other medical and administrative records. After quality control procedures, state cancer incidence data are sent to one or both of the two national cancer registry programs. The CCR, on which this brief

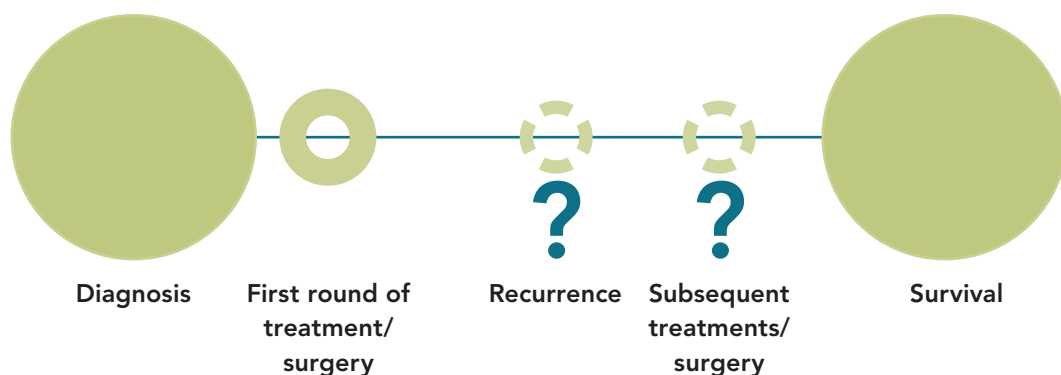
focuses, contributes to these national programs, but on its own is one of the largest population-based cancer registries in the world. Importantly, the CCR contains very accurate, critically important information on two aspects of each cancer patient: specific information on the tumor at diagnosis, and the fact and cause of death. No other data source holds these two pieces of information for the entire population of cancer patients in California, making the CCR uniquely able to contribute data that are central to assessing cancer care quality.

### Registry Data Are Necessary But Not Sufficient to Measure Quality of Care

Despite their valuable contributions, population-based cancer registry data alone, in their current form, do not provide adequate information for measuring, reporting, and therefore understanding the quality of cancer care. Although these registries contain critical, highly accurate information about who was diagnosed with cancer, what specific kind it was, and who died from it, they lack full details about the treatment provided that are vital to assessing quality (e.g., detailed information on the course of chemotherapy and radiotherapy). Some information is collected about the first course of treatment but it tends to be incomplete. Further, there is no information in the registries on recurrence and subsequent treatment after initial cancer treatment, which are likewise vital data in ultimately assessing the quality of cancer care (see Figure 1). Thus the existing strength of the population-based registries in understanding the quality of cancer care would be considerably enhanced if combined with additional types of data.

**Figure 1.**  
**Cancer Registries: Data Strengths and Weaknesses**

Cancer registries capture a wealth of information on diagnosis and survival, and some information on the first round of treatment, but nothing related to recurrence or to subsequent surgery or other treatments.



Source: Adapted from the California HealthCare Foundation.

Another limitation of cancer registry data is that generally they are made available only when the registry produces annual incidence rates which, because of rigorous quality control procedures, can take 18 months or more after cancer diagnosis. For quality measurement and especially quality improvement purposes, however, these data need to be made available much earlier so that they can be used more effectively to report on current oncologic practices and are thus more actionable for patients and providers.

It should be noted that all the limitations with registry data discussed in this section are understandable given that these registries, established decades ago, were designed for public health surveillance and not as quality measurement tools.

## Opportunities for Leveraging Registry Data with Other Sources

In the current era, when quality measurement has become more routine, expected, and potentially useful, there is an opportunity to leverage registry data with other sources of information to gain an understanding of the quality of cancer care being delivered by specific providers. The good news is that much of the information lacking in cancer registries can be found in these other data sources, in particular health insurance claims data and clinical data contained in health system EHRs. These other data sources can provide complementary information (e.g., treatment regimens, side effects

and adverse reactions, relapse rates, utilization, and costs of care) which can be used to provide a more complete picture of cancer care quality and health system performance. The gaps filled by linkages between cancer registry data and these other data sources could allow for meaningful, timely quality of care measurement and public reporting,

### Successful Linkages of Cancer Registries with Claims Data

Health insurance claims data are important to quality measurement because they contain detailed, accurate information about what treatments a patient received, some of which is missing from registry data. A number of linkages between cancer registry data and claims data (or encounter data, in the case of managed care) have already been achieved. Perhaps the most successful and productive of these has been the linkage of SEER with Medicare administrative data. Established in 1991 by NCI and the Centers for Medicare & Medicaid Services (CMS), this linkage has allowed cancer researchers to understand treatment patterns for cancer patients age 65 and over using data on Medicare-covered medical services that are not reported, or are reported incompletely, through SEER.<sup>13</sup>

### Potential for Linkage of Cancer Registries with Electronic Health Records

Health system EHR data contain yet another layer of detailed clinical information not captured in population registries or claims data. EHRs are being broadly implemented nationally and are now employed in approximately 77% of oncology practices.<sup>14</sup> However, they are not yet used for standardized reporting, for several reasons, including difficulty

extracting information from text entries and the limited interoperability of the many different proprietary EHRs currently in use. Despite these limitations, the rapid, extensive growth of EHR use, plus the relative ease with which electronic data can be transferred, makes them an attractive candidate for linkage with cancer registries, as research has shown.<sup>15</sup>

Thus, complementary data sources exist and, from a technical perspective, it is possible to successfully link these sources. However, as previously noted, current state laws do not permit cancer registries to use their data to publicly report or allow others to publicly report performance metrics by a named provider (e.g., identified hospital or medical group). Making the data meaningful to patients, providers, payers, policymakers, and others requires such public identification of providers.

## A Vision for the Future

The workgroup has developed the framework for a quality of care reporting system that could provide reliable registry data on cancer patients within six to nine months of diagnosis. It would include routine periodic linkage of registry data to health insurance claims data for cancer patients across all health systems. Eventually, adding linkages to cancer care providers' EHR data would capture additional clinical detail on treatment, recurrence, and follow-up. The data on cancer care quality generated by this reporting system could be used to inform patients and providers about care decisions, as well as benefit payers, health care systems, quality improvement organizations, and policymakers.

Ultimately, the envisioned reporting system would be bidirectional, with data flowing from claims databases to the CCR and the CCR offering timely information back to providers regarding health services received by their patients from other providers and facilities, as well as patient outcomes. The linkages would also provide the data needed to test and develop improved cancer care quality performance measures, which in turn would become available to patients, providers, payers, policymakers, and the general public, to help identify providers based on performance. Overall, the cancer registry and its existing well-developed infrastructure would serve as the cornerstone upon which additional building blocks would produce data on quality of cancer care that could be made publicly available.

Multiple steps would need to be taken to realize this vision of a reporting system for cancer care quality. Importantly, statutory, regulatory, and administrative policy changes would be needed to address legal issues. The enabling statutes of the CCR require reporting of cancer cases by each provider who diagnoses or treats cancer but the data generated may be used only for public health surveillance purposes and for approved research.<sup>16</sup> In all other respects, the data stored in the CCR are confidential.<sup>17</sup> These legal provisions effectively prevent public reporting of provider-specific data, which is essential to the proposed system, and so would have to be amended to achieve the vision articulated here.

There are also many stakeholders to consider in the development of a system to measure cancer care quality. These include cancer patients first and foremost, as well as cancer care providers, payers (both public and private), and policymakers. Patient confidentiality would be maintained, but to serve

patient decisionmaking, which is a fundamental goal of the proposed system, quality measures would be reported for identified cancer care providers. This may be a challenge due to providers' financial and reputational sensitivities as well as concerns about what constitutes meaningful measures of care. Provider stakeholders should be included in the development of the reporting system from the start, and implementation of the system should be phased in to allow time to solicit and incorporate feedback from providers, especially about the measurement methods and data collection processes.

Additionally, numerous technical issues must be addressed to establish linkages between the CCR database, health insurance claims data, and health system EHRs. Tools are needed that would apply standardized methods for reporting structured data elements to cancer registries.<sup>18</sup> The data generated for the new system would need to be of sufficiently high quality to minimize duplicate reporting and mismatches when patients visit more than one provider. Methodological challenges also must be solved. For example, because multiple oncologic specialties and sometimes multiple institutions may be involved in a single patient's care, a system must be developed to effectively assign attribution (i.e., which provider or practice is most directly responsible for a patient's care).

## Recommendations

The time is ripe for a new look at how cancer registries can be used for the benefit of individual patients, the public, health care providers, payers, and policymakers. In this newly envisioned system, the movement toward public reporting of cancer care performance metrics would be supported by the evolving technical ability to link large amounts of data from claims and EHRs with existing cancer registry data. The knowledge and capacity to realize this vision are at hand and California can lead the way. The workgroup's proposals below are intended to facilitate the needed linkages, thereby broadening and adding value to the state's existing significant cancer data infrastructure.

**1. The legislative mandate for the California Cancer Registry (California Health and Safety Code, Section 103885 et seq.) should be expanded to include use of registry data for quality of cancer care measurement and public reporting.** To accomplish this:

- ▶ Relevant oncologic care providers would need to be defined, identified, and categorized so that required reporting of cancer quality measures is appropriately specific.
- ▶ A set of quality of cancer care performance measures across all phases of care, plus other standardized data, should be identified as suitable for use in public reporting.
- ▶ A publicly transparent process should be developed to identify a neutral, trusted third party to efficiently aggregate data from the sources the workgroup has identified, and from other sources that may emerge, to serve as a broker for public reporting.

**2. The CCR, other relevant state agencies, and health care payers in the state should work toward developing a system for routinely linking CCR data with health insurance claims data.**

- ▶ This is now technically feasible, but the workforce support to implement this recommendation needs to be identified and sustained.

**3. A strategy should be developed for linking clinical data contained in health system EHRs and the CCR; cancer care providers should be deeply involved in this effort from its inception.**

- ▶ Research support to develop the best methods for such linkages is needed. Both cancer care providers and EHR vendors should be involved in this effort.

**Model Statute:** For informational purposes, the workgroup has developed a "model statute," expanding upon existing state law and intended to illustrate what the workgroup's recommendations might look like if enacted into California law. This model statute is presented in an appendix to this report.

### About the Authors

The authors are members of an ad hoc workgroup of experts convened by the California HealthCare Foundation. This workgroup explored leveraging the well-established CCR to produce quality of care metrics for cancer care in California that would be accessible to and meaningfully usable by patients, providers, payers, and policymakers. The individual authors are:

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# Appendix: A Model Statute to Amend California's Cancer Reporting Laws

This “model statute” is provided for informational purposes to illustrate what the workgroup’s recommendations might look like if enacted into California law.

The recommendations were drafted by members of an ad hoc workgroup of experts established and funded by the California HealthCare Foundation. This workgroup explored leveraging the well-established California Cancer Registry (CCR) to produce quality of care metrics for cancer care in California that are accessible to and meaningfully usable by patients, providers, payers, and policymakers. Specifically, the workgroup analyzed the technical, legal, cultural and other barriers to expanded use of the CCR. The key recommendations of the workgroup are:

1. **The legislative mandate for the California Cancer Registry (California Health and Safety Code, Section 103885 et seq.) should be expanded to include use of registry data for quality of cancer care measurement and public reporting.**
2. **The CCR, other relevant state agencies, and health care payers in the state should work toward developing a system for routinely linking CCR data with health insurance claims data.**
3. **A strategy should be developed for linking clinical data contained in health system EHRs and the CCR; cancer care providers should be deeply involved in this effort.**

The model legislation presented below reflects the workgroup’s first and second recommendations. The third recommendation is not addressed in the model statute given that issues of health information technology and interoperability are being addressed at the federal level (e.g., meaningful use) and by the private market (e.g., EHR vendors).

**Note:** Workgroup members participated in this effort as individuals, with expertise in cancer care, registries, quality measurement, and improvement. Participation in the workgroup and presentation or review of this model statute do not imply endorsement of the model statute on the part of any organization.

## Digest

Existing law has allowed California to create an excellent and highly functional cancer registry system that reports cancer statistics on new cancer cases, deaths, tumor stage at presentation, extent of disease, and survival rates. Measures of the quality of cancer care, however, are not easily accessible to patients, providers, payers, policymakers, and the general public. The current system captures detailed data on the initial occurrence of cancer and mortality, but less detail on initial treatment and no information on cancer recurrence and subsequent treatments.

Research studies have shown that linking various cancer care claims or claims databases is technically feasible and can produce a fuller picture of the nature and quality of cancer care. Linking data collected and maintained by the California Cancer Registry (CCR) to cancer care treatment claims data could provide the necessary infrastructure for public reporting on the quality of cancer care.

Existing law requires the reporting of cancer cases by each provider who diagnoses or treats the condition. The data generated are used for overall cancer reporting and can be made available for scientific research with approval by the CCR. In all other respects, however, data stored in the CCR, including provider data, are confidential.

This bill would leverage the existing strengths of cancer registration to improve decisionmaking and the quality of cancer care. It would require the director of the Department of Public Health and the CCR to develop a system for reporting cancer quality of care measures.

This bill would also require the director, with the help of a multi-stakeholder committee and technical expertise, to develop linkages between the reported cancer care data and existing databases of public and private health insurance cancer care claims. These linkages would be designed to result in improved measures of the quality of cancer care.

By requiring the assessment and public reporting of cancer care quality, this bill would help patients, providers, payers, policymakers and others assess and select cancer care providers and treatment options without compromising patient privacy.

**Note:** The bill retains the language of the existing statute but adds such language as is indicated by underlined text.

**Section 1: Section 103875 of the Health and Safety Code is amended to read:**

**§ 103875. Epidemiological assessments of incidence of cancer; program; reports**

- (a) The department shall conduct a program of epidemiological assessments of the incidence of cancer. The program shall encompass all areas of the state for which cancer incidence data are available. The program shall include the monitoring of cancers associated with suspected carcinogens encountered by the general public both in occupational locations and in the environment generally.
- (b) The program shall be under the direction of the director, who may enter into contracts as are necessary for the conduct of the program and may accept, on behalf of the state, grants of public or private funds for the program. The director shall analyze available incidence data and prepare reports and perform studies as necessary to identify cancer hazards to the public health and their remedies.
- (c) The director shall analyze data collected under the program to assess, measure and publicly report on the quality of cancer care in the state. In assessing and measuring the quality of cancer care in the state, the director shall define and identify oncology providers. In publicly reporting on the quality of cancer care in the state, the director shall identify oncology providers but not any cancer patients. The director may contract with an entity to assess, measure and publicly report on the quality of cancer care in the state.
- (d) The director shall develop a system for routine, automated linkages between data collected under the program and public and private health insurance payer cancer care claims data. The director shall convene a cancer care stakeholder committee, including public and private payer representatives and persons with appropriate technical expertise, to study and make recommendations to the director for developing the automated linkage system. The director may contract with entities or persons to provide the committee with appropriate technical expertise representation.
- (e) It is the intent of the Legislature that an appropriation be included in each Budget Act in an amount sufficient to provide for the annual cost of the program. It is the intent of the Legislature that the cancer care quality measures be available for use by the public for improving health care and population health as it relates to the prevention and treatment of cancer, including by cancer patients themselves.

**Section 2: Section 103885 of the Health and Safety Code is amended to read:**

**§ 103885. Statewide cancer reporting system; designated regional registries; reporting of cases; confidentiality of information; use of federal funds**

- (a) The director shall establish a statewide system for the collection of information determining the incidence of cancer, using population-based cancer registries modeled after the Cancer Surveillance Program of Orange County. The director shall also identify and include in the statewide system cancer care quality measures for use in public reporting. As of the effective date of this section the director shall begin phasing in the statewide cancer reporting system. By July 1, 1988, all county or regional registries shall be implemented or initiated. By July 1, 1990, the statewide cancer reporting system shall be fully operational. Within 60 days of the effective date of this section, the director shall submit an implementation and funding schedule to the Legislature.
- (b) The department may designate any demographic parts of the state as regional cancer incidence reporting areas and may establish regional cancer registries, with the responsibility and authority to carry out the intent of this section in designated areas. Designated regional registries shall provide, on a timely basis, cancer incidence data as designated by the state department to the department. The department may establish a competitive process to receive applications for, and issue, the award of a contract, grant, or allocation of funds, including, but not limited to, a cooperative agreement, subvention agreement, or any other agreement allowed by law, to an agency, including, but not limited to, a health systems agency, single county health department, multicounty health department grouping, or nonprofit professional association to operate the statewide cancer reporting system and to enter into contracts, or issue grants or funding allocations to other agencies representing a designated cancer reporting region for the purposes of collecting and collating cancer incidence data. The award of these contracts, grants, or funding allocations shall be exempt from Part 2 (commencing with Section 10100) of Division 2 of the Public Contract Code. The department shall include appropriate terms and conditions in a contract, grant, or funding allocation to ensure the proper use of state funds, including provision for reimbursement of allowable costs, financial reporting, program performance reporting, monitoring of subgrants, subcontracts, or suballocations to an agency representing a designated cancer

reporting region, retention and access requirements for records, data use and management, independent auditing, termination, and disposition of assets acquired under the contract, grant, or funding allocation.

- (c) The director shall designate cancer as a disease required to be reported in the state or any demographic parts of the state in which cancer information is collected under this section. All cancers diagnosed or treated in the reporting area shall thereafter be reported to the representative of the department authorized to compile the cancer data, or any individual, agency, or organization designated to cooperate with that representative.
- (d)(1) Any hospital or other facility providing therapy to cancer patients within an area designated as a cancer reporting area shall report each case of cancer to the department or the authorized representative of the department in a format prescribed by the department. If the hospital or other facility fails to report in a format prescribed by the department, the department's authorized representative may access the information from the hospital or the facility and report it in the appropriate format. In these cases, the hospital or other health facility shall reimburse the state department or the authorized representative for its cost to access and report the information.
- (2) Any physician and surgeon, dentist, podiatrist, or other health care practitioner diagnosing or providing treatment for cancer patients shall report each cancer case to the department 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.
- (e) Any hospital or other facility that is required to reimburse the department or its authorized representative for the cost to access and report the information pursuant to subdivision (d) shall provide payment to the department or its authorized representative within 60 days of the date this payment is demanded. In the event any hospital or other facility fails to make the payment to the department or its authorized representative within 60 days of the date the payment is demanded, the department or its authorized representative may, at its discretion, assess a late fee not to exceed 1 1/2 percent per month of the outstanding balance. Further, in the event that the department or its authorized representative takes a legal action to recover its costs and any associated fees, and the department or its authorized representative receives a judgment in its favor, the hospital or other facility shall also reimburse the department or its authorized representative for any additional costs it incurred

to pursue the legal action. Late fees and payments made to the department by hospitals or other facilities pursuant to this subdivision shall be considered as reimbursements of the additional costs incurred by the department.

- (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. Willful failure to grant access to those records shall be punishable by a fine of up to five hundred dollars (\$500) each day access is refused. Any fines collected pursuant to this subdivision shall be deposited in the General Fund.
- (g)(1) Except as otherwise provided in this section, all information collected pursuant to this section shall be confidential. For purposes of this section, this information shall be referred to as "confidential information."
- (2) The department and any regional cancer registry designated by the department shall use the information to determine the sources of malignant neoplasms, evaluate measures designed to eliminate, alleviate, or ameliorate their effect, and assess and publicly report on the quality of cancer care in the state.
- (3) The following persons who meet qualifications as determined by the department, and who agree, in writing, to maintain confidentiality, may be authorized access to confidential information: (a) persons with a valid scientific background who are engaged in demographic, epidemiologic, quality of care assessment or improvement, or other similar studies related to health; (b) persons engaged in the dissemination of data to the public as it relates to the prevention and treatment of cancer; and (c) persons engaged in improving health care and population health as it relates to the treatment and prevention of cancer, including by cancer patients themselves.
- (4) The department and any regional cancer registry designated by the department may enter into agreements to furnish confidential information to other states' cancer registries, federal cancer control agencies, local health officers, or health researchers for the purposes of determining the sources of cancer, evaluating measures designed to eliminate, alleviate, or ameliorate their effect, and assessing and publicly reporting on the quality of cancer care in the state. Before confidential information is disclosed to those agencies,



officers, researchers, or out-of-state registries, the requesting entity shall agree in writing to maintain the confidentiality of the information, and in the case of researchers, shall also do both of the following:

- (A) Obtain approval of their committee for the protection of human subjects established in accordance with Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations.
  - (B) Provide documentation to the department that demonstrates to the department's satisfaction that the entity has established the procedures and ability to maintain the confidentiality of the information.
- (5) Notwithstanding any other provision of law, any disclosure authorized by this section shall include only the information necessary for the stated purpose of the requested disclosure, used for the approved purpose, and not be further disclosed.
  - (6) The furnishing of confidential information to the department or its authorized representative in accordance with this section shall not expose any person, agency, or entity furnishing information to liability, and shall not be considered a waiver of any privilege or a violation of a confidential relationship.
  - (7) The department shall maintain an accurate record of all persons who are given access to confidential information. The record shall include: the name of the person authorizing access; name, title, address, and organizational affiliation of persons given access; dates of access; and the specific purpose for which information is to be used. The record of access shall be open to public inspection during normal operating hours of the department.
  - (8) Notwithstanding any other provision of law, no part of the confidential information shall be available for subpoena, nor shall it be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding, nor shall this information be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason.
  - (9) Nothing in this subdivision shall prohibit the publication by the department of reports and statistical compilations that do not in any way identify individual cases or individual sources of information.
  - (10) Notwithstanding the restrictions in this subdivision, the individual to whom the information pertains shall have access to his or her own information in accordance with Chapter 1 (commencing with Section 1798) of Title 1.8 of the Civil Code.

(h) For the purpose of this section, "cancer" means either of the following:

- (h)(1) All malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkins disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin.
  - (2) All primary intracranial and central nervous system (CNS) tumors occurring in the following sites, irrespective of histologic type: brain, meninges, spinal cord, caudae equina, cranial nerves and other parts of the CNS, pituitary gland, pineal gland, and craniopharyngeal duct.
- (i) Nothing in this section shall preempt the authority of facilities or individuals providing diagnostic or treatment services to patients with cancer to maintain their own facility-based cancer registries.
  - (j) It is the intent of the Legislature that the department, in establishing a system pursuant to this section, maximize the use of available federal funds.

## Endnotes

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