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Breast Cancer Survival Rates and Health Plan Services

By Joel Cohen

*Prepared at the Request of
Speaker of the Assembly
Antonio R. Villaraigosa*

JANUARY 2000

CRB-00-001

C A L I F O R N I A R E S E A R C H B U R E A U

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TABLE OF CONTENTS

INTRODUCTION	1
WHY THIS QUESTION IS IMPORTANT	1
DATA NEEDED TO ANSWER THE QUESTION	2
CALIFORNIA CANCER REGISTRY	2
DATA COLLECTION: OBSTACLES AND OPPORTUNITIES.....	5
1. DECREASED STATE FISCAL SUPPORT.....	5
2. UNEVEN ACCURACY OF PATIENT DATA	6
3. INCOMPLETE TREATMENT DATA	7
4. LIMITED HEALTHCARE PLAN INFORMATION.....	7
5. MISSED HEALTHCARE PLAN CHANGES.....	8
6. UNEVEN REPORTING BY FREESTANDING SURGERY FACILITIES	8
7. REPORTING BY IN-STATE PATHOLOGY LABORATORIES	9
8. NO REPORTING BY OUT-OF-STATE PATHOLOGY LABORATORIES	9
9. LIMITED REPORTING COMPLIANCE BY DOCTORS' OFFICES.....	9
10. INCOMPLETE FOLLOW-UP DATA.....	10
11. INSUFFICIENT TRAINING OF HOSPITAL CANCER REGISTRARS	11
APPENDIX A	12
APPENDIX B	13
APPENDIX C.....	14
BIBLIOGRAPHY	21

INTRODUCTION

Breast cancer is the most commonly diagnosed cancer in California among women regardless of age, race, and ethnicity, according to the California Cancer Registry. Over 99 percent of breast cancer patients are women. One of the most treatable types of cancer, particularly if detected early, breast cancer is still the second leading cause of women's death by cancer in California and the United States.

Speaker of the Assembly Antonio R. Villaraigosa requested that the California Research Bureau (CRB) correlate breast cancer victims' five-year survival rates with their healthcare plans. However, the research project changed when it became apparent that the data to correlate healthcare plans with breast cancer patient survival rates are not available. Thus, the Speaker requested that CRB research what it would take to collect the necessary information.

This report presents the analytical framework needed for a five-year breast cancer patient survival study. Specifically, the report explains what information is needed, what information is collected, and what information still needs to be collected. Important to that discussion is a description of the Department of Health Services' Cancer Registry's organization and activities.

Why This Question is Important

The National Academy of Sciences *Quality of Healthcare in America* project notes in a recent report that, "When agreement has been received to pursue a course of medical treatment, patients should have the assurance that it will proceed correctly and safely so they have the best chance possible of achieving the desired outcome."*

Currently, information that correlates healthcare plans to breast cancer treatment and survival is not available.◇ Therefore, when choosing a healthcare plan, a woman lacks the information by which to judge whether timely and beneficial services may be provided by her healthcare provider. Further, healthcare organizations need good information based on a sound reporting system in order to identify problems, evaluate causes, and take action to improve performance.

Some healthcare companies have begun to issue healthcare report cards that report on the uniformity and timeliness of specific services. Services may include early diagnosis, proper use of equipment, and timely reporting of test results. The medically correct application of such services can increase a breast cancer patient's longevity. Healthcare plans are annually critiqued by popular magazines including *Consumer Reports* and *U.S. News & World Report*. The California Public Employees' Retirement System (CalPERS) provides basic comparative healthcare plan information to state employees. CalPERS summarizes – in matrix format – the out-of-pocket costs associated with specific healthcare services offered by the health

* Institute of Medicine. Committee on Quality of Health Care in America. *To Err is Human, Building a Safer Health System*. November 1999.

◇We understand that a report published by the Kaiser Permanente Medical Group produced outcome studies on a variety of conditions including breast cancer.

maintenance organizations (HMOs) and preferred provider organizations (PPOs) available to state employees. The documents also provide overall employee satisfaction ratings with healthcare plans, but not with the specific services they offer. It is not currently possible to evaluate these healthcare plans according to their five-year breast cancer survival rate.

DATA NEEDED TO ANSWER THE QUESTION

The data needed to answer the question is sensitive, and consequently the Cancer Registry retains a high level of confidentiality. Three separate categories of data (not all of which currently exist) are required to evaluate the five-year survival rates of breast cancer patients by healthcare plan:

1. Individual Patient and Health Plan Records

Individual patient records generally include information on a patient's medical history, including services provided by the healthcare plan (such as inpatient and outpatient hospital care, doctors' and ambulatory care files, and laboratory results).

2. Death and Survival Data Sets

The state collects and maintains death and survival data sets. The actual death and morbidity diagnoses are collected by the Department of Health Services in the California Death Statistical Master File and the California Death Registration Program. In addition, other data sets are corroborated regarding the survival or death of individuals since the previous update.

3. Comprehensive Reporting of Cancer Cases

Comprehensive reporting of cancer cases would include all cancer cases reported by inpatient and outpatient hospitalization, freestanding medical facilities, pathology labs, and doctors' offices, and would include stage(s) of diagnosis and updates of diagnosis status. Currently, only parts of this reporting system exist, and collection is not uniform.

CALIFORNIA CANCER REGISTRY

Since 1947, various California hospitals and regional population-based registries have collected and pooled data on cancer. In 1988, the Legislature created a population-based cancer data collection system. The California Cancer Registry collects statewide data on all cancers (except for skin cancer) listed in the regional registries. The mission of the Cancer Registry is to develop statistical and data collection tools and use them as a basis for research into the prevention, causes, detection, and cures of cancer. According to the Cancer Registry, roughly 135,000 new cancer cases in California occurred in 1996 (the most recent year of complete data), of which 19,327 were breast cancer cases. The Chief of the Cancer Registry, William Wright, believes that the Cancer Registry collects information on virtually all breast cancers diagnosed in the state (based on trends of morbidity and death and comparisons with national estimates). However, CRB research presented below suggests potentially significant points at which data may be missing.

The Cancer Registry has the following goals:

- Conducting research into the causes and cures of cancer
- Identifying inequalities in cancer risk factors and incidence, and gaps in treatment and outcomes among the State's diverse population subgroups
- Building and maintaining an easily accessible data system that will support policy analysis and program decisions
- Providing up-to-date information to the public to address concerns about cancer

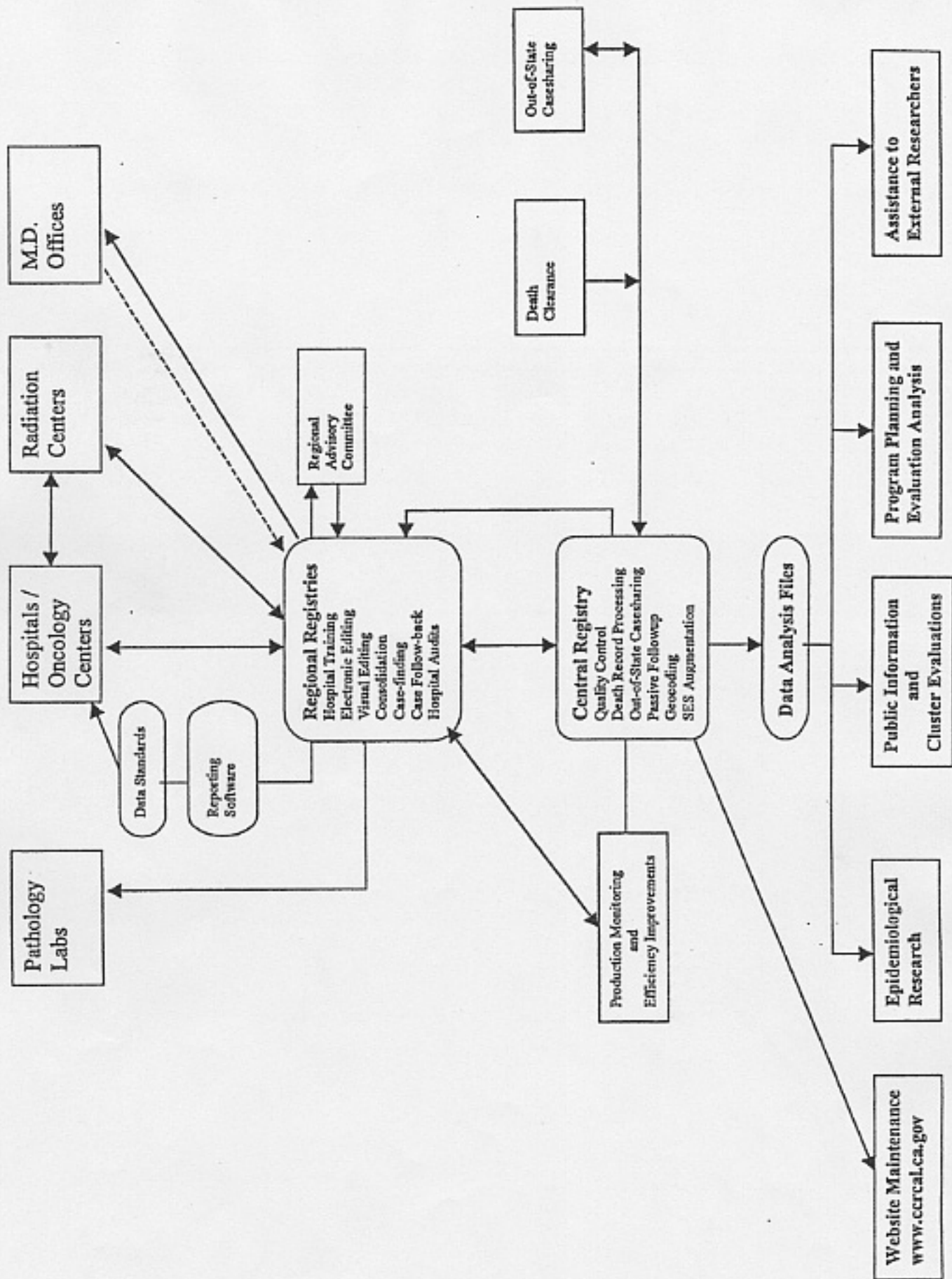
The Cancer Registry has a set of 11 operating principles (see Appendix B), the first three of which focus on data collection and integrity:

1. **Data Integrity and Standardization:** To assure that data are of scientific quality and standardized throughout all reporting sources.
2. **Confidentiality:** To protect the confidentiality of all cancer patients and ensure that the data are used only for research purposes.
3. **Regional Presence:** To maintain regional presence to certify data quality, to collaborate with local health officials for public response and education, and to use data for regionally generated research.

The Cancer Registry is composed of a central office and eight regional offices. The regional registries are responsible for collecting data incidence reports from California healthcare providers (hospitals and physicians) and relaying that information to the central office. Hospital registrars transmit and submit the data to a regional office. A diagram (Figure 1) of the Cancer Registry system is presented on the following page. The Cancer Registry regions include:

- **Central Region:** Fresno, Kern, Madera, Mariposa, Merced, Stanislaus, Tulare, and Tuolumne counties
- **Sacramento Region:** Alpine, Amador, Calaveras, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Solano, Sutter, Yolo, and Yuba counties
- **Tri-County Region:** San Luis Obispo, Santa Barbara, and Ventura counties
- **Desert Sierra Region:** Inyo, Mono, Riverside, and San Bernardino counties
- **North Region:** Butte, Colusa, Del Norte, Glenn, Humboldt, Lake, Lassen, Mendocino, Modoc, Napa, Plumas, Shasta, Siskiyou, Sonoma, Tehama, and Trinity counties

Figure 1. California Cancer Registry System Architecture



- **Bay Area Region:** Alameda, Contra Costa, Monterey, San Benito, Santa Clara and Santa Cruz, Marin, San Francisco, and San Mateo counties
- Los Angeles County
- Orange, Imperial and San Diego counties

DATA COLLECTION: OBSTACLES AND OPPORTUNITIES

The Cancer Registry data collection system is complex and has a number of links, and some of which are weak. This report identifies 11 problem areas, each of which is discussed below in detail.

1. Decreased State Fiscal Support

The Cancer Registry received \$6.7 million in state funds in FY 1998-99, more than \$1 million less than it received in FY 1990-91. State funding was reduced from \$7.79 million in FY 1990-91 to \$5.45 million in FY 1991-92, and has yet to be fully restored. (See Table 1 for funding information over the last decade.) The figures in Table 1 are in nominal and not inflationary dollars.

Table 1
Contract Funding and State Staffing History for the CCR by Fiscal Year

Fiscal Year	General Fund	Prop 99	Breast Cancer Tax Fund	Total	State FTEs	Incident Cases ^a
88/89	\$6,755,999	0	0	\$6,755,999	11.0	122,803
89/90	\$6,755,999	\$1,077,000	0	\$7,832,999	14.8	124,321
90/91	\$6,681,745	\$1,111,000	0	\$7,792,745	12.8	131,858
91/92	\$4,377,757	\$1,077,000	0	\$5,454,757	9.8	136,844
92/93	\$4,377,757	\$979,137	0	\$5,356,894	9.8	143,226
93/94	\$4,141,257	\$1,016,589	\$517,720	\$5,675,566	7.8	140,941
94/95	\$4,155,457	\$1,071,418	\$749,805	\$5,976,680	7.8	131,521 ^b
95/96	\$4,029,807	\$1,071,418	\$918,497	\$6,019,722	7.8	132,648
96/97	\$4,029,807	\$1,071,418	\$1,316,172	\$6,417,397	7.8	133,986
97/98	\$4,029,807	\$1,071,418	\$1,580,726	\$6,681,951	7.8	135,990
98/99	\$4,029,807	\$1,071,418	\$1,580,797	\$6,682,022	7.8	^c
99/00	\$4,029,807	\$1,067,110	\$1,580,527	\$6,677,444	7.0	

^a Incident cases are the number of cases reported in a calendar year. This number represents a rough estimate of workload. It does not include increasing work to maintain and service the expanding registry datafile, increasing costs to collect data for the increasing number of cases that are not hospitalized, and the increasing number of requests to investigate cancer clusters and to respond to requests from researchers.

^b Due to reduced funding, the CCR made a decision in 1994 to stop collecting cases of *in situ* cervical cancer which represented approximately 8,000 cases per year. These were the lowest priority cases due to low quality data and the cost to collect them.

^c Case reporting is not complete for 1998 or 1999 calendar years.

In response to the 1991 budget cuts, the Cancer Registry reduced the number of its central office fulltime employees from 13 to seven, decreased its activities, and closed two regional

offices. (The Silicon Valley office merged with the San Francisco office, and the San Diego/Imperial office merged with the Orange County office.) As a result, fewer field inspections examining the quality of reporting in hospitals and pathology laboratories are conducted, according to the Cancer Registry. The funding reductions impacted the following central office activities:

- Eliminated industrial occupation coding
- Eliminated visual editing of treatment data in each treatment file
- Eliminated active patient follow-up on a statewide basis
- Stopped researching quality control of breast cancer treatment in hospital settings
- Reduced writing and publishing cancer data in a more user-friendly format, more accessible for non-researchers
- Delayed the timeliness of the data

Option

The Cancer Registry estimates that it requires \$11 million, including \$4.3 million in new funds, to restore the quality and quantity of its pre-1992 data collection efforts. Funding sources might include some foundation support and/or selling of data and technical services. Currently, two regions (Los Angeles and San Francisco) receive National Institutes of Health funds to improve collection and reporting of their data. The rest of the state does not benefit from these additional funds, however, creating an uneven data collection system.

2. Uneven Accuracy of Patient Data

The Cancer Registry collects 286 data items pertaining to hospital inpatient and outpatient visits through hospital registration procedures, once per illness. In addition, doctors' offices send a report to the Cancer Registry each time they diagnose a patient with cancer, if that patient is not seen by a cancer reporting facility. These procedures allow the Cancer Registry to collect accurate initial visit data without compelling patients to complete additional and duplicative data surveys.

The items collected by hospitals and doctors' offices include patient identification, diagnosis procedures, tumor data, and treatment. All of the 286 items are checked by computer. A large percentage of the data collected is not usable for research without additional and costly analysis. For example, the patients' ages are not verified for accuracy. Of the 286 items, 13 are manually checked. (The data set of 286 items is presented in Appendix C) The Registry only certifies the following 13 checked elements:

- County of residence at diagnosis
- Sex
- Race
- Spanish/Hispanic origin
- Date of diagnosis

- Site/subsite
- Laterality (distinguishes location in a paired site, i.e., a right or left breast)
- Histology (the type of cells that make up the tumor)
- Tumor size
- Extent of Disease (EOD)-Extension
- Extent of Disease (EOD)-Lymph node involvement
- Number of regional nodes positive/examined

Option

The Cancer Registry could expand its minimum quality data set. It might include a description of the data elements required to correlate healthcare plans with breast cancer survival rates, and protocols describing how the data should be checked for accuracy.

3. Incomplete Treatment Data

The Cancer Registry only gathers information pertaining to a patient's first course of treatment in a hospital or doctor's visit. Therefore, the Cancer Registry cannot account for a complete medical history over time or provide accurate case studies of a person through inpatient hospitalization. Once a patient has registered in the system, her data file remains static unless another type of cancer materializes. A useful data system would collect information about each treatment service point.

Option

If data collection were performed on a visit-by-visit basis, it would provide a more exhaustive portrait of the course of treatment of each patient. The Cancer Registry could require a minimum level of appropriate reporting. Without this information, one cannot evaluate a healthcare provider's quality of care over the course of the disease.

4. Limited Healthcare Plan Information

Since 1996, the Cancer Registry has collected information on primary and secondary sources of health insurance data. Of the 286 data elements the Cancer Registry collects, only 13 elements are checked manually and these 13 are certified as accurate. The two healthcare plan data elements (the type of primary and secondary payment source, and a text field with the healthcare plan's name) are (like 273 other elements) not checked and therefore not certified for accuracy.

Options

There are two non-exclusive methods to recover the data on healthcare plans currently collected by the Cancer Registry in a certifiable format useful for research and evaluation purposes. The first method would be to institute manual checking of the three healthcare data elements in order to ensure accuracy. The second method would be to conduct a validation study on a statewide sampling of hospital registrations to certify that the healthcare plan data elements are accurate. This method would entail matching the data entries in the Cancer

Registry with the hospital records.

Alternatively, the State collects and evaluates inpatient, but not outpatient, hospital discharge data through the Office of Statewide Health Planning and Development (OSHPD). By 2001, OSHPD plans to also collect hospital ambulatory data as well. OSHPD's role in gathering healthcare data could be coordinated with the Cancer Registry and expanded as needed to track healthcare plans at a patient level of detail.

5. Missed Healthcare Plan Changes

According to the California Association of Health Plans, ten to 20 percent of people change their healthcare plan coverage annually. While the Cancer Registry currently records the type of healthcare plan (i.e., HMO, PPO) and the healthcare plan name, it does not gather information about changes in patients' healthcare plans. However, as a patient's coverage changes, so may services. The quality of care and treatment provided under different healthcare plans could certainly affect cancer treatment outcomes.

The inability to track changes in patients' healthcare plan coverage makes it difficult to evaluate quality of care issues. Patients change their plans for a number of reasons. One of the reasons may be poor quality of services. For example, if a patient feels that her treatment is poor, she may transfer to another healthcare plan. In the meantime, her disease may worsen and, ironically, the poor outcome could be attributed to the second healthcare plan's provider.

Option

The Cancer Registry only collects data on first report of diagnosis. If the Cancer Registry collected data for each patient visit and included information on healthcare providers over time, the result might be a better record by which to evaluate quality of care and to compare service providers.

6. Uneven Reporting by Freestanding Surgery Facilities

According to Cancer Registry data, approximately nine percent of breast cancer cases are not admitted as inpatients in hospital facilities. Freestanding outpatient surgical facilities (not hospital affiliated) are mandated to report cancer diagnosis and treatment cases. Compliance is uneven. Thus, a data subset from an important provider group may be missing from the Cancer Registry's records.

There are no estimates on the potential number of missing Cancer Registry cases attributable to procedures provided by freestanding surgical facilities. There are a number of possible service delivery models. For example, a facility may maintain its own medical patient records, which are not currently forwarded to the Cancer Registry. In other instances, the doctors may act as independent contractors, keep the records, and file accordingly. Other facilities have affiliated doctors and lease out space to unaffiliated doctors on an as-needed basis.

Option

A patient who does not receive hospital-based care may never be included in the statistics of

the Cancer Registry. Freestanding surgery facilities are in a gray zone for reporting purposes. Uneven coverage and lack of data leave a gap in tracking cancer patients. These facilities could be held to the same accountability and reporting level as other medical facilities.

7. Reporting by In-state Pathology Laboratories

The Cancer Registry regional staff annually reviews the in-state pathology laboratories and laboriously reviews thousands of files. (State law requires that in-state pathology laboratories open their files to Cancer Registry staff.) These laboratories do not independently report their cancer data to the Cancer Registry, unlike hospitals. While reviewed by Cancer Registry staff, this method is a costly and fallible way of determining cancer cases, it has some success: the Cancer Registry's review of pathology laboratories has found 6.2 percent of all those cancer cases not reported by doctors' offices and hospitals. This is a significant number of cases.

Identifying cancer cases through pathology labs also offers a means to check and double-check against cases identified by hospitals and doctors. The current manual check is a practical, yet costly, method for detecting breast cancer patients.

Option

Many hospitals report their cancer cases by computer-generated files. These files are sent electronically on a weekly basis to the Cancer Registry. The same procedures could be developed for the pathology laboratories, decreasing the cost to the Cancer Registry while significantly improving the quality of data.

8. No Reporting by Out-of-state Pathology Laboratories

Doctors have the option of examining biopsies in their offices, sending them to local pathology labs, or sending them to out-of-state pathology labs. Out-of-state pathology labs are not authorized to notify the Department of Health Services or the Cancer Registry when they evaluate a cancer biopsy. However, based on the federal Clinical Laboratory Improvement Act of 1988, out-of-state laboratories are required to present their files to Cancer Registry staff. There are 600 out-of-state pathology labs, according to a spokesperson for the federal Health and Human Services Agency, that analyze California patients' biopsies.

Option

The state may want to initiate discussions with other states about the creation of an interstate compact that could ensure that out-of-state pathology labs handling over a certain number of cases annually are required to notify state Cancer Registries. Alternatively, the federal government could require out-of-state reporting.

9. Limited Reporting Compliance by Doctors' Offices

State law requires doctors' offices to send a report to the Cancer Registry each time they have diagnosed a cancer patient, unless the patient was also seen by a cancer reporting facility. Few doctors' offices actually report cases. According to the Los Angeles Region of the Cancer Registry, doctors' offices reported only eight cases in the region in 1998. By way of

comparison, the Los Angeles regional office handles roughly 35,000 cancer cases a year from other sources.

Before the 1992 budgetary reductions, the Cancer Registry fielded staff to instruct doctors at medical conferences and conventions about the importance of filing cancer patients' records with the Cancer Registry. In addition, the Cancer Registry sent follow-up brochures and informational packets to doctors. Since 1992, the Cancer Registry has sent fewer informational packets and has not attended any medical meetings.

As the Cancer Registry has assumed a less prominent outreach role in promoting itself and the value of its cancer data collection program, doctors' offices have become less compliant in participating in the program. Thus, fewer and fewer doctors are sending data, even though they are legally mandated to do so. The Cancer Registry has never cited a doctor's office for not participating. Some doctors' offices complain that the state mandates too many reporting requirements; however, this information is vital to the Cancer Registry's mission and to cancer research.

Options

The State could fund the Cancer Registry's outreach program to doctors to reverse the trend. In addition, current mandated reporting requirements are not enforced. The Medical Board of California could enforce the reporting requirements for doctors.

10. Incomplete Follow-up Data

Follow-up data is generated by healthcare researchers using various official records including drivers' licenses, car registration, voter registration, social security data, death certificates, and credit reports. A cross analysis of these forms of identification may identify that a patient was alive as of a given date. But, except for the death certificate, none actually state morbidity or cause of death. The death certificate identifies the primary reason for death, but not comorbidity (for example, cancer or pneumonia). Researchers use a process of elimination to determine which patients have survived and which have died.

Follow-up studies using all of these records are funded, through the National Cancer Institute Surveillance, Epidemiology and End Results (SEER) program. However, only the Los Angeles and San Francisco regions participate in the SEER program, so the studies are limited to those areas of the state.

Option

Funding active follow-up studies of patients (using a variety of official records) is imperative to ascertain which patients are surviving. The Cancer Registry could develop an advisory group with the public agencies who collect pertinent data (such as Department of Motor Vehicles, Secretary of State, and federal Health and Human Services Agency) to ensure data is shared in a user friendly format for purposes of comparison.

11. Insufficient Training of Hospital Cancer Registrars

Cancer data collection is a detail-oriented and complicated process. Annual training conducted by the Cancer Registry is required to maintain proficiency in the field. About two-thirds of the state's hospitals have trained cancer registrars, especially the hospitals certified by the American College of Surgeons (see Appendix A). In contrast, about one-third of the state's hospitals rely on non-certified hospital staff, consultants and Cancer Registry staff to file and report the records. Each of these approaches has potential problems. Non-certified staff does not have the training to complete the detailed work. Consultants work on the piecemeal basis, and therefore have an incentive to finish quickly as many reports as possible; consequently, they may not be as accurate. Registry staff also collects the primary data; as they edit the reports, the process loses a second set of eyes to catch errors.

The Cancer Registry and cancer researchers depend on accurate data collection by the hospitals. Any deviation from high quality data collection has serious consequences for accuracy and completeness.

Option

Trained hospital staff are essential to accurate and complete cancer data collection. Therefore, it is important to provide low-cost, up-to-date training to hospital personnel who register the cancer cases. The Cancer Registry could explore teleconference programs and virtual classrooms. It may require some funding to create the initial programs. A partnership with the American Cancer Society might be one mechanism.

APPENDIX A

The Cancer Registry is affiliated with various state and national organizations, as well as the federal government, through funding and data sharing. Important affiliates are listed below. In addition, the Cancer Registry is affiliated with county health departments, advocacy groups, and minority advocacy groups. The Cancer Registry is also a resource for unaffiliated scientists researching cancer in California. Since 1988, Federal and not-for-profit agencies have awarded over \$146 million to California cancer researcher projects that use Cancer Registry data.

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) has a national cancer registry program that it funds for the development of state cancer registries in five-year cycles for specific research projects.

The National Cancer Institute

The National Cancer Institute (NCI), the largest funder of cancer research projects, also has a national cancer registry program. NCI funds projects through the Surveillance, Epidemiology and End Results (SEER) program, in which three of California's eight registry regions participate (Bay Area Region, Los Angeles County and Santa Clara County). These three SEER-affiliated regions have 50 percent of the cancer victims in the State.

American College of Surgeons

The American College of Surgeons (ACOS) has roughly 160 certified hospitals in California (of about 530 total hospitals.) ACOS-affiliated hospitals are required to report their data to the College. In addition, ACOS hospitals retain their own databases for research.

North American Association of Central Cancer Registries

The North American Association of Central Cancer Registries (NAACCR) is a professional organization of population (not hospital) based registries. The Cancer Registry follows the protocols of the North American Association of Central Cancer Registries in data collection and analysis.

American Cancer Society

The national office of the American Cancer Society sets the goals and the agenda for the entire organization, and includes a large research surveillance unit. The organization also funds cancer research projects. The California division of the American Cancer Society supports the Cancer Registry by offering public education campaigns, disseminating materials, and funding the publication of documents.

APPENDIX B

Eleven Operating Principles

1. **Data Integrity and Standardization:** To assure that data are of scientific quality and standardized throughout all reporting sources.
2. **Confidentiality:** To protect the confidentiality of all cancer patients and ensure that the data are used only for research purposes.
3. **Regional Presence:** To maintain regional presence to certify data quality, to collaborate with local health officials for public response and education, and to use data for regionally generated research.
4. **Data Partnerships:** To strengthen the collaboration with data providers to minimize reporting burdens, improve data reporting, and foster wider data utilization.
5. **Modernization:** To implement modern business practices to support organizational objectives, and build and support information systems and technologies to meet changing organizational needs.
6. **Stewardship:** To manage limited resources responsibly and maximize an ability to deliver on our commitments to the State.
7. **Revenue Generation:** To pursue, develop, and support opportunities for income from non-traditional sources.
8. **Strategic Partnerships:** To build sustainable ventures with other organizations.
9. **Staff success:** To implement effective management practices to foster staff's successful achievement of their duties.
10. **Research:** To promote and conduct research applied to the causes and cures of cancer.
11. **Public Information:** To provide Internet and other access to our data, and provide technical assistance to public health officials in accurate interpretation and use of our data.

APPENDIX C

The following is excerpted from the *Cancer Reporting in California Abstracting and Coding Procedures for Hospitals*, published by the Cancer Registry. It is the computerized data collection system used by hospitals.

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