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Are Cancer Registries Unconstitutional?

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Abstract

Population-based cancer registration, mandated throughout the United States, is central to quantifying the breadth and impact of cancer. It facilitates research to learn what causes cancer to develop and, in many cases, lead to death. However, as concerns about privacy increase, cancer registration has come under question. Recently, its constitutionality was challenged on the basis of 1) the vagueness of statutory aims to pursue public health versus the individual privacy interests of cancer patients, and 2) the alleged indignity of one's individual medical information being transmitted to government authorities. Examining cancer registry statutes in states covered by the US National Cancer Institute's SEER Program and the US Centers for Disease Control and Prevention's National Program of Cancer Registries, we found that cancer registration laws do state specific public health benefits, and offer reasonable limits and safeguards on the government's possession of private medical information. Thus, we argue that cancer registration would survive constitutional review, is compatible with the civil liberties protected by privacy rights in the U.S., satisfies the conditions that justify public health expenditures, and serves human rights to enjoy the highest attainable standards of health, the advances of science, and the benefits of government efforts to prevent and control disease.

Keywords

cancer registries; constitutionality; privacy; population-based epidemiology; health surveillance; USA

A Constitutional Analysis of Cancer Registration

All 50 states of the United States now have programs for cancer surveillance, the routine collection and compilation of specified demographic and clinical information about every newly diagnosed, reportable cancer, excluding basal and squamous cell carcinomas of the skin.

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In 1973, the National Cancer Institute (NCI)'s Surveillance Epidemiology and End Results (SEER) Program initiated collection of cancer data in selected states and metropolitan areas chosen to represent a cross-section of the diverse U.S. population (http://seer.cancer.gov/registries accessed Sept.7, 2009). In 1992, the U.S. Congress expanded cancer surveillance to all states with the establishment of the National Program of Cancer Registries (NPCR) to be administered by the Centers for Disease Control and Prevention (CDC) (Cancer Registries Amendment Act, 1992). The data from these cancer registration programs form the basis for systematic public health monitoring of cancer occurrence and outcomes (Jemal, Thun, Ries, Howe, Weir, & Center et al.,, 2008). Cancer registries have been the primary source of statistics regarding national trends in cancer incidence over time, including recent increases in hepatocellular and pancreatic cancer, and a rapid decline and then leveling off of breast cancer. These registries also enable detailed, population-based, epidemiologic studies of cancer causes and outcomes that can inform public health policies, and present actionable steps toward prevention and the reduction of cancer risks (Glaser, Clarke, Gomez, O'Malley, Purdie, & West, 2005).

In recent years, public concerns about privacy rights have also grown. Technologic advances in database storage and management, and successes in sequencing the code for the human genome, have raised public consciousness about identity theft and genetic discrimination, and blurred the distinctions between a person, his or her genetic or other bodily material, and personal identifying information (e.g., name, address). As a consequence, privacy concerns have begun to affect the standard protocols and efficacy of cancer surveillance. For example, citing data security concerns and public accountability, many federal Veterans Affairs hospitals withdrew from participation in state-mandated cancer registries between 2005 and 2007, first in California and later in other states where data about cases of cancer diagnosed at Veterans Affairs hospitals were also made available for research (Furlow, 2007; Kolata, 2007). The withdrawals suggested that patient medical privacy, at least among patients of Veterans Affairs hospitals, outweighs the primary goal of population-based cancer surveillance: collecting a complete census of cancer occurrence.

Challenges to state-mandated cancer registration now include legal questions about its constitutionality. At a 2006 symposium about post-9/11 surveillance, Professor of Law Wendy K. Mariner argued that the general goal of improving public health fails to provide an adequate principle for limiting government intrusions into medical privacy (Mariner, 2007). She posited that research uses of medical data obtained through mandatory disclosures may not outweigh privacy interests and an inherit loss of dignity, concluding that "[p]ublic health encompasses so many functions and activities that far more specificity is needed to begin to analyze exactly what kind of public health purposes are sufficient to override an individual's right to keep personal information private" (Mariner, 2007). Mariner also suggested that a constitutional challenge could dismantle cancer registration as supported by the SEER and NPCR programs.

Because cancer remains a major and growing public health burden, legal arguments challenging the constitutionality of population-based cancer registration pose a serious threat. Therefore, we reviewed statutes that mandate cancer registration and surveillance in states covered wholly or in part by the SEER Program, by the NPCR, or by both programs. Our survey was focused on those provisions of the statutes that declare the purposes of cancer registration and surveillance (Table 1) as well as provisions addressing access to and disclosure of cancer data. We also considered whether individuals suffer an indignity inherent to the transmission of their private information to a state-mandated registry. Recognizing that cancer registration concerns a discrete field of information, we further considered whether privacy, as protected by civil rights and liberties, could be accommodated alongside the human right to benefit from the advancement of science and its applications ("International Covenant on Economic, Social, and Cultural Rights," 1994). We structured our evaluation around the five

conditions described by Childress et al. (2002) that provide a "rough conceptual map to the terrain of public health ethics," and that, if met, would warrant continued support of cancer registration and surveillance over and above individual privacy concerns (Childress, Fadenm, Gaare, Gostin, Kahn, Bonnie, et al., 2002). These conditions include: 1) public justification that includes transparency and public accountability, 2) least infringement on individual autonomy through selection of methods and procedures, 3) effectiveness, 4) necessity, and 5) proportionality in that benefits outweigh infringed interests (Childress et al., 2002).

Public Justification: Specification of the Public Health Functions of Cancer Registries

In contrast to assertions that the public health interests at stake in cancer registration are unconstitutionally vague and that cancer registration violates individual privacy interests, we found that many cancer registration statutes do define specific aims and activities, categories of data to be gathered, reasons for doing so, and rigorous criteria for access to and release of cancer data. This conclusion matches the broader international context in which many countries similarly justify cancer registration. The enabling statute for cancer registration in Ontario, Canada, for example, states that any information or report of a case of cancer shall not be used or disclosed "for any purpose other than for compiling statistics or carrying out medical or epidemiological research" (Cancer Act, 1990)).

Among the statewide regions of the U.S. SEER Program, Connecticut was the first to establish a mandatory cancer registry, doing so under a 1935 statute authorizing investigations concerning cancer (Connecticut Gen. Statutes, Title 19a, Sect. 74 (2007)). Although arguably vague in regard to scientific methods, this statute is specific in scope to cancer and to the kinds of uses for which statewide cancer data are available. This mandate remains typical of cancer registry statutes in that while its language does not reflect recent, scientific advancements such as biomarker discoveries and micro-array analysis, it remains open to incorporating such emerging advancements into authorized cancer research. Similarly, the mandate for the Hawaii Tumor Registry which, like the Connecticut Cancer Registry, is an original SEER registry, supports a specific set of statistical analyses and a general purpose of facilitating cancer research. Although its information may be used broadly, "in the course of any cancer research study approved by the cancer commission of the Hawaii Medical Association," data disclosure is subject to procedural safeguards including restrictions on the publication of identifiable data, and a requirement of approval by the treating physician before cancer patients may be contacted for enrollment in cancer research (Hawaii Revised Statutes, Title 19, Ch. 324 (2006)). Many other cancer registries share in the specific purpose of facilitating cancer research. The Florida Cancer Registry exists to support "any study for the purpose of reducing morbidity or mortality." (Statewide Cancer Registry, FLA. stat. ch. 385.202 (2009)). The Massachusetts Cancer Registry aims to "conduct epidemiologic surveys of cancer and benign brain-related tumors and to apply appropriate preventive and control measures," (Cancer Registry, Mass. Gen. Laws ch. 111, § 111B (2007)). The statutes establishing a statewide cancer registry in Nebraska and Colorado similarly emphasize the prevention, cure, and control of cancer. (Cancer Registry, R.R.S. Neb. § 81-642 (2009); Powers and Duties of the Department of Public Health and Environment, C.R.S. 25-1.5-101 (2009)).

Review of state statutes also suggested that health concerns about environmental contamination developed in the 1970s led to state legislators being more responsive to community demands for better information about geographic cancer incidence patterns and rates (Fairchild, Bayer, & Colgrove, 2007). States like New Jersey, Louisiana, and Michigan enacted cancer registries focused on epidemiologic use of reported cancer data. Declaring that New Jersey "is suffering from the highest mortality rates for cancer in the Nation," its legislature enacted an "up-to-date" registry in 1977 (New Jersey Annotated Statutes, Title 26, Ch. 2-104-108 (2006)). Using

similar language, Michigan and Louisiana established cancer registries in 1978 (Michigan Compiled Laws Service, Public Health Code § 333.2619 (2006); Louisiana Revised Statutes, Title 40, Pt XXVII, § 1299.80 et seq.(2006)). The California Cancer Registry was established by a 1985 statute that specifically mandates use of registry data for environmental and other cancer research (California Health & Safety Code § 103875-103885 (2006)). The statute is particularly strict in regard to the terms and conditions of access to and disclosure of cancer data; it provides that "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 admissible as evidence before any tribunal for any purpose (California Health & Safety Code § 103875-103885 (2006)).

Other state statutes governing cancer registration emphasize the integration of reporting activities with enhanced clinical care that points towards more individualized courses of treatment. These statutes contemplate the more precise tumor classifications now becoming possible with the discovery of genetic and molecular determinants of cancer occurrence and outcomes, and the high-throughput technologies needed for rapid and economical characterizations. The Kentucky Cancer Registry enacted in 1990, for example, established a cancer program combining "the Kentucky Cancer Registry and the cancer patient data management system for the purpose of providing accurate and up-to-date information about cancer in Kentucky" as well as supporting a range of care activities from prevention and screening to therapy and rehabilitation (Kentucky Revised Statutes, Title 18, Sect. 214.556 (2006)). With a comparable interest in patient care, and building on a program of cancer reporting dating to the 1920s, the New Mexico Tumor Registry statute, enacted in 1972 and revised in 1979 and 1996, promotes uses of cancer data that evaluate clinical care and services in terms of cost, efficacy, and other factors (New Mexico Statutes, Title 7, Sect. 4.3.10 (G) (2009)).

Least Infringement: the Value of Public Health and the Condition of Privacy

The constitutionality of cancer registration further depends on its value relative to privacy interests, and its compatibility with privacy rights. The constitutional right to privacy is, in short, a right to be free from arbitrary and unnecessary intrusions by the government. The notion that population-based cancer research violates the privacy of individuals and represents an indignity is predicated on a characterization of privacy as an objective and inherently positive value. However, privacy can also be understood as a qualitative condition that describes the access to or knowledge about peoples' thoughts and opinions, behaviors, and personal property (Nussbaum, 2006). In everyday experience, it commands both a technical character associated with legal rights, and a cultural character associated with what people regard, as private information or intimate knowledge. In a survey of U.K. citizens, for example, researchers found that 81% of respondents did not "consider the confidential use of personal, identifiable information by the National Cancer Registry for the purposes of public health research and surveillance to be an invasion of privacy" (Barrett, Cassell, Peacock, & Coleman, 2006). Similar results were obtained from a similar survey conducted among citizens of the former West German Republic (Barrett, Cassell, Peacock, & Coleman, 2006).

Our institutional experience in cancer surveillance, epidemiologic research, and Institutional Review Board (IRB) oversight of patient-contact research in California also supports a qualified view of medical privacy, even in a country without nationalized health care. From our anecdotal experience based on the small number of inquiries to our IRB since 2005 from potential participants in epidemiologic studies (largely based on data from our regional Northern California SEER registry), we note that the critical interests of potential research participants include freedoms from the stigma of disease, from discrimination by insurance companies and employers, and from causing fear among their family members. The decision

to participate in research appears often to be predicated on confidence that research will not compromise one's freedoms or control over one's body, biological specimens, or associated data.

Because privacy can support individual freedoms and civil liberties, it merits powerful protections in constitutional law. Privacy allows a person to think and act without stigma, discrimination, or fears about the perceptions of others (Nussbaum, 2006). Yet when privacy is achieved through social isolation or exclusion, it can facilitate undesirable outcomes such as depression, suicide, substance abuse, and domestic violence and sexual abuse (Nussbaum, 2006). Privacy is thus associated with a spectrum of outcomes. It is best regarded in the context of public health not as an inherently positive moral value, but rather as a descriptive condition that applies to information, ideas, or behaviors. With respect to civil liberties, privacy about medical information may reduce shame and prevent discrimination and thus have tangible value for cancer survivors who face unemployment, poverty, fear of disease recurrence, or insecurities about their appearance or health.

Cancer patients may demand privacy regarding their personal information while also sharing a common goal of improved understanding about cancer causes and outcomes with cancer researchers who depend on such personal information to advance science. In addition, research may offer its participants tolerance and compassion, allowing them to speak openly about their experiences. The combined efforts of participants and researchers thus work to reshape how people think and talk about cancer, having an impact in both lay and scientific communities. In this way, cancer research not only enhances scientific understanding but also can change popular perceptions of normalcy. That is, our cultural view of the "normal" person can shift from a single healthy adult to a diverse plurality of individuals that includes cancer patients and survivors of both genders and all ages, the at-risk public, family members at elevated risk of being diagnosed with cancer, etc. Therefore, the suggestion that mandatory cancer registration represents an offense against personal dignity because it involves private information rejects the productive possibilities of cancer registration for science and society. Finally, dissemination of statistics produced by cancer registries has been shown to shift consciousness in the medical and public health policy communities. These statistics can inform patients and the at-risk public, as occurred when reports of steep increases in incidence rates of Kaposi sarcoma and non-Hodgkin lymphomas heralded the AIDS epidemic (Clarke & Glaser, 2001). Such data also can lead to better decisions about health and medical care, as exemplified by the marked declines in breast cancer incidence rates since 2002, shown to track closely to the mass cessation of hormone replacement therapy (HRT) beginning in the year following publication of information about the negative health impacts of HRT (Clarke & Glaser, 2007).

Critics correctly point out that U.S. cancer registries now capture personally identifying health data by statutory mandates rather than by voluntary, informed consent agreements with individual patients. However, individual SEER and NPCR registries transmit only deidentified cancer data to funding agencies (CDC and NCI) and to a certifying body (North American Association of Central Cancer Registries (NAACCR)) for compilation and quality assessment. These data contain no patient names, addresses, or contact information. Still, the existence and operation of registries nevertheless imply limits to the common-law notion of doctor-patient confidentiality central to the privacy interests of individual persons in medical information. The custodianship of individually identifiable data by state-mandated cancer registries is essential for case consolidation and quality control, as well as for linkages with, for example, the Social Security Death Index, that may yield de-identified data sets for scientific analysis.

Most privileged relationships in law function within constitutional limits to both protect private information for a specific purpose, and to accommodate social values in favor of knowledge and the discovery of facts that support the administration of justice (Cotchett & Elkind, 1993). Building on a broad duty of confidentiality, the doctor-patient evidentiary privilege ensures that doctors can have honest, uninhibited communications with patients so that patients may receive the most medically appropriate care. The attorney-client privilege ensures that meaningful counsel is available for parties' legal matters. Journalist source privileges support a free press and its contributions to democratic governance. Such privileges are, however, limited by some appropriate and even compulsory disclosures of private and confidential information. For example, exceptions to the attorney-client privilege generally apply to communications that contemplate or would further criminal activities. The limits to privacy across these and other legal privileges indicate that evaluating the appropriateness of cancer registration and the disclosures of individual cancer records to population-based cancer registries depends on the substance of and rationale for the doctor-patient relationship, and on the limited character of privacy protections in law generally. In this context, cancer registration and the research that it enables are consistent with protection of the freedoms from the stigma of disease, from discrimination by insurance companies and employers, and from causing undue fear based on the disclosure of one person's cancer to others.

Contrary to critics who believe that society must choose between science and privacy interests, cancer registration does not imply choosing the benefits that follow from advancement of medicine over and above one's freedom from arbitrary and unnecessary government intrusions on privacy. Rather, these principles can be balanced, like the principles attendant to many other legal rights. We submit that cancer registration, with its discrete purposes and various procedural safeguards, accommodates the constitutional right to freedom from arbitrary interference with one's privacy. It also balances this right to privacy as stated more broadly in Article 12 of the Universal Declaration of Human Rights with various other rights stated in the International Covenant on Economic, Social, and Cultural Rights ("Universal Declaration of Human Rights,"1994; "International Covenant on Economic, Social, and Cultural Rights," 1994). These other rights include: 1) the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; 2) the right to benefit from the efforts of government in regard to the prevention, treatment, and control of epidemic, endemic, occupational and other diseases; and 3) the right of everyone to enjoy the benefits of scientific progress and its applications ("International Covenant on Economic, Social, and Cultural Rights," 1994).

Effectiveness: The Significance and Uses of Cancer Data

Among the primary goals of state-mandated cancer registries is the reduction of cancer-related morbidity and mortality through the facilitation of cancer research and the education of scientists, clinicians, and the public. Population-based cancer registries are uniquely effective in achieving these goals in at least three ways. One way is the capability of describing cancer incidence, mortality and survival across an entire, defined population, with detailed patterns for patients classified by demographic, clinical, and tumor characteristics. The annual Report to the Nation on the Status of Cancer based on SEER and NPCR data provides strong evidence of the realization of this capability (Jemal et al., 2008), as does the sheer number (at least 5,800) of scientific publications that have used SEER data

(http://seer.cancer.gov/pubsearch/index.html). Another way in which cancer registries are effective is by facilitating detailed case-control, cohort, and other research studies that utilize or gather individual cancer case information. The SEER Program has a long history of supporting these kinds of studies, as illustrated in part by the 112 SEER Landmark Studies conducted across 26 scientific topic areas (http://seer.cancer.gov/studies). A third way in which cancer registries are effective is their usefulness for discerning unusual cancer clusters from

expected incidence patterns, which has helped to eliminate misapprehension of regional environmental conditions. (Trumbo, 2000; http://www.cdc.gov/nceh/clusters/faq.htm).

Necessity: The Need for and Uniqueness of Population-based Cancer Data

No alternatives to population-based cancer registration can provide complete and accurate epidemiologic assessments of cancer for the entire population. As a census, the data of cancer registries ensure that the experiences of populations traditionally underrepresented in clinical trials or other cancer research are actually counted and considered. As Ingelfinger and Drazen (2004) explain, "[c]ancer registries have provided valuable information about case clusters, the course of malignant conditions, and changes in the behavior of various cancers. If we have the whole story about patients' outcomes, we can learn from our mistakes and successes and optimize care for patients in the future. If we do not have the whole story, owing to partial participation in registries, our knowledge—and the care we can provide—will remain imperfect." (Ingelfinger & Drazen, 2004). Moreover, the need for cancer data will only increase with the country's growth and, particularly, the aging of its population since the incidence of cancer increases with age. Needs exist not only to monitor incidence burdens among the 77 million baby boomers entering middle age, but also to monitor the growing population of persons living with cancer. This group of patients and survivors, estimated at 9.8 million in 2005, is expected to double in number by 2050, presenting a vast range of issues regarding quality of care, outcomes, survivorship, and healthcare disparities (Wingo, Howe, Thun, Ballard-Barbash, Ward, & Brown, et al., 2005).

Proportionality: Accommodating the Benefits of Cancer Registration alongside Privacy Interests

The condition of proportionality, which requires that the benefits of cancer registration outweigh the moral considerations associated with infringed rights, is met not only by the impact of population-based cancer research but also by strict rules on access, disclosure, and use of cancer data that minimize the risks of a breach of confidentiality. For many cancer registry-based research projects, scientists use only de-identified information and biospecimens that are prepared from identifiable resources. When personal identifiers are needed for research, strict regulations for human subjects protection and for HIPAA (Health Insurance Portability and Accountability Act) compliance further reduce risks of infringing on individual rights. Some registries have additionally required that researchers seeking to contact cancer patients first contact the patients' physicians to inquire about any contraindications prior to study recruitment. Other registries may require that permission is obtained from each patient prior to the release of confidential information to a bona fide cancer researcher. In Massachusetts, the cancer registry is specifically prohibited from releasing any part of a patient's medical record obtained through quality control activities (versus case reporting), or any patient's Social Security Number. (105 C.M.R. 301.040(E) (2009)). In addition, some registries, such as the California Cancer Registry, have adopted additional measures to ensure proportionality and accountability by providing a cancer patient with the right to view his or her own cancer record and/or to request that the record be flagged permanently as "do-notcontact for research" (California Cancer Registry, 2009).

Conclusion

Critiques suggest cancer registration could be determined unconstitutional if enabling statutes violate privacy rights and declare public health objectives that are too vague. Our review of relevant state statutes, however, suggests that cancer registries and their associated research activities involve cognizable public health benefits, reasonable limits and safeguards on the possession of private medical information by government authorities, and discrete scientific

aims that would survive constitutional challenges. Cancer registration involves neither arbitrary nor unnecessary intrusions on the privacy of individual persons. Rather, state cancer registry statutes collectively reflect a concerted effort by legislators and scientists to attend to both privacy interests and the advancement of cancer research, and to do so with minimal infringement on the former.

Government's obligation to address conditions that affect the health of citizens often necessitates a balancing act between individual constitutional rights and public health needs. The conditions required to override individual rights should be compelling. We believe that population-based cancer registration satisfies such conditions, warrants continued support, and would survive a constitutional challenge. Nevertheless, for cancer registries to avoid legal challenges regarding privacy and assertions that the public health interests served by cancer registration and surveillance are vague, registries must be more effective in communicating the benefits they offer and how they safeguard privacy. Doing so will help ensure the human rights that population-based cancer science supports. (3,905 words).

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Table 1

Jurisdiction	Date of State Statute	Statutory Language Describing Purpose of a Cancer Registry and/or Program of Cancer Registration, Surveillance, and Research
Connecticut	1935	"The Department of Public Health may make investigations concerning cancer, the prevention and treatment thereof and the mortality therefrom and to take such action as it may deem will assist in bringing about a reduction in the mortality thereto." (Connecticut Gen. Statutes, Title 19a, Sect. 74, (2007))
New Mexico	1972	To "conduct studies, utilizing statewide cancer registry data, including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of screening, diagnostic, therapeutic, rehabilitative and preventive services and programs relating to cancer and any other clinical, epidemiologic or other cancer research." (New Mexico Statutes, Title 7, Sect. 4.3.10 (G), (2009)).
Hawaii	1973	"The department of health shall engage in the collection and analysis of statistical information on the morbidity and mortality of cancer in the State." "The material shall be used or published only for the purpose of advancing medical research, medical education, or education of the public in the interest of reducing morbidity or mortality." (Hawaii Revised Statutes, Title 19, Ch. 324, (2006))
New Jersey	1977	"The Department of Health and Senior Services shall establish and maintain an upto-date registry in order to conduct thorough and complete epidemiologic surveys of cancer and cancer-related diseases in this State and to apply appropriate preventative and control measures." (New Jersey Annotated Statutes, Title 26, Ch. 2-104-108, (2006)).
Michigan	1978	"The [health] department shall establish a registry to record cases of cancer and other specified tumorous and precancerous diseases that occur in the state, and to record information concerning these cases as the department considers necessary and appropriate in order to conduct epidemiologic surveys of cancer and cancer-related diseases in the state." (Michigan Compiled Laws Service, Public Health Code § 333.2619, (2006)).
Louisiana	1978	"The president of the Louisiana State University System shall establish a statewide registry program for reporting cancer cases for the purpose of gathering statistical data to aid in the assessment of cancer incidence, survival rates, possible causes of specific cancers, and other related aspects of cancer in Louisiana. The program shall collect and disseminate cancer incidence data on a statewide level" (Louisiana Revised Statutes, Title 40, Pt XXVII, § 1299.80 et seq., (2006)).
Florida	1979	"The department shall establish a statewide cancer registry program to ensure that cancer reports required under this section shall be maintained and available for use in the course of any study for the purpose of reducing morbidity or mortality." (Statewide Cancer Registry, FLA. stat. ch. 385.202 (2009)).
Massachusetts	1980	The department shall establish a registry to record certain cases of malignant disease and benign brain-related tumors that occur in residents of the commonwealth, and such information concerning these cases as it shall deem necessary and appropriate in order to conduct epidemiologic surveys of cancer and benign brain-related tumors and to apply appropriate preventive and control measures. (Cancer Registry, Mass. Gen. Laws ch. 111, § 111B (2007)).
California	1985	"The department shall conduct a program of epidemiologic assessments of the incidence of cancer." "The program shall include monitoring of cancers associated with suspected carcinogens encountered by the general public both in occupational locations and in the environment generally." "The program shall analyze available incidence data and prepare reports and perform studies as necessary to identify cancer hazards to the public health and their remedies." (California Health & Safety Code § 103875-103885, (2006)).
Nebraska	1986	"It is the intent of the Legislature to require the establishment and maintenance of a cancer registry for the State of Nebraska This cancer registry should provide a central data bank of accurate, precise, and current information which medical authorities state will assist in the research for the prevention, cure, and control of cancer. The information contained in the cancer registry may be used as a source of data for scientific and medical research. (Cancer Registry, R.R.S. Neb. § 81-642 (2009)).
Colorado	1989	"The department has the powers and duties provided in this section [t]o establish and maintain a statewide cancer registry providing for compilation and analysis of appropriate information regarding incidence, diagnosis, treatment, and end results and any

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Jurisdiction	Date of State Statute	Statutory Language Describing Purpose of a Cancer Registry and/or Program of Cancer Registration, Surveillance, and Research
		other data designed to provide more effective cancer control for the citizens of Colorado." (Powers and Duties of the Department of Public Health and Environment, C.R.S. 25-1.5-101 (2009)).
Kentucky	1990	"There is hereby established within the Kentucky cancer program the Kentucky Cancer Registry for the purpose of providing accurate and up-to-date information about cancer in Kentucky and facilitating the evaluation and improvement of cancer prevention, screening, diagnosis, therapy, rehabilitation, and community care activities for the citizens for the citizens of the Commonwealth." (Kentucky Revised Statutes, Title 18, Sect. 214 556 (2006))

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