

DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES
GUAM CANCER REGISTRY

REGULATIONS

Authority. Public Law 24-198

Purpose. The purpose of the Guam Cancer Registry is to aid in the reduction of cancer morbidity and mortality on Guam by providing basic island-wide population-based cancer incidence data for the facilitation of cancer research and the evaluation of cancer control programs.

Definitions.

- (A) "Cancer" means any primary malignant neoplasm with the exception of superficial basal and squamous cell carcinoma of the skin.
- (B) "Department" means the Guam Department of Public Health and Social Services.
- (C) "Director" means the director of the Guam Department of Public Health and Social Services.
- (D) "Health care provider" means any person providing diagnostic or treatment services for a cancer patient on Guam.
- (E) "Person" means any individual, firm, partnership, professional association, corporation, government or public service agency providing diagnostic or treatment services for cancer patients on Guam, either directly or by third party payment for services.
- (F) "Registry" means the Guam Cancer Registry.

Responsibility for reporting.

(A) Any person providing diagnostic or treatment services for cancer patients on Guam shall report each new case of cancer to the Registry on forms specified by the Registry or in such other manner as may be approved by the Registry. The report shall contain information regarding the patient which includes, but is not necessarily limited to, the following:

- (1) Last name of patient;
- (2) First name of patient;
- (3) Middle name(s) of patient;
- (4) Social security number of patient;
- (5) Village of residence at time of diagnosis;
- (6) Street address at time of diagnosis;
- (7) Zip code at time of diagnosis;
- (8) Birth date;
- (9) Where born;

- (10) Length of time patient lived on Guam;
- (11) Death date (if applicable);
- (12) Sex;
- (13) Ethnicity;
- (14) Marital status;
- (15) Usual occupation;
- (16) Date of cancer diagnosis;
- (17) Basis of diagnosis;
- (18) Anatomical site of the cancer (topography);
- (19) Cell-type of the cancer (histology);
- (20) Tumor behavior;
- (21) Tumor grade;
- (22) Tumor stage (TNM);
- (23) Treatment type;
- (24) Hospital/clinic treating patient;
- (25) Name of physician treating patient;
- (26) Patient's medical record number;
- (27) Name of person preparing report;
- (28) Name of contact for additional patient information (relative of patient);
- (29) Telephone number and mailing address of contact.

(B) Cases of cancer diagnosed on or after January first of each calendar year but before July first of the same calendar year shall be reported no later than December thirty-first of that year. Cases of cancer diagnosed on or after July first of each calendar year but before January first of the next calendar year shall be reported no later than June thirtieth of the next calendar year.

(C) Any person providing diagnostic or treatment services to patients with cancer shall grant to the Registry or its authorized representative access to all records that identify cases of cancer or establish characteristics of cancer, the treatment of cancer, the medical status of identified cancer patients or the demographic characteristics of cancer patients.

(D) This rule does not affect the authority of any person providing diagnostic or treatment services to patients with cancer to maintain facility-based tumor registries, in addition to complying with the reporting requirements of this regulation.

(E) Cases of cancer known by a health care provider to have been diagnosed at a health care facility or previously admitted to a health care facility for the diagnosis or treatment of the same cancer need not be reported by the health care provider treating such patients.

Confidentiality.

Any information, data, and reports with respect to a case of cancer which are furnished to, or procured by the registry shall be confidential and shall be used only for statistical, scientific, and medical research purposes. The Director shall take reasonable

measures to ensure that all individual identifying information is kept under secure conditions.

Research.

(A) Although information concerning individual cancer patients obtained by the registry is for the confidential use of the Department, individuals conducting bonafide medical research may be given access to confidential information if all the following conditions are met:

(1) The person conducting the research provides written information about the purpose of the research project, the nature of the data to be collected and how the researcher intends to analyze it, the records the researcher seeks to review, and the safeguards the researcher will take to protect the identity of patients whose records the researcher will be reviewing;

(2) The person conducting the research submits verification of his credentials and of the credentials of other individuals involved in conducting the research;

(3) In the view of the Director, the proposed safeguards are adequate to protect the identity of each patient whose records will be reviewed. Safeguards for the protection of the identity of patients shall include, but are not limited to, provisions to limit access to identifying data to only those individuals who, during the course of the project, need access to such information for research purposes and provisions for the maintenance of the confidentiality of identifying information after the termination of the project;

(4) The research project has clearly defined goals that pertain to cancer prevention and control;

(5) For case control studies, the research design used in the medical research project involves a sufficiently large sample size that any meaningful difference between cases and controls will be statistically significant. For other studies, the research project will provide enough cases for meaningful analysis of the data, for identification of potential risk factors and intervention strategies for cancer prevention and control; and

(6) The research project will be conducted at a university, hospital, or other medical research institution by competent researchers who have the ability to analyze and interpret data;

(7) An agreement is executed between the Department and the researcher that specifies the terms of the researcher's use of the records and prohibits the publication or release of the names of individual cancer patients or any facts tending to lead to the identification of individual cancer patients.

(B) Notwithstanding any other provisions of this rule, a researcher may, with the approval of the Department, use the names of individual cancer patients when requesting additional information for research purposes or soliciting a patient's participation in a research project. If a researcher requests additional information or a cancer patient's participation in a research project, the researcher shall first obtain the oral or written consent of the patient's attending physician. If the consent of the patient's attending physician is obtained, the researcher shall obtain the patient's written consent by having the patient complete a release of confidential information form.

(C) Notwithstanding any other provisions of this rule, the Registry may release confidential information concerning individual cancer patients to physicians for diagnostic and treatment purposes if the patient's attending physician and the patient give written consent by completing a release of confidential information form.

(D) Notwithstanding any other provisions of this rule, the Registry may release confidential information concerning individual cancer patients to a cancer registry of another state, if such registry has entered into a reciprocal agreement with the Department and the agreement provides that such registry will comply with this section and that information identifying a patient will not be released to any person without the written consent of the patient.

(E) Nothing in this rule shall prevent the release to any person of aggregated epidemiological data that does not identify individual cancer patients.

Freedom from liability.

No person furnishing any information, data, or report to the Registry in fulfillment of the provisions of this regulation shall, by reason of such furnishing, be deemed to have violated any confidential relationship, or be held liable in damages, or be held to answer for willful betrayal of a professional confidence within the meaning and intent of relevant sections of the Government Code of Guam.

**OFFICE OF EPIDEMIOLOGY AND RESEARCH
DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES
GOVERNMENT OF GUAM**

GUAM LAW CONCERNING REPORTING OF CANCER

Article 2, Chapter 3, Division 1, Part 1 of Title 10, Guam Code:

Section 3201.1. Guam Cancer Registry.

(a) There is hereby established within the Department of Public Health and Social Services ('DPHSS') a Guam Cancer Registry, which shall operate under the supervision of the Division of Public Health, Office of Epidemiology and Research, to collect information on all cases of cancer occurring within Guam, to analyze and compare such data in appropriate ways and to annually prepare and distribute a report on their findings. The Guam Epidemiologist shall be a Guam-licensed physician or a licensed veterinarian.

(b) **Injunctions.** In case of noncompliance with the provisions of this Act or with the rules and regulations of the program, the Director shall notify the respective licensing Board and may also notify the Attorney General of such noncompliance. The licensing Board shall notify the healthcare professional and may institute suspension of license for repeated noncompliance reported by the Director of DPHSS.

The Attorney General, upon receipt of such notification, may institute an appropriate action or proceeding at law or in equity to restrain, correct such noncompliance. For all cases of noncompliance referred to the Attorney General by the Director of DPHSS, quarterly reports shall be prepared by the Attorney General and submitted to the Director summarizing the status of actions taken to correct and comply.

Section [3201.2.] Regulations. The Director is authorized to promulgate rules and regulations as may be necessary for the purpose of carrying out the provisions of this Act in accordance with the Administrative Adjudication Law.

SOURCE: Added by P.L. 24-198:2,4.

Chapter 80, Division 4, Part 2 of Title 10, Guam Code Annotated:

Section 80113.1. Cancer Data Collection. The Guam Memorial Hospital Authority (GMHA) and the GMHA Medical Staff shall continue to collect information regarding cancer cases with relevant data for the Cancer Registry as established by the Department of Public Health and Social Services. GMHA shall provide DPHSS cancer information semiannually.

SOURCE: Added by P.L. 17-81:4.
Revised by P.L. 24-198.

1/7/05
01/07

**MEMORANDUM OF AGREEMENT
BETWEEN THE
UNIVERSITY OF GUAM
AND THE
DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES**

This Memorandum of Agreement is made and entered into on this 24 day of December, 2004, by and between the University of Guam (UOG) and the Guam Department of Public Health and Social Services (DPHSS).

WHEREAS, cancer is a leading cause of morbidity and mortality on Guam; and

WHEREAS, available data suggest that the impact on our community of illnesses due to cancer may be increasing; and

WHEREAS, the 9th Guam Legislature designated the responsibility for establishing and maintaining a Guam Cancer Registry with the DPHSS; and

WHEREAS, the Guam Cancer Registry has been duly established within the Office of Epidemiology and Research of the DPHSS and has produced three reports on the status of cancer on Guam; and

WHEREAS, the University of Guam has established a research center to facilitate and promote the study of cancer on Guam by its faculty and students, funded through the National Institutes of Health; and

WHEREAS, the UOG, in partnership with the University of Hawaii, has obtained federal grant funds to establish a Cancer Research Center of Guam on their campus for the above purpose; and

WHEREAS, both the UOG and the DPHSS agree that it is in the best interest of the people of Guam to establish a partnership with the Guam Cancer Research Center on the university campus thereby facilitating research into unique aspects of the occurrence of cancer among the ethnic groups represented on Guam;

NOW, THEREFORE, in consideration of the foregoing, the UOG and the DPHSS hereby agree to the following:

1. THE UNIVERSITY OF GUAM AGREES TO:

- A. Provide a secure environment for any Cancer Registry activities that will assure confidentiality of collected data.
- B. Comply with guidelines set forth in the Regulations of the Guam Cancer Registry regarding access to data collected by or for the Registry.
- C. Appoint a person designated by the Director of DPHSS to serve as co-director of the Guam Cancer Registry.

- D. Assist the DPHSS to provide complete and timely recording of all new cases of cancer occurring among the residents of Guam subsequent to this agreement.
- E. Assist the DPHSS to maintain annual active follow-up procedures to collect complete information on cancer-directed treatment on all reported cases of cancer in the Guam Cancer Registry.
- F. Maintain confidential data so that an unduplicated count of cancer cases is assured, information from multiple reporting sources pertaining to the same cancer case is accurately amalgamated, follow-up information on patient survival is obtained, and accepted rules used to distinguish cancer recurrence from new primary cancers are followed.
- G. Work with DPHSS to collect information on demographic characteristics of cancer patients, diagnostic procedures, extent of disease, and the course of cancer-directed treatments.
- H. Provide assistance to ensure the fullest utilization of cancer data resources through:
 - a. The analysis and publication of data that do not lead to the identification of any individual;
 - b. Developing research projects based on analysis of Registry data;
 - c. Supporting and maintaining the cooperation of local physicians in special studies of new cancer therapies;
 - d. Providing presentations and/or answering questions on the status of the Cancer Center of Guam's program when requested by the public, special cancer advocacy groups or the press; and
 - e. Preparing and distributing an annual report on activities of the Guam Cancer Registry within the Cancer Center of Guam's purview, including its accomplishments and significant findings.

2. THE DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES AGREES TO:

- A. Permit access of employees of the Cancer Research Center of Guam to official records of the DPHSS, including patient records and death certificates.
- B. Designate an employee to serve as liaison to the University of Guam Cancer Research Center tumor registry project.
- C. As requested, to assist in the design and implementation of epidemiologic studies on the incidence and risk factors of cancer on Guam.
- D. Through its Office of Public Health Education, produce and disseminate public information regarding cancer on Guam.

IT IS MUTUALLY AGREED:

- 1. That this AGREEMENT may be terminated by either party upon thirty (30) days written notice.
- 2. The terms of this AGREEMENT may be revised or amended in writing by mutual consent as conditions or circumstance warrant.

3. That in the event that this AGREEMENT is terminated, the Guam Cancer Registry remains under the control of the DPHSS.
4. That this AGREEMENT shall become effective immediately upon the signing of the Governor of Guam and shall remain in effect until revoked or terminated as indicated above, suspended, or amended in writing as approved by both parties.

IN WITNESS THEREOF, the parties hereto have executed this AGREEMENT on the dates indicated by the respective names:

University of Guam:

Harold L. Allen

Harold L. Allen, Ph.D.
President

Date: 12/27/04

Department of Public Health and Social Services:

Peter John Camacho

Mr. Peter John Camacho, M.P.H.
Director

Date: 12/27/04

Approved

Victorina M.Y. Renacia

Ms. Victorina M.Y. Renacia, Legal Counsel

Date: 1/5/04

Approved as to Legality and Form:

Joseph B. Moylan

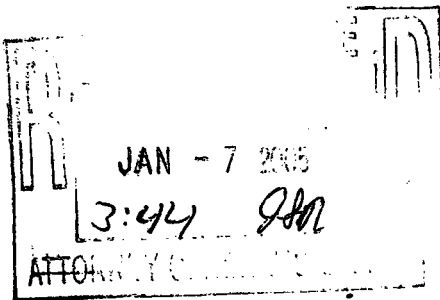
Douglas B. Moylan, Attorney General

Date: 1/11/05

Felix P. Camacho

Felix P. Camacho, Governor of Guam

Date: 2/24/05





NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES

FREQUENTLY ASKED QUESTIONS AND ANSWERS ABOUT CANCER REPORTING AND THE HIPAA PRIVACY RULE

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1. What is the HIPAA Privacy Rule?

In 1996 the U.S. Congress passed a law requiring, among other things, uniform federal privacy protections for individually identifiable health information. This law is called the Health Insurance Portability and Accountability Act of 1996, or "HIPAA." The U.S. Department of Health and Human Services recently issued final regulations implementing the privacy provisions of HIPAA. These regulations are called the "Privacy Rule." Copies of the HIPAA Privacy Rule, as well as helpful explanatory materials, may be found at the HHS Office of Civil Rights website: <http://www.hhs.gov/ocr/hipaa/>.

2. What is a 'Public Health Authority' under HIPAA?

Under HIPAA, a 'Public Health Authority' refers to "an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate."¹ "...Such agencies are authorized by law to collect or receive such information for the purposes of preventing or controlling disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions."² Central cancer registries are considered public health authorities because state laws mandate their duties.

¹ 45 CFR 164.501

² 45 CFR 164.512

3. What is a 'Covered Entity' under HIPAA?

A 'Covered Entity' is a health care plan, a healthcare clearinghouse, or a health care provider who transmits any health information in electronic form for financial and administrative transactions. A 'health care provider' is "a provider of medical or health services, and any other person who furnishes, bills or is paid for health care in the normal course of business."¹

¹ 45 CFR 160.103

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4. Is it a violation of HIPAA for a covered entity to report information about cases of cancer to the state cancer registry?

No. Reporting information about cases of cancer in accordance with the requirements of state authorizing statutes and regulations is permitted by HIPAA. The Privacy Rule contains a specific provision authorizing covered entities to disclose protected health information as required by law.¹ In fact, penalties for failure to comply with state reporting are specified in state law and often consist of significant fines.

¹45 CFR 164.512(a)(1)

5. Since HIPAA is federal, will it override the state laws?

No. HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes.

6. Is there specific legal documentation that supports the requirement to release cancer patient information to any agency?

Individual state laws and regulations document cancer reporting requirements. Central registries should consult their state laws and regulations regarding release of cancer patient information.

7. What, if any, are the consequences of not cooperating with state cancer registry requests for new cancer case information?

HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes. Penalties for failing to comply with state reporting are specified in the state law and often consist of significant fines.

8. Does HIPAA require covered entities to obtain written authorization from the individual before reporting protected health information to the state cancer registry?

No. The provision of the Privacy Rule authorizing disclosure of protected health information as required by law is an exception to the requirement for written authorization.¹

¹45 CFR 164.512(a)(1)

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NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES

9. How does HIPAA impact the data collection of non-reportable/benign diseases (i.e. benign brain, CIN III, Co-morbid conditions)?

HIPAA does not obstruct any state law that supports or mandates the reporting of any disease.

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10. Are private practice physicians still required to report new cancer cases?

Yes, in compliance with state reporting regulations. The central cancer registry has a reportable list that identifies which cancers are reportable, and all reportable cancers should be reported, as required by state law.

11. Will private practice physicians and hospitals be permitted to continue to provide follow-up and treatment information to hospital cancer registries without patient authorization?

Yes. Although private practice physicians and hospitals are health providers, and thus covered under the provisions of the HIPAA privacy regulations,¹ they may continue to provide cancer patient follow-up and treatment information to hospital cancer registries without patient authorization when both the physician and the hospital has or had a relationship with the patient.

Under the HIPAA Final Privacy Rule, private practice physicians and hospitals may disclose confidential patient information to hospitals for the purpose of treatment, payment and **health care operations** (emphasis added) (quality assessment/improvement is considered a health care operation). A business associate agreement is not required between a hospital and physician for such purposes (emphasis added).

Section 164.506(c)(4), states, in relevant part, that

"A Covered Entity may disclose protected health information to another covered entity for health care operations activities of the entity that receives the information, if each entity either has or had a relationship with the individual who is the subject of the protected health information being requested, the protected health information pertains to such relationship, and the disclosure is:

(i) For a purpose listed in paragraph (1) or (2) of the definition of health care operations Section 164.501 of the Privacy Rule defines health care operations and Paragraph (1) of the definition provides, in relevant part:

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(1) Conducting quality assessment and improvement activities, including outcomes evaluation and development of clinical guidelines, **population-based activities related to improving health** (emphasis added) or reducing health care costs, protocol development, case management and case coordination, contacting of health care providers and patients with information about treatment alternatives; and related functions that do not include treatment.

Paragraph (2) of the definition provides, in relevant part:

(2) Reviewing the competence or qualifications of health care professionals, evaluating practitioner and provider performance, health plan performance, conducting training programs in which students, trainees, or practitioners in areas of health care learn under supervision to practice or improve their skills as health care providers, training of non-health care professionals, accreditation, certification, licensing, or credentialing activities.

Thus, as hospital cancer registries collect treatment and follow-up data in compliance with state law and for the purpose of "population-based activities related to improving health" this is a permitted disclosure without requirement of patient authorization. It may also be noted that many hospital cancer registries collect this information for "conducting quality assessment and improvement activities", for "reviewing the competence or qualifications of health care professionals", for "conducting training programs" and for "accreditation, certification, licensing, or credentialing activities". All of these are specifically permitted in paragraphs (1) and (2) shown above.

Note that Section 164.506(c)(4) specifically provides for the ability of one covered entity to provide an individual's PHI to another covered entity, if the receiving covered entity "has or had" a relationship with the individual. This specific reference to the past tense is important since it means that a covered entity's ability to obtain information about a patient need not be "cut-off" if the patient no longer has a direct relationship with the covered entity.

While exchange of treatment and follow-up information is permitted without patient authorization under the provisions described above, an accounting of disclosure must still be maintained.

¹45 CFR 160.103

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Sponsoring Organizations: American Cancer Society • American College of Surgeons • American Joint Committee on Cancer • Canadian Association of Provincial Cancer Agencies • Centers for Disease Control and Prevention • Health Canada • National Cancer Institute • National Cancer Registrars Association • Statistics Canada



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12. What if a patient does not want follow-up information to be collected?

State-mandated cancer reporting typically does not require patient informed consent nor can individuals elect to be removed from reporting. In a state which allows the collection of follow-up cancer data for public health purposes, it can be collected regardless of consent from a patient.

13. Once HIPAA is in place, will pathology labs be able to continue to send new cancer case information to the state cancer registry?

Yes. Public health reporting under the authority of state law is specifically exempted from HIPAA rules

14. If the government-authorized public health entity is not located in the same state as the covered entity, is it still ok under HIPAA to provide the data?

Yes, it is not prohibited. In fact, the definition of a 'public health entity' was broadened in the section "Uses and Disclosures for Public Health Activities", which states specifically "...We broaden the scope of allowable disclosures ...by allowing covered entities to disclose protected health information not only to U.S. public health authorities but also, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority."^{1,2}

¹ FR p. 82525

² 45 CFR 164.512

15. Are covered entities required to determine whether the information about cases of cancer reported to the state cancer registry is the "minimum necessary" information required to be disclosed?

No. The Privacy Rule does include a general requirement that covered entities make reasonable efforts to limit the disclosure of protected health information to the minimum necessary to accomplish the intended purpose of the disclosure.¹ However, there is a specific exception to this requirement for disclosures that are required by law, such as the reporting of information about cases of cancer to the state cancer registry pursuant to state law and regulations.²

¹ 45 CFR 164.502(b)(1)

² 45 CFR 164.502(b)(2)(v)

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NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES

16. What information is required for a covered entity to meet the Privacy Rule's verification requirements with respect to reporting information about cases of cancer to the state cancer registry?

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The Privacy Rule requires covered entities to verify a requester's identity before disclosing protected health information.¹ In the case of disclosure to a person acting on behalf of a public official, a covered entity that reasonably relies on a written statement on appropriate government letterhead that the requester is acting under the government's authority will fulfill this requirement.² The Privacy Rule also requires covered entities to verify the requester's authority.³ A covered entity that reasonably relies on a written statement of the legal authority under which the information is requested will fulfill this requirement.⁴ To assist covered entities in meeting the verification requirements, the state cancer registry may elect to provide a written statement to cancer reporting facilities with the aforementioned information.

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¹45 CFR 164.514(h)(1)(i)

²45 CFR 164.514(h)(2)(ii)(C)

³45 CFR 164.514(h)(1)(i)

⁴45 CFR 164.514(h)(2)(iii)(A)

17. Are covered entities required to sign "business associate agreements" with regional or state cancer registries that perform on-site abstracting and cancer data reporting?

HIPAA requires business associate agreements with entities that carry out health care functions on behalf of covered entities, but state and regional registries are acting on behalf of the state when they provide on-site abstracting and reporting services, not the covered entity. Therefore, they are not business associates.

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18. Does HIPAA apply to the use or disclosure of information about cancer cases after it has been reported to the state cancer registry?

No. The Privacy Rule applies to disclosure of protected health information by covered entities as required by law; state cancer registries are not covered entities. However, state cancer registry authorizing legislation typically includes strict limits on use and disclosure of reported information.

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NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES

19. Are covered entities required to provide individuals upon request with an accounting of any protected health information that the entity has disclosed about them to the state cancer registry?

Yes. The Privacy Rule requires covered entities to provide an accounting of disclosures of protected health information.¹ The accounting must include for each disclosure:

- The date of the disclosure
- The name of the entity or person who received the protected health information and, if known, the address of such entity or person
- A brief description of the protected health information disclosed
- A brief statement of the purpose of the disclosure that reasonably informs the individual of the basis for the disclosure or, in lieu of such statement, a copy of a written request for a disclosure under §164.502(a)(2)(ii) or 164.512, if any.¹

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¹45 CFR 164.528

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