

GOVERNMENT OF GUAM
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 and includes:

(1) Any physician, surgeon, dentist, podiatrist or other health care practitioner who diagnoses or provides treatment for cancer or specified benign tumors;

(2) The designated representative of any hospital, dispensary, asylum or other similar public or private institution that diagnoses or provides treatment for cancer or specified benign tumors; and

(3) The designated representative of any laboratory that examines tissue specimens which disclose the existence of cancer or specified benign tumors;

(4) The designated representative of any public or private agency providing financial or other assistance to cancer patients including, but not limited to, insurance companies.

(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;
- (2) First name;
- (3) Middle name(s);
- (4) Social security number;
- (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 of patient;
- (9) Birth place of patient;
- (10) Length of time patient lived on Guam;
- (11) Death date of patient (if applicable);
- (12) Sex of patient;
- (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) A health care provider providing services other than disease diagnosis or treatment 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;
- (2) First name;
- (3) Middle name(s);
- (4) Birth date;
- (5) Anatomical site of the cancer (topography);

- (6) Hospital/clinic treating patient;
- (7) Name of physician treating patient;
- (8) Patient's medical record number if available.

(C) 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.

(D) 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.

(E) 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.

(F) 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.

(G) Patient follow-up. It shall be a function of the Registry to maintain lifetime follow-up of all registered cancer patients by annually determining their health and treatment status. At least once a year the Registry may contact the physician of record, the patient, or patient's family in order to secure such information.

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) The research project has been approved by the University of Guam Institutional Review Board (IRB);

(8) 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.

