UNIVERSITY OF GUAM
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Cancer Research Center
Guam Cancer Registry

GUAM CANCER REGISTRY

Policy and Procedure Manual for Reporting Facilities

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Thank you in Advance

For Partnering with Us

For Making Time to Report Cancer Cases

When You're Overworked, Understaffed

And Have Little Time.

Some of Our Friends & Relatives Have Even Less Time

They Thank You, and We Thank You

Together We Can Help Make Guam Cancer – Free!

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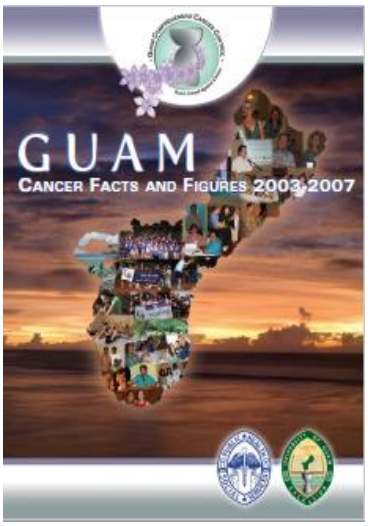
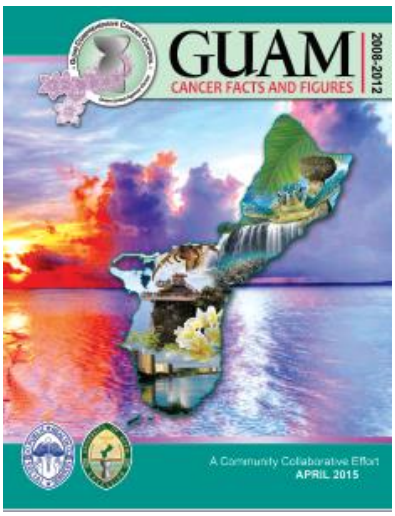




I. INTRODUCTION

Cancer became a reportable disease via Guam law (PL 24-198) on May 6, 1998. Current law requires all medical and non-medical providers of services to Guam residents newly diagnosed with cancer and other specified tumors to report such cases to the Guam Cancer Registry within a specified time period.

A. Importance / Functions of a Cancer Registry

A Cancer Registry is defined as an organized system for the collection, storage, analysis, and interpretation of data on persons with cancer.

A population-based cancer registry like the Guam Cancer Registry collects data from all health-care providers and non-medical sources within its jurisdiction. This data can reveal patterns and trends in cancer incidence and mortality, and provide a baseline against which to judge progress of cancer-control efforts over time. Registry data is useful to those working in the areas of cancer control and prevention, health policy development and advocacy, health promotion and prevention, clinical services delivery, support services for cancer patients, and healthcare financing. It is used to support cancer research and obtain funding as island stakeholders work together to reduce the burden of cancer on our island.

B. Brief History of the Guam Cancer Registry

The Guam Cancer Registry (GCR) was established by the Twenty-Fourth Guam Legislature in 1998 within the Guam Department of Public Health and Social Services (DPHSS). Public Law 24-198, introduced by Sen. Eduardo Cruz, M.D., authorized the promulgation of regulations for the registry. Detailed regulations governing the operation of the GCR became law in 1999. [See Appendix C]

GCR began as an unfunded legislative mandate of DPHSS and was operated as a collateral duty of the Territorial Epidemiologist. Initial efforts included the review of Guam death certificates back to 1970 and cancer patient registrations with the Guam office of the American Cancer Society.

National Institute of Health/National Cancer Institute funding to support the Registry was obtained in 2004 by means of a grant written by the Cancer Research Center of Hawai'i,

University of Hawai'i. This funding enabled the GCR to hire two Research Associates, in 2004 and 2007, and data collection became more "active," less "passive."

A Memorandum Of Agreement between the University of Guam (UOG) and the DPHSS formalizing joint operation of the GCR was signed by the Governor of Guam on February 24, 2005, and the GCR became a unit of the Cancer Research Center of Guam (CRCG). In recognition of its progress, in 2006 the GCR was awarded full-member status in the North American Association of Central Cancer Registries (NAACCR).

GCR and CRCG are co-located at House #7, Dean Circle of the UOG campus. They share office space with the Pacific Regional Central Cancer Registry (PRCCR), which became operational in 2007 and also is funded by grant support from the University of Hawai'i.

Regulations governing the GCR were expanded in October 2010, with approval by the Guam Legislature, to include mandatory reporting of new cancer cases by **non-medical providers** of services to persons diagnosed with cancer. DPHSS and UOG continue to cooperatively run the registry via renewed Memorandums of Understanding (MOUs) approved annually. These MOUs provide for the exchange of information and sharing of resources to support GCR operations under Public Law 30-80. PL 30-80 provides a dedicated funding source equivalent to 1% of tobacco taxes collected annually for the operational needs of the registry [see Appendix C].

II. WHO MUST REPORT?

A. Healthcare Providers

All health care providers who diagnose or treat cancer patients who are Guam residents must report confirmed cases of cancer and specified benign tumors to the GCR, including (but not limited to) the following:

- Hospitals
- Physicians (including Surgeons & Podiatrists)
- Outpatient Clinics
- Dentists
- Medical laboratories
- Freestanding radiation or medical oncology clinics
- Ambulatory outpatient surgical centers
- Nursing homes
- Dialysis treatment centers

B. Service Providers (Non-Medical)

Guam law and public health regulations were expanded in October 2010 to require non-medical service providers to report cases of clients diagnosed with cancer and specified benign tumors to include:

- Insurance Companies
- Non-Profit Service Agencies e.g. The American Cancer Society-Guam Chapter and Guam Cancer Care
- Referral Agencies e.g. Guam Medical Referral Office

C. Determining Responsibility for Reporting

1. Physicians: Must report all required cancer cases, especially those that are not referred to a hospital for further diagnosis or treatment. This includes:
   a. Patients who are clinically diagnosed and receive no further work-up or treatment;
   b. Patients who are newly diagnosed in the physician's own laboratory facility or by sending a specimen from the office to an outside laboratory;
   c. Patients whose first-course treatment is initiated in the physician's office or clinic. This includes cancer treatment by surgery, radiation, chemotherapy, immunotherapy, or hormones.
2. Dentists: Must report all required cancer cases, especially those that are not referred to a hospital for further diagnosis or treatment. This includes:
   a. Patients who are diagnosed or treated by a dentist who performs a biopsy and/or receives a pathology report of a malignant diagnosis;
   b. Cases also reported by either hospital-based or private/independent medical laboratories.
3. Medical Laboratories: Hospital-based laboratories and private or independent laboratories licensed in Guam must report all required cancer cases diagnosed in the lab, especially for patients that are not referred to a hospital for further diagnosis and treatment. This includes cases also reported by physician or dentist offices. For hospital-based laboratories, these include "path only" cases that are reported by the hospital registry staff, but not necessarily included in the hospital registry.
4. Freestanding Radiation or Medical Oncology Clinics: Must report any patient initially diagnosed with reportable cancer, or when first-course treatment is initiated at the non-hospital based facility. This includes cancer treatment by surgery, radiation, chemotherapy, immunotherapy, or hormones.
5. Surgery Centers: Freestanding surgery centers (independent centers not affiliated with any hospital) must report any patient diagnosed with cancer as a result of undergoing a biopsy or other surgical procedure at the facility. This includes cases also reported by either a hospital-based or a private/independent medical laboratory.

6. Nursing Homes:
   a. Nursing homes must report the following types of newly-diagnosed required cancer cases:
      i. Cases clinically diagnosed but not confirmed through biopsy, cytology or other microscopic methods;
      ii. Cases for which the first course of cancer treatment is initiated at the facility. Treatment may include chemotherapy, immunotherapy, or hormone therapy.
   b. Nursing homes should identify all patients with a cancer diagnosis at the time of admission, even if diagnosed and treated prior to the admission. The facility should send copies of pertinent medical records relating to the diagnosis to the Guam Cancer Registry. Section VI-D of this manual describes the records to send, as available.
7. Mammography and Other Radiology Facilities: Facilities that provide screening, diagnostic or therapeutic cancer services must report confirmed cases of reportable cancer.

III. REPORTABLE (REQUIRED) CASES

A. General Guidelines

All confirmed cases of cancer for persons residing on Guam that have been diagnosed and/or treated in Guam as of January 1, 1998, or later must be reported to the GCR. This includes both solid and hematopoietic malignancies. A clinical diagnosis or any case that is stated to be cancer by a recognized medical practitioner is reportable, even if there is no histological or cytological confirmation. Any cancer or malignancy listed on the death certificate is reportable. In addition:

- All neoplasms with behavior codes "2" (in-situ) or "3" (malignant) in the current edition of the *International Classification of Diseases for Oncology (ICD-O3) Third Edition* are reportable. **Note**: ICD-03 will soon be updated.
- All benign and borderline neoplasms of the brain and central nervous system (CNS) diagnosed January 1, 2004, or later are reportable.
- Juvenile astrocytoma is reportable.
- Basal or squamous cell carcinoma of the skin is reportable.*
- Preinvasive cervical neoplasia, including carcinoma in-situ of the cervix or cervical intraepithelial neoplasia, grade III (CINIII) IS reportable.*

*Although these cancers and pre-cancerous conditions are not reportable to U.S. Centers for Disease Control (CDC) nationally, they are "reportable-by-agreement" to the Guam Cancer Registry and in other US-Affiliated Pacific Island Jurisdiction registries.

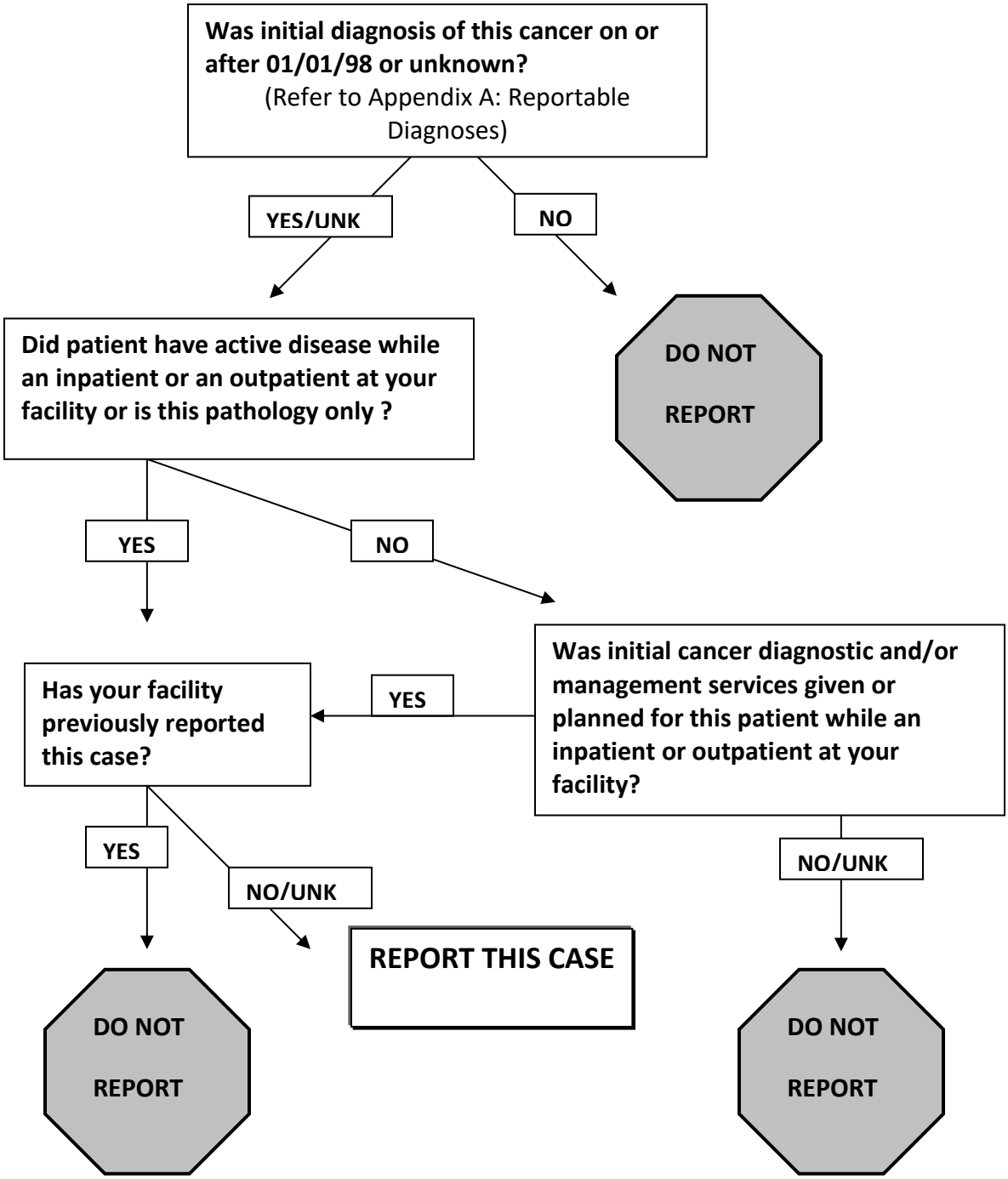
Note: The GCR, although not formally designated as a Surveillance, Epidemiology & End Results (SEER) Program Registry, follows SEER national guidelines as to the reportability of each cancer type, which may change slightly by year. SEER publishes a list of reportable cancers yearly. **Refer to *Appendix A: Lists of Reportable Neoplasms* for a comprehensive listing of reportable neoplasms as of January 1, 2010.** Lists for previous and following years can be found on the SEER website *(see Appendix E)* or can be requested from our office.

B. Exceptions: Cases That Are NOT Required or Reportable

- Preinvasive cervical neoplasia, or cervical intraepithelial neoplasia, grade I and II (CIN I and CIN II are NOT reportable);
- Prostatic intraepithelial neoplasia (PINIII) of the prostate;
- Benign and borderline tumors of the cranial bones (C410);
- A patient whose primary malignancy has previously been reported and who is receiving subsequent or second line / salvage treatment for recurrence or progression of disease;
- A patient/client who was not a resident of Guam <u>at the time of his/her cancer diagnosis.</u> Note: Cases of Guam residents who are diagnosed off-island (though still residents of Guam) ARE reportable.
- A patient who is not a resident of Guam, and who is receiving "in-transit" treatment or palliative care for a pre-diagnosed cancerous condition (e.g. tourists, visitors).

REPORTING CHART*

*Adapted from *Georgia Central Cancer Registry Reporting Guidelines, Sept.2007*



C. Terminology

Diagnoses that include the following terms are malignant neoplasms and **are reportable**:

Cancer	Leukemia	Melanoma
Carcinoma	Lymphoma	Sarcoma
Carcinoma in situ	Malignant	

Malignant diagnoses that are not histologically confirmed, but are described by one of the following **Ambiguous Terms**, are considered confirmed cases and **are reportable**:

Apparently	Favor(s)	Probable
Appears	Malignant appearing	Suspect(ed)
Comparable with	Most likely	Suspicious (for)
Compatible with	Presumed	Typical (of)
Consistent with		

Do not use substitute synonyms such as "supposed" for presumed or "equal" for comparable. Do not substitute "likely" for "most likely." Diagnoses described as "possible," "questionable," "suggests," "rule out," "worrisome," "potentially malignant," etc. **are NOT to be reported**.

Common types of cancer diagnosed and/or treated outside a hospital setting include: Melanoma, Prostate, Leukemia, Lymphoma, Multiple Myeloma, other Bone Marrow primaries, some Breast Tumors, noninvasive Bladder Tumors, tumors in Colorectal Polyps, Oral or Genital Tumors, and Small Eye Tumors.

IV. WHEN TO REPORT

How often an organization chooses to report to the GCR often depends on the number of cases that reporting entity handles yearly. Some clinics and labs choose to report cases monthly to prevent a backlog. Clinics that handle less than 10 cases per year may choose to report each case as it is diagnosed.

Existing law (PL 24-198) mandates the following **minimum Reporting Schedule**:

NEW CASES DIAGNOSED	REPORT NO LATER THAN
January 1 – June 30, 20XX (Dx Year)	December 31 of same Dx Year
July 1 – December 31, 20XX (Dx Year)	June 30 of Following Year

"*Cases of cancer diagnosed on or after January first of each calendar year 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*." – Guam Public Law 24-198

V. WHERE TO REPORT CASES

All Reporting Forms and Supporting Documentation, as described in Sections VI and IX below, should be transmitted in a sealed envelope marked "CONFIDENTIAL," or faxed with a Confidential Cover Sheet to:

LOCATION ADDRESS Attn: Cancer Registrar, Guam Cancer Registry, Guam Cancer Research Center, House #7 Dean Circle, University of Guam, Mangilao.

MAILING ADDRESS Attn: Cancer Registrar, Guam Cancer Registry, House #7 Dean Circle, 303 University Drive, UOG Station, Mangilao, Guam 96923.

GCR Staff may be reached at Phone: (671) 735-2988/89 and Fax: (671) 734-2990.

VI. HOW TO REPORT CASES

The method your organization will choose to initially report cases will depend on: a) type of entity (medical or non-medical), and b) the volume of cases it handles.

A. **Medical Providers** may choose to transmit a) Individual Case Reports or, if they have a larger case volume, b) Patient Indices/Listings for the particular reporting period, followed by Individual Case Reports or GCR staff on-site visits for active case collection. (See Section IX for detailed reporting instructions)

B. **Non-Medical Service Providers** are required to provide a more basic data set to GCR and may transmit a shorter Patient Listing form (see Appendix B).

C. **Individual Case Reports** contain most information needed by GCR to properly abstract a cancer case. Because these reports do not contain ALL data needed for the abstract, it is suggested that such reports be transmitted to GCR with supporting documentation (see list of records to send below). See detailed instructions for completing the *GCR (Individual Case) Report Form* in Section IX, and a copy of this form in Appendix B.

D. **Records to Send** include:

- Registration or Face Sheet with demographics, including physical **Address At Diagnosis**. This location address is important to help establish residency. Mailing address, e.g. P.O. Box information, is useful for GCR follow-up contacts, but cannot substitute for Location address at diagnosis – **VILLAGE** information is needed at the very least. Please include occupation and industry if available.
- Medical notes and/or summaries pertaining to cancer, e.g. History & Physical, Discharge Summary, Consultations, Progress Notes and Referrals.
- Diagnostic Tests or other staging information including: X-Rays, CT Scans, MRIs, Mammography, Ultrasound, etc.
- Biopsy, Pathology, Cytology, Laboratory, or Operative Reports.
- Treatment Records such as Treatment Plans and Treatment Summaries (surgery, chemotherapy, radiation, hormonal therapy, immunotherapy, etc.)

E. **Patient Indices/Listings** are transmitted by reporting entities with a larger case volume, such as hospitals, outpatient surgical centers and oncology clinics (see *GCR Cancer Patient Listing Form* in Appendix B). A reporting entity with a higher caseload should submit this listing as soon as possible to allow adequate time for GCR staff to conduct case collection and/or follow-back activities.

When GCR receives such a listing, staff will check all names against the existing database (DB) to see if each person is in the registry. If GCR has a record of that person, GCR staff investigate further to see if, a) the existing case needs to be updated, b) the case is a multiple primary (a new cancer case for the same person) and will need to be abstracted as a new case, or c) the case has been completed and abstracted with no new information required. Names not found in GCR's DB will be followed back as potentially new cases.

From the initial listing received, GCR staff will compile a shorter list of names/cases needing follow-back. This list will be given to the reporting entity, which can: a) submit individual case reports and supporting documents to GCR for each patient listed, or b) arrange for GCR to do an on-site case collection visit. Reporting clinic staff should pull the patient files needed in advance of GCR's scheduled visit, and may assist GCR staff to scan or copy relevant documents.

F. **Ways to Transmit Reports**:

Confidential case reports/documents may be transmitted to GCR via:

- Electronic Reporting via WebPlus (call or email GCR designated staff to establish an account) or Reporting Agency's secure, electronic reporting program;
- Mail in sealed envelope stamped "Confidential," addressed to GCR Registrar;
- Confidential Fax Transmission (Fax 734-2990 with cover page);
- Pickup and/or Delivery of Documents (call GCR staff for pickup).

Electronic Reporting: As of December 2010, the GCR began using a secure online electronic reporting system called WebPlus. Please call GCR and talk to Ms. Melani Montano to set up your company's account and password. You will receive further instructions regarding use of WebPlus, which is user-friendly and secure.

Many larger entities, such as Insurance Companies, have their own secure means for Electronic Records transmission. We encourage the use of Electronic Medical Records as they provide a more efficient, less labor-intensive means of obtaining/sharing data.

VII. CONFIDENTIALITY ISSUES

"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 …"

- Government of Guam, Department of Public Health & Social Services, Guam Cancer Registry REGULATIONS

A. **Reporting & Patient Consent**: Guam law (PL 24-198) requires the reporting of cancer cases for public health purposes. The law does NOT require patient consent to report a case, and DOES contain adequate patient protections, governing proper use and prohibiting misuse of this personal health information. Federal law (PL 102-515, 102nd US Congress) provides for state/territory access to patient records of all healthcare providers whose services involve identifying, establishing the characteristics of, treating, or assessing the status of cancer cases. [See Appendix C]

B. **Guam Cancer Registry Disclosure:** GCR disclosure of confidential information that could lead to the identification of an individual cancer patient is strictly prohibited by Guam and federal regulations. Exceptions are those allowed by law and include: disclosures to other state and hospital cancer registries, certain Government of Guam public health officers (e.g. Vital Statistics), and qualified local researchers who have gone through a stringent review process (see Section X-A).

C. **HIPAA:** The GCR is considered an exempt entity according to the Health Insurance Portability & Accountability Act (HIPAA) Privacy Rule at 45 CFR 164.512(a) because Guam law mandates cancer reporting. Therefore, HIPAA-covered entities, e.g. healthcare providers described in Section II-A & II-B are permitted to disclose protected health information (PHI) to GCR without patient or their personal representative's consent. [See HIPAA Q&A in Appendix D].

D. **Patient Protections** are provided for by federal and local laws governing registry operations. GCR takes stringent precautions to protect personal health and other confidential information, including:
- Regular staff training in confidentiality issues;
- Confidentiality Statement (pledge) signed by all regular staff, student interns, volunteers and contractors of GCR and Guam Cancer Research Center;
- Use of password-protected files, databases, and computers;
- Confidential documents kept in lockable file cabinets in a locked office with limited staff access;
- Attention to physical layout of GCR office, fax machine, desks and computer monitors to enhance privacy;
- Use of WebPlus – a secure electronic reporting system;
- Use of locked carry cases for pickup and delivery of confidential documents.

E. **Complaint Process & Procedure**: Any person or organization with complaints or concerns about GCR operations are encouraged to discuss their concerns with any appropriate staff at GCR. If, however, they are not satisfied with the staff's response and/or resolution to the stated concern, they may discuss their issue(s) with any one of the following:

- Dr. Robert Haddock, GCR Director, Phone 735-2988/89;
- Dr. Rachael Leon Guerrero, Co-Principal Investigator of UOG Cancer Research Center of Guam, Phone: 735-2004;
- Mr. Leo Casil, acting Director DPHSS, Phone: 735-7173.

Complaints may be made in verbal or written form.

> *"**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."* *-- Guam Public Law 24-198*

VIII. DATA QUALITY

A. Maintaining Completeness & Correct Data

Registry staff perform visual and computerized edits of reports to ensure completeness and accuracy of the data submitted. GCR staff may contact reporting entities when the edits identify incomplete or unclear information, or discrepancies in data are reported by multiple providers for one case. Contact will be made in writing or by telephone.

B. Audits

Periodic record audits may be conducted by GCR staff to ensure completeness and quality of reporting. Such audits may be triggered by an unusual decrease (or increase) in the number of cases submitted by a reporting entity, a noticeable increase in errors made by the reporting facility, or frequent staff changes.

GCR audits are geared to help reporting facilities with any challenges they may have in meeting their cancer case-reporting requirements, are focused on collaborative problem-solving and assistance with staff training needs.

IX. INSTRUCTIONS FOR REPORTING CANCER DATA

A. General

You may want to re-read "How to Report Cases" in Section VI. GCR has several basic Reporting Forms – copies of which are in Appendix B. Medical providers may use GCR (Individual Case) Report Forms and/or GCR Cancer Patient Listing Forms, depending on their cancer caseload. Non-medical service providers need only use the Non-Medical Provider Report Form which is a listing of persons with cancer whom they have helped.

Mandated reporters may generate and/or use their own reporting forms, so long as all information mandated by law to be reported to GCR is included. We want to make the reporting process as convenient as possible for providers.

The following are some instructions/clarification for filling out GCR forms:

- Please complete as much of the form as possible.
- Print legibly, or type all entries into the form.
- Record "N/A" (not available) if you do not know or do not have the information. We don't expect you to do extensive (and time-consuming) research to find information you don't have.
- Blanks will be interpreted as "information not available."

B. Guam Cancer Registry (Individual) Case Report Form

Medical clinics/organizations with a lower annual caseload of new cancer cases may use this form to report a newly-diagnosed cancer case for an individual (Guam resident).

Patient Demographics

1. Record patient's **Full Name, Date of Birth, Sex,** and **Social Security Number** (if any). If you are sure the patient has no S.S. number, mark N/A (not applicable).
2. **Residential Patient Address at Diagnosis**: Record the patient's usual physical home address at the time of his/her cancer diagnosis. Report the street address and village of residence, if known. **Village at diagnosis is critical to help establish Guam residency, and for demographic reporting.** Post office box information should be recorded if no street address information is available, or in addition to the physical location address of the patient.
3. **Marital Status:** Record either Single (never married), Married (including "common-law"), Separated, Divorced, or Widowed.
4. **Occupation:** Record the kind of work the patient performed during most of his/her working life. This may be different from the company or industry at time of patient's diagnosis. Do not record "Retired." If retired, note the usual occupation the patient retired from.
5. **Industry:** Record the primary type of activity carried on by the business/industry of the patient's usual occupation. This may be different from the company or industry at the time of diagnosis.
6. **Race/Ethnicity**: Be as specific as possible, for example, write "Pohnpeiian" rather than FSM, or "Japanese" rather than Asian. If the person is of mixed racial descent,

note the Race/Ethnicity claimed by the patient. You may report more than one ethnicity; if you do, please also note the patient's primary ethnic group if known.

7. **Served in USA Armed Forces** (Military Service): Mark "yes" or "no" for patient's current or past involvement with the U.S. military, if known. This is very important information so we can track the health of our Veterans.

Tumor Data

1. **Primary Site (Where the cancer started)/Laterality:** Record the topography, the specific site of origin of the tumor or malignancy and its side of origin (right or left) if applicable. Examples: Upper-outer quadrant of left breast, dome of bladder, right kidney. The primary site for leukemia is always bone marrow. Always identify the primary site, if known, and not a metastatic site. [The ICD-O, 3rd Edition is a good reference – see Appendix E]
2. **Histology:** Record the cell morphology type (e.g. infiltrating ductal carcinoma, diffuse retinoblastoma, chronic lymphocytic leukemia), often found in the pathology report.
3. **Date this cancer was first diagnosed:** Record the date the patient was first diagnosed for this malignancy by any recognized medical practitioner, whether the diagnosis was clinical or pathological. If based on a pathological analysis of a biopsy/surgical specimen, record the date the specimen was collected (versus reported by the lab). Record any (even partial) information available; if the exact month, day, and year are unavailable – approximate the date and note that it is an estimated date.
4. **Initial visit for this cancer:** Record the date this person was first seen at your facility for this cancer. If contact was with a specimen rather than the patient, record the date the specimen was obtained. If the exact month, day, and year are unavailable – approximate the date and note that it is an estimated date.
5. **Most recent visit for this cancer:** Record the last date that you had any contact with the patient. If the patient has expired, record the date of death. If the exact month, day, and year are unavailable – approximate the date and note that it is an estimated date.
6. **Method of Diagnosis:** Mark all the boxes that indicate the method(s) used to confirm this diagnosis of cancer.
7. **Patient Status (at last contact):** Mark the box that indicates whether the patient was alive or dead at your last contact with him/her, and the patient's cancer status at that time (cancer-free, some cancer still evident, or unknown).

First Course of Treatment Data

Definitions

- **Cancer-directed treatment:** Any medical procedure which is meant to modify, control, remove or destroy primary or metastatic cancer tissue. Such treatment is given to minimize the size of tumor or to delay the spread of disease. Report all known first course cancer-directed treatment.
- **Non-cancer directed treatment:** Any procedure that prolongs the patient's life, alleviates pain, increases the patient's comfort, or prepares the patient for cancer therapy. It is not meant to reduce the size of tumor or to delay the spread of disease. Procedures include diagnostic procedures and supportive (palliative) care.
- **First-course treatment:** Cancer-directed treatment that is planned by the physician(s) during or soon after the initial diagnosis of cancer. Administration of the treatment may span a month to a year or more, especially if the patient has been referred for off-island treatment or delays treatment due to financial problems. If a specific Treatment Plan or protocol is not outlined or available, consider treatment initiated within the first four (4) months after initial diagnosis (not necessarily completed) as part of first-course treatment. Treatments initiated more than four months after diagnosis are still considered "first-course" if they were part of the initial Treatment Plan.
- **Subsequent treatment:** No need to record treatment for recurrence or progression of disease. Treatment that is given after the first course is stopped is subsequent (or 2nd Course) treatment. If you wish to include it, please note that it is 2nd course treatment.

For each type of treatment patient received, record the exact date (or approximate if information unavailable) the treatment was initiated.

1. **Surgery:** Record specific type of surgical procedure(s) given, and corresponding date(s) of service. Examples: Excisional biopsy, radical or partial mastectomy, TURP, prostatectomy.
2. **Radiation:** Record the specific type and duration. Examples: External beam radiation, brachytherapy.

List any drug or drug regimen given to the patient for the purpose of modifying, controlling, removing, or destroying cancer tissue. Do not list drugs given for palliation (relief of pain or symptoms) only.

3. **Chemotherapy:** Examples: FOLFOX, 5-FU, Cisplatin, CA or AC (Adriamycin and Cytoxan).
4. **Hormone/Other Treatment:** Examples of hormone therapy are Tamoxifen, Nolvadex, Lupron. Prednizone is hormone therapy only when administered in combination with chemotherapy such as MOPP. Other treatment includes **Immunotherapy/Biological Response Modifiers (BRM)** – examples are Interferon, Levamisole, monoclonal antibodies, which are being used more and more in the treatment of cancer.

C. GCR Cancer Patient Listing Form

Medical clinics/organizations with a larger annual caseload of new cancer cases may use this form to report a listing of patients who were treated for a cancer diagnosis during a specific time period. PLEASE NOTE FACILITY NAME AND REPORTING PERIOD.

1. Record patient's **Full Name, Date of Birth, Sex,** and **Ethnicity** (if known). These personal identifiers prevent duplicate cases, and are critical for cancer analyses.
2. **Residential Patient Address at Diagnosis**: Record the patient's usual physical home address at the time of his/her cancer diagnosis. Report the street address and village of residence, if known. Village at diagnosis is critical to help establish Guam residency, and for demographic reporting**.** Post office box information should be recorded if no street address information is available, or in addition to the physical location address of the patient.
3. **ICD-9 or ICD-10 Primary Site and/or Histology:** Record the ICD-9 or ICD-10 Code, or Site and Histology of the cancer being reported. Site refers to the specific site of origin of the tumor or malignancy; Histology refers to the cell morphology.
4. **Date of Diagnosis:** Record the date the patient was first diagnosed for this malignancy by any recognized medical practitioner, whether the diagnosis was clinical or pathological.
5. **Type of Treatment:** Record the type of cancer treatment that is given as part of "first-course treatment" (see definition on previous page), such as surgery, radiation, chemotherapy, hormone treatment, or other treatment.
6. **Date of Treatment:** Record when cancer treatment was initiated and when it ended. If the exact month, day, and year are unavailable – approximate the date and note that it is an estimated date.

7. **Date of Last Contact:** Record the last date that your clinic had any contact with the patient. If the patient has expired, record the date of death. If the exact month, day, and year are unavailable – approximate the date and note that it is an estimated date.
8. **Primary Physician:** Record the patient's primary care physician.

D. GCR Non-Medical Provider Report Form

Non-medical organizations (such as American Red Cross-Guam Chapter, and Guam Medical Referral Office) that provide services to a larger annual caseload of persons with cancer may use this form to report a listing of persons with cancer who were provided services during a specific time period.

1. Record person's **Full Name** (Last, First, and Middle Initial) and **Date of Birth**.
2. **Street Address & Village**: Record the person's street address and village of residence. **Village at diagnosis is critical for demographic analysis.** Post office box information may be recorded if no street address information is available, or in addition to the physical location address of the person.
3. **Race/Ethnicity**: More specific is better (Example: Korean better than Asian, Palauan better than Micronesian). This information is important for data analysis and cancer education and outreach efforts.
4. **Primary Site of Cancer:** Record the topography, the specific site of origin of the tumor or malignancy and it's laterality (right or left) if applicable. Examples: left Breast, Bladder, right Kidney. The primary site for leukemia is always bone marrow. Always identify the primary site, and not a metastatic site.
5. **Hospital/Clinic and Primary Doctor:** Record the name of the hospital or medical clinic which is treating (or had treated) the person with cancer, and the person's primary doctor, if known.
6. **Service Date or Last Date of Contact:** Record the date when your agency provided service(s) to the consumer and/or the last date your agency had contact with the consumer. Please indicate which date you are listing (service date or last contact) if you note one date only.

E. Follow-Up Data

GCR Staff may contact your clinic/organization by phone, facsimile, or mail to request information needed to: a) complete a cancer abstract for a previously-reported case, or b) obtain updated information for the registry's annual follow-up of all persons with cancer.

Section G under Responsibility for Reporting, DPHSS Regulations for GCR, states:
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.*

Your cooperation and help with these requests for information is greatly needed and appreciated, as GCR has various internal and external deadlines to meet. Your staff may be asked to complete a simple patient follow-up form and/or submit (e.g. fax) supporting documents to complete a case.

Death Clearance is a process done quarterly, semi-annually, or annually at a minimum, and involves matching DPHSS's death certificate database with the GCR database. Its purpose is to update the vital status of all residents with cancer, and to identify cancer cases missing from the registry. It is a requirement for all cancer registries, and is essential to obtaining accurate morbidity and mortality data for our community.

X. HOW TO OBTAIN DATA FROM GCR

"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*." -- DPHSS Regulations for GCR

Qualified researchers, both students and professionals, **may request the use of GCR data** by completing and submitting the appropriate forms (in Appendix B) to GCR staff. The GCR Data Request Form is the basic form to use. Researchers are encouraged to make use of data published by GCR such as "Guam Facts & Figures 2003-2007" and other data sources listed in Appendices E & F. Those requesting access to confidential patient information must complete the "Request for Access To HIPAA-Protected Cancer Patient Information" form (with approval) and gain Institutional Review Board (IRB) approval from the University of Guam. All researchers must agree in writing that the names of individual cancer patients or any facts tending to lead to the identification of individual cancer patients will not be published or made public.

GCR takes seriously its dual responsibilities to protect and ensure the privacy of cancer patients and to support the research efforts of investigators who are working to reduce the burden of cancer in our community.

Regular Reports Generated by GCR

GCR Staff produce various reports requested by DPHSS, the Guam Comprehensive Cancer Control Coalition, the national Centers for Disease Control (CDC), and its partners such as DPHSS Breast & Cervical Cancer Early Detection Program. GCR reports and presentations can be found in Appendix F, on GCR's website: http://www.guamcrc.org, and on the Pacific Regional Central Cancer Registries (PRCCR) website at www.pacificcancer.org.

APPENDIX A-1: Annual Lists of Reportable Neoplasms

Insert Current Annual (2010 to 2017) CASEFINDING LISTs – SHORT VERSION

Online Manual: Refer to Folder

"Appendix A1: Reportable Cancers"

Current Casefinding Lists also can be found at the following National Cancer Institute website:
https://seer.cancer.gov/tools/casefinding/

APPENDIX A-2: Annual Lists of Reportable Cause of Death

(For use by DPHSS Office of Vital Statistics)

Insert Current Annual (2011 to 2017)

REP0RTABLE CAUSE OF DEATH – SHORT VERSION

Online Manual: Refer to Folder

"Appendix A2: Reportable Cause of Death"

Current Casefinding Lists also can be found at the following National Cancer Institute website:

https://seer.cancer.gov/tools/casefinding/

APPENDIX B-1: GCR Forms

Online Manual: Refer to Folder

"Appendix B: GCR Forms"

The following are GCR Forms - full-size copies inserted after this page so that you may copy these for your use. The forms also are available online on our website.

They include:

APPENDIX C-1: Guam & U.S. Laws Relevant to Establishing & Supporting the Guam Cancer Registry

Online Manual: Refer to Folder "Appendix C: Relevant Legal Documents"

The following laws are included in this Appendix:

APPENDIX D-1: HIPAA, Confidentiality, and Cancer Registry Reporting

Online Manual: Refer to Folder

"Appendix D: HIPAA & Confidentiality"

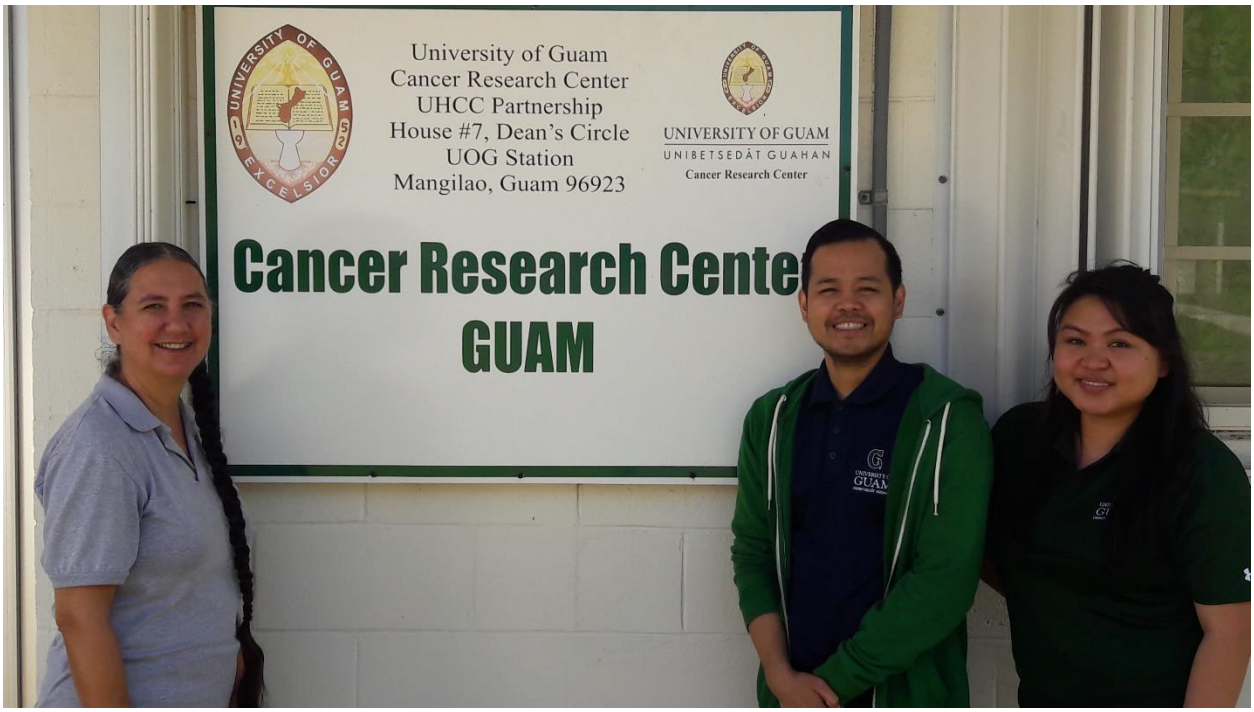
The following documents are included in this Appendix:

APPENDIX E-1: Online Resources & GCR Publications

Online Manual: Refer to Folder

"Appendix E: Resources & Publications"

The following documents are included in this Appendix:



Left to right: GCR Staff (May 2018) - Ms. Renata Bordallo, Data Collection Specialist / Supervisor; Mr. Emilio Medina, Administrative Assistant; Ms. Naomi Del Mundo, Data Collection Specialist. (Missing from picture is Dr. Robert Haddock, GCR Director)

THANK-YOU FOR TAKING THE TIME TO READ THIS REPORTING HANDBOOK. THERE WILL BE UPDATES, CORRECTIONS, ADDITIONS, AND DELETIONS TO THIS GUIDE; PLEASE ADD AND DELETE PAGES AS NEEDED (to hard-copy manuals). UPDATES (such as the yearly Reportable Cancers Listing) WILL BE POSTED ON OUR WEBSITE FOR EASY ACCESS (see above web address).

PLEASE CALL OUR GCR STAFF AT 735-2988/89 OR FAX US AT 734-2990 IF YOU HAVE ANY QUESTIONS, SUGGESTIONS, OR COMMENTS.