



GUAM CANCER REGISTRY

A Joint Project of the UOG Cancer Research Center and the
Department of Public Health & Social Services
Funded via Public Law 30-80



GUAM CANCER REGISTRY DATA REQUEST FORM

It is of the utmost importance to insure the confidentiality of individuals diagnosed with cancer when information about their cancer is entered into a database for the purpose of establishing a research resource. In order to protect this data, the U.S. Centers for Disease Control and Prevention (hereinafter, CDC) has established an Assurance of Confidentiality clause under Section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)), which provides that this data can only be used for the purpose for which it was obtained. Each U.S. Affiliated Pacific Island (USAPI) jurisdiction has a similar Assurance of Confidentiality contained within their legislation authorizing their cancer registry. In utilizing patient data for research purposes, it is absolutely necessary to insure, to the extent possible, that uses of such data will be limited to research; any effort to determine the identity of any reported cases, or to use the information for any purpose other than for health statistical reporting and analysis, would be prosecuted to the full extent of the law.

When the Guam Cancer Registry (GCR) submits information to the CDC, all direct identifiers are removed prior to submission. The CDC Division of Cancer Prevention and Control (DCPC) does all it can to assure that the identity of data subjects cannot be disclosed. All direct identifiers, as well as characteristics that might lead to patient identification, are omitted from the data set. Nevertheless it may be possible in rare instances, through complex analysis and with outside information, to ascertain from the data set the identity of particular persons. Considerable harm could ensue if this were done. In order for the GCR to provide a restricted dataset to you, it is necessary that you clearly state the data requested, intended purpose and agree to the following provisions:

1. I will not use nor permit others to use the data in any way other than for statistical reporting and analysis;
2. I will not release nor permit others to release the data sets or any part of them to any person except with the written approval of GCR;
3. I will not attempt to link nor permit others to link the data set with individually identifiable records from any other CDC or non-CDC data set;
4. I will not attempt to use the data sets or permit others to use them to learn the identity of any person or establishment included in any set; and
5. If the identity of any person or establishment should be discovered inadvertently, then
 - a) No use will be made of this knowledge,
 - b) The Director of the GCR will be notified of the incident,
 - c) The information that would identify an individual or establishment will be safeguarded or destroyed as requested by GCR, and
 - d) No one else will be informed of the discovered identity.

In addition, I will make every effort to release all statistical information in such a way as to avoid inadvertent disclosure. For example:

- No figure, including totals, should be less than 6 in tabulations, unless it is a tabulation routinely published by DCPC or GCR.
- No data on an identifiable case should be derivable through subtraction or other calculation from the combination of tables in a given publication.
- No data should permit disclosure when used in combination with other known data.



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My signature indicates my agreement to comply with the above-stated provisions with the knowledge that deliberately making a false statement regarding any matter within the jurisdiction of any department or agency of the Federal Government violates 18 USC 1001 and is punishable by a fine up to \$10,000 or up to five years in prison. There may be additional penalties levied by the USAPI jurisdiction(s) affected by any breach in confidentiality.

 Signature Date

Print or type name _____

Title _____

Organization _____

Mailing Address _____

Telephone _____

Fax _____

E-mail _____

Date information needed (staff work schedule may affect delivery): _____

Specific data items / tables requested (You may append additional pages if needed):

Proposed use (please provide a detailed explanation, including the potential for future publication):

Please return this signed and completed form to the address/fax below. Please note that even with your signature, this request requires further review and does not guarantee approval of your request. We may need to contact you for further clarification.

Approved: _____

Date: _____

Not approved [reason]: