Caribbean Registry Manual

Data Collection and Operating Procedures Module

Version 1.0

April 2018

IARC REGIONAL HUB FOR CANCER REGISTRATION CARIBBEAN

International Agency for Research on Cancer

World Health Organization

GICR GLOBAL INITIATIVE FOR CANCER REGISTRY DEVELOPMENT

CARPHA

VISION

Healthy People, Healthy Spaces, Healthy Caribbean

MISSION

A professional organisation to build Member States' capacity to prevent disease and promote health and wellness through leadership, partnership and innovation in Public Health

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1 Overview

1.1 Cancer Definition

Cancer is the division of abnormal cells that can invade normal cells and spread in the body. There are many types of cancers. Some terms that are synonymous with cancer include but are not limited to malignancy, neoplasm, cancerous, carcinoma, sarcoma, melanoma, lymphoma, and myeloma.

1.2 Cancer Registries

Cancer registries are organized systems for the collection, storage, management, analysis, interpretation, use, and dissemination of data on persons with cancer. A population-based cancer registry collects the data from many hospitals and non-hospital sources in a defined geographic area, and can serve to show incidence trends for cancer of different sites over time or between population subdivisions. With this information, incidence rates can be calculated. If the cases are then regularly followed, information on remission, exacerbation, prevalence, and survival can be obtained.

Cancer registries are important public health tools to:

- Target public health prevention programs (education, screening, etc.) in order to make the best use of limited public funds.
- Compare acceptance rates and results of different cancer treatments (hospital, local, regional, national, and international).
- Verify and analyze the occurrence of cancer clusters.
- Promote the use of cancer data in cancer control, prevention, and early detection.

1.3 Cancer Diagnosis

A medical practitioner will diagnose cancer after careful evaluation of the patient's medical history, physical exam, and test results. In most cases cancers are diagnosed after a pathologist reviews the cells or tissue under a microscope. Typically, the patient's record clearly presents the diagnosis by use of specific terms that are synonymous with cancer. However, there are occurrences when a physician will use ambiguous terminology (see Section 2.1 Reportable Tumors).

1.4 Changes to Diagnostic Information

Diagnostic information is generally restricted to information available or procedures performed within the time limits defined for each item. There are instances when missing or uncertain information becomes available with the passage of time. Thus, there may be changes in the coding of primary site, histology, extent of disease, residence, etc., over time as the information becomes more certain.

Sometimes, careful re-examination of medical records indicates that a case originally reported as cancer was not, in fact, a malignancy. This occurs most often if ambiguous terms are used or if the case was ascertained on the basis of a death certificate. Such cases must be deleted from the file.

1.5 Casefinding

The way that cancer cases are found and reported (casefinding) may vary depending on the reporting source. All possible public and private sources (see Section 2.5 Reporting Sources) of cancer information for the registry should be identified. Active casefinding occurs when the cancer registry staff assume the responsibility for the review of pathology laboratory reports (including cytology and bone marrow), medical records, disease indices and hospital admission lists, patient logs (radiology, radiation oncology, medical oncology, hematologic oncology, etc.), palliation and hospice centers, autopsy reports, and death certificates. Passive casefinding occurs when the cancer registry staff rely on someone else to identify and report the cases. It is recommended that registries review and update their list of casefinding sources.

1.5.1 Case Sharing

The population-based cancer registry should include nonresidents (off-island residents) diagnosed and/or treated in its coverage area to allow for sharing of cases with other registries. This will allow registries to share case information on a nonresident to the population-based cancer registry covering the patient's place of residence, and to obtain information on resident cases in return. Case sharing agreements should be in place between registries covering the usage and confidentiality of exchanged data.

Beginning 1/1/2019, Caribbean registries will capture data on nonresident cases for a 1-year period.

1.6 Confidentiality

It is the responsibility of the cancer registry to treat any information that specifically identifies a patient, health care professional, or an institution as confidential. Confidentiality policies and procedures (see Appendix A for an example) are required in all phases of the registry operations to:

- Protect the privacy of the individual patient.
- Protect the privacy of the facilities reporting the cases.
- Provide public assurance that the data will not be abused.
- Abide by any confidentiality protecting legislation or administrative rules that may apply.

Registry staff are responsible for the confidentiality of all information encountered during the collection, transmission, and use of cancer data. The registry staff must sign an agreement (see Appendix B for an example) that they will not release confidential information to unauthorized persons. This confidentiality agreement will remain in effect after cessation of employment.

1.6.1 Data Security and Physical Security

Data security policies should address data maintained and transmitted in both paper and electronic formats. The following should be required to assure data security:

- Suitable locks and alarm systems installed to control access to the registry. A list of persons authorized to enter the registry should be maintained by the director.

- Confidential data should be stored in a locked cabinet. Electronic data should be securely stored or encrypted.
- Confidential data should be protected against loss or damage from fire, floods, effects of natural disasters such as hurricanes, or any other interference. Establish a plan for offsite storage of data. See Appendix C for an example of the Louisiana Tumor Registry emergency preparedness plan.
- Confidential data mailed via registered mail, overnight mail, or courier services should:
    - Separate names from other data for transmission; and,
    - Use double envelopes with the confidential information in a separate envelope marked "confidential" and include a contact telephone number.
- Confidential data sent electronically should:
    - Password encrypt names using a secure encryption freeware (e.g., 7Zip) using 256 AES encryption or stronger (WinZip freeware does not support 256 AES encryption, the paid version will provide the proper level of encryption);
    - Provide the password(s) via phone or video call (not in an email) once the file is received; and
    - Maintain a record of electronically transmitted/received data.
- Confidential data should either be disposed of by a private document destruction company or through use of a shredder machine.
- Back-up of the CanReg database should be completed at the end of each day and stored in a secure location.
    - Confidential data that are backed up must be encrypted if they are not stored within the protection of the registry's office.
    - The back-up may be stored on a flash drive, external portable hard drive, CD or other electronic media, including "off-site" back-up storage. The back-up device/media should also be protected according to the guidance above.

2 Process Standards

2.1 Reportable Tumors

Include all neoplasms in the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) with a behavior code of 2 or 3. Refer to the ICD-O-3 Online for the current version. All reportable tumors in persons residing in the registry catchment area (see Section 2.3 Residency) and are diagnosed since the registry reference date (see Section 2.2 Reference Date) must be reported to the registry.

Cancers in metastatic sites (e.g., lymph nodes) are common, especially in pathology reports. These cases should be registered with the site of the primary tumor. If this is not known, register as an unknown primary site.

The following are **not** reportable (collection of these would likely require additional resources):

- 8050-8082 Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
- 8090-8110 Basal cell carcinomas of the skin (C44.0-C44.9)
- Carcinoma *in situ* (any /2) and cervical intraepithelial neoplasia (CIN III) of the cervix (C53.0-C53.9)
- Prostatic intraepithelial neoplasia III (PIN III)
- Benign/borderline brain and CNS tumors

Note 1: The above lesions are reportable for skin of the genital sites: vagina, clitoris, vulva, prepuce, penis, and scrotum (sites C52.9, C51.0-C51.9, C60.0, C60.9, C63.2).

Note 2: If a "0" or "1" behavior code term in ICD-O-3 is verified as *in situ* ("2") or malignant ("3") by a pathologist, the case is reportable.

2.1.1 Ambiguous Terminology

Rules concerning the usage of vague or inconclusive diagnostic language to determine reportability appear in the table below.

Ambiguous Terminology	
Diagnostic of Cancer	**NOT Diagnostic of Cancer**
apparent(ly)	cannot be ruled out
appears *	equivocal
comparable with *	possible
compatible with	potentially malignant
consistent with	questionable
favor(s) *	rule out
malignant appearing *	suggests
most likely	worrisome
presumed	
probable	
suspect(ed)	
suspicious (for)	
typical (of) *	
*These terms are not listed in the African Cancer Registry Network procedure manual.	

For the NOT Diagnostic of Cancer terms, do not include patients with a diagnosis consisting only of these terms. If a phrase such as "strongly suggestive" or "highly worrisome" is used, disregard the modifier ("-ly") and refer to the guidelines above regarding the primary term.

2.2 Reference Date

The reference date is the effective date when cancer registration starts in a specified at-risk population or in a specific facility. Tumors diagnosed on or after the reference date must be included. It is not the date the registry was organized or the date work begins.

The reference date typically begins on January 1 of a calendar year, but sometimes it is another date. The Caribbean Hub reference date is January 1, 2015; however, each cancer registry may have its own reference date for its country.

2.3 Residency

For a population-based registry, it is essential to include all reportable tumors occurring in the at-risk population, and rules must be in place for determining the members of that population. The goal is to use the same rules for the patients' demographic data at the time of diagnosis as those used by the national statistics office in enumerating the population. For example, a population-based registry must have rules for determining residency of part-year residents, institutionalized persons, homeless persons, military personnel, and students.

The Caribbean Hub should refer to the Caribbean Public Health Agency (CARPHA) country codes in Appendix D.

Population-based registries should include tumor reports of non-residents from facilities in their catchment areas in their databases to:

- Share tumor information that otherwise may go unreported with the residents' population-based registry.
- Facilitate death clearance and other record linkages.
- Allow preparation of complete and accurate reports to individual facilities.

Some reporting sources are less concerned with residency of the patient than the reason for admission, and might not collect data for certain categories of patients that the central registry must include, such as patients admitted to a hospice unit or transient patients who receive interim care to avoid interrupting a course of therapy. Clear rules that are well documented, widely distributed, and accepted are essential to prevent missed case reports (source records).

2.4 Multiple Primary Rules

The determination of how many primary cancers a patient has is, of course, a medical decision, but operational rules are needed in order to ensure consistency of reporting by all participants. Basic factors include the site of origin, the date of diagnosis, the histologic type, and the behavior of the neoplasm (i.e., *in situ* versus malignant). In general, if there is a difference in the site where the cancer originates, it is fairly easy to determine whether it is a separate primary, regardless of dates of detection and differences in histology. Likewise, if there is a clear-cut difference in histology, other data such as site and time of detection are not essential. In some neoplasms, however, one must be careful since different histologic terms are used, for example, "leukemic phase of" or "converting to," to describe progressive stages or phases of the same disease process.

It is recommended that cancer registries use the International Agency for Research on Cancer (IARC) multiple primary rules (see Appendix E) developed for international comparisons when reporting cancer incidence and survival.

2.5 Reporting Sources

Cancer registries should include the following reporting sources: public and private hospitals, private physician offices, hospices, public and private laboratories, and death certificates. The participation of all public and private hospitals, including inpatient and outpatient clinics, in the reporting area that diagnose and/or treat cancer is essential to ensure completeness of reporting. Cancer registries should expand their coverage into non-hospital sources to facilitate complete reporting. Some tumors are diagnosed and treated entirely outside of the hospital setting. The registry must develop mechanisms to locate and obtain information on tumors diagnosed and treated outside of the hospital setting. For example: histopathology and hematology laboratories, ambulatory surgery centers, radiation therapy centers, and medical oncology centers.

Although the expansion of reporting sources to non-hospital facilities (e.g., palliation and hospice centers) would ensure complete reporting, the registry's ability to do so may be limited by its financial resources. The registry should assess the cost of accessing each reporting source as well as types of cases (early/clinical, advanced, etc.) and consider the quality of data and the number of new incidence cases that would be obtained.

2.6 Death Certificate Only

A death certificate only (DCO) case is an abstract completed for which the only information the cancer registry has available is a death certificate stating the patient had a reportable condition as the cause of death. DCO cases are identified through the death clearance process.

Death clearance is a process of matching all registered deaths (with a reportable condition as the cause of death) with a population-based registry to identify potentially missed cases and ascertain death information for persons in the central registry database. The death clearance process will serve as a check on the completeness of reporting from other sources and often identifies cases that should have been reported from those sources but were not.

The cancer registry should determine whether they have the resources to:

- Establish a formal agreement with the vital records office covering access to the computer records (or paper files), subsequent use of death record information, and costs.
- Perform record linkage between the vital record death files and the cancer cases to identify matches, non-matches, and potential matches with a reportable condition as a cause of death.
- Train staff to abstract DCO cases.
- Train staff to follow-back on linkage discrepancies (patient and/or tumor)

3 Abstracting and Coding

3.1 Data Items

There are many data items that a cancer registry or cancer surveillance system can collect. The Caribbean HUB determines what is "Required" or "Required When Available" for data collection. Each registry should define which data items are "optional". A general description, specific codes, and definitions are provided for each data item below. See Appendix F for a sample data collection form.

Caribbean Registry Data Item	Required	Required - When Available	Optional
Registry Identifier			
Unique Cancer Registry Identification Number	X		
Patient Identifier			
Unique Patient Identification Number		X	
Cancer Registry Patient Identification Number	X		
Last Name	X		
First Name	X		
Middle Name		X	
Maiden Name		X	
Alias		X	
Gender	X		
Date of Birth	X		
Age at Diagnosis	X		
Race/Ethnicity			X
Address - Street	X		
Address - Village/Town/Parish/City	X		
Address - Country	X		
Residence Country	X		
Birthplace Country			X
Tumor Identification			
Incidence Date	X		
Primary Site Text	X		
Primary Site Code	X		
Histology Text	X		
Histology Code	X		
Behavior	X		
Grade	X		
Laterality		X	
Basis of Diagnosis	X		
Stage			X
Summary Stage			X
TNM			X
Type of Reporting Source			X
Treatment Information			
Date Initial Treatment			X
Surgery			X

Caribbean Registry Data Item	Required	Required - When Available	Optional
Radiation			X
Chemotherapy			X
Hormonal Therapy			X
Immunotherapy/Biologic Response Modifiers (BRM)			X
Follow-up Information			
Date of Last Contact	X		
Vital Status	X		
Date of Death		X	
Cause of Death		X	

3.1.1 Registry Identifier

Unique Cancer Registry Identification Number	Required
Definition: A specific code assigned to each Caribbean registry that represents the data transmission source.	
Codes: Use the country code plus a unique identifier for the registry.	

3.1.2 Patient Identifier

Unique Patient Identification Number	Required when available
Definition: A unique personal identification number (national identifier/social security number).	
Codes: Use the national identifier assigned to the patient.	

Cancer Registry Patient Identification Number	Required
Definition: A unique personal identifier assigned to an individual patient by the cancer registry. This number will be assigned to all of the patient's subsequent tumors.	
Codes: Use the country code plus a unique identifier for the patient. *For example*: The 10th patient in Bahamas would be coded 0440000010.	

Last Name	Required
Definition: The last name of the patient as recorded in the source documents.	

First Name	Required
Definition: The first name of the patient as recorded in the source documents.	

Middle Name	Required when available
Definition: The middle name of the patient as recorded in the source documents.	

Maiden Name	Required when available
Definition: For married women, the maiden name (unmarried name or name at birth) of the patient as recorded in the source documents.	

Alias	Required when available
Definition: An alternate name used by the patient, if known.	

Gender	Required
Definition: Code for the sex at birth of the patient.	
Codes: 1 – male 2 – female 3 – Other (intersex, disorders of sexual development, hermaphrodite) 9 – Unknown	

Date of Birth	Required
Definition: The date of birth of the patient.	
Codes: If date of birth is unknown and age is known, estimate the year of birth by subtracting the age from the current year, and code day as 99 and month as 99. *Date format:* YYYYMMDD *Code*: 99999999 - date of birth is unknown *For example:* The patient was diagnosed in 2017 at the age of 65. Date of Birth: 19529999.	

Age at Diagnosis	Required
Definition: The age of the patient at diagnosis in complete years.	
Codes: 000 – Less than 1 year old 001 – 1 year old, but less than 2 years 002 – 2 years old 003 – 3 years old --- 100 – 100 years old --- 999 – Unknown age	

Race/Ethnicity	Optional
Definition: The origin and/or ethnicity of the patient from the source documents. Race is a country-customizable field due to the racial variation from country to country.	

Address - Street	Required
Definition: The street address (number and street name) of the patient's residence at the time the reportable tumor was diagnosed. The patient's residence must be distinguished from a temporary address. Use the patient's residence not the temporary address. *For example:* A patient may temporarily live with a family member while receiving medical treatment.	

Address - Village/Town/Parish/City	Required
Definition: The village/town/parish/city of the patient's residence at the time the reportable tumor was diagnosed. The patient's residence must be distinguished from a temporary address. Use the patient's residence not the temporary address. *For example:* A patient may temporarily live with a family member while receiving medical treatment.	

Address - Country	Required
Definition: The country of the patient's residence at the time the reportable tumor was diagnosed. This may be the patient's temporary residence. *For example:* A patient may temporarily live with a family member while receiving medical treatment.	

Residence - Country (at diagnosis)	Required
Definition: The country of the patient's residence at the time the reportable tumor was diagnosed. The patient's residence must be distinguished from a temporary address. Use the patient's permanent (usual) country of residence.	

Birthplace Country	Optional
Definition: The country in which the patient was born.	

3.1.3 Tumor Identification

Incidence Date	Required
Definition: The date of the first event (of the six listed below) to occur chronologically should be chosen as incidence date.	
Date format: YYYYMMDD *Codes*: Code the incidence date for this tumor. If an event of higher priority occurs within 3 months of the date initially chosen, the date of the higher priority event should take precedence. Order of declining priority: 1. Date of first histological or cytological confirmation of this malignancy (with the exception of histology or cytology at autopsy). The date should be (in order of declining priority): a. Date when the specimen was taken (biopsy) b. Date of receipt by the pathologist c. Date of the pathology report 2. Date of admission to the hospital because of this malignancy. 3. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy. 4. Date of diagnosis, other than 1, 2 or 3. It may be date of first clinical investigation procedure fort the malignancy (e.g., MRI reports, CT scan reports, etc.). 5. Date of death, if no information is available other than the fact that the patient has died because of a malignancy. 6. Date of death, if the malignancy is discovered at autopsy. Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or decision not to treat, or date of death. The choice of the date of incidence does not determine the coding of the item “basis of diagnosis”.	

Primary Site Text	Required
Definition: Record the text for the primary site of the tumor being reported. The primary site is where the tumor originated and not a metastatic site. Text information may be different from the CANREG generated label which assigns the ICD-O-3 preferred term for the primary site. *For example*: The primary site text is cardioesophageal junction; ICD-O-3 code C16.0 is assigned and the generated label will be Cardia, NOS which is the ICD-O-3 preferred term.	

Primary Site Code	Required
Definition: The primary site is where the tumor originated and not a metastatic site. The topography code has a prefix of "C" followed by a 3-digit number.	
Codes: Code the primary site of the tumor using the ICD-O-3 Online topographical code. • Code the primary site as unknown (C80.9) if the primary site is unknown or if the only information available pertains to a metastatic site. • If the primary site cannot be determined exactly, it may be possible to use a NOS category of an organ or the Ill-Defined Sites. Code the tissue suggested for each ill-defined site over the NOS category when the diagnosis does not specify the tissue of origin. For example, "arm" has several component tissues and may refer to skin of arm (C44.6), soft tissue of arm (C49.1), or bone of arm C40.0), and when nothing more specific is known (arm, NOS) the primary site is coded C76.4. • Use of prefixes peri-, para-, supra-, infra-, and others are often used with topographic sites and indicates that the topographic site is ill-defined. • Use ".8" when a single tumor overlaps two or more subcategories and its point of origin cannot be determined. An overlapping lesion is a tumor that involves two or more contiguous sites. *For example*: A carcinoma of the tip and ventral surface of the tongue is coded to C02.8. • For lymphomas: a. Site of origin is in the lymph nodes (code C77). b. Multiple lymph node regions are involved (code C77.8). c. Extranodal lymphomas code to site of origin. 1. Extranodal lymphomas with unknown site of origin (code C80.9). • For leukemias code site of origin to bone marrow C42.1. a. Exception: myeloid sarcoma is a leukemic deposit in an organ or tissue and should be coded to the site of origin.	

Histology Text	Required
Definition: Record the text for the histologic type, behavior, and grade of the tumor being reported.	

Histology Code	Required
Definition: The histology code is the first 4 digits of the morphology code and describes the characteristics of the tumor.	
Codes: Code the histology of the tumor using the ICD-O-3 Online morphological codes. • Use the Multiple Primary Rules when coding the histology (see Appendix E). • The words "cancer" and "carcinoma" are not interchangeable.	

Behavior	Required
Definition: The behavior is the fifth digit of the morphology code, it describes whether the tumor is benign, *in situ*, or malignant. Code the behavior of the tumor being reported.	
Codes: Code the behavior of the tumor using the ICD-O-3 Online morphological codes. 0 – Benign 1 – Uncertain whether benign or malignant; borderline malignancy; low malignant potential; uncertain malignant potential 2 – Carcinoma *in situ*; intraepithelial; noninfiltrating; noninvasive 3 – Malignant, primary site	

Grade	Required
Definition: The grade or differentiation is the sixth digit of the morphology code, it describes the grade or differentiation of malignant tumors. Only malignant tumors are graded.	
Codes: 1 – Grade I; Well differentiated; Differentiated, NOS 2 – Grade II; Moderately differentiated; Moderately well differentiated; Intermediate differentiation 3 – Grade III; Poorly differentiated 4 – Grade IV; Undifferentiated; Anaplastic 5 – T-cell; T-precursor 6 – B-cell; Pre-B; B-precursor 7 – Null cell; Non T-non B 8 – NK cell; Natural killer cell 9 – Grade, differentiation, or cell type not determined; not stated or not applicable	

Laterality	**Required when available**
Definition: Code the side of the paired organ, or the side of the body on which the reportable tumor originated and not a metastatic site.	
Codes: 0 – Not a paired site 1 – Right 2 – Left 3 – Only one side involved, right or left origin unspecified 4 – Bilateral involvement, laterality origin unknown but stated to be a single primary, or Both ovaries involved simultaneously, single histology Bilateral retinoblastoma Bilateral Wilms tumor 5 – Midline tumor 9 – No information concerning laterality	

Basis of Diagnosis	Required
Definition: Code the most conclusive method used to distinguish how the diagnosis of the reportable tumor was made.	
Codes: This coding scheme permits the distinction between tumors diagnosed on the basis of histology of a metastasis, or from the primary site, making the use of behavior code /6 (and/9) unnecessary. 0 – Death Certificate Only 1 – Clinical: Diagnosis made before death, but without any of the following (codes 2-7) 2 – Clinical investigation: All diagnostic techniques, including x-ray, endoscopy, imaging, ultrasound, exploratory surgery (e.g., laparotomy), and autopsy, without a tissue diagnosis 3 – Autopsy without microscopic confirmation 4 – Specific tumor markers: Including biochemical and/or immunological markers that are specific for a tumor site 5 – Cytology: Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates 6 – Histology of a metastasis: Histologic examination of tissue from a metastasis, including autopsy specimens 7 – Histology of a primary tumor: Histologic examination of tissue from primary tumor, however obtained, including all cutting techniques and bone marrow biopsies; also includes autopsy specimens of primary tumor 8 – Autopsy with microscopic confirmation 9 – Unknown	

Stage	Optional
Definition: Record the stage of disease as it is found in the case record.	
Codes: If it is present, record the staging system that was used. FIGO – Female reproductive site cancers was developed by the International Federation of Gynecology and Obstetrics. DUKE's – The Duke's staging system is a classification system for colorectal cancers. UICC/AJCC stage is also widely used. If you have not been trained or are authorized to do so, DO NOT assign stage to a cancer if it is not noted in the patient's medical record.	

Summary Stage	Optional
Definition: Code for the summary stage at time of diagnosis of the reportable tumor. Summary stage is a basic way of categorizing how far a cancer has spread from the primary site.	
Codes: Summary stage should include all clinical and pathologic information available through completion of surgery(ies) in the first course of treatment or within 4 months of diagnosis in the absence of disease progression, whichever is longer. The SEER Summary Stage Manual 2000 should be used for all cases diagnosed on or after January 1, 2001. 0 – In situ 1 – Localized only 2 – Regional by direct extension only 3 – Regional lymph nodes involved only 4 – Regional by both direct extension and regional lymph nodes 5 – Regional, NOS 7 – Distant site(s) and/or node(s) involved 8 – Not applicable (optional code for benign and borderlines tumors of the brain and central nervous system) 9 – Unstaged, unknown, or unspecified; Death certificate only	

TNM	Optional
Definition: Codes for the TNM at time of diagnosis of the reportable tumor. https://www.uicc.org/resources/access-all-resources/tnm-classification-malignant-tumours/essential-tnm	

Type of Reporting Source	Optional
Definition: The Type of Reporting source documents the sources used to abstract the majority of information on the tumor being reported.	
Codes: 1 – Hospital inpatient 2 – Radiation Treatment Centers or Medical Oncology Centers (hospital-affiliated or independent) 3 – Laboratory only (hospital-affiliated or independent) 4 – Physician's office/private medical practitioner 5 – Nursing/convalescent home/hospice 6 – Autopsy only 7 – Death Certificate Only 8 – Other hospital outpatient units/surgery centers	

3.1.4 Treatment Information

Date Initial Treatment	Optional
Definition: The date that first course of cancer-directed therapy began regardless of modality (Surgery, Radiation Therapy, Chemotherapy, Hormone Therapy, Immunotherapy, or Other Therapy).	
Date format: YYYYMMDD *Codes*: Record the earliest date that any of the planned first course of cancer-directed therapy began regardless of modality. 00000000 – No cancer-directed therapy was given. Autopsy only cases. 99999999 – It is known that the patient had therapy, but it is not possible to estimate the date of first course therapy.	

Surgery	**Optional**
Definition: Record the cancer-directed surgery that modify, control, remove, or destroy cancer tissue. Surgery may be of the primary site or a metastatic site (e.g., lymph nodes, regional site, or distant site).	
Codes: 0 – No surgery performed on the primary site or metastatic site; patient diagnosed at autopsy 1 – Surgery performed on either the primary site or metastatic site 7 – Patient refused surgery 8 – Surgery recommended, unknown if received 9 – Unknown; Death certificate only	

Radiation	**Optional**
Definition: Record the cancer-directed radiation therapy (beam and implant).	
Codes: 0 – No radiotherapy given; patient diagnosed at autopsy 1 – Radiotherapy administered 7 – Patient refused radiotherapy 8 – Radiotherapy recommended, unknown if received 9 – Unknown; Death certificate only	

Chemotherapy	**Optional**
Definition: Record the chemotherapy (single agent and multi-agent regimens).	
Codes: 0 – No chemotherapy administered; patient diagnosed at autopsy 1 – Chemotherapy administered (single agent or multiple agents) 7 – Patient refused chemotherapy 8 – Chemotherapy recommended, unknown if received 9 – Unknown; Death certificate only Chemotherapeutic agents are given at a lower dose used as radiosensitizers or radioprotectants. Do not code these as chemotherapy. Radiosensitizers and radioprotectants are classified as ancillary drugs.	

Hormonal Therapy	**Optional**
Definition: Record the hormonal therapy. This includes hormone surgery (e.g., orchiectomy for prostate cancer) that is, surgical removal of organs for hormone manipulation.	
Codes: 0 – No hormonal therapy; patient diagnosed at autopsy 1 – Hormonal therapy administered 7 – Patient refused hormonal therapy 8 – Hormonal therapy recommended, unknown if received 9 – Unknown; Death certificate only	

Immunotherapy/Biologic Response Modifiers (BRM)	**Optional**
Definition: Record the immunotherapy agents (biological therapy, biotherapy, or biological response modifier). Types of immunotherapy include cancer vaccines, interferons, interleukins, and monoclonal antibodies. Types of hematologic transplants and procedures included are bone marrow transplant (BMT), BMT allogeneic, BMT autologous, conditioning (high-dose chemotherapy with or without radiation therapy prior to transplants), hematopoietic growth factors, non-myeloablative therapy, peripheral blood stem cell transplantation, rescue (BMT or stem cell transplant done after conditioning), and stem cells.	
Codes: 0 – No immunotherapy (BRM); patient diagnosed at autopsy 1 – Immunotherapy (BRM) administered 7 – Patient refused immunotherapy (BRM) 8 – Immunotherapy (BRM) recommended, unknown if received 9 – Unknown; Death certificate only	

3.1.5 Follow-up Information

Date of Last Contact	Required
Definition: The date of last contact with the patient, or date of death.	
Date format: YYYYMMDD *Codes*: 99 – Unknown month 99 – Unknown day 9999 – Unknown year	

Vital Status	Required
Definition: The vital status of the patient at the time of Date of Last Contact.	
Codes: 0 – Dead 1 – Alive 9 - Unknown	

Date of Death	Required when available
Definition: The date of the patient's death.	
Date format: YYYYMMDD *Codes*: 99 – Unknown month 99 – Unknown day 9999 – Unknown year	

Cause of Death	Required when available
Definition: The patient's underlying cause of death.	
Codes: 0 – Patient is alive 1 – Cancer is the underlying cause of death 2 – Non-cancer related underlying cause of death 9 – Unknown cause of death	

Appendix A: Example of Confidentiality, Security, and Data Use Policies and Procedures

INTRODUCTION

Confidentiality of data is of great concern to the {REGISTRY NAME} (here after referred to as Registry) and is extremely important to the operation and maintenance of the Registry. The following are critical elements of the Registry's comprehensive confidentiality policies and procedures that relate to research use, reporting and release of cancer data.

Confidentiality policies, pledges, and procedures are required in all phases of registry operation in order to:

- Protect the privacy of the individual cancer patient.
- Protect the privacy of the facilities reporting the case.
- Protect the privacy of the physicians and other providers responsible for the care of the cancer patient.
- Provide public assurance that the data will not be abused.

OFFICAL CODE OF {COUNTRY} ANNOTATED

Since {DATE} cancer has been a reportable disease in {COUNTRY} and the Registry has been delegated the responsibility for collecting data on cancer from health care facilities or providers, including but not limited to hospitals, radiation treatment centers, outpatient surgical facilities, oncology clinics, pathology laboratories, and physicians' offices.

Furthermore, since the Registry database is used for research, {COUNTRY CODE} protects persons submitting report or data to the Registry, in good faith, from liability for any civil damages.

DEFINTION OF CONFIDENTIAL DATA

The Registry considers as confidential all data that identify patient-specific information. The Registry also treats information that specifically identifies a health care provider or an institution as confidential. Information that characterizes the case load of a specific institution or health care professional is considered proprietary and confidential.

THE RESPONSIBLITIES OF REGISTRY PERSONNEL

It is the responsibility of the Registry to protect the data from unauthorized access and release. The Registry maintains the same standards of confidentiality as customarily apply to the physician-patient

relationship as well as the confidentiality of medical records. This obligation extends indefinitely, even after the patient is deceased.

The costs of inappropriate release of confidential data are many. Inappropriate release of data could damage an individual whose diagnosis of cancer is made public. In addition, support and cooperation of facilities providing data to the Registry could also be severely compromised. Registry personnel responsible for violating confidentiality policies and procedures will be administratively disciplined or dismissed. Security of data maintained both on paper and electronic form are addressed below in DATA SECURUTY.

Each staff member, as part of his/her employment agreement, reads the confidentiality policy and signs a pledge that confidential information will not be released to unauthorized persons. The pledge remains in effect after cessation of employment. The Registry maintains a file of staff members who have signed pledges.

The orientation and training of each new staff member includes instructions concerning the confidentiality of data. Failure to observe the confidentiality policies will result in firm disciplinary action or even dismissal. In extreme circumstances legal action may be warranted against a staff member who fails to comply with the Registry's confidentiality policies.

Non-registry personnel or organizations, including medical investigators, may request access to confidential registry data. Requests must be in writing with agreement to adhere to the same confidentiality standards practiced by registry staff members.

DATA SECURITY

The Registry manager is ultimately responsible for data security.

Registry staff are responsible for the confidentiality of all data encountered during the collection of cancer data.

The following components are required to assure data security in all area of registry operation.

1. Suitable locks are installed to control access to the Registry and custodial staff are notified of the importance of maintaining a secure environment.
2. Confidential data will not be transmitted from the registry by any means (mail, telephone, electronic, or facsimile) without explicit authority from the Registry manager or a staff member to whom such authority has been delegated. All mail with confidential data must be marked "Confidential".
3. Precautions must be taken, for both physical and electronic security of confidential data sent on electronic media, to include secure packaging, and tracking (i.e., using parcel tracking for deliveries to be delivered only to the appropriate person).
4. The use of desktop and laptop computers for the ascertainment and management of confidential data must be controlled by electronic and physical measures to protect the security of the data.

These include passwords, screen savers, and whole-disk encryption utilizing two-factor authentication.

5. Training and demonstration of computer systems must be performed with separate fictitious and/or anonymous data sets, or when this is not possible (i.e., training registry staff on new procedures, or during data audit for quality assurance), observers are required to sign confidentiality agreements.
6. The physical security of confidential data stored on paper documents, computer printouts, and other media present in the Registry must be ensured. For instance when reports, or computer printouts are no longer necessary, they are disposed by shredding. All paper reports are kept secure in a locked room (or locked cabinet) with limited access by the Registry staff.
7. Confidential documents to be destroyed are kept in secure environment (i.e., kept in a box labeled "Confidential documents to be shredded" and kept in a locked room with limited Registry staff access) until they are shredded.

Computer security safeguards must be followed, including, but not limited to:

- Whole-disk encryption is required for all desktops and laptops, as are secure passwords (e.g., database content is password protected, the password is changed every 90 days.)
- Secure network password and logins must be used.
- An in-house printer must be used for all print jobs (the printer/copier for reproducing confidential data should be located in a locked room).
- All back-ups of registry data must be encrypted.

RELEASE OF REGISTRY DATA

Release of registry data for clinical purposes, research, and health care planning is central to the purpose of the Registry. The Registry has developed procedures for data release which ensure maintenance of confidentiality.

For the purpose of complete case ascertainment, the Registry exchanges confidential data with the other registries with which {COUNTRY} has reciprocal case-sharing agreements. The Registry may release limited patient data to providers of health services to that patient. Such data will not include the names of the other health care providers used by the patient.

Individual patient information may also be released in response to a request to computer link or provide confidential data for approved research projects where a written agreement specifies and ensures the protection of information identifying any individual patient. Such studies must be approved by the Registry management team and the appropriate Institutional Review Board (IRB).

No information identifying an individual health care provider or facility will be made available except as required by law or with written consent of that health care provider or facility. Copies of specific patient information will not be provided to individuals (patients), except if required by law.

Confidential information will not, under any circumstances, be published or made available to the general public. In addition, measures will be taken to eliminate the possible identification of individual

patients from data table cells containing very small numbers (i.e., less than five). Any data released or published where it is known that fewer than 90% of the expected cancer cases have been registered must include a qualifier indicating this fact (e.g., "Data in this geographic area is less than 90% complete.").

Requests for data must be referred to the Medical Director, Registry Director, or another designated member of the staff at the {ORGANIZATION} who has been delegated the authority to respond and/or the cancer registry manager, epidemiologist, chronic disease epidemiologist, or other persons designated by {ORGANIZATION}.

Researchers are reminded that all publications of registry data, and/or research publications based on registry data, shall acknowledge support of appropriate funding organizations.

INAPPROPRIATE USES OF CONFIDENTIAL INFORMATION

Confidential data will never be made available for commercial purposes including but not limited to:

- Businesses that are trying to market a product to cancer patients.
- Health care institutions that are trying to recruit new patients.
- Insurance companies that are trying to determine the status of an individual patient.

The Registry has a data request form for use by researchers, registry staff, and others. The form serves as internal documentation of data requests to document all requests for information, assists in the monitoring of staff efforts, and is used to prepare periodic data request summary reports.

Statistical data requests received via the telephone and in writing (such as cancer inquiries from citizens) are processed by the Registry's Program Manager. Data is prepared for the programming staff. Copies of all correspondence along with computer output of the data are filed to be used for summary tabulations to prepare routine reports.

DATA FOR SUMMARY STATISTICS

Reports of summary statistics do not generally raise concerns about confidentiality. However, confidential information may be inadvertently conveyed through summary statistics. The Registry has instituted a policy to suppress the publication of summary statistics in some instances, especially where data are being presented for geographic areas with small populations. For example, the Registry will suppress the reporting of statistical data when there are fewer than five cases reported in a single cell of a table, if a cell of the table represents a combination of variables such as small geographic area, race, age, and sex, which can inadvertently identify individuals. However, breakdowns by age, sex, and large geographic areas such as the country of {COUNTRY} and cells with less than five cases need not be suppressed.

DATA FOR RESEARCH

The Registry uses the following guidelines for controlling access to registry data for research purposes:

1. Requests for research data must be in writing and include a detailed outline of the proposed research and justification for the need of any confidential data.
2. The Registry's review of research requests is performed by the Registry management team (i.e., Director of the Registry, Cancer Registry Manager, and Director of the Registry's daily operation and Cancer Control Director) and others who serve in an advisory capacity.
3. The written proposed research plan will be reviewed by the appropriate research team or committee to assess the following:
    - Scientific and technical merit of the study
    - Type of confidential and/or non-confidential data required
    - Adherence to Registry's guidelines on confidentiality
    - IRB approval
    - Credentials of the researcher
    - Costs incurred and budget requirements
4. {STATE} IRB approval is required before releasing registry data at the individual patient level. If the researcher is affiliated with another institution, then IRB approval is also required from that institution (e.g., academic institution, health care facility, government agency, etc.).
5. The scientific objectives of the study must be peer reviewed to ensure scientific validity.
6. After the review of the research proposal, the Registry management team may request the researcher to revise the data request, work plan and/or the cost estimate. Work will not begin on the data request until there is a mutually agreed upon plan and cost estimate.
7. The researcher must sign a written agreement to adhere to all confidentiality policies. Written agreements will include provisions for use of this information and for its return or destruction at the end of the study.
8. The researcher should demonstrate adequate resources to conduct the research, including funding, staff, and technical expertise.
9. The Registry will ensure that confidential information is not under any circumstances published or displayed in reports that summarize the research results. The Registry will retain the right to review any reports prior to their dissemination to ensure that confidentiality has been respected.
10. A researcher who receives computerized data sets from the Registry must provide assurances that any confidential data will be destroyed or returned to the Registry after the project ends. Confidential data must be protected after the research investigator leaves the employment of the institution (the researcher is liable for civil damages for improper use of data).

DATA FOR QUALITY ASSURANCE STUDIES

Quality control studies of the cancer registry data, including re-abstracting and completeness studies, will be conducted periodically by Registry staff. Registry staff and anyone with access to the data are subject to the same confidentiality standards as indicated in this document. The results of the quality control audits for each individual institution will be kept confidential and only shared with that institution.

Example of an Application/Release Form:

1. Name of Project
2. Organization Responsible for the Project
3. Person in Charge (Name, Position, Address)
4. Other Persons with Access to the Data (Name, Position, Address)
5. Venue for the Project
6. Contact Person (Name, Address, Phone, Fax, E-mail)
7. Type of Project
    a. Duration (beginning, end)
    b. Definition of the data items requested from the cancer registry
    c. Other data materials to be used, their way of use and permission received or (to be) applied for
8. Goal of the Use of the Data (Attach Project Plan)
9. Data Security Measures to be Used
10. Fate of the Cancer Registry Material Received
    a. To be destroyed: when, how
    b. To be archived: when, how
11. Assurance

I agree to handle the data according to the *Terms of Use of the Data*.

Date, signature

Person in charge of the project

Date, signature

Other persons with access to the data to be released

Date, signature

Appendix B: Example of Confidentiality Agreement

Organization

Organization Address

Telephone Fax

CONFIDENTIALITY PLEDGE

- I understand and accept the responsibility of maintaining the confidentiality of all data and information collected and processed by the {ORGANIZATION}.
- I also understand my role in ensuring the right to privacy of persons and institutions cooperating with the cancer registry data collection activities.
- I understand that the {ORGANIZATION} has policies that protect the patients' rights to consideration of their privacy regarding their medical and personal information.
- I understand that I must not reveal any confidential information to anyone except those individuals authorized to receive such information, such as another staff member or the original reporting source.
- I also understand that failure to adhere to this policy may result in disciplinary action up to and including dismissal.
- I have read and understand the {ORGANIZATION} confidentiality policy and procedures and pledge to act in accordance with these policies and procedures.

Name_____

(Please print)

Signature_____ Date_____

Witness_____ Date_____

Revised

CONFIDENTIALITY PLEDGE

Appendix C: Example Registry Emergency Preparedness Plan (Adapted From the Louisiana Tumor Registry Emergency Response Plan)

Introduction

This document is the emergency preparedness, disaster recovery, and business continuity plan for the Cancer Registry. The information in this plan guides employees in the preparation for, and recovery from, a localized or widespread emergency or disaster. Additional guidance is provided to ensure that, if employees must evacuate for extended periods of time, normal registry work can continue from the employee's remote site.

Scope

The plan described here applies to employees of the Cancer Registry.

Primary Objectives of the Plan

1. Present the rules and regulations regarding employee responsibilities in the event of weather-related emergencies.
2. Present a logical course of action for the protection and/or evacuation of data, equipment, and confidential documents in the event of a hurricane or catastrophic weather event.
3. Provide, in a checklist format, the equipment and materials each employee should be prepared to take to an evacuation site to ensure they are able to work from the evacuation site.
4. List the tasks each employee is expected to complete prior to and immediately after an evacuation.

The major hazard threatening the Caribbean region is tropical weather and the objectives above focus on tropical weather preparedness and response. Employees who learn and follow the plan to meet weather-related emergencies will be well positioned to respond to other types of hazards.

Preparedness Responsibilities of Regional Registry Offices

Regional registry staff (where this applies) should review the emergency preparedness policies of the central office. Regional staff are accountable to their institution in case of an emergency and should know the policies of their institution. In addition, each regional registry should develop a plan to safeguard registry equipment and documents and ensure continuity of work in the event of an evacuation of, or damage to, their office. The regional registries are encouraged to develop a plan similar to the one outlined below for the central office. Each region is strongly encouraged to share their institutional and registry plan with the central office.

Emergency and disaster risks in the Caribbean region

In the Caribbean, weather-related emergencies may range from heavy rainfall and street flooding to catastrophic hurricanes. However, earthquakes, fires, or a disease outbreak are all scenarios that could

result in minimal to widespread, catastrophic damage, and/or, inability to access your work site for a short to extended period of time. This plan will help you understand your role, as an employee, in preparing for and dealing with an emergency.

Weather-related emergencies

This section discusses in detail how to meet the primary objectives of this plan should there be a weather-related emergency.

The following are critically important to understand:

1. Only the Cancer Registrar can activate the Emergency Situation Response Plan. The Cancer Registrar could activate the Plan 1 full day ahead of a closure announcement to ensure that all preparations are complete before closure. Until the Cancer Registrar calls for closure of the Registry, you must still report to work.
2. In the event the Registry is declared closed and you evacuate, you must notify the Cancer Registrar with your new contact information and update the information whenever it changes while evacuated.
3. You are responsible for monitoring news channels, e-mail correspondence, and other means of communication to receive instructions regarding the state of the emergency and return to work notice.

Year-Round Emergency Preparedness: Employee Responsibilities

Each employee must be ready and willing to implement the details of the plan outlined below. All employees must be prepared for weather-related emergencies 12 months of the year. Hurricane season begins June 1 and ends November 30, but the region is vulnerable to extreme rain events at any time. Adherence to the year-round activities below will better prepare you to safeguard registry assets in any emergency:

Safeguard confidential information on paper

Do not save paper with confidential information past the date it is useful. Paper can become a serious security liability. If you can reprint the information, there is no need to save a paper copy. That paper copy, even in a locked filing cabinet, has the potential of disclosing confidential information should the cabinet be vandalized or damaged.

Electronic

Employees with a laptop are required to bring it to the office at least once a month and connect to the network. In this manner, your password can be synchronized so that you will not be locked out of your laptop should you need to evacuate with the laptop. In addition, Windows and VirusScan updates are continually pushed out to all computers on the network and your laptop needs to be updated on at least a monthly basis.

Every employee is required to use a unique user ID and strong password to protect access to the network and individual computers.

Should the Cancer Registrar declare the Registry closed due to an impending weather event or other emergency, you must shut down your computer and unplug all electronics before you leave the building.

Where possible, all laptop hard drives must be fully encrypted. All external drives (USB "thumb" drives, fire wire drive, etc.) should also be encrypted before any files are placed on the drive.

Physical security

Measures should be taken to immediately fix any problems with locks on doors, file cabinets, safes or other lockable storage areas. If the keys are lost, another copy should be requested. If the lock is jammed or does not work properly, it should be fixed promptly.

All areas in your office with physical or infrastructure problems should be identified and addressed. Examples are areas that leak when it rains or electrical outlets that are loose or spark when plugging or unplugging equipment. Notify the Cancer Registrar so they are aware of problem areas and can take steps to get it fixed.

Backups of desktop and laptop computers

All important data, documents, spreadsheets, etc., on your PC should be regularly backed up to the central server. Staff are discouraged from using external drives (e.g., USB drives) to make a quick backup copy for evacuation. In your haste during an evacuation, the external drive may be lost or damaged.

Employees with both a desktop and a laptop should keep the important files on both machines synchronized so you can evacuate with all important files on your laptop.

Contact information

Any time your local or emergency contact information changes, please notify the Cancer Registrar.

Hurricane Season: General Responsibilities

Contact information

Prior to hurricane season (June 1), all employees must update the following emergency contact information with the Cancer Registrar:

1. Local contact information: home address, home phone number, cell phone number, email address.
2. Emergency contact information, including next of kin contact information so that you can be contacted *during* or *after* an emergency.

Identification of equipment

All computers, printers, fax machines, etc., should be labeled and assigned a priority category. Equipment located near windows should be moved during emergency preparations for tropical weather. Equipment that needs to be evacuated should be tagged as high priority.

If Tropical Weather Threatens

Once the Cancer Registrar has activated the Emergency Situation Response Plan:

- You MUST bring your laptop into the office for updates.
- Field abstractors should cancel field visits and instead report to the office to make their preparations.
- You MUST shred all confidential information that has been collected.
- You MUST back up any files not already backed up to the central server. If in addition to your desktop you also have a laptop, identify what files on your desktop you may need and transfer them to your laptop.
- Prepare an "evacuation box" and put in it:
    i) Manuals, books and files you may need to work from an evacuation site.
    ii) Laptop, if you have one, and ALL components (power cord, external drive, carrying case, mouse, etc.).
    iii) A copy of this emergency preparedness document.
- Check printers, copiers, and fax machines for any confidential printouts you may have forgotten.
- Before you leave for the day:
    i) Lock and secure all file cabinets, desk drawers, etc. Put the keys back in your evacuation box.
    ii) Power down and unplug all electronic equipment. Also unplug all extension cords, power strips, or UPS units that may be plugged into the wall. If your computer is situated near a window or an area with a leak, you MUST unplug it and move it to a safer location.
    iii) Protect any materials you are leaving behind (books, pictures, etc.) by covering them with plastic or garbage bags.

If the Cancer Registrar Calls for Closure of the Registry:

Only with the official closure of the Registry are you allowed to leave your post.

The Registrar may decide to close the Registry at any time after the Plan is activated

Evacuation

Should the Cancer Registrar declare the Registry closed and employees have been granted official release, you may choose to evacuate or a mandatory evacuation may be issued.

As soon as you have evacuated to a safe place, ***you are required to:***

1. Call the Cancer Registrar to report your new location and new contact information.
2. Monitor the news, your email, and other information sources for updates.

IT staff activities and responsibilities

If the Cancer Registrar activates the Plan:

1. Assist employees with backing up files to the central server.
2. When all employees' files are backed up, make a full back up to a central server.
3. Assist employees with preparing their laptops for evacuation.
4. Identify, prepare, document, and assemble tagged priority equipment for evacuation
5. Assist employees with moving equipment away from windows.
6. For any employee on leave and not present to make preparations, secure the employee's area, locate any laptop and laptop components, and prepare an evacuation box to send to the employee should an evacuation be necessary.
7. Verify that all employees with laptops have them prepared for evacuation.

After the storm

1. Monitor conditions and wait to determine the safety of returning to the Registry.
2. Once permission to return is granted, an assessment of the damage to the equipment and infrastructure should be performed.
3. If the damage is minimal and the infrastructure is still operational, network equipment and servers should be brought back online and normal daily operation can resume.
4. If employees cannot return to the Registry, equipment to be retrieved as soon as possible includes:

    Servers (if possible)
    Desktop computers
    All remaining laptops
    Printers
    Fax machines
    Registry specific software installation CDs
    Hard drives from desktop computers of essential personnel
    Spare networking switches, hubs, wireless access point
    Spare mice, keyboards and flat panel monitors

Appendix D: CARPHA Country Codes

CARPHA Country Codes		
Country Name	**Alpha Country Code**	**Country Code**
Antigua and Barbuda	ATG	28
Anguilla	AIA	660
Aruba	ABW	533
Bahamas	BHS	44
Barbados	BRB	52
Belize	BLZ	84
Bermuda	BMU	60
Bonaire, Saba, St. Eustatius	BES	599
British Virgin Islands	VGB	92
Cayman Islands	CYM	136
Cuba	CUB	192
Curacao	CUW	531
Dominica	DMA	212
Dominican Republic	DOM	214
French Guiana	GUF	250
Grenada	GRD	308
Guadeloupe	GLP	312
Guyana	GUY	328
Haiti	HTI	332
Jamaica	JAM	388
Martinique	MTQ	474
Montserrat	MSR	500
Netherland Antilles	ANT	530
Puerto Rico	PRI	630
St. Kitts and Nevis	KNA	659
St. Lucia	LCA	662
St. Maarten	SXM	534
St. Vincent and the Grenadines	VCT	670
Suriname	SUR	740
Trinidad and Tobago	TTO	780
Turks and Caicos Islands	TCA	796
U.S. Virgin Islands	VIR	850

Appendix E: IARC International Rules for Multiple Primary Cancers

Rules for Reporting Incidence and Survival

1. The recognition of the existence of two or more primary cancers does not depend on time.
2. A primary cancer is one that originates in a primary site or tissue and is not an extension, nor a recurrence, nor a metastasis.
3. Only one tumor shall be recognized as arising in an organ or pair of organs or tissue. Some groups of codes are considered to be a single organ for the purposes of defining multiple tumors. These topography code groups are shown in Table 1.
   Multifocal tumors, discrete masses apparently not in continuity with other primary cancers originating in the same primary site or tissue, are counted as a single primary.
4. Rule 3 does not apply in two circumstances:
   a. Systemic (or multicentric) cancers potentially involving many different organs are only counted once in any individual. These are Kaposi sarcoma (group 15 in Table 2) and tumors of the hematopoietic system (groups 8-14 in Table 2).
   b. Neoplasms of different morphology should be regarded as multiple cancers (even if they are diagnosed simultaneously in the same site).

      If the morphological diagnoses fall into one category in Table 2, and arise in the same primary site, they are considered to be the same morphology for the purpose of counting multiple primaries. If the morphological diagnoses fall into two or more of the categories in Table 2, even if they concern the same site, the morphology is considered to be different, and two or more cases should be counted.

      Single tumors containing several different histologies which fall into one histological group in Table 2 are registered as a single case, using the numerically highest ICD-O morphology code.

      If one morphology is not specific (groups 5, 14 and 17) and a specific morphology is available, the case should be reported with the specific histology and the non-specific diagnosis should be ignored.

Table 1. Groups of topography codes considered a single site in the definition of multiple cancers		
ICD-O Site Code	**Label**	**If diagnosed at different times, code first diagnosis. If diagnosed at the same time use code given below.**
C01 C02	Base of tongue Other and unspecified parts of tongue	C02.9
C00 C03 C04 C05 C06	Lip Gum Floor of mouth Palate Other and unspecified parts of mouth	C06.9
C09 C10 C12 C13 C14	Tonsil Oropharynx Pyriform sinus Hypopharynx Other and ill-defined sites in lip, oral cavity and pharynx	C14.0
C19 C20	Rectosigmoid junction Rectum	C20.9
C23 C24	Gallbladder Other and unspecified parts of biliary tract	C24.9
C33 C34	Trachea Bronchus and lung	C34.9
C40 C41	Bones, joints and articular cartilage of limbs Bones, joints and articular cartilage of other and unspecified sites	C41.9
C65 C66 C67 C68	Renal pelvis Ureter Bladder Other and unspecified urinary organs	C68.9

Table 2. Groups of malignant neoplasms considered to be histologically different for the purpose of defining multiple tumors.	
1. Squamous and transitional cell carcinoma	8051-8084, 8120-8131
2. Basal cell carcinomas	8090-8110
3. Adenocarcinomas	8140-8149, 8160-8162, 8190-8221, 8260-8337, 8350-8551, 8570-8576, 8940-8941
4. Other specific carcinomas	8030-8046, 8150-8157, 8170-8180, 8230-8255, 8340-8347, 8560-8562, 8580-8671
5. Unspecified carcinomas (NOS)	8010-8015, 8020-8022, 8050
6. Sarcomas and soft tissue tumors	8680-8713, 8800-8921, 8990-8991, 9040- 9044, 9120-9125, 9130-9136, 9141-9252, 9370-9373, 9540-9582
7. Mesothelioma	9050-9055
8. Myeloid	9840, 9861-9931, 9945-9946, 9950, 9961- 9964, 9980-9987
9. B-cell neoplasms	9670-9699, 9728, 9731-9734, 9761-9767, 9769, 9823-9826, 9833, 9836, 9940
10. T-cell and NK-cell neoplasms	9700-9719, 9729, 9768, 9827-9831, 9834, 9837, 9948
11. Hodgkin lymphoma	9650-9667
12. Mast-cell tumors	9740-9742
13. Histiocytes and Accessory Lymphoid cells	9750-9758
14. Unspecified types	9590-9591, 9596, 9727, 9760, 9800- 9801, 9805, 9820, 9832, 9835, 9860, 9960, 9970, 9975, 9989
15. Kaposi sarcoma	9140
16. Other specified types of cancer	8720-8790, 8930-8936, 8950-8983, 9000- 9030, 9060-9110, 9260-9365, 9380- 9539
17. Unspecified types of cancer	8000-8005

Recommendations for Recording

1. Two tumors of different laterality, but of the same morphology, diagnosed in paired organs (e.g., breast) should be registered separately unless stated to have originated from a single primary.

   Exceptions to this rule:

   a. Tumors of the ovary (of the same morphology)
   b. Wilm's tumor (nephroblastoma) of the kidney
   c. Retinoblastoma

   which should be recorded as a single bilateral registration when they occur on both sides. Reminder: tumors in paired organs of completely different histology should be registered separately.

2. Cancers which occur in any fourth character subcategory of colon (C18) and skin (C44) should be registered as multiple primary cancers.

Appendix F: Sample Data Collection Form

Registry Identifier

Unique Cancer Registry ID: Click here to enter text.

Patient Identifier

Unique Patient ID:
Click here to enter text.

Cancer Registry Patient ID:
Click here to enter text.

Last Name:
Click here to enter text.

First Name:
Click here to enter text.

Middle Name:
Click here to enter text.

Maiden Name:
Click here to enter text.

Alias:
Click here to enter text.

Gender:
Male ☐ Female ☐
Other ☐ Unknown ☐

Date of Birth:
Click here to enter a date.

Age at Diagnosis:
Click here to enter text.

Race\Ethnicity:
Click here to enter text.

Address – Street:
Click here to enter text.

Address – Village/Town/Parish/City:
Click here to enter text.

Address – Country:
Click here to enter text.

Residence – Country:
Click here to enter text.

Birthplace – Country:
Click here to enter text.

Tumor Identification

Incidence Date:
Click here to enter a date.

Primary Site Text:
Click here to enter text.

Primary Site Code:
Click here to enter text.

Histology Text:
Click here to enter text.

Histology Code:
Click here to enter text.

Behavior:
Choose an item.

Grade:
Choose an item.

Laterality:
Choose an item.

Basis of Diagnosis:
Choose an item.

Stage:
Click here to enter text.

Summary Stage:
Choose an item.

TNM:
Click here to enter text.

Type of Reporting Source:
Choose an item.

Treatment Information

Date of Initial Treatment:	Surgery:	Radiation:
Click here to enter a date.	Choose an item.	Choose an item.
Chemotherapy:	**Hormonal Therapy:**	**Immunotherapy/BRM:**
Choose an item.	Choose an item.	Choose an item.

Follow-up Information

Date of Last Contact:	Vital Status:
Click here to enter a date.	**Dead** ☐ **Alive** ☐
Date of Death:	**Cause of Death:**
Click here to enter a date.	Choose an item.