### Physician's Cancer Reporting

United States Virgin Islands Central Cancer Registry

### **REPORTING CANCER CASES TO THE**

### VIRGIN ISLANDS CENTRAL CANCER REGISTRY



central Cancer Registry is a reliable and updated source of information for research on cancer and its causes. A cancer registry is an epidemiologic surveillance system to collect information designed regarding incidence, distribution, risk factors and mortality of the disease. This information is essential to public health professionals, researchers, the medical community, and policy makers to understand and address the cancer burden. This information is acquired through active reporting of data for cancer cases and central nervous system neoplasms in places where these patients are diagnosed or treated.

The United States Virgin Islands Central Cancer Registry (VICCR) is part of the Department of Health -Chronic Disease Prevention Program. Beginning on January 1st, 2016, the VICCR will start the collection of cancer cases. Reportable cancer cases diagnosed and/or first course of treatment done at your facility on and after this date must be submitted to the Central Cancer Registry. The collaboration of each healthcare provider in the USVI is of vital importance to achieving a successful Cancer Central Registry implementation that will result in great benefit to our community.

# Act No. 7939 from 2016: To establish a Cancer Registry for the Territory of the Virgin Islands

he reporting of cancer cases by health care professionals is required by law since 1999. An amendment done in 2016 states that: "each health care facility diagnosing or providing treatment to cancer patients shall report in an electronic format or any other format requested by the Registry each new case of a reportable



neoplasm to the Registry not later than 180 days after the date of diagnoses or date of first contact with the already diagnosed patient".

Even though there has been a law requiring cancer reporting, there has been no law enforcement since the enactment of the law. The goal for the DOH is to have a fully functional Central Cancer Registry with a reference date of January 1st, 2016. The DOH will endeavor to inform healthcare providers and answer any questions they may have regarding data collection.

It is the main goal of the USVI DOH to have a Central Cancer Registry with accurate and updated data. It is also expected to have data that can be used for research, and data that can be published nationally. To achieve all these goals, information to be collected must comply with the standards, guidelines and data requirements established by the Centers for Disease Control (CDC) - National Program for Cancer Registries (NPCR).

## Why physician's offices must report cancer cases?

Recent changes in cancer diagnosis and treatment from hospital to ambulatory healthcare settings are increasing the importance of non-hospital healthcare providers' data for cancer surveillance, especially in certain tumors that are primarily seen in an outpatient setting, such as, hematopoietic diseases, early stage melanoma, prostate, colorectal, and breast cancers. In addition, sometimes the physician is the only source of information when a patient is diagnosed at the office and then elects to pursue treatment off-island.

# Reportable Diagnoses



TION

- Invasive and in situ malignancies and Vulvar Intraepithelial Neoplasia III (VIN III), Vaginal Intraepithelial Neoplasia III (VAIN III) and Anal Intraepithelial Neoplasia III (AIN III).
- Borderline and benign primary intracranial and Central Nervous System tumors •
- Lymphoma, leukemia, and other malignant blood disorders (chronic • myeloproliferative diseases, and myelodisplastic syndromes)

The following malignancies are NOT REPORTABLE:

- Basal Cell and Squamous Cell Carcinoma of the skin (unless it is occurring in the • genitalia and vermillion of lips)
- Carcinoma in situ or intraepithelial neoplasia grade III of the cervix CIN III) and • prostate (PIN III).

\*\*\*If you have any question about determining reportability, call the VICCR for assistance.\*\*\*

## HIPAA & Cancer Registry



he Health Insurance Portability and Accountability Act (HIPAA) allows the divulgation, without individual authorization, to the public health authorities allowed by law to collect and receive this information with the purpose of disease control and prevention. HIPAA is not an obstacle for any local act that mandates the disease reporting for

public health purposes. For more information regarding this theme please visit: <u>http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm</u>.

## Report your cases in 3 easy steps...

- Identify the patient with a definitive diagnosis of any of the reportable diseases listed in the Reportable Diseases List and whose date if diagnosis is January 1st, 2016 or after.
- 2. Complete the Physicians Reporting Form the form can be completed by either printing and filling out the form (information must be legible) or using the PDF fillable format (preferred method) available under **Reporting Forms and Related Downloads** section on the DOH webpage:

### www.healthvi.org/programs/chronic-disease/cancer-registry

3. Send it to the VICCR - completed forms may be sent over fax to 718.9505 or via encrypted email (described later in this document) to viccr@vi.gov (preferred method).



#### Virgin Islands Central Cancer Registry – Physician's Cancer Report Form\* Charles Harwood Complex, 3500 Estate Richmond Christiansted, VI 00820-4370

Tel. (340) 718-1311 x 3774, 3700 / Fax (340) 718-9505 / Email: viccr@doh.vi.gov

Physician's Office Information						
Physician Name	Facility Name			Address / Phone Number		
		Patient's I	nformation			
Full Name (First, Middle and Last	i)		Social Security		Sex:	
Physical Address (please include Estate, City, State, Zip) Phone Number						
Medical Record #	Date and Place of Birth Marital				Insurance	
	Race: Caucasian / White Black Asian Native American Other Unknown ***For Hispanic patients, please select a race.				Hispanic: 🗆 Yes 🗆 No 🗆 Other	
		Cancer Ir	nformation			
Date of Diagnosis		□ Right □ N/A Histology: □ Left				
Behavior:       Diagnostic confirmation (check one):         Benign       Borderline         In Situ       Malignant         Histology       Cytology         X-ray       Clinical						
Stage (check one): 🗆 In Situ 🗆 Localized 🗆 Regional by direct extension 🗆 Regional to LN 🗆 Regional direct & LN 🗆 Distant						
TNM: T N Stage □ Clinical □ Pathological						
Tumor Markers Results (example: CA 19-9, CA 125, CEA, CGA, HPV, LDH, ER, PR, Her2/neu, KRAS, AFP, PSA, hCG, etc.)						

**Diagnostic Work Up At Diagnosis** 

Physical examination (includes high risk factors)

X-Ray / Scans / Scopes

	Treatment Information						
	Type / Description	Date	Where performed				
Surgery							
Radiation							
Chemotherapy							
Hormone							
BRM							
Other (includes alternative medicine)							

Follow Up / Patient Status	Completed by:
Referred to:	
Date of last contact:	Name:
Vital Status:  Alive Dead	
Cancer Status: □ evidence of CA □ no evidence of CA	Date:
If expired; please provide date and place of death:	

\*This form is intended for physician office setting ONLY. Not for hospitals or healthcare clinics.

\*\*Please, send the completed form to the USVI-CCR via e-mail to: viccr@doh.vi.gov

To protect our patient's privacy and to comply with HIPAA regulations the attached forms must be encrypted and password protected using encryption software. Microsoft encryption is not recommended.

### Please, attach a copy of the pathology report.

### PHYSICIAN'S CANCER REPORT FORM INSTRUCTIONS

	Facility Information
Physician Office Information Section	Record the complete name, address, and telephone number of your facility or physician's office.

	Patient Information				
Patient Name	Record the patient's full name (last name, first name and middle name)				
Social Security Number	Record the patient's social security number. Do not record a spouse's number.				
Sex	Check off the patient's sex/gender.				
Patient's Address	Record patient's permanent home address at time of diagnosis, not a temporary relocation for treatment. Street address takes priority over post office box number.				
Phone Number	Record the patient's phone number				
Medical Record Number	Record the patient's medical record number				
Date of Birth	Record patient's birth date in MM/DD/YYYY format.				
Marital status	Specify patient's marital status at time of diagnosis				
Health Insurance	Record the patient's health insurance				
Race	Check off the patient's race.				
Hispanic	Check off whether the patient considers himself or herself to be of Hispanic origin.				

	Cancer Information
Date of Diagnosis	<ul> <li>Record the date the patient was first diagnosed with cancer by a recognized medical practitioner.</li> <li>Record in MM/DD/YYYY format. If unknown, record "unk".</li> </ul>
Primary Site	Record the site of origin of the tumor. Record the subsite if known (i.e. UOQ breast, LL lung). If unknown, record "unk". It is important to identify the primary site and not a metastatic site.
Laterality (paired organ)	If the site of origin is a paired organ, check the laterality.
Histology	Record the histologic cell type of the tumor (i.e. mucinous adenocarcinoma; infiltrating ductal CA
Behavior / Grade	Check off the behavior/grade of the tumor.
Diagnostic Confirmation	Check off the most reliable method used in diagnosing this cancer. <b>Attach copy of pathology report.</b> Use the following guidelines to determine the method:
Please, attach copy of pathology report.	<ul> <li>Histology: Microscopic diagnosis based on tissue specimens (i.e. biopsy, frozen section, and surgery).</li> <li>Cytology: Microscopic diagnosis based on cells rather than tissue (i.e. smears from sputum, bronchial washings, brushings, fine needle aspirations, etc.)</li> <li>Clinical: Diagnosis not supplemented with positive microscopy (i.e. made at surgical exploration, by use of an endoscope or physician's statement that patient have cancer).</li> <li>X-ray-Radiological diagnosis (x-rays, scans) not microscopically confirmed.</li> <li>Unknown: diagnosis method is unknown.</li> </ul>
Stage	<ul> <li>Check the stage of tumor at diagnosis (extent of disease within four months of diagnosis).</li> <li>Use the following categories to determine the extent at diagnosis:</li> <li>In Situ: tumor has not progressed through the basement membrane of the organ involved.</li> <li>Local: limited to site of origin; progressed through the basement membrane but not beyond the walls of the organ involved.</li> <li>Regional - Direct Extension: direct extension to adjacent organs or tissues.</li> <li>Regional - Lymph Nodes: involvement of regional lymph nodes.</li> <li>Distant: direct extension beyond adjacent organs or tissues, or metastases to distant sites or distant lymph nodes.</li> <li>Unknown: no information is available to determine extent of disease.</li> </ul>
TNM	Record the stage according to the AJCC. Specify if it is a clinical or pathological staging.
Tumor Markers	Record date any result from tumor markers tests done to the patient during work up.

	Treatment Information
Treatment	Record all first course treatment that the patient received. Do not record second course treatment.
	First course treatment includes all cancer-directed treatment modalities given by clinicians at the time of diagnosis. When recording treatment, write the type of treatment, the date the treatment was received or began and where performed.

Follow Up / Patient Status				
Date Last Seen	Record the date the patient was last seen or date of death in MM/DD/YYYY format.			
Vital Status	Check the vital status of the patient as of the date last seen.			
Cancer Status	Check the patient's cancer status as of the date the patient was last known to be alive or dead.			
If Expired, Place of Death	If Expired, Place of Death If patient expired, record the place of death. If unknown, record "unk".			
Cause of Death	If patient expired, record the cause of death. If unknown, record "unk".			
Completed by				

Completed by				
Form Completed By Record the full name of the person completing the form.				
Date Completed	Record the date completed.			

## Saving PDF Fillable Format Forms

Once a cancer case has been identified, please complete the Physicians' Reporting Form. The form included in this document can also be downloaded from the DOH Website in a PDF fillable format. This simplifies the process by allowing typing of the information directly into the form. If you have any question filling out the form, please call 718.1311 ext.: 3774 / 3700 / 3798. Note: If you are completing multiple forms, you must <u>Save As</u> every form to avoid losing information. (Click File > Save As > Assign a name to the file > Click Save)
 After saving the form, you will be able to start a new one. Be careful not to save the form with already existing file names, otherwise you will be overwriting an existing document and losing information.

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- 2. A copy of the pathology report must be submitted along with the form.
- 3. The forms can be submitted either by:
  - a. Encrypted e-mail. For instructions on encrypting files please, read the "Encrypting Files before Sending Data to the CCR" section.
  - b. Fax: send the completed form and pathology report to 718.9505

### Encrypting Files before sending data to the Cancer Registry

Data encryption is the process of converting data from a plain-text, or readable, form into a form that can be understood by the sender and the intended recipient, and no one else. Encrypted data usually looks like a long sequence of random letters and numbers. The intended recipient of the data has the key or unique way to change the data from its encrypted form back into plain text.

Encryption is a critical component of



data security. It ensures that if the data is accessed by an unauthorized person, he or she will not be able to read it and thus cannot misuse it.

The software 7-zip available for free at: <u>http://www.7-zip.org/download.html</u> can be used to compress and encrypt files.

"Introduction to Data Encryption." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 13 Jan. 2015. Web. 26 June 2015. <a href="http://www.cdc.gov/cancer/npcr/tools/security/encryption.htm">http://www.cdc.gov/cancer/npcr/tools/security/encryption.</a>

After the Physicians' Reporting Forms are ready to be submitted to the CCR, an encryption process must take place to secure the PHI included in each form. Failing to do this will result in a data security breach. To encrypt a file, 7-zip (or other encryption software) must be installed on your computer.

1. Open the folder containing the file to be encrypted.

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2. Right Click the file to be encrypted and from the menu select 7-zip.

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3. Once you select 7-zip, select the option Add to archive.



4. The following window will open. Complete the Enter password field. Make sure to enter a safe password (do not use phrases like: password, 123456, etc.). Click **OK**.

Add to Archiv	/e					×		
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5. A new file will be created in the folder with the extension .7z.

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The file is ready to be sent as an email attachment. Multiple documents may be selected and encrypted in one folder.

# When attaching a document to an email, make sure that the selected file is the encrypted (.7z) file!!!

- 6. Send the email with the encrypted attachment to: viccr@vi.gov.
- 7. Call to the VICCR authorized person to provide the password. Never send the password via email.

## Cancer Registry Terms

Abstracting: The process of collecting and recording pertinent cancer data from a health record.

Cancer Registrar: Cancer data management professionals who collect, abstract, and report cancer statistics for or to various healthcare agencies

Case Report: A detailed report of the diagnosis, treatment, and follow-up of an individual patient. Case reports also contain some demographic information about the patient (for example, age, gender, ethnic origin).

Reference Date: starting date established for a registry, usually January 1 of a given year, after which all cases diagnosed or treated at the facility, regardless of date of initial diagnosis, must be entered into the registry.



### VIRGIN ISLANDS DEPARTMENT OF HEALTH CHRONIC DISEASE PREVENTION PROGRAM VIRGIN ISLANDS CENTRAL CANCER REGISTRY

Webpage: <a href="http://www.healthvi.org/programs/chronic-disease/cancer-registry">www.healthvi.org/programs/chronic-disease/cancer-registry</a>

Email: viccr@doh.vi.gov Phone: (340) 718-1311 x. 3774, 3793 Fax: (340) 718-9505