

REPORTING CANCER CASES TO THE
UNITED STATES VIRGIN ISLANDS CENTRAL CANCER REGISTRY



What is a Central Cancer Registry?

A 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 designed to collect information 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 (USVI-CCR) is part of the Department of Health (DOH) - Chronic Disease Prevention Program (CDPP). Beginning on January 1st, 2016, the USVI-CCR 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 Central Cancer Registry implementation that will result in great benefit to our community.

Act No. 6286 from 1999: To establish a Cancer Registry for the Territory of the Virgin Islands

The reporting of cancer cases by health care professionals is required by law since 1999. Act No. 6286 establishes that: “each health care facility diagnosing or providing treatment to cancer patients shall report each case of cancer to the Commissioner in a format prescribed by the Commissioner...”.



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 Hospice Care Centers offices must report cancer cases?

Patients with terminal disease may receive hospice care at home or in a specialty hospital unit, nursing facility, or designated hospice facility. The central cancer registry access to this information is important for case ascertainment on patients who have died with a cancer diagnosis identified only through death certification information. ¹

1. "Central Cancer Registry Data Sources". *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention. <http://www.cdc.gov/cancer/npcr/informatics/aero2/ccr/c_sources.htm>

Reportable Diagnoses

ICD-O

INTERNATIONAL
CLASSIFICATION
OF DISEASES FOR ONCOLOGY



- Invasive and in situ malignancies and VIN III, VAIN III and AIN III.
- Borderline and benign primary intracranial and CNS tumors
- Lymphoma, leukemia, and other malignant blood disorders (chronic myeloproliferative diseases, and myelodysplastic 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 USVI-CCR for assistance.****

HIPAA & Cancer Registry



The Health Insurance Portability and Accountability Act (HIPAA) allows the divulgence, 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:

<http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm> .

Report your cases in 3 easy steps...

1. Identify the patient with a definitive diagnosis of any of the reportable diseases listed in the Reportable Diseases List.
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 available under the **Forms & Applications Section** on the DOH webpage www.healthvi.gov (preferred method).
3. Send it to the USVI-CCR - completed forms may be sent over fax to 718.9505 or via encrypted email (described later in this document) to viccr@doh.vi.gov (preferred method).

United States Virgin Islands Central Cancer Registry Hospice Care Centers' Reporting Form*

Hospice Care Facility Information			
Facility Name		Phone Number	
Address			
Patient transferred/referred from/by			
Patient's Information			
Last Name	First Name	Middle Name	
Address (please include Estate, City, State, Zip)			
Social Security	Date of Birth	Medical Record #	Health Insurance
Marital Status		Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other: _____	
Cancer Information			
Date Diagnosed (mm/dd/yyyy):	Where diagnosed?		
Primary Site (e.g.: colon, breast, prostate, etc)		Histology (adenocarcinoma, sarcoma, squamous carcinoma)	
Treatment Information			
	Type / Description	Date	Where performed
Surgery			
Radiation			
Chemotherapy			
Hormone			
BRM			
Other			
Comments			
Follow Up / Patient Status		Completed by	
Date of last contact:		Name: Date:	
Vital Status: <input type="checkbox"/> Alive <input type="checkbox"/> Dead			
Cancer Status: <input type="checkbox"/> evidence of CA <input type="checkbox"/> no evidence of CA			
If expired; please provide date and place of death:			

***This form is intended for hospice care setting ONLY. Not for physicians, hospitals or healthcare clinics.**

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

In order 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.

HOSPICE'S CANCER REPORTING FORM INSTRUCTIONS

Facility Information

<i>Reporting Facility</i>	Record the complete name, address, and telephone number of your facility or physician's office.
<i>Patient transferred / referred from/by</i>	Record the facility information that referred the patient to your institution

Patient Information

<i>Patient Name (Last, First & Middle)</i>	Record the patient's full name.
<i>Patient's Address</i>	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.
<i>Social Security Number</i>	Record the patient's social security number. Do not record a spouse's number.
<i>Date of Birth</i>	Record patient's birth date in MM/DD/YYYY format.
<i>Medical Record Number</i>	Record the patient's medical record number
<i>Health Insurance</i>	Record the patient's health insurance
<i>Marital status</i>	Specify patient's marital status at time of diagnosis
<i>Sex</i>	Check off the patient's sex/gender.

Cancer Information

<i>Date of Diagnosis</i>	Record the date the patient was first diagnosed with cancer by a recognized medical practitioner. Record in MM/DD/YYYY format. If unknown, record "unk".
<i>Where Diagnosed?</i>	If the patient was diagnosed elsewhere, record the facility name and location. If unknown, record "unk".
<i>Primary Site</i>	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.
<i>Histology</i>	Record the histologic cell type of the tumor (ie. mucinous adenocarcinoma; infiltrating ductal CA

Treatment Information

<i>Treatment</i>	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.
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Follow Up / Patient Status

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

Completed by

<i>Form Completed By</i>	Record the full name of the person completing the form.
<i>Date Completed</i>	Record the date completed.

Saving PDF Fillable Format Forms

1. Once a cancer case has been identified, please complete the Physicians' Reporting Form. The form that is attached to this email is in a PDF fillable format which simplifies the process by typing the information directly into the form. If you have any question filling the form, please call 718.1311 ext.: 3198 / 3037 / 3100.

Note: If you are completing multiple forms, you must **Save As** 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.

USVI Form 001 Physicians Reporting Form_Fillable.pdf - Adobe Reader

File View Window Help

Open... Ctrl+O

CreatePDF Online...

Save Ctrl+S

Save As... Shift+Ctrl+S

Save As Other...

Share Files Using SendNow Online...

Send File...

Get Documents Signed...

Revert

Close Ctrl+W

Properties... Ctrl+D

Print... Ctrl+P

Exit Ctrl+Q

States Virgin Islands Central Cancer Registry
Physician's Cancer Report Form*

Physician's Office Information

Physician Name: Dr. Oncologist Address: 15 Estate Example Christiansted STX, 00820

Patient's Information

First Name: John Middle Name:

Example Christiansted STX, 00820

Medical Record #: 123456 Health Insurance: Medicaid

Hispanic: Yes No Other

Marital Status: Married Sex: Male Female Other:

Cancer Information

Date Diagnosed (mm/dd/yyyy): 02/08/2016 Where diagnosed?: Clinic of Oncology, STX Primary Site (where tumor arose): Prostate

Paired Organ: No Yes Histology: Adenocarcinoma GI 6(3+3)

Save As

USVI Project > Cancer Registry Forms

Search Cancer Registry ...

Organize New folder

File name: Assign a name to the file_Example_MRN_123456

Save as type: Adobe PDF Files (*.pdf)

Save Cancel

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 340.718.9505

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.



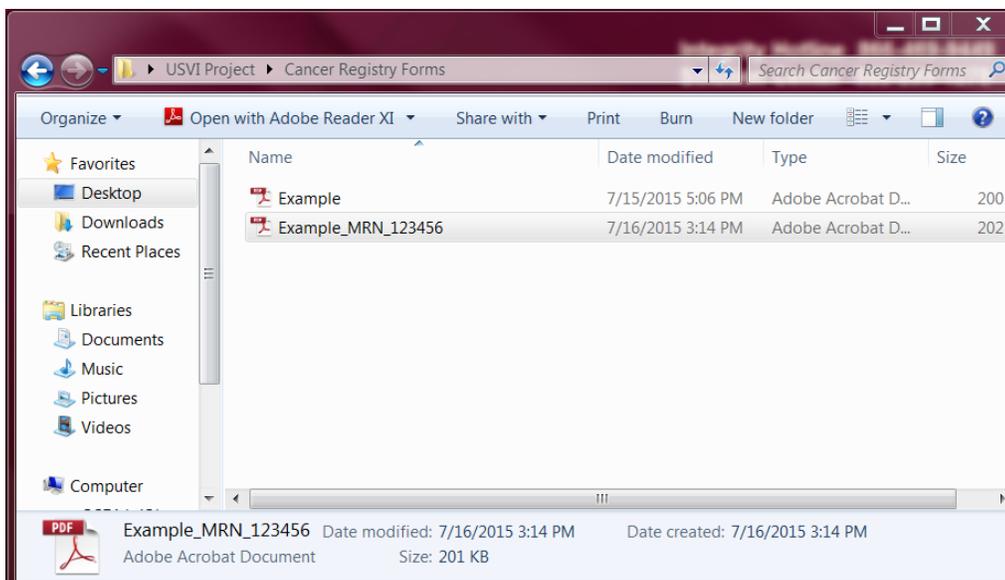
Encryption is a critical component of data security. It ensures that if the data is accessed by an unauthorized person, he or she will not be able to read it and thus cannot misuse it.

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

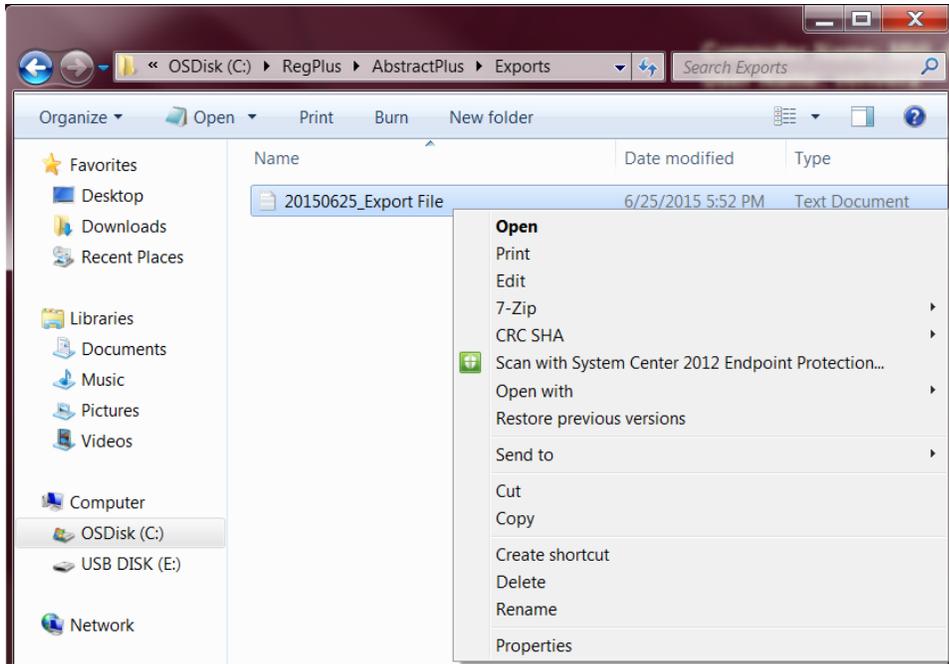
"Introduction to Data Encryption." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 13 Jan. 2015. Web. 26 June 2015. <<http://www.cdc.gov/cancer/npcr/tools/security/encryption.htm>>.

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.

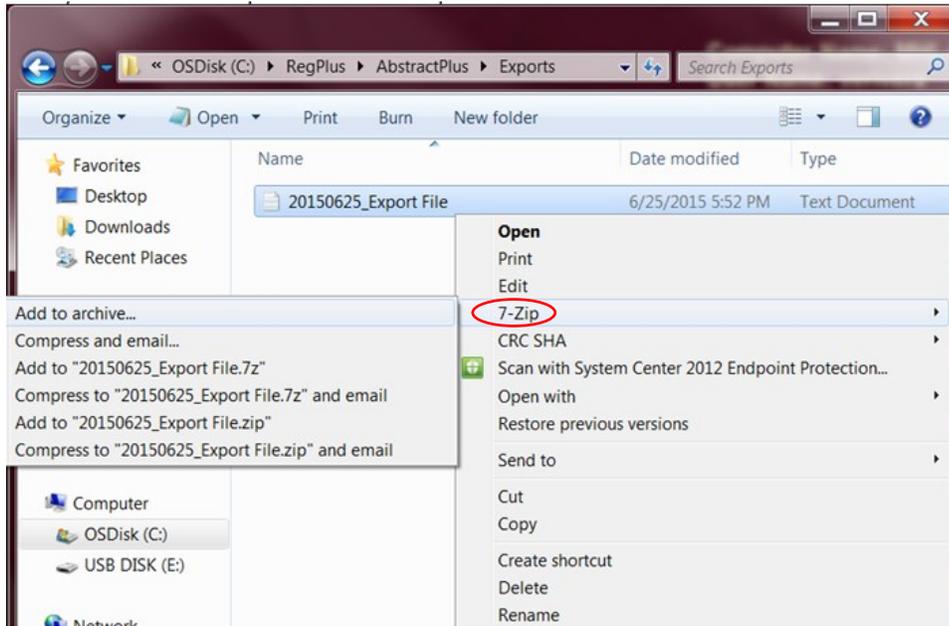
1. Open the folder containing the file to be encrypted.



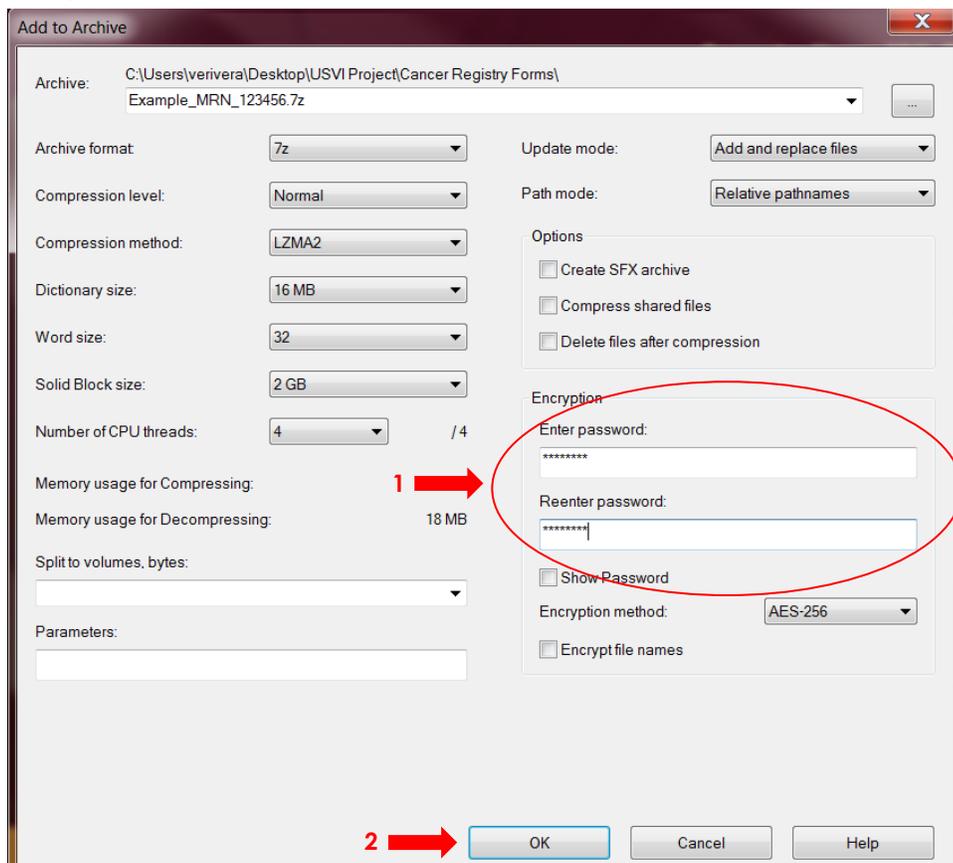
2. Right Click the file to be encrypted and from the menu select **7-zip**.



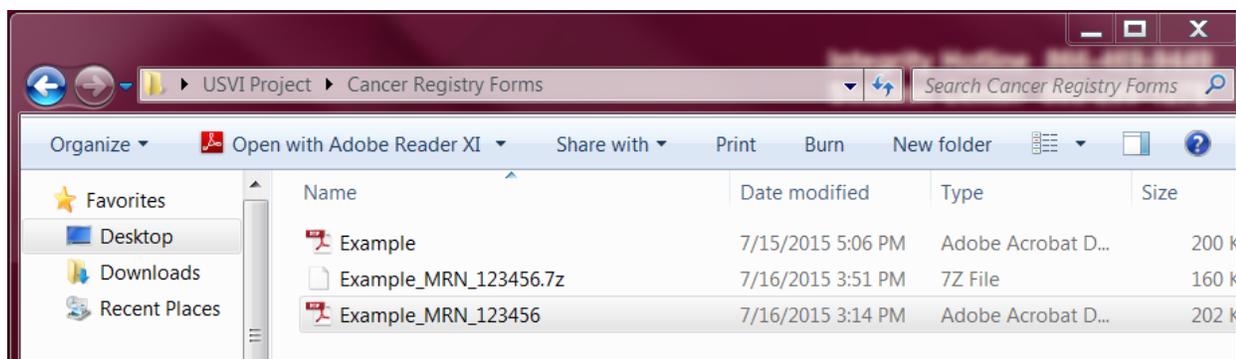
3. Once you select 7-zip, select the option **Add to archive**.



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**.



5. A new file will be created in the folder with the extension .7z.



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

Please, when attaching a document to an email, make sure that the selected file is the 7Z File!!!

6. Send the email with the encrypted attachment to: viccr@doh.vi.gov
7. Call to the USVI-CCR authorized person to provide with 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: www.healthvi.gov

Email: viccr@doh.vi.gov

Phone: (340) 718-1311 ext. 3198

Fax: (340) 718-9505