

# 2021 NPCR VIRGIN ISLANDS SUCCESS STORY

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*When the Interstate Data Agreement is Not Just a “Sometimes” Source of Information*

## National Program of Cancer Registries SUCCESS STORY

### SUMMARY

According to the North American Association of Cancer Central Registries (NAACCR) webpage: “Sometimes patients are diagnosed and/or treated in an area that is different from their residence, and agreements must be made between registries to share data.” In the Virgin Islands, it is a common practice among residents to do the annual health check-up in the United States, and it’s even more common to seek health care off-island once diagnosed with a serious illness, especially after the hurricanes that ravaged St. Thomas and St. Croix in 2017. Having the Interstate Data Agreement in place, as well as an agreement with Florida Cancer Data System (FCDS), has allowed us to include new cases in our database and, the submitted data helped complete staging and treatment for cases that were diagnosed in the Territory and whose staging workup and treatment was done off-island.

### CHALLENGE

The United States Virgin Islands (USVI), an unincorporated United States territory, consists of three main islands, St. Croix, St. Thomas, and St. John, and many other surrounding minor islands. According to the U.S. Census Bureau, as of April 1, 2020, the U.S. Virgin Islands’ population was 87,146, representing a decrease of 18.1% from the 2010 Census population of 106,405. Approximately 82% of the USVI population who are at increased risk for health conditions and are confronting several health challenges including limited access to overall health care services, and specialized care including cancer care. All three islands are designated Medically Underserved Areas (MUAs), i.e., residents have a shortage of personal health services (HHS 2015). There is an average of 1.4 physicians per 1000 in the USVI compared to 2.3 per 1,000 Stateside (range 1.6-3.2) (AAMC State Physician Workforce Data Book 2013).

The Territory has one hospital in each island district (St. Croix, and St. Thomas/St. John), one Federally Qualified Health Center (FQHC) in each island district, private practices, and the Department of Health (DOH) operated clinics on each island. Currently, there are three Hematology oncologists and no Radiation oncologists in the Territory. The Charlotte Kimelman Cancer Center that was operating in St Thomas until 2017, was destroyed by Hurricane Irma and there is no plan to rebuild the cancer center soon.

All these factors, in addition to limitations of health care services in the Territory, force patients, especially cancer patients, to seek treatment off-island where a comprehensive diagnostic workup, staging, and treatment plan can be designed and delivered.

### SOLUTION

The VICCR is part of the North American Association of Central Cancer Registries (NAACCR) Interstate Data Exchange Agreement. However, the state of Florida, where most Virgin Islanders seek treatment out of the Territory, currently is not part of such an agreement, leaving the VICCR with potentially missed cases. With the collaboration and support of our NPCR Program Consultant, we engaged in communication with the FCDS personnel, with the main purpose of establishing a Data Exchange Agreement between the FCDS and the VICCR.

### RESULTS

Data providing diagnostic workup, staging, and treatment has been received from 17 states with the State of Florida being the main source. For the diagnosis year 2016, which is our most complete year, 24% of the newly diagnosed cases were diagnosed off-island.

### SUSTAINING SUCCESS

For established registries in places where patients can get adequate health care, having the Interstate Data Agreement may provide supplemental information that may not affect incidence rates. In our case, it is necessary to maintain these relationships, and these agreements with our peers will allow our registry to collect a significant amount of information to make our data more complete.

### REGISTRY CONTACT INFORMATION

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U.S. Department of  
Health and Human Services  
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Control and Prevention