

VIRGIN ISLANDS

Virgin Islands Central Cancer Registry (VICCR); John Orr;
Verónica Rivera-López, CTR

The Virgin Islands Central Cancer Registry (VICCR) Storms into Operation

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: In 2015, the U.S Virgin Islands began a journey toward a fully operational Central Cancer Registry supported by an implementation grant from the U.S. Dept. of the Interior. Without funding for the operation of the registry, efforts moved forward to have the registry ready to collect data when operational funding could be identified. And indeed, tumor data were collected in anticipation of funding, National Program of Cancer Registries (NPCR) funding was identified and secured, and a celebratory atmosphere was building. Then disaster struck—twice.

In September 2017, with the VICCR working toward its first ever data submission, two Category 5 Hurricanes, Irma and Maria, devastated the U.S. Virgin Islands within two weeks of each other.

CHALLENGE: VICCR servers had been located on St. Thomas, and in the two weeks between hurricanes, and for months afterward, ascertaining the status of those servers was impossible. In following severe weather protocols established at the Department of Health (DOH), the servers had been secured, but could not be powered-up. Infrastructure on St. Thomas was in a state of total collapse, and bringing servers online was not a priority. Cancer registry personnel on St. Croix had secured their electronic equipment in water-proof containers that survived the storms.

The VICCR office at DOH headquarters on St. Croix was destroyed by Hurricane Maria. During the height of the storm, a veritable waterfall opened up in the ceiling as the roof was compromised and rain water poured in over desks, cabinets, chairs and everything that couldn't be protected. While protection from leaks had been the goal, no one expected the volume of water that materialized.

With roughly four months until January 2018 NPCR data submission, which would be the first ever for the Virgin Islands, VICCR had no servers and no place to operate. All equipment was disassembled and stored in a building that was still compromised.

SOLUTION: An oil storage facility on St. Croix, Limetree Bay Terminals, was approached and agreed to provide a working office space for the registry: power, internet, secure air-conditioned spaces, and limited access to IT staff to ensure a working environment. In October, one month after the second hurricane, VICCR personnel set up their office, and worked with their NPCR partners to create a mechanism for successful reporting of data.

With no connection to the servers where data was stored until the storms, we had no tools to perform consolidation, or to run edit sets other than the set available in Abstract Plus. CDC-NPCR staff suggested using Abstract Plus not just as our abstracting tool, but as our main database, as well. Knowing the limitations of Abstract Plus to function as the central Database, we developed an application capable of performing consolidation in a similar way to TLC Plus, where multiple abstracts for the same patient could be analyzed side by side, and the proper information could be selected. To apply EDITS, we exported the entire Abstract Plus database in a NAACCR format file and imported it into GenEDITS. Based on the reports, every error was manually corrected, and we repeated this process until a “clean” file was obtained.

RESULTS: Virgin Islanders have long supported the creation of a Cancer Registry, based on the local belief that “we have lots of cancer cases” in the Territory. Without a Central Cancer Registry gathering evidence-based data, there was no way to quantify such claims. On January 31, 2018, four months after two Category 5 hurricanes ravaged our Territory, the VICCR submitted, for the first time ever, a cancer incidence file to NPCR, beginning the process to identify the burden of cancer in the Virgin Islands.

NPCR
NATIONAL PROGRAM OF CANCER REGISTRIES



Centers for Disease
Control and Prevention
National Center for Chronic
Disease Prevention and
Health Promotion