

FLORIDA

Florida Cancer Data System, Gary M. Levin, BA, CTR

Reporting from the Veteran Administration Facilities

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Reporting from Veterans Administration (VA) facilities has been non-existent since 1993 in Florida. Many efforts including those by Florida Department of Health and the Center for Disease Control National Program of Cancer Registries (CDC NPCR) over the time period from 2009 to 2016 have not been successful. The six individual VA hospitals in the state of Florida were not willing to report directly to the Florida Cancer Data System (FCDS) due to scarce resources. Finally, in 2016 a data use agreement was executed between the Florida Department of Health (FDOH) and the Veterans Administration Central Cancer Registry (VACCR) in Washington D.C. to report on behalf of the six VA hospitals in Florida to the FCDS. This process has led to the reporting of 57,255 abstracts between diagnosis years 1963 and 2015 from the six VA hospitals in Florida yielding 37,688 new cancer incidence cases.

CHALLENGE: For Florida, the lack of VA reporting has caused an underreporting of primarily male cancer cases, with an emphasis on prostate cancer. To accurately produce rates and disseminate data to health professionals, decision makers, and researchers, reporting from VA facilities is critical and needed by the FCDS. Issues of security of the data, to redacting of text information, to the refusal of reporting from individual facilities and resolving data quality issues were the most difficult challenges to overcome. Additionally, the VA has had significant turnover and lacked the necessary resources for the VACCR to be able to manage the data they received. Reporting to a central cancer registry was not **the top priority of the VACCR.**

SOLUTION: Through the near seven year effort and significant amount of back and forth primarily with attorneys, the FDOH was able to come to an agreement with the VA and get a data use agreement (DUA) signed. Based on the DUA, the VA has made two submissions to Florida. Due to the inability of the VACCR to resolve edits, the FCDS had to expend significant resources to quality control the cases to clear potential demographic and tumor linkages. The VA submitted 49,580 in July 2016 and an additional 6,658 reports in November of 2017. Prior to that, the FCDS has received 1,017 cases of which the last submission was in 1993.

RESULTS: This process has led to the reporting of 57,255 abstracts between diagnosis year 1963 and 2015 from the six VA hospitals in Florida yielding 37,688 new cancer incidence cases. Of the cases submitted, approximately 97% were male, 87% were White, 96% were non-Hispanic, and 75% were 60 years of age or older. The most frequent cancer sites included prostate (25%), lung (17%) and colorectal (9.5%). Due to continued inconsistent reporting from the six VA facilities into the VACCR data repository, more VA reports were from Bay Pines VA Medical Center and resulted in greater case capture for two Florida counties, Hillsborough and Pinellas, accounting for 30% of VA cases reported.

SUSTAINING SUCCESS: Sustaining our original success has been the most difficult part of the process. The VISN8/VACCR lead on this project has retired and they have lost their sole registrar who processes the cases from the VA hospitals throughout the country. FDOH has made multiple efforts to reach out and establish consistent reporting. To date no further response has been returned by the VA. The FDOH-FCDS will continue our efforts to reengage the VACCR.

NPCR
NATIONAL PROGRAM OF CANCER REGISTRIES



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