

PUERTO RICO

Puerto Rico Central Cancer Registry (PRCCR)

Using Registry Data to Evaluate the Occurrence of HPV Related Cancer in the People Living with HIV/AIDS

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

Public Health Problem: Data of the HIV surveillance in Puerto Rico published on the HIV Surveillance Report from the CDC (Diagnoses of HIV Infection in the United States and Dependent Areas, 2011) has stated that Puerto Rico is one of the top ten states/territories with the highest number of people living with HIV/AIDS. Eighty percent of the reported cases have evolved to stage 3 of the HIV infection and the most common method of transmission was through sexual contact.

In the most recent years another commonly diagnosed sexually transmitted infection, the human papillomavirus (HPV), has been associated with cancer of the cervix, anus, vulva, vagina, penis and oropharynx. Recent studies have found that HPV infection and HPV-related cancer are higher in the people living with HIV/AIDS (PLHA) than in the general population.

Use of Surveillance and Collaboration: In Puerto Rico there were no studies that correlated these two conditions. For this reason, a group of researchers proposed using the data from the Puerto Rico Central Cancer Registry (PRCCR) to evaluate the occurrence of HPV related cancer among PLHA. The University of Puerto Rico Comprehensive Cancer Center (UPRCCC) and The University of Texas MD Anderson Cancer Center (MDACC) Partnership for Excellence in Cancer Research Grant (5U54CA096297-07) was awarded a supplemental grant to study this relationship. After fulfilling all the confidentiality agreement with both

the Institutional Review Board of the Medical Sciences Campus, University of Puerto Rico, the PRCCR, and of the Puerto Rico Department of Health (PRDOH), data from the HIV Surveillance System of the PRDOH was linked with the cancer data from the PRCCR in order to describe the incidence, mortality and survival of the HPV related cancers among PLHA in Puerto Rico.

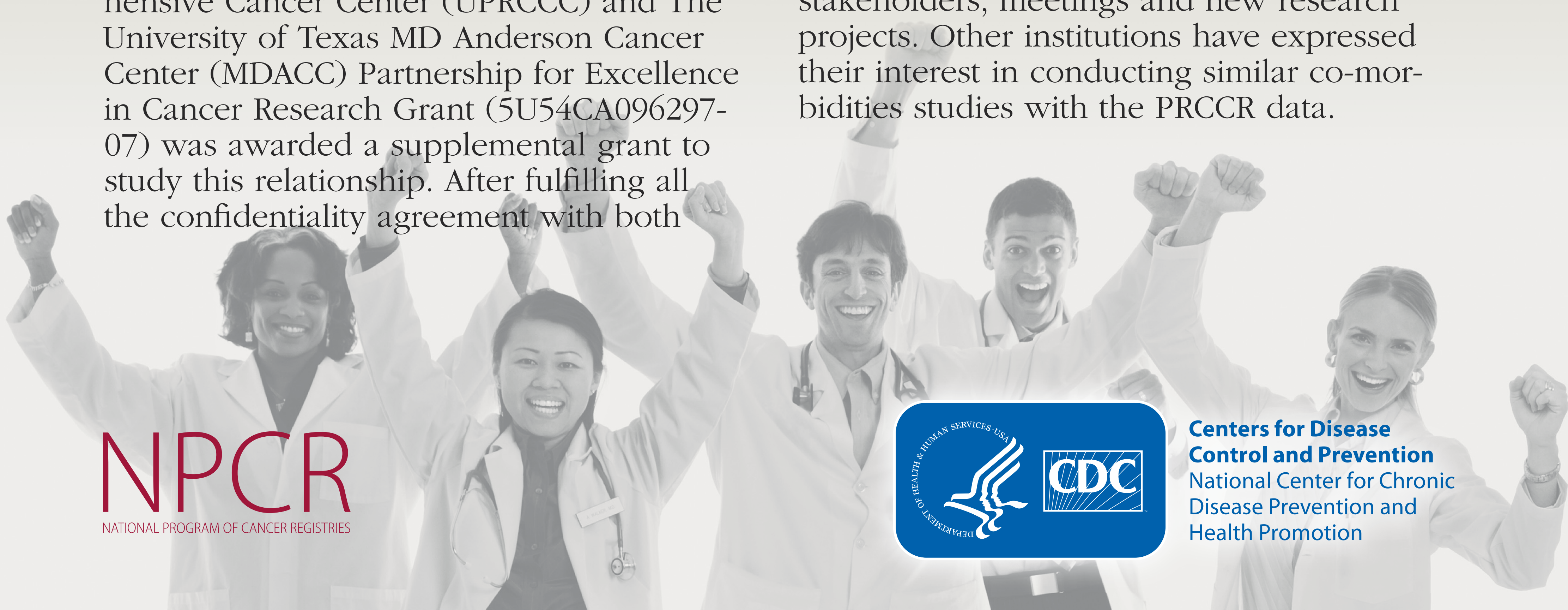
The study reported higher risk of HPV-related cancer as well as non-HPV related cancers in the PLHA as compared to the general population. Also, the study showed an excess risk of anal cancer among PLHA. Finally, the study observed a lower survival probability among PLHA who developed any type of cancer than among those who did not developed any cancer.

Public Health Outcome: This study was important because it highlighted the need of improving cancer screening, especially for anal cancer, among PLHA. Also, it allowed creating an alliance between the University, the community and health professional sector in order to evaluate more details about the disparities of cancer screening and prevention among the PLHA population. The study resulted in scientific papers, discussion-forums with partners and other stakeholders, meetings and new research projects. Other institutions have expressed their interest in conducting similar co-morbidities studies with the PRCCR data.

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PUERTO RICO

Rico Central Cancer Registry (PRCCR)

Improving Data Completeness and Quality using Health Insurance Claims: The Puerto Rico Central Cancer Registry (PRCCR) Experience

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

Public Health Problem: The Puerto Rico Central Cancer Registry (PRCCR) must meet NAACCR and NPCR standards for the Call for Data report. At the Call for Data, NAACCR and NPCR evaluate the quality of various data items including completeness, percentage of cases ascertained only by death certificate, and percentage of cases with unknown age, sex, race, and county of residence at the time of diagnosis. The PRCCR has experienced problem meeting the criteria of completeness and percentage of cases with Unknown County of residence using current sources of data. In order to address this problem, the PRCCR search for alternate strategies to meet these criteria and improved the quality of the data. The new PRCCC Law, Law num. 113 approved on July 30th, 2010 in its Article 8, Section 4 authorizes the PRCCR to request health information from institutions and health insurance companies by making the necessary agreements for the secure exchange of information. The PRCCR developed and implemented the Claims Project to identify potentially missing cases and to recover missing data.

The PRCCR established an agreement with the Government Health Insurance Administration (ASES) to obtain their health claims. ASES is the State Government Agency responsible for the providing health insurance to the population of Puerto Rico at or below the 200% FPL. ASES is responsible for implementing, administrating, and contract with Health Insurance Companies for the delivery of health services to approximately 42% of the island population (n = 1.6 M individuals). The claims

databases provide: socio-demographics (birthdates, last names, marital status, age, addresses, and social security number), diagnostic and treatment information, date of last contact, and other previously missing information. For the purpose of the project, the PRCCR developed a case-finding software for use with the claim databases. This software is also a useful tool to complement our ability to conduct passive follow-up.

Using the claim databases we were able to recover 478 cases (3.4% of all cases reported in 2010). In addition, we were able to decrease the number of death-certificate only cases from 6.3% to 3.7% and to decrease the percentage of cases with Unknown County of residence from 10.2% to 2.8%.

This project shows that Claim Databases are a great case-finding tool to obtain valuable data from diagnosis, treatment and demographics that has made our database a better source of information. In addition, these databases are important source to recover cases and data frequently difficult to obtain using regular sources. These databases were able to recover primarily cancer cases that don't require treatment at a specialized cancer center or hospital, patients treated at a physician's offices, and cases diagnostic procedures conducted in laboratories outside PR. The PRCCR will continue to develop this project in order to include information from the private insurance companies and to reach a coverage area of almost 70%. This new effort will allow our registry to further improve the quality of our data.

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