2021 NPCR NEW JERSEY SUCCESS STORY

New Jersey State Cancer Registry: Antoinette M. Stroup, PhD; Gerald Harris, PhD; Matthew Wilson, MPH; Taylor M. Black, MPH; Judith M. Graber, PhD

New Jersey's Response to the Call for Firefighter Cancer Data: Creating a Retrospective Cohort to Study Cancer Mortality among New Jersey Firefighters through Data Linkages and an Honest Broker

National Program of Cancer Registries
SUCCESS STORY

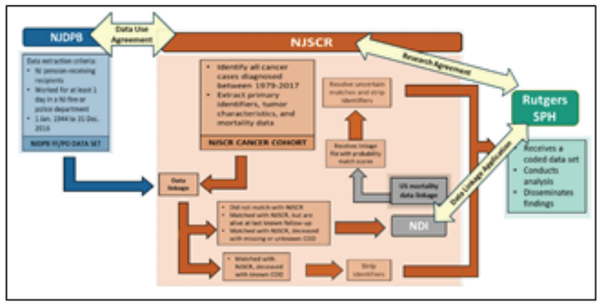
SUMMARY

The New Jersey State Cancer Registry (NJSCR) has successfully implemented a linkage protocol combining data from the New Jersey Division of Pension and Benefits (NJDP&B), NJSCR, and the National Center for Health Statistic's National Death Index (NDI). The combined dataset will serve as the basis for a cancer mortality study among one of the largest population-based cohorts of professional firefighters. The results from this study will inform state, national, and international agencies interested in advancing scientific knowledge of occupational exposures in a population considered to be at higher risk for cancer[1] but for whom sufficient research is lacking.

CHALLENGE

Although firefighting was classified as possibly carcinogenic to humans (Group 2B) in 2010 by the International Agency for Research on Cancer (IARC)[2] and the Firefighter Cancer Registry Act was passed in 2018 mandating the development of a cancer registry among firefighters, a population-based cohort of firefighters that could serve as the basis for a Firefighter Cancer Registry does not exist in New Jersey. New Jersey is home to more Superfund sites than any other state and more than 38,000 firefighters[3] who are at higher risk of exposure to toxic and carcinogenic chemicals in part due to a larger number of chemical industries and pollutants in the state. Capturing cancer and mortality data for a special population like firefighters also presented a challenge as residential mobility, retirements, and job migration within and out of state makes complete follow-up of the cohort difficult if not impossible. In fact, almost 25 percent of this cohort moved out of state after retirement. We therefore sought to utilize data sources that would not only provide a large, identifiable cohort of firefighters but provide complete information on cancer mortality while maximizing our resources; and ultimately inform prevention strategies to reduce cancer incidence and mortality among firefighters.

Figure 1. Data Linkage Process



SOLUTION

The NJSCR collaborated with occupational and cancer epidemiologist, Dr. Judith Graber, Associate Professor at the Rutgers School of Public Health, Department of Biostatistics and Epidemiology, to establish a statewide cohort of career firefighters in the State of New Jersey. We engaged with administrators at the NJDP&B to discuss the project and present the rationale for requesting their data. We successfully executed a Data Use Agreement between the NJDP&B and NJSCR. The DUA also included terms under which the NJSCR would serve as an honest broker to link NJDP&B data to the National Death Index (NDI) to obtain information on deaths that occurred out of state. Once an agreement with NJDP&B was established, the NJSCR also negotiated a DUA with NDI with the appropriate signatories on behalf of investigators at Rutgers, separate and apart from the NJSCR's DUA for cancer registry follow-up at the NJDOH. The honest broker process is described in Figure 1.

RESULTS

First responder (fire/police) data from the NJDP&B from 1/1/1944 to 12/31/2018 included name, social security number (SSN), date of birth, gender, employer information, city/state of employer, and dates of enrollment, last contribution, retirement, and death (if applicable). Of the 122,257 NJDP&B records, we captured information for 118,936 unique fire/police members (2,968 missing SSN, 18 missing date of birth). NJDP&B reported that 6,386 were deceased. About 11.4% (n=13,529) of the unique members linked to the NJSCR (77 members who died before 1979 could not be linked because they died before the NJSCR began collecting incident data).

The male firefighter cohort contained a total of 17,248 members. Of these, 2,487 (14.5%) linked to a cancer diagnosis in the NJSCR and, according to NJSCR follow-up data, 1,461 (58.7%) were deceased. The remaining 14,761 male firefighters did not match a record in NJSCR so were sent to NDI for linkage. NDI was able to provide death information on 99% (n=1,842) of the 1,861 firefighters who were known to be deceased but had an unknown cause of death. NDI provided death information on 2.4% (n=305) of the 12,900 firefighters for whom vital status was unknown (or last known alive). As a result of these successful linkages between the NJSCR, NJDP&B, and the NDI, this study of mortality will include information on total of 3,608 (21%) deceased male firefighters in New Jersey.

SUSTAINING SUCCESS

The NJSCR plans to move on to the next step in this project, which is to analyze the data and generate standardized mortality ratios (SMR) comparing the mortality rate of the NJ firefighter cohort to the general NJ population. Because we know that a large proportion of NJ's firefighter cohort move out of state, we are seeking an opportunity to conduct a linkage project with the Virtual Pooled Registry Cancer Linkage System (VPR-CLS) to assess incidence. We believe this will be possible given the success we had in negotiating and securing the appropriate data use agreements from key partners. Future linkages may also be conducted to update vital status and cause of death information.

REGISTRY CONTACT INFORMATION

609-633-0500
https://www.state.nj.us/health/ces/

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