

2019 NPCR NEW YORK SUCCESS STORY

New York Cancer Registry: Maria J. Schymura, Amy R. Kahn, and Baozhen Qiao

Cancer Among World Trade Center (WTC) Responders – a Collaboration of Three Principal Study Centers and the New York State Cancer Registry

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: In a multi-center, multi-state study to find and analyze associations between WTC exposures and cancer incidence, the New York State Cancer Registry (NYSCR) has the role of ‘honest broker.’ This brokerage entails creating a de-duplicated ‘finder file,’ coordinating linkages with twelve other central registries, and providing de-identified analytic data as well as epidemiologic and cancer-specific knowledge, to a multi-center study team.

CHALLENGE: As a result of the attacks on the World Trade Center, the CDC’s National Institute for Occupational Safety and Health (NIOSH) has funded three separate major projects in New York City to follow individuals and identify health outcomes among persons who had exposures related to the attacks and their aftermath. The World Trade Center Health Registry, operated under the auspices of the New York City Department of Health and Mental Hygiene (WTCHR), the Fire Department of the City of New York (FDNY), and the General Responder Cohort (GRC) maintained by the General Responder Data Center of the Icahn School of Medicine at Mount Sinai had been identifying preliminary results based on cancer registry linkages and publishing independently for over a decade.

Although their cohorts were based on different personal and exposure characteristics, there was overlap among the three that had not been quantified, and that might have affected study outcomes. Although we (the NYSCR) had suggested early on that collaboration and de-duplication would improve the power to detect signals and to inform the results of their respective linkages, there were substantial data definition and institutional hurdles that kept the three projects from working together.

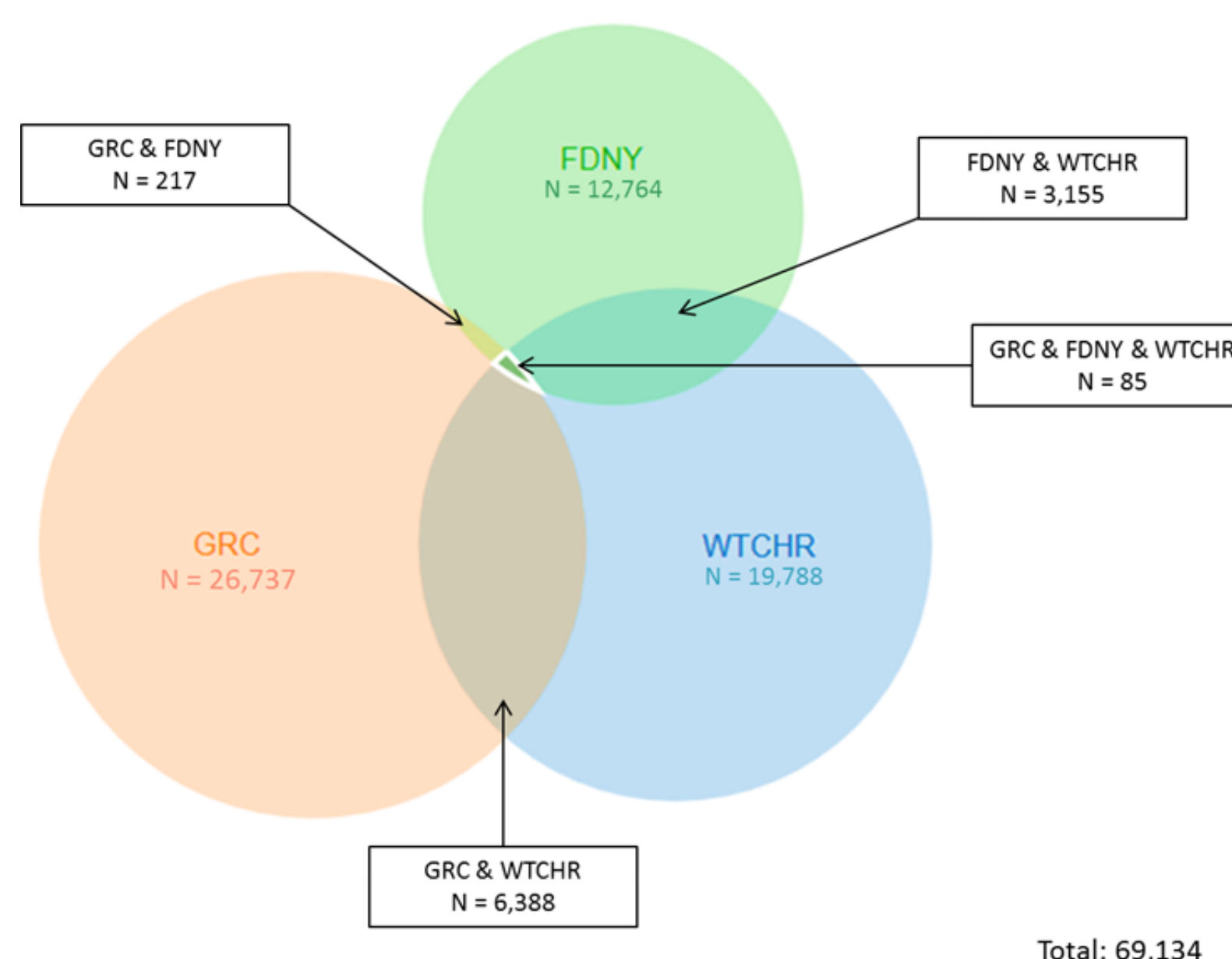
SOLUTION: Three years ago, physician-epidemiologists and biostatisticians from the FDNY approached the other two study centers and the NYSCR with the concept of working together on a project to better understand cancer incidence rates among WTC responders. The NYSCR would participate as a full collaborator, adding their expertise in cancer epidemiology. The NYSCR would also act in the role of ‘honest broker,’ creating datasets that would be used to identify all incident cancers occurring among participants from any of the three study cohorts who met a common definition of ‘responder.’ In 2016, collaboration of the four parties resulted in a proposal that was accepted for funding by NIOSH (“Incidence, Latency, and Survival of Cancer Following World Trade Center Exposure.” CDC/NIOSH U01 OH011315 AND U01 OH011932).

It would fall to the NYSCR to: 1) de-duplicate the combined cohort, using the best information available for a ‘finder file’; 2) coordinate linkages with twelve additional central registries, providing the ‘finder file’ in a format consistent with each state’s requirements and following each state’s protocol for linkages; 3) standardize and consolidate the results of the linkages; 4) provide de-identified analytic files to the study team; and 5) collaborate in the interpretation of the results.

RESULTS: The NYSCR received encrypted files from each of the cohort centers, totaling 79,062 records. We standardized the files and, using NPCR’s LinkPlus software, we matched each standardized file to the other two, identifying members of one-and-only-one cohort as well as identifying the overlapping cohort members. For each of the latter, we created a consolidated record, using the most complete information available (e.g., known versus unknown social security numbers, and adding multiple addresses and phone numbers). The result was a finder file containing 69,143 records, one record for each member of any of the three cohorts. For each unique member, we assigned a study ID and a flag indicating the underlying cohort membership.

The four main collaborating groups held both in-person and conference call meetings to ensure that all parties agreed on definitions and methods. The three cohort centers arrived at a common set of exposure variables, and each was responsible for recoding their original data items to the agreed-upon codes and definitions. Because survival is one of the outcomes of interest, and each center independently identifies deaths through linkages to the National Death Index, it was important that decisions be based on common criteria. The NYSCR provided instruction to staff of all three centers on the use of the SAS algorithm, developed by NPCR participants, for maximizing the validity of NDI-identified matches.

The NYSCR provided frequencies of the residence states of the combined cohort members, and these numbers were used to identify the states to prioritize for cancer registry linkage. The FDNY study staff coordinated obtaining IRB approvals and data use agreements for each of thirteen state cancer registries, a process that took between a few months and over two years, depending on the state. Once the approvals were in place, the NYSCR obtained file specifications from each of the other state cancer registries and sent each state an encrypted ‘finder file’ based on these specifications. As of mid-September 2019, all match results from the twelve other central cancer registries have been received by the NYSCR.



SUSTAINING SUCCESS: As of early October 2019, preliminary data analyses are ongoing and at least three separate research questions have thus far been identified. The synergy resulting from this broad-based collaboration has been appreciated by all three cohort centers. Because the responders to 9/11 were predominantly young men, this consolidated cohort will be followed for many years. The NYSCR will continue to help track and analyze the cancer incidence and survival of the responders, using our unique perspective as the population-based cancer registry that includes the epicenter of the attacks on the World Trade Center.

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