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BRIEF REPORT



## Tracking diseases related to the terrorist attacks of September 11, 2001

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### ABSTRACT

Accurate, timely, and complete disease reporting is essential to understanding the extent and long-term consequences of diseases related to the terrorist attacks of September 11, 2001 (9/11). Although there are no public health disease reporting requirements that specifically mention 9/11, other mechanisms exist to track 9/11-related illnesses. These include the availability of 9/11-exposed cohorts, some open to new member recruitment and others closed. Record linkages of 9/11 cohorts to various data registries (eg statewide cancer registries and the National Death Index) are periodically performed. This paper describes these 9/11 cohorts and the efforts to track their health experience.

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### Background

This is one in a series of papers to promote the practice of high-quality, evidence-based medicine when evaluating, diagnosing, and treating persons who were directly exposed to the September 11, 2001 (9/11) terrorist attacks and their aftermath (see Calvert et al<sup>1</sup> for more background details). This paper focuses on tracking illnesses related to those 9/11 exposures.


Protection against occupational and environmental hazards often relies on accurate reporting to public health authorities of the illnesses and injuries caused by those hazards. With these reporting data, public health authorities can assess the long-term consequences of occupational and environmental exposures, as well as evaluate the magnitude and distribution of these illnesses and injuries across time, geography, and demographic characteristics. In addition, they can investigate the root cause of the illnesses and injuries, make prevention recommendations, and implement interventions to control future diseases and injuries. Finally, these findings can be used as a basis for epidemiologic research.

State-based public health surveillance systems require health care provider reporting of various diseases of public health importance, including some diseases related to 9/11 exposures. For example, in New York state (NYS), physicians, healthcare facilities, and

clinical labs are required to report occupational lung diseases within 10 days of diagnosis ([www.health.ny.gov/professionals/reportable\\_conditions/](http://www.health.ny.gov/professionals/reportable_conditions/)). Note that the list of diseases required to be reported to state-based public health surveillance systems varies across states.<sup>2</sup> However, all states require the reporting of cancer cases. In NYS, healthcare providers must report within 180 days every case of cancer under their care.

Accurate, timely, and complete reporting is also essential to monitoring and understanding the extent of 9/11-related disease. This continues to be true despite it being more than 20 years since the terrorist attacks of September 11, 2001. However, to our knowledge, there are no public health disease reporting requirements that specifically mention 9/11 (the NYS voluntary reporting of World Trade Center [WTC] responder deaths ended in 2009<sup>3</sup>).

Given the lack of reporting requirements, other mechanisms are used to track 9/11-related illnesses. These include cancer detection by linking 9/11-exposed cohorts to cancer registries, mortality detection by linking the same cohorts to the National Death Index, disease detection through linking with the NYS Statewide Planning and Research Cooperative System (SPARCS) ([www.health.ny.gov/statistics/sparcs/](http://www.health.ny.gov/statistics/sparcs/)), and through medical interviews and

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review of medical records collected on persons participating in the WTC Health Program or the WTC Health Registry. Each of these approaches is discussed in more detail below.

### Cohorts of 9/11-exposed persons

Soon after the 9/11 terrorist attacks, the public health community recognized the need to assess the long-term health consequences of the exposures arising on 9/11.<sup>4</sup> This led to the creation of 9/11-exposed cohorts. There are four such cohorts (Table 1).

#### FDNY responders

These are active and retired members of the Fire Department of the City of New York (FDNY). The size of this cohort is approximately 17,100 individuals. These responders provided at least 4 h of rescue and recovery effort at any of the former WTC sites (including Ground Zero, the Staten Island Landfill, and the New York City Chief Medical Examiner's Office). The cohort also includes certain surviving immediate family members of an FDNY member (whether fire or emergency personnel, active or retired) who was killed at Ground Zero on September 11, 2001 (42 United States Code [USC] §§ 300–300 mm-61).

#### WTC general responders

These are workers or volunteers who provided rescue, recovery, debris cleanup, and related support services south of Canal Street in Lower Manhattan and at other related sites for certain amounts of time during

the period between September 11, 2001 and July 31, 2002.<sup>5</sup> This group of General Responders excludes FDNY Responders, and Pentagon and Shanksville, PA Responders. This group is estimated to consist of approximately 80,000 persons.<sup>6</sup>

#### WTC survivors

Also known as New York City (NYC) Survivors. This cohort includes individuals with the following types of exposure: those who were present in the dust or dust cloud on September 11, 2001 in the NYC Disaster Area (i.e., the area in Manhattan south of Houston Street and any block in Brooklyn wholly or partially contained within a 1.5-mile radius of the former WTC complex); individuals who lived, worked, or went to school or childcare, or adult daycare in the NYC Disaster Area for a certain amount of time during the period between September 11, 2001 and July 31, 2002; and certain individuals eligible (or whose place of employment was eligible) to receive certain grants from the Lower Manhattan Development Corporation between September 11, 2001 and May 31, 2003, and who resided or whose place of employment was in the NYC Disaster Area during that time frame. This group is estimated to consist of at least 362,000 persons.<sup>6,7</sup>

#### Responders to the Pentagon and Shanksville, PA attack sites

These are workers or volunteers who provided rescue, recovery, debris cleanup, and related support services at the Pentagon, in Arlington, Virginia, or the Shanksville, PA crash sites. At the Pentagon site,

**Table 1.** Estimated WTC cohort sizes, and counts of persons enrolled in the WTC Health Program and WTC Health Registry.

Cohort	Total cohort size estimate <sup>a</sup>	Number enrolled in WTC Health Program <sup>b</sup>	Number enrolled in WTC Health Registry <sup>a</sup>
FDNY Responders	17,100	17,038	3,196
Non-FDNY General Responders to the NYC attacks	80,469	65,635	27,469
WTC Survivors	362,092	34,979	47,660
Responders to the Pentagon and Shanksville, PA attack sites	NA	1,197	NE
Total	409,492 <sup>c</sup>	118,849	71,437 <sup>c</sup>

Abbreviations: FDNY: Fire Department of the City of New York; NA: not available; NE: not eligible; WTC: World Trade Center; NYC: New York City.

<sup>a</sup>Based on estimates in Table 1 of Farfel et al (5), except for FDNY responders. Farfel estimated 11,000 FDNY responders, which is far lower than the number who are enrolled in the WTC Health Program. As such, the estimate for FDNY responders is based on the number enrolled in the WTC Health Program. Also note that Farfel et al (5) stratified survivors into three groups: students/school staff south of Canal Street; residents south of Canal Street; and, building occupants/passersby/people in transit south of Chambers Street on 9/11. Given the overlap in these three groups, we used only their estimate for the "Building occupants/passersby/people in transit south of Chambers Street on 9/11" ( $n = 362,092$ ). Finally, note that some persons included in this column may not be eligible for WTC Health Program enrollment (e.g., some persons may not satisfy 9/11 exposure requirements established by the Program), and other eligible persons may have been excluded from this column (eg Manhattan residents who lived north of Canal street but south of Houston Street, and Brooklyn residents who lived within a 1.5-mile radius of the former World Trade Center site).

<sup>b</sup>Counts are as of July 31, 2022. Updated numbers of persons enrolled in the WTC Health program are available at [www.cdc.gov/wtc/ataglance.html#enrollmentWTC](http://www.cdc.gov/wtc/ataglance.html#enrollmentWTC).

<sup>c</sup>Since persons can belong to more than one cohort, the sum of the individual cohorts exceeds the total count. In contrast, cohorts in the WTC Health Program are mutually exclusive.

responders who worked between September 11, 2001 and November 19, 2001 may be eligible for WTC Health Program enrollment. At the Shanksville, PA attack site, responders who worked between September 11, 2001 and October 3, 2001 may be eligible for such enrollment. Estimates of the total size of this group are not available. However, as of July 31, 2022, there were 1072 Pentagon responders and 125 Shanksville responders enrolled in the WTC Health Program. To our knowledge, responders to the Pentagon and Shanksville, PA attack sites have not been included in any research. However, efforts are underway by the WTC General Responder Data Center to obtain research consent from these persons so that they can be included in future research activities.

### **WTC Health Program**

The persons in the four cohorts described above may be eligible for enrollment in the WTC Health Program. To be enrolled, these persons must meet minimum 9/11 exposure duration requirements. Details on the minimum exposure duration requirements for enrollment are available at the WTC Health Program website ([www.cdc.gov/wtc/eligiblegroups.html](http://www.cdc.gov/wtc/eligiblegroups.html)). Enrolled persons are eligible for certain limited health benefits. Enrolled members who sign an informed consent form are included in longitudinal research studies. This is an open and growing cohort (e.g., on July 31, 2022, the WTC Health Program included 118,849 persons and grew by 5% in the preceding 12 months). Within the WTC Health Program, the FDNY cohort is maintained by the FDNY WTC Data Center ([www.fdnwtcdata.org/](http://www.fdnwtcdata.org/)), and the general responder cohort is maintained by the WTC General Responder Data Center ([icahn.mssm.edu/about/departments/environmental-public-health/research/wtc-data-center](http://icahn.mssm.edu/about/departments/environmental-public-health/research/wtc-data-center)). The survivor cohort is maintained by the Survivor Data Center (link to the WTC Environmental Health Center is [www.nychealthandhospitals.org/services/wtc-environmental-health-center/](http://www.nychealthandhospitals.org/services/wtc-environmental-health-center/) [note that a sublink to the Data Center is not currently available, but will be soon]).

### **WTC Health Registry**

This is a longitudinal study conducted by the New York City Department of Health and Mental Hygiene to document and evaluate the long-term physical and mental health effects of the 9/11 terrorist attacks. The cohort consists of FDNY responders, WTC General

Responders, and WTC survivors (responders to the Pentagon and Shanksville, PA attack sites are not included). The Registry includes 71,437 voluntary participants.<sup>6–8</sup> These participants received baseline interviews between September 2003 and November 2004.<sup>9</sup> This cohort is closed and does not accept new participants. Additional information on the Registry's methods is available.<sup>6</sup> More information on this cohort is available at [www1.nyc.gov/site/911health/about/wtc-health-registry.page](http://www1.nyc.gov/site/911health/about/wtc-health-registry.page).

There is an overlap between the WTC Health Program and the WTC Health Registry. For example, among the 3,196 FDNY responders enrolled in the Registry, 3,155 (99%) are also enrolled in the WTC Health Program.<sup>10</sup> Similar counts for WTC General Responders are 27,469 and 6,377 (23%), respectively.

### **Cancer registry record linkages**

Currently cancer registries are operated in all US states and collect information on cancer, including treatment and case demographics. Cancer registry data are used to generate US annual cancer statistics, including the overall magnitude and trend of cancer in the US. CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) is tasked with administering the National Program of Cancer Registries (NPCR), which supports cancer registries and promotes the use of cancer registry data in 46 states, the District of Columbia, Puerto Rico, and the US Pacific Island Jurisdictions, and the US Virgin Islands. The remaining four states and six metropolitan areas operate cancer registries through funding from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. The NPCR and SEER programs, together, collect cancer data for the entire US population.<sup>11</sup>

Population-based registries collect data for all cancer cases within a specific geographic area and monitor cancer incidence across the region. By law, medical care facilities are required to report new cancer cases to a regional or central cancer registry. Medical care facilities include hospitals, outpatient clinics, radiology departments, doctors' offices, laboratories, and surgical centers. Cancer registration (i.e., the process of cancer data collection) is primarily performed by cancer registrars. The cancer registrar identifies cancer cases by reviewing pathology and other records. Once identified, the patient's medical record is reviewed by the cancer registrar and all information relevant to the cancer registry report is abstracted. Information capture is strictly records based, as the

cancer registrar is forbidden to speak directly to the cancer patient or their family. Cancer cases identified by the cancer registrar are reported to the regional or statewide cancer registry. It is estimated that statewide cancer registries capture almost all eligible cancer cases within their state.<sup>12</sup> However, non-melanoma skin cancers are not tracked by them.<sup>13</sup>

9/11 cohort members with cancer are identified by linking the list of cohort members with the cancer registry's list of persons with cancer. These two lists are matched by name, sex, race, birth date, social security number when available, and/or home addresses. Currently, a separate linkage is conducted at each statewide cancer registry of interest, one-by-one. However, this process may soon be streamlined using the Virtual Pooled Registry Cancer Linkage System (VPR-CLS). VPR-CLS, which is operated by the North American Association of Central Cancer Registries, is a single system to link with multiple statewide cancer registries. More information on VPR-CLS is available at [www.naacr.org/about-vpr-cls/](http://www.naacr.org/about-vpr-cls/).

### **Cancer registry linkages with 9/11 cohorts**

Findings from recent linkages with the WTC Health Program's FDNY<sup>14</sup> and WTC General Responder cohorts<sup>15</sup> have been published in peer-reviewed scientific journals. Cancer linkage findings from responders and survivors enrolled in the WTC Health Registry have also been published.<sup>16</sup> In addition, findings from a cancer registry linkage with a combined deduplicated cohort of FDNY and general responders from the WTC Health Program and the WTC Health Registry has also been published.<sup>17</sup> The sample size ( $N=69,102$ ) of the combined responder cohort is substantially larger compared to the individual responder cohorts,<sup>18</sup> which increases the statistical power to detect associations between 9/11 exposure and rare cancers. All four of these studies used both external and internal comparison groups.

### **Mortality tracking**

Death certificate data are another important tool to track disease. The immediate and underlying causes of death are entered on the death certificate by physicians who were present at or near the time of death. Death certificate information is reported to local vital statistics agencies and then sent to state vital statistics agencies. These state agencies then provide the data to the National Death Index (NDI). NDI standardizes the underlying cause of death using computer algorithms and nosologist reviews. NDI, which is maintained by

CDCs National Center for Health Statistics, is the most comprehensive source of death information in the United States ([www.cdc.gov/nchs/ndi/](http://www.cdc.gov/nchs/ndi/)). It includes all US death records since 1979 and is available for use in public health and medical research studies.

There are limitations to death certificate data. One limitation is that the cause of death recorded by the physician may be incomplete or inaccurate. This is supported by studies that compared death certificate data with autopsy information<sup>19</sup> and detailed medical records.<sup>20</sup> Inaccurate reporting on death certificates may arise from several factors, including a lack of physician knowledge of the information to be included on the death certificate, and incomplete knowledge of the decedent's full medical history. Another limitation of death certificate data is that it is ineffective for capturing non-fatal disease.

### **Mortality linkages with the National Death Index**

NDI linkages are often conducted on the 9/11 cohorts described earlier in this paper. Recent mortality findings using NDI data are available on the WTC Health Program's FDNY cohort,<sup>21</sup> the WTC General Responder cohort,<sup>22</sup> as well as the WTC Health Registry cohort<sup>8</sup>, with Registry findings on responders and survivors reported separately. Mortality findings from the combined responder cohorts (FDNY and General Responders from the WTC Health Program and WTC Health Registry) are also available.<sup>23</sup> All four of these studies used both external and internal comparison groups.

### **Registry of WTC responder deaths**

In 2006, to determine if responders were at elevated risk for certain causes of death, the New York State Department of Health (NYSDOH) initiated the WTC Responders Fatality Investigation (RFI) program.<sup>3</sup> NYSDOH sought information on any WTC responder death that occurred between September 12, 2001 and June 30, 2009. A major limitation was the lack of a comprehensive list of all individuals who were involved in the WTC response. If such a comprehensive list were available, NYSDOH could have conducted an NDI linkage. Instead, among the 814 deaths included in the RFI final report, the largest proportion (45%) were detected through daily reviews of on-line newspapers in New York and surrounding states, and from national obituary search engines. In addition, outreach was made to over 200 groups, including clinician groups, requesting information on WTC responder deaths. Data sharing agreements were

also adopted with FDNY, the health programs that monitored general responders (eg the Mount Sinai Consortium), and the WTC Health Registry. A report summarizing the RFI findings is available.<sup>3</sup>

### Hospital discharge data

Hospital and emergency department (ED) discharge information provide another source for disease tracking. In NYS, the state where slightly more than 50% of persons affected by the 9/11 attacks still reside, linkage with hospital and ED discharge data can be accomplished through the NYS Statewide Planning and Research Cooperative System (SPARCS) ([www.health.ny.gov/statistics/sparcs/](http://www.health.ny.gov/statistics/sparcs/)). SPARCS contains data on all inpatient (1982-present) and ED discharges (2005-present) in NYS, except for federal and psychiatric hospitals. Each SPARCS discharge record contains personal identifier data (e.g., name and date of birth), the admitting diagnosis, the principal diagnosis (i.e., the condition chiefly responsible for the admission) and 24 secondary diagnoses (i.e., other conditions affecting treatment and/or length of stay).

One limitation with hospital and ED discharge data is the possibility of disease code entry errors which can lead to chronic disease misreporting and underreporting/overreporting. Another limitation is that hospitalization and ED data are limited to certain geographic regions, and therefore cannot provide data on persons outside that region. We are aware of at least two papers involving 9/11 cohorts that used SPARCS data to identify disease outcomes.<sup>24,25</sup>

### Longitudinal cohort studies

The WTC Health Program and the WTC Health Registry support longitudinal research on their cohorts. As authorized by the James Zadroga 9/11 Health and Compensation Act of 2010 (and reauthorized in 2015), the WTC Health Program has a monitoring program in which enrolled responder members are invited for an annual health evaluation. In contrast, the Act allows all enrolled survivors to receive an initial health evaluation but are eligible for annual medical exams only if they have been certified for a WTC-related condition (for members in the WTC Health Program, medical conditions are certified when they meet diagnostic and 9/11 exposure requirements, and when a CCE/NPN-affiliated physician has attested to 9/11 exposures having aggravated, contributed to or caused the condition). The health evaluation includes the administration of health questionnaires to assess physical and mental health

conditions, a physical exam, pulmonary function testing, chest X-rays, and blood and urine testing. Medical records may also be obtained to support self-reported health conditions. If the health evaluation leads to suspicion of a WTC-related condition, the member is referred for a diagnostic work-up that is paid for by the Program.

The WTC Health Registry generally collects its longitudinal health information through health interview surveys. These interviews are conducted in-person, by telephone, or on the internet. WTC Health Registry interviews are conducted approximately every four years, during specified time periods (referred to as a “wave”). Medical records may also be obtained to confirm self-reported health conditions.

Analyzing the data collected from these longitudinal cohorts can detect disease trends and newly emerging 9/11-related conditions. Findings from these longitudinal cohorts are based on record linkages (using the systems described earlier in this paper) and on analyses of self-reported health conditions. Internal comparisons, that is comparing health outcomes among those with greater exposure to those with lesser exposure, can be helpful for identifying conditions possibly related to 9/11 exposures (e.g., see Cohen et al.<sup>26</sup>)

Limitations with these longitudinal cohorts exist. First, participation in the WTC Health Program monitoring program and in the WTC Health Registry health interview surveys is not complete, which may produce selection bias.<sup>27</sup> For example, those who are ill may be less likely to participate. Second, because a master list of all persons with 9/11 exposures is non-existent (with the possible exception of 9/11-exposed FDNY responders), it's unclear if these cohorts are representative of the source population. However, the counts provided in Table 1 suggest that the NYC responder population is likely representative. Third, WTC survivors who aren't certified for a WTC-related health condition are not eligible to receive annual health evaluations from the WTC Health Program. As such, there is under-representation of healthy survivors in that Program. And fourth, these longitudinal cohorts generally don't have a non-exposed comparison group that receive similar ongoing health monitoring. The possible exception is the Career Firefighter Health Study, a study of firefighters in three non-NYC metropolitan areas who undergo periodic health monitoring, which serves as a comparison group to FDNY responders.<sup>28</sup>

### Conclusion

Given the lack of public health reporting requirements specifically for diseases caused by 9/11, other mechanisms

are used to track these illnesses, often with excellent success. These include record linkages of 9/11 cohorts to various data registries, for example, statewide cancer registries, the National Death Index, and SPARCS. In addition, the health of various 9/11 cohorts are longitudinally followed using periodic surveys and annual health evaluations. Because the mixture of physical exposures (e.g., debris, dust, smoke, and fumes) experienced by 9/11-exposed persons was never completely characterized,<sup>1,29</sup> generalizing their health findings to other occupational or environmental populations is challenging. However, other 9/11 health findings may be more generalizable (e.g., those involving exposures to disturbing and psychologically traumatizing scenes and events). By using various mechanisms to track illness, the Program serves as an example for future large-scale environmental disasters and can guide the recognition of and response to the complex health issues that may arise.

### Disclaimer

The findings and conclusions in this report are those of the author and do not necessarily represent the official position of the National Institute for Occupational Safety and Health (NIOSH), Centers for Disease Control and Prevention (CDC). Mention of any company or product does not constitute endorsement by NIOSH/CDC. In addition, citations to websites external to NIOSH do not constitute NIOSH endorsement of the sponsoring organizations or their programs or products. Furthermore, NIOSH is not responsible for the content of these websites. All web addresses referenced in this document were accessible as of the publication date.

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The author reports that there are no competing interests to declare.

### Institutional review board (IRB) review

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