



World Trade Center Health Registry External Research Opportunities



About the WTC Health Registry

The World Trade Center (WTC) Health Registry is an epidemiological cohort study created as a public health response to 9/11. Its objectives are to:

- Document the short- and long-term physical and mental health effects of 9/11
- Assess disaster-related risk factors for 9/11-related outcomes
- Help identify people with 9/11-related health needs and refer them to appropriate treatment facilities.

The Registry was planned by the New York City Department of Health and Mental Hygiene and the federal Agency for Toxic Substances and Disease Registry (ATSDR). It is housed in a dedicated research unit within the Health Department's Division of Epidemiology.

Eligibility

Eligibility was based on the potential for direct exposure to physical hazards and emotional trauma resulting from 9/11. Enrollees fall in one or more of the following categories:

- Occupants of and evacuees from the 35 damaged or destroyed buildings and/or people who were in a building, on the street or on the subway in lower Manhattan on 9/11
- Residents living south of Canal Street
- Students and staff in schools (pre-K–12th grades) or daycare facilities south of Canal Street
- Rescue, recovery or clean-up workers or volunteers at the WTC site, or the WTC recovery operations on Staten Island or transport barges.

Baseline Health Survey

More than 71,000 people completed a baseline interview and enrolled in the WTC Health Registry between September 2003 and November 2004. Data collection involved a 30-minute telephone or in-person interview. The cohort included 2,869 children 18 years of age or younger. Data for children were collected by proxy interviews with a parent or guardian.

Follow-Up Health Survey

The Registry surveyed adult enrollees from November 2006 to December 2007, with 68% responding. The survey used three data collection methods or modes, which included 18,708 web-based interviews, 19,323 paper questionnaires via mail and 5,175 telephone interviews.

The Registry conducted a separate follow-up survey for child and adolescent enrollees through December 2008. Findings will be available in late 2009.



Research Opportunities

The Registry welcomes proposals for new studies from external researchers. As of February 2009, there are nine external research investigators or groups engaged in research projects using Registry resources. Registry data can be used to:

- Analyze existing survey data
- Recruit enrollees for new studies.

The second research model can involve:

- Gathering new data on a subpopulation within the Registry
- Modifying existing questionnaires or developing new questionnaires, or administering standard instruments not previously used in Registry studies
- Distributing information to Registry enrollees
- Conducting clinical exams of selected enrollees
- Collecting completed questionnaires/study materials, data entry and analysis.

The Registry must be the initial contact with potential participants. This contact may result in the enrollees' consent to participate, at which point identifying information may be released to the external researcher.

Health Data Tools

Researchers can also download a de-identified subset of the WTC Health Registry 2003/2004 baseline survey and the codebook at:
<http://www.nyc.gov/html/doh/wtc/html/registry/epiquery.shtml>.

Only certain variables are included to protect enrollees' confidentiality. See the codebook for these indicators. Data can be downloaded in SAS or as a comma delimited file.

Registry Collaboration

External research applicants are not required or expected to share their research project data with the Registry. However, it may be beneficial to explore collaborative opportunities in light of Registry scientists' experience and familiarity with the study population and data.



Financial Support

The Registry does not provide financial support to external researchers. However, we will provide necessary in kind support to approved projects. The Registry, at its discretion, may carry out a limited amount of data preparation necessary to establish the scope of a project prior to application submission. The external researcher is responsible for all additional costs associated with the project, and will be asked to pay the postage for mailings to enrollees. Researchers are encouraged to develop cost estimates and to secure adequate funding through grants or other sources.

Restrictions

The use of Registry data is restricted to medical, public health or emergency preparedness research or related scientific research. The data may not be used for marketing purposes or for legal, administrative or other actions that may directly affect identified people or establishments because of their participation in the Registry.

Current External Research

Principal Investigator(s)	Institution	Project
Christina Hoven, DrPH	Columbia University/New York State Psychiatric Institute/ Mailman School of Public Health	Violence and Mental Health: Children of First Responders
Robyn Gershon, DrPH	Columbia University Mailman School of Public Health	World Trade Center Evacuation Study
Franklin Schneier, MD Eun-Jung Suh, PhD	Columbia University/New York State Psychiatric Institute	Combination Treatment for Post-Traumatic Stress Disorder (PTSD) After the World Trade Center (WTC) Attack
Kimberly Yonkers, MD	Yale School of Medicine	Maternal PTSD and Risk of Adverse Pregnancy Outcomes
David Silbersweig, MD James Root, MD	Weill Cornell Medical College	Functional Neuroimaging of Post-Traumatic Stress Responses to 9/11
Sandro Galea, MD, DrPH	University of Michigan School of Public Health	PTSD and Self-Reported Physical Health in the Aftermath of a Mass Trauma
Kitty Gelberg, PhD, MPH	New York State Department of Health	World Trade Center Responders Fatality Investigation Program
Katherine Henry, MD, MEd	NYU School of Medicine/Bellevue Hospital Center	Headache among Registrants in the World Trade Center Health Registry
Rosemary Bowler, PhD, MPH	San Francisco State University	Physical and Mental Health among Police Responders to the 2001 WTC Disaster



Findings

Registry findings have been published in a variety of scientific journals. Below are the publications as of June 2009.

Findings have focused on newly diagnosed asthma and post-traumatic stress disorder as primary short-term outcomes, and include most enrollees. We encourage prospective researchers to explore other outcomes as well.

Brackbill RM, Thorpe LE, DiGrande L, et al. Surveillance for World Trade Center disaster health effects among survivors of collapsed and damaged buildings. *Morbidity and Mortality Weekly Report* 2006;55:1-18.

DiGrande L, Perrin MA, Thorpe LE, et al. Posttraumatic stress symptoms, PTSD, and risk factors among lower Manhattan residents 2-3 years after the September 11, 2001 terrorist attacks. *Journal of Traumatic Stress* 2008;21:264-73.

Farfel M, DiGrande L, Brackbill R, et al. An overview of 9/11 experiences and respiratory and mental health conditions among World Trade Center Health Registry enrollees. *Journal of Urban Health* 2008;85:880-909.

Murphy J, Brackbill RM, Thalji L, et al. Measuring and maximizing coverage in the World Trade Center Health Registry. *Statistics in Medicine* 2007;26:1688-701.

Murphy J. Estimating the World Trade Center tower population on September 11, 2001: a capture-recapture approach. *American Journal of Public Health* 2009;99:65-7.

Perrin M, DiGrande L, Wheeler K, et al. Differences in PTSD prevalence and associated risk factors among World Trade Center disaster rescue and recovery workers. *American Journal of Psychiatry* 2007;164:1385-94.

Thomas PA, Brackbill R, Thalji L, et al. Respiratory and other health effects reported in children exposed to the World Trade Center disaster of 11 September 2001. *Environmental Health Perspectives* 2008;116:1383-90.

Wheeler K, McKelvey W, Thorpe L, et al. Asthma diagnosed after 11 September 2001 among rescue and recovery workers: findings from the World Trade Center Health Registry. *Environmental Health Perspectives* 2007;115:1584-90.

How to Apply

Please contact Steven D. Stellman, PhD, MPH, to discuss your ideas. If your research is feasible and within the Registry's scope and objectives, you will be invited to submit a formal application to the WTC Health Registry Review Committee. If approved by the Review Committee, it should then be submitted to your and the Health Department's Institutional Review Boards.

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