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


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

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


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.

Steven D. Stellman, PhD, MPH
Director of Research, WTC Health Registry
New York City Department of Health and Mental Hygiene
233 Broadway, 26th Floor
New York, NY 10279-2600
Phone: (212) 442-2446
Email: sstellma@health.nyc.gov