

World Trade Center Health Registry

Research, surveillance & treatment referral in response
to the 9/11/01 disaster in New York City

Update for the
WTC Health Program Scientific/Technical Advisory
Committee (STAC) meeting

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26 Federal Plaza, NYC

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NYC DOHMH

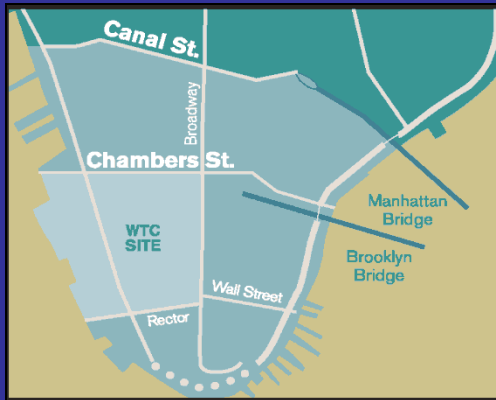
Registry at a Glance

- Cohort study (20+years) of 71,434 exposed people with updates on health & access to care every 3 to 4 years
- Expanded data gathering for research
 - Mortality, cancer & hospitalization data obtained through matching with administrative databases
 - In-depth/clinical studies of selected subgroups
- Platform for independent & collaborative studies by external researchers
- Facilitation of 9/11 monitoring & healthcare for enrollees & their families in need

Eligibility Groups

Highly Exposed by Time and Place

<u>Group</u>	<u>N</u>
Building occupants & passers-by south of Chambers St. on 9/11	43,487
Rescue/recovery workers & volunteers at the site (9/11/01 to 6/30/02)	30,665
Residents south of Canal St. on 9/11	14,665
Children & staff in schools (pre K–12) south of Canal St. on 9/11	2,646

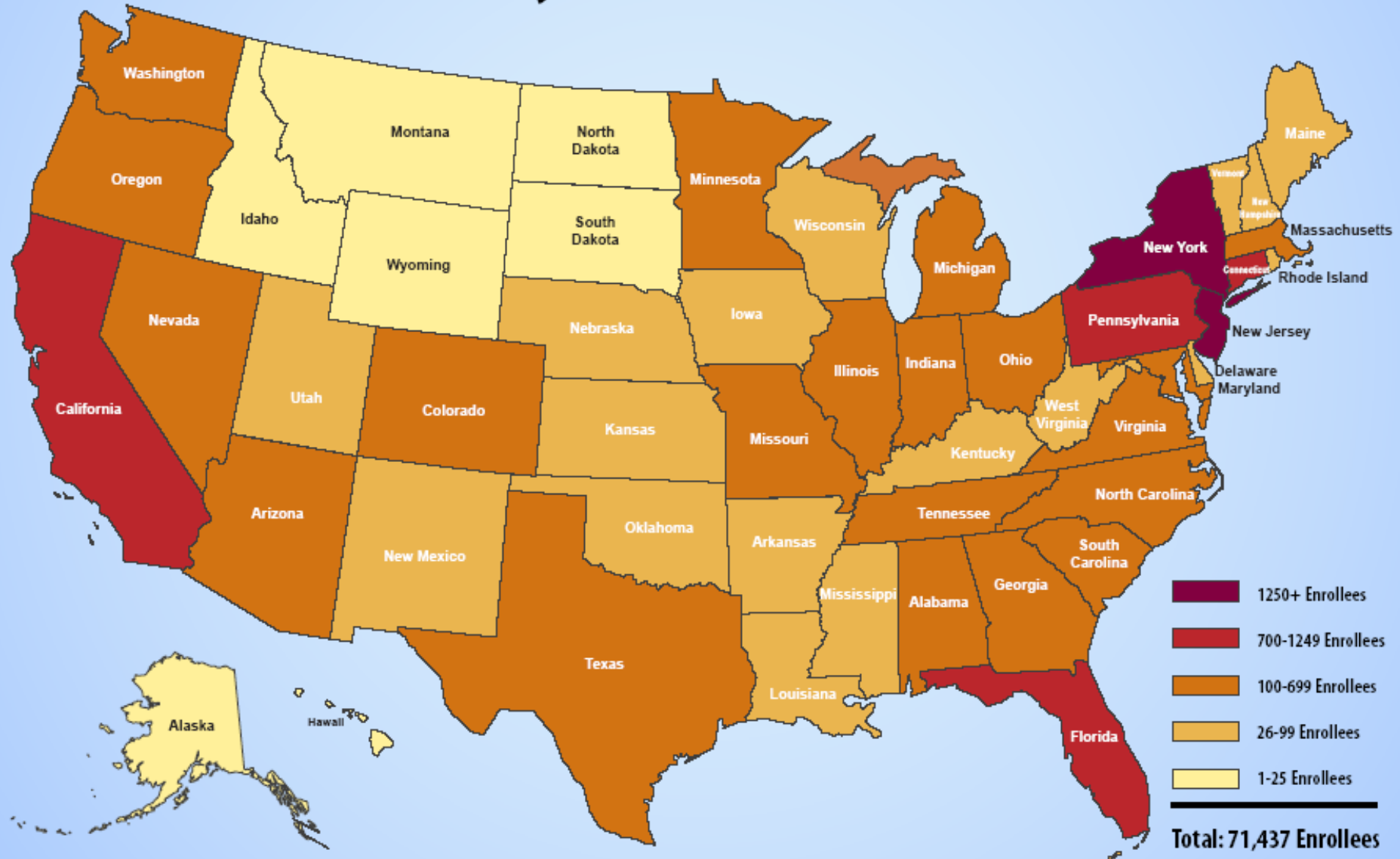


~400,000 were eligible across the 4 groups.

Exposed persons *did not need to be ill* to be eligible for enrollment. Individuals may belong to more than one group.

World Trade Center Health Registry Enrollment by State

Every State Affected



History

Largest US effort to monitor health after a disaster

- **2002:** Funded by FEMA/ATSDR as exposure registry
- **2003-04:** Wave 1 survey of health & 9/11 exposures
- **2006-07:** Wave 2 survey
- **2010-11:** Staten Island landfill and barge workers
- **2011-12:** Wave 3 survey
- **2013:** Hurricane Sandy exposure & health update
- **2014:** Autoimmune disease survey
- **2015:** Wave 4 survey

Funded by NIOSH since April 2009

Scientific Outputs*

- Publications: 58
- External researcher publications: 22
- Conference/meeting presentations: 107
- Doctoral & master's theses: 20
- Technical reports & clinical guidelines: 12
- In-depth studies & surveillance projects: 12
- Public use data tools: 4

* through April 2015

Strengths

- Large, diverse groups of exposed people
- Depth & breadth of scientific outputs
- Findings inform 9/11 healthcare policy & disaster preparedness and response planning
- Major source of new applications to WTCHP
- Recognized platform for external research
- Collaboration with distinguished scientists & institutions
- High commitment of enrollees
- Dedicated staff for research, cohort maintenance, public affairs & treatment referral

Registry research addresses STAC recommendations

- ✓ Investigate emerging conditions
- ✓ Examine patterns of health care utilization, delivery and the value & efficacy of medical monitoring
- ✓ Evaluate & improve the utility/use of WTCHP data for monitoring health conditions
- ✓ Determine the value of biomarkers for the early detection of WTC associated conditions
- ✓ Assess effect of WTC exposure on gestation & early life
- ✓ Develop methods of diagnosing and treating WTC disaster-related psychopathology

Publications/Studies 2006 - May 2015*

Physical Health

- Asthma & other respiratory conditions*
- Asthma control*
- Diabetes*
- Respiratory protection
- Cardiovascular disease
- GERD symptoms
- Sarcoidosis
- Skin rash

Mental Health

- PTSD trajectories*
- PTSD and co-occurring mental /physical conditions*
- Adolescent behavior*
- Cognitive impairment*

Other Areas

- Alcohol use*
- Smoking*
- Hurricane Sandy outcomes*
- Birth outcomes
- Mortality
- Cancer
- Disaster response
- Unmet health care needs
- 9/11 injury
- Building evacuation

* Publications since last STAC update 02/2014

Recent Findings

Mental health/behavior in adults and children

Adult PTSD

- Comorbid PTSD & depression is common & associated with more unemployment & unmet care needs, lower QOL vs either condition
- Responder PTSD trajectories through 9 years post 9/11 (e.g., chronic, late onset, improving, resilient) are generally similar across occupations
- Hurricane Sandy PTSD is ~7x more likely in those with 9/11 PTSD

Adolescent behavior

- Behavioral difficulties 6-7 yrs after 9/11 were associated with 9/11 exposures, respiratory symptoms, 9/11-related injury or death of a family member, and PTSD in a parent.

Recent Findings

Mental health/behavior in adults

Binge drinking and smoking

- Enrollees with PTSD reported more frequent binge drinking than those without PTSD (15% vs. 6%). Greater 9/11 exposure was also a risk factor.
- Smoking prevalence was higher among enrollees with PTSD, and PTSD was associated with reduced odds of quitting.

Cognitive impairment (CI)

- CI 10 years after 9/11 is associated with 9/11-related PTSD. An independent dose response relationship was found between CI & 9/11 exposure.

Recent Findings

Physical effects in adults

Heart disease

- Intensive rescue/recovery work was associated with increased risk of heart disease hospitalization among men. Risks were higher among men & women with PTSD at Wave 1.

Asthma control

- Most (68%) persons with early post-9/11 asthma before 2005 had poorly or very poorly controlled symptoms. Dose-response found between number of mental health conditions & poorer control.

Diabetes

- ~~Enrollees with PTSD at Wave 1 were 30% more likely to develop diabetes 6 to 8 years later than those without PTSD.~~

Recent Findings

Physical effects in adults and children

9/11 injury is a risk factor for chronic disease 5-6 years later

- Persons with multiple types of injury (MTI) were twice as likely to report a respiratory illness as those not injured
- Those with MTI & PTSD were three times more likely to report heart disease than those without injury & PTSD

Children's respiratory symptoms

- Symptoms 6 to 7 years after 9/11 were associated with 9/11 dust cloud exposure.

Analyses in Progress

Physical health

- Birth outcomes
- Adolescent health
- GERD
- Staten Island asthma
- Respiratory outcomes 10-11 years after 9/11
- Alcohol and mortality
- 10-yr cancer/mortality
- PTSD as mediator for heart/respiratory disease
- Respiratory hospitalizations

Mental health

- 9 yr time course of survivor PTSD
- Cognitive impairment
- Adolescent risk behaviors
- Human remains exposure & PTSD
- Generalized anxiety disorder (GAD)
- Substance use related mortality
- PTSD & early retirement

Evaluation/ Methods

- Provider knowledge of 9/11 conditions & clinical services
- Cancer assessment methods
- Adapting survey grids for smartphones

Wave 4 Survey

April – December 2015

- Objective:** Assess potential emerging conditions & course of conditions reported previously with a focus on:
- Chronic health conditions
 - Mental health treatment and hospitalization (new)
 - Functional status and QOL
 - Asthma control (via separate survey to ~15K)
- Population:** All ~67K adult enrollees ≥ 18 yrs in 2015
- Methods:** Web & paper surveys; 3 languages paper
- Status:** >12,000 surveys rec'd so far, highest responding groups: responders & W2/W3 participants

Update on Nested Studies

- Hurricane Sandy Survey
- Follow-up Respiratory Study
- Autoimmune Disease Study
- 9/11 Injury Study

Hurricane Sandy Survey

April – Nov. 2013

- Objective:** Assess Sandy experiences & health outcomes among 9/11-exposed people
- Methods:** Web/paper survey to W3 participants, tri-state area
~4,300 residents of inundation zones & sample (~4,300) of enrollees not in these zones
- Status:** 4,558 participants (~53% response rate)
- Publications:** Post-Sandy Injuries (*MMWR* 2014; 63:950-954)
Sandy PTSD (*Int J Emerg Mental Health*, in press)
Household emergency preparedness (*accepted*)
Factors influencing evacuation (*in preparation*)

Respiratory Follow-up Study 2012-14

Background: 2008-10 case-control study of persistent lower respiratory symptoms (LRS) among area residents/workers, with NYU/Bellevue

- LRS risk factors: dust cloud, home/workplace exposures
- Cases had abnormal PFTs (spirometry/IOS)

Objective: Assess longer-term course of LRS, PFT's, quality of life, and PTSD comorbidity

Status: 545 persons completed interviews & PFTs (74% response rate), data analysis underway

Autoimmune Disease Study

- Objective:** Surveillance of potential emerging condition
- Method:** Web/paper surveys sent to 2,786 enrollees reporting an autoimmune disease at Wave 3
- Status:** 2,022 participants (May-Dec. 2014), 73% RR*
- Next:** Physician confirmation & analysis of association with 9/11-exposures

*RR= response rate

9/11 Injury Study

- Objective:** To understand long-term consequences
- Methods:** Phase 1 in-depth interviews with ~40 enrollees with 9/11 injury (in progress)*
- Next:** Conduct qualitative data analysis to inform development of a survey of injury type & severity, quality of life, and functioning
- Planned:** Conduct survey of injured enrollees if funding available

* In collaboration with Dr. Robyn Gershon at UCSF

A Resource for External Researchers

- Active encouragement of external research proposals
- Options:
 - Collaborate with Registry investigators
 - Registry-facilitated recruitment of enrollees
 - De-identified data for secondary analysis
- Applications reviewed by Registry & advisors
- 23 studies approved to date from US & international institutions

External/Collaborative Research in Progress

- Physical Health Consequences of Childhood Exposure to 9/11
 - Dr. Leo Trasande, NYU Medical Center
- Impact of 9/11 on Youth: Mental Health, Substance Use and Other Risk Behaviors *and*
- Mental Health Service Need and Use among WTC Exposed Youth
 - Dr. Christina Hoven, Columbia University and NYS Psychiatric Institute
- Mental Health Impact and Use among Asian Survivors and RRW
 - Dr. Winnie Kung, Fordham
- Trace Elements in Autopsy Tissues from WTC Decedents
 - Dr. Michael Marmor, NYU Medical Center
- Social Integration and Social Support among WTC Exposed Police
 - Dr. Rosemarie Bowler, San Francisco State University

External/Collaborative Research in Progress (cont.)

- Responder Stress Management Study
 - Dr. Adam Gonzales, Stony Brook
- Cognitive Functioning among Adult WTC Health Registry Enrollees
 - Dr. Valerie Edwards, Centers for Disease Control and Prevention
- PTSD among Police Responders
 - Dr. Rosemarie Bowler, SF State University
- Normative Data for Impulse Oscillometry
 - Dr. Ken Berger, NYU School of Medicine
- GIS Analysis of Residents' Respiratory Conditions & Exposures
 - Dr. Vinicius Antao, ATSDR/CDC

Responding to Health Concerns: Treatment Referral Program

- In 2009-11, outreach to ~8,500 enrollee survivors to encourage care at HHC's WTC Environ. Health Center
 - ~1,100 made 1st appointment
 - Addressed barriers to care, e.g., lack of knowledge about WTC programs, mental health stigmatization
- Expanded in July 2013 to include responders in & outside NYC & out-of-state survivors in collaboration with WTCHP
 - Personalized outreach based on Wave 3 updates (~9k so far)
 - Dedicated staff trained in motivational interviewing
 - 2,600 Registry-branded applications rec'd by WTCHP to-date

Ongoing Collaborations with VCF and WTCHP

- Wave 1 responses provided as needed to help document 9/11 exposure & eligibility
- Initiated by enrollee request & matches to VCF lists of applicants with weak documentation
- Reports provided to-date with enrollee consent
 - ~1,300 directly to VCF (as of 5/20/15)
 - ~2,500 to enrollees to include with their WTCHP applications (as of 04/30/15)

Next Steps 2015-16

- Complete Wave 4 data collection
- Update cancer & mortality assessment
- Submit manuscripts to peer-review journals based on ongoing research
- Share published findings with public & policy makers
- Continue treatment referral outreach and collaborations with external researchers
- Apply for NIOSH continuation funding, if available

Acknowledgments

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- Agency for Toxic Substances and Disease Registry
- Registry/NYC DOHMH staff
- Members of our scientific, community, and labor advisory committees
- Registry enrollees for their ongoing involvement