

WTC Health Registry



WTC Health Program
Scientific/Technical
Advisory Committee
(STAC) meeting, NYC

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Director

Registry Aims

- Expand knowledge about the long-term health effects of the 9/11 disaster & gaps in health care
- Respond to the health concerns & needs of enrollees & others exposed to 9/11
- Maintain an updated Registry as a public health resource

History

Largest US effort to monitor health after a disaster

- **2002: Launched as an exposure registry**
 - Funding from FEMA, ATSDR cooperative agreement
 - Input from scientific, community & labor advisors
- **2003-04: Wave 1 Survey**
 - 30-minute telephone interview on health and exposures
 - 71,437 enrolled, including >3,000 children
- **2006-08: Wave 2 Survey**
 - Course of symptoms, exposure clarification, emerging conditions, unmet healthcare needs
 - 46,322 adults participated (68.1% response rate)
 - 1,022 parent proxies responded (50.1% response rate)
- **2011-12 Wave 3 Survey**
 - All enrollees: launched July 2011 to adults & November to children
 - Course of conditions, emerging conditions, healthcare needs/use

Eligibility Groups

Highly Exposed by Time and Place

Group

N

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.

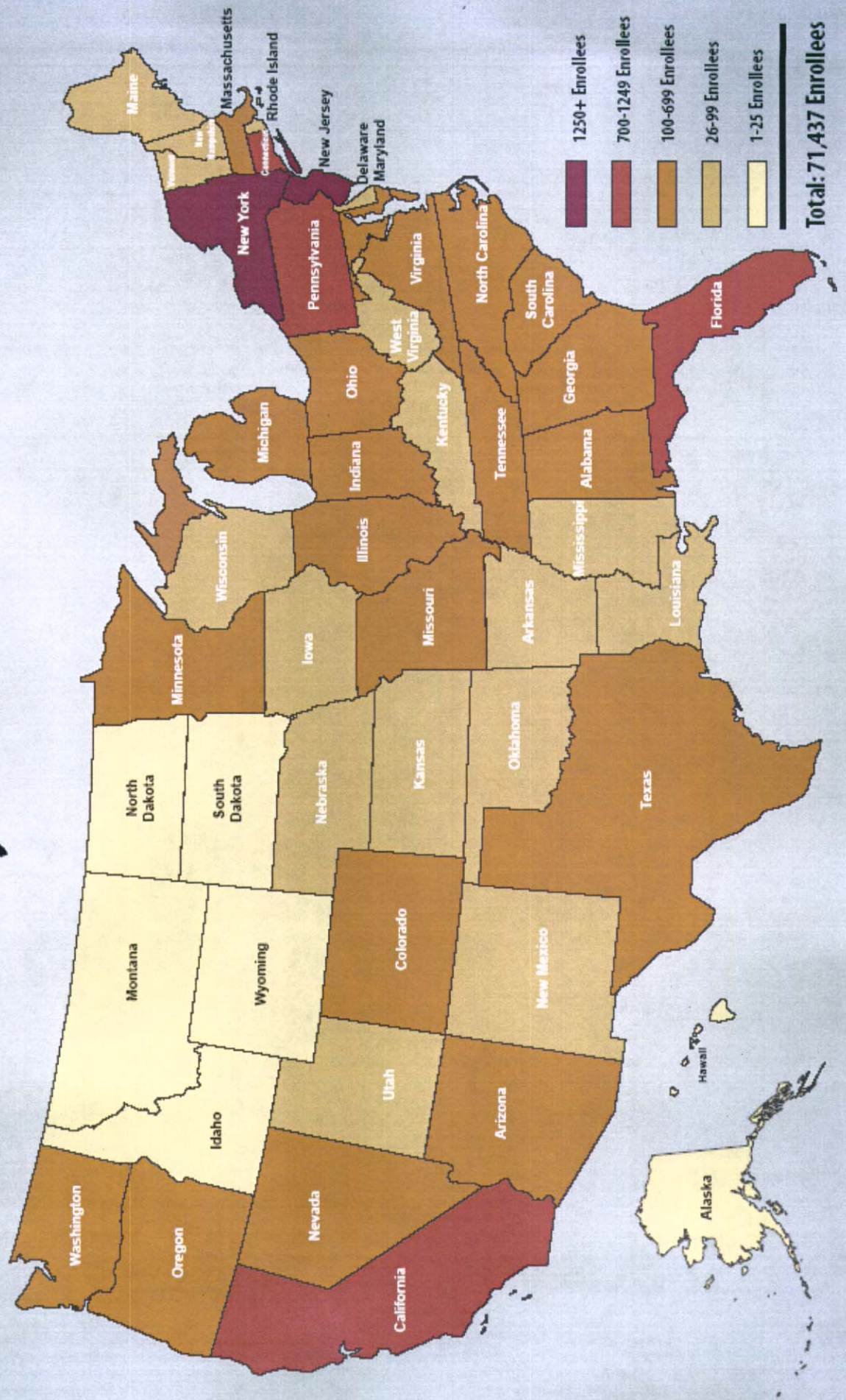
Exposed persons *did not need to be ill* to be eligible for enrollment. Individuals may belong to more than one group.

Recruitment

- **List-identified (30% of enrollees)**
 - Lists of names from employers/volunteer organizations
 - Residents through publicly available directories
 - 273 lists with >135,000 potential enrollees
- **Self-Identified (70% of enrollees)**
 - Pre-registration WTCHR web site
 - Toll-free telephone numbers for inbound interviews
 - Extensive media awareness & outreach campaigns
 - Newspaper, bus, subway, ferry ads, brochure stands
 - Letters to parents of school children

World Trade Center Health Registry Enrollment by State

Every State Affected



Unique Strengths of the Registry

- Published the only estimates of the number of exposed persons
- Follows and compares diverse groups directly exposed to 9/11
- Provides vehicle for external researchers to conduct WTC research

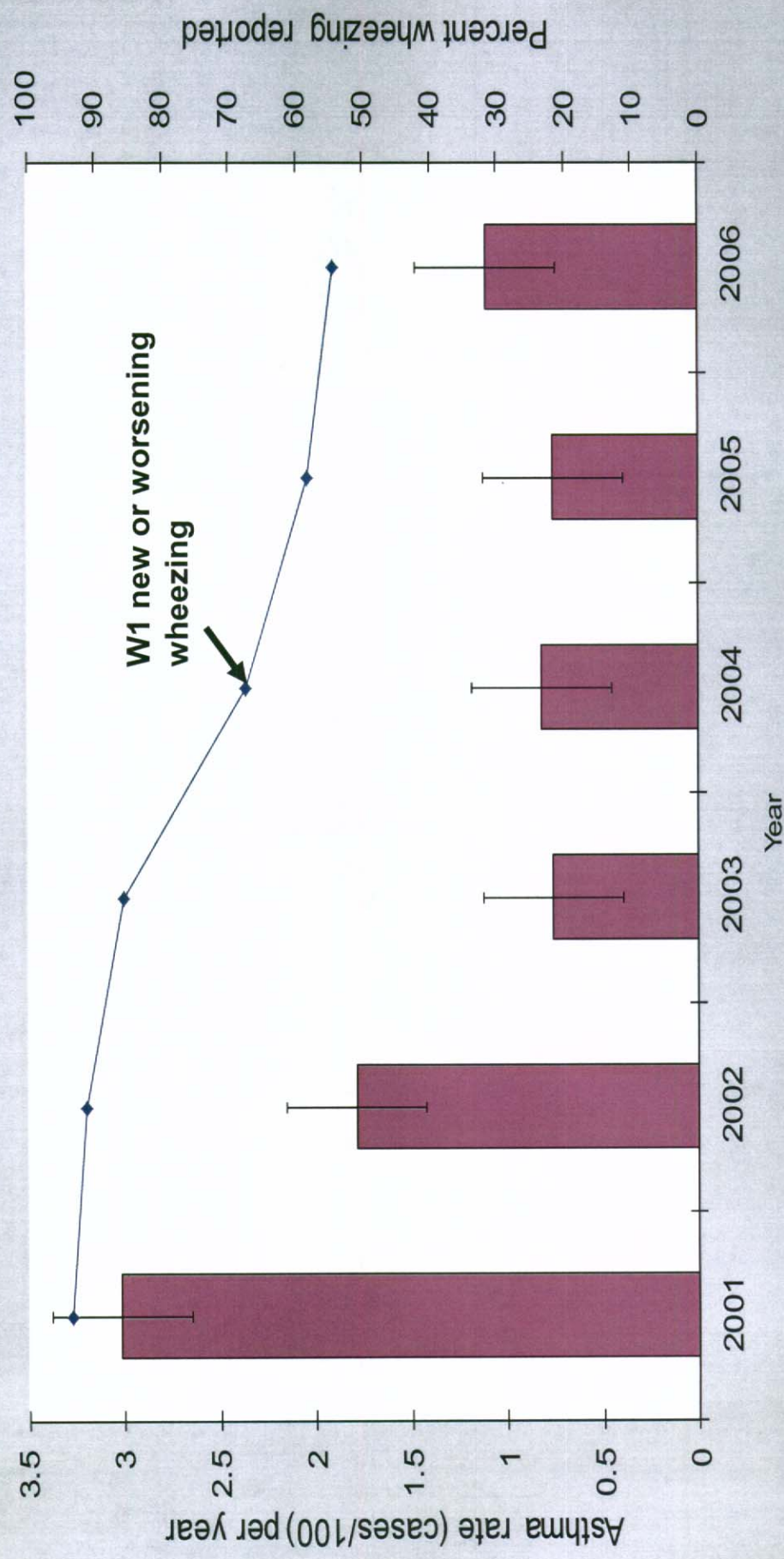
Probable posttraumatic stress disorder (PTSD): adults

- 24% had new onset PTSD 5-6 years after 9/11 - US pop=4%
- Most with chronic or late onset PTSD reported:
 - Poor mental health in past month
 - No mental health care in past year
- Rates varied by occupation & training (7%-24%)
- Risk factors:
 - Caught in dust cloud*, witnessed horror, and injured on 9/11
 - Heavy dust in home or workplace*
 - Early arrival, longer duration of rescue/recovery work*
 - Event-related loss of spouse or job, low social support
- Risk factors for new asthma after 9/11

Brackbill et al., 2009; DiGrande et al 2008; Perrin et al 2007

Annualized incidence of post 9-11 diagnosed asthma: adult enrollees

WORLD TRADE CENTER HEALTH REGISTRY



NYC Health

Error bars: 95% confidence intervals

Brackbill et al., 2009

Recent Findings (1)

Common physical effects:

- Pulmonary function tests (oscillometry) showed lower airways disease among residents & area workers associated with symptoms, exposure
- Responders using respirators less likely to report respiratory symptoms/conditions than those reporting no or lower levels of respiratory protection
- Dust exposure & psychological trauma associated with elevated risk of non-fatal heart disease 2-6 years post 9/11. PTSD independently associated with HD.
- Persistent symptoms of gastroesophageal reflux disease associated with 9/11 exposures

Recent Findings (2)

Less common physical effect:

- Sarcoidosis after 9/11 associated with recovery work on pile

Co-morbidity:

- Enrollees with co-occurring PTSD & asthma reported lower quality of life, more unmet healthcare needs than those with PTSD or asthma only

Volunteers:

- Lay volunteers more highly exposed than affiliated volunteers and at greater risk for post 9/11 asthma & PTSD

Mortality:

- Overall mortality below population rates, but elevated all-cause and cardiovascular mortality in “intensely exposed” survivors relative to those less exposed

Ongoing Research: Matching to other health registries

Matching to State Cancer Registries

- To what extent is there evidence of excess incidence of cancer among WTC-CHR enrollees?
- If so, are any of the WTC-related exposures or other identifiable risk factors associated with cancer incidence?

Matching to Vital Records/National Death Index

- To what extent is there evidence of excess mortality among WTC-CHR enrollees?
- If so, are any of the WTC-related exposures or other identifiable risk factors associated with mortality?

Matching to NYS Hospital Discharge Data:

To validate self-reported health conditions (e.g., heart disease)

Selected Ongoing Research: Analysis of Wave 2 & 3 data

- **Unmet mental healthcare needs:** Which groups are underserved based on enrollees' perceived needs?
- **Treatment Referral Evaluation:** Have enrollees kept their appointments? Has their health status improved?
- **Injury:** What are long-term health effects of 9/11 injuries?
- **Alcohol use:** Is 9/11 exposure related to heavy drinking?
- **Pediatric asthma:** Is there persistent asthma?
- **Parent-child pairs:** Is parental PTSD related to stress symptoms and behavioral problems in children?
- **Late emerging conditions:** What is the course of symptoms and conditions 10-years post 9/11. Are there emerging conditions?

Initial Cancer Study

Methods

Compare numbers of incident cancer (observed cases) with “expected” cancer numbers

Population: WTCHR enrollees who were NYS residents on 9/11

Cancer Data Source: Linkage with State CRs through 2008

Case Definition: 1st primary invasive (or borderline bladder)

Comparison: NYS reference population rates

Person-years: Enrollment to whichever earlier:

- cancer diagnosis, death, or 12/31/2008

Timeline

Submit to peer-reviewed journal early 2012

Wave 3 Survey Status

- **Adult Survey**
 - All 67k adults were sent a survey before 9/11/11
 - 3 modes (web, paper, phone) and 3 languages
 - 29,500 surveys completed to date (RR=44%)
 - Rescue/recovery workers responding best so far
- **Child Survey**
 - Launched 11/01/2011 to parents of 1,200 children
 - Separate parent and adolescent surveys
 - Web (English) and paper (English, Spanish, Chinese)
 - Respiratory outcomes, emotional & behavioral scales, parent's physical and mental health

Wave 3 Adult Survey Content

- **Update Wave 2 items, including**
 - Physical health symptoms & conditions (eg asthma, CVD)
 - Mental health: PCL-checklist, K-6, diagnosed conditions
 - General health status/quality of life
 - Social support, life events, alcohol use
 - Health care utilization and unmet needs
- **New for Wave 3, including**
 - GERD, sleep apnea, pulmonary fibrosis, asbestosis
 - Medication and hospitalization for health conditions
 - Asthma control
 - Depression & anxiety assessments
 - History of trauma
 - Health insurance coverage

Responding to Health Concerns: Treatment Referral Program

- **Objective:** Encourage eligible enrollees to seek care at HHC's WTC Center of Excellence at no cost to enrollee
- **Initial Focus:** Residents & area workers in NYC reporting
 - Unmet health care needs and
 - Physical symptoms and/or probable PTSD
- **Methods:** Personalized outreach and dedicated staff
 - >9000 enrollees to date, including ~4100 with PTSD
 - ~900 enrollees have made 1st appointment
- **Update:** Now refer to WTC Health Program; plan to include survivors outside the NYC area and responders

Next Steps

- Complete Wave 3 survey by March 2012
- Submit manuscripts to peer-review journals based on ongoing research, including cancer study and analysis of Wave 2 & 3 data
- Share new published findings with public & policy makers
- Apply for NIOSH continuation funding