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

<table>
<thead>
<tr>
<th>Group</th>
<th>Population</th>
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<tbody>
<tr>
<td>N</td>
<td>43,487</td>
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<tr>
<td>Rescue/recovery workers &amp; volunteers at the site (9/11/01 to 6/30/02)</td>
<td>30,665</td>
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<tr>
<td>Residents south of Canal St. on 9/11</td>
<td>14,665</td>
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<tr>
<td>Children &amp; staff in schools (pre K-12) south of Canal St. on 9/11</td>
<td>2,646</td>
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</tbody>
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~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 WTC
- 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

Totals: 71,437 Enrollees
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

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 WTCHR 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 WTCHR 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 (e.g., 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

- Apply for NIOSH continuation funding
- Policy makers
- Share new published findings with public
- Study and analysis of Wave 2-3 data
- Submit manuscript to peer-reviewed journals
- Complete Wave 3 survey by March 2012