World Trade Center Health Registry – A Model for a Gulf Oil Spill Exposure Registry?

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WTCHR Registry Aims

- Expand knowledge about the long-term health effects of the 9/11 disaster & gaps in health care
  - Periodic surveys, in-depth studies, publications, serve as platform for external researchers, inform policy
- Respond to the health concerns & needs of enrollees & others exposed to 9/11
  - Provide resource information, healthcare referrals, interventions and clinical guidelines
- Maintain an updated Registry as a public health resource
## Exposure Sequence

<table>
<thead>
<tr>
<th>Time period</th>
<th>Predominant sources of pollution</th>
<th>Airborne pollutants</th>
</tr>
</thead>
<tbody>
<tr>
<td>First 12 hours after collapse, 11 September 2001</td>
<td>Burning Jet Fuel Fires Collapse of the Twin Towers</td>
<td>Combustion products, gases and particulates Evaporating gases from the collapse of towers Coarse particles</td>
</tr>
<tr>
<td>Days 1 and 2</td>
<td>Burning Jet Fuel Resuspension of settled dust/smoke</td>
<td>Combustion Products, gases and particulates Resuspended coarse particles</td>
</tr>
<tr>
<td>Days 3-13</td>
<td>Smoldering fires Resuspension of settled dust/smoke</td>
<td>Combustion Products, gases and particulates Resuspended coarse particles Diesel exhaust</td>
</tr>
<tr>
<td>Days 14 thru 12/20/01</td>
<td>Smoldering fires Removal of debris by trucks, heavy equipment</td>
<td>Combustion Products, gases and particulates Diesel exhaust</td>
</tr>
</tbody>
</table>

Landrigan P 2004
Determinants of Exposure

- Types of Pollutants
  - Chemical and physical characteristics
  - Variability with time and source distance
- Exposure Pathways
  - Largely inhalation but ingestion also possible
- Pollutant Concentrations
  - Dust cloud exposure, home and workplace dust exposure
  - Proximity to WTC site - collapsing buildings
  - Atmospheric dispersion patterns and building canyon effect
- Onset and Duration of Exposure
  - Rescue and Recovery Workers:
    - Work on 9/11, 9/12, 9/13-17, 9/18-12/31/01, 1/1/02-6/30/02
    - # of days worked at WTC site, # of hours / day – 12 hour shifts common among workers, use and adequacy of respiratory protection
  - Residents, area workers and students:
    - Evacuation, date of return, building condition, thickness of settled dust
  - Passersby: Location, time of exposure to dust cloud
Pollutants of Interest - Dusts

- Major dust components - gypsum, concrete, wood, paper, and man-made mineral fibers (MMMF)
- Lesser dust components – chrysotile (0.8-3.0% of mass), 99% of dust mass consisted of particles with largely upper airway deposition.
- pH 9-11

Single-walled and multi-walled carbon nanotubes found in dust and lung biopsies of workers with interstitial lung disease – Wu 2010

Photomicrograph of settled dust from the WTC containing cement particles and MMMF fibers, collected 9/12/2001. – Landrigan P 2004
History of WTCHR

Largest US effort to monitor health after a disaster

- **2002**: Launched as an exposure registry
  - Funding from FEMA, ATSDR cooperative agreement

- **2003-04**: Wave 1 Survey
  - 30-minute telephone interview by RTI on health & exposures
  - 71,437 enrolled, including >3,000 children

- **2006-08**: Wave 2 Survey
  - Course of symptoms, emerging conditions, unmet healthcare needs,
    - Respiratory protection type, training, cleaning of respirators
    - Clarification of dust cloud experience, home cleaning details
  - 46,322 adults participated (68.1% response rate)
  - 1,022 parent proxies responded for children (50.1% response rate)

- **2011-12**: Wave 3 Survey (NIOSH funded)
  - All enrollees, with focused recruitment on non-participants in W2
Eligibility Groups
Highly Exposed by Time and Place

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building occupants &amp; passers-by south of Chambers St. on 9/11</td>
<td>43,487</td>
<td>12.0%</td>
</tr>
<tr>
<td>Rescue/recovery workers &amp; volunteers at the site (9/11/01 to 6/30/02)</td>
<td>30,665</td>
<td>33.5%</td>
</tr>
<tr>
<td>Residents south of Canal St. on 9/11</td>
<td>14,665</td>
<td>25.5%</td>
</tr>
<tr>
<td>Children &amp; staff in schools (pre K–12) south of Canal St. on 9/11</td>
<td>2,646</td>
<td>17.4%</td>
</tr>
</tbody>
</table>

Exposed individuals *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)
- Pre-registration list building
- Requested lists of names from employers/volunteer orgs
- Identified residents through publicly available directories
- Obtained 273 lists with >135,000 potential enrollees

Self-identified (70% of enrollees)
- Extensive media awareness & outreach campaigns
- Newspaper, bus, subway, ferry ads
- Letters to parents of school children
- Interviews, presentations & brochure stands, visits to FDNY firehouses, NYPD roll calls
- Toll-free telephone number and web site

“We need to know about the long-term health effects of 9/11.”

Murphy J 2006
Types of Health Data

- Self-reported exposure history
- Reported health conditions, pre- and post-disaster
- Reported symptoms between 9/11/01 and W1
- Reported symptoms in month prior to W2
- Cancer – via self-report and periodic matching to state cancer registries
- Mortality – via proxy reports and periodic matching to National Death Index, SS Administration
- Hospitalization – In the future, via matching to state hospital discharge data
Wave 1 Results: Asthma

- 926 workers reported new asthma diagnosis after 9/11
  - Higher for work on pile
  - 3.6% 3-year risk (adult population rate- 0.3%)
  - PPE and Asthma Cumulative Incidence
    - 4.9% among those using masks immediately
    - 15.7% among never-users of masks/respirators
    - Highest among those arriving 9/11, working longest

Wheeler et al., 2007
Farfel et al., 2008
Wave 1 Results: PTSD

- PTSD Prevalence 16.3%
  - 14.2% in Rescue/Recovery Workers
  - 15.5% in Lower Manhattan residents
  - 19.4% in Building Occupants
  - Varied by occupation (7.2%-24.7%), tasks performed
  - Risk factors
    - Dust cloud exposure, witnessing horror, injury, late evacuation
    - Older age, female, Hispanic, low income

Perrin et al., 2007, DiGrande et al., 2008, Bowler 2010
Wave 2 Results - Asthma

By 2006-07, new asthma diagnosed in 12.2% of rescue/recovery workers, 8% of others

– Annualized incidence declined from 3% after 9-11 to < 1%
– Intense dust cloud exposure consistently associated with post 9-11 asthma in all eligibility groups, OR ~ 1.4

Brackbill et al., 2009
Wave 2 Results: PTSD

- 23.8% with no prior PTSD history had PTSD symptoms at either Wave 1 (14.3%) or Wave 2 (19.1%)
  - Prevalence at Wave 2 was greatest in passersby (23.2%), lowest in residents (16.3%). Prevalence among women (20%) higher than men (14%).
  - Prevalence at both Waves = 9.6%
- Risk factors similar for both asthma and PTSD
  - Intense dust cloud exposure
  - Sustaining an injury on 9/11
  - Witnessing horror
  - Post-9/11 job loss, bereavement, lack of social support

Brackbill et al., 2009
Lessons Learned

• Establishing an exposure registry of this magnitude required:
  – Close coordination between governmental agencies at the local and federal level
  – Multiple institutional review board approvals
  – Timely development of eligibility criteria and questionnaires
  – Extensive outreach
  – Multimodal data collection
  – Advisory groups provided ongoing input on research and outreach activities:
    • Scientific, Community, Labor
Lessons Learned

• Challenges in development and implementation:
  – Incomplete or absent exposure data for defining eligibility for inclusion
    • No personal or area environmental monitoring data on 9/11 - extent of exposure to dust from collapse of buildings is unknown
    • Geographical boundaries of Canal Street for residents, Chambers Street for those passersby or area workers on 9/11 easily understood but controversial
  – Suspicion of governmental response to the disaster
    • Release findings as soon as possible
    • Transparency through community and labor advisory committees. Earlier in the process is better.
    • Broad dissemination of reports
      – web and mailed reports
Lessons Learned - Maintenance

- Periodic tracing is needed to maintain up-to-date contact information
- Timely communications & feedback essential to address enrollees’ concerns and keep them engaged
- Core funding – periodic surveys, maintaining contact with enrollees
- External funding for in-depth studies and interventions to respond to enrollee concerns
Lessons Learned: Keep stakeholders informed

• Publish results
  – Balance overview publications with reports of results of more analytic studies, results from subgroup analyses
  – Translate into clinical guidelines, updates

• Meet with stakeholders regularly
  – WTCHR scientific, labor and community advisory groups meet 3-4 times per year
  – Outreach to community boards, etc.
  – Public meeting presentations
Lessons Learned

• Keep results accessible
  - Public Access Database
  - Interactive web application (EpiQuery)

• Establish an institutional home with adequate resources for:
  - Longitudinal research (in-house scientists, statistical, and epidemiologic expertise, access to consultants)
  - Cohort maintenance
  - Core communications with enrollees, advisors and the public