

World Trade Center Health Registry

Session 3:
Lessons learned from setting up
population monitoring registries

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Registry at a Glance

- Closed cohort of 71,434 exposed people who voluntarily enrolled for long-term (20+ years) follow-up via health surveys every 3 to 4 years
- Expanded data gathering for research
 - Matching with administrative databases
 - Nested/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

WTC 9/11 Exposures



Dust, smoke, fumes containing complex mixture of volatile chemicals, respirable particulate materials, pulverized building components and suspected or known carcinogens (asbestos, silica, benzene, polycyclic aromatic hydrocarbons, VOCs, metals)

Psychological exposures, e.g., witnessing traumatic events, loss of coworker/family member, perceived life threat

Registry History

- Conceived at NYC DOHMH shortly after 9/11/01
- DOHMH received initial funding/administrative support from ATSDR, FEMA and EPA for an exposure registry (7/2002)
- Hired vendors, obtained IRB approvals, conducted extensive outreach for recruitment (2002-03)
- Conducted enrollment and Wave 1 interviews on 9/11 experiences/exposures and health (2003-04)
- Conducted Waves 2-4 and 5 nested surveys (2005-18)

Funded by NIOSH since April 2009
cooperative agreement U50-OH009739

Eligibility Groups

Highly Exposed by Time and Place

<u>Group</u>	<u>N</u>
Rescue/recovery workers & volunteers at the site (9/11/01 to 6/30/02)	30,665
Building occupants & passers-by south of Chambers St. on 9/11	43,487
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

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

Snapshot of Registry Findings

- Enduring adverse impacts of 9/11 on physical and mental health of responders and community survivors
- Most common health outcomes: PTSD, depression, asthma, GERD symptoms, and co-occurring conditions
- Co-occurring conditions are associated with reduced QOL, functioning and greater unmet health care needs
- Other conditions associated with 9/11-exposure:
 - heart disease, stroke, sarcoidosis, hearing loss, smoking/alcohol use, health-related early retirement, adverse birth outcomes, adolescent behavior changes

Setting up the Registry Scientific Challenges

- Establishment of inclusion and exclusion criteria
- Limited documentation of contaminants & exposures early post-9/11 for relating to longer-term outcomes
- Lack of non-exposed comparison groups

Setting up the Registry

Socio-political Challenges

- Distrust of government impeded:
 - ✓ Gaining input/support from stakeholders (community, labor, city agencies, business entities/employers) for protocol development and recruitment outreach
 - ✓ Coordinating research agendas and methods across the 9/11 exposed cohorts
- Cross-agency collaboration
- Competition for disaster research funding

Setting up the Registry Administrative Challenge

- Obtaining timely approvals from three different IRBs
 - DOHMH
 - CDC
 - Vendor IRB (RTI)

Setting up the Registry

Enabling Factors

- DOHMH leadership understood the need for a Registry
- High level of scientific capacity in DOHMH workforce
- Strong political will to secure funds
- Federal partner with:
 - Experience creating registries (ATSDR)
 - Ability to quickly secure a vendor for cohort formation
- Obtaining a federal certificate of confidentiality early on