

# World Trade Center Responders Fatality Investigation Program - Methodologic Issues

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# Background



- Funded by CDC/NIOSH in September 2006 to maintain a registry of WTC responders who died after 9/11
  - Multiple studies have demonstrated health effects and symptoms in WTC response workers
  - No studies have examined fatalities occurring among response workers

# WTC Programs

- **WTC Health Registry**
  - Voluntary for people who lived, worked or went to school in the area of the WTC disaster, or were involved in rescue and recovery efforts
  - Approximately 31,000 responders
- **Medical Monitoring and Treatment Programs**
  - Voluntary for responders/workers, except FDNY
  - Approximately 40,000 responders

# Inclusion Criteria

- Death occurred between 9/12/2001 – 6/30/2009
- Included first responders, workers and volunteers
- Worked at Ground Zero, the secure/exclusion zone, the morgue or waste stream corridor including the Fresh Kills landfill between 9/11/2001 – 6/30/2002

***Criteria identical to WTC  
HR***



# Immediate Issues

- No record of who responded, volunteered, or worked at site – **NO COHORT**
- No idea of the number of workers – **NO DENOMINATOR**
  - WTC HR estimated worker population using employer rosters, government agencies, unions, etc.
  - Estimated 91,469 workers
  - Medical monitoring and treatment programs estimate 60,000 – 70,000 workers

# Methods to identify deceased

- Conducted daily internet searches using key words such as “Ground Zero”, “WTC”, “World Trade Center” and “9/11”
  - of online newspapers in NJ, CT, NY and eastern PA;
  - used national obituary search engines
- Partnered with WTC Health Registry; Attorney; WTC Medical Monitoring and Treatment Program; FDNY for data sharing
- Contacted over 200 groups including unions, attorneys, worker advocacy organizations, NYS Sheriffs, ambulance services & fire companies; coroner/medical examiners, and companies that responded

# Source of First Report

	N	%
Newspaper/Obituary	363	44.6
Attorney	150	18.4
WTC Health Registry	224	27.5
Unions	27	3.3
Other	50	6.1

# Data Collected

- **Full death certificate** for confirmation of death and cause of death
- **Interviews** with personal representative of the estate on all non-traumatic/non-suicide fatalities that occurred since 1/1/2006
- **Medical records** from pertinent post-9/11/01 clinical visits, employee health exams, and doctor visits up to 2 years prior to 9/11/01
- **Autopsy results** including toxicologic results and ME notes
- **Employers** for confirmation of exposure

***Multi-state study meant multiple Human Subjects Review***



# Analyses

- Conducted Proportionate Mortality Ratios (PMRs), Standardized Mortality Ratios (SMRs), and Proportionate Cancer Mortality Ratios (PCMRs)
  - Used PCMRs to compensate for an unusually high rate of deaths due to cancer
- Cause of death data is delayed from NCHS – only available until 2006
  - Extrapolated cause of death data from 2006 for 2007 – 2009 using predicted values based on time trends from 1999 through 2006

# Analyses

- No similar worker/volunteer population to compare rates to
- Used 3 comparison populations standardized for age and sex:
  - US General Population
  - New York City Region – 16 counties including and surrounding NYC where 61% of identified deaths occurred
  - New York City

# Denominator???

- Created sample cohort of 91,469 by extrapolating start dates at WTC, ages and sexes of the 30,665 responders in the WTC Health Registry population
- Compared demographics of WTC HR cohort of FDNY employees to FDNY WTC cohort
  - Were not similar

***Strong possibility that WTC HR cohort is not representative of the WTC responder population***

# Outcomes

- Used NCHS list of 113 selected causes of death
  - Analyses were conducted only on those categories in which there were at least 5 deaths (n=42)
- *A priori* hypotheses:
  - Cancers due to colon, kidney, brain, NHL, multiple myeloma
  - Cardiovascular diseases, specifically hypertensive disease, ischaemic heart disease and cerebrovascular disease
  - Use of alcohol/drugs and injuries/poisonings

# Other Analyses

- Calculated estimates of “true” number of deaths
  - Capture-recapture analyses comparing 4 different sources of reports
    - Media, Attorney, WTC HR, Other
  - Applied expected general US mortality rates to the generated random sample

# Results

- 836 deaths met the inclusion criteria
  - Obtained death certificates for 785
  - Cause of death confirmed for another 29 individuals
  - Cause of death confirmed for **814 deaths**
- Deaths identified in 42 states
  - 38% in NYC
  - 22% in rest of NYS
  - 11% in NJ
  - 3% outside of US

# Characteristics of the confirmed responder deaths

	N	%
Sex		
Male	710	87.2
Female	104	12.8
Industry at WTC		
Fire department	125	15.4
Law enforcement	125	15.4
Government	154	18.9
Volunteer	129	15.8
Medical / EMS	54	6.6
Construction	146	17.9
Other	67	8.2
Missing	14	1.7

# Characteristics of the confirmed responder deaths

	N	%
Age at death		
<25	7	0.9
25-44	214	26.2
45-64	480	59.0
65+	113	13.9
Year of death		
2001	6	0.7
2002	37	4.5
2003	52	6.4
2004	112	13.8
2005	128	15.7
2006	148	18.2
2007	155	19.0
2008	127	15.6
2009	49	6.0



# SMRs

Cause of death	US General Population		NYC Region		NYC	
	N	SMR (95% CI)	N	SMR (95% CI)	N	SMR (95% CI)
Overall	814	0.31 (0.29 - 0.33)	510	0.39 (0.36 - 0.43)	311	0.39 (0.35 - 0.43)
Viral hepatitis	6	0.25 (0.09 - 0.54)	5	0.25 (0.08 - 0.59)	5	0.29 (0.09 - 0.67)
Human immunodeficiency virus disease	10	0.19 (0.09 - 0.34)	8	0.14 (0.06 - 0.27)	4 <sup>b</sup>	0.06 (0.02 - 0.16)
Cancers	342	0.58 (0.52 - 0.64)	222	0.70 (0.61 - 0.79)	129	0.68 (0.57 - 0.81)
Lip, oral cavity and pharynx	5	0.34 (0.11 - 0.79)	3 <sup>b</sup>	0.42 (0.09 - 1.24)	2 <sup>b</sup>	0.41 (0.05 - 1.47)
Esophageal	16	0.68 (0.39 - 1.10)	12	0.97 (0.50 - 1.69)	8	1.25 (0.54 - 2.46)
Stomach	9	0.62 (0.29 - 1.18)	7	0.57 (0.23 - 1.17)	4 <sup>b</sup>	0.51 (0.14 - 1.30)
Colon, rectum and anus	27	0.49 (0.33 - 0.72)	19	0.59 (0.36 - 0.92)	13	0.68 (0.36 - 1.16)
Liver and bile duct	15	0.47 (0.26 - 0.77)	11	0.48 (0.24 - 0.86)	9	0.48 (0.22 - 0.92)
Pancreatic	25	0.69 (0.45 - 1.01)	18	0.89 (0.53 - 1.41)	8	0.66 (0.28 - 1.29)
Larynx	5	0.83 (0.27 - 1.93)	4 <sup>b</sup>	0.88 (0.24 - 2.26)	1 <sup>b</sup>	0.30 (0.01 - 1.69)
Trachea, bronchus and lung	88	0.53 (0.42 - 0.65)	55	0.78 (0.59 - 1.02)	31	0.80 (0.54 - 1.13)
Melanoma of the skin	10	0.68 (0.33 - 1.25)	6	1.04 (0.38 - 2.26)	2 <sup>b</sup>	1.11 (0.13 - 4.01)
Breast	10	0.36 (0.17 - 0.66)	3 <sup>b</sup>	0.18 (0.04 - 0.51)	1 <sup>b</sup>	0.08 (0.00 - 0.44)
Ovary	5	0.60 (0.19 - 1.40)	4 <sup>b</sup>	0.83 (0.23 - 2.13)	3 <sup>b</sup>	0.96 (0.20 - 2.80)
Prostate	8	0.52 (0.22 - 1.02)	3 <sup>b</sup>	0.41 (0.08 - 1.19)	3 <sup>b</sup>	0.77 (0.16 - 2.25)
Kidney and renal pelvis	12	0.72 (0.37 - 1.26)	9	1.26 (0.58 - 2.39)	5	1.35 (0.44 - 3.15)
Bladder	7	0.68 (0.27 - 1.40)	2 <sup>b</sup>	0.42 (0.05 - 1.51)	2 <sup>b</sup>	1.12 (0.14 - 4.04)
Meninges, brain and other parts of central nervous system	19	0.78 (0.47 - 1.22)	15	3.14 (1.76 - 5.17)	10	1.20 (0.57 - 2.20)
<u>Lymphoid, hematopoietic and related tissue</u>	49	0.93 (0.69 - 1.23)	32	0.97 (0.66 - 1.37)	13	0.62 (0.33 - 1.06)
Non-Hodgkins lymphoma	18	0.99 (0.59 - 1.57)	15	1.22 (0.69 - 2.02)	6	0.70 (0.26 - 1.52)
Leukemia	20	0.91 (0.56 - 1.40)	10	0.82 (0.39 - 1.50)	4 <sup>b</sup>	0.63 (0.17 - 1.61)
Multiple myeloma and immunological	8	0.82 (0.35 - 1.61)	5	0.91 (0.29 - 2.11)	2 <sup>b</sup>	0.52 (0.06 - 1.87)
All other and unspecified malignancies	32	0.43 (0.29 - 0.60)	19	0.44 (0.27 - 0.69)	14	0.64 (0.35 - 1.07)
Diabetes mellitus	10	0.12 (0.06 - 0.22)	4 <sup>b</sup>	0.09 (0.02 - 0.23)	3 <sup>b</sup>	0.12 (0.02 - 0.34)
Cardiovascular disease	145	0.23 (0.19 - 0.27)	95	0.29 (0.23 - 0.35)	62	0.28 (0.21 - 0.36)
Hypertensive heart disease	10	0.20 (0.10 - 0.37)	9	0.22 (0.10 - 0.42)	6	0.14 (0.05 - 0.31)
Acute myocardial infarction	26	0.22 (0.14 - 0.32)	17	0.42 (0.25 - 0.68)	10	0.44 (0.21 - 0.81)

# PCMRs

	US General Population		NYC Region		NYC	
	N	PCMR	N	PCMR	N	PCMR
Lip, oral cavity and pharynx	5	1.09 (0.35 – 2.54)	3	1.23 (0.25 – 3.59)	2	1.08 (0.13 – 3.91)
Esophageal	16	1.04 (0.60 – 1.69)	12	1.40 (0.72 – 2.45)	7	1.79 (0.72 – 3.70)
Stomach	9	1.47 (0.67 – 2.79)	7	1.34 (0.54 – 2.77)	4	1.60 (0.44 – 4.10)
Colon, rectum and anus	27	0.62 (0.41 – 0.90)	19	0.64 (0.39 – 1.00)	13	0.89 (0.47 – 1.52)
Liver and bile duct	15	0.69 (0.39 – 1.14)	11	0.68 (0.34 – 1.22)	9	1.05 (0.48 – 2.00)
Pancreatic	25	1.24 (0.80 – 1.83)	18	1.40 (0.83 – 2.21)	8	2.04 (0.88 – 4.02)
Larynx	5	3.42 (1.11 – 7.99)	4	2.67 (0.73 – 6.83)	1	5.26 (0.13 – 29.32)
Trachea, bronchus and lung	88	0.56 (0.45 – 0.69)	55	0.68 (0.51 – 0.89)	31	0.85 (0.58 – 1.21)
Melanoma of the skin	10	1.61 (0.77 – 2.96)	6	3.41 (1.25 – 7.42)	2	8.70 (1.05 – 31.41)
Breast	10	0.90 (0.43 – 1.65)	3	2.05 (0.42 – 6.00)	1	1.12 (0.03 – 6.26)
<b>Ovary</b>	<b>5</b>	<b>3.55 (1.15 – 8.28)</b>	<b>4</b>	<b>5.88 (1.60 – 15.06)</b>	<b>3</b>	<b>9.09 (1.87 – 26.57)</b>
Prostate	8	2.09 (0.90 – 4.12)	3	2.11 (0.44-6.17)	3	2.65 (0.55 – 7.76)
Kidney and renal pelvis	12	1.63 (0.84 – 2.85)	9	3.90 (1.78 – 7.40)	5	12.82 (4.16 – 29.92)
Bladder	7	3.18 (1.28 – 6.56)	2	2.63 (0.32 – 9.51)	1	6.67 (0.17 – 37.14)
Meninges, brain and other CNS	19	0.79 (0.48 – 1.23)	15	4.87 (2.73 – 8.03)	10	2.01 (0.96 – 3.70)
Lymphoid, hematopoietic tissue	49	0.82 (0.61 – 1.09)	32	0.84 (0.58 – 1.19)	13	0.80 (0.42 – 1.36)
Non-Hodgkins lymphoma	18	1.30 (0.77 – 2.06)	15	1.32 (0.74 – 2.18)	6	1.12 (0.41 – 2.43)
Leukemia	20	1.40 (0.85 – 2.16)	10	1.77 (0.85 – 3.25)	4	1.69 (0.46 – 4.34)
<b>Multiple myeloma and immun.</b>	<b>8</b>	<b>5.59 (2.42 – 11.02)</b>	<b>5</b>	<b>12.82 (4.16 – 29.92)</b>	<b>2</b>	<b>12.5 (1.51 – 45.15)</b>

# Estimated Population Size

- Capture – recapture analysis:
  - 1,567 deaths
  - 53% missing
- Expected general US mortality rates:
  - 3,135 deaths
  - 73% missing

# Limitations

- No record of who responded
  - Unknown how many responders were there
  - Used WTC Health Registry estimates
    - These differ from other researchers
    - Demographics of enrollees don't match demographics of decedents
- Incomplete death ascertainment
  - Results of PMR analyses unreliable
  - Reduced results from SMRs
  - Identified deaths may not be representative of all deaths

# Limitations - Continued

- Expect that as the responder population ages, the number of deaths occurring each year would increase
  - Had a decrease in number of deaths for 2008 and half of 2009
    - Lack of NDI matches (used by WTC Health Registry)
    - Less mention of WTC work in obituaries

# Limitations - Healthy Worker Effect

(mortality rates in a working population are lower than the general population)

- More apparent among those in physically demanding occupations or in occupations with specific physical fitness requirements in hiring practices
- An inappropriate comparison population can contribute to this
  - Used 3 comparison populations, but all were general citizens, not just workers

# What did we learn?

- Disasters pose methodological challenges since systems are not in place to adequately track exposures or health outcomes before, during or after the disaster
  - Study designs examining health impacts can deviate from traditional epidemiology
  - WTC RFI was an attempt at developing a mortality registry relying primarily on observational research design

# Where do we go from here?

- Need identification of the majority of responders
  - Will miss a substantial number of survivors who carry out most of the initial disaster response and those responders who are self-dispatched
- Need cohesive human subjects review process that allows for medical and exposure information to be shared between researchers studying the same population
- Recommend WTC programs conduct NDI matching of their cohorts using internal comparisons





**Questions?**