An Analysis of Nonresponse Bias in the World Trade Center Health Registry

Presented by

Joe Murphy, M.A. ¹, Robert Brackbill, Ph.D. ²,³, James H Sapp II, M.S. ³,
Lisa Thalji, M.A.,¹, Paul Pulliam¹

¹RTI International; ²New York City Department of Health and Mental Hygiene;
³Agency for Toxic Substances and Disease Registry

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Outline

• Background and purpose of the Registry
• Exposure groups and eligibility
• Study design and nonresponse issues
• Gauging nonresponse bias and adjusting
• Conclusions and take-home lessons
What is the World Trade Center (WTC) Health Registry?

- Database for following people most exposed to the September 11, 2001 WTC disaster
- Joint effort of the New York City Department of Health and Mental Hygiene (NYC DOHMH) and the federal Agency for Toxic Substances and Disease Registry (ATSDR)
- RTI International contracted to assist with all aspects of Registry building
- Funded by the Federal Emergency Management Agency (FEMA)
What is the World Trade Center (WTC) Health Registry?

- Largest environmental exposure registry in the United States
- Evaluate potential short and long-term physical and mental health effects of exposure
- Provide data for more in-depth studies on selected subpopulations and specific issues
- Completed baseline enrollment phase in November, 2004
- 71,437 people enrolled and completed 30-minute baseline health interview over the phone or in-person
- Plan is to follow individuals for the next 20 years
Registry Health Interview

To enroll, potential registrants were asked to report on:

- Demographic information
- Their location on 9/11
- What they saw
- Exposure to dust, smoke, and debris
- Amount of time before returning to work or home
- Physical health before and after 9/11
- Mental health before and after 9/11
- Contact information to assist with future follow-up
Eligibility Criteria

Eligible population includes those who may have been present in lower Manhattan on the morning of 9/11 when the two towers collapsed or in the subsequent dust/debris

- Rescue, recovery, and cleanup workers and volunteers
- Residents
- Students and school staff
- Building occupants, people in transit, and pedestrians
Eligibility Boundaries
Businesses in Damaged or Destroyed Buildings and Structures
Eligible Population Split into Two Priority Groups

For sample building purposes, the broadly defined exposure types were separated into two groups:

Group 1: High priority exposed persons

 Individuals who had relatively high levels of exposure to the environmental effects of the disaster

Group 2: Lower priority exposed persons

 Individuals who may have had lower levels of exposure or who were more difficult to identify in advance, such as passersby on the street south of Chambers on 9/11
Recruitment Methods for Priority Groups

Group 1: Enrolled via active tracing and contacting
- Rescue, recovery, and cleanup workers and volunteers
- Residents south of Chambers Street
- Students and school staff south of Canal Street
- Occupants of 35 damaged or destroyed buildings and 3 damaged structures

Group 2: Enrolled primarily via self-identification
- Residents between Canal and Chambers Streets
- Building occupants, people in transit, and pedestrians south of Chambers (not in damaged/destroyed buildings)
Study Design

Attempt to locate and interview all exposed persons

- >360,000 individuals
- Sample records obtained from multiple (>200) lists
- Eligible individuals could also self-identify
- Purpose of building a sampling frame for future studies

Unequal representation

- Unequal likelihood of being included on lists
- Self-selection bias
- Nonresponse bias
Bias

Differences between those who enrolled and those who did not need to be considered in relation to exposure and health outcomes.

- Responders or those with the highest propensity to respond may be different from nonresponders in terms of exposure or outcome differences.
- For example, people who believe they experienced a dangerous exposure may over report health symptoms.
Research Questions

1) Is nonresponse bias sufficient to alter results differentially among sample types?

2) Can nonresponse adjustment weights be computed simply to address this and provide indication of the direction and degree of the bias by sample type?
Data Description:
1. Process Measures

- Measures available for both responders and nonresponders in the sample database
- Can be used to calibrate respondent data to match sample marginals
  - List source vs. self-identification
  - Number of calls
  - Percent of calls with a human contact
  - Ever refused to be interviewed
Data Description:
2. Population Measures

- Data available for responders and the true eligible population.
- Can be used to adjust sample data to match population marginals
  - Workers and Volunteers
    - FDNY, NYPD, Dept. of Sanitation, other
  - Residents
    - age, gender, race/ethnicity, ZIP Code
  - Students/Staff
    - public school, private school, preschool/daycare
  - Building Occupants
    - in the WTC Towers on 9/11 (yes/no)
For this paper, we look at just a few examples

- New or worse cough since 9/11
- New or worse breathing problems since 9/11
- New or worse depression since 9/11
Example: Process Data for Workers – Sample distribution

- Overall
- Did not Self-Identify
- Did Self-Identify
- 0-1 Calls
- 2-6 Calls
- 7 to 29 Calls
- 30 or More Calls
- 0-49% Human Contact
- 50-100% Human Contact
- Never Refused
- Ever Refused
Example: Process Data for Workers – Percent interviewed
Example: Process Data for Workers – Percent with new/worse cough since 9/11
Example: Process Data for Workers – Percent with new/worse breathing problems since 9/11
Example: Process Data for Workers – Percent new/worse depression since 9/11

[Bar chart showing the percentage of new/worse depression among workers in different categories, such as number of calls and percentage of human contact, with bars indicating the percentage for each category.]
Adjustment Method

Raking ratio estimation (Kalton, 1983; Creel, 2005)

- Adjusts data so marginal totals match specified control totals on a specified set of variables (Battaglia, et al., 2004)
  - Step 1: Process data used to adjust respondent data to sample marginals
  - Step 2: Population data used to adjust sample data to population totals
- We used the IHB raking macro in SAS (Izreal, et al., 2004)
Raking

Population

Sample
Raking Population Sample
Raking

Population

Sample
Raking

Population

Sample
Raking

Population

Sample
Raking

Population

Sample
Raking

Population

Sample
Raking

Population

Sample
Identify raking variables via logistic regression predicting response (Farooque et al., 1999)

- We only want to include variables that have some correlation with nonresponse, controlling for other factors, to assure meaningful adjustments.

- Example model for process data
  - Response = Ever Refused + # Calls + % Human Contact + Self-Identified

- Use variables with significant correlation to response for raking adjustments
Logistic regression results

## True Eligible Population

<table>
<thead>
<tr>
<th></th>
<th>Workers</th>
<th>Residents</th>
<th>Students</th>
<th>Occupants</th>
<th>Residents</th>
<th>Occupants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>91,469</td>
<td>20,160</td>
<td>9,971</td>
<td>47,228</td>
<td>28,942</td>
<td>167,496</td>
</tr>
<tr>
<td>Group 2</td>
<td>28,942</td>
<td>167,496</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Eligible+Indeterminate Eligible Sample

<table>
<thead>
<tr>
<th></th>
<th>Workers</th>
<th>Residents</th>
<th>Students</th>
<th>Occupants</th>
<th>Residents</th>
<th>Occupants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>46,792</td>
<td>14,663</td>
<td>2,445</td>
<td>32,297</td>
<td>16,314</td>
<td>19,322</td>
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<tr>
<td>Group 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Odds Ratios

<table>
<thead>
<tr>
<th>Metric</th>
<th>Workers</th>
<th>Residents</th>
<th>Students</th>
<th>Occupants</th>
<th>Residents</th>
<th>Occupants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever Refused</td>
<td>0.18</td>
<td>0.18</td>
<td>0.28</td>
<td>0.09</td>
<td>0.69</td>
<td>0.14</td>
</tr>
<tr>
<td># Calls</td>
<td>0.74</td>
<td>0.69</td>
<td>0.43</td>
<td>0.82</td>
<td>0.74</td>
<td>0.27</td>
</tr>
<tr>
<td>% Human Contact</td>
<td>3.17</td>
<td>3.82</td>
<td>2.22</td>
<td>2.25</td>
<td>2.98</td>
<td>2.98</td>
</tr>
<tr>
<td>Self-Identified</td>
<td>21.77</td>
<td>7.89</td>
<td>3.80</td>
<td>57.83</td>
<td>8.98</td>
<td>0.04</td>
</tr>
<tr>
<td>R-sq</td>
<td>0.35</td>
<td>0.33</td>
<td>0.27</td>
<td>0.38</td>
<td>0.21</td>
<td>0.08</td>
</tr>
</tbody>
</table>

All estimates significant at p<.001
Post raking: Adjusted rates for new/worse cough

Workers Residents Students/Staff Occupants Residents Occupants

Group 1  Group 2

Unadjusted
Raking to sample totals
Raking to population totals
Post raking:
Adjusted rates for new/worse breathing problems

Unadjusted
Raking to sample totals
Raking to population totals

Group 1
Workers
Residents
Students/Staff
Occupants

Group 2
Workers
Residents
Occupants
Post raking:
Adjusted rates for new/worse depression

Group 1

Group 2
Conclusions

1) Is nonresponse bias sufficient to alter results differentially among sample types?

- Yes, unadjusted estimates appeared inflated, in general.
- There appears to be more bias for sample types with high rates of self-selection (e.g. Group 2 Residents)
2) Can nonresponse adjustment weights be computed simply to address this and provide indication of the direction and degree of the bias by sample type?

• We believe we’ve demonstrated it can.
• More time and resources devoted to the issue could find most ideal method for addressing nonresponse and coverage issues in this and other registries.
• More direct measures from nonrespondents could be extremely informative and provide a more accurate picture of the direction and degree of bias.
• Analyses of WTC Health Registry should acknowledge that nonresponse bias is present and generally inflates health outcomes estimates to a modest degree. The effect is not constant across sample types.
Take-home lessons

• Adjustment weights for nonresponse can be computed and may be important to analysis. This paper provides an example of a cursory analysis that suggests a more detailed investigation may be warranted.
Information on the degree and direction of nonresponse bias can be obtained using methods like the ones used in this paper. They need not be extraordinarily complex at first, and are worth the effort, especially for surveys and registries allowing for self-identification.
References


More Information

For more information about the WTC Health Registry, please visit:

www.wtcregistry.org

For a copy of this presentation, please visit:

www.rti.org/jsm

Contact:

Joe Murphy – jmurphy@rti.org