

# An Update on the World Trade Center Health Registry: *Post-Enrollment Activities*

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Eleventh Meeting of the WTC Expert Technical Review Panel  
July 12, 2005

*Recap:*

# What is the World Trade Center Health Registry?

## World Trade Center Attack on September 11, 2001



Hundreds of thousands of people were exposed to:

- the dust and debris cloud
- witnessing traumatic events
- the indoor dust
- the fumes from persistent fires

# The World Trade Center Health Registry (WTCHR)

- The WTCHR was conceived as an imperative public health response to document and evaluate the impact of the disaster on a large and diverse population
- A collaborative scientific effort between NYC DOHMH and ATSDR
- Initial funding provided by FEMA, ATSDR and NYC DOHMH (*funding for out years is not yet secured*)
- Enrollment from September 5, 2003 – November 20, 2004
- Input from external scientific, community and labor advisors
- Largest health registry in U.S. history (over 71,000 enrollees)

# Role of Health Registries

- Create a roster of affected individuals - an “address book” – as a critical resource to be used for related research over time
- Track and investigate illnesses resulting from disasters and exposures
- Inform the public and medical sector of findings
- Create guidelines for preparedness and reduce possible injuries from future events
- Examples: Three Mile Island Registry (1979); Oklahoma City Bombing Registry (1995); Tremolite Asbestos Registry

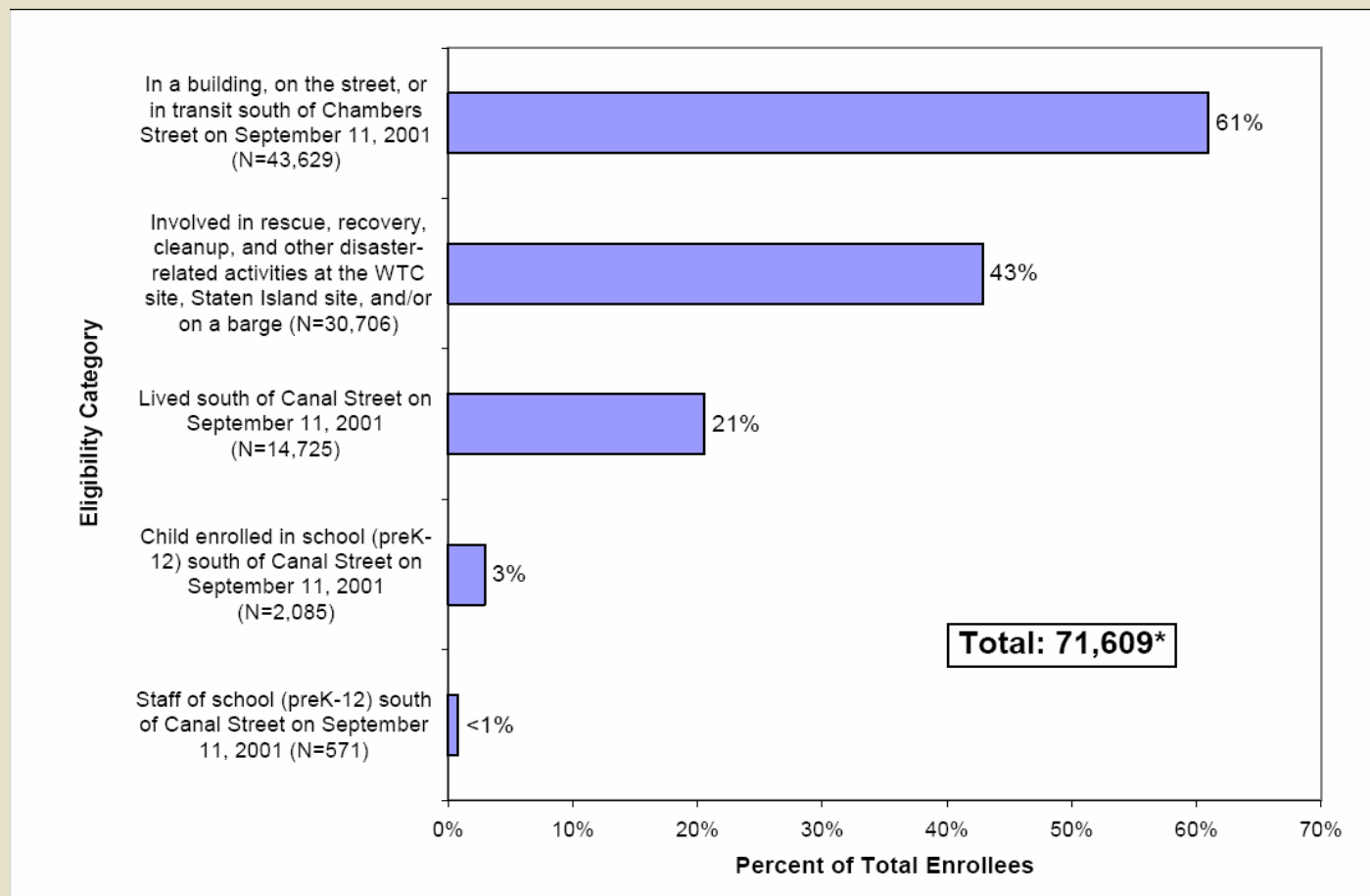
# World Trade Center Health Registry (WTCHR) Objectives

- To provide a means for long-term follow-up (20 years) of highly exposed persons
- To help document and evaluate the public health impact of the disaster on directly affected populations
- To ascertain short- and long-term physical and mental health effects associated with a wide range of exposures
- To facilitate specific follow-up studies and identify subgroups in need of in-depth study
- To identify public health needs (gaps) among registrants and the larger population of persons exposed to the WTC disaster

# *Post-Enrollment Overview*

# Enrollment

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*\* Approximately 25% of enrollees are in more than one exposure category; the sum of the percentages is thus greater than 100%. Graph represents completed live interviews.*

## Preliminary Health Findings\*\*

\*\*Of first 60,000 registrants

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- More than half adult enrollees (54%) reported new or worsened respiratory health symptoms following 9/11/2001:
  - Sinus problems/nose irritation/post nasal irritation (47%)
  - Shortness of breath (42%)
  - Wheezing (38%)
  - Throat irritation (38%)
  - Persistent cough (37%)
- At the time of the interview, adult enrollees reported higher rates of psychological distress than the citywide average:
  - WTCHR enrollees (8%)
  - 2003 NYC Community Health Survey (5%)

# Publication of Preliminary Health Findings

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## DATA SNAPSHOT UNDERSTANDING THE HEALTH IMPACT OF 9/11

NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE NOVEMBER 2004 VOLUME 2, 1

### THE WTCHR QUARTERLY ENROLLMENT UPDATE DATA THROUGH FRIDAY, SEPTEMBER 10, 2004

This report is the fifth in a series providing updates on characteristics of World Trade Center Health Registry (WTCHR) enrollees. It is the first report to contain information on physical and mental health conditions reported by enrollees. This report summarizes the completed interviews of 61,087 people conducted from September 5, 2003 to September 10, 2004. Criteria for inclusion in the WTCHR include:

- People who were living south of Canal Street on 9/11/01
- People who were in a building, on the street, or on the subway south of Chambers Street on 9/11/01
- People involved in the rescue, recovery, clean-up and other disaster-related activities at the WTC site and/or WTC Recovery Operations on Staten Island any time between 9/11/01 and 6/30/02
- Children enrolled in schools (pre K-12<sup>th</sup> grade) or day care centers south of Canal Street on 9/11/01
- Staff employed or volunteering at schools (pre K-12<sup>th</sup> grade) or day care centers south of Canal Street on 9/11/01

While pre-registration of enrollees has ended, interviews are still being completed through November for persons who volunteered prior to the

and of pre-registration and active outreach. The next Quarterly Report in January will present final enrollment information.

This report includes an update on the number of enrollees by place of residence and eligibility criteria, as well as preliminary information on physical and mental health outcomes reported. Future analyses will explore the relationship between certain exposures (e.g. being in the dust cloud, or working at the WTC site) and health outcomes.

#### CHARTS AND FIGURES

- Figure 1. Place of Residence of Registry Enrollees
- Figure 2. Table of Enrollees by State of Residence on 9/11/01
- Figure 3. Local Map of Enrollees' Zip Code of Residence on 9/11/01
- Figure 4. Lower Manhattan Map of Enrollees' Census Tract of Residence on 9/11/01
- Figure 5. Proportion of People Enrolled in the WTCHR by Exposure Category
- Figure 6. Demographics of WTCHR Enrollees
- Figure 7. Injuries Sustained on 9/11/01 Among Enrollees
- Figure 8. New and Worsened Health Symptoms Following 9/11/01
- Figure 9. Psychological Distress in the 30 Days Prior to Interview

# Post-Enrollment Activities

- Data preparation and analysis
- Building productive long-term relationships with advisory groups
- Updating enrollee contact information
- Establishing a mechanism to review external research requests
- Preparing a long-term follow-up strategy
- Developing a follow-up questionnaire for early 2006 survey

## Post-Enrollment Activities (continued)

- Creating a public use dataset (de-identified data)
- Providing general information to enrollees and the public
- Responding to individual queries from enrollees
- Developing treatment-related resources

## Data cleaning and analysis

- Data preparation/recoding
- Key analysis and papers in preparation
  - Surveillance for injuries and physical health effects among WTC tower survivors (and survivors of damaged buildings)
  - Prevalence of probable PTSD among residents
  - Prevalence of probable PTSD among WTC tower survivors
  - Asthma and mental health distress among children

# Building productive long-term relationships with advisory groups

- Community Advisory Board (CAB)
- Labor Advisory Committee (LAC)
- Scientific Advisory Committee (SAC)

# Community Advisory Board (CAB) Successes

- **10/04:** Timely dissemination of WTCHR results **Ongoing**
- **1/05:** Improved sensitivity to concerns of non-English speaking registrants, such as non-endorsing cover letter (in English, Spanish and Chinese) in any external study solicitation packets sent to enrollees **Done**
- **1/05:** Expanded mental health questions in follow up. **Done (final version pending)**
- **4/05:** Advertise opportunities for research using WTCHR. CAB members stressed that many enrollees want to participate in future studies. **Pending (July/August)**
- **4/05:** Send health promotion materials to enrollees. **Ongoing**

# Labor Advisory Committee (LAC) Successes

- **12/04:** Added counts of enrollees by multiple eligibility categories and by uniformed services to quarterly report. **Done**
- **3/05:** Added additional LAC representation on external review committee. **Done.**
- **3/05:** Increased construction union representation in LAC. Assistance offered by LAC. **Pending**
- **6/05:** Expanded follow-up survey to include office worker cleaning exposure. **Pending (Planned for FU survey)**
- **6/05:** Distributed a lay person's abstract of external research proposals to all LAC members not just the Review Committee representative. **Done**

# Scientific Advisory Committee (SAC) Successes

- **12/04:** Made Quarterly Reports more informative for external researchers and enrollees. **Done**
- **3/05:** Changed scoring of external proposals, giving increased weight if researchers demonstrate labor and community support. **Done**
- **3/05:** Send internal DOHMH proposals also to the Review Committee. **Done**
- **6/05:** Expanded follow-up survey to add questions on health utilization, health insurance, changes in family and economic stability since 9/11, loss of loved ones on 9/11. **Pending (Planned for FU survey)**
- **6/05:** SAC member reports a very high response rate of completed surveys to first external research mailing to enrollees (tower survivors).

# Updating enrollee contact information

- Annual letter sent to all ~ 71,000 enrollees in Jan 2005
  - Prior estimates suggest that at least 5% may move per year (n=3550)
  - ~2,600 enrollees returned enclosed postcard with updated info
  - Updated information received from post office (n~100)
- WTCHR website Update Contact Information page
  - Enrollees (n~1,500 provided updated information to date)
- Updates received directly from enrollees (calls, emails) (n~300)
- Mass emails sent to all enrollees who provided email addresses (n~ 44,000) - quarterly reminders to update contact information

## Establishing mechanism to review external research requests

- Most enrollees (91%) provided consent at baseline to receive information about external studies
- Developed Guidelines for External Researchers
  - Researcher submits proposal with request for:
    - De-identified baseline data or
    - DOHMH to send information about their study to selected WTCHR enrollees
  - Proposals limited to medical, public health or other scientific research
- WTCHR Review Committee
  - 7 members (representatives from CAB,LAC,SAC, ATSDR & DOHMH)
  - Applications reviewed and scored for scientific value and the expected contribution to study participants and the community

## Preparing a long term follow-up strategy

Based on experiences shared by investigators from large successful health registries, DOHMH has developed the following plan:

- **Participant Tracing:** Search national mailing, telephone and other electronic databases to obtain up-to-date contact info
- **Follow-up:** Administer brief health surveys (every 2 years) to track physical and mental health status and identify subgroups for focused studies
- **Regular Feedback and Outreach:** Distribute newsletters, annual cards and emails to inform enrollees and sustain interest
- **Promotion of Registry Access:** Increasing the number of external scientific proposals and providing administrative support for approved external studies

## Developing the first follow-up survey

- Develop draft questionnaire
- Distribute draft questionnaire to WTCHR advisory groups for review and feedback
  - SAC: June, 2005
  - LAC: June, 2005
  - CAB: July, 2005
- Revise questionnaire
- Data collection: Beginning in early 2006 (6 month period)

## Highlights from the first follow-up survey

- Draft questionnaire includes the following topics:
  - general health
  - physical health symptoms and conditions
  - alcohol and tobacco use
  - mental health status and social support
  - additional questions on dust cloud exposure
  - union membership
  - health utilization practices
- Two additional modules:
  - Residents: cleaning questions
  - Occupants of buildings: evacuation and clean up questions

## Creating a public use dataset

- A tool for the public and external researchers
- De-identified data (to protect confidentiality)
- Early version will permit simple queries by users (e.g. frequencies of health symptoms/conditions by zip codes)
  - Queries will run live against the public use dataset
  - To be released on WTCHR website in early 2006
- Downloadable dataset and resources will be available later

# Providing information to enrollees and the public

- WTCHR Website
- Quarterly Newsletters (n=7 to date)
  - Nov 2004: preliminary health effects
  - Jan 2005: final enrollment characteristics
  - May 2005: new newsletter format
- Resource Guide
- Press Releases
- E-mail health promotional material (*flu shots, how to find a doctor, preventing childhood lead poisoning, etc.*)

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New York City Department of Health and Mental Hygiene  
Health & Mental Hygiene News — Volume 3, Number 10

## Health Bulletin: How to Find a Doctor



#23 in a series of Health Bulletins on issues of pressing interest to all New Yorkers

### A regular doctor or other health care provider can help you and your family stay healthy.

- People with a regular doctor are more likely to live longer and healthier lives.
- A doctor who knows you and your medical history is best able to provide the care you need, based on your specific health needs.
- You're more likely to feel comfortable with a doctor you see regularly, so you can talk about *any* health issue, including sexual health and alcohol and drug use.
- No one should have to go without medical care because they don't have money to pay for it – help is available!

#### How to Find a Doctor or Other Health Care Provider

If you **DO** have health insurance:

- Get a regular doctor through your health plan.
- Many health plans require you to choose a *primary care provider* as your regular doctor.

If you **DON'T** have health insurance:

- Many people and families qualify for free or low-cost government health insurance programs (see page 2).
- Other health insurance options are available for small businesses and working individuals (see [More Information](#)).
- Even if you don't qualify for insurance, you can still get good health care, regardless of your immigration status or ability to pay. Call 311 to find out how to get medical or dental care at a public hospital, child health clinic, or community health clinic.

#### How a Regular Doctor Can Help Keep You Healthy

The doctor you see for most of your medical care is called a *primary care provider*. This doctor will:

- Take your medical history and conduct physical examinations.
- Prescribe medications and give immunizations.
- Check your weight, cholesterol, and blood pressure regularly and help you keep them under control.
- Make sure you get important tests, such as screening to prevent cancer.
- Talk to you about your personal health risks and explain how to reduce them.
- Coordinate your health care and refer you to specialists when needed.

#### Steps You Can Take

1. Think about what kind of doctor you want.
  - Is the doctor experienced with your particular health conditions or needs?
  - Is the doctor board certified? (This means the doctor has special training and has passed an advanced exam in a particular area of medicine.)
  - Is the doctor highly rated by a person or group you respect?
  - Are you more comfortable seeing a woman or a man?
  - Are you more comfortable seeing a doctor who speaks your native language?
  - Does the doctor or a member of the staff give advice over the phone for common medical problems?
  - How long will you need to wait before you can get an appointment?
  - Can the doctor see people on short notice if you need care right away?
  - Are the doctor's office location and hours convenient for you?
2. Get a list of doctors to choose from.
  - If you have insurance, get a list of providers from your health plan.
  - Get a recommendation from a health care worker (such as a nurse).
  - Ask family, friends, or neighbors about their doctors.
  - Call the doctor referral service at the hospital of your choice.
3. Find out about the doctors on your list.
  - Call or visit and ask questions (see Step 1).
  - Ask if the doctor is a participating provider with your insurance plan and can take new patients.

Available in Spanish and Chinese call 311 or visit [nyc.gov/health](http://nyc.gov/health)  
Español: llame al 311 o visite [nyc.gov/health](http://nyc.gov/health)  
中文: 拨打 311 或访问 [nyc.gov/health](http://nyc.gov/health)



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## Developing treatment-related resources

- Updated resource guide
  - Just released, June 2005
  - Includes updated information on resources (n=53) in the tri-state area for people affected by 9/11:
    - occupational, respiratory and mental health facilities
    - environmental cleaning
    - scholarships
    - other health services
- Physician guidelines
  - To be released in Fall 2005
  - Will include suggestions for physicians providing care to people affected by the events of 9/11

## Responding to individual queries from enrollees

- Is my health problem related to 9/11? (n~ 500)
- Where can I go for medical treatment or for help with mental health issues? (n~325)
- Where can I obtain assistance (e.g., disability, unemployment, health insurance, financial)? (n~50)
- I've encountered problems applying for assistance (e.g. NYS workers compensation, Red Cross). (n~15)

## Future plans

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- Secure long-term funding for WTCHR
- Maintain long-term relationship with enrollees to sustain interest, reflect needs, and keep up-to-date contact
- Expand WTCHR research at DOHMH and by external researchers

## Limitations of WTCHR

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- Not all affected groups were eligible for enrollment
- Baseline survey had several limitations:
  - *Included only self-reported health conditions, no screening*
  - *Pre-9/11 mental health history not obtained*
  - *Severity of current physical symptoms not assessed*
  - *Health utilization questions not included*
  - *Union memberships not obtained*
  - *Additional detail on dust cloud exposure and resident/office cleaning needed*
- Routine follow up surveys will likely be based on self-report

## Strengths of WTCHR

- A large, defined population of affected individuals with diverse exposures has been established
- Many enrollees (30%) were recruited from lists with known denominators, reducing selection bias and allowing for estimates of population impact.
- Routine assessments of all enrollees will be obtained, through self-report surveys and data matches
- WTCHR is a roster of individuals from which subgroups may be reached for in-depth, specialized studies
- WTCHR is accessible to external researchers via review process

## Contact information

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### **World Trade Center Health Registry (WTCHR):**

[www.wtcregistry.org](http://www.wtcregistry.org)

email: [wtchr@health.nyc.gov](mailto:wtchr@health.nyc.gov)

Telephone: 212-442-1585

### **NYC Department of Health and Mental Hygiene (NYC DOHMH):**

<http://nyc.gov/health>

### **Agency for Toxic Substances and Disease Registry (ATSDR):**

[www.atsdr.cdc.gov](http://www.atsdr.cdc.gov)