

WORLD TRADE CENTER

HEALTH REGISTRY

ADOLESCENT FOLLOW-UP SURVEY 2007



Hello:

The World Trade Center Health Registry is a research project looking at how the WTC disaster affects people's health. A couple of years ago your parent or guardian answered questions for you on the World Trade Center Health Registry's initial interview. This year, as an older child (11-17 years old), you are able to answer some questions for yourself. We have put these questions in this Adolescent Booklet starting on page 2. During the next 15-20 years, we will ask you and the other 71,000 enrollees about your physical and mental health every 2-3 years.

Your parent or guardian will also be answering questions for us. These questions are in a separate booklet for parents and guardians.

The questions for you are about how you feel **now**. You will be asked about your physical health and your feelings. Some questions are about other things such as what happened to you on September 11, 2001. Filling out the survey will take you about 15 minutes. You don't have to answer a question if you don't want to or if you find it too troubling.

This study may not help you directly, but what we learn from the study may help other people.

We promise that the answers you provide will be kept as confidential as possible. If you feel upset or are having trouble getting along with others or are having trouble sleeping, we recommend you talk to your parents/guardians about how you feel. If you don't feel comfortable talking to your parents/guardians about how you are feeling, you can call a hotline called LifeNet (1-800-LIFENET) to talk to someone in private or get a referral through this free and confidential mental health service 24 hours a day, 7 days a week.

You do not have to complete this survey. It is voluntary. No one will be mad at you if you choose not to fill out this survey or if you don't answer all of the questions.

We thank you for being a part of the World Trade Center Health Registry.

Sincerely,

Thomas R. Frieden, M.D.,M.P.H.
Commissioner, NYC DOHMH

Mark Farfel, Sc.D.
Director, WTCHR
Principal Investigator, WTCHR

Robert Brackbill, Ph.D.,M.P.H.
Founding Principal
Investigator, WTCHR

1-866-NYC-WTCR

1-866-692-9827

Your answers are confidential.

SURVEY INSTRUCTIONS

Who should complete this survey?

You have received this survey because your parent or guardian enrolled you in the World Trade Center Health Registry and answered the questions for you in the Registry's first survey in 2003-2004. This first follow-up survey is designed to give adolescents an opportunity to tell us about their health and what they experienced by completing the enclosed booklet for adolescents.

There are two survey booklets. One is for your parent/guardian to complete. This booklet is the **ADOLESCENT BOOKLET**. It should be completed by you. We hope that you can complete this booklet by yourself. If you have difficulty understanding or answering some of the questions or feel more comfortable answering questions with someone else, you may ask your parent or guardian for help. You can also fill out the entire booklet together. Please remember to tell us how your booklet was completed by checking one of the boxes on the last page of this booklet.

How should this survey be completed?

Mark answers with an X or enter a number where appropriate. Answer questions based on your own experiences. Report all health issues, not just those that may be related to 9/11. Please pay careful attention to the wording of questions. For example, some questions ask about your health in the "last 30 days" or "last 12 months" or "last 4 weeks". For most of the questions in this survey, we are interested in ALL of your symptoms and experiences in the time frame specified, not just those that seem unusual or those that might be related to the events of September 11, 2001. For those questions where we do want to know specifically about symptoms that may be related to September 11, this has been noted in the instructions for those questions.

What if I get upset while answering questions?

Many people still get upset when thinking about 9/11. If you want to talk about your feelings, you can speak to your parent/guardian or call LifeNet (800-LIFENET), a confidential and free mental health referral and crisis hotline. It is available 24 hours a day, 7 days a week.

What do I do when I am done with my booklet?

For your privacy, you should place your completed booklet in one of the small envelopes that came in your packet. Your parent/guardian should complete the parent/guardian booklet on his or her own and place it in the other small envelope. Both envelopes should then be placed together in the large, postage-paid return envelope that came in the packet and mailed to:

WTC Health Registry, 116 John Street Rm 800, New York, NY 10038

In summary, the steps you should take to complete the survey are as follows:

Step 1: Read the cover letter and survey instructions.

Step 2: Complete your Adolescent Booklet.

Step 3: Place your booklet in the small envelope provided and seal it.

Step 4: You and your parent/guardian should each put your sealed envelopes into the pre-addressed, postage paid return envelope.

Step 5: Drop the return envelope into the mail.

If you have any questions about your rights as a WTCHR enrollee, please contact the New York City Department of Health and Mental Hygiene (NYC DOHMH) Institutional Review Board Chairperson, Dr. Olivette Burton, at 212-788-4438. If you have any questions about the Registry or the survey, please contact Registry staff at 212-442-1585, 1-866-NYC-WTCR (866-692-9827), or wtchr@health.nyc.gov. Your parent/guardian can also contact us for you.

ADOLESCENT FOLLOW-UP SURVEY 2007 – ADOLESCENT BOOKLET

Please read the survey instructions on the opposite page. Mark your answers with an "x" or provide a number.

1 What is your date of birth?

/ /
(Month / Day / Year)

2 What is your gender?

₁ Male
₂ Female

3 What is your name?

First Name: _____

Last Name: _____

4 Would you say that in general your health is:
(Choose ONE answer.)

₁ Excellent
₂ Very good
₃ Good
₄ Fair
₅ Poor

5 For Questions 5a through 5c, please answer the following questions for the last 30 days.

a. Thinking about your physical health, which includes physical illness and injury, for how many days during the last 30 days was your physical health not good?

Enter number of days OR None

b. Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the last 30 days was your mental health not good?

Enter number of days OR None

c. For how many days did poor physical or mental health keep you from doing your usual activities, during the last 30 days?

Enter number of days OR None

6 The next set of questions are about tobacco use.

a. Does anyone who lives in your home smoke cigarettes, cigars, or pipes anywhere inside the home? (Include all the homes that you live in)

₁ Yes
₂ No

b. Have you ever tried smoking, even one or two puffs?

₁ Yes
₂ No

c. Do you now smoke cigarettes every day, some days, or not at all?

₁ Every day
₂ Some days
₃ Not at all

d. About how many cigarettes on average do you smoke per day?

Enter number of cigarettes: OR None

7 The next 3 questions ask about drinking alcohol.

A drink of alcohol is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor.

a. Have you ever had a drink of alcohol, other than a few sips?

₁ Yes
₂ No

b. During the last 30 days, did you have at least one drink of alcohol other than a few sips?

₁ Yes
₂ No

c. During the last 30 days, did you have 5 or more drinks of alcohol in a row, that is, within a couple of hours?

₁ Yes
₂ No

Continue on the next page →

ADOLESCENT FOLLOW-UP SURVEY 2007 – ADOLESCENT BOOKLET

Below is a list of problems or complaints that people sometimes have in response to stressful experiences like the events of September 11, 2001.

8 Please think about each question carefully and answer about how you have been feeling and acting in the last 4 weeks, which is from about one month ago up to today.

In the last 4 weeks...	Yes	No
a. Have you often thought about what happened at the WTC site or what you saw?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
b. Have you had problems falling asleep or staying asleep?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
c. Have you had nightmares about what happened?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
d. Have you tried hard not to think about the WTC attack and not to hear or talk about it?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
e. Have you stopped going places or doing things that might make you think about the attack?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
f. Have you tried to keep away from people who might remind you of the WTC attack?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
g. Have you stopped thinking about the future or about things you might do when you are older?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
h. Has it been harder for you to keep your mind on things or to concentrate?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

9 Now think about the problems you may have been having in the last 4 weeks. Consider problems at home, at school or with other people because of the way you have been feeling or acting. Please mark if you have had these problems not at all, hardly ever, some of the time, a lot of the time.

Because of the way you have been feeling or acting in the <u>last 4 weeks</u> ,	Not at all	Hardly ever	Some of the time	A lot of the time
a. How often have your parents (or guardians) felt worried about you?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. How often have your parents (or guardians) gotten annoyed or upset with you?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. How often have you not been able to do things or go places with your family?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
d. How often did you feel bad or upset?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. How often have you not been able to do things or go places with other people your age?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
f. How often have your teachers gotten annoyed or upset with you?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
g. How much of a problem have you had with schoolwork or grades?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Sometimes people exposed to a traumatic event experience ongoing symptoms of distress following the event. Some people may suffer emotionally and have difficulties even after a lot of time has passed.

If you or someone else you know is having problems since 9/11, you can call 1-800-LIFENET (1-800-543-3638), a toll free number that you can call 24 hours a day, 7 days a week to get information about how to get help.

10 The next set of questions asks about your exposure to the dust and debris cloud on September 11, 2001. We asked similar questions during the initial WTCHR interview, but we want to obtain additional information about your dust and debris cloud experience.

a. On September 11, 2001, were you in the dust and debris cloud that resulted from the collapse of the World Trade Center towers?

- ₁ Yes
- ₂ No → SKIP to Question 11

b. On September 11, 2001, when were you first caught in the dust and debris cloud?

- ₁ After the first tower began to collapse but before the collapse of the second tower.
- ₂ Less than 1 hour after the collapse of the second tower.
- ₃ More than 1 hour after the collapse of the second tower.

c. When you were in the dust and debris cloud, which of the following did you experience?
(Check ALL that apply.)

- ₁ I could not see more than a couple of feet in front of me
- ₂ I had trouble walking or finding my way because the dust was so thick
- ₃ I had to find shelter like under a car or in a doorway
- ₄ I was covered from head to toe with dust and debris
- ₅ I could not hear anything

11 The next set of questions asks about loss as a result of September 11, 2001.

The WTC Health Registry staff sincerely extends our sympathy to all who suffered any loss during or following the WTC disaster. The following questions are asked because it is important for the WTCHR to understand the full impact of the disaster on enrollees.

a. Was any member of your family in the WTC disaster, but escaped unhurt?

- ₁ Yes
- ₂ No
- ₃ I don't know
- ₄ I don't remember

b. Was any member of your family injured or hurt in the WTC disaster?

- ₁ Yes
- ₂ No
- ₃ I don't know
- ₄ I don't remember

c. Did you **personally** know anyone who died as result of the WTC disaster?

- ₁ Yes
- ₂ No → SKIP to Question 11e
- ₃ I don't know
- ₄ I don't remember

d. **Would you please tell us who lost their lives?**
(Please indicate all persons you personally knew.)

- ₁ Not applicable, I did not know anyone who died as a result of the disaster
- ₂ My mother (biological, step, foster, adoptive)
- ₃ My father (biological, step, foster, adoptive)
- ₄ My sibling (brother or sister, biological, step, foster, adoptive)
- ₅ My grandparent
- ₆ Other family member, please specify:

- ₇ My legal guardian who is NOT a family member
- ₈ A friend
- ₉ A friend of the family
- ₁₀ The parent of a friend
- ₁₁ Someone else, please specify the relationship, not name: _____

e. Did you know of anyone else who died as a result of the WTC disaster?

- ₁ Yes
- ₂ No → SKIP to Question 12

f. How did you know this person(s)?

12 The next two questions ask about what you thought might happen on September 11, 2001 after you realized there was an emergency in the downtown area. Please answer based on what you thought or felt on that day.

a. Did you think that your parents or guardians might be injured or killed during the WTC disaster on September 11, 2001?

- ₁ Yes
- ₂ No

b. Did you think that you might be injured or killed during the WTC disaster on September 11, 2001?

- ₁ Yes
- ₂ No

Please continue on the next page. Remember that if you have any upsetting feelings about 9/11 or other events in your life, you can call LIFENET 24 hours, 7 days a week to speak to someone about how you feel. The number is 1-800-LIFENET.

ADOLESCENT FOLLOW-UP SURVEY 2007 – ADOLESCENT BOOKLET

13 For this next section, please mark the box for Not True, Somewhat True, or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your behavior over the last 6 months.

Over the <u>last 6 months</u>...	Not True	Somewhat True	Certainly True
a. I try to be nice to other people; I care about their feelings	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b. I am restless; I cannot stay still for long	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c. I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d. I usually share with others, for example CD's, games, food	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
e. I get very angry and often lose my temper	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
f. I would rather be alone than with people of my age	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
g. I usually do as I am told	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
h. I worry a lot	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
i. I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
j. I am constantly fidgeting or squirming	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
k. I have one good friend or more	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
l. I fight a lot; I can make other people do what I want	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
m. I am often unhappy, depressed or tearful	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
n. Other people my age generally like me	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
o. I am easily distracted; I find it difficult to concentrate	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
p. I am nervous in new situations; I easily lose confidence	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
q. I am kind to younger children	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
r. I am often accused of lying or cheating	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
s. Other adolescents or young people pick on me or bully me	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
t. I often offer to help others (parents, teachers, adolescents)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
u. I think before I do things	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
v. I take things that are not mine from home, school or elsewhere	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
w. I get along better with adults than with people my own age	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
x. I have many fears; I am easily scared	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
y. I finish the work I'm doing; my attention is good	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

ADOLESCENT FOLLOW-UP SURVEY 2007 – ADOLESCENT BOOKLET

14 What is your current e-mail address?

(This information will be used to update our records in order to contact you in the future.)

Enter e-mail address: _____

15 Please let us know if you have any other health concerns about yourself since September 11, 2001:

THANK YOU for participating in the first WTC Health Registry follow-up survey. The WTC Health Registry is an important public health endeavor for the New York City metropolitan area and the nation. Your contribution will help researchers understand the full scope of the health effects related to this tragedy. We greatly appreciate your cooperation, the time you took to complete this booklet, and the information you provided.

Who filled out this booklet? Please check one of the boxes below.

How was this booklet completed?

- By yourself
- By yourself but with your parent/guardian's help
- Together with your parent/guardian
- Your parent/guardian completed it for you

This is the end of the Adolescent Booklet.

Please place this booklet in one of the small envelopes provided. Then place it in the large, pre-addressed, postage-paid return envelope. When both booklets (Parent AND Adolescent) are in the large envelope, mail the envelope back to:

WTC Health Registry, 116 John Street – Rm 800, New York, NY 10038



**the mental health association
of new york city, inc.**

LifeNet

If you or a family member has a mental health emergency or crisis, call

1-800-LifeNet (1-800-543-3638)

1-212-982-5284 (TTY)

For more information, go online at: www.nyc.gov/html/doh