WORLD TRADE CENTER HEALTH REGISTRY
2011-2012 ADULT SURVEY

This survey is for enrollee:

INSTRUCTIONS:

- **Please fill in circles completely using a black or blue ink pen.** → **Example:** ○ ● ○
- **Written answers should be printed in capital letters.** → **Example:** J A 1 2

Today's date:

☐☐ / ☐☐ / ☐☐☐☐

(Month) (Day) (Year)

1 Are you the enrollee named above?

○ Yes

○ No → **a But I am completing this survey for the enrollee named above** → **Go to Question 2**

OR

b The enrollee is deceased → **Go to Question A1 on the last page**

IMPORTANT! In all questions "you" and "your" refer to the enrollee (even when another person is answering questions for the enrollee.)

2 What is your date of birth?

☐☐ / ☐☐ / ☐☐☐☐

(Month) (Day) (Year)

3 What is your gender?

○ Male
○ Female

4 What is your <u>current</u> marital status?

○ Never married
○ Married
○ Not married, living with a partner
○ Widowed
○ Divorced or separated

5 Are you currently: (Fill in <u>all</u> that apply)

○ Employed for full-time wages
○ Employed for part-time wages
○ Unable to work because of health
○ Self-employed
○ Out of work for 1 year or more
○ Out of work for less than 1 year
○ A homemaker
○ A student
○ Retired
○ On maternity or parental leave
○ Looking for work

6 **What was your total household income in 2010 before taxes?**

- ○ $25,000 or less
- ○ $25,001 - $50,000
- ○ $50,001 - $75,000
- ○ $75,001 - $150,000
- ○ More than $150,000

7 **In general, how satisfied are you with your life?**

- ○ Very satisfied
- ○ Satisfied
- ○ Dissatisfied
- ○ Very dissatisfied

8 **In general, would you say that your health is:**

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor

9 **For questions 9a-c, please provide answers based on 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 ○

10 **During the last month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?**

- ○ Yes
- ○ No

11 **a. What is your height (without shoes)?**

Height: ☐ feet / ☐☐ inches

b. What is your current weight?

Weight: ☐☐☐ pounds

c. During the last 12 months, did you lose or gain more than 10 pounds without trying?

- ○ Yes
- ○ No

12 **In the last 7 days, how often have you had trouble remembering where you put things, like your keys or wallet?**

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Very often

13 **In the last 7 days, how often have you had trouble concentrating?**

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Very often

14 **During the last 12 months, have you experienced confusion or memory loss, other than occasionally forgetting the name of someone you recently met?**

- ○ Yes
- ○ No → **Go to Question 16**

15 **During the last 12 months, has your confusion or memory loss happened more often or gotten worse?**

- ○ Yes
- ○ No

16 **Have you ever been told by a doctor or other health professional that you had any of these conditions? IF YES, continue to answer the additional questions in each row. IF NO, go to the next row for another condition.**

	No	Yes	Year first told	Are you taking any medication (prescription or over-the-counter) for this condition? No	Are you taking any medication (prescription or over-the-counter) for this condition? Yes	During the last 12 months, have you been hospitalized overnight for this condition? No	During the last 12 months, have you been hospitalized overnight for this condition? Yes
a. Hypertension, or high blood pressure	○	○ →		○	○	○	○
b. Angina, also called angina pectoris	○	○ →		○	○	○	○
c. Heart attack or myocardial infarction	○	○ →		○	○	○	○
d. Coronary heart disease	○	○ →		○	○	○	○
e. Stroke	○	○ →		○	○	○	○
f. Diabetes, or sugar diabetes	○	○ →		○	○	○	○
g. Chronic bronchitis	○	○ →		○	○	○	○
h. Emphysema or COPD	○	○ →		○	○	○	○
i. Reactive airway dysfunction syndrome, or RADS	○	○ →		○	○	○	○
j. Sarcoidosis	○	○ →		○	○	○	○
k. Pulmonary fibrosis	○	○ →		○	○	○	○
l. Asbestosis	○	○ →		○	○	○	○
m. Thyroid disease	○	○ →		○	○	○	○
n. Multiple sclerosis (MS) or amyotrophic lateral sclerosis (ALS)	○	○ →		○	○	○	○
o. Rheumatoid arthritis	○	○ →		○	○	○	○
p. Other auto-immune disorders (e.g., lupus, scleroderma, polymyositis)	○	○ →		○	○	○	○
q. Sleep apnea	○	○ →		○	○	○	○
r. Gastroesophageal reflux disease, or GERD	○	○ →		○	○		
s. High cholesterol	○	○ →		○	○		
t. Other disease, please specify: (Note: Cancer and Asthma are covered later in this survey.)	○	○ →		○	○	○	○

17 **For each of the following symptoms, indicate No or Yes. IF YES, continue to answer the additional questions in each row.**

In the last 30 days, have you experienced any of these symptoms when you did not have a cold, the flu, or seasonal allergies?	No	Yes	If Yes, in the last 30 days, how many days did you experience this symptom? Number of days	In the last 12 months, have you seen a doctor or other health professional for this symptom? No	Yes
a. Shortness of breath	○	○ →	☐☐ →	○	○
b. Wheezing	○	○ →	☐☐ →	○	○
c. Persistent cough	○	○ →	☐☐ →	○	○

18 **During the last 30 days, have you ever been awakened during the night by a cough, wheezing, or shortness of breath when you did not have a cold, the flu, or seasonal allergies?**

○ Yes
○ No

19 **During the last 30 days, have you used an inhaler prescribed by a doctor for any breathing problem?**

○ Yes
○ No

20 **a. In the last 12 months, have you experienced frequent severe headaches?**

○ Yes
○ No → **Go to Question 21**

b. In the last 12 months, have you seen a doctor or other health professional for frequent severe headaches?

○ Yes
○ No

21 **a. In the last 12 months, how often have you experienced heartburn or acid reflux?**

○ Never
○ Less than once a month
○ About once a month
○ About once a week
○ At least twice a week

b. In the last 12 months, have you seen a doctor or other health professional for heartburn or acid reflux?

○ Yes
○ No

c. In the last 30 days, have you experienced heartburn or acid reflux? If yes, indicate the number of days.

○ Yes → Number of days: ☐☐
○ No

d. In the last 30 days, have you taken any medications for heartburn or acid reflux?

○ Yes
○ No

22 **Have you <u>ever</u> been told by a doctor or other health professional that you had asthma?**

○ **Yes** ○ **No** → **Go to Question 25 on the next page**

23 **a. In what year were you <u>first</u> told by a doctor or other health professional that you had asthma?**

Year first told: ☐☐☐☐

b. During the <u>last 12 months</u>, have you had an episode of asthma or an asthma attack?

○ Yes
○ No

c. During the <u>last 12 months</u>, how many times did you visit an emergency room or urgent care center because of asthma?

Number of visits: ☐☐ **OR** None ○

d. In the <u>last 12 months</u>, have you used an inhaler or other medications prescribed by a doctor for asthma?

○ Yes
○ No

e. During the <u>last 12 months</u>, have you been hospitalized overnight for asthma?

○ Yes
○ No

24 **a. In the <u>last 30 days</u>, how much of the time did your asthma keep you from getting as much done at work, school, or at home?**

○ All the time
○ Most of the time
○ Some of the time
○ A little of the time
○ None of the time

b. During the <u>last 30 days</u>, how often have you had shortness of breath?

○ More than once a day
○ Once a day
○ 3 to 6 times a week
○ Once or twice a week
○ Not at all

c. During the <u>last 30 days</u>, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness, or pain) wake you up at night or earlier than usual in the morning?

○ 4 or more nights a week
○ 2 or 3 nights a week
○ Once a week
○ Once or twice
○ Not at all

d. During the <u>last 30 days</u>, how often have you used a rescue inhaler or nebulizer medication (such as albuterol)?

○ 3 or more times per day
○ 1 or 2 times per day
○ 2 or 3 times per week
○ Once a week or less
○ Not at all

e. How would you rate your asthma control during the <u>last 30 days</u>?

○ Not controlled at all
○ Poorly controlled
○ Somewhat controlled
○ Well controlled
○ Completely controlled

25 **Have you ever been told by a doctor or other health professional that you had cancer (sometimes called a malignancy)? IF YES, enter your age at diagnosis and the state you lived in at that time.**

○ Yes ↓ ○ No → **Go to Question 26**

Type of Cancer	No	Yes	How old were you when you were first told that you had this cancer?	What state did you live in when you were first told that you had this cancer (e.g., NY)?
a. Breast	○	○ →	Age: ☐☐	State: ☐☐
b. Prostate	○	○ →	☐☐	☐☐
c. Lung	○	○ →	☐☐	☐☐
d. Colon	○	○ →	☐☐	☐☐
e. Thyroid	○	○ →	☐☐	☐☐
f. Blood or lymph system (e.g.,leukemia, Hodgkin's disease, non-Hodgkin's or other lymphoma, multiple myeloma)	○	○ →	☐☐	☐☐
g. Malignant melanoma	○	○ →	☐☐	☐☐
h. Skin cancer other than melanoma (e.g., Basal cell or squamous cell cancer)	○	○ →	☐☐	☐☐
i. Other cancer, please specify: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐	○	○ →	☐☐	☐☐

26 **Do you have any kind of health insurance coverage, including private health insurance, prepaid plans such as an HMO, managed care, or government plans such as Medicare or Medicaid?**

○ Yes
○ No

27 **Do you have at least one person or location you think of as your personal doctor or health care provider?**

○ Yes
○ No

28 **a. Since 09/11/2001, were you without health insurance at any point?**

○ Yes
○ No → **Go to Question 29**

b. Within the last 12 months, were you without health insurance at any point?

○ Yes
○ No

29 **When did you last visit a doctor for a routine check-up (not for a specific injury, illness, or condition)?**

○ Within the last 12 months
○ Over a year ago but less than 2 years ago
○ Over 2 years ago but less than 5 years ago
○ 5 or more years ago
○ Never in my life

30 **a. During the last 12 months, was there ever a time when you needed health care for physical health problems, but didn't receive it?**

- ○ Yes
- ○ No → **Go to Question 31**

b. Why didn't you get the physical health care that you needed? (Fill in all that apply)

- ○ Preferred to manage myself
- ○ Didn't think anything could help
- ○ Couldn't afford to pay
- ○ No insurance or not covered by my insurance
- ○ Problems with transportation, scheduling, childcare, or other family responsibilities
- ○ Did not know where to go or what kind of doctor to go to for care
- ○ Was unable to find a provider who could diagnose or treat my condition
- ○ Afraid to ask for help or of what others would think
- ○ Didn't get around to it or didn't bother

31 **a. During the last 12 months, was there ever a time when you needed mental health care or counseling, but didn't receive it?**

- ○ Yes
- ○ No → **Go to Question 32**

b. Why didn't you get the mental health care or counseling that you needed? (Fill in all that apply)

- ○ Preferred to manage myself
- ○ Didn't think anything could help
- ○ Couldn't afford to pay
- ○ No insurance or not covered by my insurance
- ○ Problems with transportation, scheduling, childcare, or other family responsibilities
- ○ Did not know where to go or what kind of doctor to go to for care
- ○ Was unable to find a provider who could diagnose or treat my condition
- ○ Afraid to ask for help or of what others would think
- ○ Didn't get around to it or didn't bother

32 **a. Have you ever received services from any World Trade Center (WTC) health program?**

- ○ **Yes**
- ○ **No**

b. Which WTC health program did you receive services from? (Fill in all that apply)

- ○ Mount Sinai School of Medicine
- ○ SUNY - Stony Brook
- ○ Queens College
- ○ UMDNJ-University of Medicine and Dentistry of New Jersey
- ○ FDNY
- ○ NYPD
- ○ WTC National Responder Health Program outside NYC
- ○ NYU/Bellevue Hospital Center, Gouverneur Health Care Services or Elmhurst Hospital Center
- ○ Other:_____

c. What are the reasons you have never received services from a WTC health program? (Fill in all that apply)

- ○ I did not need 9/11-related health services
- ○ I wasn't aware of these services
- ○ I was told that I wasn't eligible
- ○ I am under the care of my personal physican, therapist, or other health care provider
- ○ They are not convenient for me
- ○ It was difficult to make an appointment
- ○ I have insurance
- ○ I find it stressful to think that my problems might be related to 9/11
- ○ Other:_____

33 How much have you been bothered by the following problems in the last 30 days?	Not at all	A little bit	Moderately	Quite a bit	Extremely
a. Repeated, disturbing memories, thoughts, or images of the events of 9/11?	○	○	○	○	○
b. Repeated, disturbing dreams of the events of 9/11?	○	○	○	○	○
c. Suddenly acting or feeling as if the events of 9/11 were happening again (as if you were reliving it)?	○	○	○	○	○
d. Feeling very upset when something reminded you of the events of 9/11?	○	○	○	○	○
e. Having physical reactions (e.g., heart pounding, trouble breathing, sweating) when something reminded you of the events of 9/11?	○	○	○	○	○
f. Avoiding thinking about or talking about the events of 9/11 or avoiding having feelings related to it ?	○	○	○	○	○
g. Avoiding activities or situations because they remind you of the events of 9/11?	○	○	○	○	○
h. Trouble remembering important parts of the events of 9/11?	○	○	○	○	○
i. Loss of interest in activities that you used to enjoy?	○	○	○	○	○
j. Feeling distant or cut off from other people?	○	○	○	○	○
k. Feeling emotionally numb or being unable to have loving feelings for those close to you?	○	○	○	○	○
l. Feeling as if your future will somehow be cut short?	○	○	○	○	○
m. Trouble falling or staying asleep?	○	○	○	○	○
n. Feeling irritable or having angry outbursts?	○	○	○	○	○
o. Having difficulty concentrating?	○	○	○	○	○
p. Being "super alert" or watchful or on guard?	○	○	○	○	○
q. Feeling jumpy or easily startled?	○	○	○	○	○

If you answered "NOT AT ALL" to all of the questions above (33a-q),
→ **Go to Question 35.**

34 **Thinking about the previous questions in (33a-q):**

a. **How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?**

- ○ Not difficult at all
- ○ Somewhat difficult
- ○ Very difficult
- ○ Extremely difficult

b. **In the last 12 months, have you experienced any of these problems continuously for longer than 1 month?**

- ○ Yes
- ○ No

c. **In the last 12 months, have you sought treatment for any of these problems?**

- ○ Yes
- ○ No

35 **Over the last 2 weeks, how often have you been bothered by any of the following problems?**	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
a. Little interest or pleasure in doing things?	○	○	○	○
b. Feeling down, depressed, or hopeless?	○	○	○	○
c. Trouble falling or staying asleep, or sleeping too much?	○	○	○	○
d. Feeling tired or having little energy?	○	○	○	○
e. Poor appetite or overeating?	○	○	○	○
f. Feeling bad about yourself, or that you are a failure or have let yourself or your family down?	○	○	○	○
g. Trouble concentrating on things, such as reading the newspaper or watching television?	○	○	○	○
h. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	○	○	○	○

If you answered "NOT AT ALL" to all of the previous questions (35a-h), → **Go to Question 37.**

36 **Thinking about the questions in (35a-h), how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?**

- ○ Not difficult at all
- ○ Somewhat difficult
- ○ Very difficult
- ○ Extremely difficult

37 **In the last 30 days, about how often did you feel:**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. So sad that nothing could cheer you up?	○	○	○	○	○
b. Nervous?	○	○	○	○	○
c. Restless or fidgety?	○	○	○	○	○
d. Hopeless?	○	○	○	○	○
e. That everything was an effort?	○	○	○	○	○
f. Worthless?	○	○	○	○	○

38 **Have you ever been told by a doctor or other health professional that you had any of these conditions?**

	No	Yes	Year first told
a. Depression	○	○ →	☐☐☐☐
b. Post-traumatic stress disorder or PTSD	○	○ →	☐☐☐☐
c. Anxiety disorder, other than PTSD	○	○ →	☐☐☐☐

39 **During the last 12 months, have you seen a doctor or other health professional for the following conditions?**

	No	Yes
a. Depression	○	○
b. Post-traumatic stress disorder (PTSD)	○	○
c. Anxiety disorder, other than PTSD	○	○
d. Nerves, emotions, or other mental health problems	○	○

40 **During the last 12 months, have you taken any prescription medication for the following conditions?**

	No	Yes
a. Depression	○	○
b. Post-traumatic stress disorder (PTSD)	○	○
c. Anxiety disorder, other than PTSD	○	○
d. Nerves, emotions, or other mental health problems	○	○

The next few questions will ask about events that may have happened to you. We know that these may be sensitive topics and we appreciate your responses. Please do not include the 9/11 disaster when answering the following questions.

41 **Excluding the 9/11 disaster, was your life ever threatened by any of the following events or situations? Answer Yes only if you thought you would be (or were) physically harmed.**

	No	Yes	Did this occur before 9/11? No	Did this occur before 9/11? Yes	Did this occur after 9/11? No	Did this occur after 9/11? Yes
a. A natural or human-made disaster	○	○ →	○	○	○	○
b. A serious accident at work, in a car, or somewhere else	○	○ →	○	○	○	○
c. An attack with a gun, knife, or some other weapon	○	○ →	○	○	○	○
d. An attack without a weapon, but with the intent to kill or seriously injure you	○	○ →	○	○	○	○
e. A situation where someone used physical force or threat of force to make you have some type of unwanted sexual contact	○	○ →	○	○	○	○
f. Any other situation in which you were seriously injured or feared you might be killed or seriously injured	○	○ →	○	○	○	○
g. A situation where you saw someone seriously injured or violently killed	○	○ →	○	○	○	○
h. A life-threatening illness	○	○ →	○	○	○	○

42 **Since September 11, 2001, have you ever experienced any of the following situations?**

	No	Yes	Did this occur in the last 12 months? No	Did this occur in the last 12 months? Yes
a. Could not pay for food, housing, or other basic necessities for a period of 3 months or longer?	○	○ →	○	○
b. Serious problems at work or lost a job?	○	○ →	○	○
c. Serious family problems involving your spouse, child, or parents?	○	○ →	○	○
d. Took care of a close family member or friend with a serious or life threatening illness?	○	○ →	○	○
e. Serious legal problems?	○	○ →	○	○
f. Lost someone close to you due to accidental death, murder, or suicide?	○	○ →	○	○

43 **In the last 2 months, have you experienced the death of a spouse or partner, close family member, or friend?**

○ Yes
○ No

44 Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
a. Feeling nervous, anxious, or on edge?	○	○	○	○
b. Not being able to stop or control worrying?	○	○	○	○
c. Worrying too much about different things?	○	○	○	○
d. Trouble relaxing?	○	○	○	○
e. Being so restless that it is hard to sit still?	○	○	○	○
f. Becoming easily annoyed or irritable?	○	○	○	○
g. Feeling afraid as if something awful might happen?	○	○	○	○

45 How often is someone available:	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. To take you to the doctor if you need to go?	○	○	○	○	○
b. To have a good time with?	○	○	○	○	○
c. To hug you?	○	○	○	○	○
d. To prepare your meals if you are unable to do it yourself?	○	○	○	○	○
e. To understand your problems?	○	○	○	○	○

46 **In the last 30 days have you:**

a. Visited, talked, or emailed with friends at least twice?
- ○ Yes
- ○ No

b. Attended a religious service at least twice?
- ○ Yes
- ○ No

c. Been actively involved in a volunteer organization or club?
- ○ Yes
- ○ No

47 **About how many close friends or relatives do you have now? (By close friends or relatives, we mean people you feel at ease with and can talk with about what is on your mind.)**

Number of close friends or relatives: ☐☐ **OR** None ○

48 **Do you now smoke cigarettes every day, some days, or not at all?**

- ○ Every day
- ○ Some days
- ○ Not at all → **Go to Question 50**

49 **On average, about how many cigarettes do you smoke per day?**

Number of cigarettes: ☐☐

50 **For questions 50 to 52: 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. During the last 30 days, how many days did you have at least one drink of any alcoholic beverage?

Number of days: ☐☐ **OR** None ○

b. On the days when you drank, about how many drinks did you drink on average?

Number of drinks: ☐☐

c. What is the maximum number of drinks you have consumed on one single occasion in the last 30 days?

Number of drinks: ☐☐

MALES ONLY

51 **a. During the last 12 months, about how often did you drink 5 or more drinks in a single day?**

- ○ Never → **Go to Question 57**
- ○ Once
- ○ More than once

b. Considering all types of alcoholic beverages, how many times during the last 30 days did you have 5 or more drinks on one occasion?

Number of times: ☐☐ **OR** None ○

Go to Question 57 on the next page →

FEMALES ONLY

52 **a. During the last 12 months, about how often did you drink 4 or more drinks in a single day?**

- ○ Never → **Go to Question 53**
- ○ Once
- ○ More than once

b. Considering all types of alcoholic beverages, how many times during the last 30 days did you have 4 or more drinks on one occasion?

Number of times: ☐☐ **OR** None ○

FEMALES continue to answer Questions 53-56:

53 **How old were you when you had your first monthly period?**

Age: ☐☐

○ Period not started yet → **Go to Question 57**

54 **Do you still have your monthly periods?**

- ○ Yes → **Go to Question 57**
- ○ No

55 **How old were you when your monthly periods stopped?**

Age: ☐☐

56 **Why did your monthly periods stop?**

- ○ Menopause or change of life
- ○ Pregnant or nursing
- ○ Surgery, medicine, or radiation

For questions 57 to 60: the following information is requested from you to properly keep track of who is enrolled in the Registry. This information will remain strictly confidential. If you would like to provide us with your full Social Security number, please call us at 866-692-9827.

57 **Enter the last 4 digits of your Social Security Number:** ☐☐☐☐

58 **What is your current email address?**

☐☐

59 **What is (was) your father's last name?**

☐☐☐☐☐☐☐☐☐☐☐☐

60 **Where were you born?**

U.S. State: ☐☐ **OR** Country (If outside of U.S.): _____

Note: If you are completing the survey for someone else, or if the enrollee has died, please also answer questions A1 to A3 below.

Thank you for completing the survey

Please place the completed survey in the envelope provided. If the envelope was not included or lost, call us at 866-692-9827.

Visit nyc.gov/9-11healthinfo for the latest information on 9/11-related research and services.

A1
Your name: ☐☐☐☐☐☐☐☐☐☐
First
☐☐☐☐☐☐☐☐☐☐☐☐
Last
Phone number: ☐☐☐ - ☐☐☐ - ☐☐☐☐

A2 **What prevented the enrollee from completing the survey?**

- ○ A physical or mental disability
- ○ A language barrier
- ○ The survey was too difficult for the person to read
- ○ The enrollee is deceased
- ○ Other reason, please specify:_____

A3 **If the enrollee has died, please accept our condolences. Complete only the information below and mail back the survey or call us at 866-692-9827.**

Date of death: ☐☐ / ☐☐ / ☐☐☐☐
(Month) (Day) (Year)

Place of death: U.S. State: ☐☐

OR

Country (If outside of U.S.):_____