

# **WTC Health Program Background and Process for Requesting Data**

## **1. History of the FDNY WTC Program**

One month after the attacks on the WTC, under the guidance of our Chief Medical Officers, Dr. Kerry Kelly and Dr. David Prezant, FDNY-BHS began comprehensive medical screenings. Both doctors were caught in the collapse and understood the potential short- and long-term health impacts of the unique exposures experienced at the WTC sites by our FDNY rescue workers (firefighters and EMS members). FDNY-BHS co-designed this program specifically for FDNY members, partnering with the Uniformed Firefighters Association (UFA), the Uniformed Fire Officers Association (UFOA), the International Association of Firefighters (IAFF), and Uniformed Emergency Medical Technicians and Paramedics (UEP), Uniformed EMS Officers (UEMSO) and the Supervising Officers Association (SOA).

The periodic medicals and treatment programs already in place for active members supplied the foundation for the FDNY WTC Program, and enabled FDNY-BHS to institute the program rapidly. We are proud that our BHS physicians were the first to identify and treat WTC-related illnesses and that the FDNY WTC Program helped to inform other WTC medical programs, including those performed by the Mount Sinai Consortium's WTC Medical Monitoring and Treatment Program for non-FDNY responders, and the Bellevue Hospital WTC Environmental Health Center's Treatment Program.

Recognizing the potential for long-term health consequences from the exposures experienced at the WTC site, the FDNY WTC Program expanded its initial screening programs to include long-term monitoring, disease surveillance for late emerging problems, and treatment. Over time, the FDNY WTC Program also included many scientific partners including the Centers for Disease Control and Prevention (CDC), the National Institute for Occupational Safety and Health (NIOSH), the Mt. Sinai NY/NJ WTC Health Consortium for non-FDNY responders, the Bellevue Hospital WTC Environmental Health Center, the WTC Registry, Robert Wood Johnson Medical School, NYU Pulmonary Division, Montefiore Medical Center, and the Albert Einstein College of Medicine. As of September 30, 2010, over 15,400 FDNY WTC rescue workers have had medical monitoring examinations. Outreach activities continue in an effort to give monitoring examinations to all of the approximately 16,000 members with potential WTC exposure that the FDNY WTC Program has been in active contact with. Monitoring and treatment takes place at the FDNY Headquarters clinic as well as a handful of FDNY satellite clinics throughout the NYS area.

The FDNY WTC Health Program has expanded to provide WTC-related medications to active and retired members. Treatment provided under the FDNY WTC Health Program only includes services for WTC-designated conditions.

## **2. Medical and Exposure Assessment Methods**

FDNY WTC-exposed rescue workers receive medical monitoring (physical and mental health) and if needed free treatment and medications for WTC-related conditions in the following categories: Pulmonary, Aerodigestive, Gastrointestinal, Musculoskeletal, Cancer and Mental Health. WTC members are given monitoring exams on a yearly basis. The exam is comprised of several sections some of which are required in order for the exam to qualify as complete and some may be declined (requirements differ for active and retired members). The sections are as follows: vitals, PFT, ECG, Hearing, Physical Health Survey, Mental Health Survey, blood work/urine, and physician exam.

The surveys have been developed to assess the long-term physical and psychological impacts of 9/11. Full questionnaire texts are available below.

### 3. Requesting Data

The demographic information has been provided below and has been selected so as to provide as much useful information as possible to patients, stakeholders and potential research collaborators who might benefit from this data sharing project while still protecting the identity of our members according to HIPAA and NIH regulations.

A sample data dictionary is supplied below. A complete data dictionary will be supplied if requested. Our members' personal information and FDNY internal documentation data will not be shared. Data will not be shared on groups so small where it might be possible to identify the individual group members (for example, the group of female firefighters exposed to the WTC or Fire Marshals). No data is available on substance abuse. Every request for data will be subject to review by the WTC Health Program directors and must be part of an IRB proposal for WTC-related research. Please note that the WTC Health Program requires all requesters to be registered with the Montefiore Institutional Review Board before any data can be shared.

If any of this information is of interest to your research and you wish to request access to values of these (de-identified) variables for analysis, please fill out the brief contact form below and our research team representative will contact you with follow-up questions.

### 4. Contact Form for Requesting WTC MMTP Data

- Name, title
- Place of employment
- Academic Affiliation
- Phone, email
- Name of project, web link if available
- IRB Approval (yes, pending)
- Name, title of the principal investigator of project
- Title of research project
- Goal and/or hypothesis of research project
- Briefly describe your intended use of the data which you are requesting
- The source and amount of budgetary support you have for this project

### 5. Demographic Information

End Date Class  
10/31/2016 EMS, Fire

Counts as of Last Data Refresh Date:  
November 25, 2016

**Demographics Summary of All Enrolled Members**

Date run: 11/28/2016

Class	Total
Fire	13185
EMS	2174

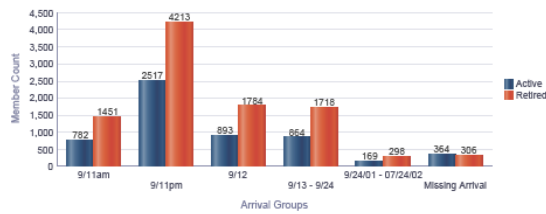
ENROLLED is equal to / is in Y  
and DOD is null  
or CAST (DOD AS DATE ) is greater than 10/31/2016  
and CLASS\_CODE is equal to E , F  
and CLASS\_DESC is equal to EMS , Fire

**WTC Arrival**

Date run: 11/28/2016

Rank Hierarchy Total

Time first arrived at WTC site based on self reported survey responses



	Total	9/11am	9/11pm	9/12	9/13 - 9/24	9/24/01 - 07/24/02	Missing Arrival
Member Count							
Active		782	2517	893	864	169	364
Retired		1451	4213	1784	1718	298	306

ENROLLED is equal to / is in Y  
and DOD is null  
or CAST (DOD AS DATE ) is greater than 10/31/2016  
and CLASS\_CODE is equal to E , F  
and CLASS\_DESC is equal to EMS , Fire

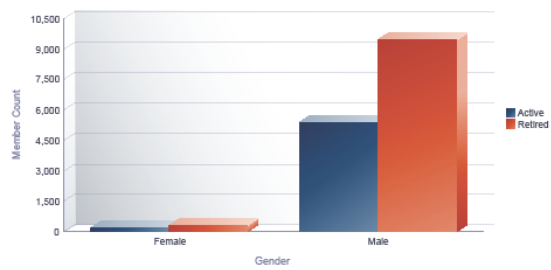
**Gender**

Date run: 11/28/2016

Gender	Total			Fire			EMS		
	Active	Retired	Total	Active	Retired	Total	Active	Retired	Total
Female	198	300	504	15	19	34	183	287	470
Male	5,391	9,464	14,855	4,839	8,512	13,151	752	952	1,704

Ran Total k

Gender by Employment Status



ENROLLED is equal to / is in Y  
and DOD is null  
or CAST (DOD AS DATE ) is greater than 10/31/2016  
and CLASS\_CODE is equal to E , F  
and CLASS\_DESC is equal to EMS , Fire

**Race**

Date run: 11/28/2016

Race	Total			Fire			EMS		
	Active	Retired	Total	Active	Retired	Total	Active	Retired	Total
Race Total	5589	9770	15359	4654	8531	13185	935	1230	2174
African American	329	531	860	126	257	383	203	274	477
American Indian	6	8	14	4	7	11	2	1	3
Asian	57	30	87	28	16	44	29	23	52
Caucasian	4698	8621	13319	4242	7900	12202	456	861	1117
Hispanic	499	528	1027	254	249	503	245	279	524
Other	0	43	43	0	42	42	0	1	1

Ran Total k

## 6. Data Dictionary - Short Version: A Complete Dictionary will be supplied if requested

Table Name: D_EMP (EXCERPT)		
Table Definition:	EMP_RESEARCH_V is the view format for D_EMP. Table contains ALL demographic and stagnant data associated with any member {FDNY employee (firefighter, EMS, civilian), family member, or candidate}. Each row in this table will correspond to 1 person.	
Column Name	Data Type	Column Definition
SSN	VARCHAR(9)	Social Security Number of the employee, family member, or candidate (old method FDNY used to uniquely identify an employee).
NIOSH_ID	VARCHAR(20)	NIOSH provided ID for this employee, family member, or candidate.
FIRST_NAME	VARCHAR(20)	First name of the employee, family member, or candidate
LAST_NAME	VARCHAR(50)	Last name of the employee, family member, or candidate
BIRTH_DT	DATE	Birth date of the employee, family member, or candidate
AGE_ON_911	INTEGER	Age of this employee, family member, or candidate on 9/11/2001. Calculated field
CLASS_CD	VARCHAR(20)	Class code (fire fighter, EMT, etc.) of this employee, family member, or candidate. Class codes and descriptions are: (E: EMS, F: Fire, C: Civilian, H: Healthcare)
WORK_LOC_DESC	VARCHAR(50)	Description of the primary work location of the employee, family member, or candidate
CLASS_ON_911	VARCHAR(2)	Class of member on 9/11/2001.
HIRE_DT	DATE	Date which this employee, family member, or candidate was hired by FDNY
RETIRED_F	NUMBER(1)	Flag indicating if this person has retired from FDNY services.
HEIGHT		Height of the individual
DEATH_DT	DATE	This column stores the confirmed death date, if this employee, family member, or candidate is deceased
CURR_PHONE_NBR	VARCHAR(10)	Most recent primary phone number of the employee, family member, or candidate
CURR_STREET	VARCHAR(100)	Most recent street name and number of the employee, family member, or candidate

Table Name: F_PFT (EXCERPT)		
Table Definition:	Contains pulmonary function test results and frequently used calculations. Each row represents one PFT exam date: one person combination	
Column Name	Data Type	Column Definition
STUDY_ID	VARCHAR2 (50 Byte)	Unique code that is used by FDNY to identify an employee.
EXAM_DATE	DATE	Date the exam was taken
FEV1_GRADE	NUMBER	Overall rating of quality for the forced expiratory volume measurement
FEV_1_ACTUAL	NUMBER	Actual forced expiratory volume in 1 second. The volume of air that can forcibly be blown out in one second, after full inspiration, measured in liters
FVC_ACTUAL	NUMBER	Actual forced vital capacity. The volume of air that can forcibly be blown out after full inspiration, measured in liters
FEF2575_ACTUAL	NUMBER (6,3)	Actual forced expiratory flow. The average forced expiratory flow during the mid (25 - 75%) portion of the FVC, measured in liters per second
FEV1_FVC_RATIO	NUMBER	Ratio of forced expiratory volume to forced vital capacity
FEV_1_LLN	NUMBER	Lower limit of normal for forced expiratory volume
FEV1_FVC_RATIO_LLN	NUMBER	Lower limit of normal for ratio of forced expiratory volume to forced vital capacity
FEV_1_PREDICTED	NUMBER	Predicted forced expiratory volume based on height, gender, age, race/ethnicity
FEV1_FVC_RATIO_PREDICTED	NUMBER	Predicted ratio of forced expiratory volume to forced vital capacity based on height, gender, age, race/ethnicity
FEV1_PCT_PRED	NUMBER	The test result as a percent of the predicted values for forced expiratory volume (see FEV_1_PREDICTED for how predicted values are derived)
FLAG	NUMBER	Flag for unusual measurements

Table Name: D_COMMON_EXP (EXCERPT)		
Table Definition:	This table contains several exposure variables which are commonly used in World Trade Center health-related research. Types of exposure include a composite variable (TYPE), location worked by time period, and tasks performed on 9/11 (day 1).	
Column Name	Data Type	Column Definition
TYPE_CD	VARCHAR(1)	Code representing the type of exposure: A,B,C,D
TYPE_DESC	VARCHAR(500)	Description of TYPE_CD: <b>A</b> =Was located inside or outside during either tower during the collapses, <b>B</b> =Was not present at either tower during the collapses, but was performing any of the following activities on 9/11 (day 1) {Fire Suppression at site, Rescue/Recovery at site, Digging at site, Direct Supervision at site, Welding or

Table Name: D_COMMON_EXP (EXCERPT)		
		Steel Cutting at site, EMS or CFRD Activities at site, Handling of bodies or body parts at site), C=Was present but not near either tower during the collapses and was not present at the site on 9/11 (day 1) to perform any tasks, D=Was not present at the site on 9/11 (day 1) to perform any tasks
WORK_911	NUMBER	Coded as 1 if the member performed any of the following activities at the site on 9/11 (day 1): {see TYPE_DESC for list of tasks indicated for Level B}, 0 otherwise
WORK_912	NUMBER	Coded as 1 if the member performed any of the following activities at the site on 9/12 (day 2): {see TYPE_DESC for list of tasks indicated for Level B}, 0 otherwise
WORK_913_917	NUMBER	Coded as 1 if the member worked 4 to 16 or more days at the site during the month of September 2001, 0 otherwise
WORK_918_1231	NUMBER	Coded as 1 if the member worked at the site (on- or off-duty) for at least one day in 10/01, 11/01 and/or 12/01, 0 otherwise
WORK_11_630	NUMBER	Coded as 1 if the member worked at the site (on- or off-duty) for at least one day in 01/02, 02/02, 03/02, 04/02, 05/02, and/or 06/02, 0 otherwise
TASK_FIRESUP	NUMBER	Coded as 1 if the member performed fire suppression at the site on 9/11 (day 1), 0 otherwise
TASK_RESREC	NUMBER	Coded as 1 if the member performed rescue or recovery at the site on 9/11 (day 1), 0 otherwise
TASK_DIG	NUMBER	Coded as 1 if the member performed digging at the site on 9/11 (day 1), 0 otherwise
TASK_WELD	NUMBER	Coded as 1 if the member performed welding or steel cutting at the site on 9/11 (day 1), 0 otherwise

Table Name: PH_HEALTH_BEHAV (EXCERPT)		
Table Definition:	Contains survey questions categorized as Health Behaviors (Smoking and Tobacco Use, Alcohol Use, etc.). Each row represents one member: exam date combination. Variables beginning with Q are coded as binary.	
Column Name	Data Type	Column Definition
SSN	VARCHAR2 (10)	Social Security Number of the employee, family member, or candidate which can be used as a unique identifier.
EXAM_DATE	DATE	Date the questionnaire was taken
SEPT_11_YR	NUMBER (4)	The (SEPT_11_YR)th year after 9/11/2001 (i.e. a questionnaire taken on 9/12/2002 falls into SEPT_11_YR = 2)
Q230_132	NUMBER	Question: Have you ever, regularly smoked a pipe or cigars or used chewing tobacco? We define "regular" as at least once every day for 6 months. / Answer No: 132 / Answer: Never
Q230_299	NUMBER	Question: (see Q230_132) / Answer No: 299 / Answer: Yes, but no longer
Q230_73	NUMBER	Question: (see Q230_132) / Answer No: 73 / Answer: Yes, currently
Q231_1	NUMBER	Question: CURRENTLY, do you smoke cigarettes (not electronic cigarettes)? / Answer No: 1 / Answer: Yes
Q231_1492	NUMBER	Question: (see Q231_1) / Answer No: 1492 / Answer: No, never smoked
Q231_1493	NUMBER	Question: (see Q231_1) / Answer No: 1493 / Answer: No, ex-smoker
Q232_1184	VARCHAR2 (10)	Question: How old were you when you last smoked cigarettes regularly? / Answer No: 1184 / Answer: [AGE]
Q232_2093	VARCHAR2 (10)	Question: (see Q232_1184) / Answer No: 2093 / Answer: NUM(9-80)
Q233_2100	VARCHAR2 (10)	Question: For how many years did/have you smoked cigarettes in total? / Answer No: 2100 / Answer: NUM(0-80)
Q233_923	VARCHAR2 (10)	Question: (see Q233_2100) / Answer No: 923 / Answer: NUM(0-100)

Table Name: PH_UPPER_RESP_SYMP (EXCERPT)		
Table Definition:	Contains survey questions categorized as Upper Respiratory Symptoms/ Conditions from various surveys. Each row represents one member: exam date combination. Variables beginning with Q are coded as binary.	
Column Name	Data Type	Column Definition
SSN	VARCHAR(10)	Social Security Number of the employee, family member, or candidate which can be used as a unique identifier.
EXAM_DATE	DATE	Date the questionnaire was taken
SEPT_11_YR	NUMBER(4)	The (SEPT_11_YR)th year after 9/11/2001 (i.e. a questionnaire taken on 9/12/2002 falls into SEPT_11_YR = 2)
Q91_2	NUMBER	Question: IN THE PAST 12 MONTHS, apart from when you had a cold or flu, did you have any of the following symptoms? / Answer No: 2 / Answer: No
Q91_236	NUMBER	Question: (see Q91_2) / Answer No: 236 / Answer: Frequent headaches
Q91_237	NUMBER	Question: (see Q91_2) / Answer No: 237 / Answer: Sinus or face pain or pressure
Q91_238	NUMBER	Question: (see Q91_2) / Answer No: 238 / Answer: Nasal or sinus congestion
Q91_240	NUMBER	Question: (see Q91_2) / Answer No: 240 / Answer: Nose irritation, soreness, or burning
Q91_241	NUMBER	Question: (see Q91_2) / Answer No: 241 / Answer: Frequent nosebleeds
Q91_243	NUMBER	Question: (see Q91_2) / Answer No: 243 / Answer: Runny nose or postnasal drip
Q92_2	NUMBER	Question: IN THE SPRING OR FALL are any of the following symptoms worse? / Answer No: 2 / Answer: No
Q92_236	NUMBER	Question: (see Q92_2) / Answer No: 236 / Answer: Frequent headaches
Q92_237	NUMBER	Question: (see Q92_2) / Answer No: 237 / Answer: Sinus or face pain or pressure

Table Name: PH_UPPER_RESP_SYMP (EXCERPT)		
Q92_238	NUMBER	Question: (see Q92_2) / Answer No: 238 / Answer: Nasal or sinus congestion
Q92_240	NUMBER	Question: (see Q92_2) / Answer No: 240 / Answer: Nose irritation, soreness, or burning
Q92_241	NUMBER	Question: (see Q92_2) / Answer No: 241 / Answer: Frequent nosebleeds
Q92_243	NUMBER	Question: (see Q92_2) / Answer No: 243 / Answer: Runny nose or postnasal drip