Final Progress Report

for

The World Trade Center Responder Health Consortium Data and Coordination Center (U10-OH008232)

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List of Terms and Abbreviations

Term/Abbreviation	Description
CC	Clinical Center
DCC	Data and Coordination Center
DIS	Diagnostic Interview Schedule
DMC	Data Management Core
FDNY	Fire Department of New York
HIPAA	Health Insurance Portability and Accountability Act
HOC	Health Outcomes Core
ICD	International Classification of Diseases
LHI	Logistics Health Inc.
MMTP	Medical Monitoring and Treatment Program
MSC	Member Services Core
NIOSH	National Institute for Occupational Safety and Health
NYPD	New York Police Department
PEF	Public Employees Federation (New York)
PFT	Pulmonary Function Test
PI	Principal Investigator
QA	Quality Assurance
QTC	QTC Management, Inc.
SAS	Statistical Analysis System (SAS Institute, Inc., Cary, NC)
SOP	Standard Operating Procedure
WTC	World Trade Center

Abstract

The September 11^{th}, 2001, attacks on the World Trade Center (WTC), resulted in major public health issues for the many thousands of responders who worked or volunteered on the WTC rescue and recovery effort.

As a response to the attacks, the Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine of the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine in New York City proposed the establishment of a comprehensive World Trade Center Worker and Volunteer Medical Screening Program. This was approved by the National Institute for Occupational Safety and Health and began on April 8^{th}, 2002. The first screening examinations were conducted on July 16, 2002. The Screening Program provided free, confidential, initial exams to the WTC responders and, in 2004, became the World Trade Center Medical Monitoring Program which provides periodic exams of the responders. Treatment was added in 2006.

Incidence of most conditions was highest in the first two years after September 11^{th}, 2001 and in responders with the greatest exposure. As well as being common, the health effects are persistent; nine years after the attacks of September 11^{th}, 2001, responders continue to experience a substantial burden of often co-existing physical and mental health problems.

The key findings of this work have been the identification of the need for ongoing monitoring and treatment of the 9/11 responder population, and the importance of providing adequate health coverage for these men and women. In addition, it is clear that planning for future disasters must anticipate the likelihood of persistent physical and mental illness in responders.

Section I

Highlights and Significant Findings

There are many important conclusions that can be drawn from the experiences of the Data and Coordination Center (DCC) over the course of the Monitoring Program, and the DCC has produced several important responder-based results. There have been multiple sets of Specific Aims for the Data and Coordination Center, corresponding to the different phases of the Monitoring Program, making the relating of conclusions and results to particular specific aims less relevant than for a more conventional, hypothesis-based study. Instead, for the DCC, it is more appropriate to present the overall highlights and findings.

Critical Factors in setting up Medical Monitoring Program

- The pre-existing, long-established relationships between the Irving J. Selikoff Center for Occupational and Environmental Medicine and labor organizations, public agencies, the employer community, and occupational health and safety experts, were critical to the establishment of the responder programs.
- A coordinated, cooperative effort between clinics is essential to the success of such programs. When it is absent, responders suffer.
- Monitoring and treatment need to incorporate a multidisciplinary approach.
- A broad spectrum of expertise in public health and occupational medicine is needed.
- There is a need for both ongoing monitoring of these responders, and ongoing care for their chronic diseases.

Responder Health Findings

- A substantial proportion of responders developed persistent upper and/or lower respiratory symptoms as well as GERD.
- Many responders suffer from multiple physical and mental health conditions, often concurrently.
- Persistent mental health conditions, including PTSD, have also been prevalent in this population.

Highlights

- Accelerated set-up of a medical screening and monitoring program following a disaster.
- Importance of prior clinical experience of occupational medicine specialists at the Irving J. Selikoff Center for Occupational and Environmental Medicine in the evaluation of responders.
- Massive, proactive outreach program specifically geared to the responders.
- The number of data collection instruments created, customized, and/or optimized (approximately two dozen).
- The number of standardized, clinical protocols developed (approximately ten).
- The number of exams conducted (approximately 73,500).
- The number of responders seen (approximately 30,500)

- The amount of data collected (over 15 million data elements).
- The number of articles written (approximately 50).
- The number of meetings and teleconferences facilitated (hundreds).
- Years of working closely with the community and unions involved as key stakeholders.
- Centralized steering committee and governance structure.
- Centralized administrative and data management structure.
- Centralized Phone Bank with a toll-free phone number and multilingual communication capacity (English, Spanish, and Polish, principally).
- The broad variety of English-language educational materials created, gathered and/or adapted and translated into Spanish and Polish.

Translation of Findings

The critical factors in setting up a medical monitoring program following such an attack/disaster as 9/11, and the findings pertaining to responder health, can, and should, both be seminal in informing the setting up and deployment of any such programs that might prove necessary in the future. Ground Zero was a workplace that resulted in both disease and injury for the WTC responders. Specifically, as just two examples, monitoring programs needs to be set up rapidly and staffed by occupational health professionals, and planning for future occurrences must anticipate high rates of persistent morbidity.

Outcomes/Relevance/Impact

The unusual (and hopefully unique) nature of Ground Zero as a workplace results in the outcomes of the monitoring program being potential (findings, results and recommendations that impact future workplace risk, if used) in nature, rather than intermediate (changes in current practices, legislation or product design) or 'end' outcomes (contributions to documented reductions in work-related morbidity, mortality or exposure). Nevertheless, the work of the monitoring program certainly had both an intermediate outcome and an end outcome in its influence on clinical treatment guidelines for WTC-related conditions. The potential outcomes of the monitoring program speak to the establishment and implementation of any such programs that might prove necessary in the future; rapid deployment of a program staffed with appropriate expertise and planning with the expectation of high rates of persistent illness, with frequent comorbidity between physical and mental health conditions.

Section II

Scientific Report

Background

The September 11^{th}, 2001, attacks on the World Trade Center (WTC), resulted in injuries and illnesses related to the disaster among the many thousands of responders who worked or volunteered on the WTC rescue and recovery effort. These responders potentially sustained exposures to: 1) a range of environmental toxins, including cement and glass dust, asbestos, fiberglass, respirable and larger particulate matter – much of it highly alkaline – as well as lead and other heavy metals, Poly-Chlorinated Biphenyls, dibenzofurans, volatile organic compounds and other products of combustion; 2) psychological trauma; and 3) physical hazards including fire, collapsing buildings, falling debris, noise and extremes of temperature. Short-term health effects of exposures in the WTC rescue and recovery effort included acute musculoskeletal injuries, respiratory illnesses and psychological disorders. Long-term health effects may include chronic lung diseases, chronic conditions of the upper respiratory tract, chronic musculoskeletal disorders, psychological disorders, and possible long-latency diseases including cancer.

The Mount Sinai-Irving J. Selikoff Center for Occupational and Environmental Medicine of the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine in New York City, based on the efforts of New York's' labor organizations and with the support of the Centers for Disease Control and Prevention (CDC) / The National Institute for Occupational Safety and Health (NIOSH), established a comprehensive World Trade Center Worker and Volunteer Medical Screening Program on April 8^{th}, 2002, to provide free medical assessments, diagnostic and treatment referrals and occupational health education for responders exposed to hazards during the WTC rescue and recovery effort. The WTC Medical Screening Program examined approximately 10,500 workers, about 1,700 of whom received examinations at facilities other than Mount Sinai in the greater New York/New Jersey metropolitan area, and about 500 nationally, under the auspices of the Association of Occupational and Environmental Clinics.

The clinical evidence of persistent, WTC-related disease in this population, and the concern that some of the health problems that the responders were experiencing might become chronic if left untreated or inappropriately treated according to current standards of care, again with help from organized labor, led to Congressional appropriation of funds for a long-term medical monitoring program for these responders. This appropriation in turn led to RFA-OH-04-004 (World Trade Center Responder Health Consortium) that identified the crucial need for a Data and Coordinating Center to oversee and coordinate many of the functions and aspects that would be common to all the Clinical Centers providing examinations and to manage the data derived from them. This is a progress report from the non-firefighter Responder Health Consortium's DCC.

Specific Aims and Accomplishments

This progress report presents the accomplishments of the World Trade Center (WTC) Medical Monitoring and Treatment Program (MMTP) Data and Coordination Center (DCC) (U10-

OH008232) since its inception – from June 1st, 2004 through June 30th, 2011 – in meeting its Specific Aims. The Specific Aims and, consequently, the accomplishments of the program changed over time and are presented in the three major groupings into which they fell: *a)* Original (from the initial proposal); *b)* Additional; and *c)* Supplemental. The groups are presented in reverse chronological order because the most recent aims and accomplishments are of most relevance to the current state of the program.

(a) Supplemental Specific Aims and Accomplishments

1. Redesign and implement the WTC MMTP reports and forms.

New reporting requirements from NIOSH, provided to the DCC in early 2010, resulted in the DCC staff working closely with members from NIOSH and with the Clinical Center (CC) Principal Investigators (PI) to make refinements to the DCC "WebApp" data collection instruments. A comprehensive list of 'covered' WTC physical and mental health conditions, along with their respective International Classification of Diseases (ICD 9) codes was created *via* collaboration with the CC PIs, Fire Department of New York (FDNY) PI, Director of the National Program and members of NIOSH. This list of covered conditions was based on the needs of the responders coming into the Treatment Program. The purpose of the list was to serve as a guide, for the clinicians and administrators of the WTC treatment program, to the conditions and the respective treatments that would be paid for by NIOSH. This list was intended to replace the previous list of physical and mental health conditions that were outlined in the Healthcare Provider forms of the DCC WebApp. The DCC-designed paper versions of the new Patient Information Forms and Healthcare Provider forms, *per* the new reporting requirements, incorporated the comprehensive WTC-covered conditions list. The DCC also simultaneously redesigned and developed the new Patient Information and Healthcare Provider electronic forms in TrialDB (the then-current data collection system) to include of the new, covered conditions list. The electronic forms were thoroughly tested and were ready for use by the clinical centers on 1/3/2011 in TrialDB, effectively retiring the DCC WebApp. The DCC provided, to users in the CCs, several in-person and web-based training sessions on the data collection and data entry of the new paper and electronic forms in TrialDB. The DCC also provided training manuals for the use of the new forms in TrialDB. However, due to difficulties encountered by the CCs in reporting *per* the new requirements, it was decided, with NIOSH's approval, to withdraw the new forms and go back to reporting under the former DCC WebApp.

2. Data Dictionaries/Codebooks

The Health Outcomes Core (HOC) of the DCC created a series of data dictionaries/codebooks for use by data analysts who need to understand the content and structure of the datasets. These codebooks provide detailed information about the type, formats and values of the variables in each dataset (which is usually in Statistical Analysis System (SAS®) format). These codebooks are updated as required.

3. Datasets

Physical Health and Mental Health datasets for Visits 1-5 are cleaned and updated for data up to and including those of 9/11/10, for more than 2,000 variables that were identified as 'priority' by the various working group members. Priority variables include all Environmental Assessment Questionnaire variables, all Self-Administered Mental Health Questionnaire variables, and the majority of variables from the Interviewer-Administered Medical Questionnaire (excluded were variables related to musculoskeletal conditions, intervening medical tests and medications). In addition, all Physical Exam and demographic variables are available for analysis. Longitudinal datasets for key self-reported conditions and symptoms and selected covariates have also been completed.

4. Data mapping

Variables for physician-diagnosed conditions and self-reported symptoms have been mapped longitudinally across visits in consultation with content-area-experts. Visit 1 variables from the initially employed electronic medical record (Logician®) have been mapped to their TrialDB equivalents. The new WebApp was never fully implemented, so variable mapping was not necessary.

5. Quality Assurance (QA)

The DCC designed and implemented a variety of quality assurance reports to better assist the DCC and the CCs in their operational and scientific activities. Examples of QA measures include providing: weekly and monthly data entry status reports for the various questionnaires/forms, reports on missing questionnaires for visits, reports on the percentage of missing variables in the questionnaires, and a review-based report on submissions from the CCs of documents required for payment certification of monitoring exams. In addition, the DCC performed a PFT quality review and provided feedback to the CCs.

The DCC identified quality indicators for the data collection systems and provided the CCs with weekly and monthly data entry status reports on the WebApp forms, to identify data entry gaps. The DCC also provided the CCs with a weekly listing of patients who were eligible to participate in the program and returned for a follow-up visit.

Pulmonary Function Testing (PFT) QA reports were generated by the DCC and provided to Dr. Skloot for review and comment. Dr. Skloot's recommendations and comments on the quality of the PFTs were provided to the Consortium. The PFT technicians were provided with feedback to improve their performance and, consequently, the quality of the PFTs that they administer to the responders. When necessary, PFT technicians received personalized retraining to improve overall performance.

The DCC also performed continuous and on-going review of consent entries; periodic review of missing forms to resolve form status; and a complete review of clinic assignment by patients.

The DCC conducted a complete review of possible duplicate registrations stemming from name variations and from the list of responders received from the administrators of the program for responders residing outside the New York Metropolitan area (Logistics Health Inc., LHI), and integrated the responder lists from LHI (both new patients and exam dates for all patients) into the DCC data.

6. Future scientific projects

On June 4th, 2010, the DCC convened a meeting of the PIs, members of NIOSH, representatives from labor, content experts and analysts from each scientific working group to discuss plans for future WTC MMTP scientific projects. Projects were presented by the pulmonary, exposure, mental health, and cancer working groups and prioritized based on the input from those in attendance. In this meeting, any additional variables that should be extracted, cleaned and verified for use in future analyses were identified.

7. Consortium-wide Health and Education Conference for WTC Responders

The Member Services Core (MSC) initiated, planned, and organized the 2011 WTC MMTP Health and Education Conference for WTC Responders.

The conference was held on Saturday, May 7th, 2011 at the United Federation of Teachers headquarters in lower Manhattan. The purpose of the conference was to inform and update WTC responders and their families on 9/11-related physical and mental health conditions, benefits relevant to 9/11 workers and volunteers, and the state of 9/11 health care under the James Zadroga Act. There was an event for children of conference participants given at the same time, hosted by Tuesday's Children 9/11 First Responder Alliance. The conference was free of charge.

The conference was planned in response to an electronic survey of WTC responders that the MSC designed and disseminated to WTC responders *via* the WTC MMTP DCC email listserv. The survey asked responders to identify topics that they would be interested in learning more about at the conference and also offered an option for responders to write in additional topics of interest.

During the course of the day, two keynote speeches were presented. The first keynote speech, presented by Dr. John Howard of NIOSH, addressed the state of 9/11 healthcare under the Zadroga Act. The second keynote speech provided an update on 9/11 physical and mental health findings and emerging conditions. In addition, the conference offered three breakout sessions, in which smaller workshops were offered about a variety of topics such as mental health, lower airway conditions, wellness techniques, and other topics.

8. Training in occupational illness and disability systems for New York Police Department (NYPD) Law Enforcement responders.

Law enforcement responders currently comprise approximately 40% of the overall WTC MMTP patient population. These responders access disability benefits and healthcare for line-of-duty injuries through specific systems like Line-of-Duty Injury, WTC Disability Pension, Heart Bill, and others, and do not participate in the NYS Workers' Compensation system. The results of the WTC MMTP Benefits Assistance Survey implemented in May/June 2009, indicated that clinical providers need and would like more information and guidance on those systems unique to NYPD law enforcement responders, how they interact with each other, and what information is needed from clinical providers in order to assist patients negotiating these systems. In response, the DCC

Member Services Core planned and hosted NYPD Disability Benefits Training on June 16th, 2010 at Bellevue Hospital. Attendees included social workers, mental health providers, benefits coordinators, and outreach workers from all WTC MMTP consortium clinical centers, the FDNY WTC MMTP, the WTC Environmental Health Center, and the WTC Health Registry. This one-day training offered information on Line of Duty Insurance (LODI), WTC Disability Pension, Heart Bill, health benefits for active and retired law enforcement responders, and other topics, and included presentations from law enforcement union attorneys and health and safety welfare officers, WTC MMTP and Law Enforcement Cardiac Screening Program personnel, NYPD Medical Division staff, and Pension Board members. Completed training evaluation forms indicated that attendees found the training useful and relevant to their work as well as informative and interesting.

9. Consortium-wide Social Worker Professional Development Series.

The results of the Benefits Assistance Survey (mentioned above) indicated a need for ongoing training and refresher courses for WTC MMTP social workers and benefits coordinators in a variety of areas key to their work within the program. In response, the DCC initiated a professional development series for social workers which included presentations and trainings on topics that social workers indicated a need to learn more about *via* the Benefits Assistance Survey The NYPD Disability Benefits Training was the first training of this series.

The second event in this series was a presentation and discussion on cancer-specific resources that was conducted during a monthly consortium-wide social work conference call in June of 2010. This presentation, conducted by an oncology social worker, offered information about the roles of social workers in assisting persons with cancer and their families, resources and benefits available for persons with cancer, and contact information for persons who are experts in this area.

The third event in this professional development series, the Grief, Bereavement, and End-of Life Issues Training was initiated, planned, organized, and implemented by the DCC MSC, in coordination with social workers from the Mount Sinai and Bellevue CCs, and the FDNY WTC MMTP. This training took place on April 12th, 2011 at FDNY. Attendees included social workers, mental health providers, and nurses from all WTC MMTP consortium clinical centers, the FDNY WTC MMTP, the WTC Environmental Health Center, the WTC Health Registry, Tuesday's Children, Police Organization Providing Peer Assistance (POPPA), and the WTC Tribute Center. Topics covered included general concepts of normal and abnormal grief, stages of grief, grief symptoms in children, and spiritual and cultural considerations in the dying and grief process. In addition, self-care techniques were demonstrated and discussed and various organizations presented on death-related resources, grief counseling services, and logistics, such as living wills and advanced directives.

DCC MSC work on the professional development series for social workers and benefits coordinators was ongoing and necessary to ensure quality service delivery and benefits counseling for WTC responders seen in each of the CCs.

10. Develop and implement a Consortium-Wide Social Services Resource Guide.

The DCC initiated, developed, drafted and piloted a consortium-wide social services resource guide. This work was spearheaded by the DCC MSC, but has involved participation of a task force of WTC MMTP social workers from the Queens, Bellevue, Long Island, and Sinai CCs. This resource guide contains information on various resources and benefits relevant to meeting the needs of WTC responders participating in the program. This was an ongoing project as these resources and benefits systems were frequently modified.

11. Experts Meetings

The DCC worked with the FDNY WTC program to coordinate a meeting of external experts in June, 2010, to discuss key clinical, medical and/or scientific questions that have arisen within the program. The forum consisted of PIs, members from NIOSH and the Steering Committee, and content experts. The format of the forum was for particular scientific questions to be posed ahead of time and for experts to present data on answers. After comprehensively reviewing these presentations, PIs and NIOSH created a standardized approach to particular clinical dilemmas. It was been agreed upon by the CC PIs and members of NIOSH to investigate further about GERD.

12. IRB issues

The DCC provided ongoing assistance to the CCs to determine the appropriate language to be used in consents and IRB submissions to ensure uniformity across the CCs. A "universal consent" was adopted by all CCs and, when signed by the responders, provided consent to utilize all research data from the MMTP visit of the time, and all past and future MMTP visits. The DCC assisted the CCs with updating and revising consents, protocol summaries, other IRB submissions, and outlined issues the DCC believed should be discussed with the CCs' IRBs.

The specific tasks the DCC assisted with included: circulating IRB approval letters and submissions to other CCs, providing template language to facilitate consent and protocol summary revisions, and developing standard operating procedures for projects that required follow up of other CC patients. IRB approval to link the WTC MMTP data with the State Tumor Registries and to use the Treatment program data for research purposes was obtained for all CCs. The IRB of two CCs required that Responders sign an updated consent that specifically mentioned linkages with State Tumor Registries. The IRB of three CCs approved a waiver of informed consent for responders who consented to data aggregation but who had not returned for a MMTP visit and thus had not had the opportunity to sign an updated consent.

The DCC assisted CCs in submitting applications to their respective IRBs for linkage with State Cancer Registries and the National Death Index. All CCs updated their consents with regard to these linkages and all respective IRBs approved of linkages with State Cancer Registries. Two IRBs had more stringent guidelines with respect to linkages and required that Responders sign updated consents that specifically described linkages with state Cancer Registries in order for their information to be included in linkage files. Files of enrolled and consented responders were sent to the NY and PA State Tumor Registries and the National Death Index. Additional linkages with NJ, CT, FL and NC State Tumor Registries are underway. These linkages will enhance public health reporting and disease surveillance activities.

13. Emerging conditions

All self-reported cases of cancer (through 12/31/09) were maintained in a Cancer Surveillance Database. These self-reports originated from a) responses to the Interviewer Administered Medical Questionnaire; b) the WebApp; c) responder notification to the Phone Bank, d) WTC MMTP Physician notification, and e) from Physicians outside of the MMTP. The process of updating the database to include cases reported through 9/11/2010 was begun. The Cancer Surveillance Team is reviewing every self-reported cancer in this database to ensure that diagnosis dates and cancer codes are accurate, to eliminate duplications or cases that were diagnosed prior to 9/11/2001, and to add newly identified cancers. This process requires a detailed review of all the WTC MMTP databases, clinical charts, and follow up with the CCs and treating physicians. In addition, each self-reported cancer is being assigned a Surveillance, Epidemiology and End Results (SEER) cancer code in order to facilitate reporting of cancers in a standardized way and matching with state tumor registries. Lastly, data from outside medical records, when available, is being abstracted and noted in this Cancer database.

The Cancer Surveillance Team also worked with the Data Management Core (DMC) to develop a Cancer Surveillance Form in TrialDB. Once completed, this will allow for improved cancer surveillance and appropriate evaluation of whether specific types of cancer can be identified as a WTC-related condition. In addition, this will allow staff from the other CCs to view and add to this information during Monitoring and/or Treatment visits so that our records are up-to-date and accurate.

The WTC MMTP Cancer Surveillance Team continued to work intensively to confirm all self-reported cancers. As suggested by the Expert Panel, all cancers were tracked and verified at this time. A senior, highly experienced nurse was hired to engage in the process of interviewing every responder who reported cancer and who had also consented to have their MMTP examination data aggregated. Similar to the process used for hematological malignancies, the case ascertainment process included a detailed review of MMTP charts, a brief phone interview with each patient, and extensive efforts to obtain external medical records that document the particular diagnosis. External medical records were reviewed and data pertaining to cancer type, histology, grade, stage, diagnosis date and other pertinent information were abstracted. Cases that are difficult to code were reviewed with an expert. Depending on the type of malignancy, each case was considered confirmed on the basis of official documentation pathology or other laboratory confirmation. In addition, data from the State Tumor Registries are being utilized to validate and supplement WTC Responder cohort data. A detailed classification scheme developed by FDNY, NIOSH and WTC MMTP is being utilized to determine whether a case is confirmed, probable, or possible. As suggested by the Expert Panel that convened in June 2010, exposure levels of all confirmed cancer cases will be analyzed to determine whether a dose-response relationship exists.

In addition to its case ascertainment efforts, the DCC also linked its data on cancer in responders with State Tumor Registries in NY, NJ, PA, CT, FL and NC (98% of the consented responders reside in those states). As residence patterns for responders shift, linkages with additional state Tumor Registries may be necessary. Such linkages will enable us to compare data on the numbers of cancers reported by responders with expected numbers of cancers in the general population. To obtain expected numbers of cancer cases, SEER data from the National Cancer

Institute (NCI) will be used. Ongoing analyses of NY State Tumor Registry data are currently underway.

14. Continuation of Ongoing Activities

A. Clinical Coordination The Clinical Coordination Core performed a variety of ongoing activities including: development of policies and protocols; coordination of meetings and teleconferences with a variety of program and other WTC entities; coordination of working groups; refinement of questionnaires; facilitation of compliance and scientific discussions; coordination with the DMC and HOC for programming and updated datasets; work with the Outreach/Retention Core to implement public reporting using the WTC website and to identify additional ways to disseminate information about health trends to responders and the public in a more timely way; work with the Disease Surveillance Team and HOC to develop case definitions for use in health reporting and scientific projects; facilitation of discussion among CC PIs about standardized approaches for common clinical dilemmas; provision of assistance to the CCs to determine the appropriate language to be used in "universal consents" and IRB submissions to ensure uniformity across the CCs; work with CC PIs and content area experts to develop diagnostic workups and referral algorithms (such as asthma, GI and GERD) as needed; establishment of a Mental Health Forum with NIOSH, FDNY, CC PIs, and mental health professionals to improve the mental health exam by determining better ways to capture data, administer the exam more efficiently, and utilize the data longitudinally; and, work with the CC PIs and NIOSH to identify and define elements of the Monitoring examination to be used in public reporting.

B. Outreach/Retention The Outreach/Retention Core performed a variety of programmatic ongoing activities including: coordination of outreach events and opportunities; planning, facilitation, and hosting of monthly consortium-wide calls; design, development, writing/editing, and production of both print- and e-newsletters; and, maintenance of factual and current content of WTC MMTP website. A list of newsletter and news articles can be found in the Appendix.

C. Health Outcomes The Health Outcomes Core performed a variety of ongoing activities including: tracking and reporting of health outcomes by the medical working groups and the disease surveillance team; provision of epidemiologic and biostatistical analysis support; mapping of data for uploading to a single platform; production of reports; and assurance of data quality.

D. Data Management: The Data Management Core performed a variety of ongoing activities including: operation and administration of all electronic data collection systems; provision of support for all application, end-user, and other technical issues; administration and maintenance of all databases containing program data; and provision of data extractions to fulfill data requests for scientific analyses and operational purposes.

E. Administration: The Administration Core performed a variety of ongoing program support activities including: provision of internal/external administration; ensuring of HIPAA/IRB compliance for PHI and ePHI; coordination of CC Administrator conference calls; Human

Resources management; management of consultant agreements; and preparation of grant renewals and budgets.

(b) Additional Aims and Accomplishments

The original Specific Aims were added to, in response to requests by NIOSH, to ensure that the program remained aligned with the evolving health needs of the WTC responders. The resulting additional Specific Aims and their respective accomplishments are given in this subsection.

1. Expansion of the cohort
    a. Supported eligible WTC responders who live outside the metropolitan NYC area.
        i. Created the National Program for eligible WTC responders who moved outside the metropolitan NYC area.
        ii. Worked closely with NIOSH to expand the National Program by contracting QTC Management Inc., to provide increased access to WTC MMTP services.
        iii. Worked closely with NIOSH to smoothly transition the National Program from QTC to LHI with the least possible interruption of services.
    b. Included two other categories of eligible WTC responder groups:
        i. New York State Responders: Funding was identified to enable NY State employees to enter this program by receiving a visit 1 examination at any of the NY State clinics under contract with the DCC. Letters were sent to the Public Employees Federation (New York) (PEF) and Civil Service Employees Association (New York) unions, as well as to the NY State Troopers' union to announce this opportunity to the many workers who were eligible. Letters were drafted by the DCC and revised and mailed by the first two unions to all their WTC responder workers. PEF also obtained agreement from their management to sign a memorandum of understanding providing release-time for both exam and travel time in this program.
        ii. Federal Responders: The DCC obtained funding to schedule visit 1 examinations for retired federal and "federalized" workers whose eligibility had been determined by Federal Occupational Health.
    c. Expanded the Phone Bank for additional eligibility determination, tracking contact information, and changing preferred CC.
    d. Expanded the MSC for the increased number of materials to be produced and distributed.
    e. Increased time needed for Data Entry for Visit 1 and legacy backlog and data cleaning.
    f. Data Management was required to expand its server capacity.
    g. Analysis of the resulting, large datasets was made more complicated and time-consuming.
    h. As the cohort size grew, the clinical coordination of activities became more complicated.
2. Addition of Patient Retention activities to Outreach, in response to recognition of the need to retain participants and persuade them to return for their annual monitoring visits.
    a. Convened outreach/retention site visits to the CCs. The purpose of these visits was to learn more about each CC's outreach and retention strategies, and how they were implemented. Assistance in evaluating those strategies and development of a program-wide collaboration and support strategy was implemented.

b. Communicated with CCs periodically to re-assess their retention needs and the appropriate role for DCC involvement.
c. Implemented and distributed an improved union retention report.
d. Sent out a program-wide retention letter mailing to responders who had not returned for monitoring and treatment visits for 24 months or longer. The letter informed these responders of changes and improvements made to the MMTP, flexible exam hours availability, convenient geographic locations, and other services available *via* the CCs. These letters were co-signed by the DCC and the individual responder's/recipient's CC PI, and were sent to approximately 9,350 responders. Utilizing call system data, each CC was able to investigate their CC-specific responses to the retention letter for performing targeted follow-up. As a result, the CCs achieved a favorable response rate of 10.6% (992 patients retained).

3. Worked closely with NIOSH and the CC PIs to develop and deploy the federally funded Treatment Program.
   a. Generated a list of conditions, procedures, and medications that would be covered under the federal Treatment Program, as well as a process for amending these lists based on the CCs evolving understanding of WTC-related conditions.
   b. Worked with NIOSH and representatives from each of the NY/NJ CCs to rapidly develop a set of forms, for both patients and healthcare providers to complete, designed to capture limited information (demographics, employment status, insurance status, and diagnoses) from each healthcare provider encounter which could then be used to generate the NIOSH-mandated MMTP quarterly reports. These forms were then programmed into the DCC WebApp into which all CCs entered the appropriate information.
   c. Worked with a health services expert to develop an estimate of the cost of providing responders with treatment for all WTC-related conditions.
   d. Because responders had increased rates of pulmonary function abnormalities, coupled with the emerging concern about interstitial lung diseases, the DCC worked, *via* a consensus-building process, with a group of pulmonologists familiar with WTC-related conditions to develop protocols for the evaluation of responders with pulmonary abnormalities and of responders found to have a low forced vital capacity and/or other abnormalities requiring further diagnostic evaluation. Finalized and distributed the diagnostic workups and referral algorithms to each of the CCs to ensure uniformity of follow-up evaluation for patients with abnormal pulmonary function tests, radiographic findings, or persistent pulmonary symptoms.

4. Developed a WTC-related disease tracking and surveillance, case ascertainment, and reporting system to identify and investigate any newly emerging diseases, conditions, or patterns among WTC responders.
   a. Initiated and implemented the system to fully investigate any newly emerging disease patterns, as well as case reports of any unusual conditions that may be WTC-related, such as Sarcoidosis (or "Sarcoid-like Granulomatous"), Interstitial Lung Disease, and Hematological Malignancies. All cases of leukemia, lymphoma and multiple myeloma have been tracked through September 11th, 2010, and case ascertainment is ongoing. Identification of these cases has employed a number of different search strategies to ensure that all cases are identified.

DCC closely collaborated with healthcare professionals from NIOSH who were leading this project, as well as with CC PIs, and the outreach team to determine a periodic follow-up examination that would appropriately capture the information needed to meet the goals of the program.

f. Collaborated with the CC PIs and NIOSH to design and modify the visit 1 medical questionnaires to address recall bias and to model them after the annual visit follow-up questionnaires. The revised questionnaire was designed and implemented into TrialDB by the DCC. Training in the administration of the questionnaire was provided to the CC clinicians.

2. Develop and distribute to responders educational materials focused on WTC exposures, health consequences, occupational exposure reduction, and information about benefit programs.
   a. Developed all materials in English, Spanish, and Polish; the principal languages spoken by the responders.
   b. Developed and distributed the initial WTC-related educational flyers and other materials describing the program to inform people about the program.
   c. Informed responders, in collaboration with labor unions and other organizations, about the importance of staying engaged in the MMTP.
   d. Educated each of the CCs about the importance of, and specific information contained in, the WTC-12 program and the deadline for filing. This program allowed responders to preserve their right to file for Workers' Compensation at a later date, if they became sick. Assisted each of the CCs in identifying the best way to reach their participant population to encourage them to file the WTC-12.
   e. Produced both written educational materials and several Public Service Announcements to raise public awareness of both the WTC-12 and the MMTP and its services.
   f. Worked with a health literacy expert to assess and improve the readability and usability of all WTC-related educational materials (including fact sheets, newsletters and web site materials).
   g. Produced written newsletters, e-newsletters, program brochures, and fact sheets about WTC-related topics. (A list can be found in the Appendix.)
3. Provide training to the CCs regarding the examination content and protocols, generation of reports to examinees (clinical/diagnostic impressions, referrals for care), educational efforts, data entry and transmission to the DCC and quality assurance/improvement protocols.
   a. In July 2004, training was conducted for the nurses and physicians of the (then) Monitoring Program at the Mount Sinai CC. The training covered the monitoring examination protocol and was conducted by Dr. Stephen Levin, DCC PI. The training provided an overview of the objectives of the Monitoring Program examination, the administration of the consent and questionnaires, the questionnaire content (particularly the skip patterns of the questions), and the contents of the immediate, urgent and final letters that were provided to the responders.
   b. The interviewer-administered mental health questionnaire (Diagnostic Interview Schedule, DIS) was still being developed and was ready to be implemented in January 2005. Training in the administration of the DIS was provided by Dr. Rebecca Smith to the CC mental health clinicians who were involved in providing mental health care.
   c. Because the protocol mandated the provision of Pulmonary Function Tests (PFT) to all responders at every visit, Dr. Paul Enright and Dr. Gwen Skloot provided hands-on PFT

training to all the CC PFT technicians. The DCC staff also provided training to the CC staff on the completion and provision of letters to the responders in a timely and consistent manner.

d. DCC staff went to each and every CC and conducted training sessions on the Monitoring examination protocols for the nurses, physicians and mental health clinicians as each CC became ready to see responders. The DCC also provided continuous support to the staff at the CCs for all aspects of the administration of the monitoring examinations.
e. The DCC was funded with the task of providing monitoring services to responders who were not living within the tri-state area (referred to as 'national' responders) and who, consequently, could not come in for examinations at one of the tri-state CCs. A National Program was established that was administered by the DCC. Occupational health physicians were contracted to provide the medical monitoring examinations to the national responders. DCC staff traveled to the clinics that were contracted through the DCC National Program and conducted training of the staff there.
f. Following recommendations from NIOSH, the DCC contracted with Yale Center for Medical Informatics (YCMI) to implement the questionnaires for the first follow-up (visit 2) examinations in an electronic system. Initially it was felt that the responses to the questionnaires would be entered into the electronic forms by the data entry staff at the DCC. However, as the DCC and YCMI worked together, it became apparent that a web-based data entry system that allowed the CCs to access the questionnaires would be beneficial. This would alleviate the need to copy the questionnaires and send them to the DCC for data entry by the CC, as was happening for the visit 1 examinations.
g. The DCC and YCMI collaborated to design the visit 2 questionnaires in TrialDB; a platform that was being used at Yale University and other medical centers across the nation to enter data for clinical trials. The questionnaires for the monitoring program, both self-administered and interviewer-administered, as well as the physical examination forms were designed, validated and made user-friendly for utilization by the clinicians for real-time interviews and examinations. The questionnaires were developed and implemented in TrialDB at different time periods. The DCC staff went to each CC and provided training in real-time data entry to the CC's nurses, physicians and other clinic staff. Group training and individual trainings were provided to various staff members. Standardized data-entry instructions for the questionnaires were provided to the CCs.
h. Because the implementation of the web-based forms occurred much later than the actual visit 2 examinations, several thousand questionnaires needed to be data entered into the TrialDB forms. The DCC took on the task of eliminating this data entry backlog. A data entry instruction manual for the various forms and training was provided to the data entry staff at the DCC by the team that collaborated with YCMI. With each additional year of continuation of the WTC Monitoring program, the DCC worked with YCMI to design the appropriate questionnaires associated with the visit. Upon completion of designing and testing the forms, the DCC staff provided in-person and web-based group and individual training to the end users at the CCs. Each time a form or set of forms for the monitoring examinations were developed in TrialDB, the DCC staff provided the necessary training and manuals to the requisite staff at the clinical centers.
i. The DCC discontinued its collaborative services with YCMI in 2009 and has been able to independently host TrialDB on its servers since then. Additionally, the DCC Data Management Core staff were able to independently design and implement any new forms

and other changes related to TrialDB. The DCC staff provided training and appraised the end users at the CCs of any changes to the TrialDB forms.

4. Develop outreach strategies and materials (*e.g.* newsletters and websites for use by the CCs in maintaining contact with responders for examinations and strategies to track responders with whom contact had been lost).
   a. Wrote and sent out invitations, an informational letter, a newsletter, and a flyer to all eligible responders.
   b. Adapted and expanded the Screening Program web site to become the MMTP website for use by the CCs and responders (www.wtcexams.org).
   c. Organized and conducted a press conference, featuring (then) Senator Hillary Rodham Clinton, to announce the start of the Monitoring program.
   d. Distributed announcements enhancing awareness among responders that the Monitoring Program provided an opportunity for new baseline examinations as well as follow-up examinations for those whose activities following the WTC attacks met the eligibility criteria.
   e. Held a conference for responders and their families, attended by more than 200 people, presented in English (with simultaneous interpretation into Spanish and Polish) providing information on the physical health, mental health, and socio-economic impacts of the WTC attacks on the responders.
   f. Created a method to track responders' contact information changes.
5. Conduct centralized and standardized eligibility determinations following recruitment by the CCs of responders eligible for the monitoring program but not previously examined in the initial screening program.
   a. Expanded the Phone Bank created for the screening program so that responders wishing to become part of the monitoring program could call a single, toll-free number.
   b. Modified the eligibility questionnaires and protocols established during the screening program to incorporate certain eligibility changes while continuing the process of using a centralized and standardized procedure for determining eligibility.
6. Develop a common database in which to centralize the data obtained from examinations, along with methods for data transfer from the CCs to the DCC in a manner compliant with HIPAA and New York State laws.
   a. Kept Logician® from the screening program for visit 1 data entry by DCC staff.
   b. Collaborated with the Yale Medical Informatics Team to adopt a web-based data capture system (TrialDB) for monitoring data from Visits 2 and 3, rolled-out TrialDB to all the CCs, and trained all personnel from all CCs in its use.
   c. Moved and deployed the TrialDB system to Mount Sinai to improve the ability of the DCC to utilize, modify, and rapidly analyze data collected in this web-based application.
   d. Published user-friendly data processing documentation including: 1) annotated data collection instruments to easily identify variable names utilized in the analytic data sets; 2) data cleaning rules and recommendations; 3) dataset format/labels specification and comments, 4) data collection Standard Operating Procedures (SOPs), and 5) SOPs for data entry.
   e. Continued to produce SAS® analytic datasets for research purposes.
7. Develop a Quality Assurance program for internal auditing by each CC and for oversight by the DCC.

a. Provided monthly spirometry (PFT) quality assurance reports, summary technician performance reports, and evaluation letters for each CC. Provided training for technicians whose performance needed improvement.
b. Collected a variety of program parameters including number of patients scheduled and no-shows; number of patients seen by monitoring and treatment program; type of visit conducted; number of non-English exams performed; and number of new eligible responders. These figures were reported monthly to the Steering Committee to permit assessment of responder monitoring and treatment exams for each individual CC.
c. Sent weekly and monthly reports to the CCs on results of data capture to assess the completion of data entry.
d. Certified monitoring examinations based on the following criteria: receipt of copies of a responder's consent form, face sheet (summary page which indicates which elements of a monitoring exam were completed), and final letter.

8. Provide administrative and statistical support and analyses as requested by the Steering Committee, NIOSH, the Scientific Program Administrator, the Expert Advisory Panel and other committees of the program, regarding outreach efforts, enrollment, examinations conducted, compliance with quality assurance procedures and policies, clinical findings and outcomes. Organized meetings and conference calls, prepared and distributed the minutes and action items from meetings and providing timelines for the completion of action items and updates on the status of action items as required.
   a. Provided ongoing administrative support to the Steering Committee by: organizing monthly Steering Committee meetings and conference calls, taking minutes, preparing and distributing a packet of materials (including the minutes and action items from those meetings/calls), reports on CC visits, retention rates, and outreach activities.
   b. Provided ongoing administrative support to NIOSH by organizing meetings and conference calls, providing statistics, enrollment information, and operational information when requested, preparing quarterly reports, discussing program issues, and resolving questions.
   c. Provided ongoing statistical support and analyses for research working groups.
   d. Organized a program-wide meeting of experts on the issue of "subject retention in longitudinal studies".
   e. Coordinated with the National Responder Program, FDNY WTC MMTP, World Trade Center Environmental Health Center, and the WTC Health Registry.
   f. Worked with the CC PIs and NIOSH to identify and define elements of the monitoring examination to be used in public reporting: symptoms, spirometry, standardized mental health exam scores and patient reports of physician-diagnosed diseases.
   g. Coordinated program-wide scientific activity describing the health of the WTC responder population, and their exposures.
   h. Tracked and reported health outcomes identified by the medical working groups and disease surveillance team, including the provision of data extracts, assistance in literature searches, participation in medical working groups, and the performance of data analysis.
   i. Implemented a customer service model that supported and serviced the CCs. In an effort to ensure collaboration with each of the CCs, multiple working groups were established to cover various areas that might have needed support. The DCC reached out to individual CCs biweekly to troubleshoot, triage, prioritize, and address any needed technical support. Topics included, but were not limited to:

i. Troubleshooting of the WebApp application: addressing issues such as correction of responder names and contact information, inability to locate responders, assignment of responders to the appropriate clinics, correction of dates of visit, and the generation of call lists.
ii. Troubleshooting TrialDB: addressing issues such as correction of responder names and contact information, inability to locate responders, assignment of responders to the appropriate clinics, correction of dates of visit, and data transfer protocol.
iii. Eligibility 'call list' generation
iv. Clarification of transfer protocol, phone bank functions, TrialDB, WebApp.
v. Data Entry of mental health interview into TrialDB: coordination with CCs, planning for retrieval of charts, receipt of the charts by the DCC, logging of charts, data entry, tracking of completed *cf.* 'not done' charts
vi. Refinements to the WebApp patient search functions based on the clinic preference algorithm.

9. Develop a Research Oversight Committee to review and evaluate requests to conduct research on data obtained from the responders and to review the manuscripts before publication.
   a. Created the Population Protection Committee (PPC) to evaluate requests for conducting research on WTC Screening, Monitoring, and Treatment Program participants. The purpose of the PPC was to assure that health needs of the responder population were fully considered and not harmed by any analytic projects or public statements based on screening program or MMTP findings.

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Inclusion of gender and minority study subjects.

Not applicable

Inclusion of Children

Not applicable

Materials Available for Other Investigators

Datasets have already been extracted for numerous operational and research projects.

Appendix: Newsletter/e-Newsletter Articles

2004: "WTC Responders Suffer Health Consequences", "WTC Medical Monitoring Funded for Five Years", "FYI Column: Winter Asthma", and "WTC Worker and Volunteer Medical Screening Program Provided Medical Exams to Over 12,000 Responders".

2005: "Responders' Conference Gives Hope and Help", "Clinical Centers Open", "WTC Responder Urges Return Visit", and "Ask the Doctor: Dr. Steven Levin", "Treatment Available for WTC-related Illnesses and Injuries", "Marvin Bethea: Paramedic, WTC Responder, Worker Advocate", "WTC Mental Health Services Available", "Free Educational Workshops".

2006: "Health Problems Continue: New Report Puts Numbers to WTC Responders' Experiences", "The Doctors Understand Our Issues", "New Disease Tracking System Under Way", "Congress Funds WTC-related Treatment for the 1st Time", "Workers Comp Filing Date Extended for WTC Responders", "Participating Clinical Centers", "9/11: Living With the Aftermath".

2007: "WTC Medical Treatment Gets Federal Funding", "Securing Resources for 9/11 Responders", "Patient-Activist Profile: Jeffrey Endean", "Ask the Doctor: Dr. Maria Padilla, Pulmonologist", "Disease Tracking Is Up and Running", "WTC-12 Deadline Fast Approaching", "Social Worker Profile: Jocelyn Pletz", "Benefits Counseling Services for WTC Responders", "Workers' Compensation Filing Date Extended for WTC Responders", and "WTC Wellness Group".

2008: "9/11's Emotional Effects Linger", "Ask the Doctor on PTSD: Dr. Fatih Ozbay, Psychiatrist", "High Blood Pressure Relieved by the 9/11 Neediest Medical Campaign", "WTC MM & TP Participating Clinical Centers", "Patient Profile: Dayne Clarke: Whatever Happens – I'll Come Back for Every Exam", "WTC MMTP Data: Number of People Treated for 9/11-related Conditions", "The State of Congressional Funding for WTC Programs", "9/11 Worker Protection Task Force Issued Recommendations to NY State", "Workers' Compensation Registration Deadline is August 13, 2008", "Save the

Date: WTC Responder Day (Saturday, 6/14/08)", "Mount Sinai Clinical Center Introduces its Director of Social Work Services", "Benefits Counseling Services for WTC Responders", "Free Legal Clinics for Workers' Compensation Registration", and "Law Enforcement Personnel Group – Active and Retired".

<u>2009</u>: (Winter) - "Dear 9/11 Responders", "What Does the WTC MMTP Do?", "WTC MMTP Timeline: 2001-2009", "What To Expect from Each of Your Medical Monitoring Exams", "9/11 Responder Profile: Freddy Noboa, WTC Treatment Program Patient", "Free Medical Treatment for 9/11 Responders", "Recent Findings from the WTC MMTP", "A Report on Responders' Mental Health from the Monitoring Program", "Common Conditions Seen in the Treatment Program", "Benefits Counseling Services for WTC Responders", "Meet Your Program Directors", "A Word on Runny Noses", "WTC Covered Conditions", and "WTC MM & TP Participating Clinical Centers". (Spring) – "Dear 9/11 Responders", "Clarification on Benefits Assistance", "Five Letters with Questions from 9/11 Responders and the Responses from the DCC", "Mount Sinai Offers Responders Choice of Clinic Locations", "Mental Health Counseling and Benefits Coordination", and "Workers' Compensation Legal Clinics to Begin Again in Fall".

<u>2010</u>: "Dear 9/11 Responders", "What Is Trauma?", "Journey Toward Recovery", "Ask the Therapist: Janet Lavelle, LCSW", "Ask the Psychiatrist: Dr. Alicia Hurtado, M.D.", "9/11 Responder on His Experience with Mental Health Treatment", "Things You Can do to Help Yourself and Your Loved Ones Feel Better", "In Their Own Words: How Responders Cope with the Emotional Impact of 9/11", "Mental Health Support Groups", "Cardiac Screening for Law Enforcement Members", "Workers' Compensation Registration Deadline for WTC Responders", "Legislative Update: 'Zadroga Act' – Key Provisions of the 9/11 Health and Compensation Act", "Responder Profile: Q&A with Paul Gerasimczk, Ret-NYPD Officer", "Leslie Garcia, LCSW: New WTCMMTP Social Work Coordinator", "Save the Date: May 7, 2011 – WTC MMTP Conference for Program Participants", "Senator Gillibrand Visits Staten Island CC", "Newest Mount Sinai Affiliate Brings Experienced Care to Staten Island", and "WTC MM & TP Participating Clinical Centers.