

## FDNY WTC Data Coordinating Center Summary Report, 7/1/04 – 6/30/11

### **REQUIRED QUESTIONS TO THE GRANT'S PRINCIPAL INVESTIGATOR:**

1. Has there been a change in the other support of key personnel since the last reporting period? – NO
2. Will there be, in the next budget period a significant change in the level of effort for the PI or other personnel designated on the Notice of Grant Award from what was approved for this project? – This cooperative agreement is ending and a contract has been awarded to FDNY to continue this effort.
3. Is it anticipated that an estimated un-obligated balance (including prior year carryover) will be greater than 25% of the current year's total budget? – NO.

### **INTRODUCTION**

During the award period there was significant expansion of the FDNY's World Trade Center (WTC) Data Coordinating Center (DCC) work output. The DCC enabled and assisted the FDNY-WTC Clinical Center of Excellence (CCE) to systematically collect reported symptoms, diagnoses, medication use, test results and disease surveillance information obtained at WTC monitoring and treatment visits. The DCC administration provided training to the clinical center for FDNY-WTC and DCC personnel as needed on data management, quality assurance, analysis and regulatory issues. In close collaboration with the CCE clinical experts, the DCC created treatment algorithms for upper and lower respiratory conditions that were the basis for the NYC Department of Health and Mental Hygiene WTC Adult Treatment Guidelines that FDNY co-authored and then helped revise. Through this medical education publication and our many peer-reviewed articles/reviews, the collective knowledge gained from our program was extended to other physicians so that similarly affected non-FDNY patients can receive state-of-the-art, clinically informed medical evaluation and treatment. A secondary benefit is that the FDNY Program developed instruments for screening, monitoring and treatment that would be directly applicable to victims of any mass disaster with exposure(s) resulting in potential health concerns.

### **A. SPECIFIC AIMS**

The Specific Aims of the program have evolved as different patient and program needs were recognized. This included the integration of NIOSH-funded treatment and disease surveillance into the FDNY pre-existing monitoring activities, with a concomitant enhancement of these monitoring activities.

### **B. STUDIES AND RESULTS**

#### **1. MONITORING**

**Specific Aim 1:** Expand and manage the Fire Department of the City of New York (DCC-FDNY-WTC).

- During the award period, there was significant expansion of the DCC-FDNY-WTC's work output. This included budgetary, disease/condition surveillance, epidemiological and statistical analyses at FDNY and through our scientific partnership with Montefiore Medical Center/Albert Einstein College of Medicine (the Montefiore subcontract). The management of the analysis staff included fostering greater collaboration among these subcontracted professionals and FDNY staff through expanded weekly on-site meetings with the PI, monthly meetings with all staff members, and frequent (at least weekly) meetings with team members responsible for specific projects. These

efforts resulted in the development of analytic staff members with a wide range of expertise and experience ultimately leading to greater productivity throughout the analysis unit.

**Specific Aim 2:** Provide or arrange for training to the clinical center for CCE and DCC personnel as needed on data management, quality assurance, analysis and regulatory issues (IRB, HIPAA, NIOSH etc).

- Extensive training of WTC clinical personnel on newly created/revised WC electronic medical record systems was provided by the DCC. In FY10, training expanded beyond staff centrally located at BHS Headquarters in 9 Metrotech Center to FDNY's five clinical satellite locations. DCC personnel were sent to visit each satellite for training on a variety of WTC systems including a newly created WTC Mental Health electronic medical record that was utilized at each location.
- WTC clinical staff training from Chief Medical Officers (DCC and CCE PIs) to CCE healthcare personnel was regularly provided in order to review WTC clinical monitoring/treatment guidelines and any new WTC grant-related regulations.
- DCC and compliance staff trained all WTC employees involved in consent administration on the meaning and significance of the consent forms and how to properly and effectively administer consent to Program participants in order to maximize member retention.
- DCC staff ensured compliance with the regulations of our affiliated IRB at Montefiore Medical Center.
- DCC staff members oversaw the training of the WTC Members Services staff on scheduling, eligibility verification, and other WTC Program-wide considerations. These training activities occurred mostly at our main facility (headquarters 9 Metrotech Center), but were also relevant to our satellites (throughout the metropolitan area).
- The FDNY WTC team of statisticians performed daily analyses on data collected by the WTC Monitoring and Treatment Programs, and Data Center staff was also responsible for troubleshooting and reconciling improper data uploads from every clinical station on every day of WTC Program operation. This provided a quality assurance component to the functionality of the CCE.
- Our supervising PFT technician (hired through our sub-contract & scientific partnership with Montefiore) supervised and provided quality assurance for performing PFTs and subsequent data collection. In FY10, maintaining high quality standards ( $\geq 85\%$  of PFTs receiving a QA score of an "A" or "B") required increasing the frequency with which trials were compared against each other, ensuring that multiple validations were performed, confirming the accuracy of quality scores that were applied, and many additional QA processes that had to be done on every PFT. In order to remain confident that data were passing appropriately through every step, a statistician performed a daily process to confirm that every FDNY member who signed in for a WTC monitoring exam each day has a corresponding "best PFT" result in the final data set.

**Specific Aim 3:** Assist CCE-FDNY-WTC with enrollment (FDNY Firefighters, EMS healthcare workers and Officers; incumbents and retirees), scheduling, follow-up; disseminate clinical reports and information to enrollees to meet our clinical mandates; provide clinical and general information; and provide early warnings with risk factor modification plans and treatment referrals. All of the above services reduced longitudinal dropout.

- In FY07, we entered into a contract with RTI to perform both outreach to and appointment scheduling for WTC FDNY retirees. As RTI's commitment to operate a WTC call center on FDNY's behalf came to a close in the final months of FY09, the DCC staff successfully managed the transition from an outsourced retiree outreach/contact campaign to an internally conducted WTC retiree retention initiative. By integrating RTI's expertise and lessons learned into building

new processes for FDNY WTC staff to implement, the DCC leveraged both industry-leading expertise and past experience to form a more efficient and effective outreach infrastructure. The smooth transition did not interrupt outreach operations in any way and allowed FDNY to dramatically reduce costs without sacrificing retention outcomes. With calls being made by a few highly-trained Member Services Representatives on site at FDNY, retiree participation in the WTC monitoring program continued to increase, and in the final year of the Program there were approximately four times as many retirees participating as there were before this outreach initiative.

- Another major area of RTI support provided by the DCC was the web-based scheduling program jointly developed to accommodate retiree WTC monitoring appointments, which was available to FDNY even after the transition to an internal retiree retention initiative. DCC staff performed iterative quality assurance on the RTI products throughout their life cycles on this project. Further, continuous quality improvement activities ensured that the WTC systems created continued to meet FDNY's evolving needs. The DCC was responsible for ensuring that the RTI scheduling and reporting systems fully met the needs of all WTC Program staff, and for maintaining the accessibility of the medical and mental health phone-based questionnaire for retired members who could not physically come in for a monitoring exam.
- An enhanced WTC electronic medical record suite developed by DCC programming staff was made available in FY10 to clinicians who perform WTC Medical Monitoring and WTC treatment. These applications were web-based so that they could be accessed from any satellite. The applications included additional QA features and easier access to longitudinal data that compared each patient's most recent findings to those of his or her previous exams, resulting in more informed and effective treatment decisions.
  - Our Wellness and Fitness Computerized electronic medical record system for monitoring exams is used for recording/reviewing annual medical exam data. In FY10 we updated the system to make the longitudinal data much easier for clinicians to access so that past data could be used not only for analysis by the DCC but, most importantly, by the clinician and patient to review progress and the need for diagnostic and/or treatment plan modifications. Among other improvements, the update made the longitudinal data much easier for users to read; important data are displayed in graphical form for a medical history "at a glance".
  - The Test Tracking System (TTS) was a data entry program which allowed for results of tests done by out-of-network vendors to be summarized by clinicians in a single electronic resource. TTS was populated with procedures authorized by FDNY/WTC physicians. The application allowed medical staff to easily identify which test results were received by FDNY and indicated which outstanding test results still needed to be requested from the treatment provider. Once results were received and summarized by a clinician, a PDF summary report was available throughout our entire EMR. The test types for which this system was developed include GI endoscopies, Chest CT scans, and Sinus CT scans. PFTs will soon be added to this system
  - The Lab Review System deployed in FY10 (a modification of the TTS system) allowed physicians to review WTC blood/urine test results electronically and to specify which follow-up actions (if any) were indicated for each case. The system increased clinical efficiency by prompting nurses to act on those results that required a nurses' action but not forcing them to review all tests. It also streamlined the mailing of results, as PDF files of the lab reports were printed and sent out to patients through an automated process. This significantly reduced the WTC clinical staff time required to mail blood test results to patients and thus allowed increased time for nurse-patient interactions. Near the end of the

grant period many of the TTS systems mentioned above were modified to include the additional features of the Lab Review System.

- The MH1 - A mental health electronic medical record that provides the highest standards of client confidentiality, with data stored separately from any of the physical health data. It is web-based enabling access from any CSU location. It also allowed for longitudinal comparison of a client's visit data. The data from this medical record are stored on FDNY servers, easily accessible to the proper users for analysis and reporting.
- Scanning system: hard copy reports from non-FDNY facilities have not been part of our electronic medical record system. This makes their retrieval, especially at the satellites, difficult. We have been phasing in an indexing and scanning system to integrate these reports into our system
- Digital Chest Radiographs: A new digital radiograph system has been installed and is fully operational. All chest radiographs are now available on-line for a radiologist official interpretation and for review by our WTC physicians through a separate software app.
- The DCC made individual FDNY WTC medical records available to our members upon request through a process designed to facilitate communication among WTC Programs (including Mount Sinai and LHI). This process was streamlined in FY10.
- The DCC facilitated the installation and networking of digital radiology equipment (partially funded by NIOSH) in the CCE. By connecting the Clinical Center's new machines to appropriate network resources, the DCC enabled chest x-rays and accompanying reports to be captured electronically. In FY10, the DCC staff coordinated the integration of the Radiology Information System (RIS) into FDNY WTC clinical processes. This allowed for enhanced patient care, as doctors anywhere in our network were able to view current and prior WTC Monitoring x-rays during their patient interactions. In FY10, these results were more seamlessly integrated into the FDNY WTC electronic medical record, so that fewer key strokes were required to bring up images/reports.

**Specific Aim 4:** Collaborate with the CCE-FDNY-WTC to provide statistical support and analysis in all aspects of the CCE-FDNY-WTC medical monitoring program for use by the CCE-FDNY-WTC, DCC-FDNY-WTC, Steering Committees, Scientific Oversight Committee for the FDNY-WTC medical programs, subcommittees and approved investigators. Aggregate results from approved studies were made available to the public (i.e., FDNY, Labor, Fire Service and Scientific Peer Reviewed Publications, Newsletters and Web sites). Data analysis plans submitted to NIOSH formed the basis for Specific Aim 4 activities.

- The DCC provided statistics on internal WTC clinic data, such as numbers of monitoring exams performed and numbers of satellite visits that assisted a variety of QA processes. These metrics informed operational decisions in the CCE, FDNY, and WTC Consortium and provided an overview for constructing more specialized or detailed analytical objectives. A sample of these operating metrics is provided below.

<b>Number Monitoring Patients seen this year</b>	<b>FF Active</b>	<b>FF Retired</b>	<b>EMS Active</b>	<b>EMS Retired</b>	<b>Total</b>
<b>1st Visit</b>	44	67	0	18	<b>129</b>
<b>2nd Visit</b>	54	208	0	21	<b>283</b>
<b>3rd Visit</b>	116	407	0	36	<b>559</b>
<b>4th Visit</b>	348	885	1	45	<b>1,279</b>
<b>5th Visit</b>	790	1,174	14	31	<b>2,009</b>
<b>6th Visit</b>	1,607	844	80	36	<b>2,567</b>
<b>7th Visit</b>	1,584	462	230	50	<b>2,326</b>
<b>8th Visit</b>	750	161	445	39	<b>1,395</b>
<b>9th Visit</b>	144	18	487	12	<b>661</b>
<b>10th Visit</b>	3	0	214	3	<b>220</b>
<b>Total</b>	<b>5,440</b>	<b>4,226</b>	<b>1,471</b>	<b>291</b>	<b>11,428</b>

- Project analysis was performed by staff hired through the Montefiore subcontract. Staff included both physical and mental health epidemiologists, statisticians, and statistical modelers. These professionals provided quality assurance; offered continuing education and supervision of in-house statisticians; ensured that information collected by the CCE is accurately captured and appropriately stored electronically; made information from the CCE available for operational reporting; made information from the CCE available for public health reporting, disease surveillance, and clinical decision support; created epidemiological analysis-grade data sets as needed; and performed descriptive analyses on WTC Program data to inform academic and clinical communities via peer-reviewed publications.

In order for precise incidence, prevalence, and other metrics describing the FDNY WTC cohort to be generated, QA/cleaning of critical data collected by the Clinical Center was performed. This process ensured that information stored was consistent with other similar data sets in the system, which proved vital for a network of integrated information sources such as the FDNY WTC Program. Common inconsistencies may have been originally caused by evolving definitions of similar fields (such as wording changes when a questionnaire is revised), user entry errors, or corruption in the course of transmission or storage. Allowing inaccurate or inconsistent data to remain in the WTC databases could lead to false conclusions and, therefore, inappropriate distributions of resources. To ensure FDNY was using high quality data, we performed audits through a variety of statistical methods to confirm standards of completeness, validity, consistency, and uniformity. Prioritization rules were applied so that critical data received the highest level of attention. For the FDNY WTC Program, the top data cleaning priorities were to ensure the accuracy of basic patient health information such as height, weight, alcohol use, tobacco use, WTC exposure, answers to diagnostic questions in the self-administered questionnaires, and pulmonary function tests. These variables included multiple records on each of over 15,000 cohort members in tables spread throughout the FDNY system. Successfully undertaking this data cleaning process required both the epidemiological and data management expertise provided by our Montefiore subcontract.

The following WTC data categories were put through intensive QA during the Program.

1. Spirometry (9/11/01 through 9/10/09)
  2. Physical characteristics required for PFT percent prediction equations and trends analyses (height, gender, race/ethnicity, age, years of service to FDNY, body weight)
  3. WTC exposure variables (arrival time and cumulative months)
  4. Cancer Registry data
  5. Disability pension data
  6. Date of death and WTC-relatedness
  7. Prioritized sections of the self-administered physical and mental health questions
  8. Blood test results
  9. Prescriptions written by FDNY WTC physicians and those filled by FDNY members
- Clinical epidemiologists at Montefiore took the lead on drafting studies for peer-reviewed journals. Each proposed project underwent a formal FDNY-WTC data analysis review that included senior analysis staff. First, a line of potential inquiry was introduced and vetted at our internal weekly data review meeting. The initial evaluation centered on the hypothesis and study objectives. If sufficient merit was found to prioritize the proposal, then a review occurred as to whether existing data sets are adequate to address the objectives, the extent of QA needed to prepare the existing data sets for analysis, and the appropriate statistical methodology to be used. Each project was also assessed to determine whether it would require new or amended IRB approval.
  - The DCC analytic plan and proposal review process resulted in more than 40 FDNY-WTC studies that have been published or accepted for publication from 9/12/01 to the end of the grant period, 6/30/11. A full list is included in the final pages of this summary report.

**Specific Aim 5:** Provide administrative reports to the NIOSH Scientific Program Administrator, the CCE-FDNY-WTC, the Steering Committees and Sub-committees based on statistical aggregate analyses related to the CCE-FDNY-WTC core data set (recruitment, patient screenings, compliance, adverse events, diagnostic findings, disease surveillance and patient outcomes), or other needs arising during this program and its associated projects or studies.

- In order to better address the evolving reporting needs of both NIOSH and the FDNY WTC Clinical Center that occurred throughout the award period, we took many steps to improve our reporting infrastructure. This included using an advanced web-based Oracle Business Intelligence reporting system that provided current metrics and trend analyses to appropriate WTC staff across all clinical locations. A dedicated DCC staff member assessed reporting needs and designed reports, while another prepared data for reporting purposes and programmed the reports in the Oracle environment.
- The DCC took on the expanded NIOSH reporting requirements to provide monthly, quarterly, and yearly administrative reports that included both monitoring and treatment data. These reports included “rolling 12” metrics that reflect activity in the 12 months preceding the end of the reporting period for most tracked data points. Gathering these numbers required, in many cases, manipulating joins among multiple databases that could not be accomplished by administrative staff. Specially trained DCC employees were needed to meet the operational reporting requirements of a Program that grew in complexity over time.
- The DCC responded to a Consortium-wide shift in WTC Program focus toward patient retention by prioritizing those metrics for monthly reports disseminated to the WTC Steering Committee. A sample of these retention reports submitted to NIOSH is included below.

	<b>Retention (6/30/11)</b>				
<b>% of participating patients to have Monitoring Exams <i>who completed the previous visit</i></b>					
<b>(% of total cohort shown in parentheses)</b>					
	<b>FF Active</b>	<b>FF Retired</b>	<b>EMS Act.</b>	<b>EMS Ret.</b>	<b>Total</b>
<b>First Visit</b>	<b>N/A (100)</b>	<b>N/A (100)</b>	<b>N/A (100)</b>	<b>N/A (100)</b>	<b>N/A (100)</b>
<b>Second Visit</b>	<b>99 (99)</b>	<b>91 (91)</b>	<b>100 (100)</b>	<b>84 (84)</b>	<b>95 (95)</b>
<b>Third Visit</b>	<b>99 (98)</b>	<b>89 (81)</b>	<b>100 (100)</b>	<b>82 (69)</b>	<b>94 (89)</b>
<b>Fourth Visit</b>	<b>98 (96)</b>	<b>86 (69)</b>	<b>100 (100)</b>	<b>82 (56)</b>	<b>92 (82)</b>
<b>Fifth Visit</b>	<b>93 (89)</b>	<b>73 (50)</b>	<b>100 (100)</b>	<b>78 (43)</b>	<b>86 (70)</b>
<b>Sixth Visit</b>	<b>84 (75)</b>	<b>57 (28)</b>	<b>99 (99)</b>	<b>77 (33)</b>	<b>78 (55)</b>

- Our contracts with RTI significantly expanded and empowered the reporting capabilities of the FDNY WTC Program. These allowed us to carefully track retiree contact information including eligibility verifications completed, appointments scheduled, retirees who decline appointments, etc. Such information enabled FDNY to optimize our patient retention and minimize longitudinal dropout. The WTC scheduling system put in place with RTI continued to aid our retention activities even after the transition to an in-house retention plan.
- Our contract with ESI (pharmacy benefits management program) markedly increased the reporting capabilities of the FDNY WTC Program with respect to prescription medication usage. These reports allowed us to carefully track medication program performance (including number of prescriptions filled, costs of prescriptions filled, balance of generic and brand medications used, etc.). Such information enabled FDNY to contact patients with medical recommendations based on accepted standards of care (e.g., recommended GI diagnostic testing when suffering from chronic GERD who required medication for more than 3 months).
- In FY07, the NIOSH WTC CCE Grant funding to FDNY began coverage for specialized, out-of-network diagnostic testing (formerly provided by ARC). Reporting of these tests became more complex as the Treatment Program matured. The DCC staff, which developed additional statistical and analytic expertise, was responsible for the management of this information.

**Specific Aim 6:** Store, catalog and disseminate information resulting from the WTC long-term medical monitoring program.

The DCC developed a Data Sharing Plan using a proposed data warehouse infrastructure. The DCC was transitioning to provide two types of information on a public-access website: basic aggregate cohort descriptors and definitions of the data fields available for research. Basic de-identified descriptors would include aggregate data on cohort numbers in monitoring and treatment, demographics, WTC exposure characterization, and key diagnostic and treatment outcome measures. Definitions of the data fields available for research would include the text of FDNY-WTC Monitoring Program self-administered questionnaires and a list of key data elements that have already been quality assured and are ready for data warehousing, in addition to a limited sample set of data to illustrate what could be provided to external investigators on a prioritized basis. If requests by external researchers were received by this Program, the required data sets with associated documentation would be made available only to users who have IRB approval, external funding that includes support for the data preparation by the FDNY-WTC DCC, and provide written agreement to a data-sharing agreement that provides commitments to: (1) use the data only for research purposes, (2) not to identify any individual participant surmised due to unique demographics even though the data is de-identified; (3) secure the data using appropriate computer technology; and (4) destroy or return the data after analyses are completed.

- The DCC also scanned paper-based WTC medical records and captured them as electronic files. This initiative dramatically increased the efficiency of records retrieval for clinical staff and contributed further to the richness of the FDNY WTC electronic medical record.

**Specific Aim 7:** Provide administrative support and coordination to the CCE-FDNY-WTC, Steering Committees, Subcommittees, and NIOSH Scientific Program Administrator.

- Bi-directional communication between the DCC and CCE administration, which occurred on a virtually daily basis throughout the award period, allowed lessons learned in each center to be shared with the other.
- Representatives from the DCC attended and were active participants in every WTC Steering Committee meeting. FDNY also hosted every other WTC Steering Committee meeting at Headquarters and coordinated resources to support those gatherings.
- FDNY CCE and/or DCC principal investigators or designees attended informational meetings with membership and leadership of each of our unions (UFA, UFOA, EMS) monthly throughout the grant period. This allowed us to update our patients and union members on findings and plans.
- In FY06, we cooperated with the NY/NJ WTC Consortium in the design and revisions of self-administered mental health and physical health questionnaires to the extent of providing an executable file designed and programmed by FDNY data staff.
- The DCC principal investigator was responsible for co-leading the effort to coordinate an expert scientific meeting on the appropriate methodology for approaching cancer incidence analysis in this unique cohort for the benefit of all NY/NJ Consortium clinics.
- The DCC principal investigator was responsible for working closely with the NIOSH Scientific Program Administrator and his representatives on developing processes for transitioning from the cooperative agreement to a contractual agreement. This included definitions and processes for:
  - f* Enrollment
  - f* Certification of Diagnoses
  - f* Credentialing of Physicians
  - f* Claims Submission
  - f* Pharmacy Benefits Program Rules
  - f* Consent Forms
  - f* Reporting

## **2. TREATMENT**

**Specific Aim 8:** Integrate all aspects of the FDNY WTC Monitoring & Treatment Program including: administration, the clinical center, data coordinating center, patient care coordination, claims processing for out-of-network services and pharmaceuticals

- Electronic systems created and run by the DCC, with input from the CCE, allowed this integration to occur. A sample operational report of quarterly treatment visits is included below.

<b>Quarterly Treatment Visits this year</b>	<b>7/1/10 to 9/30/10</b>	<b>10/1/10 to 12/31/11</b>	<b>1/1/11 to 3/31/11</b>	<b>4/1/11 to 6/30/11</b>	<b>7/1/10 to 6/30/11</b>
<b>Physical Health (PH)</b>	3,295	3,635	3,930	3,536	14,396
<b>Mental Health (MH)</b>	3,952	4,106	4,150	4,409	16,617
<b>Total</b>	<b>7,732</b>	<b>8,405</b>	<b>8,539</b>	<b>8,462</b>	<b>33,138</b>

- The DCC facilitated the establishment of satellite clinics that were able to perform both WTC monitoring and treatment. This initiative included the development and deployment of a new, fully secure, web-based electronic medical record system that provided all WTC clinicians—regardless of location—easy access to each patient’s comprehensive WTC-related electronic medical record.
- To further integrate monitoring and treatment (physical health and mental health), the DCC also developed and deployed a companion WTC Treatment application that provided a fully secure, web-based environment for clinicians to authorize WTC-related treatment/procedures.
- Worked with FDNY sub-contractor to deploy an web-based portal for non-FDNY healthcare providers within our network to submit claims electronically for WTC-related treatments/procedures that FDNY physicians had authorized
- The Test Tracking System described above (see Specific Aim 3) streamlined the record-keeping processes necessary to actively manage WTC referrals to out-of-network diagnostic procedures.
- ***Diagnostic Testing and Focused Treatment***

In October 2007, the FDNY-WTC Program piloted the transfer of funding sources for diagnostic testing services from the American Red Cross to NIOSH. At the end of December 2006, the full transition was made, and WTC-related diagnostic testing services began to be paid for exclusively by NIOSH. The data source used for the tracking of outside referrals is the FDNY Workers’ Compensation Claims System (WCCS), which processes all out-of-network diagnostic testing related to the WTC. Because of lags in the claims processing system beyond our control, we used the payment date instead of the service date for categorizing all numbers chronologically in reports submitted to NIOSH.

In these reports, a “new” client is defined as a member who has never received the particular service in question; if this same member had a different type of service previously, he would still be counted as a new client. Repeat clients received the service in question at a previous time during the period of either ARC or NIOSH funding. The total number of services in each period applied to both new and repeat patients. These reports will be revised and updated to meet NIOSH requirements post 6/30/2011 under the Zadroga Act.

**Specific Aim 9:** Use clinical experience and data analysis to characterize the evolution of WTC-related health conditions, including disease surveillance of new health conditions among WTC responders.

- This was a shared specific aim by both the CCE and the DCC. The CCE performed disease surveillance since September of 2001. The DCC designed systems to electronically capture, transfer, and analyze the information gathered during clinical visits. These data served as the foundation for numerous publications in peer-reviewed medical journals.
- The DCC also supported the disease surveillance efforts of the CCE by maintaining an electronic cancer registry that combined data from multiple sources. Such information included patient self-reports and data imported from the New York State Cancer Registry; matches with additional state registries were also pursued. The FDNY electronic cancer tracking system was vital in preparing information for incidence analyses. This successful effort formed the basis for other disease surveillance initiatives.
- The DCC staff was instrumental to the maintenance and smooth functionality of the FDNY-WTC Cancer registry as well as previously-established systems capturing disease data, as mentioned above. The DCC took the lead on analyses of the disease surveillance data in an effort to characterize the evolution of WTC-related health conditions.

### **C. SIGNIFICANCE**

The DCC enabled and assisted the CCE to systematically collect reported symptoms, diagnoses, medication use, test results and disease surveillance information obtained at WTC monitoring and treatment visits. The DCC designed and deployed electronic medical record systems to achieve these aims. In close collaboration with the CCE clinical experts, the DCC created treatment algorithms for upper and lower respiratory conditions that were the basis for the NYC Department of Health and Mental Hygiene WTC Adult Treatment Guidelines that FDNY co-authored and then helped to revise. Through this medical education publication and our many peer-reviewed articles/reviews, the collective knowledge gained from the FDNY WTC Program was extended to other physicians so that similarly affected non-FDNY patients can receive state-of-the-art, clinically informed medical evaluations and treatments. A secondary benefit is that the FDNY WTC program developed instruments for screening, monitoring and treatment that would be directly applicable to victims of any mass disaster with exposure(s) resulting in potential health concerns.

### **D. FUTURE PLANS**

This cooperative agreement is ending on 6/30/2011. FDNY has been awarded a contract by NIOSH to continue the DCC under the Zadroga Act. During the next year our efforts will be directed in continuing our current services to our patients while at the same time adding or redirecting resources to comply with new contractual obligations.

**E. MEDICAL LITERATURE FROM THE FDNY WTC MEDICAL PROGRAM – Submitted as of 6/30/11:**

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[http://www.wtcexams.org/pdfs/clinicians\\_guide\\_to\\_irritative\\_and\\_respiratory\\_problems\\_v3.pdf](http://www.wtcexams.org/pdfs/clinicians_guide_to_irritative_and_respiratory_problems_v3.pdf), accessed May 3, 2005\*
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