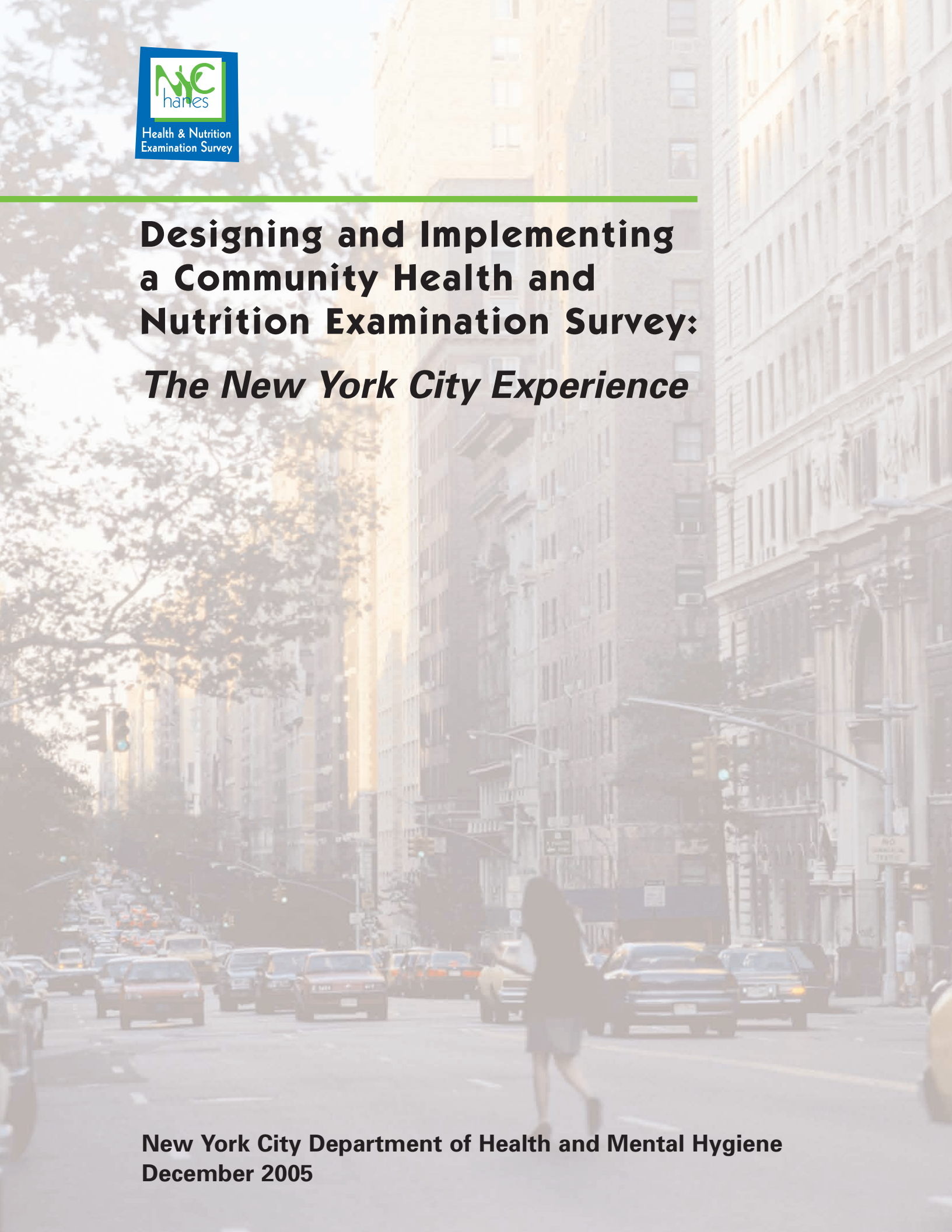


Designing and Implementing a Community Health and Nutrition Examination Survey:

The New York City Experience

New York City Department of Health and Mental Hygiene
December 2005

Designing and Implementing a Community Health and Nutrition Examination Survey:

The New York City Experience

Dear Reader:

We are pleased to present this guide that outlines lessons learned from the 2004 New York City Health and Nutrition Examination Survey (NYC HANES). The NYC HANES is an important component of the New York City Health Department's data-driven approach to reducing the burden of disease. Data from this survey enables us to assess the prevalence of select health conditions in New York City residents – conditions whose recognition often require a physical examination. Moreover, we can now assess the extent of residents' awareness and successful management of these conditions. This information is used to inform programs, target initiatives, and, in the future, track progress in improving health, as outlined in our major health policy initiative – Take Care New York. We hope this guide will be useful to organizations in any stage of planning and implementing a community HANES.

Thomas R. Frieden, M.D., M.P.H.
Commissioner
New York City Department of Health and Mental Hygiene

Lorna Thorpe, Ph.D., M.P.H.,
Deputy Commissioner, Division of Epidemiology

How to Use this Manual

This document was written to share initial lessons learned through the New York City Health and Nutrition Examination Survey (HANES) experience. Here we present a rationale for conducting a community HANES, describe critical planning steps that precede implementation and discuss issues that might arise during data collection. Specific examples from the NYC HANES survey are provided in colored boxes to illustrate many of the concepts presented. This manual does not begin to encompass all the planning steps and decisions, documents, forms and protocols associated with NYC HANES. Rather, it is written as an instructional guide, offering pointers based on our experience. We hope this manual will prove useful to those either beginning to contemplate a community HANES or those who have already begun the planning process. As a complement to this manual, we have developed a website (www.nyc.gov/health/nychanes) containing many of the documents created for and used during the New York City study. Readers who are already in the planning stages may find this site especially helpful. Additionally, hypertext links to key documents on the website can be found throughout the text.

Acknowledgements

When the New York City Department of Health and Mental Hygiene announced plans to conduct the first Community Health and Nutrition Examination Survey in the United States, several state and local health departments had already begun to discuss the importance of carrying out their own examination surveys. Some of these states began to meet in 2004 to discuss early HANES planning efforts as part of the U.S. Centers for Disease Control and Prevention (CDC) Environmental Public Health Tracking Program. At that time the State & Community HANES Intergovernmental Planning Project (SHIPP) was also created. We are indebted to the members of SHIPP from the states of Washington, New York, New Mexico, Wisconsin, California, Connecticut and New Jersey for helping to identify a set of questions that we could attempt to answer based on the experience of New York City's HANES. We would also like to acknowledge the support provided by the CDC Environmental Public Health Tracking Program for this document. Thanks also to all of the NYC HANES staff and the NYC DOHMH employees whose hard work and diligence resulted in the success of our survey.

The opinions expressed in this manual are entirely those of the NYC Department of Health and Mental Hygiene.

Table of Contents

I. Introduction

In 2004 the NYC Department of Health and Mental Hygiene conducted a community Health and Nutrition Examination Survey (HANES), called NYC HANES. The survey was modeled largely on the National Health and Nutrition Examination Survey, conducted by the U.S. Centers for Disease Control and Prevention, with adaptations to account for the uniqueness of New York City and to obtain measurements of local interest. This section provides a brief history of the national survey, presents a rationale for conducting a community HANES, and describes the collaboration between the NYC Department of Health and Mental Hygiene and the Centers for Disease Control and Prevention.

A. History of NHANES

In the early 1960s, at the request of Congress, the National Center for Health Statistics conducted the first nationwide survey to determine the amount, distribution and effects of illness and disability in the United States. A representative sample of 6,672 civilian, non-institutionalized adults from 18-79 years of age, from all parts of the country, was selected and asked to undergo extensive health interviews and physical examinations. Results from that survey, called the Health Examination Survey, Cycle I, and the subsequent congressionally mandated surveys that followed have been providing a snapshot of the nation's health for more than 40 years. The eighth cycle of the survey now operating is the National Health and Nutrition Examination Survey (NHANES) which began in 1999 and collects information on both children and adults. Data from NHANES have influenced generations of U.S. public health policy and planning decisions. NHANES findings have been the basis for key interventions that have had profound impacts on the health of Americans, including developing growth chart standards for children, adding folic acid to foods to prevent birth defects, and eliminating lead in gasoline.

B. Why Conduct a Community HANES?

State and local health departments face many public health challenges for which there are insufficient data to guide local strategies, particularly around chronic health conditions. In order to develop meaningful public health intervention strategies, health departments need to understand the burden of these diseases on their communities. Although

The Origin of HANES

The National Health and Nutrition Examination Surveys (NHANES) are designed to provide an overview of the amount, distribution and effects of illness and disability in our country as a whole. Three initial studies, called the National Health Examination Surveys (NHES I-III), focused on health questions. Four subsequent surveys included dietary interviews (NHANES I-III and the Hispanic Health and Nutrition Examination Survey). NHANES is now conducted on a continuous basis, with approximately 6,000 individuals interviewed every year. The goal of these continuing surveys is to monitor changes in the health needs of the nation's growing population.

For more information, visit the NHANES website at **www.cdc.gov/nchs/nhanes.htm.**

NHANES provides excellent data on many conditions, national data cannot adequately characterize the health of a state or city. In New York City, the diversity of the population impedes the extrapolation of national statistics to the local level. For example, more than 36 percent of New York City's population is foreign-born compared to just 11 percent nationally.

The New York City Department of Health and Mental Hygiene (NYC DOHMH), like many state and local public health agencies, uses several data sources to assess the health status of its residents. These include routine surveillance data (hospital admissions and vital statistics), citywide telephone surveys, and targeted sub-group or community surveys. These sources provide valuable insight into the health of New Yorkers, and are used to guide public health policy. However, they do not provide objectively measured prevalence estimates or information about the awareness, treatment and control of chronic conditions such as high blood pressure and diabetes, nor can they capture the true prevalence of conditions which may be undiagnosed or under-diagnosed. By conducting a community HANES, the NYC DOHMH is now able to assess these measures, and compare citywide estimates against an established national survey with similar components.

C. Collaboration with the Centers for Disease Control

The NYC HANES was a collaboration between the NYC DOHMH and the country's principal health statistics agency, the National Center for Health Statistics (NCHS), a division of the U.S. Centers for Disease Control and Prevention (CDC). Because of NCHS's experience in designing, conducting and analyzing NHANES, its assistance and input was invaluable to the NYC DOHMH. From the earliest stages, senior staff at NCHS helped NYC HANES planners conceptualize a community HANES for New York City that would observe the standards and rigor of the national study but be adapted to local needs and capacity level. Through a contractual arrangement NCHS also consulted on many aspects of the study design and operations, particularly data collection, data management and data technology issues. NCHS staff was instrumental in training NYC's senior investigators and NYC HANES managers, as well as field and clinic staff. NCHS also played an important supporting role throughout the entire data collection and processing phases.

The Objectives of NYC HANES

- To estimate the number and percent of people in the NYC population with selected diseases and risk factors.
- To estimate citywide awareness, treatment and control of selected diseases.
- To estimate prevalence, awareness, treatment and control of selected diseases among a limited set of demographic subgroups, identified by race/ethnicity, gender, broad age bands and borough.
- To monitor prevalence of selected environmental exposures in NYC.
- To analyze risk factors for selected diseases in NYC.
- To establish a population-based serologic repository that can be used to explore emerging public health issues in NYC.

II. Designing A Community HANES

This section explores critical decisions to be made early in the design and planning stages of a community HANES. The choices made at this stage serve as the blueprint for the entire survey.

A. Determine Key Goals, Objectives and Subject Area Priorities

1. What does the agency already know, and what are the limitations of these data?

Many states and cities compile statistics on leading causes of morbidity and mortality, such as diabetes, obesity, heart disease, asthma and/or infectious diseases. Health behaviors such as sexual practices or cigarette smoking are also commonly tracked. Thinking about the types of morbidity and mortality data already available within your organization will help determine your study objectives.

Like most local health agencies, NYC uses death certificates and hospital records to gauge trends in morbidity and mortality. Other information on self-reported conditions are also collected through an annual population-based, telephone survey. While these sources provide useful information on various health conditions, there are some important limitations. For example, undiagnosed conditions are not reported and often there is poor recall of health conditions and behaviors. In addition, self-reported blood pressure, cholesterol level and other health measures may be inaccurate, and truthful responses to sensitive questions can be hard to obtain.

2. What does the agency want to find out?

A review of the available statistical data and survey results can help to identify specific health conditions in the community that merit investigation. For example, planners had some insight into the burden of cardiovascular disease and diabetes from hospitalization records and death certificates. However, what was not known was how many people suffered from or were aware that they had these conditions, or were currently undergoing treatment. Having information on the prevalence, awareness and treatment of chronic diseases and their precursors, as determined through objective measurements, can now help the chronic disease programs target their outreach and public information efforts.

3. What conditions can only be evaluated via a physical exam, and/or a biological specimen?

Nationally, NHANES provides unique and valuable information on health conditions that require:

- Physical examination (e.g., blood pressure, height and weight)
- Biologic specimen testing (e.g., fasting plasma glucose and blood lipid profile)
- Information on sensitive conditions that are not easily ascertained by a brief telephone survey (e.g., mental health and sexual behavior)

Because it is more cost-effective to collect non-sensitive, self-reported data via other approaches (such as telephone interviews), HANES organizers may wish to concentrate on conditions that are best measured by a clinical examination, laboratory analysis and private and confidential questionnaire methods.

For example, if an agency wants to explore the level of mercury exposure among adults in the community, surveillance data or telephone interviews would not be very useful, since this information is collected and reported only for a select number of people who are sufficiently concerned or knowledgeable about mercury. And only those who have been recently tested will likely recall their test results. The most accurate way to assess community mercury exposure would be to conduct biological testing on a representative sample.

[View: NYC HANES data & research questions *http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_design_dandr_questions.pdf]*

B. Solicit Input

As organizers begin to think about what conditions to measure, it is important to solicit input from programs within the agency that will be using the data. The first step is to identify programs within the agency that should be involved. Their support and cooperation will be essential to the study's success:

Two basic questions to ask during planning are:

- What do these agency programs want to know?
- What do they believe are the best methods for collecting this information?

C. Determine the Feasibility

After creating an inventory of study topics and measures, study organizers should determine how best to obtain each piece of information. These methods will include ascertaining infomation through survey questions, conducting physical assessments and/or collecting blood and urine for biological testing. The study planners' task is to determine which of these methods may be best suited to answer each question, and whether it can realistically be accomplished. For example, asthma can be assessed via lung function testing. However, such tests require specialized equipment and skilled staff. Alternatively, obesity is evaluated via a simple physical examination that measures height and weight, and central adiposity. Striking a balance between the desire to have a physical measurement and the practical and logistical costs of obtaining it is an important consideration.

In determining the best way to measure conditions of interest, study planners should always strive for standardization with NHANES' methods. Comparability between national rates and community-level rates can only be achieved if conditions are measured using standard protocols. NYC HANES planners worked closely with NCHS staff during the study design phase to ensure comparability.

DOHMH Programs Involved in Conceptualizing NYC HANES

Office of the Commissioner

Division of Epidemiology
- Bureau of Epidemiology Services

Division of Health Promotion and Disease Prevention
- Bureau of Chronic Disease Prevention
- Bureau of Tobacco Control and Prevention

Division of Environmental Health Services
- Environmental Public Health Tracking Program
- Environmental & Occupational Disease Epidemiology

Division of Disease Control
- Public Health Laboratories
- Bureau of Sexually Transmitted Disease Control

Division of Financial & Strategic Management
- Bureau of Communications

Pesticide Exposure in New York City

DOHMH is a part of a national effort led by CDC's National Center for Environmental Health (NCEH) to build an Environmental Public Health Tracking Network **(http://www.cdc.gov/nceh/tracking/)**. NYC's work involves creating a pesticide tracking system to evaluate the extent of pest infestation and risks to health from pests as well as pest control.* Though substantial data is available on pesticide use from several sources such as a statewide registry of reports of pesticide applications, telephone surveys conducted by DOHMH, and the agency's poison control center, exposure data was still lacking.

NYC's Environmental Public Health Tracking staff worked alongside NYC HANES planners to incorporate an evaluation of pesticide exposure into the physical examination component of the survey. Working with the NCEH laboratories at CDC, planners determined that for relatively little additional cost, urine samples could be collected and analyzed for metabolites of two important classes of pesticides commonly used for structural pest control in cities – organophosphates and pyrethrins/pyrethroids. Collecting urine samples also enabled NYC HANES to evaluate urinary metals analytes and to create an additional specimen repository for future analysis.

These analyses will permit NYC to answer several key questions:

- How does an urban population's pesticide exposure differ from that of the nation as a whole?
- Do exposure profiles differ among major demographic sub-groups?
- What characteristics are associated with higher and lower exposures?
- Does exposure to banned pesticides persist?

*Kass D, Thier A, Leighton J, Cone J, Jeffery N (2004). "Developing a comprehensive pesticide health effects tracking system for an urban setting: New York City's experience. Environmental Health Perspectives. 112(14): 1419-23.

HIV Testing and NYC HANES

In the initial planning phases, NYC HANES planners considered conducting testing for HIV as part of the main study. However New York state law requires that persons tested for HIV undergo pretest counseling and that those who test positive for HIV undergo a face-to-face post-test counseling interview. This type of lengthy counseling represented a logistical challenge for planners, as they wanted to minimize both the time burden on the participant and the invasiveness of the study components, so as not to impact response rates. Ultimately, the decision was made to not include HIV testing in the NYC HANES protocol.

Health Measures Assessed in NYC HANES

NYC HANES planners worked closely with NCHS staff to ensure comparability with NHANES data collection protocols for all aspect of the survey.

Medical exams

- Blood pressure (systolic and diastolic)
- Height, weight, arm and waist circumference
- Venipuncture and urine collection

Blood tests

- Lipid profile
- Diabetes measures (fasting plasma glucose, glycohemoglobin)
- Cotinine (a by-product of tobacco smoke)
- Hepatitis C virus
- Herpes simplex 2 virus
- Mercury, cadmium and lead

Urine tests

- Exposure to pesticides and metals

In-person interviews

- Health status questions
- Nutrition questions
- Tobacco use
- Reproductive health
- Mental health

Audio Computer Assisted Self Interview (ACASI)

- Sexual experience
- Drug and alcohol use

D. Identify the Target Population

Determining your target population is the first and most important step in designing any survey. The target population may be evident from the priorities within your agency. The final study component list and feasibility factors will also influence your choice. For example, if your research goals involve learning more about the diseases and health conditions that impact children, your target population may be limited to persons under 18 years old.

Time and budget considerations will also directly impact the number of participants that can be recruited into any study. Planners will need to narrow their focus to identify the target population that will best match the research goals.

NYC HANES was designed as an adult survey to assess adult risk behaviors and conditions; therefore the target population consisted of adults aged 20 and older. Each community will need to determine its' population of interest. Planners wishing to include children will need to consider additional factors such as parental consent and logistical challenges involved in interviewing and examining this population.

E. Determine Optimal and Feasible Budgets

Whether conducted at the state or community level, a HANES can be a large, expensive project. In the planning stages several different strategies may need to be considered to arrive at the most cost-effective study design.

1. What are the major costs to consider?

The first step in planning a HANES budget is to determine the major cost categories that are required to implement the survey plan. For NYC HANES, major costs included:

- Staff
- Facilities and equipment
- Sample design and selection
- Data collection systems
- Materials
- Transportation
- Participant remuneration
- Laboratory analysis

2. How much will it cost to collect the data?

The next step is to estimate how much money will be needed to fund each major category. For example, if new staff members are to be hired, the number and type of staff will need to be estimated, as well as the associated salary costs. If your study design requires a large sample, this will affect the costs associated with materials and laboratory analyses. Also consider whether remuneration will be provided as an incentive for recruitment, and if transportation to clinic facilities will be provided.

3. How much money is available and from where?

Study organizers should have an initial idea of how much money is available from departmental funds or special project allocations. If local funding is not available or is not sufficient, there may be state, federal or private grant funding available. Planners may also want to consider partnering with academic institutions that can offer critical intellectual, staff and monetary resources.

NYC HANES was financed primarily through city funding, however several components were funded from other sources. For example, grant funds were used to finance the environmental bio-monitoring component (metals and pesticides) while the New York State Department of Health supported the environmental tobacco smoke component.

4. How can the survey design and operations be tailored to fit a specific budget?

As often happens, the funds available to implement a project may be lower than the projected costs. To reduce costs, survey organizers should consider maximizing existing resources and relationships. To arrive at the most cost-effective plan, NYC HANES planners tried to take advantage of currently available equipment, supplies, physical facilities and DOHMH personnel. Although some equipment and space were borrowed from other parts of the agency, extensive purchasing of specialized equipment and supplies was still required.

NYC HANES' Target Population

New York City's population is a heterogeneous mix of ethnic and socioeconomic groups throughout five boroughs (The Bronx, Brooklyn, Manhattan, Staten Island and Queens). To adequately sample this broad mix, the NYC HANES targeted adults in every borough and included non-English speakers, illiterate individuals, pregnant women, and the mentally or developmentally disabled. However, adults living in group quarters such as college dormitories, homeless shelters, or nursing homes were excluded.

F. Develop the Sampling Design

After decisions regarding the target population and budget have been made, the next step involves developing the sampling design. Important considerations include determining the sample size that will be needed and deciding how participants will be selected into the study.

1. Estimate the Required Sample Size

The size of your target sample will depend on the total population, the expected disease and exposure prevalence in that population, your estimated response rate, and the budget available. The goal is to choose a sample size that provides sufficient statistical power to accurately estimate the prevalence of diseases of interest that can be evaluated given your budget, staff and time limitations.

The NHANES sampling frame is developed through contract with Westat, a private consulting firm. In consultation with NYC HANES project leaders Westat constructed the NYC HANES sample design. Using NHANES sample size calculations, as well as locally available data, Westat calculated the sample needed to produce reliable NYC estimates for conditions of interest, such as diabetes and hypertension. A minimum target sample size for NYC HANES of 2,000 participants was set in order to ensure enough statistical power to estimate important health conditions in NYC. Because of the diversity of the New York City population, there was no need to over-sample different demographic groups.

2. Estimate the response rate

Once the sample size has been determined, you will need to estimate how many households will need to be contacted in order to recruit enough participants to achieve your required sample size. Response rates reflect the degree of success you will have in contacting selected households, completing a short eligibility interview, and enrolling selected survey participants into the study.

To get an idea of the expected response rate, it may be possible to assess response rates from similar surveys conducted in your community. It will be important to draw from the experience of programs that have conducted population surveys, or university researchers that may have carried out similar studies. If the expected local response rate is low, this can introduce bias into the study findings and potentially threaten the study's statistical power and accuracy. In this case organizers may want to consider increasing the target sample size. Several factors are likely to affect a response rate:

- Staff training and skills: Well-trained staff members are better equipped at reaching residents of selected households, using screening instruments properly, and persuading selected residents to participate.
- Vacancy rate: A certain proportion of households will be vacant, influencing the number of households that need to be approached. This information is available from the U.S. Census Bureau. Vacancy rates can also be estimated from American Housing Survey and American Community Survey data. In NYC a triennial Housing and Vacancy Survey is conducted that provides neighborhood-scale vacancy rates.
- Appointment availability: The availability of early morning, evening and weekend appointments for both the clinic setting and/or home visits can increase response rates.
- Burden of participation: The amount of time required to complete the interview and exam, and how far a participant must travel will also directly affect response rates.
- Incentives: Providing remuneration, a prize or other incentives, such as transportation, to participants can increase the response rate.

NYC HANES Response Rate and Estimates

For several reasons NYC HANES planners anticipated lower response rates than those attained in NHANES. Experience had shown that response rates in Northeastern urban cities tend to be lower than in other parts of the country. Additionally, NYC HANES field staff would be less experienced overall in survey techniques than NHANES staff.

The study design team assumed that:

- 8 percent of all households approached would be vacant.
- 80 percent of selected households would successfully complete an initial screening questionnaire used to determine eligibility.
- 75 percent of selected eligible survey participants would successfully complete the interview and examination, yielding a
- 60 percent overall response rate.

Based on these estimates, NYC HANES was designed to target:

- 4,082 dwelling units, to yield
- 3,004 screened households, to obtain
- 2,657 subjects and
- **2,000 participants** completing the full examination.

3. Develop a Sampling Plan

The goal of the NYC HANES sampling plan was to obtain a representative sample such that every eligible person in the population of interest had an equal chance of being selected. The best way to achieve a representative sample is to randomly select members of the population. In most situations this may not be a feasible option due to the cost and logistical difficulty of preparing a representative list of all residents. The commonly used alternative approach is a multi-stage probability sample. NHANES uses a four-stage probability sample to obtain a representative sample of the U.S. population. For NYC HANES, a three-stage cluster-sampling plan was used.

G. Develop a Data Collection Model

Once the sampling plans are in place, the survey needs to be operationalized. While operational plans will vary depending on geographic area and the characteristics of the community, some important issues should be considered:

a) How will the staff approach households to determine eligibility? Will they go door-to-door, obtain telephone numbers and call, or contact residents by mail? (A combination of methods could be used.)

b) Where will identified survey participants go to complete the survey? Will interviews and exams be done in their home, at a fixed-site facility or a mobile facility?

NYC HANES Sample Design

Stage 1: Select geographic segments

- The geographic segments, consisting of a block or group of proximal blocks within a given NYC census tract, were selected based on probability proportional to size (PPS).
- 144 geographic area segments were randomly selected across the five boroughs of the city.

Stage 2: Select households

- All households in a selected geographic segment were enumerated.
- A random sample of households was generated from all enumerated households in the segments. This included the targeted number of households and a reserve sample to be used if response rates were below target and the sample size was too small.
- A sample of 5,699 households (including the reserve sample) was randomly selected from the 144 segments.

Stage 3: Select individuals

- Adults within households were selected for inclusion in the study.
- Eligible adults age 20 and older were randomly selected based on an a *priori* computer-generated sampling flag.
- The adult sampling procedure in NYC was designed to select either zero, one, or two adults from each selected household, depending on the total number of adults residing in that unit.
- To be sure that all adults had the same probability of being selected, sampling rates were varied based on the number of people in each household.
- 2000 adults were targeted for selection (the final number depended on the household composition encountered).

[View: NYC HANES sample design description
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_design_sample_description.pdf]

c) Given the data that is being collected, what equipment and space will be required?

d) What staffing model is right for the survey? Should existing staff be used, new staff hired, or will outside staff be contracted, either individually or through a business entity?

e) How will data be captured? On paper, electronically or a combination of the two? What are the existing data capacities within the agency?

f) Given answers to the above questions, what are the discreet groups of people/jobs required?

NYC HANES Operational Model

NYC HANES operations took place in three distinct operational groups:

1. Field Operations – Recruitment staff approached and screened selected households to determine participant eligibility.
2. Clinic Operations – Clinic staff working at fixed-site facilities conducted interviews and exams.
3. Central Office Operations – The central office served as the coordinating center for all NYC HANES operations. The staff's main functions included scheduling and facilitating appointments; processing household visits and follow-up information; handling data management; and coordinating communication among staff.

H. Establish the Timeline

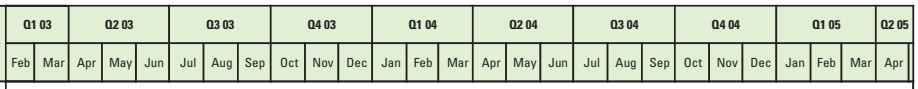
Once key decisions about the data collection model have been made, the next step is to develop an overall timeline for the project. Discrete phases that will require allocated time may include:

- Determining the sample design
- Developing the survey content
- Preparing the study protocol & Internal Review Board (IRB) review
- Staff recruitment and training
- A staff dress rehearsal
- Data collection
- Data preparation
- Data analysis and dissemination

As you establish the schedule for your community HANES, remember to include some leeway for delays and unanticipated problems.

NYC HANES Timeline

ID	Task Name	Start	Finish	Duration
1	**PHASE I: STUDY DEVELOPMENT**	2/3/2003	12/30/2003	47w 2d
2	Solidify proposal with consultant	2/3/2003	7/15/2003	23w 2d
3	Determine sampling design	5/1/2003	7/30/2003	13w
4	Prepare study protocol	7/15/2003	8/29/2003	6w 4d
5	IRB protocol review	9/1/2003	4/29/2004	34w 4d
6	Content development	2/3/2003	9/30/2003	34w 2d
7	Application development & implementation	6/2/2003	12/30/2003	30w 2d
8	**PHASE II: PILOT TESTING**	1/15/2004	4/30/2004	15w 2d
9	Pilot Phase 1: Mock interviewing	1/15/2004	2/13/2004	4w 2d
10	Pilot Phase 2: Revisions	3/1/2004	3/22/2004	3w 1d
11	NYC deployment	3/29/2004	4/12/2004	2w 1d
12	Staff training	5/11/2004	5/20/2004	1w 3d
13	Dress rehearsal	5/14/2004	6/2/2004	2w 4d
14	**PHASE III: DATA COLLECTION**	6/16/2004	12/17/2004	26w 3d
15	**PHASE IV: DATA PREPARATION**	12/20/2004	4/11/2005	16w 1d
16	**PHASE V: DATA ANALYSIS & DISSEMINATION**	3/1/2005	on going	on going



III. How to Get Started

Once the data collection model, including the survey design and content, has been finalized it is time to begin planning the study implementation. The first area discussed below – writing the survey protocol – is an opportunity to think through many of the details of data collection, management of the day-to-day operations of the survey, and development of a more detailed budget.

A. Write the Survey Protocol and Obtain Approvals

Careful documentation is the key to organizing the study and ensuring that all procedures are standardized. The first step toward standardization is development of a clear and detailed protocol. The writing process will shed light on many issues that are best thought through at this early stage. The development of the survey protocol is also a critical piece in gaining Institutional Review Board (IRB) approval for your study. While getting IRB approvals is not unique to a community HANES, there are several issues that may require particular attention.

[View: NYC HANES Protocol & Attachments:
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_protocol.pdf
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_protocolatta.pdf]

1. Informed consent procedures and materials

All studies will require that participants recruited into the study give informed consent. In developing informed consent procedures for a community HANES, planners should give special attention to the burden placed on the participant due to the potentially lengthy interview and exam. Also consider any potential risks due to invasive procedures, as well as potential benefits (e.g., provision of exam results and remuneration). Finally, consider any future uses of data (e.g., specimen storage).

NYC HANES Informed Consent

NYC HANES produced and distributed to all eligible participants a brochure that included the informed consent form, and explained the purpose, procedures, potential risks and benefits, and voluntary nature of the study.

All materials were written for comprehension at a sixth grade reading level. In addition to English, the consent form was translated into seven major languages (Arabic, Cantonese, French Creole, Italian, Korean, Russian, and Spanish). Because NYC HANES involved a specimen repository, separate consent for future storage had to be given by each participant.

The informational brochure and consent information were provided to eligible survey participants during recruitment. Upon arrival at the NYC HANES clinic, the clinic coordinator explained all components of the survey and obtained written consent for both the survey and specimen repository.

[View: NYC HANES consent & future specimen informed consent:
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_consentform.pdf
http://www.nyc.gov/html/doh/downloads/pdf/hanes/hanes_start_specconsent.pdf]

The NYC HANES Confidentiality Statement

The NYC HANES confidentiality statement informed participants that their data would be de-identified and combined with that of other study participants for both analysis and publication. All NYC HANES staff attended a mandatory training, conducted by study coordinators, on confidentiality protocols and penalties for breaching protocol. To further ensure protection against requests, subpoenas and other demands for data, NYC HANES obtained a Certificate of Confidentiality from the National Institutes of Health [42 USC 241(d)].

[View: Confidentiality statement:
http://www.nyc.gov/html/doh/download/pdf/hanes/HANES_start_confid.pdf]

NYC HANES Report of Findings Procedures

At the Clinic:

Preliminary reports on body mass index and blood pressure were provided at the conclusion of each clinic visit. Participants also received targeted, personalized referrals in response to abnormal or unhealthy test results, and proactive age- and gender-specific health care referrals for clinical preventive services.

Results from Laboratory Testing:

If a participant's laboratory tests indicated the presence of disease, the participant was notified (either by letter or phone call) of the condition. If results indicated highly abnormal levels or an emergent health condition, a phone call was placed to the participant upon receiving the findings from the laboratory. All participants received a cover letter and a final report of findings by mail, once all the laboratory test results were available. These were sent to participants on a rolling basis.

Referral System:

It was expected that some survey participants would have questions about their test results ranging from basic health concerns, to options for further testing, to the availability of medical care in their area. To answer these questions, a dedicated phone referral hotline, staffed by DOHMH nurses, was established. Hotline staff received specialized training on conditions covered by NYC HANES. The staff was also equipped to provide participants with information regarding free or low cost health care facilities in their borough.

[View: Report of findings protocol, and referral website
http://www.nyc.gov/html/doh/downloads/hanes/HANES_plan_report.pdf
http://www.nyc.gov/html/doh/html/downloads/hanes/refdirectory.shtml]

2. Developing a confidentiality statement

Documenting the procedures that are in place to protect the confidentiality of participant information is essential for a community HANES. A confidentiality statement should be developed and provided to potential participants to specifically address how the data will be used. Organizers should also clearly acknowledge if any state or local regulations require that personal information be disclosed to health authorities for reportable conditions.

3. Recruitment Procedures

Due to the effort and expense involved in conducting a community HANES, repeated contact will likely be necessary with households that may not initially be interested in order to achieve a high response rate. Refusal conversion procedures (methods to convince reluctant participants to enroll) and the number of times that a household can be contacted will need to be carefully considered and outlined in your protocol. In the NYC HANES protocol, "hard" and "soft" refusals were defined and the maximum allowable number of contacts per household was specified.

4. Report of Findings & Referrals

Because a community HANES will involve the measurement of health indicators, organizers will need to consider if any test results should be reported back to participants. If so, decisions about what will be reported (all results or only abnormalities), and where and when reports will be provided (immediately after the clinic or home exam, or through mailed notification after the study) will need to be made. Study planners should also consider:

- Protocols for handling abnormal results
- Additional resources to be provided to participants
- How participants' questions or concerns will be answered
- Whether abnormal individual results are reportable to state or local health departments

B. Create a Detailed Budget & Develop Contracts

Budgets are rarely fixed objects. While the initial budget plan provides a good outline for overall budgeting, a more detailed budget will need to include confirmed cost figures from contractors and suppliers. Prior to purchasing supplies and equipment, or paying salaries, clear procedures for tracking purchasing and spending should be developed with the agency's fiscal office.

Once contracting needs have been determined, organizers should begin the contracting process. It can take weeks or even months to find the right contractor, negotiate the price, and execute a final contract. Some of the more time-consuming aspects of negotiating the terms of contracts may involve data ownership, publicity and publication rights. It is important that your agency go into the selection and negotiation processes with a clear idea of how these issues should be handled. Looking at similar agency contracts executed with the vendors under consideration, or similar vendors, can inform this process. Key issues to consider when developing a contract are the exact task to be performed, the deliverables expected and the time schedule for the submission of reports and other deliverables.

*[**View: Lab contract check list***
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_contractcheck.pdf]

NYC HANES Major Budget Areas

Sample Design: Contracted services required to design a population sampling scheme and to draw the sample.

Central Office: Labor costs for the staff supervising data collection.

Publicity and Communication: Costs associated with press-related activities and production of recruitment materials.

Screening and Interviewing: Labor costs to approach and screen selected households.

Facilities and Exams: Labor, equipment and supply costs required to operate fixed-site clinics.

Information Technology: Labor, hardware and software needed to collect the study data.

Training: Costs to conduct training sessions with all interviewers, central office and exam staff.

Remuneration: Compensation for all survey participants for their participation in the study, including study incentives ($100 per participant) and transportation.

Laboratory: Costs of conducting laboratory tests, including analysis kits, materials, specimen storage and shipping, and labor.

Weighting: Costs associated with computing survey weights that are used in the analysis of the data to account for the sample design and ensure that data findings are representative of the NYC population.

*[**View: Percentage cost of major budget items***
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_budget.pdf]

C. Obtain Physical Facilities, Equipment and Supplies

An examination study requires particular attention to facilities, equipment and supply needs. For example, conducting a physical examination may require appropriate examining rooms, patient gowns and specialized equipment such as blood pressure cuffs and scales for weight and height measurements.

If specimens are being collected, specialized laboratory supplies will be needed for collection, processing and storage. A step-by-step review of processing procedures will be required to determine the number and types of specimen collection tubes needed, the transportation requirements, and the necessary processing procedures and equipment. In determining this process, study planners will want to include agency or outside staff responsible for transporting, processing, and analyzing specimens.

NYC HANES: Use of Outside Contractors

NYC HANES organizers decided to use outside contractors for data systems design, laboratory analysis, and other services. All contracts specified requirements including timeliness, reporting protocols and confidentiality.

National Center for Health Statistics provided:

- Adaptation/development of data collection software
- Staff training assistance

Westat provided:

- Sample design
- Calculation of analytic weights

State, federal and private laboratories performed:

- Analysis of blood and urine specimens

Car services provided:

- Transportation for selected survey participants

Language interpretation services provided:

- Interpretation assistance in the field and at NYC HANES clinics

NYC HANES Facilities/Equipment/Supplies

Facilities

Each of the four NYC HANES clinics included:

- Three private interview rooms
- A phlebotomy room used for blood draw, processing and storage
- A bathroom
- A waiting area

Exam Equipment

- Desktop manometers
- Blood pressure cuffs
- Digital floor scales
- Telescopic stadiometers
- Adult stethoscopes
- Metal tape measures
- Paper gowns

Information Technology Equipment

- Laptop computers
- Touch screen monitors
- Headphones

Laboratory Supplies

- Barcode scanners
- Dymo label writers
- Datamax printers
- Datamax labels
- Transport coolers
- Refrigerators/freezers
- Cryovials (various sizes)
- Centrifuge & centrifuge tubes
- Safety goggles
- Mercury spill control kits
- Urine container cups with lids
- Tubes (10 ml, 15 ml, 25 ml)
- Transfer pipettes
- Racks

[View: NYC HANES equipment and supplies
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_equip.pdf]

NYC HANES Specimen Processing

The NYC HANES staff developed detailed flow charts that outlined all procedures for collecting and processing specimens at the clinic, transporting the specimens to the central DOHMH laboratory for additional processing, and shipment of the processed specimens to the contracted testing laboratories.

In developing these procedures, NYC staff worked closely with NCHS, the DOHMH staff responsible for the transport of specimens, and the contracted laboratories to ensure compatibility with NHANES and compliance with quality assurance and quality control procedures.

[View: Specimen processing flow chart
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_specflow.pdf]

NYC HANES Overall Survey Schedule

NYC HANES opted to undertake field recruitment in a sequential manner. Therefore, exam site operations were started and finished in one area before moving to another area. This decision was based primarily on budgetary and staff restraints, and a desire to target public relations and outreach efforts in support of participant recruitment. Because so many New Yorkers work in the borough of Manhattan, regardless of their borough of residence, the Manhattan clinic operated throughout the survey.

June & July 2004

- Field recruitment in the Bronx, Brooklyn and Staten Island
- Clinics operating in the Bronx, Brooklyn and Manhattan

August & September 2004

- Field recruitment in Manhattan and Queens
- Clinics operating in Manhattan and Queens

Study Extension through December 2004

- Limited field recruitment in all communities (clean up)
- Clinic operating in Manhattan only

D. Develop the HANES Schedule

Planners will need to determine the survey schedule; this will include the time period for the entire survey, as well as the day-to-day operational schedules.

1. The survey schedule

The overall schedule will most likely be based on several factors including the survey budget, the data collection model, the geographic area to be covered, and the laboratory capacity for specimen processing. In planning the overall schedule, consider the following:

- How long will it take to interview and examine the survey sample to achieve the targeted response rate?
- How will the rollout of the survey occur?
- How will staff recruit participants, sequentially through neighborhoods, or in all areas simultaneously?
- How will decisions about recruitment times and operations affect the schedule of exam sites?

2. The operational schedule

Decisions about the schedule of daily data collection activities will depend upon both the survey schedule and the staffing model. Some issues to be considered in developing the operational schedule are described below.

Exam Schedule: Determine when survey participants are most likely to be available for the interview and exam – daytime, evenings or weekends. This information will be helpful in constructing the best schedule to recruit and examine participants. Key questions include:

- How many appointments need to be offered in total?
- How many appointments need to be offered per day/per week?

NYC HANES Clinic, Field, and Central Office Schedules

Clinic

- Monday through Friday daytime appointments – 7:30 am to 5:00 pm
- Monday and Wednesday evening appointments – 5:00 pm to 9:30 pm
- Saturday appointments – 8:30 am to 5:00 pm
- Sunday appointments were added during the last month of data collection

Field Recruitment

- Weekday hours – 11:30 am to 8:30 pm
- Saturday hours – 8:30 am to 4:30 pm
- Sunday hours – 10:00 am to 4:00 pm

Central Office

- A staff person was available in the central office at all times field or exam site operations were scheduled (see above)
- Additionally, a senior staff person was available evenings and weekends via a rotating manager-on-duty system

*[**View: NYC HANES operational survey schedule***
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_opsched.pdf]

- What is the timeframe needed to conduct all of the exams - weeks, months, etc?

Recruitment Schedule: If participants are recruited from their homes, be sure to consider the following:

- When are interviewers most likely to find people at home?
- How often should staff recruit – 5, 6 or 7 days per week?
- What time of year will the survey be conducted?
- How late in the day can recruitment occur?

Central Office Schedule: The role played by the central office will impact its operational schedule. In NYC HANES, the central office served as an information hub, and thus operated during all recruitment and examination hours.

E. Assess Logistical Needs

Planning also involves a critical assessment of the operational resources necessary to manage the staff and schedule. Two major logistical concerns will include transportation and communication.

1. Transportation

Any community HANES will involve challenges related to transportation, both for staff members and survey participants. Though NYC HANES encompassed the five NYC boroughs, a community HANES that covers a wide geographic area may face even larger, more complex challenges than those described here.

Staff: If recruitment staff will be going door-to-door, you will need to determine how they will travel to each neighborhood, and how examination staff will travel to examination sites. Depending upon the geographic area, public transportation networks may cover many of the selected neighborhoods; however organizers should verify that bus and train schedules match field recruitment hours. Because staff may not be familiar with all the selected areas, providing detailed maps and directions is advisable. Study planners will also want to consider transportation safety issues for staff traveling at night.

Survey participants: Survey participant travel to examination sites is another important consideration. Planners will need to gauge whether most participants will be able to travel on their own or if the study will need to provide transportation. This will largely be dependent on vehicle ownership rates among the sample population, the distance participants will need to travel, and the availability of public transportation. Special thought will need to be given to elderly or infirmed survey participants. Planners may also want to prepare detailed directions to clinic locations that can be provided to participants during recruitment.

Supplies & Specimens: If the data collection model involves multiple examination sites, a system for transporting supplies to and between the sites may become critical. If blood and urine specimens are to be collected, specialized transportation (equipped with dry ice or other temperature controls) may need to be arranged between the sites and the lab, or at the labs where processing will occur.

2. Communication

Recruitment and examination staff will need to communicate frequently with survey organizers and the central office staff. Survey organizers will also need to communicate routinely with all staff members, in order to provide assistance and troubleshoot problems. Having the appropriate mechanisms and technology in place will be critical to good communication.

NYC HANES Transportation

New York City has an excellent and extensive public transportation system. Clinic locations were selected for their proximity to public transportation, allowing many staff members and survey participants to use trains and buses. However, because of the breadth of the survey area, other arrangements were needed for staff, participants and supply movement in some neighborhoods.

Staff:

- Field recruiters used a combination of public transportation, department-owned cars, and personal cars (with reimbursement for mileage).

Study participants:

- Most participants used public transportation to reach clinic sites.
- Taxi service companies were contracted to provide transportation for elderly and infirmed participants, and to participants who refused to travel otherwise.

Supplies:

- A transportation system was developed to pick-up blood and urine specimens from the exam sites for delivery to the processing laboratory.
- Transportation systems were also developed for periodic delivery of supplies to the exam sites.

NYC HANES Communication

With nearly 50 NYC HANES staff members spread across numerous neighborhoods and in various clinics on a typical day, maintaining on-going communication was a critical issue. NYC HANES organizers designated the central office as the communication hub for all survey operations, serving as the collection and dissemination point for all field and clinic staff. Senior study staff worked from the central office (when not in the field or at a clinic). All senior staff, field staff and clinic coordinators were issued pre-programmed cell phones with two-way walkie-talkie and conference features. These formed the backbone of the day-to-day communication system. Additionally, standard meeting times were scheduled for clinic, field and central office staff. A weekly newsletter kept all personnel informed of study news and events.

[View: NYC HANES sample weekly newsletter
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_work_newsletter.pdf]

F. Data Management: Systems for Capturing Important Data Elements

1. Identify Important Data Elements

The data collection model you choose will largely determine how survey results will be collected, captured, delivered and stored. Many system options and combinations exist, including manual paper data gathering, electronic recording and electronic transmission. Factors to consider include:

- Budget
- Existing data infrastructure
- Collaborating institutions' contributions and needs
- Field, clinic and central office logistics
- Staff skills
- Timeliness of data needs

Whatever system or combination of systems is adopted, data collection will need to include:

1. Tracking of recruitment efforts and outcomes at the household level (e.g., no response, participant enrolled).
2. Tracking all identified survey participants and their enrollment status (all participant information should be linked to household information).
3. Scheduling and noting any special circumstances of selected participants.
4. Recording interview responses and exam measurement information.
5. Specimen tracking of blood and urine samples.
6. Quality control monitoring, including the aggregating and comparing of survey data from multiple examination sites, calculating response rates, report generation and bench-marking status against goals.

2. Pilot Test Data Collection Systems

After the data collection systems have been designed and developed it is important to test each system to be sure that the correct information is being collected, the information being collected is consistent with operational procedures at each collection point, and data collection systems are integrated (e.g. the necessary information is being transferred from one system to another). Pilot testing of data collection systems is important regardless of the media on which data are being collected. For example, if the household contact information that is critical to recruitment efforts is being collected on paper, planners will want to consider when and how that data will be stored and supplied to those who use this information.

NYC HANES Data Collection Components

- Tracking Household Visit Outcomes
- Tracking Identified Study Participants
- Appointment Scheduling
- Clinic Flow Management
- Interview and Exam Data Collection
- Specimen Tracking
- Electronic Laboratory Reporting

[View: NYC HANES data collection architecture
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_dataarch.pdf]

Additionally, if specimens are being sent to laboratories for testing, planners will have to determine how those data will be captured and linked to participant information. Extensive testing of the data collection systems will need to occur well in advance of the staff training and dress rehearsal, so as to identify and solve major system problems prior to study implementation.

G. Thinking Ahead About Outreach

Before beginning a community HANES it is important to gain the support of key stakeholders in the community, and to think through communication strategies for reaching potential survey participants. As the survey progresses, community and media contacts may prove critical in disseminating information about the survey and its importance. Outreach efforts during the survey are described in more detail in Section VI.

Getting the word out about a community HANES survey (or any population-based survey) presents interesting challenges. Unlike other public health media campaigns, the goal of outreach during a community HANES is not to reach everyone with your message. While it is important to raise the general level of awareness about the survey, outreach efforts and resources are best targeted to neighborhoods selected for the survey.

1. Key stakeholders

Key stakeholders are community leaders and elected officials who have the most relevance and influence within the geographic area covered by the survey, specifically the neighborhoods where potential survey participants live. In New York City, we contacted members of congress, and state and local elected officials to inform them about NYC HANES and ask for letters of support. Influential community and religious leaders were also briefed on the importance of the survey for their constituents and for the city as a whole.

2. The media

The agency's community relations or press offices will have experience in transmitting important information to residents through the media and community organizations. Their expertise and connections can be crucial to the success of your survey. They can also help study planners shape their messages, as well as anticipate any negative attitudes or sentiments toward the project.

NYC HANES Makes the News

For NYC HANES, the DOHMH press office used its contacts with local television, radio stations and city newspapers to get the word out about NYC HANES.

Headlines from NYC HANES-related newspaper articles included:

"Health Workers Go Door to Door in Attempt to Take the City's Pulse"

"Say 'Aaaah,' New Yorkers, It's a Citywide Health Checkup"

"City to Conduct Comprehensive Health Study"

"Big Apple Wants Your Health Stats"

"Mediran Salud de Neoyorquinos"

[View: Press coverage articles, and outreach documents
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_samplepress.pdf
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_outreach.pdf]

The press office may be able to plan a press conference or other informational events, as well as identify important local and ethnic media outlets to generate articles and gain cooperation in specific neighborhoods or among particular groups.

3. Potential Survey Participants

The most important outreach efforts should be directed at potential survey participants – individuals who live in households selected for inclusion in the survey. While these individuals may be positively influenced by media coverage and letters of support from prominent government and community leaders, the most direct influence that study planners will have is through well-prepared staff and effective recruitment materials.

In the early stages, organizers should brainstorm about the types of participant recruitment materials they will need. Once a list is constructed, planners should develop a production schedule, allowing time for approvals and translations, if necessary.

NYC HANES Outreach and Recruitment Plan

Three months prior to survey kickoff, senior staff:

- Made presentations to elected officials at the borough and neighborhood levels.
- Solicited letters of support from elected officials and community organizations.
- Planned a kickoff press conference with the DOHMH press office.

One week prior to survey kickoff, senior staff:

- Held a press conference and issued a press release.
- Offered the press an opportunity to "ride along" with field recruitment staff.

NYC HANES Recruitment Materials

Three months prior to survey kickoff:

NYC HANES staff prepared the following materials:

- Advance letter
- NYC HANES flyer
- NYC HANES informational brochure
- NYC HANES confidentiality statement

All materials were translated into Arabic, Chinese, French Creole, Italian, Korean Russian and Spanish.

Two weeks prior to survey kickoff:

Advance letters and flyers were sent to selected households in the first neighborhoods to be visited.

[View: Recruitment materials
http://www.nyc.gov/html/doh/html/hanes/section3.shtml]
(Note: When accessing this link, please scroll down to the bottom of the webpage)

IV. Staffing a Community HANES

The next step is to determine how the survey will be staffed and what skills staff members will need. Before beginning to recruit or hire staff, planners will need to consider how many staff members are needed for each function, what skills are required, and how best to recruit the most qualified staff. All of these issues will be largely dependent on the study schedule and budget.

A. Define Main Staffing Functions

The success of a community HANES depends largely on the effectiveness of the staff at accomplishing the aims of their respective jobs. To ensure smooth operations, a clear division of responsibilities and the creation of a chain of command are vital.

B. Survey Coordination and Management

The staff charged with coordinating the different functional areas of the survey will form the survey management team. This team will drive the day-to-day operations of the survey, make decisions concerning adaptations of protocols and procedures, ensure adequate allocation of resources, and provide updates as the survey progresses. While it may be desirable to have a coordinator dedicated to each of the main study functions described below, resource limitations may require that the same person fill more than one of these functions. Functions may vary across different community HANES study models.

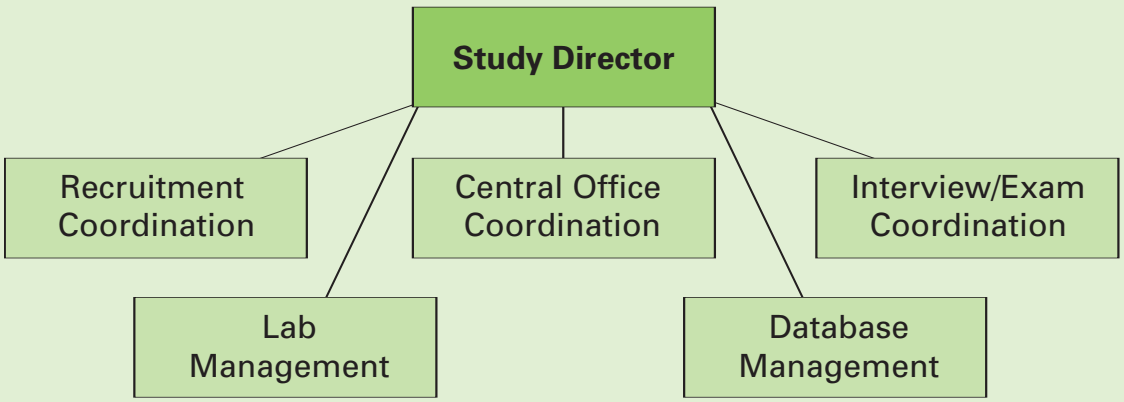
Study Director: Oversees the management of all areas of survey operations. The study director is intimately involved in the development of the survey protocol and the data collection methods.

Recruitment Coordinator: Manages all aspects of survey participant recruitment including staff scheduling, logistics, quality of recruitment data collection and outreach efforts. The recruitment coordinator will supervise how recruitment staff interact with the community and must promote professionalism at all times.

Interview/Exam Coordinator: Manages all aspects of the examination site operations including monitoring data quality, overseeing staff performance, and managing inventory and supply issues. Depending on the data collection model used, there may be one or several fixed site or mobile examination locations, which may involve one or more exam coordinators.

Survey Management Functional Areas

NYC HANES encompassed the five functional areas below:



Central Office Coordinator: Manages and coordinates the activities of the central office. The central office coordinator should be a senior staff person capable of managing and problem solving around appointment scheduling, participant transportation, inquiries from the public, data entry, and communications from the field and clinics. The central office coordinator will need to work closely with the recruitment coordinator and the exam coordinator to ensure continuity.

Database Manager: Monitors and manages the data being collected from various sources. The database manager ensures the reliable functioning of data collection processes by continually monitoring the quality of the data collected. Other responsibilities may include development of data entry procedures, production of reports to monitor study progress, quality assurance checks on incoming data, review of incoming lab results, and performing data queries as needed.

Laboratory Manager: If blood and urine specimens are to be collected and tested, a staff person will need to oversee the entire process from collection to laboratory analysis. The laboratory manager will be involved in the development of specimen processing, shipping, and tracking procedures that satisfy the requirements of the testing protocols. This person will also act as the liaison between the site where specimens are being collected and the laboratories conducting analyses.

C. Survey Staff

Once the coordination and management of the main functional areas of the survey have been determined, the number and types of staff required within each area should be assessed. Decisions regarding staffing the survey will depend largely on the operational model being used.

Recruitment Staff:

Recruitment staff will have the first and most important interactions with potential survey participants. These staff members are responsible for locating and approaching selected households (if house-to-house sampling is part of the survey model), determining eligibility, and persuading selected household members to participate in the study. To be effective, recruitment staff should be well informed, resourceful, polite, persistent and persuasive. In addition to these skills, team leaders, who oversee smaller groups of recruitment staff, need good management and problem-solving skills.

Examination/Interview Staff:

To determine the type and number of examination staff needed, study planners should carefully think through study components, the number of sites in operation and the appointment times offered. All examination staff need to be good communicators, detail-oriented and friendly. Other needed skills will depend on their specific job function.

Central Office Staff:

Regardless of the data collection model used, the central office will likely take on clerical and customer service roles. Central office staff should have excellent clerical skills, be friendly, adaptable to change, and enjoy a fast-paced work environment. If the community to be surveyed is multilingual, having central office staff that are bi- or multilingual is highly desirable.

D. Recruiting Staff

Having a motivated, dedicated staff will be critical to the survey's success. Once study planners know whether they will be relying on internal staff, hiring outside staff, or contracting with an outside institution, a detailed job description for each position will facilitate targeted recruitment.

NYC HANES Staffing Needs

Based on the sample size, area and study schedule, NYC HANES organizers determined that approximately 40 full-time staff and 50 part-time staff would be needed for the four months of the study (which was later extended to six months).

Position	Full-Time Staff	Part-Time Staff (evenings and weekends)
Field Operations		
Field Team Leaders	3	4
Field Staff	15	20-25
Clinic Operations		
Clinic Coordinators	3	3
Health Technicians	12-15	12-15
Phlebotomists	3	3
Lab Assistants	3	3
Central Office Operations	2	5
Total	**41 - 44**	**50-58**

[View: Organizational chart and staff role descriptions
http://www.nyc.gov/html/doh/html/hanes/section4.shtml]

NYC HANES: Field/Recruitment Positions

NYC HANES had two or three recruitment teams in the field at all times during the survey operations. A **Field Team Leader** managed team logistics and answered procedural questions while teams were in the field. They also served as liaisons to the recruitment coordinator.

Field staff members, called **Field Screeners**, were grouped into borough-based teams (New York City is divided into five boroughs) and worked in pairs. These staff members were responsible for locating and approaching selected households, determining eligibility by using a household composition questionnaire and selection formula, persuading selected household members to participate in the study, and setting up exam appointments for participants by calling the central office.

NYC HANES: Examination Site Positions

NYC HANES components included a set of interviews, a physical examination and specimen collection which were conducted in a fixed site clinic. The various clinic positions required for the survey are described below.

Clinic Coordinator (on-site): Clinic coordinators managed the day-to-day operations of the clinics. Clinic coordinators were extremely responsible, adaptable and detail-oriented. Their main responsibility was to ensure that study participants move through each component of the survey process without long waits. The clinic coordinator was also responsible for welcoming and orienting all survey participants to the survey process, including explaining informed consent procedures, as well as managing clinic staff, serving as the liaison to the interview/exam coordinator, and handling any emergencies.

Health Technicians: The health technicians had the most sustained contact with the study participants as they collected the interview data. To ensure data quality, it was imperative that the health technicians observed standardized data collection procedures and protocols. Health technicians were friendly, detailed oriented, and proficient with specialized data collection instruments.

Phlebotomist: The phlebotomists managed blood and urine specimen draws, as well as processing, labeling and storage, according to study procedures. The phlebotomists' ability to thoroughly and confidently explain blood draw procedures and the importance of specimen collection were critical to ensuring a high rate of participation for this component.

Lab Assistant: Because NYC HANES collected both blood and urine specimens, and because the procedures required on-site processing, each clinic was staffed with a lab assistant as well as a phlebotomist. The lab assistants provided assistance to the phlebotomist in all aspects of specimen collection, processing and transport.

NYC HANES Staffing Model & Recruitment

Early on, NYC HANES organizers decided to rely upon existing agency staff. This decision was based on cost considerations, the presence of existing field and clinic expertise, and the desire to build capacity within the agency for large-scale survey work.

Because this meant that some full-time staff would be removed from their regular program for four months, it was critical that managers throughout the agency understood the importance of the NYC HANES project. This was accomplished via communications directly from our commissioner of health.

To target recruitment efforts within the agency, study planners determined which agency positions most closely matched the specific skills needed for various survey positions. Information sessions tailored to individuals in those jobs were held several months prior to the beginning of survey operations. In addition to information sessions, study organizers used the agency intranet to disseminate information about both full-time and part-time opportunities. Interested staff were invited to submit their resume for consideration and clearance by their supervisors.

V. Training & Dress Rehearsal

A well-trained staff is the foundation for quality data collection. Once study staff have been selected, your next consideration will be to train staff according to their job descriptions. Staff training manuals and other written materials will need to be created and training sessions will need to be designed and executed. Optimally, a survey dress rehearsal will be held, so staff have the opportunity to put their new skills to practice.

A. Training Staff

1. Manuals and Written Materials

Once all protocols and procedures for the study have been fully developed, these can be adapted to create manuals both for training, and as a reference for staff while on the job.

2. Training Format and Trainers

Depending upon the components of the survey, it may be necessary to have a combination of in-house and outside trainers. Once organizers have identified the training content required, they will need to create an agenda and decide who will lead the various training sessions. The trainers and study planners should consider which formats would be most effective for each topic. Some options include lectures, demonstrations, role-playing, small group work or a combination.

NYC HANES Training Manuals

Before the start of training, NYC HANES staff, together with the National Center for Health Statistics (NCHS), developed a series of manuals that described the data systems, tools and procedures used for each job. Manuals included:

- **Central Office Procedures**
  - Scheduling appointments
  - Arranging transportation
  - Scheduling an interpreter
- **Clinic Operations**
  - Body measures and blood pressure procedures
  - Clinic coordinator procedures
  - Phlebotomy and urine collection procedures
  - Interview procedures
  - Physical exam procedures
- **Field Operations Procedures**
  - Completing the eligibility interview
  - Documenting household information
  - Refusal conversion

To view the NHANES manuals and other materials, go to:
http://www.cdc.gov/nchs/about/major/nhanes/current_nhanes_01_02.htm

NYC HANES Trainers

NYC HANES relied upon experts from NCHS for several aspects of staff training including field screening procedures, training related to the physical exam and taking blood pressure measurements.

Study organizers utilized staff from within the agency to conduct training on issues such as confidentiality and informed consent, emergency procedures for mercury spills, and safety in the field.

3. Training Schedule and Content

It is important to carefully think through the training schedule to most effectively use both staff and trainers' time. Depending upon the staffing model, your staff may have limited availability. Organizers should also consider which training components are applicable to all staff, and when to divide the staff into separate groups according to their jobs.

Depending on the length of the data collection period, study organizers may also want to plan a mid-study refresher training. This additional training opportunity will reinvigorate existing staff and provide a formal foundation for staff that may join the project throughout the study.

B. Dress Rehearsal

When planned and executed properly, a dress rehearsal serves as a critical bridge between the procedures introduced in training and the reality of working with actual survey participants. If the decision is made to have a dress rehearsal, it can involve either volunteers or actual community participants whose data will not be included as part of the study. A dress rehearsal will provide staff with an invaluable opportunity to test their skills, become familiar with procedures and work flow, and build confidence without worrying that their mistakes will jeopardize the data being collected.

1. Planning a Dress Rehearsal

The procedures that can be practiced during the dress rehearsal will include: locating selected households, completing the eligibility interview, making appointments for the exam, and all procedures associated with data collection. The coordination of a dress rehearsal will require significant planning. When thinking through a dress rehearsal, study organizers may want to consider:

- What are the critical elements that should be practiced?
- When will the dress rehearsal take place and how long it will last?
- How will the recruitment and examination dress rehearsals be coordinated?
- Who will be selected as dress rehearsal participants?
- Who will observe and evaluate the dress rehearsal?
- How will staff debrief from the dress rehearsal?
- What will the feedback mechanism be so that adjustments to procedures can be made?

NYC HANES Staff Training

NYC HANES Staff Training was divided into two phases to minimize disruption to the agency. Field and central office staff were trained in the first phase, clinic staff in the second. All staff members were provided with basic information about the survey, followed by more specialized training related to their particular function.

Field Staff Training included:

Explanations and demonstrations of the field screening process

A "walk-through" on using the field operations manual, household folders and recruitment materials

Hands-on practice packing travel bags with materials needed in the field

Working on a 30-second and 60-second "pitch" to explain the study to potential study participants

Role-playing the interview process with various types of household participants

Central Office Staff Training included:

Explanations and demonstrations of the field screening process

Practice answering, making and recording the results of phone calls

Using scripts to answer questions and schedule appointments

Instruction and practice on entering data from household folders

[View: Training agendas and manuals *http://www.nyc.gov/html/doh/html/hanes/section5.shtml]*

Clinic Operations Staff Training:

- **Clinic Coordinators:**
  - Controlling and maintaining clinic flow
  - Monitoring data quality
  - Check-in and checkout procedures
  - Informed consent forms
  - Issuing remuneration
  - Emergency protocols
- **Health Technicians:**
  - Taking blood pressure and body measures using standardized methods
  - Maintaining exam room equipment and supplies
  - Conducting interviews
  - Entering data
- **Phlebotomists and Lab Assistants:**
  - Strategies for gaining study participant cooperation
  - Maintaining equipment and supplies
  - Standardized procedures for blood draw, urine collection and specimen preparation
  - Labeling and processing of clinic specimens
  - Data entry
  - Infection control

NYC HANES: Dress Rehearsal

The NYC HANES' dress rehearsal was designed to mirror the actual survey as closely as possible. Field staff recruited and scheduled study participants from three extra segments designated for the dress rehearsal. At the clinic, dress rehearsal participants gave informed consent, completed all components of the survey, and received remuneration.

Field and Central Office Dress Rehearsal

The field and central office dress rehearsals were scheduled in advance of the clinic dress rehearsal to allow the field screeners to complete recruitment and schedule participants for clinic appointments. All field staff was split into three large groups. Each group was assigned to a selected dress rehearsal segment, and given specific households to approach.

Over the course of several days, including evenings and weekends, field screeners approached their assigned households where they attempted to make contact, complete the household composition questionnaire, determine eligibility, and ultimately schedule a clinic appointment. During this same period the Central Office staff was available to receive calls from field screeners to schedule clinic appointments.

Clinic Dress Rehearsal

The clinic dress rehearsal was scheduled one and a half weeks prior to the official opening of the clinics. The dress rehearsal took place in two phases.

Phase I

Phase I was a two-day period during which select DOHMH staff and local officials were invited to the clinic as guests. Each guest completed the interview and examination process. This phase gave staff a chance to practice procedures in a comfortable environment, and allowed key agency staff (the health commissioner, community relations and press office staff) to experience the NYC HANES survey.

Phase II

Survey participants from dress rehearsal segments were scheduled during the final three days. This phase gave staff additional practice and study planners time to monitor data collection procedures and make adjustments as necessary.

*[**View: Dress rehearsal schedule***
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_rehearsal_sched.pdf]

2. "Debriefing" to Discuss Lessons Learned

Immediately after the dress rehearsal, organizers may want to hold a "debriefing session" to determine:

- What went well?
- What challenges came up and how they were handled?
- What additional practice was needed?
- Are any protocol changes warranted?

During the debriefing, it is important to get feedback from the entire survey staff. Study organizers should carefully consider staff comments to determine which issues can be handled with training and which require procedural changes. If adjustments to data collection procedures are necessary study planners should communicate these changes to all staff, and modify any documentation that may be referenced in the future.

Debriefing from the NYC HANES Dress Rehearsal

During the NYC HANES dress rehearsals, NCHS staff were present to provide technical support and observe operations. They helped troubleshoot and advise staff about problems they observed. Senior NYC HANES staff also elicited feedback from DOHMH guests on how to improve the flow of the clinic and the performance of clinic staff. Some of the issues identified during the dress rehearsal were:

- Additional training was needed for field screeners in locating the correct house or apartment when the address provided was incorrect or did not accurately reflect the physical layout of an apartment building.
- Difficulties were identified in the management of the clinic flow. Clinic coordinators found that there were quiet stretches due to "no shows," followed by a rush of study participants, causing long waits.
- Additional training was needed for several health technicians who failed to follow standardized interview and exam procedures.
- Additional training was needed for phlebotomists and lab assistants, regarding labeling conventions for blood and urine specimens.
- Communication resources were needed, as central office staff were unable to easily relay messages and other important information to field staff.

Once these issues were identified, survey managers worked to quickly resolve these problems. For example, further training and practice sessions were scheduled, field screener cell phone numbers were posted in the central office, and adjustments to appointment scheduling protocols were made.

3. The Final Details

If possible, planners should allow one to two weeks between the end of the dress rehearsal and the official start of survey operations. This time can be used for last minute adjustments to procedures, edits of manuals and other documents, and additional staff training and practice. During this time, organizers may also want to plan a kickoff press conference and mail survey information packets to the first neighborhoods to be recruited.

NYC HANES Final Details

In the two weeks preceding the beginning of survey operations, NYC HANES staff worked with a local mailing house to send information packets to all selected households to be visited in the first month of recruitment. The information packet contained an "advance" letter signed by the commissioner and an informational brochure. The purpose of the packet was to:

- Explain the objectives and the value of the community HANES project
- Provide a brief description of the study
- Ask for resident cooperation when approached by field recruitment staff

NYC HANES staff also worked with the DOHMH Press Office to hold a kickoff press conference, and a press ride-along during the first day of field recruitment.

VI. Now the Work Begins

No matter how well planned, each community HANES will change and evolve between conception and completion. Therefore, it is essential to have a structure in place that demands consistency, but is flexible enough to incorporate change.

A. Maintaining Staff Communication and Coordination

At the start of the survey, unanticipated procedural issues are likely to arise. Establishing a chain of command for communication will help staff members when they have a question or concern. It is also important to have a plan for how to make procedural changes when necessary, and communicate these changes to affected staff.

B. Quality Assurance

Throughout the data collection period, senior study staff should plan to monitor staff performance, as well as the interview and measurement data being collected, to ensure overall quality. Frequent feedback to staff on their performance, and the overall progress of the study, is critical to maintaining staff morale.

1. Assessing Staff

The study protocol should include methods for assessing staff performance. These methods ensure that the staff is following specified procedures and can help determine when additional training is needed. Scheduling days when senior staff can shadow the field, clinic and central office staff during their regular operations also provides an opportunity for evaluating staff performance and adherence to protocols.

2. Data Quality Assurance

To maintain the integrity of the data, it is important to establish procedures to assess all data collected during recruitment, interviews, examinations and laboratory analysis. It is also important that clear procedures are in place for documenting the identification and correction of data errors. As data quality procedures and protocols are updated, it is important that staff are made aware of changes and know how and where to access the most up to date documentation. Monitoring data quality will be an on-going process.

3. Survey progress updates

Keeping people informed within your program as well as around the agency is also a high priority. Creating and disseminating reports on progress can accomplish this. In designing progress reports organizers should consider what indicators will best illustrate survey progress and who within the agency needs to receive these reports.

NYC HANES Staff Communication Methods

NYC HANES senior staff instituted weekly meetings for each operational area – the central office, field and clinic. During these meetings the staff discussed successes and challenges from the previous week, and were trained on any procedural changes made since the previous meeting. Because it was difficult to bring all survey staff together on a regular basis, senior study staff produced a weekly newsletter to update staff on global survey issues, such as study progress, technical issues, upcoming events and milestones.

[View: NYC HANES sample weekly newsletter, and field screener weekly meeting agenda http://www.nyc.gov/html/doh/html/hanes/section6.shtml]

NYC HANES Quality Assurance

During NYC HANES, senior staff produced and examined weekly data reports. Feedback was provided to all staff to ensure that data collection procedures were being followed. Some examples of information reported include:

- The mean and distribution of blood pressure measurements for each health technician.
- Timing reports of the interview and examination components for each health technician.
- The status of all households visited the previous week.

NYC HANES Program Monitoring

Weekly overall progress reports were generated and sent to key staff members within the agency. Weekly geographic segment reports were used internally to assess field recruitment progress. Periodic narrative progress reports went out to larger audiences within the agency and the community. Additionally, the local media were alerted when important milestones were reached.

Internal Reporting

For internal use by survey staff, weekly reports were produced that showed the number of:

- Households who completed an eligibility questionnaire (completed screeners).
- Eligible survey participants who made an appointment (enrollment rate).
- Participants who kept their appointments (completed interviews).
- Response rates for each geographic segment.

These reports were used to drive decisions regarding the amount of field coverage needed in certain neighborhoods, whether outreach was necessary to community groups and the media, and whether to consider extending the survey period.

[View: Sample progress report
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_work_progressreport.pdf]

C. Keeping Staff Motivated

The difficult work and long hours required to conduct a community HANES study can be a recipe for burnout. Recruitment staff may encounter household residents who are angry or suspicious, and they may tire of the same routine week after week. Other issues may plague examination staff including erratic participant flow (slow periods interspersed with busy periods) or survey participants who are upset or distressed. Devising methods to keep staff motivated is critical.

D. Keeping the Community Informed

Another critical piece of conducting a successful survey is keeping the community informed. It is important to both raise the general awareness in the community, and to reach out to the media and community leaders who may be able to sway residents in selected areas toward participation. Outreach efforts should be both proactive and reactive.

1. Proactive Outreach

As recruitment begins in each new neighborhood, it is important to publicize the survey so that residents of selected households will have some awareness of recruitment efforts and knowledge about what participation in the survey involves. Even vague recognition of the survey can improve response rates.

2. Reactive Outreach

As data collection progresses, recruitment problems may emerge in particular neighborhoods or among specific populations. Weekly progress reports and feedback from recruitment staff can help define the extent of the problem and the reasons behind it. Existing relationships with influential community organizations, elected officials and the media will be critical to increasing response rates.

E. Making Changes Midstream

No matter how carefully study procedures are thought through, it is likely that minor, and sometimes major changes will need to be made mid-study. For example, the recruitment schedule could be disrupted by a long heat wave or continual storms; crucial staff members may quit and be difficult to replace; or a batch of specimens may be damaged during shipping. Being prepared for surprises, and ready to modify operational systems will enable organizers to overcome unforeseen obstacles.

NYC HANES: How We Kept Staff Motivated

NYC HANES coordinators found that relaxed weekly meetings were key to maintaining morale. Meetings gave staff members the chance to socialize and discuss their successes and challenges. Coordinators listened to the ideas presented by the staff and implemented many changes that improved operations. Regular meetings also provided the opportunity to re-emphasize the importance of the survey and create a sense of "ownership" among all staff.

Senior staff developed ways to recognize the contributions of staff members. At weekly field meetings, the field screener who enrolled the greatest number of participants the previous week was named "Screener of the Week." At clinic staff meetings, small contests with prizes kept staff engaged. Short articles in the weekly newsletter also highlighted the efforts of various staff members by explaining their role within the survey.

NYC HANES Proactive Outreach Efforts

NYC HANES proactive outreach efforts included:

- A kickoff press conference
- Follow-up press releases at survey milestones
- The use of citywide, neighborhood and ethnic press
- Letters of support from influential community leaders
- Packets sent to potential survey participants that included a follow-up letter and recent newspaper articles about the survey
- Copies of articles distributed at community meetings and in selected buildings
- "Outreach binder" containing copies of press releases, newspaper articles, and letters of support from elected officials and community leaders to be used by field staff.

[View: Outreach Documents
http://www.nyc.gov/html/doh/html/hanes/section3.shtml]

NYC HANES Reactive Outreach Examples

Resistance and Reticence in the Bronx

When field screeners encountered strong resistance among some members of the Hispanic community in the Bronx because of concerns about undocumented immigration status, senior staff worked with DOHMH's community affairs staff to reach out to churches and community-based organizations, as well as Spanish print and broadcast outlets. Field staff also emphasized the study's strict confidentiality policies.

Hard to Reach Residents on the Upper East Side

NYC HANES included several segments on the Upper East Side of Manhattan, where many affluent residents live in high-rise buildings staffed by doormen. Finding residents at home and communicating with them via doormen and other gatekeepers proved extremely difficult. For assistance, study planners reached out to Community Boards and building management. With the help of the DOHMH press office, the interest of *The New York Times* was captured and an article documenting the difficulties faced in this particular neighborhood was published.

[View: NY Times article
http://www.nyc.gov/html/doh/downloads/pdf/hanes/HANES_start_nytimes.pdf]

NYC HANES: Developing the Home Interview Option

NYC HANES found that some participants would not travel to clinic locations. This was especially true for elderly participants or those caring for sick family members. To increase participation rates, a special team of home interviewers was trained. These interviewers visited participants to conduct a portion of the interview, and take blood pressure and body measurements in the home. Home interviewers traveled in department-owned cars, equipped with laptop computers, scales, stadiometers, manometers, mercury spill kits and blood pressure cuffs.

Participants who were interviewed in their homes were then strongly encouraged to come to one of the NYC HANES clinics to provide blood and urine specimens and complete the more sensitive portions of the interview.

VII. Data Preparation, Analysis, and Dissemination

As data collection comes to a close it will be important to think through how and when findings will be released to programs within the agency, the scientific community and the public. Just as a timeline was developed to plan and implement the main study, a timeline should be developed to guide the data preparation and analysis efforts.

The first step of data preparation will involve assessing the quality of the data collected and checking the household and participant level response rate information. This data will be critical in the development of sample weights if a multi-stage sampling design is used. Once the preliminary data checks are complete and the sample weights have been developed, further data cleaning will need to be conducted on the interview and examination data. Determining what data will be released, both internally and externally, is an important consideration, in terms of ensuring the integrity and confidentiality of the data. Finally, the creation of a data codebook and analytic guidance documentation will be necessary to assist potential data users.

As study planners think through reporting, it is important to identify key analyses that will be conducted and how and when those findings will be disseminated. The first priority may be to provide internal reports to agency staff, other health and health care organizations, and the local community. Researchers may also wish to present results at scientific conferences and submit papers for publication in peer-reviewed journals. There are likely to be people in the agency who have the expertise to organize and analyze the data and to write research papers and manuscripts. Additionally, people within and outside of the agency may be interested in the development of a public-use data set. The analysis plan should provide a mechanism to prioritize analyses, identify lead authors, and set deadlines for dissemination.

Reporting Findings to the Public and the Scientific Community

NYC HANES plans to report study findings to the public in a number of ways including:

- Press releases to the local media
- Presentations for community groups, elected officials and others
- Creating a public-use data set available to outside researchers and interested community members

For the scientific community, NYC HANES will be the basis of several papers to be submitted to peer-reviewed journals. Planned analyses include:

- Abdominal adiposity and prevalence of obesity in NYC adults
- Cardiovascular disease risk among NYC adults
- Prevalence and control of hypertension and hypercholesterolemia
- Diabetes, impaired fasting glucose and metabolic syndrome
- Exposure to pesticides among New York City adults

VIII. Summary/Conclusion

Designing and implementing a community HANES survey, whether done with existing resources or contracted externally, is a huge undertaking. The goals and objectives of such a survey require careful consideration.

The NYC HANES project produced some unexpected organizational benefits for the New York City Department of Health and Mental Hygiene. Mobilizing the staff of several agency divisions created camaraderie, helped staff learn about other departments, and built an infrastructure in the agency capable of performing other large-scale surveys. On an individual level, staff members benefited tremendously from the acquisition of new skills and leadership roles.

The data provided by the NYC HANES effort are likely to influence planning decisions for public health in New York City for years to come. As we begin to disseminate our findings, the NYC Department of Health and Mental Hygiene hopes that the benefits will carry over to other cities and states throughout the country.

Suggested citation

Gwynn, C. Mandel-Ricci, J. Kass, D. Goldfarb, T. Thorpe, L. Designing and Implementing a Community HANES: The New York City Experience, New York City Department of Health and Mental Hygiene, 2005.

Notes:

New York City Department of Health and Mental Hygiene, Division of Epidemiology

125 Worth Street, Rm. 315, CN-6, New York, NY 10013

NYC HANES
Health & Nutrition Examination Survey

NYC Health
nyc.gov/health

THE NEW YORK CITY DEPARTMENT of HEALTH and MENTAL HYGIENE
Michael R. Bloomberg, Mayor
Thomas R. Frieden, M.D., M.P.H., Commissioner